DEVELOPMENT AND EVALUATION OF BOUNDARY OBJECTS IN THE HETEROGENEOUS DOMAIN OF COMPLEX CHRONIC CONDITIONS

by

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DEDICATION PAGE

This thesis is dedicated to the memory of my father,

Rajan Natampalli

न हि ज्ञानेन सदृशं पवित्रमिह विद्यते

'nahi jnanena sadrisham pavitramiha vidhyathe'

English Translation of Sanskrit quotation:

Here (In this world) there is nothing as sublime as knowledge

Source: Bhagvat Gita

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ABSTRACT

Complex and chronic health conditions with multiple diagnoses and lacking in clinical practice guidelines often require a multidisciplinary care management scheme. Research has shown that the domain knowledge for these conditions is multidisciplinary, inconsistent, non-standardized and poorly categorized making them heterogeneous and consequently challenging for collaborative work.

The application of the boundary objects approach has come to the forefront as a way of closing communication gaps in collaborative work. There are limited research efforts in the application of boundary objects in the health care field and almost none in the area of complex chronic conditions. Research investigation of the application of boundary objects in heterogeneous domains is also limited.

The primary objective of this thesis is to develop, test and evaluate a model and a methodology for creating boundary objects in the heterogeneous domain of complex chronic conditions. The methodology in this research applies a two-staged approach for enabling interoperability in the domain. The first stage is the development of a controlled vocabulary as a boundary object and the second stage of the two-staged approach is the development of an ontology as a boundary object to generate syntactic, semantic and pragmatic levels of interoperability in the dynamic domain. Towards these objectives, the boundary objects developed in the study satisfies certain unique requirements, namely, have pragmatic boundaries, be dynamic in nature and be in standardized forms. To the best of our knowledge, this research is the first to investigate the development of boundary objects in the heterogeneous domain for complex chronic conditions.

The outcome of this research is the development of a model for the generation of boundary objects to enhance communication among multidisciplinary clinicians. The model is developed in the heterogeneous domain of two complex chronic health conditions, namely, multiple chemical sensitivity and chronic pain. A testing and an evaluation process conducted in this research demonstrates that a high percentage of clinicians (>80%) agree on the overall usefulness of the boundary objects. The results from the research are promising in terms of the potential applications of boundary objects in closing communication gaps in the heterogeneous domains of complex conditions.

LIST OF ABBREVIATIONS USED

CFS	Chronic Fatigue Syndrome
CMV	Controlled Medical Vocabulary
CLINICLUE	SNOMED CT Browser
FM	Fibromyalgia
MCS	Multiple Chemical Sensitivity
SNOMED CT	Systematized Nomenclature of Medicine – Clinical Terms
SNOCAT	SNOMED CT Browser
OWL	Web Ontology Language

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CHAPTER 1 INTRODUCTION

Chronic diseases have grown in recent years with an increasing proportion of the population having multiple chronic illnesses or its risk factors [1]. Complex medical conditions with multiple co-morbidities and limited knowledge base come with an additional layer of challenge given the limited documentation and accepted or standardized treatment strategies. Clinicians often have to devise care plans in isolation [2]. In a report by Statistics Canada, at least 5% of Canadians have symptoms that cannot be medically explained [1, 2]. These include conditions such as multiple chemical sensitivity (MCS), fibromyalgia (FM), chronic pain, and chronic fatigue syndrome (CFS). Patients with these conditions occupy a disproportionate amount of physician time [3], and it has been argued that in the recent years there are increasing encounters of these disorders in primary care [4-6].

Multidisciplinary care teams have come to the forefront as an effective management strategy for these conditions. The variety and recurring nature of symptoms in patients with complex chronic illness have led to the belief that the management scheme may benefit from the insights of different bodies of knowledge such as medicine, nursing, occupational therapy, psychology, and nutrition [7-11]. Studies have shown the consequences of poor communication among multidisciplinary care providers resulting in poor care experiences for patients and errors in care management such as repetitive or redundant medical tests, misdiagnoses, delayed care and inaccurate treatment plans [12-16]. Studies have also demonstrated that clinical documentation is the primary source of communication among multiple and multidisciplinary clinicians in the management of chronic conditions [17-19, 22]. Studies have discussed the significant need to identify methods to improve collaboration and communication among care providers in order to facilitate seamless care for patients with complex health conditions [17-19].

Multiple Chemical Sensitivity (MCS) and chronic pain are complex and chronic medical conditions that have the domain characteristics and all of the challenges outlined above. There is growing evidence of the benefits of multidisciplinary care management for these conditions [7, 8, 10]. Patients with these conditions exhibit a wide range of symptoms

from physical to psychological [7-11]. The nature of the multifaceted symptoms require a multidisciplinary management approach with a comprehensive assessment of all factors affecting the individual's health such as physical, psychosocial, economic, nutrition and medical areas of health focus. The increasing incidence of occurrence in primary care, medical errors, repeated medical tests and poor understanding of the health conditions has made it critical to improve communication among clinicians involved in the care management.

The process of improving communication in the management of complex and chronic conditions requires many important considerations. Improving communication involves the organization and standardization of the knowledge that exists in the clinical documentation to facilitate shared understanding. There is very little in the known realm for these conditions that is widely accepted in the general medical community [4-6] or is consistently being used among experts in the field [2]. Improving communication involves extraction of the knowledge that exists as experiential or implicit knowledge among experts, i.e. tacit knowledge.

An exploration of the domain knowledge and clinical documentation, and working with domain experts has to start at the most basic layer of recognized or essential knowledge. The patient profile document or the problem list of the patient is a key clinical document that is essential for consequential, timely and relevant delivery of care for patients [20, 21]. Multiple health care providers and health care disciplines will often refer to the profile document at various stages of the care management. The patient profile document can thus be viewed as a binding object in the collaborative care among multiple providers. However, in reality the information in the patient profile documents is often localized in its meanings with the emphasis on health discipline-specific or organization-specific interpretations [22, 23]. This localized vocabulary that is often non-standardized, multidisciplinary and inconsistent in its usage can become a major impediment in the communication channels among multiple care providers. It may even lead to repetitive medical procedures or errors or the devise of an ineffective care plan for the patient [14, 15]. Above all, it can prove to be a challenge for informaticians and researchers to

retrieve information from charts in order to build up a functional knowledge base of the medical conditions [23].

1.1 Why Are There Communication Gaps In The Collaborative Care For Complex Health Conditions?

As discussed in the previous section, there is growing evidence in recent years to demonstrate the importance of multidisciplinary care management of complex chronic conditions [7-11]. There are many challenges to effective collaboration among multiple disciplines in the management of complex health conditions. Barriers to effective communication include dealing with poorly categorized knowledge with multidisciplinary, inconsistent and non-standardized clinical documentation with new knowledge emerging on an ongoing basis among various knowledge communities or groups of experts. Figure 1 shows there are six important challenges in the management of complex chronic conditions.

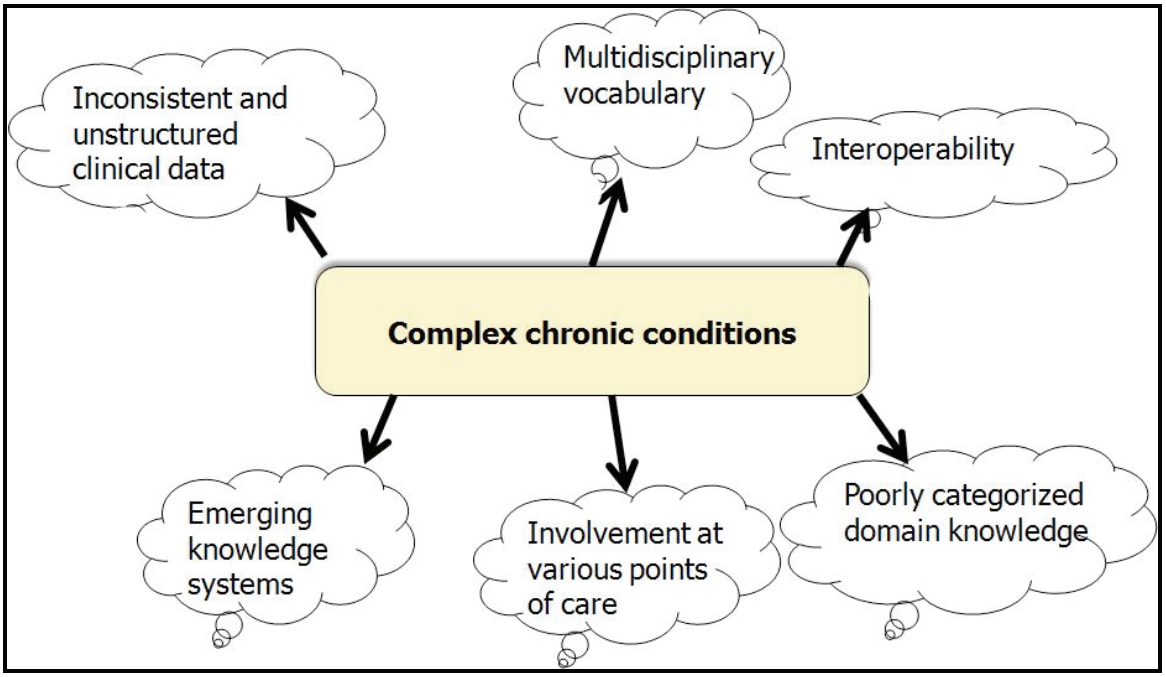

Figure 1 Challenges in the management of complex and chronic conditions.

The challenges of enabling shared communication in these conditions are related to the limited, unstructured and inconsistent knowledge that exists in the patient charts [15, 17]. The terminologies in the patient charts may include multiple terms for a concept that has similar clinical intentions. For instance, the term *fatigue* can be inconsistently used as *lack of energy*, *no energy*, *tired*, *very tired* or *poor energy*. The inconsistent pattern of documentation can result in loss of useful knowledge when terms relevant to the condition are being retrieved at a later time.

The domain consists of multidisciplinary vocabularies since more than one health discipline is generally involved in the care management scheme such as physicians, nurses, dietitians or psychologists [7-13]. The clinical documentation in the patient charts includes terms that are discipline specific and lack in clarity for other disciplines involved in care. The clinical intention of a term or a concept plays a key role in helping other disciplines understand the care process for patients [23, 24]. For instance, the term *Light sensitivity* can have an interpretation of *sensory intolerance* or *pain in the eye*. In the context of a patient with a diagnosis of multiple chemical sensitivity, this term involves addressing sensory intolerance. Adding semantic (intended meaning) and pragmatic (translation in the context of care) levels of shareability for the terms may help overcome the challenges of multidisciplinary vocabulary.

This leads to the challenge of interoperability which can be hindered by terms that are inconsistently used and that are non-standardized. Interoperability is the ability for two or more systems or individuals to understand and use information accurately. Interoperability can exist at various levels such as syntactic (identified or controlled terminologies), semantic (intended meaning) and pragmatic (translation). All of these levels are a challenge in the heterogeneous domain of complex conditions due to the inconsistent, non-standardized and multidisciplinary terminologies.

These challenges in turn lead to the knowledge in the domain being poorly categorized. Poor categorization also stems from a significant amount of knowledge that exists as tacit or experiential knowledge among experts [16]. There is a good level of consensus among

researchers that the health care field has a significant amount of knowledge that is tacit. This challenge is compounded for complex conditions that do not have clinical practice guidelines or standardized treatment strategies as a lot of the known knowledge still remains to be explicated.

Furthermore, these conditions can be viewed as emerging or dynamic knowledge systems with new knowledge continuing to build among groups of experts [17-19]. Building knowledge in silos and in unstructured formats makes it challenging to share or integrate knowledge of these conditions in a common domain [24]. Research has shown that in emerging knowledge systems, allowing new knowledge to grow in an ad hoc manner can be an impediment to collaborative work as well as knowledge retrieval. The benefits of building communication bridges that can be understood and shared by knowledge communities at the design phase itself have been discussed by researchers [25].

Care providers get involved at various points in care due to the prevalence of a multitude of symptoms and overlapping diagnoses for patients with complex conditions. All of the outlined issues can thus make it challenging for a clinician to accurately interpret the clinical evidence and offer timely care for patients.

1.2 Boundary Objects And Their Applications

One of the promising and emerging areas to address communication gaps in collaborative work is the concept of *boundary objects*. Boundary objects, introduced by Star and Griesemer [27], refer to objects that serve as an interface between different communities of practice. Boundary objects are entities that can be shared by several different communities but viewed or used differently by each of them to serve their individual needs. Boundary objects were first introduced in the field of ecology [27] following which they have been researched in the field of management [28], among design teams [29], information technology [31], architecture [30], manufacturing systems [32-34], and in health care [35-38]. There are many conceptual models and hypothetical research in the literature on boundary objects [27-31]. However, there is limited research in the development of boundary objects and research that demonstrate their impact in process improvement. There are even fewer studies that have explored the use of boundary objects in health care in the areas

of chronic care management [38, 39], addressing communication gaps among care providers [37, 39] and in the management of complex health conditions [38]. There is one research study that has explored boundary objects to improve collaboration for chronic kidney condition but with the assumption of a homogeneous knowledge base, i.e., the domain knowledge is considered to have a level of consistency and definition [40]. Literature indicates a couple of studies have outlined the challenges of developing boundary objects and consistency in poorly categorized domain [40, 41]. To the best of our knowledge, there is no research to-date that has developed boundary objects in the heterogeneous domain of complex chronic conditions in which the knowledge is inconsistent, multidisciplinary, non-standardized and poorly categorized.

1.3 Developing Boundary Objects In Heterogeneous Domains

Research on boundary objects is predominantly in homogeneous domains with very few studies that have examined the development of boundary objects in heterogeneous domains. The differences in a homogeneous domain as compared to a heterogeneous domain, as relevant to this research, include stable processes or interactions, homogeneous and structured domain knowledge that can allow objects of mediation to be identified and applied in collaborative work.

Paterson [39] explored the use of a boundary object in the management of a chronic kidney condition. This research assumed a homogeneous domain and developed the boundary object, a discharge summary based on the information from a single patient.

A study by Lin et. al. [40] discussed the challenges of developing boundary objects in poorly categorized, inconsistent and non-standardized domains. The broad objective of this research was to improve communication among a group of mental health professionals through an ontology approach. This study outlined the importance and the challenges of building ontologies in heterogeneous knowledge systems. The primary interaction in this study is between a domain expert and an ontology engineer. The study highlighted the challenges that exist in the knowledge capture for a domain that has obscure definitions, unstructured data, inconsistent use of vocabulary and assessment

scales, and emerging knowledge with time. Despite these challenges, the authors have identified the need to enable the domain knowledge in a machine retrievable format to facilitate efficient information retrieval. The study identified the importance of developing structure and consistency in such situations as a preliminary step to developing the domain ontology.

Another study by Laron and Martone [41] outlined the challenges of formalizing knowledge for neuroscience. The authors claimed that formalizing knowledge about poorly understood biological systems presents many obstacles to the development of knowledge sharing platforms such as ontologies. The authors concluded that in scenarios where the domain knowledge is emerging, poorly categorized and non-standardized, it is important to develop standardization at a basic level prior to enabling a high level specification tool such as an ontology.

Clinical documentation is the primary method of communication and collaboration among multidisciplinary care providers [22]. Therefore, this is the platform considered to enhance communication and collaboration. Also, the patient profile or problem list is the document that will be referred by multiple care providers at various points of care. This is the basic level at which standardization and organization can be examined.

This thesis proposes a model with a two-staged approach to the development of boundary objects in the heterogeneous domain of complex chronic conditions. The broad goal of this research is to improve communication and collaborative work of clinicians involved in the care through organization and standardization of knowledge that exist in the patient profile domain for complex chronic conditions.

1.4 Goals Of The Dissertation

The existence of knowledge heterogeneity and communication gaps in the collaborative management of complex health conditions has motivated our research for developing

boundary objects in heterogeneous knowledge domains. The ultimate goal of this research is to solve the problem of collaborative communication and enabling pragmatic level of interoperability among multidisciplinary team of clinicians involved in the care of complex chronic health conditions. More specifically, we aim to develop a generic methodology to develop boundary objects in heterogeneous knowledge domains and propose a model with a two-staged approach to achieve this objective. It is our hypothesis that creating boundary objects in heterogeneous environments can reduce communication gaps in complex and dynamic collaborations which have drawn the attention of many researchers (14, 25, 40-43).

The primary objective of this thesis work is to improve collaboration in the heterogeneous domain of complex chronic conditions by developing boundary objects that can facilitate pragmatic interoperability (capability of translation and re-use of knowledge), be a standardized form of knowledge and be dynamic to allow the growth of new knowledge. We examined the following questions related to improving communication for multidisciplinary clinicians through the use of boundary objects:

1. Is it possible to develop a methodology to create boundary objects in knowledge systems that are inconsistent, unstructured poorly categorized and multidisciplinary in nature i.e. heterogeneous knowledge systems?
2. Are the boundary objects developed in this research robust and flexible enough to share knowledge across disciplines of care and across communities of practice?
3. Is this methodology generalizable to other complex and chronic health conditions that have similar requirements of knowledge sharing and knowledge expansion?

The anticipated outcome of this research is a shared platform of communication in the form of a controlled vocabulary and a patient profile ontology for not only multiple disciplines of care but for the numerous communities of practice involved in the management of complex conditions. The direct goal of this research did not include improved health outcomes.

1.5 Overview Of Our Solutions

Generally speaking, our efforts to enhance collaboration among multidisciplinary care providers and providers across communities of practice in the heterogeneous domain of complex chronic conditions has applied the boundary objects approach [27]. Our research considered the heterogeneous domains of two complex chronic conditions, Multiple Chemical Sensitivity [7] and chronic pain [8] to investigate, develop and evaluate the boundary objects approach to improving collaboration.

The boundary object approach is based on identifying knowledge gaps in collaborative work and enabling platforms in the form of physical artifacts or processes that can build shared understanding. The methodology proposed in this study applies the involvement of the domain experts and end users of the domain knowledge in the development, testing and evaluation of the boundary objects. The proposed solutions have taken into consideration the prevalent challenges of the heterogeneous domain knowledge developing shared understanding and applied a two-staged approach to the development of boundary objects. The challenges of heterogeneity include poorly categorized, inconsistent, non-standardized and multidisciplinary domain knowledge.

The characteristics of the boundary objects developed in the study had to fulfil certain requirements in order to overcome the challenges of heterogeneity in the domain knowledge. Using the boundary objects approach, we have developed a pragmatic level of interoperability as outlined by Carlile [43] for clinicians collaborating in the care management of complex health conditions. We have also applied standardized forms of boundary objects taking into consideration the issues raised by Fujimura [44] around too much flexibility leading to loss of identity. We have also designed the boundary objects such that they have the capacity to maintain a dynamic nature to enable the growth of new knowledge [32]. These characteristics have been described in detail in Chapter 3.

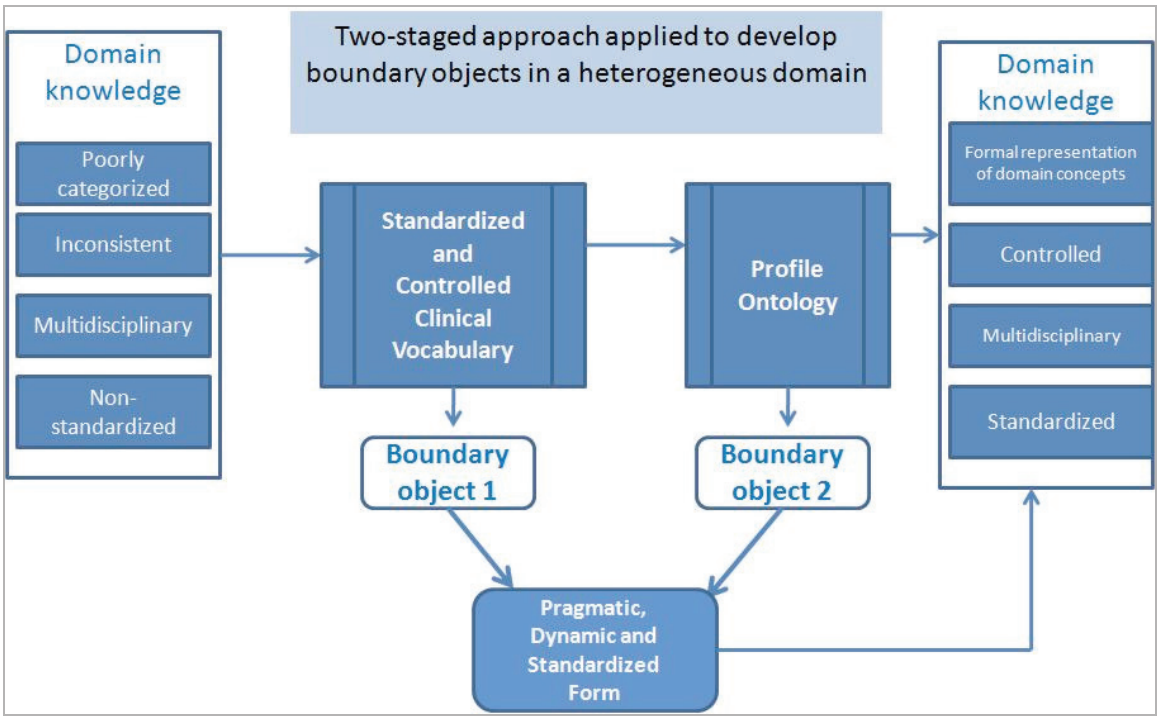

Figure 2 An architectural view of the solutions proposed in this research.

Figure 2 is a depiction of the architecture of the proposed methodology to develop boundary objects in heterogeneous knowledge domains. The methodology used in this research to develop and evaluate boundary objects consisted of a two-staged approach. The first stage was the development of a controlled vocabulary to enable standardization, organization and consistency of the heterogeneous domain knowledge [45]. The second stage was the development of an ontology from the controlled vocabulary to enable organization, formal representation of the domain concepts, description of the domain concepts and definition of relations between the concepts [46]. The two boundary objects developed have the characteristics of the pragmatic level of shareability, have the capacity to be dynamic in nature and are in standardized forms. A detailed description of the approach is presented in chapter 4.

The key phases involved in the methodology are outlined in Figure 2:

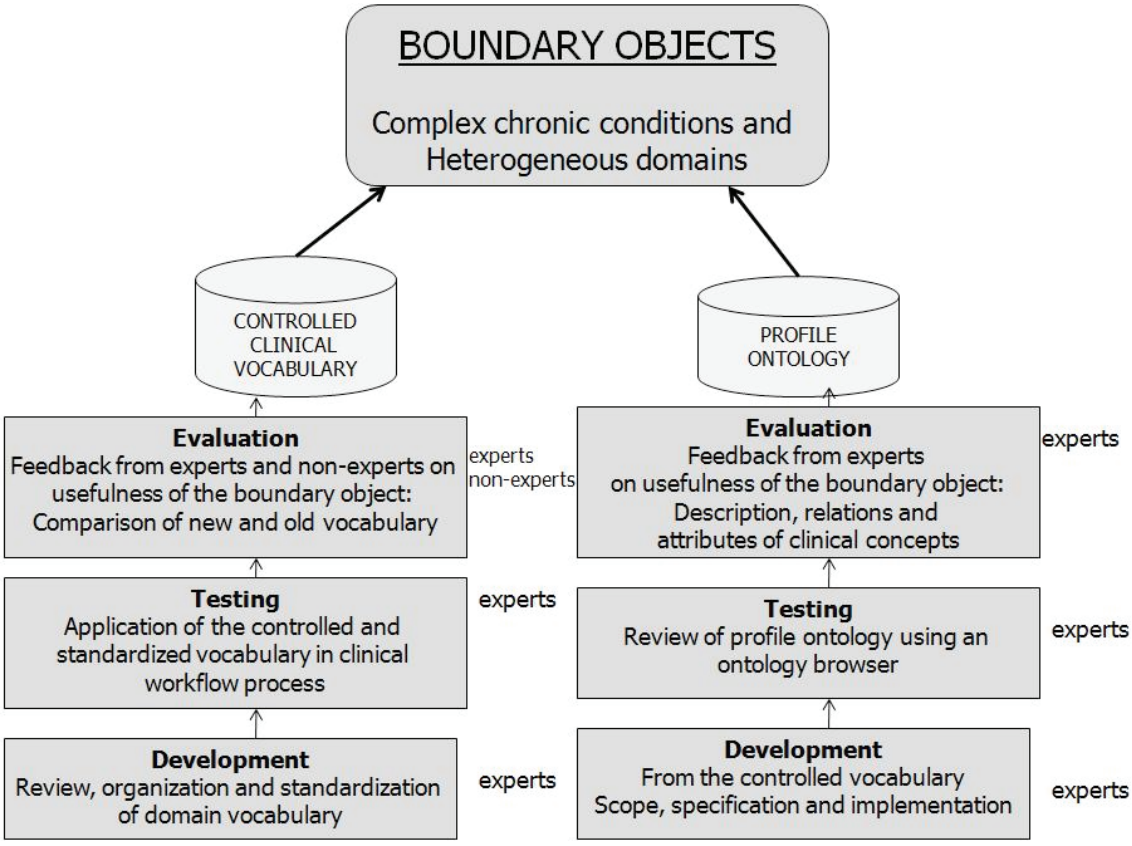

Figure 3 Key phases of the research methodology.

The methodology has applied key considerations of relevance in a heterogeneous domain proposed by other researchers. These include the participation of experts and non-experts of the domain knowledge [22, 23], iterative process in the organization of knowledge to reach consensus [47], involvement of domain experts from the development to the evaluation phase [24, 30, 48], testing of the boundary objects in clinical workflow processes [39, 48] and evaluation of the boundary objects [22,48].

The key phases of the methodology thus include:

- Development of boundary objects
- Testing of the boundary objects in clinical environment
- Evaluation and feedback from experts and non-experts of the domain knowledge

The broader and long-term benefits of this research include:

- A better understanding of the knowledge of the complex conditions in a consistent and standardized manner for experts and non-experts using the information.
- Facilitate the growth of new knowledge in the shared domain in a consistent and semantically operable manner which is very important for emerging knowledge systems.
- Better care environment with timely referrals to specialists and relevant treatment.
- Reduce the burden on the health care system by reducing frequency of redundant tests and treatment, and medical errors.

1.6 CONTRIBUTIONS OF THE DISSERTATION

The contributions of the dissertation can be summarized as follows:

1. Development and validation of a methodology for the creation of boundary objects that are pragmatic, dynamic and standardized form in heterogeneous knowledge domains.
2. Development of a controlled clinical vocabulary and ontology for a complex, chronic condition, namely, multiple chemical sensitivity
3. Development of a controlled clinical vocabulary and ontology for a complex, chronic condition, namely, chronic pain.

1.7 Outline Of This Document

The rest of the thesis is organized as follows. Chapter 2 presents an overview of the problems and challenges that exist in the domain of complex chronic health conditions. Chapter 3 is the background section and contains the necessary information required to understand the research concepts applied in this thesis such as boundary objects, controlled vocabulary, ontology and heterogeneous environments. Chapter 4 presents a comprehensive literature review conducted to identify gaps in the literature in the areas of relevance to this research. These include characteristics of the boundary objects developed in this study, boundary objects in heterogeneous domains, controlled vocabulary as a boundary object and ontology as a boundary object. Chapter 5 presents a detailed discussion of the model of the research. This chapter outlines the methodology used in the development of the controlled vocabularies and the ontologies for the complex chronic conditions, multiple chemical sensitivity and chronic pain. Chapters 6 and 7 presents the results of the research in the domain of multiple chemical sensitivity and results of the validation study in the domain of chronic pain. Chapter 8 presents a comparative analysis of results in the multiple chemical sensitivity and chronic pain groups. Chapter 9 presents discussion, conclusions and future work.

CHAPTER 2 CHALLENGES AND PROBLEM DEFINITION

In this chapter, a description of the challenges and problems in the domain of complex chronic conditions is presented. The chapter begins with a definition of key terms and concepts of relevance to this research work. Following this, importance of collaboration and communication in health care is presented. The heterogeneous nature of collaboration in the management of complex conditions and the associated challenges is then presented. A brief view into the nature of heterogeneity in other contexts is also presented.

2.1 TERMINOLOGY

Complex and chronic health conditions have multiple comorbidities, a multitude of symptoms, a lack of clinical practice guidelines and poorly categorized domain knowledge [13,40].

Interoperability is the ability of two or more systems or individuals to exchange information and to translate and use the information that has been exchanged [49].

Pragmatic interoperability is the capability of different information systems or individuals to communicate information/knowledge consistent with the intended meaning and have the ability to translate and re-use the information/ knowledge [43].

Knowledge Heterogeneity in this research refers to the inconsistency, non-standardization, multidisciplinarity and poor categorization in knowledge that can happen at three levels, i.e., syntax, semantic and pragmatic levels [40, 41].

Boundary Objects are objects that exist at the boundaries of knowledge communities and serve as common ground for the interactions between the communities [27].

Controlled Vocabulary is "a list of terms that have been enumerated explicitly " for the purpose of organizing and representing information to facilitate information retrieval"[45].

Ontology is a formal, explicit specification of a shared conceptualization [46].

2.2 Importance Of Collaboration And Communication In Health Care Setting

A study by Clements et al. [50] reviewed the importance of teamwork and inter-professional collaborations in health care. In health care, studies have suggested that teamwork, when enhanced by inter-professional collaboration, could have a range of benefits. A study by Oandasan et al. [51] suggested a possible link to quality and safety such as reduction of medical errors, improving quality of care and building cohesion between health care professionals. A study by Morey et al. [52] showed the clinical error rates in emergency care were significantly reduced from 30.9% to 4.4% by focussing on improving collaboration and team work. This type of result has been confirmed in other studies that have either reported an increase in errors when there is lack of collaboration or reduction in errors when there is improved collaboration.

A range of potential benefits from effective teamwork was identified in the study by Clements et al. [50] summarized from selected teamwork initiatives:

- Improved communication and partnership among health providers and patients
- Clarity on the role of all health providers
- Better response processes in addressing the determinants of health
- Improved coordination of health care services
- High levels of satisfaction on the delivery of services
- Effective use of health resources

There is a general acknowledgement in the literature that improving collaboration in health care translates to improving communication among care providers [53-58]. In a study by Woods et al. [53], clinicians' perspectives of improving communication and patient safety were explored through a focus study. The electronic medical record, communication around care plan and transition care and team oriented solutions were among the key themes identified. Many other studies have explored the role of effective communication in collaborative work in health care [54-58].

The effect of vocabulary differences on patient-patient communication has long been recognized and studied by medical anthropologists and practitioners [59,24]. The importance of patient-physician communication for patient satisfaction and health outcomes is increasingly recognized [60] and communication skills are increasingly promoted as a necessary part of medical education [61].

There is also recognition that the platform to enable better communication is in the knowledge that exists in patient records [22, 53]. The patient profile documents generated by integrated care teams for complex and chronic conditions are important since they may be used by multiple providers at various times in the delivery of care [21]. The patient profile document is thus a key clinical document that is essential for consequential, timely and relevant delivery of care for patients. Multiple health care providers and health care disciplines will often refer to the profile document at various stages of the care management. The patient profile or the problem list document is thus a binding object that can maintain a seamless and relevant exchange of patient information among care providers if generated with the intent of enabling shared understanding. Patient records form a binding object for care providers that are multidisciplinary but could be involved in different communities of practice and at various times of care.

2.3 Lack Of Collaboration And Communication In The Management of Complex Chronic Conditions

The challenges related to collaboration in the management of complex health conditions can be viewed as being consistent in other fields with similar levels of complexity [28,30]. The outcome of ineffective collaboration in health care can however be significant as they can result in medical errors and serious consequences for patients. There are several studies that have discussed these challenges which could result in serious outcomes such as medical errors [15,36], delay in care or lack of timely referrals [17, 19], poor quality of care and experience for patients [14] that can lead to increasing costs in health care system [1,2].

Recent studies have demonstrated that the problems associated with lack of collaboration and communication can no longer be ignored for complex health conditions despite the challenges that exist in enabling them. Schoen et al. [14] explored the experiences of patients with complex conditions in eight countries. The study concluded that among the negative experiences in the health system for patients with complex conditions, error rates due to inadequate coordination was found to be 34% in the US and 25% in Canada.

A study by Kennedy [15] explored the errors in clinical documentation related to inconsistency and incompleteness. A study by Pace et al. [16] reviewed the medical errors reported by 34 primary practices to a patient reporting system. Some of the results from the study included ambiguous communication of recommendations, unclear records and failure to negotiate treatment plan effectively among other care providers. A study by Walsh [22] discussed some of the challenges experienced by clinicians in working together such as timely sharing of patient information, use of technology and the need for formats to build structured gathering and sharing of patient information in clinical documents.

As outlined earlier in chapter 1 and in this chapter, these conditions have a heterogeneous knowledge base that is inconsistent, non-standardized, multidisciplinary and poorly

categorized. The next section discusses the collaboration challenges in heterogeneous environments.

2.4 Collaboration Challenges In Heterogeneous Environments

Collaborations in heterogeneous environments are a fairly extensive topic, widely researched with many interpretations on the nature of heterogeneity and exploration of potential solutions.

2.4.1 Heterogeneous Computer Systems

This is a widely discussed topic in the context of heterogeneity in the computing environment. There have been varied solutions offered to integrate the interactions between heterogeneous computer systems, programs and environments. We have presented a few research studies of relevance that have used middleware as boundary object to improve communication among heterogeneous computer systems.

Most of these studies tried to work with the middleware component of the interaction between systems. Middleware sits "in the middle" between application softwares that may be working on different operating systems [62]. A study by Drosos et al. [63], the potential for enabling collaboration among heterogeneous systems, devices ranging from simple everyday objects with sensing, actuating and communication capabilities to complex computer systems was evaluated. The aim was to look at how collections of such distributed objects can collaborate and provide functionality that exceeds the sum of their parts. A middleware was developed that could support building, configuring, reconfiguring ubiquitous computing applications using distributed objects.

In another study by Allan et al. [64], the problem tackled was the heterogeneous sharing in synchronous collaboration in diverse computing environments, such as wearable computers and handheld devices. The authors built a robust middleware having a distributed repository of shared data objects and client-server-based infrastructure in order to facilitate a framework that can allow building collaborative applications for clients in a heterogeneous environment, i.e., different display and processing capabilities.

The authors evaluated the middleware and the framework using four complex sample applications that demonstrate scalability, good performance and high degree of code reusability. In another study by Chowdhury et al. [65], the enhancement of effective collaboration of an adaptive quality-of-service management is queried in a heterogeneous environment (weird and wireless). The client profiles and system resources can be significantly different and dynamic thus posing a challenge for collaboration. The study presented a design and a prototype implementation of a framework for collaborative multimedia applications in a distributed and heterogeneous environment. The key consideration was to ensure that the semantic content was maintained while catering the diverse requirements of the environment. The study included a preliminary evaluation of the framework for wired and wireless clients.

While it is challenging to draw a direct analogy from these studies to the scenario that is under consideration, some high level analogies of relevance have been drawn from these studies. Most of these studies have identified the key area of impact that can facilitate collaborative work such as the middleware among computer systems. The studies considered the importance of identifying the nature of collaborations and develop, implement and evaluate a framework that could best serve to enhance the communication in the existing scenario.

2.4.2 Challenges Of Heterogeneity In Interactions Among Humans

This section will present discussions that exist in the literature on the challenges that exist in human interactions and the key factors that could contribute towards the heterogeneity.

Ackerman [66] discussed the challenges of building systems that could handle the complexity of social activity. Based on survey findings, he concluded that computational entities have to be flexible, nuanced and contextualized to match human activity. Ackerman's findings are supported by other studies. They show that a gap arises when "rigid and brittle" technical systems fail to handle the flexibility and the detail essential to conduct collaborative work and social interactions. In this study, the lack of

compatibility with rigid interfaces was viewed as a contributor for heterogeneity in collaborative interactions among the technicians involved in the work.

Tacit knowledge is another area that has been implicated in the creation of gaps in collaborative work.

"Tacit knowledge is knowledge that has not been formulated completely explicitly and therefore cannot effectively be stored or transferred entirely by impersonal means." (MacKenzie and Spinardi [67]).

There has been extensive discussion in the literature on the difficulties of working with knowledge that is tacit [68-74]. The software development community has realized that a large number of problems can be attributed to implicit and unshared knowledge, specifically the need of knowing 'who knows what', the need for distance collaboration, and the need for recording the lessons learned and best practices. Information and knowledge obtained during meetings, email correspondences, and instant messaging need to be captured easily, stored and shared effectively.

Studies have also discussed the complexities involved in the collaborative work for individuals dealing with cutting edge or dynamic knowledge domains. In an observational study, Kinti and Hayword [75,76] discussed the challenges of a multidisciplinary team that is working with a cutting edge technology developing a prototype for digital mammography. The authors describe the nature of the collaborative work to be characterized by high levels of uncertainty, tension and conflict. In an extension to this work, they compared the work of such specialized collaborations as being additionally challenging due to the goal of the activity not being given or poorly defined. However, they argued that process of innovation in these collaborations requires the experts working with poorly defined problems thus emphasizing the importance of enhancing communication for collaborators. These challenges are similar to the ones that exist in the management of complex chronic conditions such as multiple chemical sensitivity, chronic fatigue syndrome and chronic pain where explicit knowledge is very

limited, awareness of the conditions in the medical community is sparse and new knowledge continues to build in an ad hoc manner and in silos.

A study by Fong et al. [25] in the context of designing projects for military work described the advantages of seeing a common vision in the design stages of the project to facilitate the building of the right type of knowledge. They describe the struggle of two groups that start with different visions to achieve the same goal and demonstrate how having a common vision to achieve the goal helps build the right type of bridge to close the gap and communicate at the design phase itself.

Engeström [42] stated in a study about collaborative work: "*There is a new generation of expertise around, not based on supreme and supposedly stable individual knowledge and ability but on the capacity of working communities to cross boundaries, negotiate and improvise "knots" of collaboration in meeting constantly changing challenges and reshaping their own activities*". In other words, experts in this field have to work with evolving and dynamic knowledge.

In a study by Warner [77], a team model was developed based on two case study scenarios. In this study the authors explored team collaboration and decision-making in complex, data-rich situations to better understand the cognitive processes employed when teams collaborate to solve problems. The key processes identified in this research included (1) individual knowledge building, (2) developing knowledge inter-operability, (3) team shared understanding, and (4) developing team consensus.

Poor documentation can also lead to ineffective collaboration in human interactions [59]. This study outlined the importance of proper documentation to maintain the stability in the interactions among stakeholders. In addition to having the design and the system well documented, the authors emphasized the importance of keeping the documentation up-to-date. In order to prevent incorrect assumptions and ambiguity, the authors suggested that documentation must be current and reflect the work that is being done by various teams or members.

Collaboration over distance can face the loss of the rich, subtle interactions that collocated teams use to coordinate their work. Research in distributed software engineering suggests that working across sites introduces substantial delays to the development cycle because of reduced communication, difficulty in finding the right person and establishing contact, as well as not having an effective collaborative session [78]. In this study, the authors demonstrated that when engineers' offices were about 30 meters or more apart, the frequency of communication would drop to nearly the same low level as people with offices separated by many miles Another study showed that the rate at which scientists collaborated spontaneously with one another was a function of distance between offices [79].

There are considerable discussions in the literature around the challenges involved in the collaboration of multiple individuals working in complex and heterogeneous work environments. Some of these challenges include the complexities involved in social interactions, tacit knowledge, collaborations in emerging or cutting edge technologies, poorly categorized domain knowledge, poor documentation all of which apply to the interactions among clinicians involved in the care of complex and chronic conditions considered in this research.

2.5 Problem Definition

In this thesis, the potential of the boundary objects approach has been investigated with overall objective of developing consistency, standardization and pragmatic interoperability in the heterogeneous domain of complex health conditions.

In this thesis, heterogeneity is defined as a knowledge domain that is poorly categorized, multidisciplinary, inconsistent and non-standardized. In the earlier section in this chapter, an overview of the outcomes of poor collaboration and communication among clinicians in the management of complex conditions was presented. This section describes the heterogeneity for complex conditions that is consistent with the outlined

factors that contribute towards heterogeneity in human interactions identified in the previous section.

Tacit knowledge is a widely recognized problem in health care as well where domain experts maintain a significant amount of clinical knowledge on conditions as purely experiential or tacit. This makes it challenging for new users or users with limited experience to have access to the complete knowledge of the health conditions. This is consistent with the type of health conditions considered in this research where primary care providers are often unable to develop complete understanding of the conditions due to knowledge being tacit among experts [3]. This can be a key contributor in the poor categorization of domain knowledge for complex health conditions.

The inconsistent and non-standardized clinical vocabulary found in clinical documentation can also result in poor categorization of the domain knowledge for complex conditions [38,39]. Two studies have examined this aspect in complex chronic conditions at different levels of exploration. Aroujo [38] presented a discussion of the challenges encountered by clinicians in the management of Fibromyalgia and Somatization Disorder which have overlapping clinical terminologies that have inconsistent and non-standardized usage. He explored the hypothetical advantages of developing consistency and standardization of usage for these terminologies to improve communication among clinicians. Paterson [39] examined the standardization of knowledge in patient discharge summaries for chronic kidney conditions. This study assumed a homogeneous domain for chronic kidney condition.

The domain knowledge for complex chronic conditions consists of multidisciplinary vocabulary since more than one health discipline is generally involved in the care management scheme such as physicians, nurses, dietitians or psychologists [7-13]. Challenges related to multidisciplinary vocabulary has not been explored in the literature. However, the challenges in the collaboration of multidisciplinary clinicians have certainly been examined [80,81].

In this thesis, a model is proposed to address the problem of heterogeneity that exists in the domain of complex chronic conditions that can contribute towards communication gaps among multidisciplinary clinicians involved in the care management of these conditions.

CHAPTER 3 BACKGROUND

This chapter presents the background information of relevance to this thesis. The subsequent sections will present an overview of the relevant background information that is required to understand the core contents of this thesis work. Then a detailed description of boundary objects is provided with definition and presentation of relevant background information on boundary objects. An overview of the boundary objects developed in this study, controlled vocabularies, SNOMED CT, ontologies and ontology browsers are also presented in this chapter.

3.1 Boundary Objects Approach To Building Shared Understanding

The essential criteria are that it should facilitate communication between communities of practice and disciplines of care and have flexibility to meet individual needs and community needs [27-43].

Boundary objects are entities that are flexible enough to adapt to local needs and the constraints of stakeholders employing them, yet specific enough to maintain a common identity across different interpretations. Boundary objects essentially exist and are used at the interfaces between these communities of practices. A community of practice has a shared understanding of what the community does, of how to do it, and of how it relates to other communities and their practices. The boundary object provides communities avenues to communicate, coordinate and collaborate. Furthermore, boundary objects carry information and context that can be used to translate, transfer and transform knowledge between communities of practice [27,43]. Furthermore, these objects can also be dynamic [32]. They can be changed and manipulated to carry more information or context. As a result of the evolutionary characteristic of a boundary object and its ability to carry information and context, different communities can communicate and collaborate with each other.

3.1.1 Boundary Objects Approach

Boundary objects is a concept introduced by Star and Griesemer [27] that refers to objects that serve as a common ground among knowledge communities. It was first studied in the field of ecology by Star and in the context of enabling knowledge exchange among social communities with varying backgrounds of knowledge. Star and Griesemer used the instance of the specimens in a zoological museum as boundary objects to establish the importance of this concept in shared work. Zoologists used the specimens for research activities and maintained information on where and when the specimen was collected with all aspects around habitat of species being important to their work. Amateur collectors with varying background were involved in finding these specimens and providing them to the museum. In this work the authors discuss how the knowledge groups maintain aspects of the information that overlap with other groups at the boundaries of intersections which are available for transformations, negotiations and modifications as necessary to assist in collaborative work.

The boundary objects approach developed from the Actor Network Theory (ANT) developed by Akrich and Latour [82]. A brief overview of ANT is provided in the next sub-section.

3.1.2 Actor Network Theory

The notion of boundary objects evolved out of the Actor Network Theory (ANT) [83]. At the basic level ANT assumes the existence of heterogeneous networks that could be made up of humans and non-human actors. Translation is a core concept in ANT and it describes the transformation and the possibility of one thing to stand for another or to be interpreted as another entity as long as they become integrated into a network of unified idea such as an organization or a node in a higher level of network [82-84]. ANT is important in the concept of socio-technical gap paradigm as it considers the possibility of a gap from both sides. A key concept of the interaction is embedded in the possibility of translation that should exist and the influence the actors in the network have on each

other in relation to this. Akrich [82] stated that "a large part of the work of innovators is that of inscribing their vision of the world in the technical content of a new object." ANT suggests that this inscription process can align the interests of all of the actors in the network, and that "a translation process supposes a medium or a material in which it is inscribed." An understanding of how this translation and abstraction works can be useful building major information systems.

An instance of ANT in play is the heterogeneous group of actors in a hospital environment [85]. A hospital is made of human and non-human actors. Human actors include physicians, patients, nurses, allied professionals, technicians and administrators. The human actors are diverse in their roles, disciplines, interests and interactions. Non-human actors can include medical devices and clinical information systems. The clinical information systems add a layer of heterogeneity in their functions and accessibility. Berg [86] writes that "approaching health care practices as heterogeneous networks is a crucial first step towards systems that will articulate more powerfully and more artfully with their surrounding networks."

The ANT lead to the conceptualization of entities or objects, namely, boundary objects [27] that can work as translation devices in collaborative work, intersecting social worlds and satisfying the needs of the intersection of the worlds as well as at the individual level.

Star and Griesemer addressed the heterogeneity that exists in participants involved in knowledge sharing and the translation that is required in their social worlds through the concept of boundary objects. They used the example of participants in the Berkeley Museum for Vertebrate Zoology in their study. This problem of translation led them to conceptualize boundary objects as objects that crossed the boundaries between multiple social worlds, being used within and adapted to many of them simultaneously. Successful negotiation requires careful management of the boundary objects, their representations, and the interfaces they provide between social worlds as noted by the authors. They examined the social worlds of the museum‘s director, the museum‘s founder and chief patron, amateur collectors, trappers, and the University of California administration in

order to fully document and explain the museum‘s growth and success. They then identified boundary objects that crossed between these worlds, including specimens, field notes, museums and maps of particular territories, which were used to accomplish the shared goals of the stakeholders. In particular, they found four different types of boundary objects: repositories (e.g. libraries or museums), ideal types (such as species and atlases) abstracted from all domains, geographic spaces (e.g. California), and standardized forms (e.g. for collected artifacts).

As considered in the basic theory of ANT and boundary objects, the heterogeneity is reference to the multiple actors involved and considered the common point of interaction or mediation in the stable world of multiple actors, i.e., each world has stability in the knowledge. In this research heterogeneity is interpreted as the unstable knowledge in the individual worlds as well as in the mediating point in terms of lack of standardization, multidisciplinary, constantly evolving and dynamic or unstable domain knowledge [40]. The application of the appropriate type of boundary object to fit this knowledge domain is examined in the next section.

3.1.3 Characteristics Of Boundary Objects

In reviewing the literature, it is evident that research is at an elementary level in this area with efforts seen mostly in the conceptualization of theoretical models for the application of boundary objects [28-39] with a few that have identified pre-existing objects and a few that have attempted to create boundary objects for collaborative work [39]. Some important characteristics of boundary objects have been explored in the literature. These include primary and secondary boundary objects, visionary and ideal boundary objects, dynamic boundary objects and flexible and standardized boundary objects.

Primary and Secondary boundary objects

Aspects of the boundary objects discussed in the literature include the primary and secondary boundary objects in socio-technical projects. Garrety and Badham [87] identified technology as the primary object in their study, the material artefact around

which the activity is organized. The secondary boundary object being other physical or abstract entities that enable communication across social communities (e.g. contracts).

Ideal and visionary boundary objects

Ideal and visionary boundary objects have been outlined by Briers and Chua [88] in which they discuss the nature of visionary boundary objects which are conceptual and harder to be argued against with example being institutional "best practice". Ideal boundary objects are considered easier to identify and create compared to visionary boundary objects which are more abstract and are built around conceptual values that may not translate into tangible mediation objects in collaborative work.

Temporal boundary objects

There are a myriad of studies that have explored the characteristics of boundary objects in various contexts. Different artefacts in different contexts have been studied as boundary objects: primary, secondary, ideal and temporal. Yakura [29] looked at timelines (i.e., a graphical representation of a set of temporal units in the lifetime of a project) as boundary objects, and demonstrated their ability to reconcile diverse socially constructed temporal arrangements.

Dynamic Boundary Objects

Although the types and use of boundary objects have been examined in a variety of organizational and social settings, most research on boundary objects has examined them in a context of relatively stable settings and/or for short periods of time.

Henderson [33, 34] emphasized the role of visual representations as boundary objects in the world of design engineers. Wenger suggested that boundary objects can be used as a means to bridge across boundaries between communities of practice in order to enhance

inter-organizational learning activities [89]. Subrahmanian etc. al. [90] and Tajfel [91] discussed changes in design and manufacturing teams and the consequent affects they have on boundary objects. They claimed that changes disrupt common grounds among organizations and therefore open a debate on the role of existing boundary objects, but fall short of exploring the dynamic process by which boundary objects relate to social infrastructures and identities.

Most studies have maintained the concept of boundary objects in a static approach assuming a constant role and a relatively stable environment [92,32]. Gal and colleagues [32], highlight the importance of the interplay between social communities and identities with boundary objects drawing on a three year interview based study of modeling technologies. They argued that, in addition to serving as translation device to overcome informational differences, boundary objects are 'used as a resource to form social identities' in a relational process. It is thus important to ensure that the boundary objects do not become too rigid and the boundaries less permeable, and the knowledge sharing more problematic. In the current research, it is important to consider this aspect of boundary objects as the domain knowledge is evolving and rigid boundary objects may present a problem in fluid domain knowledge such as the ones in this study.

Standardized Forms

Henderson [33,34] examined the role of sketches, drawings, and other visual diagrams in the work of engineers, particularly how the introduction of formal systems that computerized these diagrams significantly affected the relations between social worlds. The author used boundary object theory to conceptualize the diagrams as boundary objects, also adding knowledge about conceptualization of conscription devices. Henderson defined these as deliberately constructed objects that enlist group participation and contain knowledge created and adjusted through group interaction with a common goal. Since these conscription devices were used by different roles (designers, shop workers, etc.), The diagrams had to remain sufficiently flexible to allow transfer of knowledge between these workers and result in a successful project. Henderson's

extensions to boundary object theory paved its way into the discussion of flexibility and standardization of boundary objects. Star has said that most studies using her theory have not considered this as strongly as necessary [93].

Fujimura [94] argued that boundary objects were disadvantageous for establishing stabilization of domains if they are too flexible. Rather than providing a standardized set of facts and methods, boundary objects can result in some facts and methods becoming distributed and accepted across multiple social worlds, while others may not. Thus facts may not be as stable as desired. Fujimura conceptualized standardized packages as less abstract and more structured than boundary objects. Such packages combined multiple boundary objects with standardized methods in ways which further restrict and define each object, reducing the possible interpretations without entirely defining them.

Fujimura then used this concept in a study of why and how the molecular biological approach in cancer research developed. The author found that the standardized package of abstract, general oncogene theory and the specific, standardized technologies promoted to study cancer allowed this approach to gain traction with scientists and researchers across multiple social worlds. Unlike boundary objects, Fujimura argued, the standardized package fundamentally changed local practices in enrolled scientific laboratories in ways which extended and solidified molecular genetic representations of cancer. One can consider Fujimura‘s work either an extension of boundary object theory or a new theory that adopts some of its concepts. Fujimura’s discussion of standardized forms is important to this research. The domain knowledge is dynamic with multiple communities contributing towards and applying the knowledge that exist in the common space. In this thesis, a need for two layers of standardization is identified to ensure they maintain the flexibility while allowing the translation to occur in the intended form and format to facilitate collaborative sharing of knowledge.

Pragmatic Boundary

Carlile [26,43] distinguished among the rules followed by boundary objects– syntactic, semantic, and pragmatic. Depicted in Figure 4 are the rules for boundary objects proposed by Carlile.

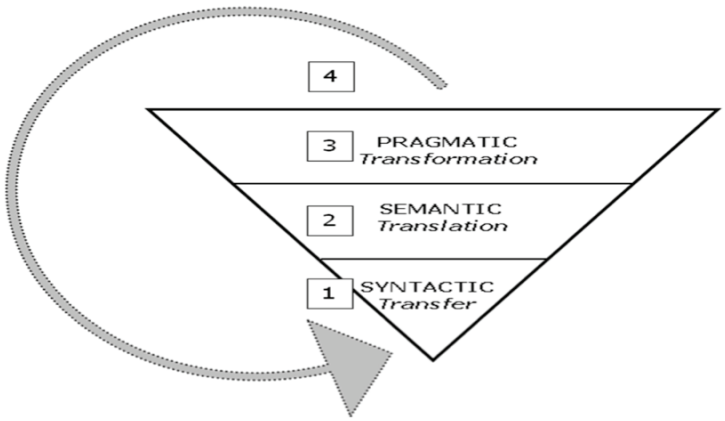

Figure 4 Syntactic, semantic and pragmatic boundaries (adapted from Carlile's work [26]).

1. Establishes some shared language/syntax for representing each other's knowledge - syntactic
2. Provides individuals a concrete means of specifying their differences and dependencies - semantic
3. Facilitates individuals in negotiating and transforming their knowledge in order to create new knowledge - pragmatic
4. Supports an iterative approach where individuals get better at representing, specifying and transforming knowledge.

The three rules described by Carlile are important in the context of meeting the needs of knowledge communities that use the boundary objects. For instance, a group of experts in the management of a certain medical condition can create a repository of terms at a syntactic level to describe profile characteristics of patients such as fatigue, shortness of breath with exertion and food sensitivities facilitating shared understanding in the group. The group can also create a "shared meaning" at a semantic level for the terms

facilitating translation of the terms for the multidisciplinary clinicians such as “fatigue “ meaning low energy or tiredness. In addition, the group can develop a pragmatic layer facilitating knowledge transformation in the form of boundary objects using standardized terminologies such as Systematized Nomenclature of Medicine – Clinical Terms, SNOMED CT [95] that can be understood and interpreted by a larger audience. The term “fatigue” can be described with a concept ID of 84229001 as an energy and stamina finding with synonyms being tiredness and weariness. This allows different groups to share, translate and transform knowledge at the boundary level. Carlile proposed that pragmatic boundaries can facilitate interactions among social groups that will go beyond the level of mere translation.

Carlile also considered the standardized methods along with the types of boundaries. She explored standardization in terms of the form that could produce the highest levels of coherence and convergence among the interacting communities. It is a useful consideration to boundary object theory as it explores the balance between flexibility and standardized form of boundary objects.

In this thesis, it is essential to consider the pragmatic level of sharing of the boundary objects since experts and non-experts, clinicians with multidisciplinary backgrounds and at various times in care will share the knowledge that exists in these objects. It was essential to ensure the knowledge can be easily and accurately translated and re-used.

3.1.4 Application Of Boundary Objects

Boundary objects have found their applications in collaborative works in the field of management [28], among design teams [29], information technology [31], architecture [30], manufacturing systems [32-34], and in health care [35-39]. Other studies have examined the nature of collaborative work and identified artifacts that can be considered boundary objects given the nature of collaboration. Henderson [33,34] studied the efficacy of hand drawn sketches of design to CAD-CAM drawings in an organization

designing new turbine engine packages. A study by Carlile [26] showed the effectiveness of a re-designed assembly drawing as a boundary objects in the development of new safety valves for a manufacturing firm.

The recent trends of application have been in the fields of library and information science (LIS) and computer science. Applications of boundary object theory have included the study of communities, organizations, information systems, and information behaviour. A particular focus in LIS, especially more recently, has been on the information behaviour of users, communities, and organizations and how it relates to information systems such as databases and digital libraries serving as boundary objects. Such studies also examine the various social and information worlds and various communities of practice that these objects necessarily translate and interface between.

Besides the original study in conjunction with Griesemer [27], Star has conducted other studies the theory of boundary objects. Initially, the author applied the theory to scientific groups (as seen in the original study) and within the field of artificial intelligence. Star‘s work with Bowker and Neumann [92], used boundary object theory and the concept of convergence to study the information behaviour of research scientists and students using information artifacts, specifically digital libraries. They found the convergence between these boundary objects and the individuals‘ information worlds was the deepest for those with the most experience, since their worlds were much more stable and they were much more comfortable with which systems which boundary objects fit the best for them.

Several other researchers have also applied boundary objects. Bødker and Christiansen [93] are amongst a number of other researchers who have applied boundary object theory to studying and/or theorizing on a variety of problems; in their case, to the design of computer and information systems for supporting cooperative work. Drawing from both activity theory and boundary object theory, they considered the tools used for such design as springboards and boundary objects. They felt the tools played a role in supporting and keeping track of the systematic reflection about design ideas, reflections often shared in large projects that crossed the boundaries of communities of practice. Bødker and

Christiansen concentrated on the use of scenarios as boundary objects, providing a mutual understanding of problems of the current work which would then act as a springboard for further designs and changes. While they did not extend boundary object theory, they did use it as a basis for further theorizing on the role of scenarios in the design and development of information systems. Bannon [96] loosely applied boundary object theory to examine the use of the very concept of the interface by the field of human-computer interaction (HCI), particularly how it acted as a frame for the work of many different groups despite their differing perspectives. The author compared this against the use of a much greater variety of boundary objects in the field of computer-supported cooperative work (CSCW), concluding that the latter showed more potential for being an ongoing, interdisciplinary field of research and practice because of a larger core set of common boundary objects.

Gal et al. [32] as discussed earlier also used boundary object theory to examine users of information in the context of the architecture and engineering industry. The systems and information artifacts used by construction firms, artifacts, and engineers acted as ever-changing boundary objects that changed and shaped the social and information worlds of these users, as well as their information behaviour. As noted above, they developed a model focusing on the dynamic interplay between social identity, infrastructure, community, and the boundary objects themselves.

Gasson [97] used elements of boundary object theory albeit loosely in applying Carlile‘s [26] characteristics of the different types of boundary objects discussed above to the design and manufacture of products for the telecommunications industry by an engineering firm. Her study found that new uses of boundary objects signalled a change in genre for the group, where each stage in the process of design used different boundary objects with different characteristics in different ways. From the findings, Gasson developed a model of modes of knowledge use during each of the stages of design, which she felt could be applied to the sharing and construction of knowledge for problem-solving in most organizations.

Application of boundary objects in health care has been scarce as discussed earlier.

A study by Patel et al. [36] examined the potential of pharmacy labels as boundary objects in the collaborative work of multiple stakeholders. They examined the impact of the introduction of a new technology, pharmacy labels in the collaborative work of pharmacists and technicians [36-39]. They concluded that dynamic boundaries introduce spatial and task restructuring within the interacting communities.

A study by Aroujo [38] explored a hypothetical scenario considering the shifts in interaction among providers in the management of complex conditions, Fibromyalgia and Somatization Disorder where the commonly used terminologies of relevance are standardized and used as boundary objects.

There are three studies of relevance to this research that are mentioned in this section but will be discussed in detail in the literature review chapter. A study by Te-Shu [37] explored the application of boundary objects in process improvement in a hospital setting. They introduced a problem response report to improve the collaborative work among multiple stakeholders in a hospital to improve the identification and solution of administrative process related issues. A study by Paterson [39] examined the development of a standardized discharge summary as a boundary object for chronic kidney conditions. A study by Lin et al. [40] examined the challenges of developing an ontology as a boundary object in the collaborative work of a group of mental health professionals.

3.2 CONTROLLED VOCABULARY

A controlled vocabulary can be defined as "a list of terms that have been enumerated explicitly" [45] for the purpose of organizing and representing information to facilitate information retrieval.

A controlled vocabulary adds an interpretive layer of semantics between terms entered by the user and the underlying database to represent the original intention of the user. This is an important aspect not only to establish clarity between a user and the database but when a domain is used by multiple users with varying levels of expertise and backgrounds. In the absence of a controlled vocabulary, information can be introduced in a very ad hoc manner by multiple users of the domain. For instance, a term “fatigue” can be captured as fatigue by a user at one time while other users or the same user may capture it as “very tired”, “without energy” or “low energy” at other times. But when it comes to retrieving useful knowledge from the database, using an uncontrolled vocabulary will lead to the results including only the terms entered by the retriever. If the retriever entered "Fatigue" in the search box, they will not get any of the results for documents that use the terms “low energy", “without energy” or “very tired”. This leaves all of the information that is relevant to this query in the domain knowledge.

Controlled vocabularies range from classification schemes and taxonomies with semantic relationships to complex thesauri showing associative relationships between terms [98,99]. The steps for the development of controlled vocabularies are well defined in the literature [45,100]. There are examples of well known vocabularies in use that have been extensively discussed such as the Metathesaurus, Eurodicautom, Unified Medical Language System, Systematized Nomenclature of Medicine – Clinical Terms (SNOMED CT) to name a few. The literature on controlled vocabularies can be grouped under those that have discussed their design [100,101], those that have discussed methodological considerations in the design [98, 99, 102], studies that have discussed the qualities of a good vocabulary [45] and studies that have highlighted the evaluation of controlled vocabularies [48]. There are several studies that have evaluated the use of SNOMED CT, in the creation of controlled vocabularies for various health conditions [47, 103-108].

Controlled vocabularies, such as the Library of Congress Subject Headings, are an essential component of bibliography, the study and classification of books. They were initially developed in library and information science. In the 1950s, government agencies began to develop controlled vocabularies for the burgeoning journal literature in specialized fields; an example is the Medical Subject Headings (MeSH) developed by the

U.S. National Library of Medicine. Subsequently, for-profit firms (called Abstracting and indexing services) emerged to index the fast-growing literature in every field of knowledge. In the 1980s, the first full text databases appeared; these databases contain the full text of the indexed articles as well as the bibliographic information. Online bibliographic databases have migrated to the Internet and are now publicly available; however, most are proprietary and can be expensive to use. Students enrolled in colleges and universities may be able to access some of these services without charge; some of these services may be accessible without charge at a public library.

Web searching could be dramatically improved by the development of a controlled vocabulary for describing web pages; the use of such a vocabulary could culminate in a Semantic Web, in which the content of web pages is described using a machine-readable metadata scheme. One of the first proposals for such a scheme is the Dublin Core Initiative [109]. An example of a controlled vocabulary which is usable for indexing web pages is Polythematic Structured Subject Heading [110].

Controlled Medical Vocabularies [107] enable shared understanding among medical communities. They are a tool used to standardize information for purposes of capturing, storing, exchanging, searching, and analyzing data. Controlled medical vocabularies are chosen words used to tag units of information for the purpose of easy retrieval through searches in the medical field. These are compiled based on the input of experts and authorities in specific areas, the occurrence in literature and reference from documents of authority. They contain terms that are chosen by consideration of structure and scope of the vocabulary. When it comes to these vocabularies in the medical fields, they take on more specific needs and obstacles ever present in the wealth of information of the health care arena.

The purposes of these vocabularies include:

- reduce ambiguity that is inherent in normal human languages
- exchange information consistently between different providers, care settings, researchers, etc.

- overcome differences in medical information recording from one place to another (unified medical terminology system needed)
- summarize medical information
- allow symbolic manipulation of data (searches for specific analysis)
- automated reasoning (i.e. clinical decision support)

Some examples of these medical vocabularies include Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT®), Logical Observation Identifiers Names and Codes (LOINC), OpenGALEN, and the Unified Medical Language System (UMLS). In this study we have considered the use of a widely accepted reference medical vocabulary, SNOMED CT®. This reference terminology is described in detail in the next section in this chapter.

3.2.1 Systematized Nomenclature of Medicine – Clinical Terms

SNOMED CT® or Systematized Nomenclature of Medicine SNOMED CT® [95] is a comprehensive, multilingual, controlled clinical reference terminology, with comprehensive coverage of diseases, clinical findings, etiologies, procedures, living organisms, and outcomes used for recording clinical data. It provides a common language that enables a consistent way of capturing, sharing, and aggregating health data across specialties and sites of care. SNOMED CT® is relational, concept-based system with more than 300,000 unique concepts and more than 900,000 descriptions. Concepts are organized by defined relationships and organized in 19 hierarchies or facets. Certain concepts can exist in multiple hierarchies. Studies have explored the use of this standardized terminology in capturing disease concepts and some have even studied the benefits of such standardization in improving collaborative care management. The main advantages of SNOMED CT® are that it is multiaxial, hierarchical and has the provision to express the underlying knowledge.

Studies have explored the breadth of SNOMED CT® coverage in representing various complex clinical concepts and areas of medicine [20, 47,104-108]. Asbeh et al. [106] applied SNOMED CT® to develop a consistent and minimal diagnosis set for developmental disorders and found SNOMED CT® to provide coverage up to 85.7% of the terms required to organize the terminologies. In a study by Elkin at al. [20], the ability of SNOMED CT® to represent common problem lists in the Mayo Clinic was evaluated. SNOMED CT® was able to represent 92.3% of the terms used in the medical problem lists. According to the authors of this study, improvements to synonymy and adding missing modifiers could lead to greater coverage of common problem statements.

A few others have discussed the standardization of clinical vocabulary used in clinical documentation using SNOMED CT® and evaluated the application of the controlled vocabulary in improving patient care processes. A study by Elevitch [108], discussed the improvement in safety standards by using a reference vocabulary in anesthesia care. A study by Paterson [39] explored the enhancement of semantic interoperability of clinical documents for chronic conditions such as chronic kidney disease, hypertension and diabetes. In this study, a semantically interoperable discharge summary was generated as a boundary object by creating a standardization platform for the vocabulary used in the document from reference vocabularies such as SNOMED CT®.

3.3 ONTOLOGY

An ontology is “an explicit and formal specification of a conceptualization” [46]. An ontology consists of a finite list of terms or concepts and the relationship between these terms.

Despite their high level of specification of these classes and relationships, ontologies also allow a great deal of flexibility. Hine [111] discussed the use of ontologies in integrating and standardizing experimental data from sources in the genetic, cognitive and neuroanatomical domains, with the Gene Ontology being the most prominent among them. The Open Biomedical Ontologies website contains an extensive collection of open

biomedical ontologies and related information. The challenges discussed by Hine include building common and formalized knowledge framework that can be used across different disciplines and communities of practice. Dominigue et al. [112] in their paper reviewed the key requirements for an ontology approach to knowledge management as community's perspectives being stable on an issue with "well defined roles", "specified criteria" and "codified procedures".

3.3.1 Web Ontology Language OWL

The Web Ontology Language (OWL) is a semantic mark-up language for ontology representation [113, 114]. OWL provides the capability of creating classes, properties and instances. OWL is derived from DAML+OIL (DARPA Agent Mark-up Language + Ontology Inference layer). Resource Description Framework (RDF) is a standard model for data interchange on the Web. RDF has features that facilitate data merging even if the underlying schemas differ, and it specifically supports the evolution of schemas over time without requiring all the data consumers to be changed. OWL uses both URIs for naming and the description framework for the Web provided by RDF to add the following capabilities to ontologies:

- Ability to be distributed across many systems
- Scalability to Web needs
- Compatibility with Web standards for accessibility and internationalization
- Openness and extensibility

OWL is considered to have large vocabulary and a rich syntax. There are three variants of OWL with corresponding to different levels of expressiveness, OWL Lite, OWL DL and OWL Full.

OWL is derived from DAML+OIL (DARPA Agent Mark-up Language + Ontology Inference layer).

There are three sub-languages of OWL:

OWL Full: It is an extension of RDF. It permits an ontology to enhance the semantics of pre-defined RDF/OWL vocabulary.

OWL DL: It is a part of OWL Full that is in the Description Logic framework. It supports maximum expressiveness while preserving computational completeness and decidability. Although OWL DL contains all OWL language constructs, they can be utilized under specific precincts, e.g., a class cannot be an individual of another class.

OWL Lite: It is a subset of OWL DL. It allows classification hierarchy and simple constraints

Since OWL DL provides maximum expressiveness along with computational guarantees and allows decidable reasoning, given the complex nature of the domain under consideration, OWL DL is the best choice for representation of knowledge in the form of domain ontology. A brief overview of components of OWL DL of relevance to this thesis is presented below.

Class: A class includes group of individuals that belong together because they share some properties. Built-in most general class for OWL is called Thing. Thing is a super-class of all OWL classes and class for all the individuals in an ontology. In the profile ontology developed in the study, psychosocial profile is a class that contains all individuals that share some properties related to this class.

subClassOf: This feature is used to organize the classes in a hierarchy. For example if Energy Finding is a subclass of Physical Profile, then a reasoner can conclude that if an individual such as Fatigue is Energy Finding, then it will also be a Physical Profile.

Property: Property is used to establish relationships between individuals (object properties) or with data values (datatype properties). Object properties can include *hasProfile* or *hasPatient*. Data properties can include *has Age* or *has Address*.

domain: It is the class to which a property belongs. When a property specifies a class as its domain, and relates an individual to another individual, then this individual must belong to the property domain class.

range: If a property relates an individual to another individual, and if it specifies a class as its range then, the other individual must belong to the class specified as range.

Individual: These are instances of classes. One individual is related to another individual by means of properties.

OWL Property Characteristics

In addition to ObjectProperty and DatatypeProperty, as mentioned previously, OWL has many other property characteristics:

inverseOf: If a property A is inverse of property B, and if an individual C is related to D via A then individual D will also be related to C via B. For example, hasPatients is inverse of another property hasOrganization, an individual with MCS is patient of organization.

SymmetricProperty: Properties can be stated to be symmetric. For example isSymptom can be regarded as a symmetric property, whereby, Pain is a symptom of Fatigue and Fatigue can be a symptom of Pain.

FunctionalProperty: When a property can hold one and only one value which is unique. It means that the maximum cardinality for this property is 1. For example hasAge is a functional property since an individual can have one and only one age.

OWL Header Information

An OWL ontology begins with the declaration of namespaces. This tag contains the OWL-metadata for the document.

OWL Annotation Properties

OWL DL allows annotations on classes, properties, individuals and ontology headers.

3.3.2 Protégé

Protégé [114] is a free, open-source platform that provides a growing user community with a suite of tools to construct domain models and knowledge-based applications with ontologies. At its core, Protégé implements a rich set of knowledge-modeling structures and actions that support the creation, visualization, and manipulation of ontologies in various representation formats. Protégé can be customized to provide domain-friendly support for creating knowledge models and entering data.

The Protégé-OWL editor supports the Web Ontology Language (OWL). "An OWL ontology may include descriptions of classes, properties and their instances. Given such an ontology, the OWL formal semantics specifies how to derive its logical consequences, i.e. facts not literally present in the ontology, but entailed by the semantics.

The Protégé-OWL editor enables users to:

- Load and save OWL and RDF ontologies.
- Edit and visualize classes, and properties.
- Define logical class characteristics as OWL expressions.
- Execute reasoners such as description logic classifiers.
- Edit OWL individuals for Semantic Web markup.

3.3.2 Ontology Browsers

The clinicians had to review the ontology developed in the study using an ontology browser. The four ontology browsers considered in this study were Jambalaya [114], TGViz [114], Google ontology browser [115] and OwlSight [116].

***TGViz and Jambalaya**:*

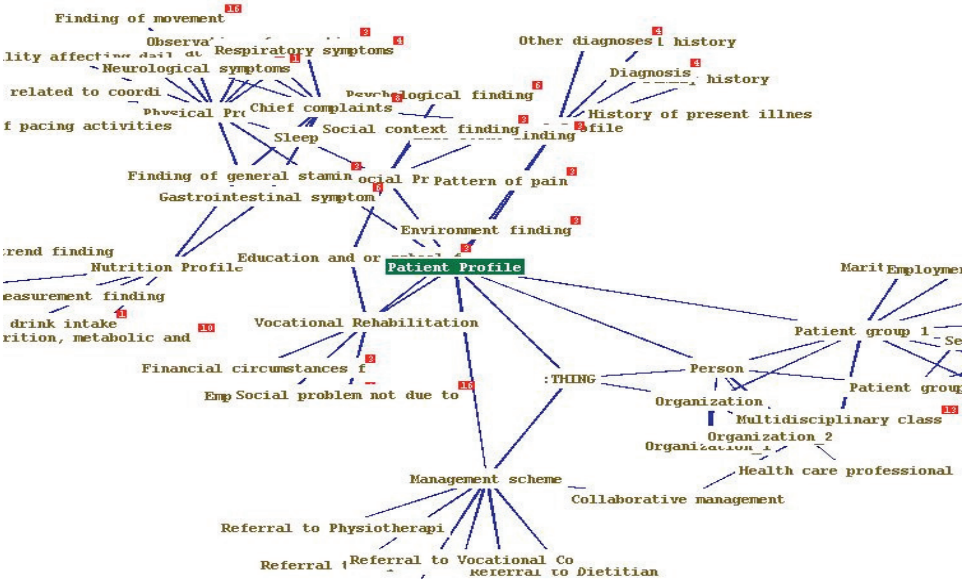

Figure 5 Display of patient profile in TGViz ontology browser.

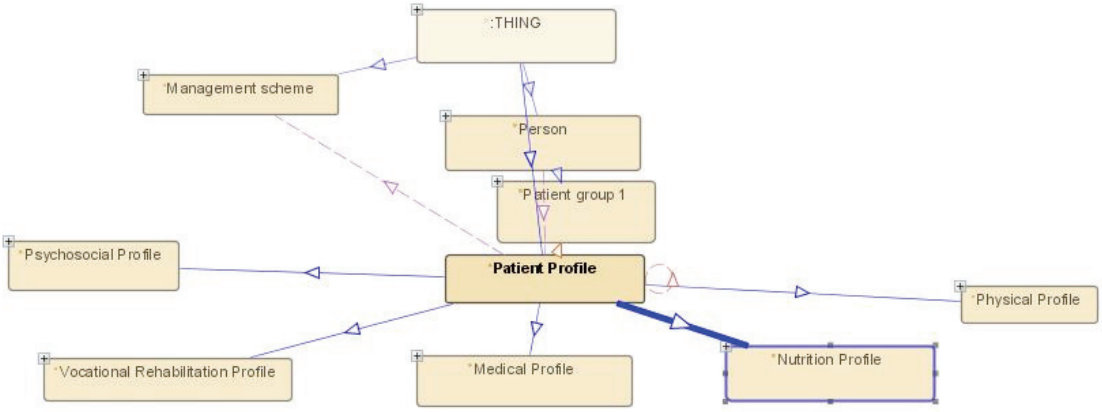

Figure 6 Display of patient profile in Jambalaya ontology browser.

TGViz and Jambalaya are Protégé visualization tools and are plug-ins in Protégé (Figures 5 and 6). Both are great visualization tools and provide opportunities to query the ontology. The following challenges were identified related to the requirements of this study:

1. They are both Protégé plug-ins and can be accessed only if Protégé is downloaded on a computer. This was a challenge for the study as clinicians preferred a web-based access and had to browse the ontology from multiple physical locations. A web-based browser would be preferable over Protégé plug-ins.
2. Both tools require technical knowledge of Protégé in order to be able to navigate and browse the ontology.
3. The visualization schemes do not allow access to the information or interpretations presented in the ontology of the health conditions

OwlSight and Google ontology browser

Both browsers are open access online browsers with capabilities to accept upload of ontologies in a web-based browsing format. OwlSight is an OWL ontology browser that runs in any modern web browser; it is developed with the Google Web Toolkit. OwlSight uses an OWL reasoner.

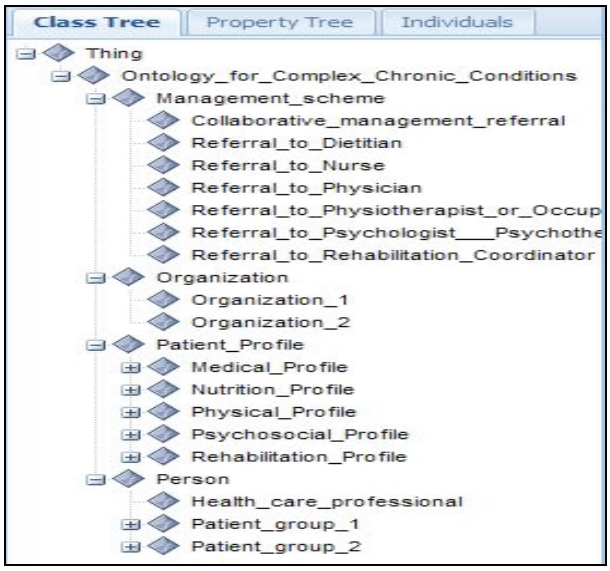

Figure 7 View of profile ontology in OwlSight ontology browser.

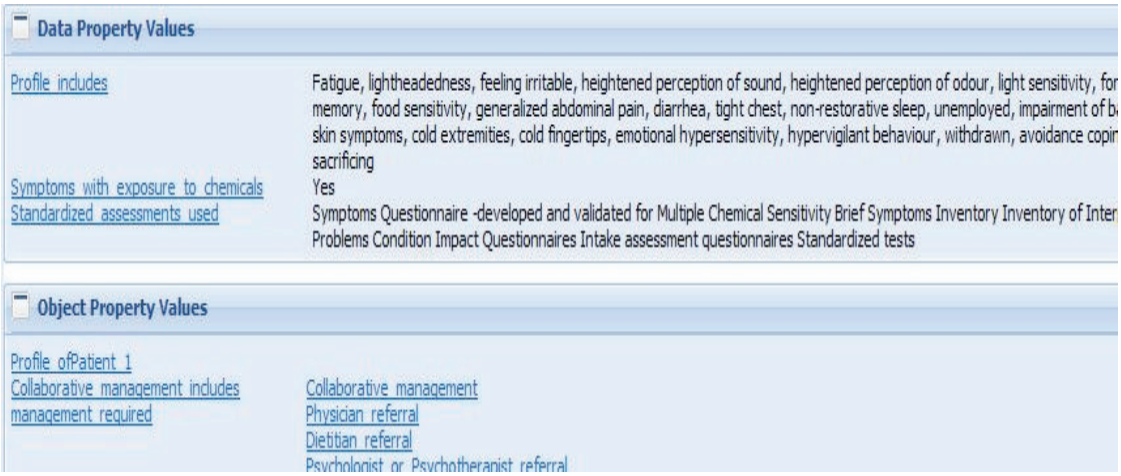

Figure 8 View of profile information for a patient in OwlSight ontology browser.

Figures 7 and 8 show the browser views of the profile ontology and specifics of a profile in the OwlSight, a web-based browser.

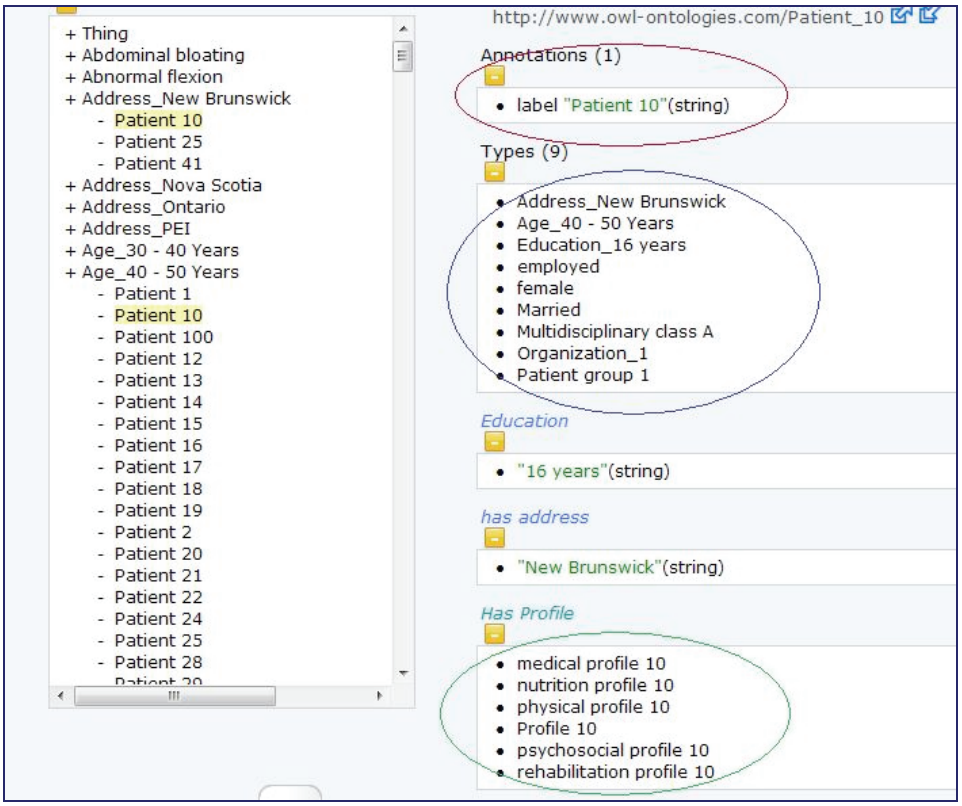

Figure 9 View of ontology in Google ontology browser.

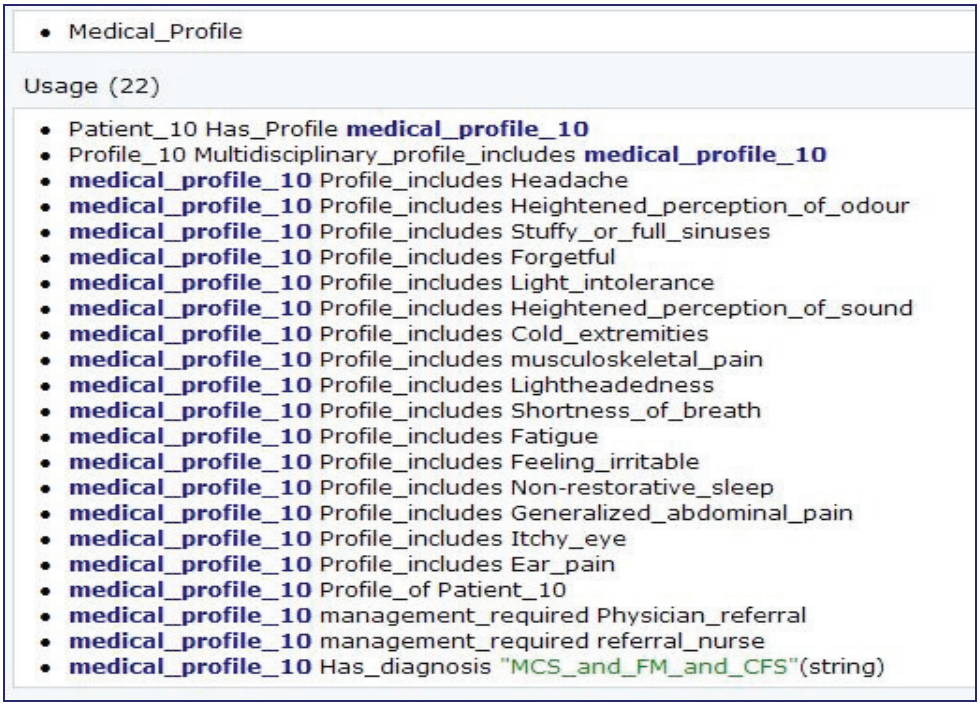

Figure 10 View of a patient profile in Google ontology browser.

Figures 9 and 10 show the browser views of the profile ontology and specific profile of a patient in the google ontology browser [115]. Google ontology browser developed by a research group in Manchester performed better than OwlSight in the following aspects:

1. Reliable upload capabilities
2. Better navigation capabilities that included viewing multiple levels of details and being able to return to original view
3. Minimum to none crashing of the server during browsing protocols
4. Better visualization capabilities
5. Google ontology browser allows user to select each concept in the ontology through hyperlinks
6. Querying abilities not available in OwlSight

Google ontology browser was thus selected as the browser that will be used by clinicians to evaluate the usefulness of the ontology.

3.4 Controlled Vocabulary And Ontology

A controlled vocabulary can be thought of as the backbone of an ontology. It is a set of terms in a subject domain that may have been given definitions and unique identifiers, but which has no explicit relationships among these terms.

Ontologies consist of a set of classes that represent concepts defining a field and the relationships among these classes. These are distinguished from other ways of organizing knowledge, such as controlled vocabularies and taxonomies, by the richness and expressiveness of relationships. An ontology builds upon a controlled vocabulary by adding the ability to define other relationships between entities beyond identifier, definition, and place in the hierarchy. Relationships such as “part of” allow entities within the ontology to be related to one another across the taxonomic hierarchy. These relationships themselves are entities that can be rigorously defined based on what is required to describe the knowledge domain. In order to manage and perform computations on the different relationships between entities, ontologies are usually

encoded into a language that allows a machine to manage and utilize the information. Tools that act like the "word processor" of an ontology such as Protégé [114] use a language like OWL as a convenient standard. Once this knowledge has been captured in a machine processable form, it becomes easier to exchange and utilize this knowledge within information systems. The ontology can be e-mailed or posted on the internet, merged with descriptions of other domains, split apart, and modified algorithmically.

In the next chapter, a detailed literature review that was conducted to support the proposed model and methodology is presented. The methodology requires the development of boundary objects that are dynamic, stable and easily translated in the heterogeneous domain of complex chronic conditions with a global objective of improving collaboration among multidisciplinary clinicians. The chapter on literature review presents a discussion of the latest research and identifies gaps in the areas outlined.

CHAPTER 4 LITERATURE REVIEW

This chapter presents the detailed literature review conducted to support the model and the methodology developed in this thesis work. The chapter begins with a discussion on the methods and techniques in use to improve communication in health care of relevance to the current research. Then a review and identification of gaps identified in boundary objects literature in health care is presented. Following this, the review conducted to examine the status of literature on using controlled clinical vocabulary and ontology as boundary objects and in heterogeneous domains is presented.

4.1 METHODS AND TECHNIQUES TO IMPROVE COLLABORATION IN HEALTH CARE

In homogeneous environments, there are many approaches that have been discussed as methods to improve collaboration in health care such as controlled vocabulary, ontology, through health care routines, and medical rounds. Discussed in the subsequent sections are some important approaches in use in health care to improve collaborations. These approaches are compared to the methodology used in this study.

4.1.1 Health care Routines

A study by Greenhalgh [117], discusses the role of routines in collaborative work in health care. In this theoretical exploration, the author discusses overcoming the complex collaborations in health care through the use of organizational routines. An organizational routine is "a repetitive, recognizable pattern of interdependent actions, involving multiple actors." It is suggested that the routine may be the most fruitful unit of analysis when researching organizational change and set out its defining characteristics. One purpose of routines in organizations is to reduce uncertainty. In the context of this work it is important to draw attention to the fact that one of the primary challenges that needs to be addressed in this research is that interactions among the collaborators are ad hoc and do not have routines. The collaborations are in fact inconsistent and require a level of

standardization. This method cannot be adopted given that there are no identifiable organizational routines that can improve collaboration. The other point of consideration is that multiple communities of practice are involved and hence it will be a significant challenge to develop a global routine for all the stakeholders that are involved.

4.1.2 Delphi Technique

It is worth mentioning the Delphi technique for reaching consensus around collaborative work. In the Delphi method, group members are given questionnaires soliciting their opinions and reasons for them [118]. Results are compiled and sent out in a second round of questionnaires. After each round of questionnaires, information is consolidated and Team Decision Making again circulated anonymously among group members, until the results yield a group decision. This method takes a good amount of time and effort, but the results are a consensus, well thought out decision. Computer methods of administering the Delphi technique speed up the process. This method should only be used when making big, long-term decisions since it is so time intensive. In the proposed methodology, aspects of this approach are used in the iterative process in which clinicians are involved in reviewing the group information, providing feedback and reaching a consensus. However, given the nature of complexity of the research, there are other aspects that are above the layer of merely developing a consensus regarding the collaborative work. The study participants are involved in the actual development, testing and evaluation of the objects / processes that will enhance collaborative work. Furthermore, there are two groups that are involved in the process, experts and non-experts of the domain knowledge.

4.1.3 Nominal Group Technique

The nominal group technique [119] takes advantage of the benefits of working as a group while avoiding many of the potential problems. First, team members individually create solutions to the problem, and then each member describes his/her solution to the rest of

the group. In this first phase, team members are not allowed to criticize the solution, only to clarify it. Next, members vote on the solutions, picking only the top five (or whatever number is decided). The solution and member reasoning for choosing the solution is then shared with the group, starting with the solution given the most votes, and so on. Questions may be asked by all team members. Finally, members rank the solutions, and the votes are compiled until a solution is reached. This method is good to use in situations where input from all is necessary and self-limiting behaviour is potential problem. It avoids self-limiting behaviour by requiring all members to participate. Similar to the Delphi technique, the current research objective requires a more sophisticated methodology as it involves multiple groups and development, testing and evaluation of the objects to be used in the collaborative work. The participating clinicians did use a Likert scale (ranking scheme) to show their level agreement on the proposed solutions.

4.1.4 Methodology And Model For Collaboration In This Research

Based on the review conducted, a unique methodology and model has been developed in this work that has considered the requirements and the level of complexity involved in the heterogeneous domains of complex conditions. The methodology and model has elements of the Delphi technique and nominal group technique embedded in it. In this methodology, the clinicians were offered opportunities to be involved in the development, testing and evaluation of the collaborative processes / boundary objects. They offered their individual feedback and as a group in an iterative process to reach consensus towards the controlled vocabulary and the ontology developed in this study. Other elements integrated into the methodology included interviews, testing and evaluation of the boundary objects given the complex nature of interactions and the heterogeneous nature of the domain knowledge. A detailed discussion of the methodology is provided in Chapter 5.

4.2 Boundary Objects In Health care

There is very limited research in the health care literature on the application of boundary objects that is relevant to this work in the areas of improving collaboration and process, in chronic health conditions and in heterogeneous environments.

One study stands out as it attempted to use an artifact as a boundary object to improve collaboration and gathered some preliminary data from the users of the boundary object to determine process improvement. In a study conducted by Te-Shu [37], improvements in the collaborative functioning of multiple departments of a hospital is investigated through the use of a boundary object, a problem response report known as the A3 report to integrate the operations of various departments. The A3 report was adapted from a report created for Toyota Motor Company which used these reports in the problem report and solution process among the various departments so they could collectively understand how they impacted each other's work. This study uses interviews with the stakeholders to generate the contents of the report, created a feedback tool and validated it in a pilot study and obtained feedback from the end users on the usefulness of the A3 report in the collaborative work. This study did not attempt to create a boundary object based on the users' needs. Feedback is obtained from the users about the useability, knowledge integration and communicability of the tool. The feedback shows higher scores for useability and communicability subscales versus knowledge integration. The study reinforces that the users feel more inclined to use such tools when their opinion has been sought on the usefulness during earlier phases of implementation. The limitations of this work include the feedback from only one department in the hospital. It did not involve the stakeholders in the design or identification of a suitable boundary object. Furthermore, the study did not demonstrate the feedback across multiple departments in the hospital.

There is limited research on developing boundary objects for complex health conditions. In a hypothetical study by Araújo [38], the potential for the use of common symptom terminologies as mediating or boundary objects to integrate the work among professionals dealing with Fibromyalgia and somatic functional syndromes is discussed. The authors conclude that identifying mediating objects and using them consistently can create a shared understanding in the management of conditions such as fibromyalgia. However, this study is hypothetical and did not explore beyond proposing the importance of integrating vocabulary in the management of complex chronic conditions.

Study by Paterson [39] explores the prospective for a controlled vocabulary as a boundary object in the management of a chronic kidney condition. In this work by Paterson, a text corpus is created by manually and automatically retrieving commonly used terms in a patient chart. The terms and concepts are mapped to Systematized Nomenclature of Medicine – Clinical Terms, (SNOMED CT®) using a browser. The discharge summary data was standardized to unique Unified Medical Language System, UMLS concept identifiers. Trainees tested the vocabulary using the information for the same patient. The trainees could insert information in three ways: by typing into a text box, by choosing from a menu option or by selecting entries from a look up file. The discharge summary is then saved in an XML (extended mark up language) format. This study did not consider unstructured data inserted by the trainees. The author indicates a proposed evaluation phase of the vocabulary by nurses, physicians and other clinicians but the details and results of this evaluation are not available at the present time. However, an assumption of this study is that the domain knowledge is homogeneous and a single patient chart is used to develop the boundary object.

Application of boundary objects in heterogeneous environments as defined in the context of this research is limited. A study by Lin et al. [40] examines the potential to create a common understanding among a group of mental health professionals through an ontology approach. This study outlines the importance and the challenges of building ontologies in heterogeneous knowledge systems. The study highlights the challenges that exist in the knowledge capture for a domain that has obscure definitions, unstructured

data, inconsistent use of vocabulary and assessment scales, and emerging knowledge with time.

The study by Larson and Martone [41], acknowledges similar challenges in the development of ontologies in obscure domain in their exploration of developing ontology for neuroscience. They suggest introducing a structure to the unstructured domain as a starting point for the ontology.

In heterogeneous knowledge domains, it may be necessary to build a layer of standardization and consistency prior to building a descriptive knowledge of the domain. In a study by Qin and Paling [120], the development of knowledge models in environmental science and ecological science in the collaborative work of a community of scientists and information managers is presented. This study outlines a method to transfer a stable and well categorized controlled vocabulary into an ontology that can introduce a higher level of enrichment and expressiveness to the domain knowledge. Digital objects which are concepts in the Gateway to Educational Materials vocabulary are multi-dimensional in their characteristics. The authors suggest that a conventional cataloguing code will be inadequate to describe crucial and essential details as many of these elements do not even exist in the vocabulary.

In reviewing the literature, the application of boundary objects is definitely gaining popularity as methods to develop shared understanding among communities of practice. More recent trends have seen increase in application in the areas of library information science and information technology. There is a clear paucity in the area of health care with limited studies exploring the potential of applying boundary objects in chronic health conditions in general or to lesser known conditions as the ones considered in this research. The other trend identified in the literature is to apply boundary objects in homogeneous knowledge bases or stable within individual communities. Study of Lin et al. [40] and Larson and Martone [41] identify the paucity in research in developing boundary objects in poorly categorized domains similar to the one being considered in this research. They describe the importance of creating a level of standardization in the domain knowledge as a starting point for bringing organization to the domain.

4.3 Controlled Vocabulary In A Heterogeneous Domain And As A Boundary Object

Controlled vocabularies have been predominantly developed in stable or well categorized domains in health care. As outlined earlier, controlled vocabularies require the consensus from domain experts and consistency in usage. SNOMED CT® has been used to develop controlled vocabularies for several conditions seen in primary care [103-108]. However, for lesser known conditions with limited documentation, inconsistent usage and lack of clinical practical guidelines, challenges are involved in terms of building consensus on the terminologies and concepts that are in usage or are required to be used.

The steps for the development of controlled vocabularies are well defined in the literature [45, 100, 101]. However there is an emphasis in the literature on the importance of identifying the needs of the users who will use the vocabulary, domain and activities in the creation of good vocabularies [98, 99, 102]. Hjørland [98,99] said a domain can be organized in multiple equally valid ways, depending on the particular epistemological stance taken. Hjørland in his work described the four approaches to designing a controlled vocabulary which could lead to different types of classifications:

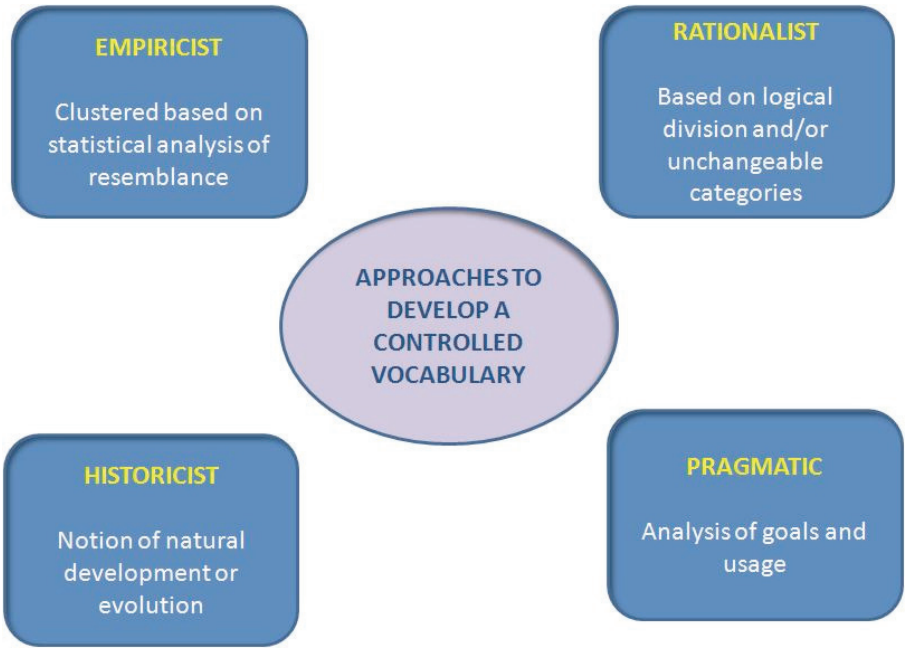

Figure 11 Different approaches to creating controlled vocabularies.

The four approaches are empiricist, rationalist, historicist and pragmatic (Figure 11). Empiricist, rationalist approaches require homogeneous knowledgebase and historicist approaches requires level of confidence in how knowledge exists or will develop. The pragmatic approach however places emphasis on reviewing the goals and the usage in the development of controlled vocabulary.

Certain methodological considerations around the development of a controlled vocabulary in a heterogeneous domain have been outlined by researchers.

a) Goal and Purpose: In a discussion paper by Mai [102], the author outlines the importance of the goals and usage of the pragmatic approach as being the most important aspect in the creation of vocabularies to match the users' needs. This result follows from a line of thinking that argues that a controlled vocabulary "is always required for a [specific] purpose, and why a consideration of that purpose is the most important part of the methodology of information science."

In a study by Helena and Christoph [121] knowledge integration among the multiple users in data warehouse projects is examined. The challenge of non-members of language communities and access to the boundary object was brought to the forefront. The authors suggest that alignment of the community's terminology to the common goal is essential for the viability of the boundary object.

Edman *et al* [30] have made a theoretical proposal for the enhancement of communication between a Swedish design company and its users in the early phases of development to ensure success of implementation. They propose three main phases in their theoretical methodology, namely, a) mapping out existing methods, patterns and situations used by leading practitioners; b) experiments in order to develop improved design methods for user involvement for service innovation; and c) reflections around (a) and (b) in order to find theoretical patterns for global level inference and transference of knowledge.

b) Pragmatic layer of knowledge: Carlile's rules [26] followed by boundary objects– pragmatic is of relevance and importance in building consistency in heterogeneous systems.

c) Standardized format: As outlined by Fujimura [94], controlled vocabularies in fluid or unstable domains require a certain level of standardization so they do not lose their intended identity.

d) Dynamic in nature: The controlled vocabulary has to be dynamic as the domain knowledge will continue to evolve and multiple users will contribute to the evolving knowledge [32].

e) User involvement: Fewer studies have attempted to develop boundary objects with the goal of addressing specific user needs or engaged users in a feedback process [48]. This process is important where the domain knowledge can either be tacit or dynamic. It is important to engage the users in the development and implementation phases so the feedback and enthusiasm towards the new technology is facilitated.

Again, the studies by Paterson and Araujo are the only two of relevance that have examined controlled vocabulary as a boundary object for chronic conditions. Controlled vocabularies are gaining popularity as a way of enabling shared understanding of disease concepts in collaborative care management. Most of the research presented in the literature has developed controlled vocabularies from well-outlined and well-defined health conditions with homogeneous or stable domain knowledge [38,39].

There is limited research on developing boundary objects for complex health conditions. In a hypothetical study by Araújo [38], the potential for the use of common symptom terminologies as mediating or boundary objects to integrate the work among professionals dealing with Fibromyalgia and somatic functional syndromes is discussed. From the hypothetical analysis, the author concludes that identifying mediating objects

and using them consistently can create a shared understanding in the management of conditions such as fibromyalgia.

As discussed earlier, Paterson [39] studied the prospective for a controlled vocabulary as a boundary object in the management of a chronic kidney condition. In this work by Paterson, a text corpus is created by manually and automatically retrieving commonly used terms in a patient chart. The terms and concepts were mapped to Systematized Nomenclature of Medicine – Clinical Terms, (SNOMED CT®) using a browser. The discharge summary data was standardized to unique Unified Medical Language System, UMLS concept identifiers. Trainees tested the vocabulary using the information for the same patient. This study did not consider unstructured data inserted by the trainees. The author indicates a proposed evaluation phase of the vocabulary by nurses, physicians and other clinicians but the details and results of this evaluation are not available at the present time. However, an assumption of this study was that the domain knowledge is homogeneous and a single patient chart was used to develop the controlled vocabulary.

4.4 Ontology In A Heterogeneous Domain And As A Boundary Object

An ontology approach to capturing domain knowledge is explored as a possible modus operandi to organizing knowledge in a heterogeneous knowledge base. Ontologies have gained importance in recent years as a knowledge management platform in many areas including health care [111, 112, 122-124]. Ontologies are preferred to conventional classifications due to the higher level of expressiveness that is possible in describing concepts and their relationships [46]. Hine [111] discusses the use of ontologies in integrating and standardizing experimental data from sources in the genetic, cognitive and neuroanatomical domains, with the Gene Ontology being the most prominent among them. The Open Biomedical Ontologies website contains an extensive collection of open biomedical ontologies and related information. The challenges outlined by Hine include building a common and formalized knowledge framework that can be used across

different disciplines and communities of practice. Dominigue et al. [112] identify the key requirements for an ontology approach to knowledge management as a community's perspectives being stable on an issue with "well defined roles", "specified criteria" and "codified procedures".

In a study by Qin and Paling [120], the development of knowledge models in environmental science and ecological science in the collaborative work of a community of scientists and information managers is described. The research describes the creation of an ontology from a well defined and well used controlled vocabulary in order to provide a higher level of semantics to the concepts in the vocabulary. Digital objects, such as those in the Gateway to Educational Materials (GEM ontology) encompass multiple dimensions of characteristics which often play important roles for users in search of precise information in an efficient manner. The authors provide an example of a lesson plan of arithmetic for fifth graders which may contain information on pedagogy, class activities, math games, test samples, educational standards for fifth grade mathematics curriculum; and as a digital object, it may include text, images, audio/video clips; and it may be a parent object of a collection of child objects or a child object of a parent object. The authors suggest that a conventional cataloguing code will be inadequate to describe these details in a lesson plan, as many of these elements do not even exist in the vocabulary. When an information repository has heterogeneous digital objects, interoperability becomes the first obstacle to provide access to these resources. An important aspect to note about this research is that the ontology was developed from a stable and well defined controlled vocabulary, a key requirement emphasized by Dominique et al [112].

In another study by Lin et al. [40], the challenges of a mental health group of professionals working with emerging knowledge was discussed with a potential to create a common understanding among multiple stakeholders through an ontology approach in a project titled Neuropsygrid. This study describes the challenges and importance of building knowledge through ontologies in heterogeneous situations. The initiative of this work is between a domain expert and an ontology engineer. This study presents the

preliminary challenges that exist in the knowledge capture for a domain that has obscure definitions, unstructured data, inconsistent use of vocabulary and assessment scales, emerging knowledge with time and the challenges associated with domain experts trying to enable the unstructured information to be captured in a machine retrievable format. A significant challenge encountered in this work was to bring structure to knowledge that continues to be generated in an ad hoc manner. The results of this study and a methodology of how the authors are addressing these issues are currently unavailable in the literature.

A study by Laron and Martone [41], the challenges of formalizing knowledge for neuroscience were explored. The authors claimed that formalizing knowledge about poorly understood biological systems presents many obstacles to the development of ontologies. Those who are tasked to do so can find it a daunting and ultimately unproductive task. However, through multiple iterations and by application of ontology best practices formulated and promulgated by the Open Biological Ontologies (OBO) community, the authors were able to come up with a strategy to make the problem manageable. First, they limited our scope to design ontologies for the purpose of applying them to data. The ontologies were designed to provide the links between data acquired by a researcher and the biological concepts used to communicate about their meaning and significance. The overall goal was not, therefore, to encapsulate within the ontology everything that was known about biological systems, but rather to create a structure that would enable clear communication about the data.

The studies clearly outline the challenges that exist in developing ontology as boundary objects in poorly categorized domain. The study by Qin and Paling does offer a process that has been adopted by this research. A controlled vocabulary is created as the first step to enabling organization of domain knowledge.

4.6 Limitations Of Previous Work And Challenges

The literature review was conducted with the following areas in mind, namely, collaboration in the management of complex health conditions, boundary objects in health care and in heterogeneous environments as defined in this research, controlled vocabularies as boundary objects and ontologies as boundary objects.

In reviewing the literature on boundary objects, we found very few studies that have gone beyond the conceptual models [28-32], to the identification of boundary objects in collaborative processes [33-36], to the creation of boundary objects [39] and finally to the actual testing of the impact of the boundary objects in enhancing collaborative work [37]. We found there was paucity of research that had attempted to create boundary objects in unstable or heterogeneous processes. There was also a severe paucity of research on boundary objects in the collaborative work around complex chronic conditions.

The literature on controlled vocabularies can be grouped under those that have discussed their design [85,86], those that have discussed methodological considerations in the design [98-100], studies that have discussed the qualities of a good vocabulary [45] and studies that have highlighted the evaluation of controlled vocabularies [48]. There are several studies that have evaluated the use of SNOMED CT® in the creation of controlled vocabularies for various health conditions [103-108]. In reviewing the literature on controlled vocabulary, we found studies had mostly developed controlled vocabularies for well categorized medical conditions and studies that had explored the availability of disease concepts in SNOMED CT® for well defined and some lesser known medical conditions. However, we found only one study that had used a controlled vocabulary as a boundary object in the context of enhancing communication for providers in a chronic condition. This was the study by Paterson [39] which initiated this process for a chronic kidney condition by developing a discharge summary as a boundary object. There are certain methods used in the research that may require revisions as it relates to our research proposal such as the development of the controlled vocabulary from one patient chart which indicates assumption of a homogeneous knowledge base, absence of

involvement of experts in the design, testing and evaluation of the vocabulary. These aspects come to the forefront when building knowledge domains for lesser known or complex conditions with heterogeneous knowledgebase that have unstructured information, multidimensional and inconsistent vocabularies.

In the ontology work, we found the research primarily focussed on building ontologies from homogeneous knowledge systems [GEM] such as the one by Qin and Paling [120] with the intention of adding another layer of semantic operability to the terminologies found in controlled vocabularies. However, as outlined in the preliminary work of Lin [40] around the mental health group, the challenges are exemplified when working with unstructured and unstable knowledge systems where knowledge is still at its infancy with no agreed consensus of domain knowledge among experts and non-experts users of the knowledge. Laron and Martone [41], also outlined the challenges of formalizing knowledge in poorly categorized and understood domain such as neuroscience. The authors in this research discussed the importance of not trying to encapsulate everything in the ontology in such domains but instead enabling a starting point with the intention of introducing a structure into the poorly categorized domain.

These limitations and challenges have motivated the model proposed in this thesis.

CHAPTER 5 PROPOSED MODEL AND METHODOLOGY OF BOUNDARY OBJECTS APPROACH IN HETEROGENEOUS DOMAINS

This chapter describes the model and methodology designed in this research to develop boundary objects in the heterogeneous domain of complex and chronic health conditions. The chapter begins with a section on the research objectives followed by methodological considerations and the two-staged approach applied in this research to generate standardization, consistency and pragmatic interoperability is presented. Following this, the model development in the domain of two complex and chronic health conditions considered in this research, MCS and chronic pain is presented.[1]

[1] . *Sampalli T, Shepherd M, Fox R. Boundary objects in the multidisciplinary care management of chronic conditions: multiple chemical sensitivity. Stud Health Technol Inform. 2009;143:534-9*

5.1 Research Objectives

In this research, the objective was to develop a model and a methodology for the development of boundary objects in the heterogeneous domain of complex chronic health conditions. The two-staged approach applied in this research is shown in Figure 12.

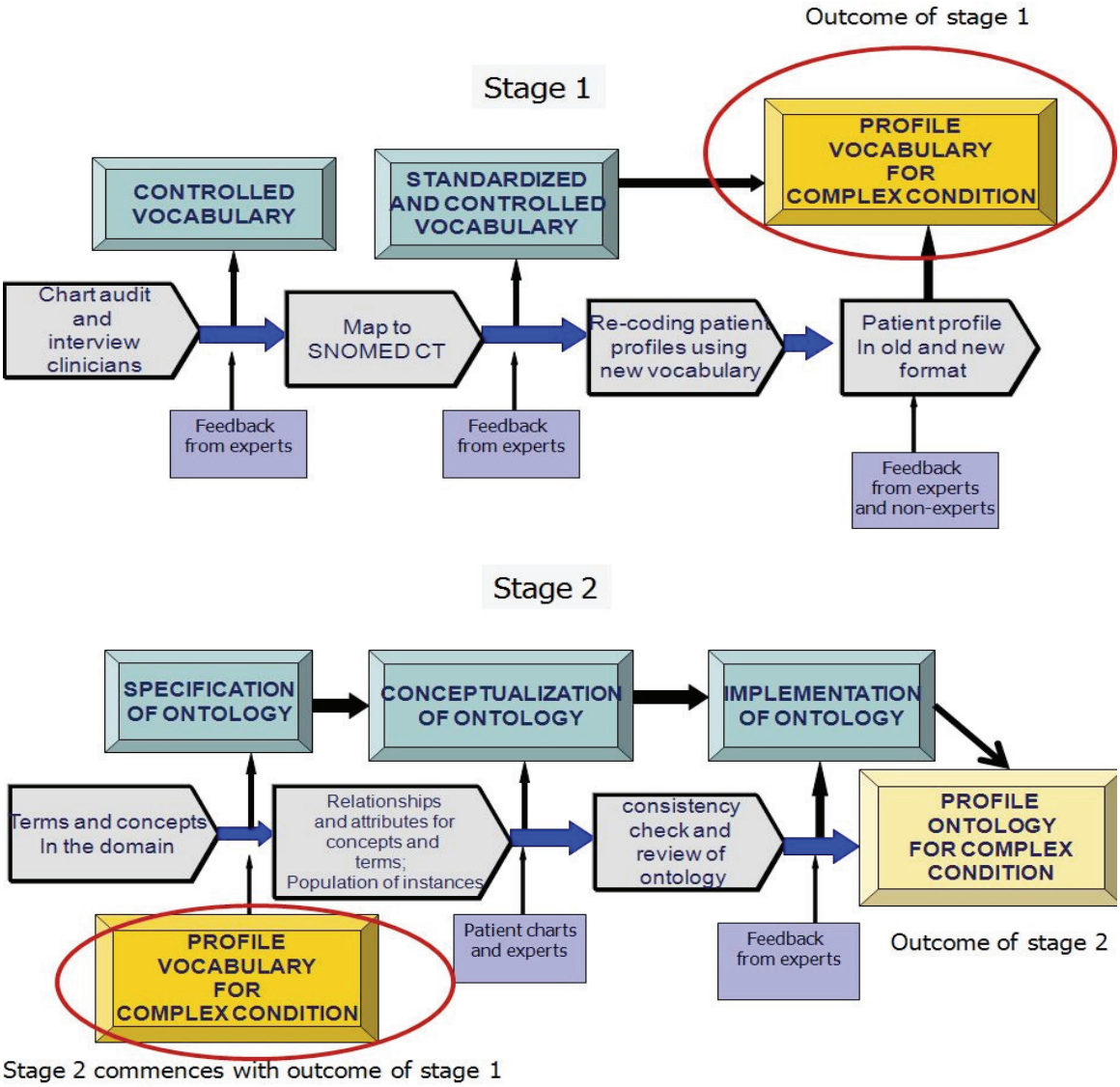

Figure 12 The two-staged methodology applied in the research.

The first stage of the two-staged approach included the creation of a controlled vocabulary consisting of 3 phases: Development, testing and evaluation. The development phase involved experts in the review, organization and standardization of the domain knowledge. The testing phase involved the experts in using the new vocabulary in a clinical workflow process, i.e., re-coding of patient profiles with the new vocabulary. The evaluation phase included obtaining feedback from experts and non-experts of the domain on the usefulness of the controlled vocabulary as a boundary object by comparing the old and the new vocabulary. The clinicians evaluated the vocabulary in the domains of scope (extent of the required knowledge), specificity (detail, granularity and accuracy of knowledge) and structure (organization of knowledge).

The second stage of the two-staged approach was the creation of an ontology as a boundary object consisting of 3 phases: Development, testing and evaluation. The development phase included the experts in the domain specifying and organizing the knowledge in the domain. This phase primarily drew the knowledge from the controlled vocabulary. The testing phase included the clinicians browsing the profile ontology developed in this research to examine the concepts in the ontology, the relationships between concepts, concept attributes and the individuals populated in the ontology. Following this was an evaluation phase that included feedback from the domain experts on the overall usefulness of the ontology as a boundary object with emphasis on usefulness from a health discipline perspective, from the combined knowledge that exists and the multidisciplinary nature of interactions captured in the ontology.

5.2 Characteristics Of Boundary Objects Developed In This Research

The nature of the domain knowledge required that the boundary objects are flexible to account for evolving knowledge that is heterogeneous, can bring a level of organization to knowledge that is unstructured and non-standardized, and can be translated and applied by multiple communities of practice and multidisciplinary groups of clinicians.

The following characteristics are seen important in developing boundary objects in a heterogeneous knowledge domain:

1. Boundary objects that can have pragmatic boundaries [26] – the common knowledge will require capability to be translated and re-used at global and individual levels to create new knowledge
2. Boundary objects that are dynamic in nature – social identities of all social worlds involved will change [32] - interacting communities will change as will the knowledge in the boundary objects as more communities share knowledge
3. Standard forms of boundary objects [94] – important to maintain a level of standardization along with flexibility in order to ensure that the unstable domain knowledge in the common space does not lose the identity or the purpose of the creation.

5.3 Methodology For The Development Of Controlled Vocabulary As A Boundary Object

A standardized and controlled multidisciplinary clinical vocabulary with terminologies standardized using a reference terminology as a boundary object for chronic health conditions is developed in this research. SNOMED CT® , a widely used reference terminology has been used to standardize the concepts and terminologies found in the patient charts.

A pragmatic approach has been applied in the development of the controlled vocabulary as the domain knowledge is heterogeneous.

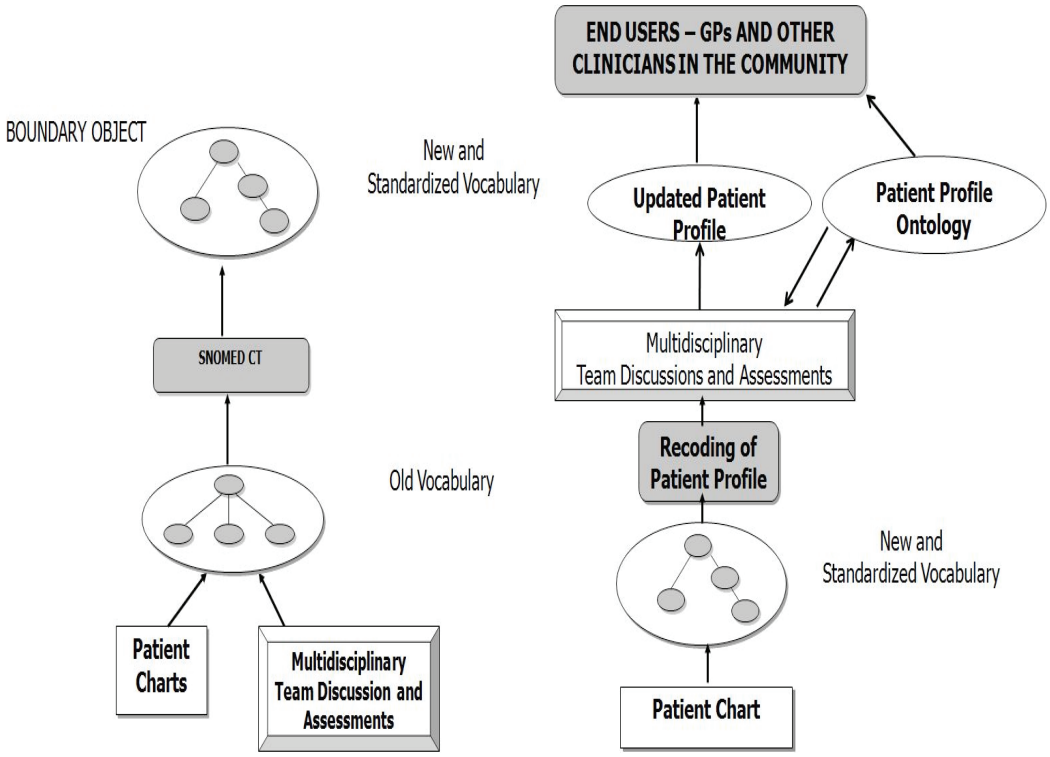

Figure 13 Schematic of the proposed model for the creation of controlled vocabulary.

The model presented for controlled vocabulary will include developing the vocabulary at the levels of syntactic, semantic and pragmatic interoperability. The method for creating the controlled vocabulary will thus fall under the following categories that are driven by the purpose of generating the goal and usage of the vocabulary: chart audit and interviews with experts to identify key concepts in the domain of the complex condition (syntactic), standardization of the vocabulary (semantic), and testing and evaluation of the vocabulary by the users (pragmatic) as shown in Figure 13. The chart audit and interviews with experts helped generate the vocabulary. The re-coding, evaluation and feedback from the domain experts tested and evaluated the vocabulary. A further step in the evaluation included feedback from clinicians in the community.

The research has used the evaluation format proposed by Toews [48] to determine the usefulness of the controlled vocabulary by users and end users of the vocabulary. Description of the concepts captured under these categories is provided below:

Scope: Is the vocabulary capable of representing all of the concepts found in the complete patient record? Does the vocabulary have the terms necessary to represent the full range of health? Does the vocabulary encompass the terminology used to describe the procedures performed by care providers? Does the vocabulary use terms that are commonly used by care providers?

Specificity: Is the vocabulary specific enough to accurately represent the many aspects of health care reality? Is there minimal loss of clinical detail when data are encoded in the vocabulary?

Structure: Are the vocabulary hierarchies logical and complete? Does the vocabulary contain redundant terms?

Useability: Does the vocabulary meet the needs of a range of end users?

5.4 Methodology For The Development Of Ontology As A Boundary Object

A range of methods and techniques to building an ontology have been highlighted in the literature [125-130].

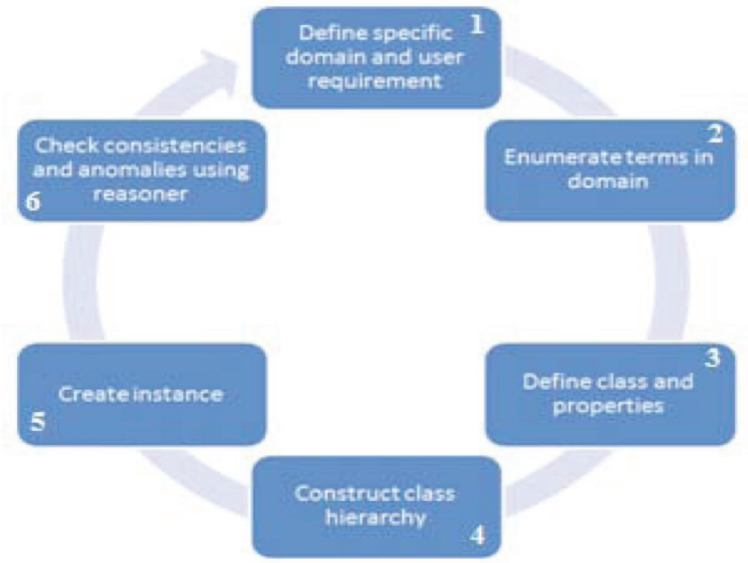

Figure 14 Steps in the creation of ontology (Figure adapted from the work of N.F.Noy [130]).

The methodology for the design of the ontology is adapted from the approach proposed by N F Noy [130] as shown in figure 14.

1. Define specific domain and user requirement. The profile ontology domain has to be defined based on the user requirement.
2. A review of the existing ontologies has been made to ensure that an ontology for this domain has not already been defined by other groups. The terms in the domain will be enumerated. A suggested approach is to write down the terms that exist in the domain in unstructured lists and then sort the nouns as class names and verbs as basis for property names.

3. Define class and properties. Define class and properties based on the list of terms identified in step 2. Class is a set that contains a set of individuals. Each class has properties. Property is a relationship between two classes.
4. Construct class hierarchy. After the identification of relevant terms as class and properties, these terms must be organized in a taxonomic hierarchy.
5. Create Instances.
6. Checking the ontology for consistency – subsumption test and consistency test.

This research has used OWL DL to model the ontology since it is designed to provide maximum expressiveness possible while retaining computational completeness, decidability and availability of practical reasoning. Protégé OWL which allows users to edit ontologies in the Web Ontology Language (OWL) and use description logic classifiers to maintain consistency of their ontologies was used in this research. The ontology development in this research followed the constructs of the controlled vocabulary in its design. Google ontology browser has been used to allow clinicians to browse the ontology.

5.4.1 Methodological Considerations For The Development Of An Ontology In A Heterogeneous Domain

The generic framework for the development of an ontology was divided into three important phases: a specification phase, a conceptualization phase, and an implementation phase [130]. Figure 15 is a depiction of the generic steps and the variations that are involved in the development of an ontology in a heterogeneous domain such as a development of controlled vocabulary and involvement of domain experts.

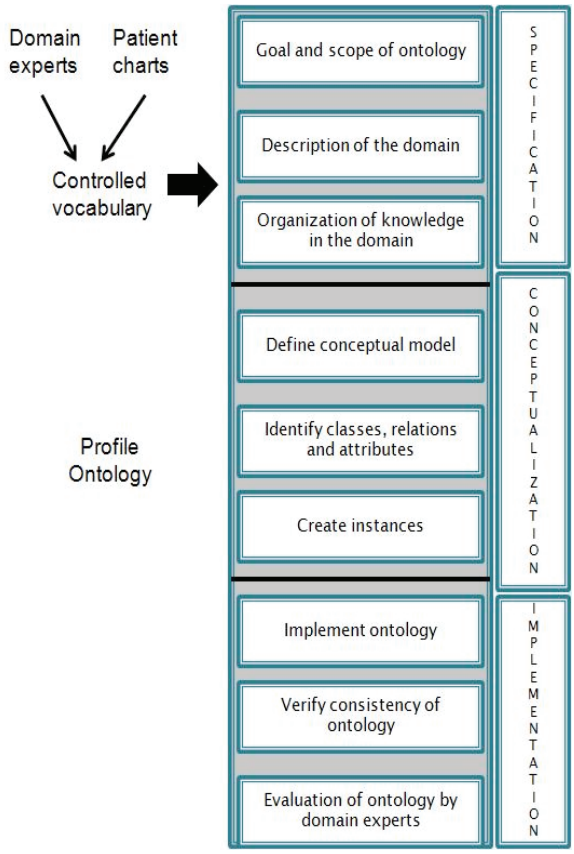

Figure 15 Model for the development of ontology in heterogeneous domain.

The specification phase is to acquire knowledge of the domain. This can be achieved by identifying the primary knowledge sources in the domain, which in this case are the patient charts and the domain experts, i.e., the clinicians.

The goal of the conceptualization phase is to organize and structure the knowledge such as outlining the key classes and relations among these classes in the ontology. The implementation phase involves verifying the ontology through consistency check and user feedback.

The model proposed in this study used the standardized framework for the development of an ontology as outlined above but with special considerations for organization of knowledge in a heterogeneous domain. The specific steps developed to address this in our design have been explained in the subsequent subsections.

5.4.2 Specification

Goal and scope of the ontology

Establishing the goal and scope was the first step in developing the ontology in the heterogeneous domain of complex health conditions. The goal of an ontology determines the overall objective for developing an ontology. The goal of the profile ontology developed in this study was to create a comprehensive hierarchical controlled vocabulary and a representation of the multidisciplinary and multidimensional relationships that exist among the concepts in the controlled vocabulary. Defining the scope of the ontology helps identify the key elements that need to be included in the ontology. The explicit knowledge in the domain for these conditions is limited and the implicit knowledge is very vast. Therefore the scope of the ontology for this research was maintained in the first layer of organization, that is, in the domain of patient profiles. A patient profile or problem list generation is typically the starting point of a care management scheme for patients. The elements in this ontology were maintained on the knowledge that existed in this domain.

Domain description

Complex chronic conditions typically have symptoms that are attributed to a multitude of contributing factors such as physical and psychosocial [7-13]. Multidisciplinary care teams have come to the forefront as an effective management strategy for these conditions. The variety and recurring nature of symptoms in patients with complex chronic illness has led to the belief that management may benefit from the insights of different bodies of knowledge such as medical, nursing, occupational therapy, psychology, and nutrition. Patient profile categorization is therefore more detailed than the typical problem lists that are generated for well categorized medical conditions [21]. Given the involvement of multiple health care disciplines in the care management scheme, the domain contains multidisciplinary concepts. Patient profile knowledge for most health conditions exists primarily in the intake assessments conducted by clinicians.

Organization of domain knowledge

The domain knowledge is unstructured and poorly categorized in the medical records [40,41]. There is also a significant amount of knowledge that exists as tacit knowledge among experts [71]. Knowledge in this domain is heterogeneous and dynamic as outlined in the previous section.

It was thus essential to first generate operational knowledge in the patient profile domain. This process included developing a layer of consistency to the concepts frequently used in the domain [120]. The controlled vocabulary developed in this study helped achieve this layer of consistency. Furthermore, it was essential to develop a level of standardization to the concepts in the controlled vocabulary so the knowledge can be shared among multiple users crossing communities of practice.

5.4.4 Conceptualization

The conceptualization of the ontology commenced with the concepts that exist in the patient profile domain for complex health conditions. As identified in the previous section, it was essential to create a standardized controlled vocabulary that contained the key concepts that existed in this domain following which the relations between these concepts were established. As the knowledge in this domain is still evolving among domain experts, it is essential to involve the domain experts in the conceptualization phase. A key phase of the conceptualization phase was the development of the standardized controlled vocabulary for complex health conditions. The development of the controlled vocabulary included reviewing patient charts, compiling a list of routinely used terms in the patient profile domain with the help of domain experts, standardization of the controlled vocabulary and review of the vocabulary by the domain experts. The creation of the controlled vocabulary helped in the development of top level classes of the ontology. The relations and attributes are then developed with the help of knowledge in the patient charts and domain experts. Described in the next few sections are the key

phases involved in the development of the controlled vocabulary. Figure 2 shows the schematic for the development of the controlled vocabulary. The subsequent sub-sections provide explanation for the components of the schematic.

Review of patient charts

A retrospective audit of 100 patient charts was conducted to identify recurring concepts and terminologies used by the multidisciplinary team of clinicians caring for patients. The identified chart audit terms were grouped under the relevant areas of health focus and by the frequency of occurrence. A review was done by a multidisciplinary team of clinicians to validate the retrieved terms for accuracy and relevancy.

Standardization of terms using Systematized Nomenclature of Medicine – Clinical Terms, SNOMED CT®

SNOMED CT® [95] was used as a reference terminology to standardize the terms retrieved in the chart audit process. The standardization of the chart audit concepts included the following steps.

i. A clinical term was identified for standardization from the chart audit process when the term is a recurring term used to describe a patient profile.

ii. A manual search for an identical match to the source term was made using a SNOMED CT® browser.

iii. A search was made for alternative terms / synonyms when an exact match is not found with the same clinical meaning (i.e. concept match) to the source term.

iv. No match terms were identified.

The multidisciplinary team reviewed the standardized terms for accuracy and completeness.

Re-coding of patient profiles using the controlled vocabulary

A controlled vocabulary with the relevant grouping of standardized concepts in the patient profile domain was created. The multidisciplinary team of clinicians re-coded 3 prototypical patient charts using the new vocabulary. The clinicians used a web-based form to generate the profiles for patients using the controlled vocabulary. The domain experts tested the accuracy, completeness and relevancy of the standardized concepts included in the controlled vocabulary.

5.4.5 Implementation

Protégé 3.4.2 was used to implement the patient profile ontology. The profile ontology was exported into the Web Ontology Language (OWL). The profile ontology presented the formalized description of concepts in the domain of complex health conditions. It included basic concepts and properties that characterize the profile of patients from multiple areas of health. The information for the ontology was developed from the knowledge contained in the controlled vocabulary.

A consistency check of the classes in the ontology was conducted. Consistency checking helped detect classes that cannot have instances. The ontology evaluation also included the review by domain experts for accuracy and completeness of the knowledge represented in the ontology. The google ontology browser was used by clinicians to browse the ontology. They provided feedback on its usefulness using a survey questionnaire.

Study included a review of the ontology by the domain experts, multidisciplinary clinicians involved in the care of the complex health conditions. The evaluation phase included the clinicians browsing various aspects of the ontology such as the classification

scheme, relations, instances, multidisciplinary interactions, standardization of concepts and the overall knowledge of the conditions in the ontology using an ontology browser. For the purpose of this evaluation, four ontology browsers were examined by the researcher to identify a browser that was user-friendly for clinicians in navigation capabilities and effective visualization capabilities.

5.5 Methodology For MCS

A complex and chronic health condition was selected to test the viability of the proposed methodology in a heterogeneous knowledge system. Multiple Chemical Sensitivity (MCS) is a chronic condition that affects multiple body systems [131].

The domain knowledge for this condition was considered to be heterogeneous as it is unstructured, multidisciplinary, poorly categorized, non-standardized along with a significant portion existing as tacit knowledge. This health condition was thus considered to be suitable to test the methodology to organize knowledge using the boundary objects approach in a heterogeneous knowledge domain. This study used a convenience sample approach in testing the model. The focus of the study was to organize the knowledge in the patient profile domain. As outlined in the literature review, the patient profile document is a key document that is essential for collaborative work as multiple and multidisciplinary clinicians get involved at various points of care for patients. Also, it is considered a starting point of work for research of this nature. It is also our hypothesis that organizing and creating a common understanding of this area will pave the way for organization of the treatment domain for this health condition in the future.

A convenience sample of 9 multidisciplinary clinicians and 100 patients participated in the study to develop the controlled vocabulary and the profile ontology in the patient profile domain for MCS.

The creation of the controlled vocabulary included auditing patient charts, interviewing clinicians, and a review of terminology by clinicians for relevancy and accuracy in the domain of patient profile knowledge for MCS. The source terms were then standardized using SNOMED CT® as the reference terminology. The domain experts were also involved in reviewing the standardized vocabulary to ensure accuracy and completeness of the concepts. Community clinicians reviewed the vocabulary for its usefulness by reviewing the old and the new vocabulary for patient profile categorization for MCS.

5.5.1 Development Of A Controlled Vocabulary In The Patient Profile Domain For MCS

Chart audit Patient charts of 100 patients with a diagnosis of MCS were audited to create a text corpus of commonly occurring clinical terminologies and themes used by the multidisciplinary team of clinicians in describing the profile of a patient. The review in the chart audit process was restricted to the intake clinical documents generated by the multidisciplinary team of clinicians since the objective was to identify terminologies and concepts required to describe the profile of a patient with MCS. The descriptives and recurring terminologies existing in these documents were reviewed to generate the current vocabulary used to categorize the patient profile.

The multidisciplinary clinicians were interviewed to receive clarification of terminologies as required in this process. The chart audit and feedback from clinicians were used to identify recurring themes and key terminologies or concepts used in the categorization of the patient profile. The frequency of occurrence of a term in the form of a percentage determined its importance in the patient profile categorization.

Mapping to SNOMED CT® : This work used Systematized Nomenclature of Medicine, Clinical Terms, SNOMED CT® as the reference terminology to standardize the chart audit terms. SNOMED CT® was selected due to the availability of extensive concepts as described in the literature, excellent coverage of complex clinical concepts for many

health conditions and the indication of preference over other terminologies in the literature. The mapping of the concepts included the following steps.

i. A clinical term was identified for mapping from the chart audit when the term is considered as a recurring term used to describe the patient profile. For example, fatigue also expressed as very tired occurred in 96 charts

ii. A manual search for an identical match to the source term was made using the SNOMED CT® browser, CLINICLUE 5.0 [132] and SNOCAT [133]. Fatigue was found as an exact match in SNOMED CT®.

iii. A search was made for alternative terms / synonym when exact match was not found with the same clinical meaning (i.e. concept match) to the source term using the browser. For instance, "withdraws" a source term was not available but the term "withdrawn" was available conveying the same clinical meaning in the psychosocial profile category.

iv. No match terms were identified. Terms with close relevance to the condition MCS were not available in SNOMED CT®. The term "Multiple Chemical Sensitivity" is a no match term in SNOMED CT®.

A quality score of 1 was used when no similar SNOMED CT® concept is found. A quality score of 2 was used when a similar concept is found. A quality score of 3 was assigned when the SNOMED CT® term exactly matches the clinical term. The scoring scheme is primarily done to align organization of terminologies. Fatigue received a score of 3 as it had an exact match in SNOMED CT® .

Involvement of clinicians in the review of mapped terms: The clinicians from the relevant health care disciplines involved in the care of MCS reviewed the mapped information relevant to their disciplines and provided feedback on the accuracy and completeness of the clinical terms standardized using SNOMED CT® . The clinicians reviewed only the exact matches and synonyms. They attempted to identify the missing concepts and

terminologies by reviewing the patient charts. The vocabulary was revised further based on the feedback from the clinicians on the missing terms. The missing terms identified by the clinicians and the researcher were put through a second round of mapping in SNOMED CT®. The "no match" terms from the second round of mapping were included in the controlled vocabulary for completeness of the vocabulary.

Cohen's Kappa [129] statistic was conducted for interrater reliability to determine consistency among the two categories of raters, the researcher and the clinicians for the "missing terms" grouping. Cohen's kappa, which works for two raters, improve upon the joint probability analysis in that they take into account the amount of agreement that could be expected to occur through chance. Cohen's kappa is generally thought to be a more robust measure than simple percent agreement calculation since κ takes into account this agreement occurring by chance.

Controlled vocabulary as a boundary object across disciplines of care

Re-coding of patient profiles using the controlled vocabulary:
A representative sample of 3 patient charts that was prototypical representation of the patient population was selected by a key member of the multidisciplinary care team, the Medical Director. The patient charts selected for the re-coding process were not from the 100 charts used to create the controlled vocabulary. The selection was validated by another member of the care team, a physician who assigned a rating from 0 – 10 to express agreement or disagreement for the selection of the patient profile for re-coding.

The information from the 3 prototypical charts was used. The clinicians were randomly assigned to coding group A and coding group B. Each coding group comprised of a physician, a nurse, a physiotherapist, a rehabilitation coordinator, a dietician, a psychologist (psychotherapist).

A web-based form containing the terminologies from the controlled vocabulary was created to help the clinicians re-code the patient profiles as shown in Figure 5. The

clinicians had access to a tutorial as a link in the web-based form to assist with the process of re-coding. The clinicians printed the re-coded profiles and provided the printed profiles to the researcher. Each terminology in the web-based form had a link to the hierarchical classification of the term as it existed in SNOMED CT® . This provided an opportunity for the clinicians to view the parent concepts, the concept ID, and synonyms for the clinical terminology. This allowed the clinicians to query the accuracy of the concepts in SNOMED CT to represent accurately the intended clinical concepts of the source terms. Through the re-coding process, the clinicians had additional opportunity to identify missing terminologies or concepts in the controlled vocabulary required to code the profile of the patient. The missing category was captured by the clinicians in the space allocated in the web form for free text. The requests submitted by clinicians for additional terms were reviewed by the researchers for terms that exist in the controlled vocabulary and may have been missed; for terms that may not directly describe profile of a patient. The terms that still are considered relevant and missing in the controlled vocabulary were passed through a third attempt of mapping and included in the controlled vocabulary.

Cohen's Kappa [134] was used to analyze the inter-rater reliability of the coding disciplines with the same area of health focus such as a Psychologist and Psychotherapist for the area of psychosocial factors. The Kappa score was used to determine the reliability in the number of terms identified as missing terms in the new vocabulary.

Feedback of the controlled vocabulary by the experts or the coding group:

The clinicians who tested the vocabulary in the re-coding process offered their feedback on the usefulness, accuracy and user friendliness of the new vocabulary. An evaluation questionnaire on a 5-point Likert scale validated in another study with questions about the scope, specificity, and structure of the clinical vocabulary was used to obtain feedback [48].

The questions on the scope of the vocabulary included feedback on the completeness of the coverage of concepts, use of familiar or commonly used terms by the clinicians

(Figure 6). The questions on the specificity of the vocabulary included feedback on the accuracy of terms and the loss of clinical detail. The structure component obtained feedback on the hierarchical classification of the term in the vocabulary and the repetitiveness of a term in multiple hierarchies. The questionnaire also obtained an overall rating for the vocabulary.
Questions of views as in — strongly agree, agree, neutral, disagree, strongly disagree were gathered using a 5-point Likert scale.

Each response category was assigned a numeric value. A greatest negative response (strongly disagree) was scored as "1" and a highest positive response (strongly agree) was scored as "5". Responses to each item were analyzed as the percentage of reviewers who agreed/disagreed (strongly or not). The reliability (internal consistency) of the questionnaire was determined using Cronbach's alpha [135] which is a widely accepted reliability measure of internal consistency in survey research.

Controlled vocabulary across communities of practice

Feedback of the controlled vocabulary by the end users: Clinicians in the community such as GPs and other care providers who may have to treat patients with MCS were approached to obtain feedback on the usefulness of the patient profiles generated using the controlled vocabulary. A convenience sample of clinicians from the community was recruited through an email invitation to participate sent to the department heads and managers and recruited through community health teams. The individuals willing to participate were contacted by the researcher via email. The information package which included an overview of the study, the consent form, 3 patient profiles in the old and new vocabularies and the survey questionnaire were mailed to the participants. The participants contacted the researcher when additional clarity was required. The participants then returned the completed survey questionnaire and signed consent form via fax or mail to the researcher. The usefulness was evaluated on the basis of the scope, specificity and usefulness of standardization on a 5-point Likert scale (Figure 7).

The reliability (internal consistency) of the questionnaire was determined using Cronbach's alpha. Cohen's Kappa was calculated to study the agreement among various disciplines. Kendall's Tau [136] was calculated to determine agreement among multiple raters.

5.5.2 Development Of An Ontology In The Patient Profile Domain For MCS

Specification of patient profile ontology for MCS

Goal and scope of the profile ontology

Establishing the goal and scope was the first step in developing the ontology as outlined in the general methodology section. The goal of an ontology determines the overall objective for developing an ontology. The goal of the MCS profile ontology developed in this study was to create a comprehensive hierarchical controlled vocabulary and a representation of the multidisciplinary and multidimensional relationships that exist among the concepts in the vocabulary for MCS. The profile ontology for MCS created a comprehensive understanding of the type of multidisciplinary involvement and interactions that existed in this convenience sampling of experts in generating the profile characteristics for MCS. These included, who are the clinicians involved, what are the types of terminologies they use, what are the overlaps or interactions that exist among these categorizations to name a few.

The scope helped identify the key elements that needed to be included in the ontology. The explicit knowledge in the domain for these conditions was limited and the implicit knowledge was very vast. As mentioned earlier, the elements in this ontology were maintained on the knowledge that existed in this domain. The information was generated from the intake documents retrieved from the chart review. The interactions and terminologies were gathered from patient charts and from feedback from the experts.

Domain description for MCS

As outlined earlier, patient profile categorization was more detailed than the typical problem lists that are generated for well categorized medical conditions. The symptoms can range from physical to psychological with areas of focus that include medical, physical, psychosocial, nutrition and vocational. Given the involvement of multiple health care disciplines in the care management scheme, the domain contains multidisciplinary concepts. The domain description for MCS was compiled through a retrospective chart audit process, feedback from clinicians and interview of clinicians as needed.

Organization of domain knowledge for MCS

As discussed in the earlier sections, the domain knowledge for MCS is unstructured and poorly categorized in the medical records. There is also a significant amount of knowledge that exists as tacit knowledge among domain experts. It was thus essential to first generate operational knowledge in the patient profile domain through developing a layer of consistency to frequently used concepts in the categorization of patient profiles for MCS. A controlled vocabulary in the patient profile domain was developed. The concepts in the vocabulary were standardized using a widely used reference terminology, SNOMED CT® so the knowledge can be shared among multiple users crossing communities of practice. The steps for the creation of the controlled vocabulary are outlined in section 4.5.1.

Conceptualization

The conceptualization of the ontology commenced with the concepts that exist in the patient profile domain for complex health conditions. As identified in the previous section, it was essential to create a standardized controlled vocabulary that contained the key concepts that exist in this domain that following which the relations between these concepts were established. The development of the controlled vocabulary for MCS

included reviewing patient charts, compiling a list of routinely used terms in the patient profile domain with the help of domain experts, standardization of the controlled vocabulary and review of the vocabulary by the domain experts. The creation of the controlled vocabulary helped in the development of top level classes of the ontology. The relations and attributes were then developed with the help of knowledge in the patient charts and domain experts. For instance, key classes in the profile ontology for MCS included patient profile, management scheme, patient and organization. The patient profile and management scheme have relations such as psychosocial profile has *management required by* psychologist or psychotherapist.

Implementation of the ontology

Protégé 3.4.2 was used to implement the patient profile ontology. The profile ontology presents the formalized description of concepts in the domain of complex health conditions. It includes basic concepts and properties that characterize the profile of patients from multiple areas of health. The information for the ontology is developed from the knowledge contained in the controlled vocabulary.

A consistency check of the classes in the ontology was conducted. Consistency checking helps detect classes that cannot have instances. The ontology evaluation also included the review by domain experts for accuracy and completeness of the knowledge represented in the ontology. Google Ontology Browser was used by MCS clinicians to browse the profile ontology for MCS. Clinicians received a tutorial to assist with the browsing of the ontology in the form of a powerpoint presentation.

5.6 METHODOLOGY FOR CHRONIC PAIN

Another complex and chronic health condition was selected to validate the viability of the proposed methodology of developing a controlled vocabulary and a profile ontology in a heterogeneous knowledge system. Revisions to the method were made based on the feedback obtained from the clinicians involved in the MCS research.

Chronic pain is a chronic condition in which symptoms are prevalent in multiple body systems [137, 138]. Common chronic pain complaints include headache, low back pain, cancer pain, arthritis pain, neurogenic pain (pain resulting from damage to the peripheral nerves or to the central nervous system itself), psychogenic pain (pain not due to past disease or injury or any visible sign of damage inside or outside the nervous system). A person may have two or more co-existing chronic pain conditions. Such conditions can include chronic fatigue syndrome, endometriosis, fibromyalgia, irritable bowel syndrome, interstitial cystitis, temporomandibular joint dysfunction, and vulvodynia. Patient with chronic pain often experience psychosocial symptoms along with physical symptoms. Describing and classifying chronic pain syndrome can often be found to be unsuccessful. Examination of the pain site, consideration of the medical diagnosis, and results of diagnostic testing fail to capture the biopsychosocial problem of chronic pain. A number of authors have emphasized the need for multidimensional assessment of patients in the context of their lives. The domain knowledge for this condition is considered to be heterogeneous as it is unstructured, multidisciplinary, non-standardized, and poorly categorized.

A convenience sample of 8 multidisciplinary clinicians, 42 clinicians in the community and 100 patients participated in the study to develop the controlled vocabulary and the profile ontology in the patient profile domain for chronic pain.

The creation of the controlled vocabulary included auditing patient charts, interviewing clinicians as required and review of terminology by clinicians for relevancy and accuracy

in the domain of patient profile knowledge for chronic pain. The source terms were then standardized using SNOMED CT® as the reference terminology. The domain experts were also involved in reviewing the standardized vocabulary to ensure accuracy and completeness of the concepts. The experts evaluated the usefulness of the vocabulary by using the controlled vocabulary to re-code profiles of patients and offered feedback on the usefulness through a survey questionnaire. Clinicians in the community reviewed the old and the new vocabulary and offered their feedback through a survey questionnaire.

5.6.1 Development Of A Controlled Vocabulary In The Patient Profile Domain For Chronic Pain

Chart audit Patient charts of 100 patients with a diagnosis of chronic pain were audited to create a text corpus of commonly occurring clinical terminologies and themes used by the multidisciplinary team of clinicians in describing the profile of a patient. The review in the chart audit process was restricted to the intake clinical documents generated by the multidisciplinary team of clinicians since the objective was to identify terminologies and concepts required to describe the profile of a patient with chronic pain.
The chart audit and feedback from clinicians were used to identify recurring themes and key terminologies or concepts used in the categorization of the patient profile. The frequency of occurrence of a term in the form of a percentage determined its importance in the patient profile categorization. The chart audit terms were grouped by percentage of occurrence into three categories: > 60%, 30% - 60% and < 30%. They were also grouped by areas of health focus. Terminologies or concepts such as over 60% of the patients having chronic low back pain as a pain symptom and a diagnosis.

Mapping to SNOMED CT® : This work used Systematized Nomenclature of Medicine, Clinical Terms, SNOMED CT® as the reference terminology to standardize the chart audit terms. SNOMED CT® was selected due to the availability of extensive concepts as described in the literature, excellent coverage of complex clinical concepts for many health conditions and the indication of preference over other terminologies in the literature. The mapping of the concepts included the following steps.

i. A clinical term was identified for mapping from the chart audit when the term is considered as a recurring term used to describe the patient profile. Terms in the chart audit such as radiating pain occurred in 24 patient charts of the 100 charts reviewed

ii. A manual search for an identical match to the source term was made using the SNOMED CT® browsers, CLINICLUE 5.0 and SNOCAT. Radiating pain was an exact match available in SNOMED CT® .

iii. A search for alternative terms / synonym when exact match is not found with the same clinical meaning (i.e. concept match) to the source term was made using the browser

iv. No match terms was identified

A quality score of 1 was used when no similar SNOMED CT® concept is found. A quality score of 2 was used when a similar concept is found. A quality score of 3 was assigned when the SNOMED CT® term exactly matches the clinical term. The scoring scheme was primarily done to align organization of terminologies. For instance, radiating pain was assigned a score of "3".

Involvement of clinicians in the review of mapped terms: The clinicians from the relevant health care disciplines involved in the care of chronic pain reviewed the chart audit terms and the standardized terms in SNOMED CT® in the first round of review. This was a change in the process from the MCS group. The feedback from the MCS clinicians indicated that it was difficult to review the chart audit terms separate from the standardized terms. So, the chronic pain clinicians viewed them together in round 1 of review.

The clinicians reviewed the information relevant to their disciplines and provided feedback on the accuracy and completeness of the clinical terms standardized in

SNOMED CT®. The clinicians reviewed only the exact matches and synonyms. They attempted to identify the missing concepts and terminologies by reviewing the patient charts. The vocabulary was revised further based on the feedback from the clinicians on the missing terms. The missing terms identified by the clinicians and the researcher were put through a second round of mapping in SNOMED CT®. The "no match" terms from the second round of mapping were included in the controlled vocabulary for completeness of the vocabulary. A large percentage of the terms in the *physical profile* category were ``no match`` terms in SNOMED CT®.

Cohen's Kappa statistic was conducted for interrater reliability to determine consistency among the two categories of raters, the researcher and the clinicians for the "no match" or the "missing terms" grouping.

Controlled vocabulary as a boundary object across disciplines of care

Re-coding of patient profiles using the controlled vocabulary:

A representative sample of four charts that was prototypical representation of the patient population was selected by a key member of the multidisciplinary care team, Medical Director. This was another change in the method from the MCS research. Some clinicians in the MCS group suggested that 3 patient charts were not sufficient to generate an opinion of the controlled vocabulary. So, a fourth chart was added to the chronic pain re-coding process. The patient charts selected for the re-coding were not from the 100 charts used to create the controlled vocabulary. The selection was validated by another member of the care team, a physician who assigned a rating from 0 – 10 to express agreement or disagreement for the selection of the patient profile for re-coding.

The information from the patient charts were used in the re-coding of the profile using the controlled vocabulary. The clinicians were randomly assigned to coding group A and coding group B. Each coding group was comprised of a physician, nurse, an occupational therapist and a physiotherapist.

A web-based form containing the terminologies from the controlled vocabulary was created to help the clinicians re-code the patient profiles. The clinicians had access to a tutorial to assist with the process of re-coding through a link in the web-based form. They also had access to the researcher through this phase to seek additional help with the process. The clinicians completed the re-coding process using the web-based form by referring to the electronic version of the original patient chart information. The clinicians were provided with 3 patient charts for re-coding and given an option to review a fourth chart if they felt they needed to test the vocabulary further. Another change to the process was made based on the feedback from the MCS research. A question was raised about the amount of time spent by clinicians in the re-coding of profiles. The web-based form created provided time spent by each clinician by capturing the start and end time (submission of the form) for the re-coding process. Each terminology in the web-based form had a link to the hierarchical classification of the term as it exists in SNOMED CT®. This provided an opportunity for the clinician to view the parent concepts, the concept ID, and synonyms for the clinical terminology in order to determine the accuracy and completeness of the concepts represented in the standardized form in SNOMED CT®. They were able to query the accuracy of the standardized term in representing the intended clinical concepts of the source terms. Through the re-coding process, the clinicians had an additional opportunity to identify missing terminologies or concepts in the controlled vocabulary required to code the profile of a patient. The missing terms and concepts were captured by the clinicians in the space allocated in the web form for free text. The requests for additional terms submitted by the clinicians were reviewed by the researchers for terms that exist in the controlled vocabulary and may have been missed or for terms that may not directly describe profile of a patient. The terms that were still considered relevant and missing in the controlled vocabulary were passed through a third attempt of mapping and included in the controlled vocabulary. All the `no match` that were determined relevant by the domain experts were included in the controlled vocabulary.

Cohen's Kappa was used to analyze the inter-rater reliability of the coding disciplines with the same area of health focus such as physicians in the area of medical profile. The

Kappa score was used to determine the reliability in the number of terms identified as missing terms in the new vocabulary.

Feedback of the controlled vocabulary by the experts or the coding group:

The clinicians who tested the vocabulary in the re-coding process offered their feedback on the usefulness, accuracy and user friendliness of the new vocabulary. An evaluation questionnaire on a 5-point Likert scale validated in another study with questions about the scope, specificity, and structure of the clinical vocabulary was used to obtain feedback.

The questions on the scope of the vocabulary included feedback on the completeness of the coverage of concepts, use of familiar or commonly used terms by the clinicians. The questions on the specificity of the vocabulary included feedback on the accuracy of terms and the loss of clinical detail. The structure component obtained feedback on the hierarchical classification of the term in the vocabulary and the repetitiveness of a term in multiple hierarchies. The questionnaire also obtained an overall rating for the vocabulary. Questions of views as in — strongly agree, agree, neutral, disagree, strongly disagree were gathered using a 5-point Likert scale.

Each response category was assigned a numeric value. A greatest negative response (strongly disagree) was scored as "1" and a highest positive response (strongly agree) was scored as "5". Responses to each item were analyzed as the percentage of reviewers who agreed/disagreed (strongly or not). The reliability (internal consistency) of the questionnaire was determined using Cronbach's alpha which is a widely accepted reliability measure of internal consistency in survey research.

Controlled vocabulary across communities of practice

Feedback on the controlled vocabulary by the end users: Clinicians in the community such as GPs and other care providers who may have to treat patients with chronic pain were approached to obtain feedback on the usefulness of the patient profiles generated using the controlled vocabulary. A convenience sample of clinicians from the community

was recruited through an email invitation to participate sent to the department heads and managers and recruited through community health teams. The individuals willing to participate were contacted by the researcher via email. The information package which included an overview of the study, the consent form, 3 patient profiles in the old and new vocabularies and the survey questionnaire were mailed to the participants. The participants contacted the researchers when additional clarity was required. The participants then returned the completed survey questionnaire and signed consent form via fax or mail to the researcher. The usefulness was evaluated by clinicians on the basis of the scope, specificity and usefulness of standardization on a 5-point Likert scale.

The reliability (internal consistency) of the questionnaire was determined using Cronbach's alpha. Cohen's Kappa was calculated to study the agreement among various disciplines. Kendall's Tau was calculated to determine agreement among multiple raters.

5.6.2 Development Of An Ontology In The Patient Profile Domain For Chronic Pain

A specification phase, a conceptualization phase, and an implementation phase was involved as outlined in the global methodology.

The specification phase was to acquire knowledge of the domain. This was achieved by identifying the primary knowledge sources in the domain, which in this case were the patient charts and the domain experts, i.e., multidisciplinary clinicians involved in the care. This step involved specification of terminologies and concepts essential to describe the profile of a patient with chronic pain. This was obtained from the knowledge acquired from the controlled vocabulary for chronic pain developed in this study.

The goal of the conceptualization phase was to organize and structure the knowledge such as outlining the key classes and relations among these classes in the ontology. This was done from the knowledge in the patient charts and feedback from experts in the domain.

The implementation phase involved verifying the chronic pain profile ontology through consistency check and user feedback. The multidisciplinary clinicians involved in the care of chronic pain reviewed the ontology using an ontology browser powered by Google.

Specification Phase

Goal and scope of the ontology of patient profile ontology for chronic pain

Establishing the goal and scope was the first step in developing the ontology as outlined in the general methodology section. The goal of an ontology determines the overall objective for developing an ontology. The goal of the chronic pain profile ontology developed in this study was to create a comprehensive hierarchical controlled vocabulary and a representation of the multidisciplinary and multidimensional relationships that existed among the concepts in the vocabulary for chronic pain. The profile ontology for chronic pain creates an in-depth understanding of the type of multidisciplinary involvement that exists in this convenience sampling of experts in generating the profile characteristics for chronic pain. These include, who are the clinicians involved, what are the types of terminologies they use, what are the overlaps or interactions that exist among these categorizations to name a few.

The scope helps identify the key elements that need to be included in the ontology. The explicit knowledge in the domain for these conditions is limited and the implicit knowledge is very vast. As mentioned earlier, the elements in this ontology were maintained on the knowledge that existed in this domain. The information was generated from the intake documents retrieved from the chart review. The interactions and terminologies were gathered from patient charts, from feedback from the experts and predominantly from the controlled vocabulary. For instance, the controlled vocabulary contained 182 concepts retrieved from the chart audit process which were standardized and included along with closely related terms or synonyms for the chart audit terms.

Domain description for chronic pain

As outlined earlier, patient profile categorization for conditions like chronic pain is more detailed than the typical problem lists that are generated for well categorized medical conditions. The symptoms can range from physical to psychological with areas of focus that include medical, physical, psychosocial, nutrition and vocational. Given the involvement of multiple health care disciplines in the care management scheme, the domain contains multidisciplinary concepts. The domain description for chronic pain was compiled through a retrospective chart audit process, feedback from clinicians and interview of clinicians as required.

Organization of domain knowledge for chronic pain

As described earlier, the organization of domain knowledge required developing a layer of consistency in the form of a controlled vocabulary. The concepts in the vocabulary were standardized using a widely used reference terminology, SNOMED CT® so the knowledge can be shared among multiple users crossing communities of practice. The steps for the creation of the controlled vocabulary are outlined in 4.5.1. The profile ontology for chronic pain was developed from the controlled vocabulary by adding another layer of pragmatic operability and standardization in the form of establishing relations between concepts in the vocabulary.

Conceptualization Phase

The conceptualization of the ontology commences with the concepts that exist in the patient profile domain for chronic pain. As identified in the previous section, it is essential to create a standardized controlled vocabulary that contains the key concepts that exist in this domain. The development of the controlled vocabulary for MCS included reviewing patient charts, compiling a list of routinely used terms in the patient profile domain with the help of domain experts, standardization of the controlled vocabulary and review of the vocabulary by the domain experts [4.5.1]. The creation of

the controlled vocabulary helped in the development of top level classes of the ontology. The relations and attributes were then developed with the help of knowledge in the patient charts and domain experts. The key classes in the chronic pain ontology included *patient profile, organization, management scheme and patient*. Relations were then identified between the classes in the ontology. For instance, class patient *has profile* medical profile, patient *hasorganization* organization_chronic pain and patient *hasdiagnosis* chronic low back pain.

Implementation Phase

Protégé 3.4.2 was used to implement the patient profile ontology. The profile ontology presents the formalized description of concepts in the domain of complex health conditions. It includes basic concepts and properties that characterize the profile of patients from multiple areas of health. The information for the ontology is developed from the knowledge contained in the controlled vocabulary.

A consistency check of the classes in the ontology is conducted. Consistency checking helps detect classes that cannot have instances. The ontology evaluation also includes the review by domain experts for accuracy and completeness of the knowledge represented in the ontology. Google Ontology Browser was used by clinicians to browse the profile ontology for MCS.

The clinicians were provided access to a video tutorial so they could understand how to use the Google ontology browser and how to browse the ontology. This was a change in the method compared to the MCS group who received a powerpoint presentation as a tutorial.

CHAPTER 6 RESULTS AND EVALUATION OF THE MODEL AND METHODOLOGY PROPOSED IN THIS RESEARCH FOR MCS

A controlled vocabulary and an ontology was developed in the patient profile and heterogeneous domain for MCS.

6.1 CONTROLLED VOCABULARY FOR MCS[2]

One hundred patients, nine domain experts and thirty-six clinicians in the community participated in the study. The phases of development of controlled vocabulary as a boundary object included creating syntactic, semantic and pragmatic levels [25] of shareability of the domain knowledge. The controlled vocabulary was also developed as a dynamic boundary object [31] and as a standard form [94].

[2] *Sampalli T, Shepherd M, Duffy J, Fox R. An evaluation of SNOMED CT in the domain of complex chronic conditions. Int J Integr Care. 2010 Mar 24;10*
Sampalli T, Shepherd M, Duffy J: A standardized and controlled clinical vocabulary in the multidisciplinary care management of a complex and chronic condition: Multiple Chemical Sensitivity. J Multidiscip Healthc. 2011 Apr 7;2:53-9

Syntactic layer of knowledge

A total of 100 patient charts were audited to retrieve key concepts and terminologies that were relevant to the patient profile categorization of MCS as shown in Table 1.

Table 1 Sample of chart audit terms in the vocabulary for MCS (Full list in Appendix B).

INSTANCES OF FREQUENTLY USED CLINICAL TERMS (>60%)		
Physical	*Psychosocial*	*Nutrition*
Fatigue	Difficulty coping with illness	Food sensitivity
Light-headedness	Hypervigilant behaviour	Abdominal bloating
Light sensitivity	Avoidance coping	Abdominal pain
Pain	Anxiety	Constipation
Heightened perception of sound	Overly accommodating	Sinus congestion
Heightened sense of smell	Self sacrificing	Constipation
Sinus congestion	Pain	Light-headedness
INSTANCES OF MODERATELY USED CLINICAL TERMS (30 - 60%)		
Physical	*Psychosocial*	*Nutrition*
Health problems as a child	History of child abuse	Abdominal cramps
Musculoskeletal pain	Withdrawn	Diarrhea
Poor balance	Feels angry	BMI > 25
Low energy	Anxiety	Reflux
INSTANCES OF INFREQUENTELY USED CLINICAL TERMS (<30%)		
Physical	*Psychosocial*	*Nutrition*
Increasing sensitivity	Emotional eating	IBS
Metallic taste in mouth	Obsessive compulsive	Nausea
Migraine	Emotional hypersensitivity	Obese
Skin symptoms	Difficulty coping with pain	Emotional eating
Throat irritation	Paranoid ideation	Food allergies

Five hundred and twelve concepts/ terminologies in use were retrieved in the multidisciplinary areas of health focus: physical, psychosocial, nutrition, rehabilitation and medical. In the top one-third consortium, symptoms in the various body systems

included blood and gland symptoms (*fatigue*); nervous system symptoms such as *light-headedness*, *cold fingertips*, *cold extremities* and *irritability*; eye symptoms (*eye irritation, itchy eyes*) and nose symptoms (*sinus congestion*). Along with symptoms in the body systems such as *pain* (multiple body systems), *non-restorative sleep* (nervous system), *poor memory* (nervous system) and *food sensitivity* and *bloating* (stomach and bowel), there is a manifestation of other determinants of health such as psychosocial factors (*non-assertiveness, self criticism and overly accommodative*) that add to the patient profile. In the middle third grouping, there is further evidence of the influence of multidimensional health factors in the patient profile characteristics for MCS. There are additional manifestations of stomach and bowel symptoms (*reflux, diarrhea, abdominal cramps*), nervous system symptoms such as *depressed mood*; rehabilitation elements such as the *"not working"* status, onset of illness work related and characteristics of home environment; sign of diminished physical capacity such as *low step count* measured using a pedometer over a two week period and more psychosocial characteristics such as *withdrawal*, *stifled emotions* and *somatization*. Psychosocial characteristics that have an impact also include *childhood abuse* seen in 47% of the study sample. Poor balance and chest pain add to other clinical features of this illness. Psychosocial characteristics such as *emotional eating* along with other nutritional symptoms such as *nausea* are prevalent in the bottom third grouping.

Semantic layer of knowledge and standard form of boundary object

Four hundred and twenty two (82%) of these concepts were available in SNOMED CT®. Table 2 shows the semantic level of standardization that is possible using SNOMED CT® for the inconsistent terminologies retrieved through the chart audit process. The instances shown in the table include *Fibromyalgia* and *poor balance*. Both terms have other descriptions in the clinical notes. With standardization using SNOMED CT®, each concept has a unique concept ID, a preferred term, synonyms when available and parent concepts. These explicit specifications enable a better understanding of the terminologies used to describe these lesser known conditions.

Table 2 Standardization of multidisciplinary vocabulary for MCS using SNOMED CT®.

SNOMED CT Tree	Definition	Instance 1	Instance 2
Concept	Each concept is a single unit of clinical meaning	**Fibromyalgia** – concept in clinical notes – search SNOMED CT browser	**Poor balance** – concept in clinical notes – search in SNOMED CT browser
Concept ID	A unique numeric identifier	Concept ID: 24693007	Concept ID: 249985001
Fully Specified Name (FSN)	The FSN uniquely identifies the concept in an unambiguous way. No two concepts can have the same FSN.	Fibromyositis (disorder)	Poor balance (finding)
Preferred Term	Each concept has a preferred term. It is the term most commonly used by clinicians to describe a clinical concept. The preferred term is not always unique.	Fibromyositis	Poor balance
Synonym	A concept may have other words or phrases that have the same clinical meaning as the fully specified name. Synonyms are identified by the same concept ID but have individual description ID's.	Myofascial pain syndrome Fibromyalgia Diffuse myofascial pain syndrome Fibrositis MPDS – Myofacial pain dysfunction syndrome	Bad balance
Hierarchy/Sub-hierarchy	Concepts are organised into 19 hierarchies and each hierarchy has numerous sub-hierarchies underneath it.	Disease --disorder by body site --disorder of body system ---disorder of musculoskeletal system ----disorder of skeletal muscle --myositis --fibromyositis	Clinical Finding --Clinical history and observations finding --Finding of balance --Impairment of balance

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Table 3 Inconsistencies in chart audit notes for MCS.

Terminologies in clinical notes	**SNOMED CT concepts (hierarchy) and concept ID**
Fatigue, low energy, very tired, extremely tired, heavy feeling	Fatigue (finding) 84229001
Light sensitivity, hypersensitivity to light, intolerance to light	Light intolerance (finding) 62481005
Fibromyalgia, FM, Myalgia	Fibromyositis (disorder) 24693007
Poor balance, balance impairment, loss of balance, unsteady	Poor balance (finding) 249985001 Impairment of balance (finding) 387603000
Poor sleep, sleep problems, sleep issues, unrefreshed sleep, non-restorative sleep	Unrefreshed by sleep (disorder) 248260009 Poor sleep pattern (finding) 314938000
BMI	Body measure (observable entity)
SCL-90R	Symptom checklist (assessment scale) 273859002

Table 3 shows examples of inconsistent terminologies retrieved from various areas of health focus and standardized using SNOMED CT®. The number of concepts in each field was medical 356, physical 136, psychosocial 122, rehabilitation 118, and nutrition 80 (full list in Appendix B).

Table 4 Mapping scheme used to standardize concepts for MCS in SNOMED CT®.

TERM	VALUE	ALTERNATIVE	CODE
Multiple Chemical Sensitivity	1		
Non-restorative sleep	1		
Duty to accommodate	1		
Irritability	2	Feeling irritable	55929007
Fibromyalgia	2	Fibromyositis	24693007
Food Sensitivity	2	Food Intolerance	235719002
Chronic Fatigue Syndrome	3		52702003
Light-headedness	3		386705008
Repression	3		87305000

The clinical vocabulary identified from the chart review was mapped to SNOMED CT® to identify the exact matches (assigned 3), synonyms (assigned 2) and no matches (assigned 1). Examples include *Multiple Chemical Sensitivity* with a score of 1 for "no match" terms, *Fibromyalgia* with a score of 2 for "synonym" and *Chronic Fatigue Syndrome* with a score of 3 for "exact match" in SNOMED CT® (Table 4). Out of the 512 clinical terms that were identified in the chart audit process as relevant to categorization of MCS, there were a total of 422 concepts (82%) found in SNOMED

CT® through the manual string matching technique. About five percent of the 422 concepts required the use of expanded term matching approach. Some examples include source terms such as CFS expanded to Chronic Fatigue Syndrome, IBS for Irritable Bowel Syndrome and low BP for low blood pressure. The remaining terms were mapped using the normalized string matching technique. The percentage of exact matches and synonyms or closely related words found in the various health care disciplines is shown in the figure. The number of exact matches in nutrition and psychosocial focus of care were 61% and 57% respectively while medical, physical and rehabilitation disciplines had 57%, 69%, and 55% of closely related terms in SNOMED CT® (Figure 16). Medical and physical areas of health focus had the lower number of exact matches compared to other areas of health focus.

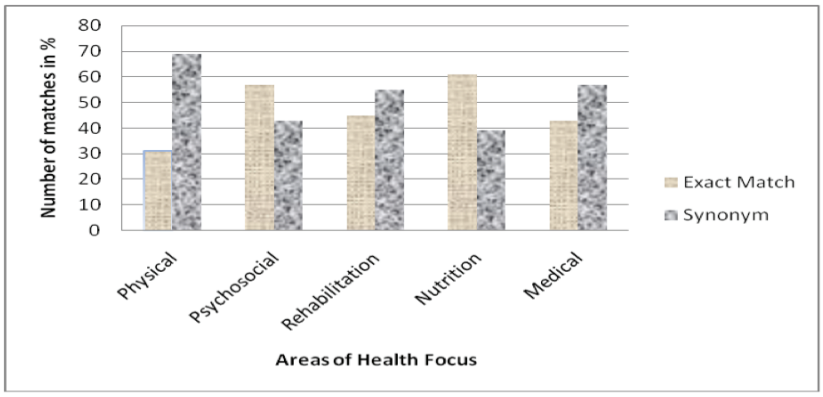

Figure 16 Percentage of exact matches and synonyms found in SNOMED CT® for the chart audit terms grouped under the relevant areas of health care focus.

Tables 5 shows instances of source terms grouped by areas of health focus with their corresponding terms mapped in SNOMED CT®. The table also includes the SNOMED CT ID for these mapped terms and their corresponding parent concepts. These terms were selected by clinicians as accurate representation for the source terms.

Table 5 Standardization of multidisciplinary vocabulary for MCS: medical, nutrition and psychosocial.

Discipline of Care	Source terms	Terms from SNOMED CT® SNOMED CT ID, Parent concept and synonyms
Medical	• Fatigue, tired, low energy	**Fatigue** - 84229001 (finding) Parents: Energy and stamina finding General problem AND/OR complaint (finding)
	• Cold extremities	**Cold extremities** (finding) – 15336001 Parent: Temperature change at anatomical site (finding)
	• Fibromyalgia, FM, Myalgia Encephalitis	**Fibryomyositis** – 24693007 (disorder) Synonyms: Fibromyalgia, Myofascial pain syndrome Parent: Myositis
Nutrition	• Bloating, feeling bloated	**Bloating symptom** (finding) 248490000 Parent: Finding reported by subject or history provider (finding) Swollen abdomen (finding)
	• Food sensitivity, food intolerance, sensitivity to food	**Propensity to adverse reactions to food** 418471000 Parent: Propensity to adverse reaction to substance (disorder) Synonym: food sensitivity
Psychosocial	• Withdraw, withdrawn	**Withdrawn** (finding) 247755007 Parent: Finding of level of interest (finding)
	• Childhood abuse, trauma in childhood related to abuse	**Victim of child abuse** (finding) 397940009 Synonym – child abuse
	• Feels angry, anger, angry	**Feeling angry** (finding) 75408008 Parent: mood finding Synonym: anger

Among the terms that were missing in the vocabulary, 90 terms were those of relative importance to the condition of MCS. Although alternate terms were found, the experts were not in agreement with the accuracy or completeness of these terms in capturing the intended meaning as used in the charts. There were terms and concepts of direct relevance and importance to MCS that could not be found in SNOMED CT®. The term "*Multiple Chemical Sensitivity*" itself is not available in SNOMED CT®. Other terms of relevance to the condition not available in SNOMED CT® included "*heightened reactivity to the environment*", "*increasing sensitivity to chemicals*", symptoms related to exposures such as "*shortness of breath with exposure*", "*dizziness with exposure*", "*metallic taste in mouth with exposure*" and other terms related to cognitive abilities such as *brain fog* and *trouble finding the right words*. For 74% (67 terms) of the terms with direct relation to MCS, post-coordination was possible with some level of complexity with a few attribute value pairs required for the process. These results have not been included as they were not reviewed by the domain experts.

Pragmatic layer of knowledge and dynamic nature of boundary object

The level of translatability and dynamic nature of the controlled vocabulary was tested by the domain experts through a re-coding process to explore the translatability and usefulness of the standardized vocabulary in clinical practice. The pragmatic and dynamic nature of the vocabulary was further queried through feedback from domain experts and clinicians in the community (experts and non-experts) using a survey questionnaire. Twelve clinicians participating in the re-coding process completed their evaluation of the vocabulary using a 5-point Likert scale that measured the usefulness of the vocabulary under an overall category and under sub-categories of scope, specificity and structure.

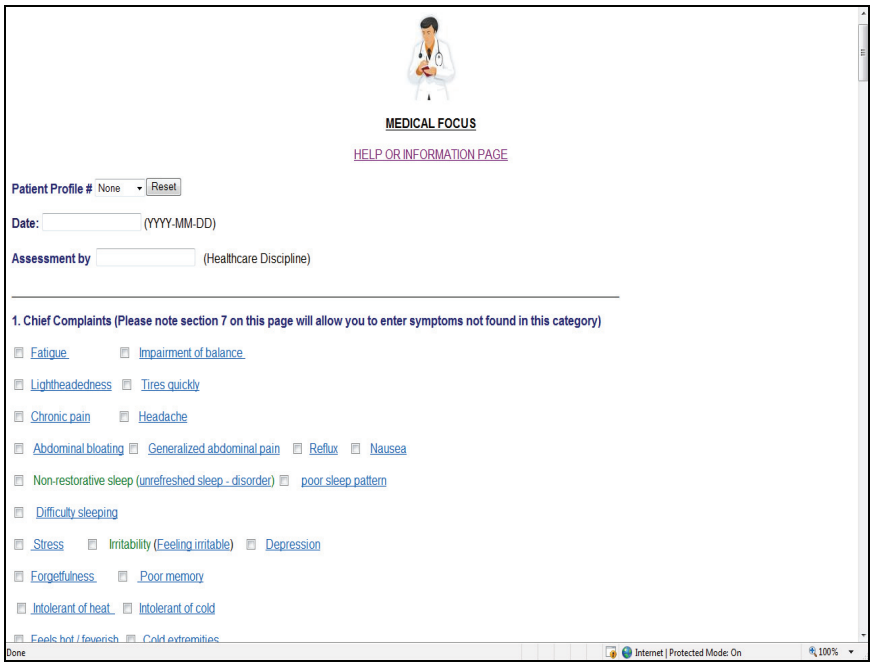

Figure 17 Web-based form used by MCS domain experts in the re-coding of patient profiles.

A web-based form was used by the clinicians to re-code the patient profiles (Figure 17). The clinicians from various health disciplines used the vocabulary of relevance to their area to re-code profiles of patients using the new controlled vocabulary. The web-based form allowed clinicians to select relevant concepts in the re-coding process and allowed them to leave comments when terms were not available in comments box found under each category of re-coding.

Table 6 Missing terms in the MCS vocabulary identified by researcher and clinicians.

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Focus of Care Management	Missing terms identified by researcher	Missing terms identified by clinicians
Medical	32	35
Psychosocial	14	12
Physiotherapy	25	28
Nutrition	6	9
Rehabilitation	12	15

*(Higher value terms contain all of the terms in the lower value column in addition to some extra terms)

Table 6 shows the number of missing terms identified by the researcher and the clinicians. The higher numbers of missing terms in the table include all of the lower numbers of missing terms for that focus of care management. The inter-rater reliability for the raters in the category using the Cohen's Kappa analysis was found to be Kappa = 0.95 indicating an excellent level of agreement among the two groups.

Table 7 Cohen's Kappa for interrater agreement among clinicians for new term look up.

Health Care Discipline	Cohen's Kappa for inter-rater reliability New term look up (N = 2)
PSYCHOSOCIAL Psychologist; Psychotherapist	0.59
NURSING Nurse 1; Nurse 2	0.47
PHYSIOTHERAPY Physiotherapist; Nurse	0.4
REHABILITATION Rehabilitation Co-ordinator; Nurse	0.55
NUTRITION Dietician; Nurse	0.88
PHYSICIAN Physician1; Physician 2	0.5

* < 0 as indicating no agreement and 0–.20 as slight, .21–.40 as fair, .41–.60 as moderate, .61–.80 as substantial, and .81–1 as almost perfect agreement

Cohen's kappa analysis was conducted to determine the level of agreement among the domain experts on the controlled vocabulary (Table 7). Highest level of agreement was among the clinicians around the nutrition vocabulary with a score of 0.88. The other disciplines had moderate level of agreement (0.4 – 0.6). All cohen's kappa coefficients reached statistical significance but there is general agreement that a useful coefficient level start at 0.41.

The clinicians offered their feedback on the usefulness of the vocabulary using a survey questionnaire. Eighty percent of the multidisciplinary clinicians (experts in the domain) agreed on the overall usefulness of the controlled vocabulary (Figure 18). The sub-categories also had an overall high level of agreement with the question on the use of

terms familiar to the clinicians under the scope category getting the maximum level of agreement from the clinicians (90%). Questions under structure and specificity brought a level of disagreement from a small percentage of the clinicians. Cronbach's alpha analysis was conducted to determine the internal reliability of the survey questionnaire. Higher values of alpha are more desirable. Some professionals require a reliability of 0.70 or higher before they would consider using an instrument. A good level of internal reliability was obtained with an alpha score of 0.84.

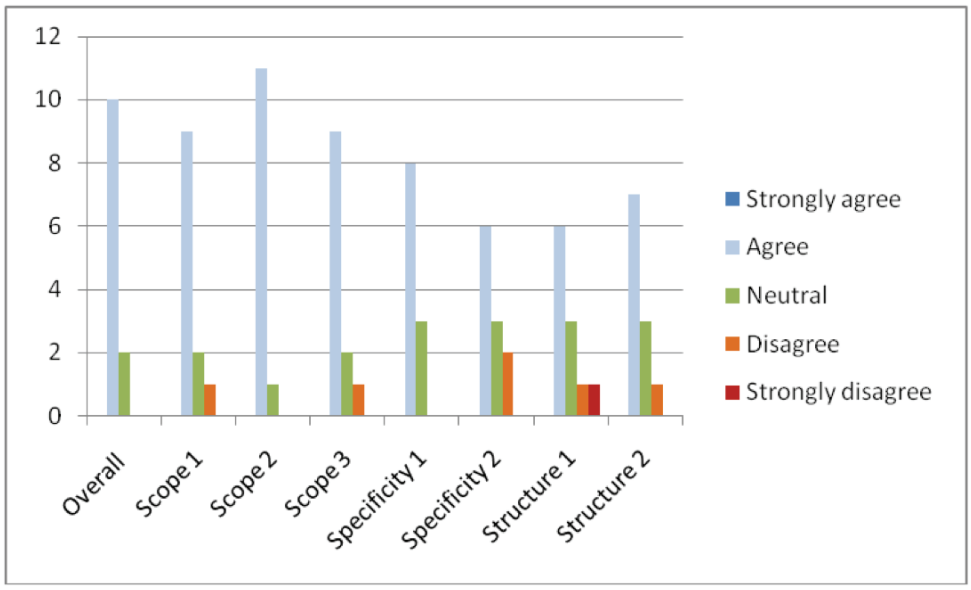

Figure 18 Feedback from the domain experts on the controlled vocabulary for MCS (y-axis shows the number of clinicians).

Evaluation of the controlled vocabulary by clinicians in the community (experts or non-experts)

Thirty-six clinicians from various disciplines in health care participated in the study, seven physicians, five psychologists, seven physiotherapists, six dietitians, seven nurses and four occupational therapists. They reviewed the patient charts in the old vocabulary and the new vocabulary.

An overall agreement to the usefulness of the vocabulary was reached among the experts in most categories (Figure 19).

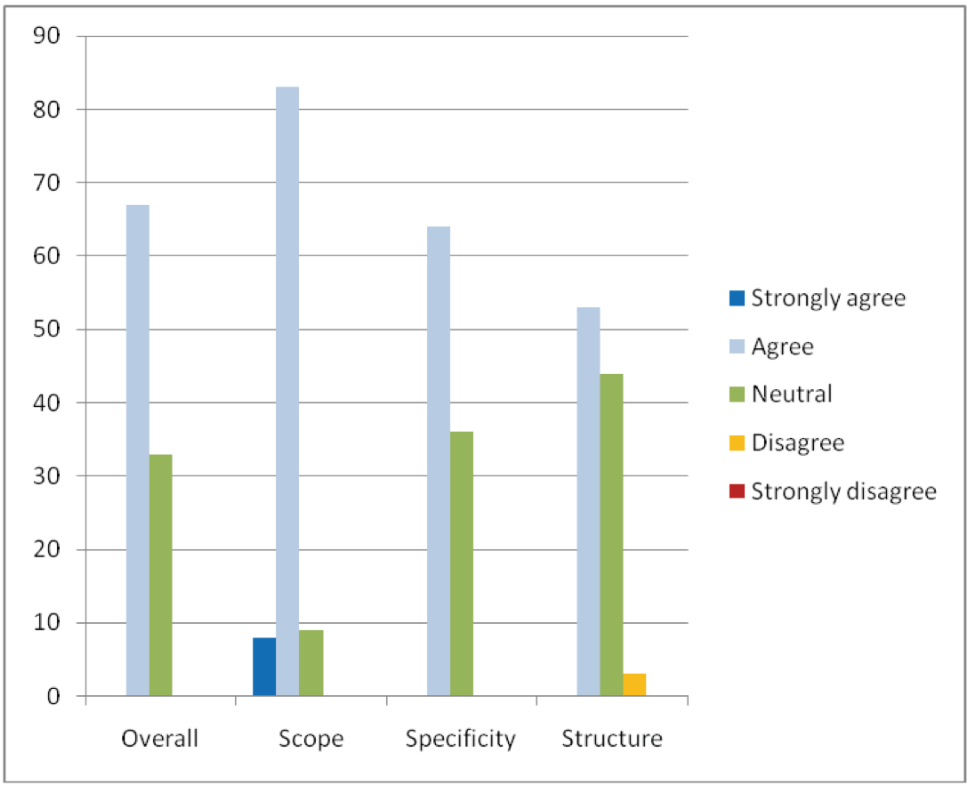

Figure 19 Feedback from the clinicians in the community on the controlled vocabulary for MCS (y-axis shows the percentage of clinicians).

Over 65% of the clinicians agreed on the overall usefulness of the vocabulary. A high level of agreement was obtained in the scope category (>80%). Internal validity of questionnaire was tested using the Cronbach's alpha analysis and ranged in the good level of validity with a value of 0.73 for the 36 raters. The mean value for the various disciplines had a better level of validity with Cronbach's Alpha being 0.89.

Figures 20 to 25 show the survey feedback obtained by area of discipline. Figures 20 to 22 show that the higher level of agreement with a small percentage of strong agreement was obtained for the disciplines of dietitians, occupational therapists and nurses.

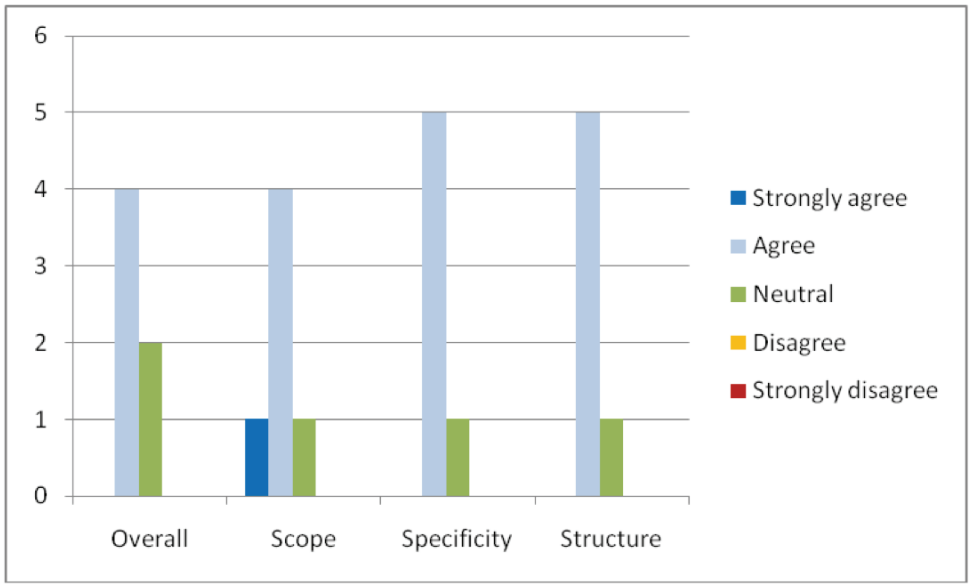

Figure 20 Feedback from the dietitians in the community on the controlled vocabulary for MCS (y-axis shows the number of clinicians, n=6).

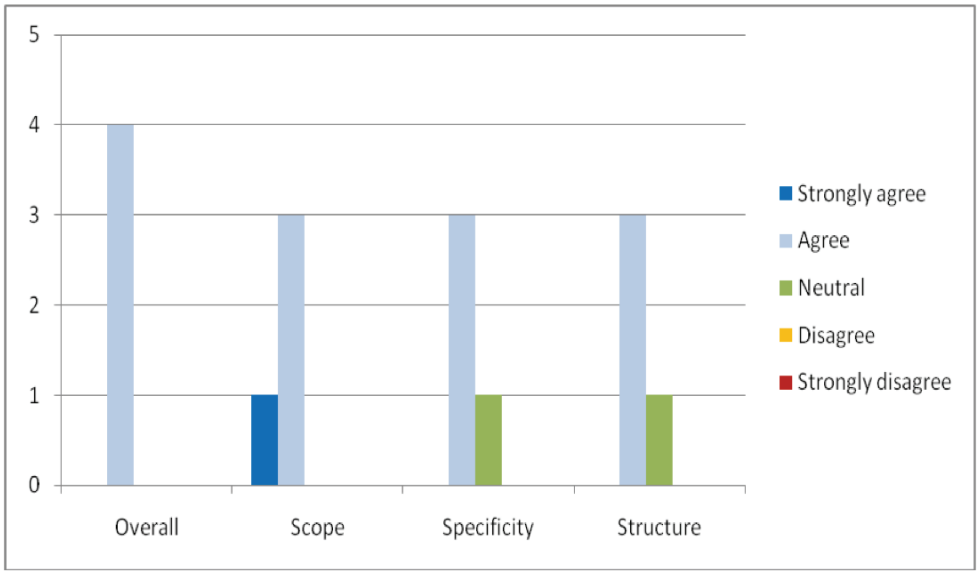

Figure 21 Feedback from the occupational therapists in the community on the controlled vocabulary for MCS (y-axis shows the number of clinicians, n=4).

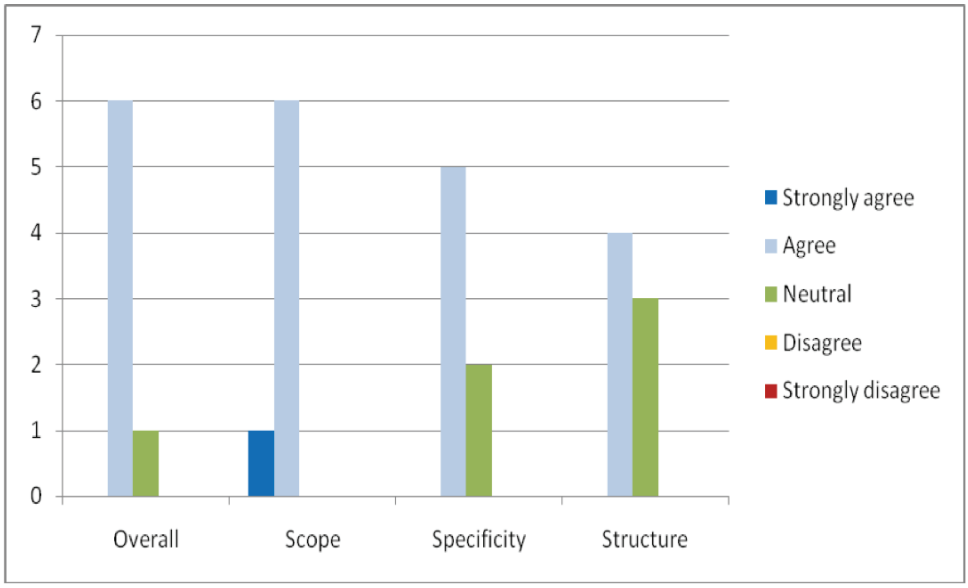

Figure 22 Feedback from the nurses in the community on the controlled vocabulary for MCS (y-axis shows the number of clinicians, n=7).

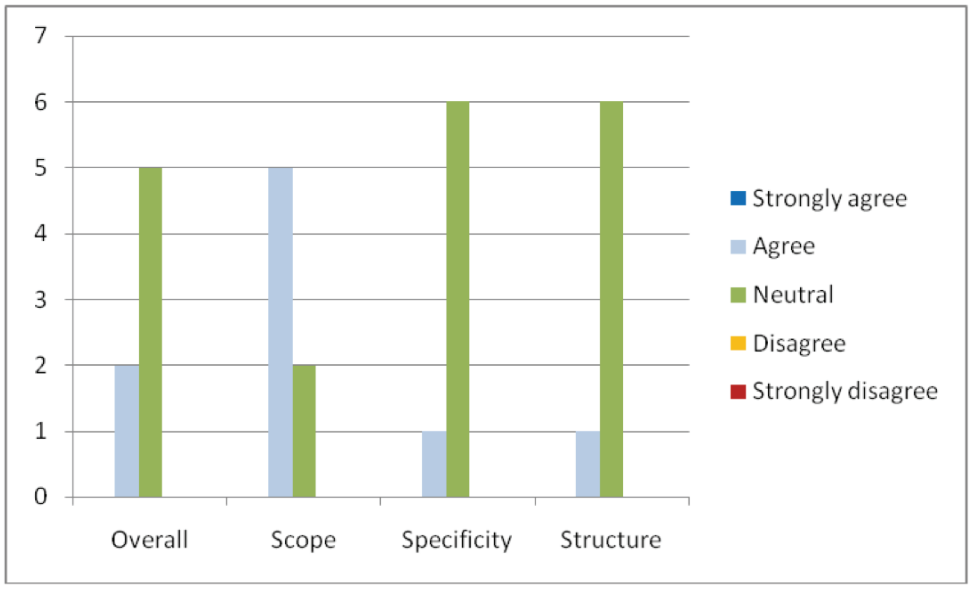

Figure 23 Feedback from the physicians in the community on the controlled vocabulary for MCS (y-axis shows the number of clinicians, n=7).

As shown in figure 23, the physicians showed more neutral scores with some level of agreement in the overall usefulness category and highest level of agreement in the scope category.

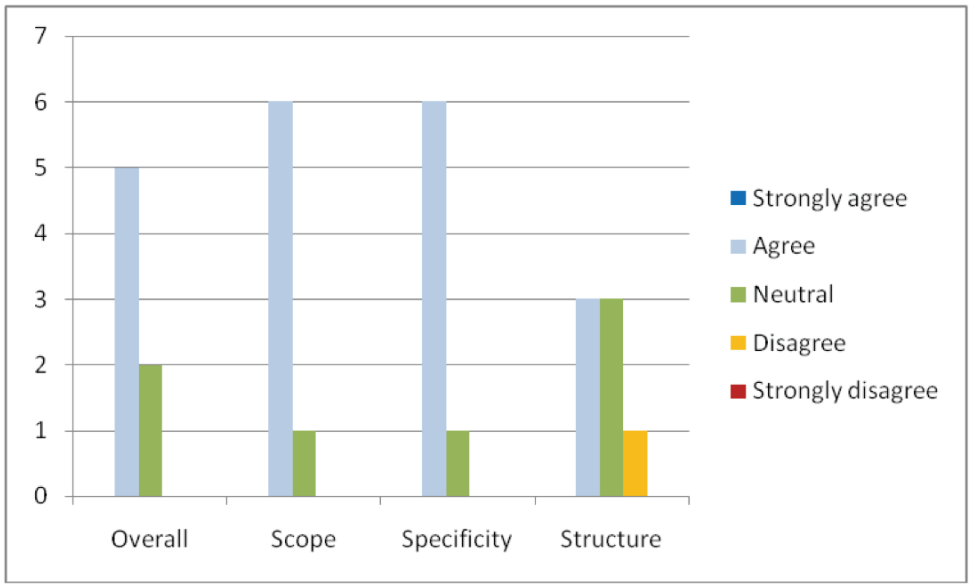

Figure 24 Feedback from the physiotherapists in the community on the controlled vocabulary for MCS (y-axis shows the number of clinicians, n=7).

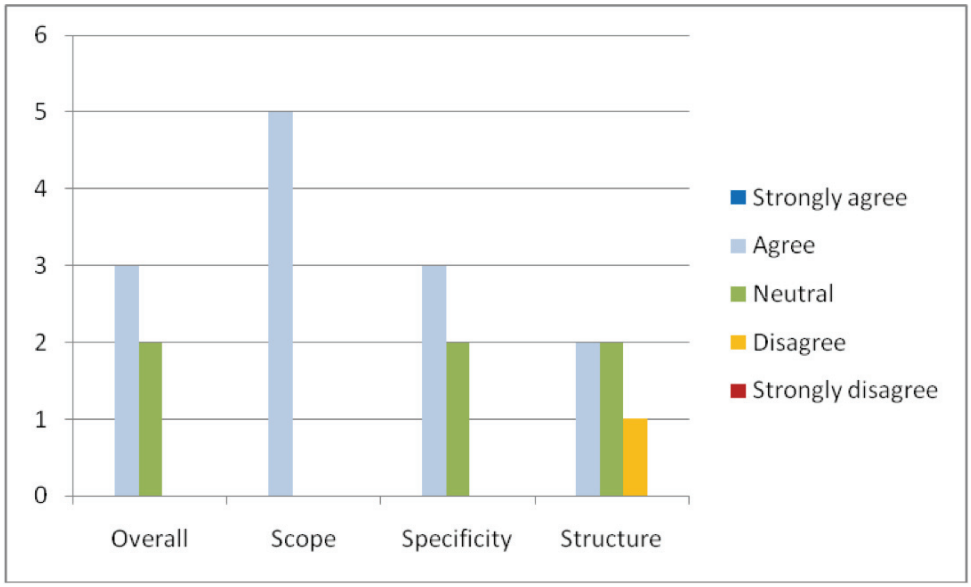

Figure 25 Feedback from the psychologists in the community on the controlled vocabulary for MCS (y-axis shows the number of clinicians, n=5).

Figures 24 and 25 show that the physiotherapists and psychologists showed a small percentage of disagreement in the category of usefulness but demonstrated a good level

of agreement on the overall usefulness and an even higher level of agreement in the scope category.

Kendall's Tau was calculated to determine concordance among multiple raters. Table 8 below shows Kendall's tau values by level of concordance explored for various categories of the questionnaire.

Table 8 Kendall's Tau values from the feedback on MCS vocabulary (n=36 raters) (red highlight indicates values that are significant).

Correlations for all pairs of data series with p-values			
pair	Pearson r	Spearman rho	Kendall tau
Overall;Scope	0.433	0.433	0.4243
p-value	(0.0083)	(0.0083)	(0.0104)
Overall;Specificity	0.5725	0.5725	0.5725
p-value	<0.0001	<0.0001	<0.0001
Overall;Structure	0.4981	0.4912	0.485
p-value	(0.002)	(0.0024)	(0.0037)
Scope;Specificity	0.2833	0.2833	0.2776
p-value	**(0.0941)**	**(0.0941)**	**(0.0937)**
Scope;Structure	0.3697	0.3284	0.3191
p-value	(0.0265)	(0.0506)	(0.0511)
Specificity;Structure	0.2241	0.2569	0.2537
p-value	**(0.189)**	**(0.1304)**	**(0.1286)**

Trends followed what was apparent in the graphs showing the evaluation scores. Lower values were evident for the specificity and structure in the graphs. The table above shows similar trends. Highest levels of concordance were seen for overall with scope, overall and specificity and overall and standardization. Scope and specificity did not reach significance (≥ 0.05). Specificity and structure got the least level of concordance as shown by the scores of Kendall's Tau.

Cohen's Kappa for the dietician's group showed the highest level of agreement with a score of 0.84. Cohen's Kappa for agreement across disciplines showed low agreement

between physicians and dieticians (0.2) and a moderate level of agreement between physicians and physiotherapists (0.5).

Qualitative feedback was obtained from the clinicians in the community through open-ended questions. Presented in Table 9 are some comments that were presented by clinicians from various health disciplines. The emerging themes show that clinicians are receptive of this move towards bringing consistency and standardization to the clinical vocabulary to build a better understanding of complex health conditions.

Table 9 Qualitative feedback from clinicians in the community following review of controlled vocabulary (patient profiles in old and new format).

Discipline of Care	Feedback
Dietician	Standardization is helpful to understand conditions like MCS; we are commencing standardization within our group
Occupational Therapist	Standardization is helpful
Psychologist	Helpful to understand the condition but unable to decide about the standardization
Physician	Will standardization be restrictive in describing the condition, need to see and understand more about standardization Organization of the information was helpful to understand the condition
Nurse	Could understand the condition better
Physiotherapist	Unable to fully appreciate the benefits of standardization

6.2 PROFILE ONTOLOGY FOR MCS[3]

Outcome of the specification phase

A total of five hundred and twelve concepts were retrieved relevant to the patient profile domain for MCS from the retrospective chart audit process. The concepts were grouped under five major areas of health focus: medical, physical, psychosocial, rehabilitation and nutrition. The number of concepts in the medical, physical, psychosocial, nutrition and rehabilitation areas of health care focus was 356, 136, 122, 80 and 118 respectively. Four hundred and twenty-two of these concepts (82%) were standardized using SNOMED CT®. However, some key concepts related to *Multiple Chemical Sensitivity* were absent in the reference terminology.

Post co-ordination was applied to improve the availability of necessary concepts for the health condition. For instance, the term *Multiple Chemical Sensitivity* does not exist in SNOMED CT®. Seventy-four percent of the missing concepts were included this way (n = 67). The remaining terminologies of relevance (n = 23) were maintained in the controlled vocabulary as determined by the domain experts. The clinicians tested the usefulness of the vocabulary by applying it to recode the profiles for three patients with a diagnosis of MCS. Eighty percent of the clinicians agreed on the overall usefulness of organizing the domain knowledge through a controlled vocabulary.

Description and organization of the knowledge in the domain

An important consideration of this phase was to develop consistency in the description of the knowledge in the domain. This was achieved through the development of the controlled vocabulary. The standardization offered another layer of clarity to assist in the organization of the knowledge in the domain. For instance the concept "*Light sensitivity*"

[3] *Tara Sampalli, Michael Shepherd, Jack Duffy, "A Patient Profile Ontology in the Heterogeneous Domain of Complex and Chronic Health Conditions," hicss, pp.1-10, 2011 44th Hawaii International Conference on System Sciences, 2011*

can be interpreted as sensory intolerance or pain in the eye. The intended clinical meaning relates to sensory intolerance which can now be tagged using a consistent terminology and a unique concept ID.

The controlled vocabulary was organized in a hierarchical structure with concepts being presented the way they were depicted or captured in the patient charts by the various health care disciplines.

Figures 26 to 29 show the organization of the controlled vocabulary under various areas of health focus.

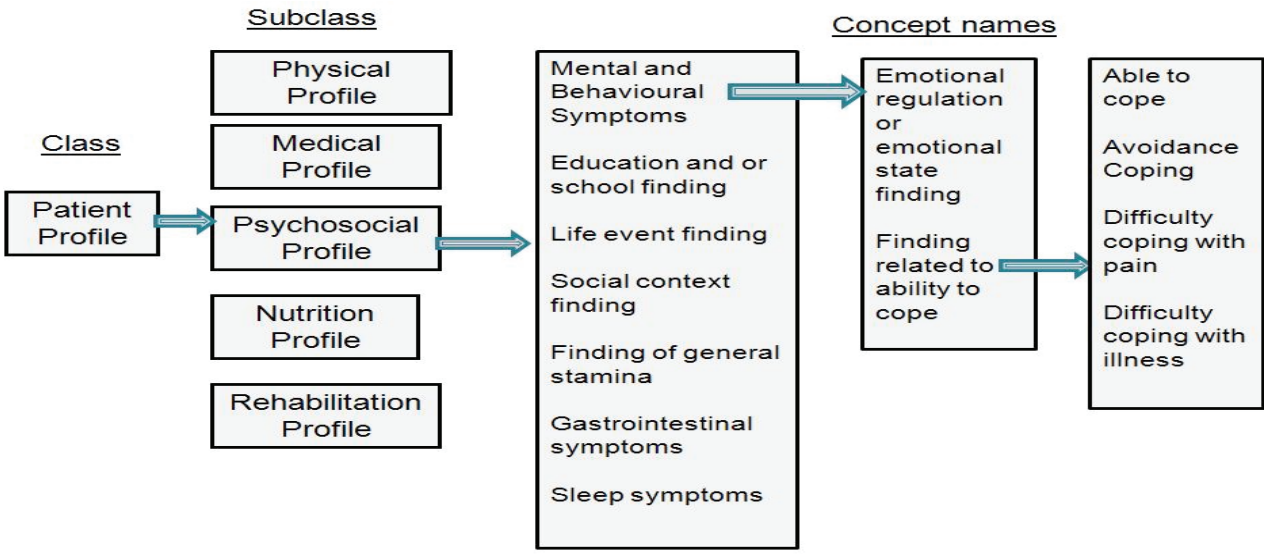

Figure 26 Organization of psychosocial vocabulary for MCS.

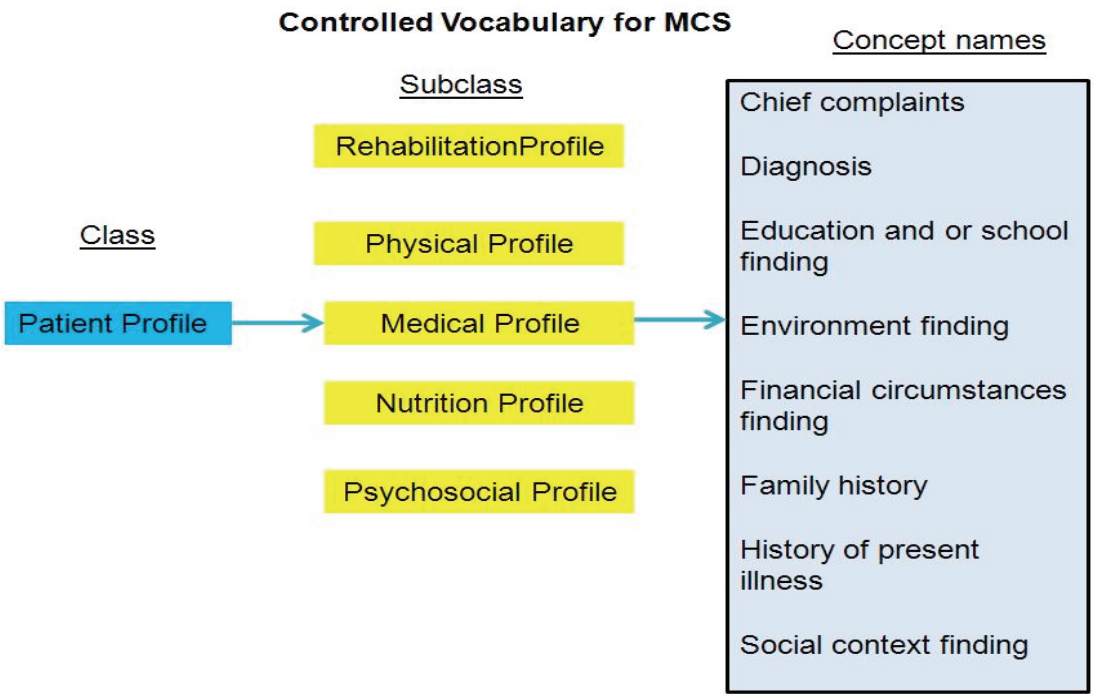

Figure 27 Organization of medical profile vocabulary for MCS.

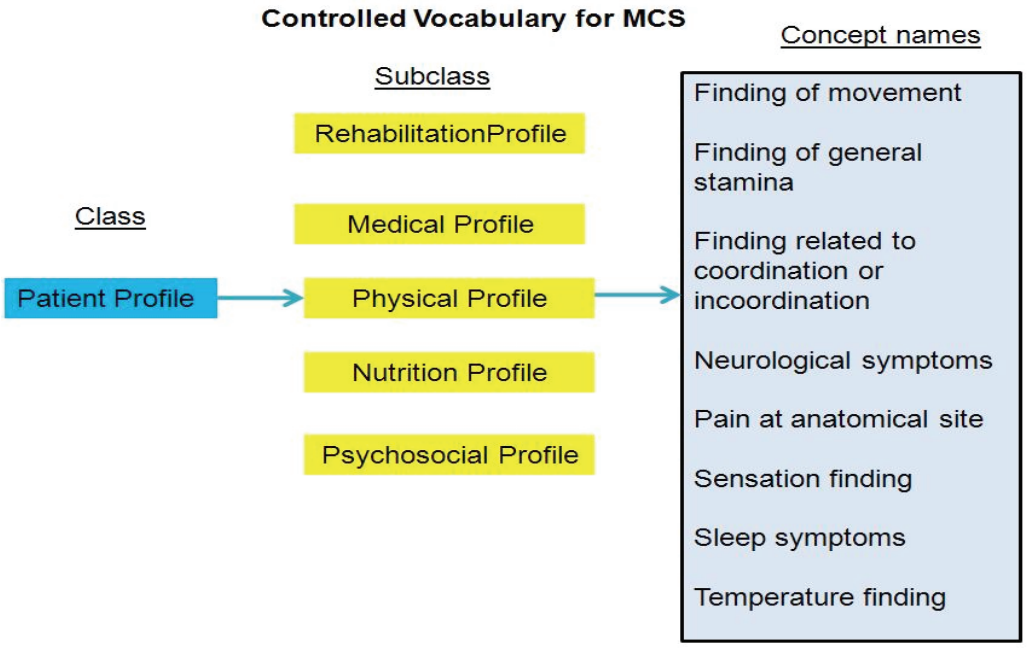

Figure 28 Organization of physical profile vocabulary for MCS.

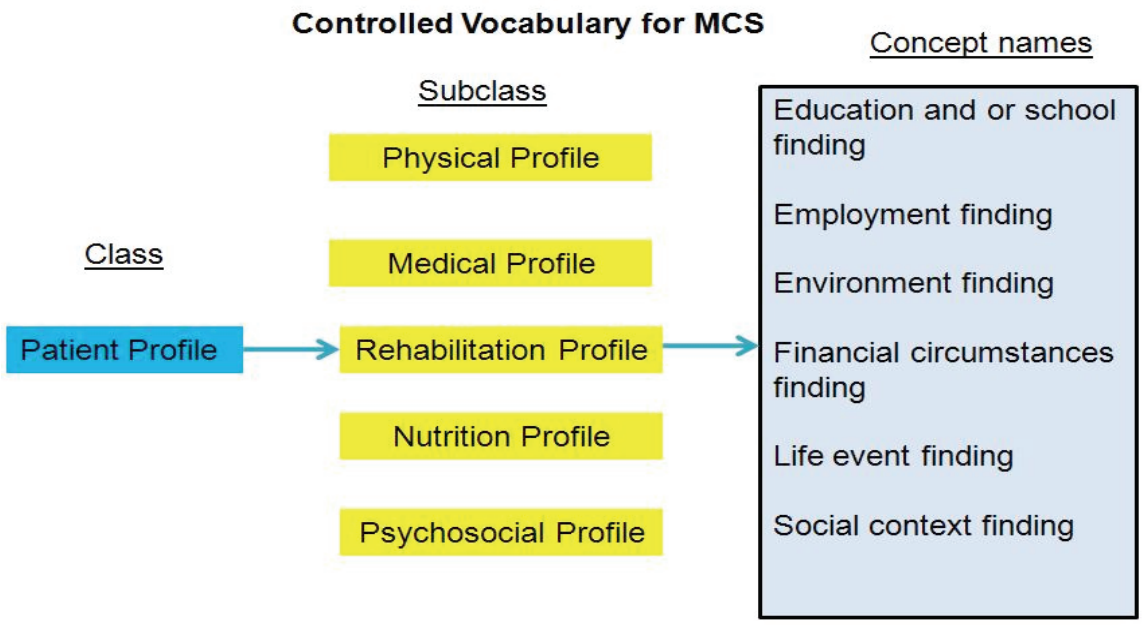

Figure 29 Organization of rehabilitation/vocational profile vocabulary for MCS.

Outcome of the conceptualization phase

Protégé 3.4.2 was used to develop the ontology. The ontology presents a detailed taxonomic overview of the complex health condition domain. The ontology contained 408 classes describing the profile concepts for the condition of MCS. At the basic level there are five relevant super-classes under the primary areas of health focus identified for the condition of MCS: Medical, Physical, Psychosocial, Rehabilitation and Nutrition. Figure 30 presents the Protégé tool displaying the relevant super classes from the Complex Conditions ontology.

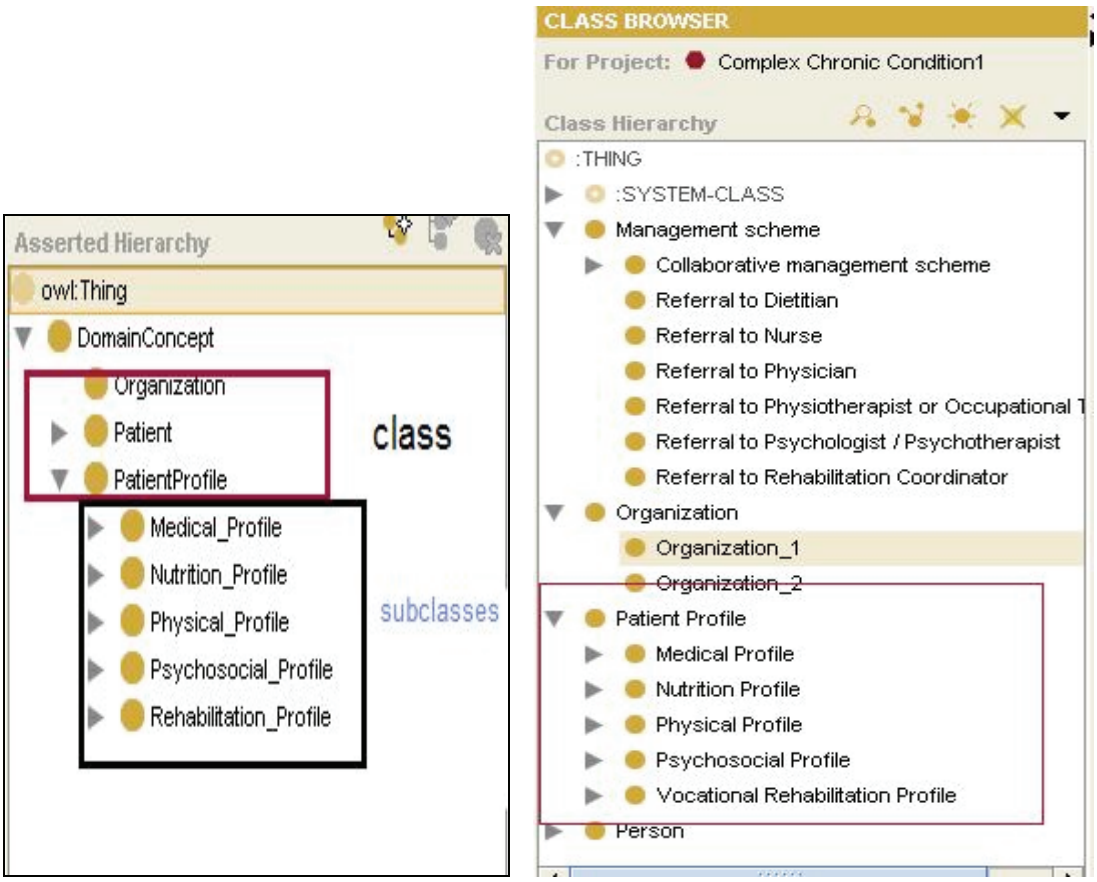

Figure 30 Profile ontology for MCS.

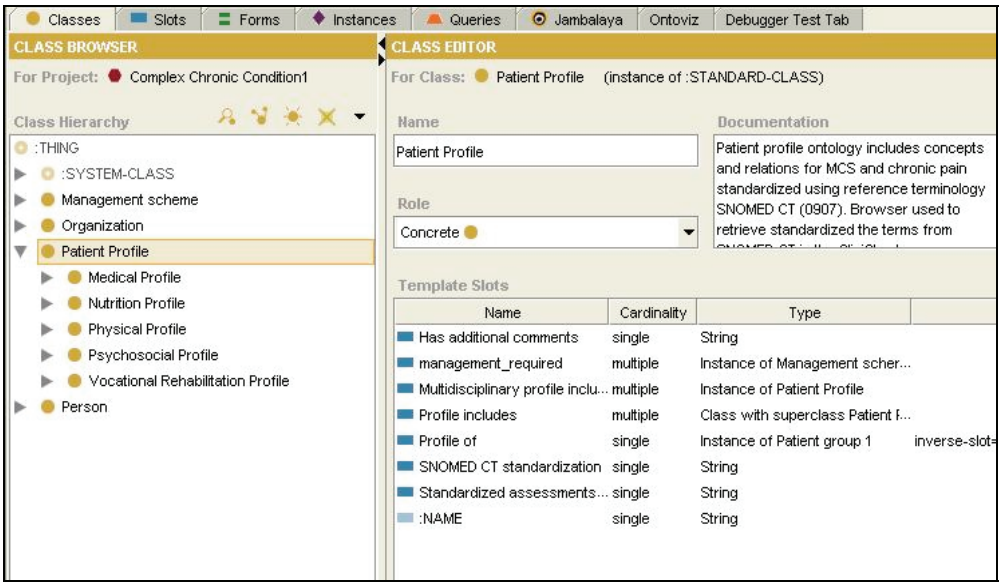

Figure 31 Pragmatic boundary of the MCS profile ontology.

The profile ontology for MCS contains explanation for all concepts included in the ontology such as the multidisciplinary nature of patient profile, the management scheme and the various concepts under each area of health focus.

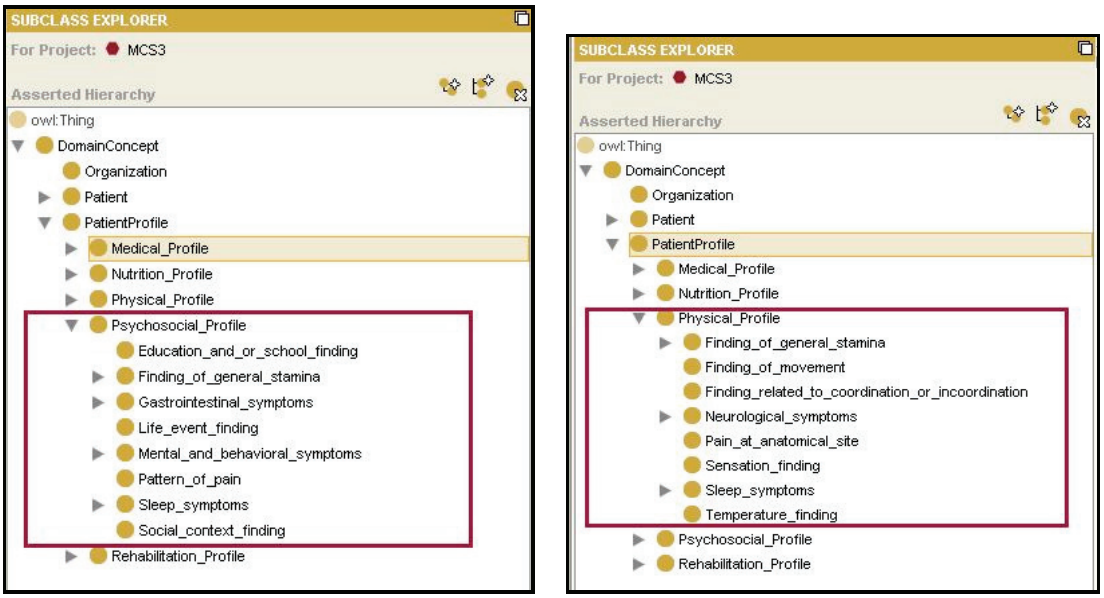

Figure 32 Physical and psychosocial profiles in the MCS profile ontology.

Figures 32 and 33 show the organization of the domain knowledge based on the knowledge retrieved from the controlled vocabulary. The knowledge is organized under the key areas of health focus as organized in the controlled vocabulary and as retrieved from the patient charts.

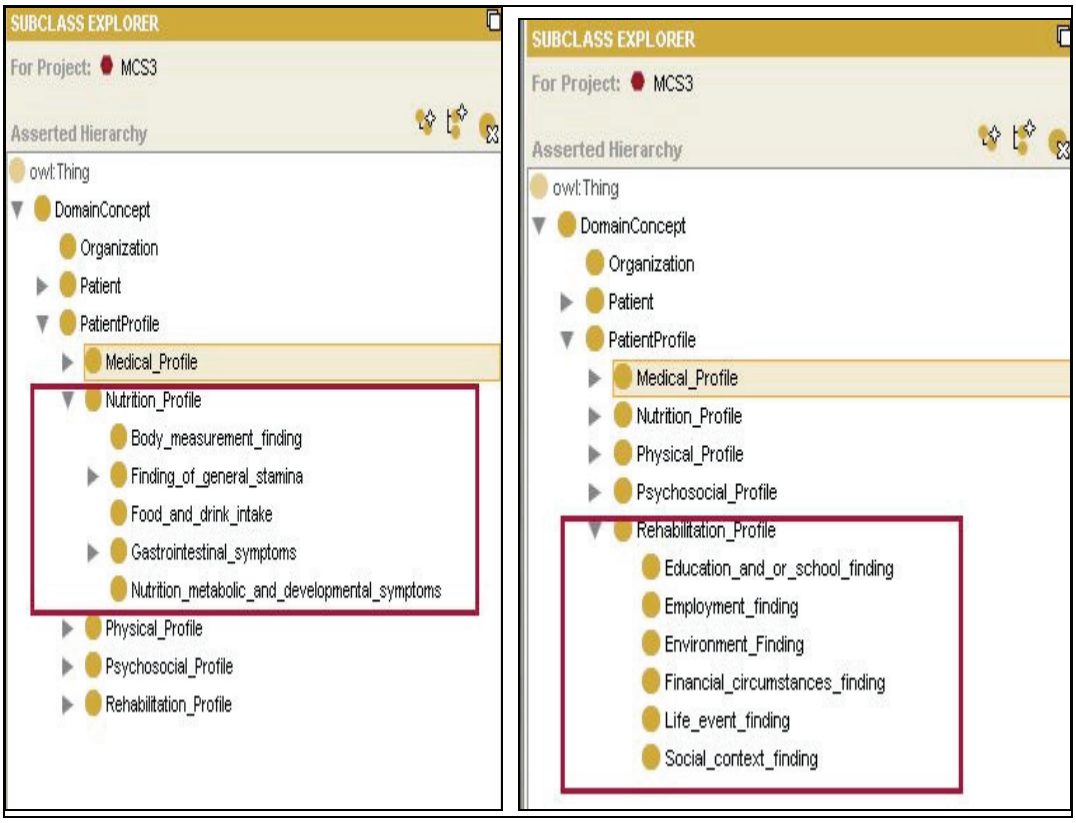

Figure 33 Nutrition and rehabilitation profiles in the MCS profile ontology.

The properties in the ontology introduce relations among concepts. A patient *HasOrganization* and the organization is inversely linked to the class Patient by *HasPatient*. The class Profile is linked to the class Management Scheme by property *hasCollaborativeManagement*. The class Psychosocial Profile is linked to the management scheme by property *ManagementRequired* which has individual *dietitian_referral* or *physician_referral*. The profile ontology includes definitions of over 70 properties, 46 data and 30 object properties.

The profile ontology is developed as a boundary object in this study to create a standard form [44] and as a dynamic object [32] that will allow knowledge to grow with the interaction and sharing of knowledge by multiple users.

The profile ontology contains standardized expression of concepts created in the controlled vocabulary to explicate the intended clinical meaning as seen by experts in the domain. Standardized concepts are specified with their SNOMED CT ID number

(Concept Unique Identifier) and with a list of synonyms. Class Fatigue has a SNOMED CT concept ID of 84229001 with parent concept being *Energy and Stamina* and synonyms *Weariness* and *Tiredness* (Figure 34).

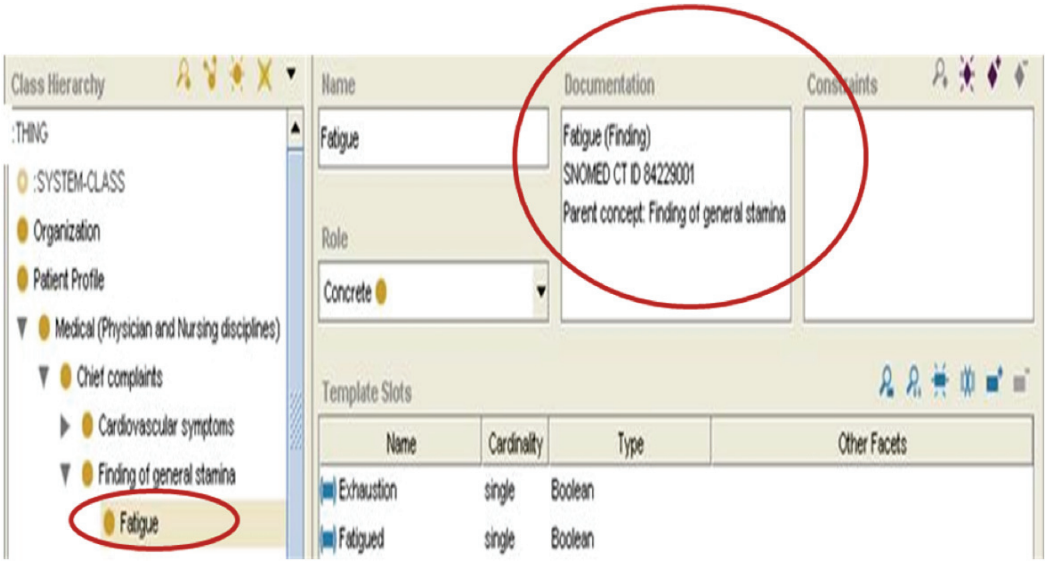

Figure 34 Standardized terminology in the MCS profile ontology, standard form of boundary object.

Examples of more intricate concepts that benefit from standardization and consistency relevant to this health condition include *heightened visual perception*, *heightened auditory perception*, *emotional hypersensitivity*, *impairment of balance*, *emotional regulation* or *emotional state finding* and *hypervigilant behaviour*.

Individuals or instances are used in the profile ontology to present list of concrete concepts of relevance for each class. For example, the ontology contains 100 individuals with MCS in the class Organization. A patient has data properties such as education, marital status and object properties such as *HasProfile* and *HasOrganization* that link it to other classes in the ontology.

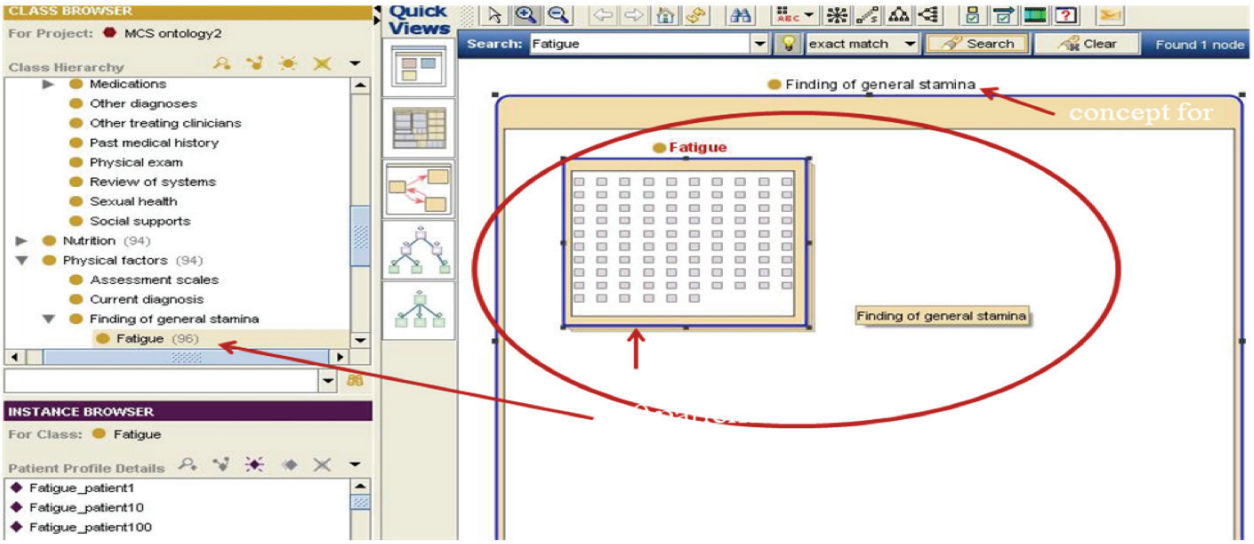

Figure 35 Query of a symptom in the MCS profile ontology.

The ontology also contains instances of 100 profiles for the class Patient Profile. The instances in profiles show the multifaceted nature of symptoms as substantiated under each area of health focus that exist in the domain of a complex patient (Figures 35 and 36). The user can query by a symptom such as *Fatigue* shown in figure 35 or query the multidisciplinary profile shown in figure 36.

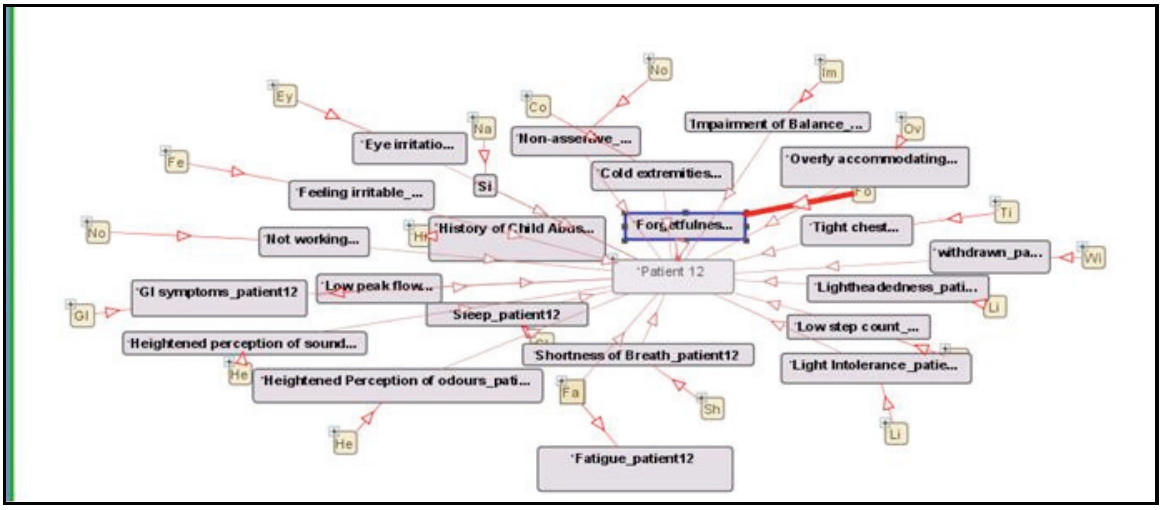

Figure 36 Multidisciplinary profile of a patient in the MCS profile ontology.

The ontology can be queried to view the profiles of the 100 patients populated in the ontology. The ontology allows users to understand the complex nature of patient profile for individuals with MCS.

The ontology can also be queried to view the multidisciplinary interactions that exist in the management of the symptoms for individuals with MCS.

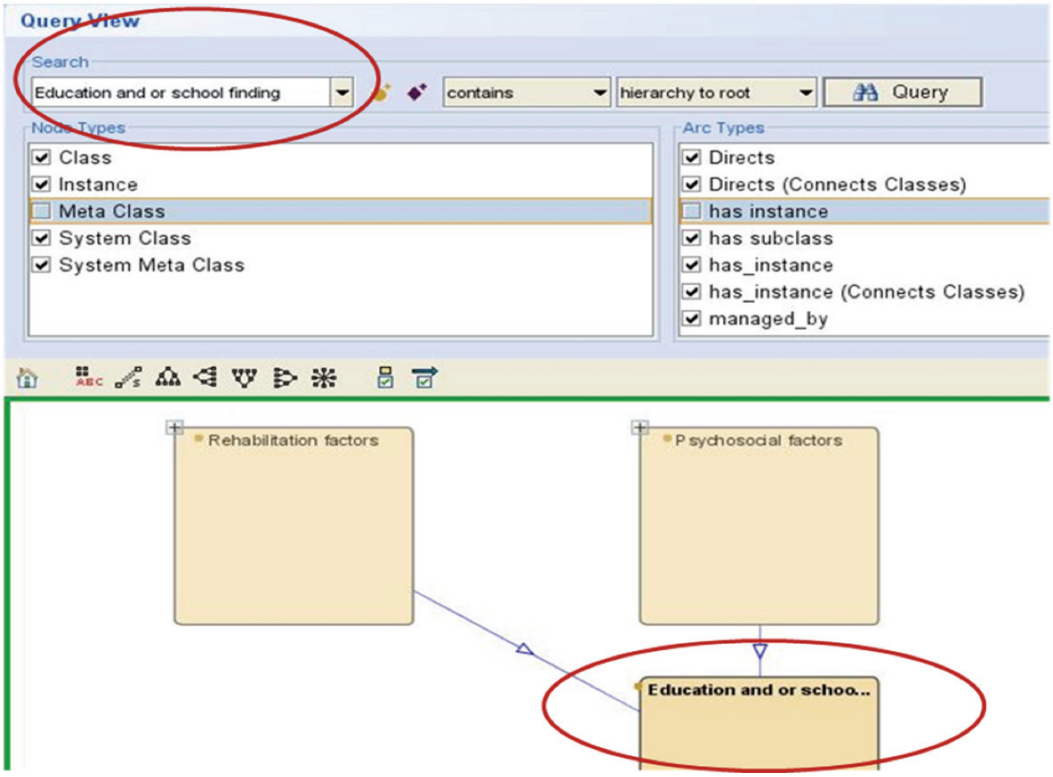

Figure 37 Multidisciplinary interactions in the categorization of *Education and school finding*.

For instance, the clinicians can view in a graphical interface the way a particular symptom or area of concern may play out as the focus of care for multiple disciplines (Figure 37). Bullying identified in the super class *Education and school finding* in SNOMED CT® can be a consideration for a psychologist and a rehabilitation coordinator

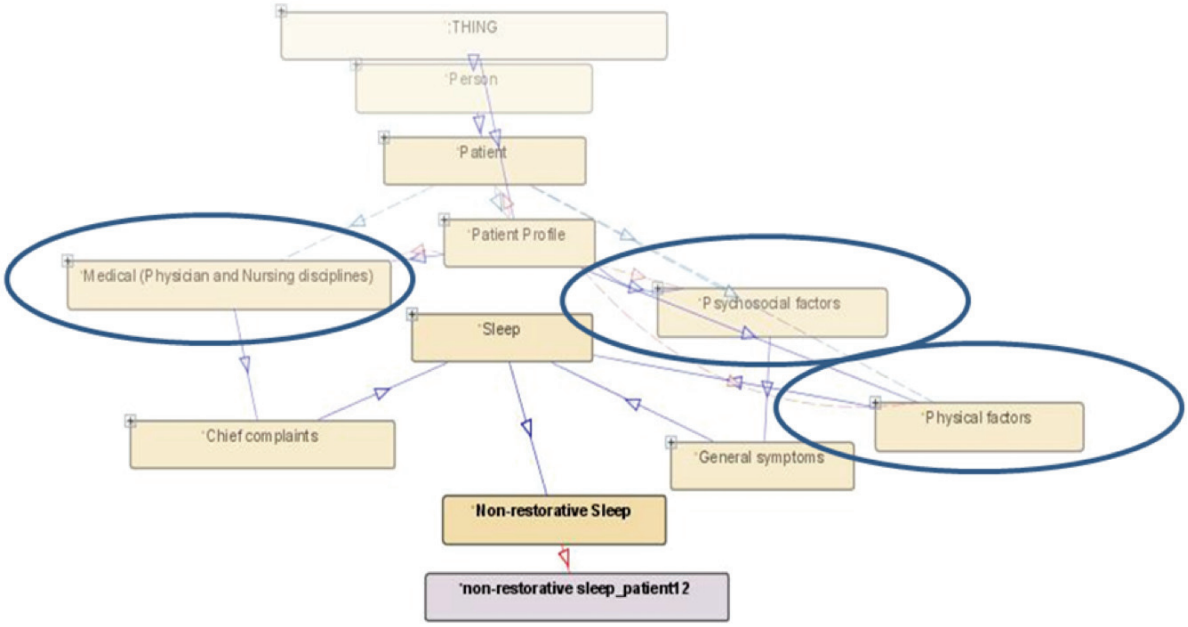

Figure 38 Multidisciplinary interactions in the categorization of *Non-restorative sleep*.

Non-restorative sleep is another symptom that is of interest in the medical, psychosocial and physical areas of health focus as shown in figure 38.

Pain symptom as presented in the patient charts has been viewed in the patient charts by a psychotherapist, physician or physiotherapist from various angles of importance such as pattern of pain, anatomical site or in relation to the pain threshold. Figure 39 shows the view of a patient profile.

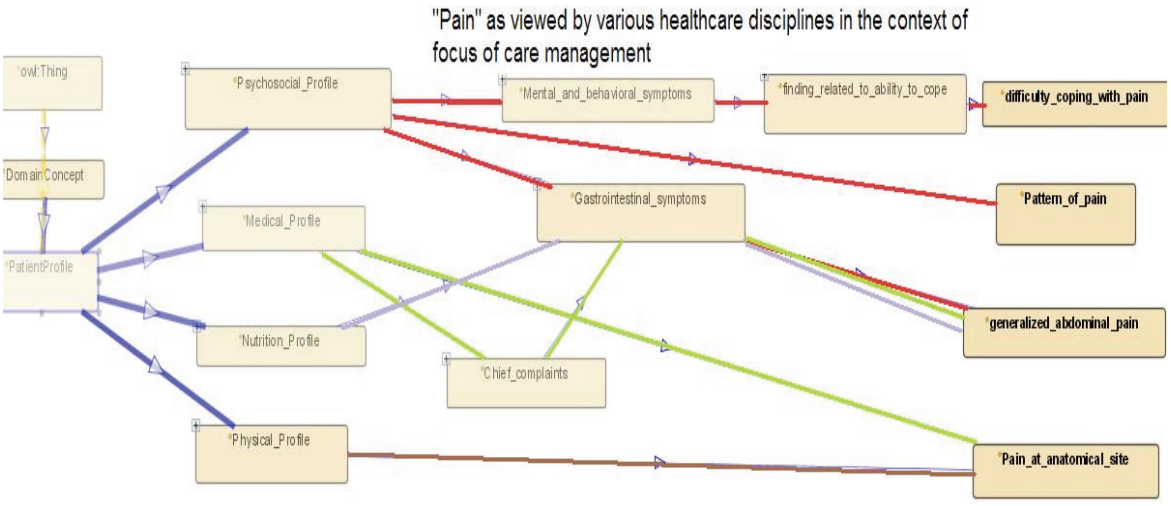

Figure 39 Multidisciplinary interactions in the categorization of *Pain*.

Implementation phase – Pragmatic level, standard forms and dynamic nature

Protégé 3.4.2 was used to do the consistency check for the ontology. There were no inconsistencies in the profile ontology.

An ontology evaluation was conducted by the domain experts checking the ontology for accuracy and completeness of knowledge representation. The clinicians also explored the multidisciplinary interactions and multidimensional concepts available in this comprehensive ontology. Four browsing tools were explored to determine the format that was most suitable and user friendly for the study on hand. Google ontology browser was preferred over Jambalaya, TGViz and OwlSight.

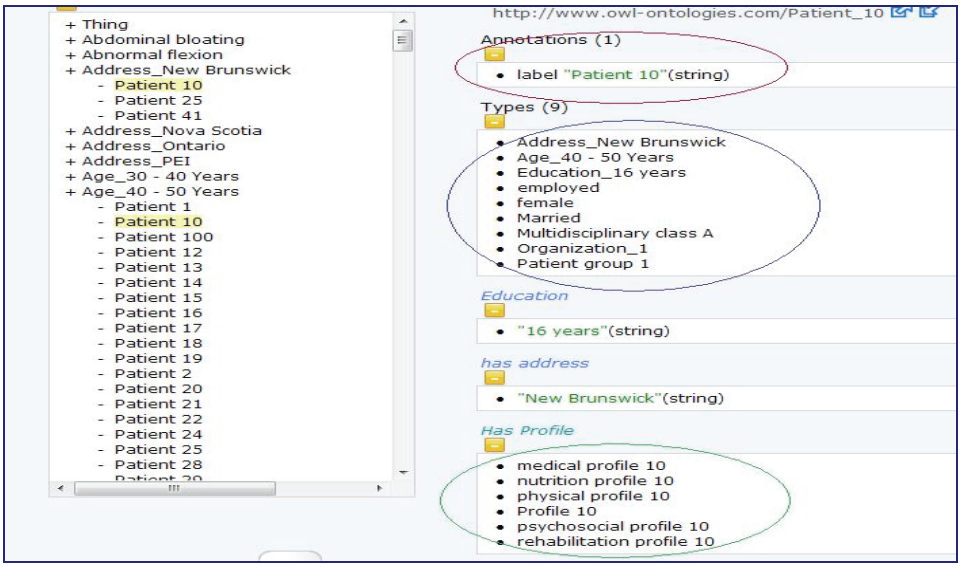

Figure 40 Profile of patient 10 using google ontology browser.

The clinicians queried the information about a patient to view background information on a patient such as the age, gender, marital status, employment status, organization and patient profile as shown in figure 40.

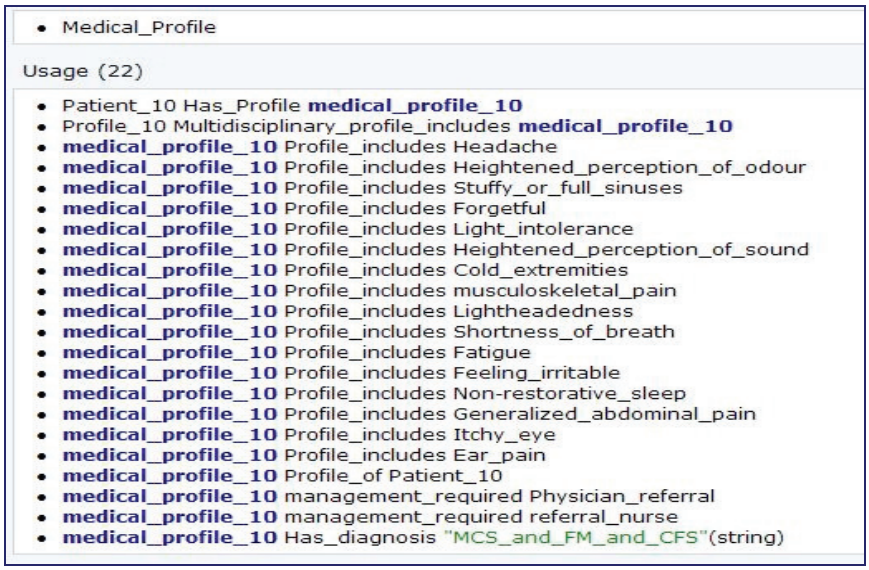

Figure 41 Medical profile for patient 10 in Google ontology browser.

Clinicians were able to view details in each of the profiles as shown in Figures 41 and 42 in which the details of the medical and psychosocial profiles for a patient are displayed.

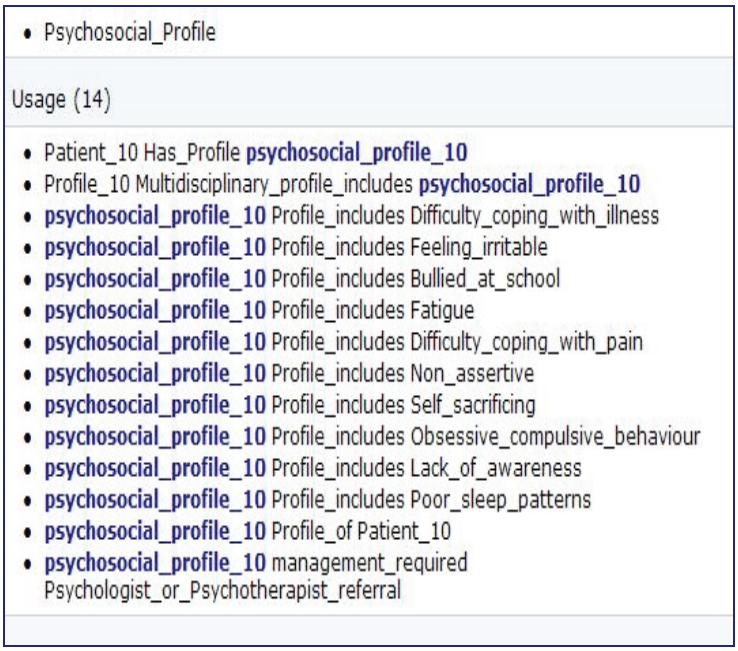

Figure 42 Psychosocial profile for patient 10 in Google ontology browser.

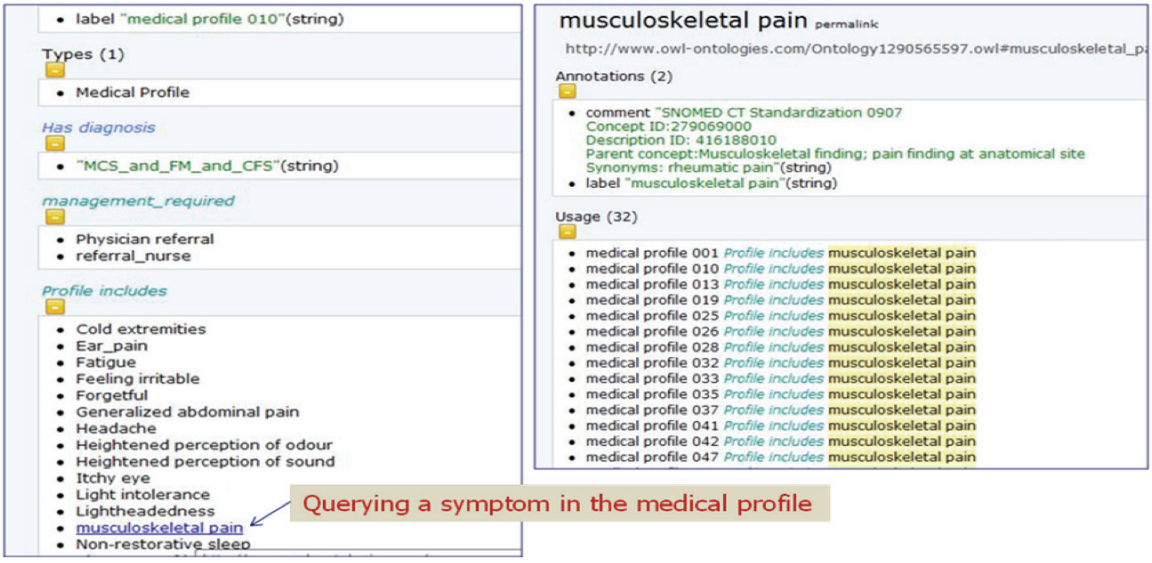

Figure 43 Query of a symptom in the Google ontology browser.

The clinicians also viewed information on various symptoms including the profiles under which a symptom was categorized, the number of patients that had a symptom and the standardization information for the symptoms as shown in figure 43.

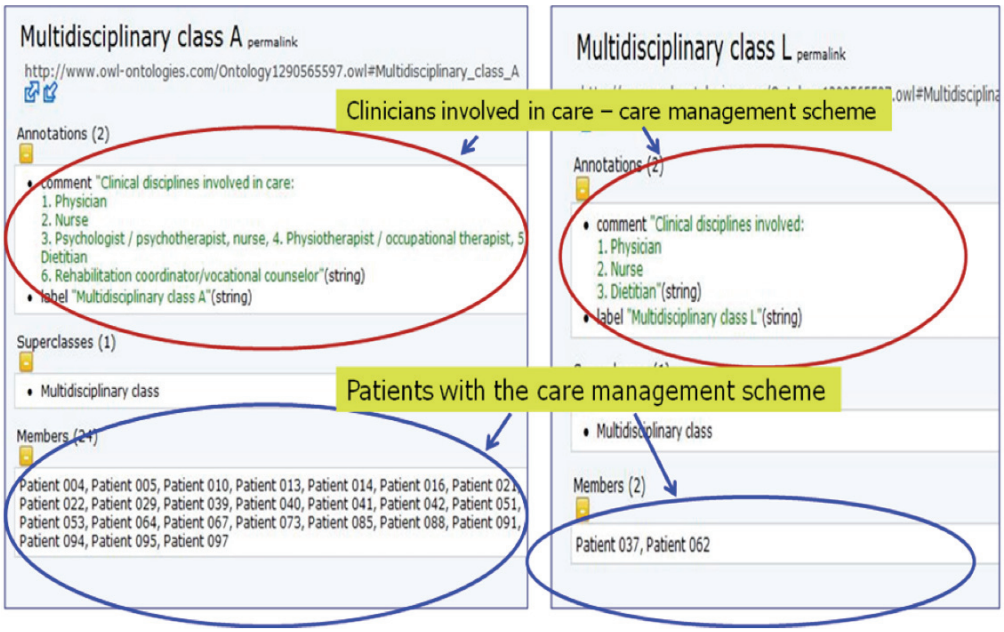

Figure 44 Multidisciplinary class in the MCS profile ontology.

Multidisciplinary classes were also created in the profile ontology (figure 44) which shows the involvement of various grouping of clinicians in the management of the multidisciplinary symptoms for patients with a diagnosis of MCS. For instance, Multidisciplinary class A involved the management by a physician, a nurse, a psychologist or a psychotherapist, a vocational counselor and a physiotherapist or an occupational therapist. Multidisciplinary class L involves the management by a physician, a nurse and a dietitian. The knowledge of these classes demonstrated to the experts that despite the diagnosis of MCS, the management schemes were driven by the presenting symptoms which could vary despite the diagnosis for patients. This was evident in the knowledge that was retrieved from the 100 patient charts.

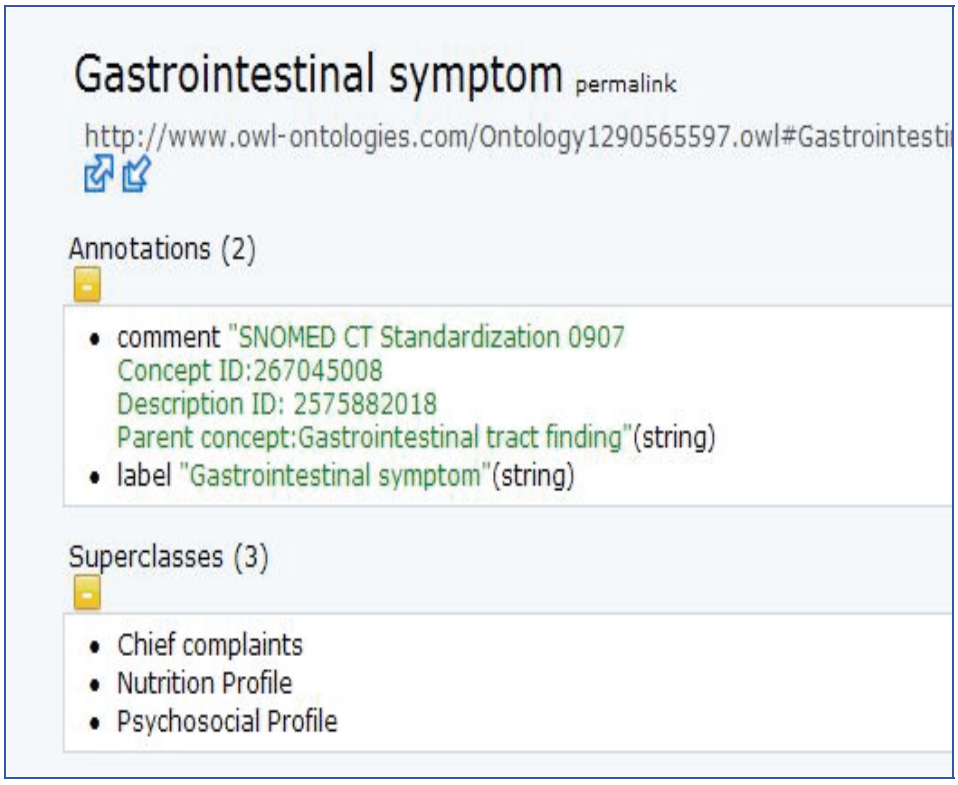

Figure 45 Display of standardization of concept in the Google ontology browser.

Figure 45 shows another view of the ontology in the browser where the standardization of a symptom concept in the ontology and the various profiles under which the symptom was categorized are displayed.

Seven domain experts were recruited to participate in the review of the ontology. Clinicians used the user friendly Google ontology browser to navigate through the ontology and were given an option to query the multidisciplinary interactions and the patient profile knowledge that exists in the populated instances of the ontology. Clinicians then used a survey questionnaire to provide feedback on the usefulness of the ontology. They provided feedback on the overall usefulness of the ontology, relevance of the ontology to their health discipline, usefulness of viewing information generated from other health disciplines and the usefulness of viewing multidisciplinary interactions.

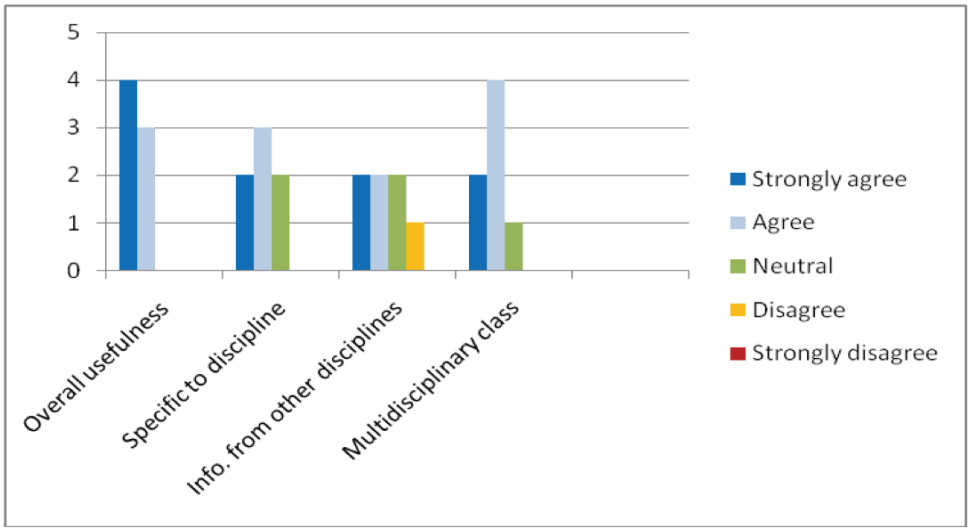

Figure 46 Feedback from the domain experts on the MCS profile ontology using a survey questionnaire.

A strong level of agreement was obtained in all categories of the survey questionnaire (Figure 46). The highest level of strong agreement was obtained in the overall usefulness category. Highest level of agreement was obtained on the usefulness of the multidisciplinary classes. A small amount of disagreement was obtained in the category of usefulness of the information from other health disciplines.

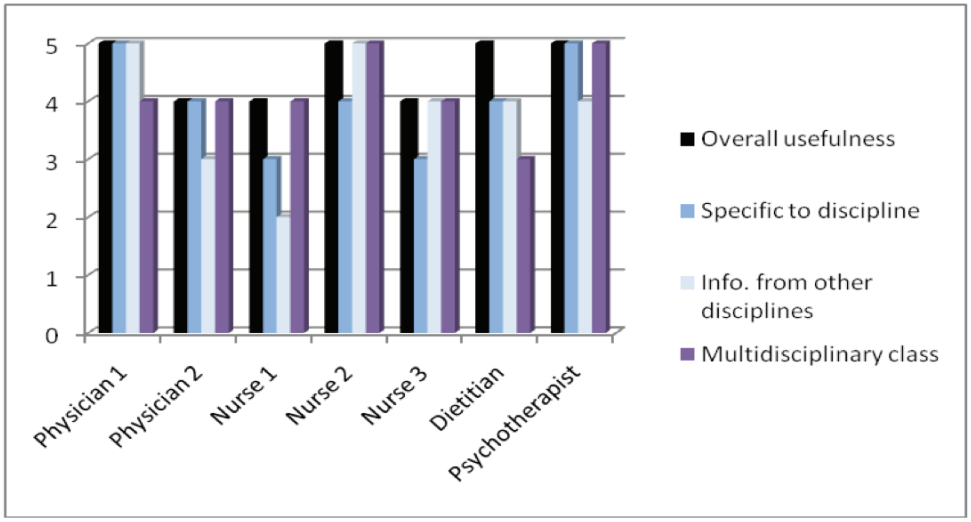

Figure 47 Feedback on the MCS profile ontology by disciplines of care.

In Figure 47, the level of agreement on the usefulness by a health discipline is shown. Over half the clinicians showed a strong level of agreement and agreement on the overall

usefulness of the ontology and most categories of the survey questionnaires. There were no specific trends by a health discipline or by a category in the survey questionnaire.

CHAPTER 7 VALIDATION OF THE MODEL AND METHODOLOGY PROPOSED IN THIS RESEARCH FOR CHRONIC PAIN

A controlled vocabulary and an ontology was developed in the patient profile and heterogeneous domain for chronic pain.

7.1 CONTROLLED VOCABULARY FOR CHRONIC PAIN

One hundred patients, eight domain experts and forty-two clinicians in the community participated in the study. The phases of development of controlled vocabulary as a boundary object included creating syntactic, semantic and pragmatic levels of shareability [25] of the domain knowledge. The controlled vocabulary was also developed as a dynamic boundary object [31] and as a standard form [109].

Syntactic layer of knowledge

A total of 100 patient charts were audited to retrieve key concepts and terminologies that were relevant to the patient profile categorization of MCS as shown in Table 10.

Table 10 Sample of chart audit terms for chronic pain (complete list in Appendix C).

INSTANCES OF FREQUENTLY USED CLINICAL TERMS (> 60%)		
Medical	Physical	Psychosocial
Chronic low back pain	Fatigue	Low mood
Chronic headache	Low energy	Depression
Hyperesthesia	Unable to do activities of daily living	Anxiety
Allodynia	Loss of strength	Loss of appetite due to pain
Shoulder pain	Difficulty initiating sleep	Difficulty coping with pain
Sharp pain	Sleep problems	Feeling irritable
INSTANCES OF MODERATELY USED CLINICAL TERMS (30 – 60%)		
Medical	Physical	Psychosocial
Neuropathic pain	Ambulation slow and guarded	Mood – frustrated
Post traumatic low back pain	Antalgic gait	Not working
Migraine	Low activity	Mood – angry
Arthritis	Deconditioning	Diarrhea
Hip pain	Reduced tolerance to prolonged sitting and standing	Feeling frustrated
INSTANCES OF INFREQUENTLY USED CLINICAL TERMS (<30%)		
Medical	Physical	Psychosocial
Vulvodynia	Unable to do work	Does not have social support
Fibromyalgia	Light headedness	Weight gain
Thoracic spinal stenosis	Tired	Difficulty working
Diabetic neuropathy	Limited range of motion	Abdominal pain
Psychogenic pain	Restricted cervical range of motion	Financial stressors

One hundred and eighty two concepts/ terminologies in use were retrieved in the multidisciplinary areas of health focus: physical, psychosocial, and medical. In the top one-third consortium (> 60%), were terminologies and concepts of related to medical

diagnoses such as *chronic low back pain*, *chronic headache* and *osteoarthritis*. Terminologies in this grouping also included co morbidities such as *diabetes*, *hypertension* and *COPD*. Terminologies related to pain location, pattern of pain and pain sensation also made it to this category. These include pain location sites such as *back pain*, *low back pain*, *foot pain*, *shoulder pain*; terms related to pattern of pain such as *achiness*, *throbbing pain*, *sharp pain*, and pain sensation terms such as *pin and needles* and *hot pain*. Terms related to physical examination such as *hyperesthesia*, *allodynia*, *weakness in arms*, *reduced tolerance to physical activity* were also found in the top consortium. Functional characteristics such as *difficulty staying asleep*, *difficulty initiating sleep*, *fatigue*, *low energy*, *loss of strength*, *unable to do activities of daily living* were also prevalent in this category. Psychosocial terminologies such as *depression*, *anxiety*, *coping abilities*, *low mood* were found in this consortium. The middle consortium (30 – 60%), had more terminologies related to diagnoses, symptoms of pain, patterns and sensation of pain. Functional and psychosocial characteristics were also prevalent. The last third consortium included some rare diagnoses such as *vulvodynia*, *fibromyalgia* along with comorbidities such as *platelet disorder* and *multiple chemical sensitivity*.

Semantic layer of knowledge and standard form of boundary object

One hundred and thirty seven (%) of these concepts were available in SNOMED CT® .

Table 11 Standardization of multidisciplinary vocabulary for chronic pain using SNOMED CT® .

SNOMED CT Tree	Instance 1 – chronic pain	Instance 2 – chronic pain
Concept	Vulvodynia – concept in clinical notes - search SNOMED CT browser	Achiness – concept in clinical notes – search in SNOMED CT browser
Concept ID	Concept ID: 238968009	Concept ID: 27635008
Fully Specified Name (FSN)	Vulvodynia (disorder)	Aching pain (finding)
Preferred Term	Vulvodynia	Aching pain
Parent concept	Disorder of vulva and disorder characterized by pain	Pain by sensation quality (finding)
Hierarchy/Sub-hierarchy	Disease --disorder by body site --disorder of body system ---disorder of vulva Finding site: Vulval structure (body structure) Has definitional manifestation: Pain (finding)	Clinical Finding --Clinical history and observations finding --Pain (finding) --Pain by sensation quality (finding)

Table 11 demonstrates the levels of standardization that are possible for concepts related to patient profile retrieved by patient charts. *Vulvodynia* and *achiness* are examples shown in the table. The concepts are standardized with a unique concept ID, a preferred term, synonyms and parent concepts. The levels of translation can lead to the level of

granularity that is required. This is one of the advantages of the hierarchical structure of SNOMED CT®.

Table 12 Inconsistencies in chart notes for chronic pain.

Terminologies in clinical notes	SNOMED CT concepts (hierarchy) and concept ID
Fatigue, low energy, very tired, extremely tired	Fatigue (finding) 84229001
Right shoulder pain, right pain in shoulder	Pain radiating to right shoulder (finding) 426142001
Fibromyalgia, FM, Myalgia	Fibromyositis (disorder) 24693007
Tenderness of knee joint, knee joint tender, knee joint tenderness	Knee joint - tender, 299372009
Difficulty falling asleep, cannot fall asleep, difficulty initiating sleep	Difficulty falling asleep 5905008

Table 12 shows examples of inconsistent terminologies retrieved from the patient charts under various areas of health focus. These concepts are standardized using SNOMED CT® to remove inconsistencies and improve knowledge sharing as well as knowledge translation. An example could include the use of tenderness of knee joint expressed in a number of ways in the patient charts. Standardizing the usage of this concept as it exists in SNOMED CT®, knee joint – tender enables consistent knowledge sharing as well as knowledge retrieval in the future.

Table 13 Mapping scheme used for chronic pain vocabulary.

TERM	VALUE	ALTERNATIVE	CODE
Mechanical pain of shoulder	1		
Loss of sensation in leg	1		
Tenderness in the paraspinous area	1		
Tenderness in thoracic spine	2	Thoracic spine - tender	298578004
Stomach pain	2	Abdominal pain	21522001
Depression	2	Symptoms of depression	394924000
Difficulty coping with pain	3		16399001
Antalgic gait	3		67141003
Chronic low back pain	3		279040009

The terms from the chart audit were mapped to concepts in SNOMED CT®. A score of "1" was assigned to "no match" terms, score of "2" to synonyms and "3" to exact match terms (Table 13). A total of 182 clinical terms were retrieved through the chart audit process out of which 137 concepts were standardized (75%) in SNOMED CT® through the manual string matching technique. The terms were mapped using the normalized string matching technique. The percentage of exact matches and synonyms or closely related words found in the various health care disciplines is as shown in Figure 1. A total

of 95 terms in the medical category, 16 terms in the physical and 28 terms in the psychosocial areas of health focus related to profile categorization was retrieved and standardized. A total of 77%, 67% and 80% terms were standardized in the medical, functional and psychosocial areas of health focus (Figure 48). The psychosocial area had the highest level of available concepts in SNOMED CT® . The physical area of health focus had the highest number of no match terms.

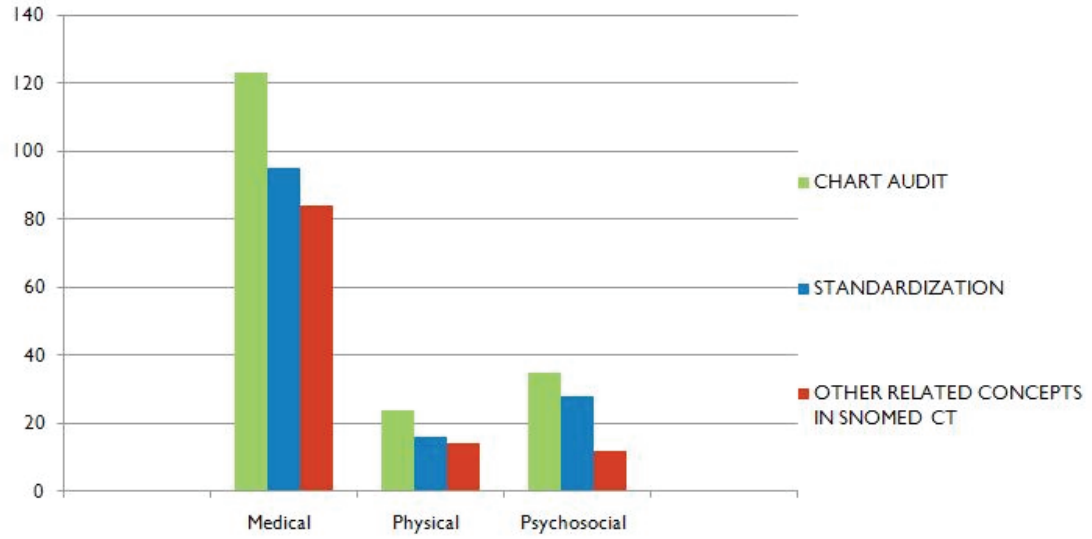

Figure 48 Number of chronic pain concepts retrieved from patient charts and standardized using SNOMED CT® .

Pragmatic layer of knowledge and dynamic nature of boundary object: Testing and evaluation of the vocabulary

This phase of the study included exploring the pragmatic and dynamic characteristics of the boundary object by testing the controlled vocabulary in clinical process through a re-coding process. The pragmatic and dynamic characteristics were also examined through a feedback from the domain experts and clinicians in the community (experts and non-experts).

Seven clinicians participating in the re-coding process completed their evaluation of the vocabulary using a 5-point Likert scale that measured the usefulness of the vocabulary under an overall category and under sub-categories of scope, specificity and structure.

The clinicians used a web-based form to complete the re-coding process. They were provided 3 patient charts containing the intake information on patients and given the option to use a fourth chart in the re-coding process if they wanted to explore the controlled vocabulary further. Figure 49 shows the web-based form used in the re-coding process.

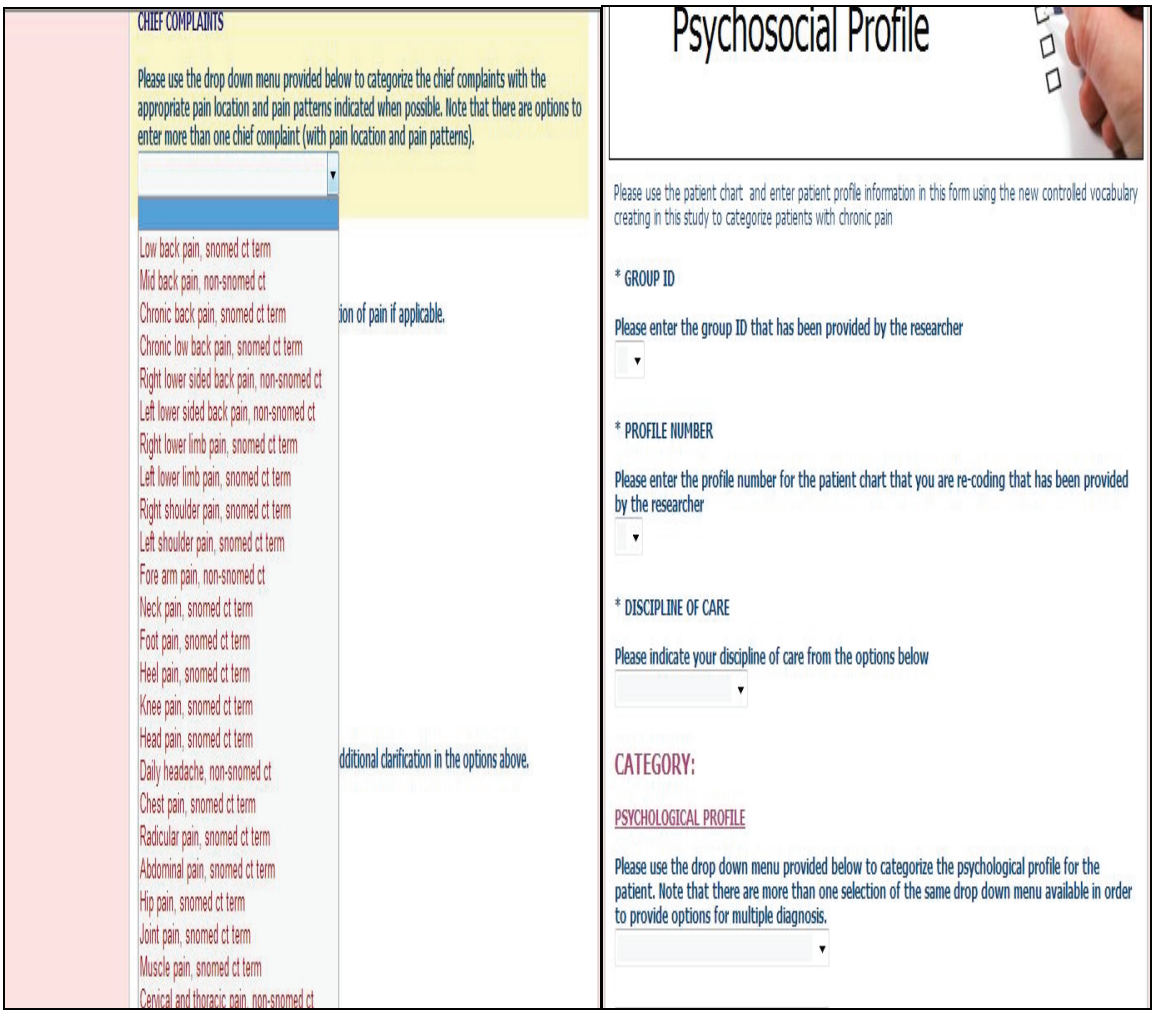

Figure 49 Web-based form used by chronic pain domain experts in the re-coding of patient profiles.

The web-based form developed for the re-coding process was grouped under various areas of health focus as they were grouped in patient charts. The clinicians used drop-down menus to select terminologies for re-coding. The clinicians entered missing terms and concepts in a comments box that was available under each category of re-coding.

Table 14 Missing terms in the vocabulary identified by researcher and the clinicians (Higher value terms contain all of the terms in the lower value column and some additional terms).

Focus of Care Management	Missing terms identified by researcher	Missing terms requested by clinicians
Physical	12	8
Psychosocial	5	4
Medical	30	55

Cohen's kappa analysis was conducted to determine the correlation in the missing terms identified by researcher and the clinicians (domain experts) (Table 14). A kappa score of 0.69 indicating a good level of agreement (< 0 as indicating no agreement and 0–.20 as slight, .21–.40 as fair, .41–.60 as moderate, .61–.80 as substantial, and .81–1 being almost perfect). The medical category had the highest level of disparity between terms identified by researcher and the clinicians.

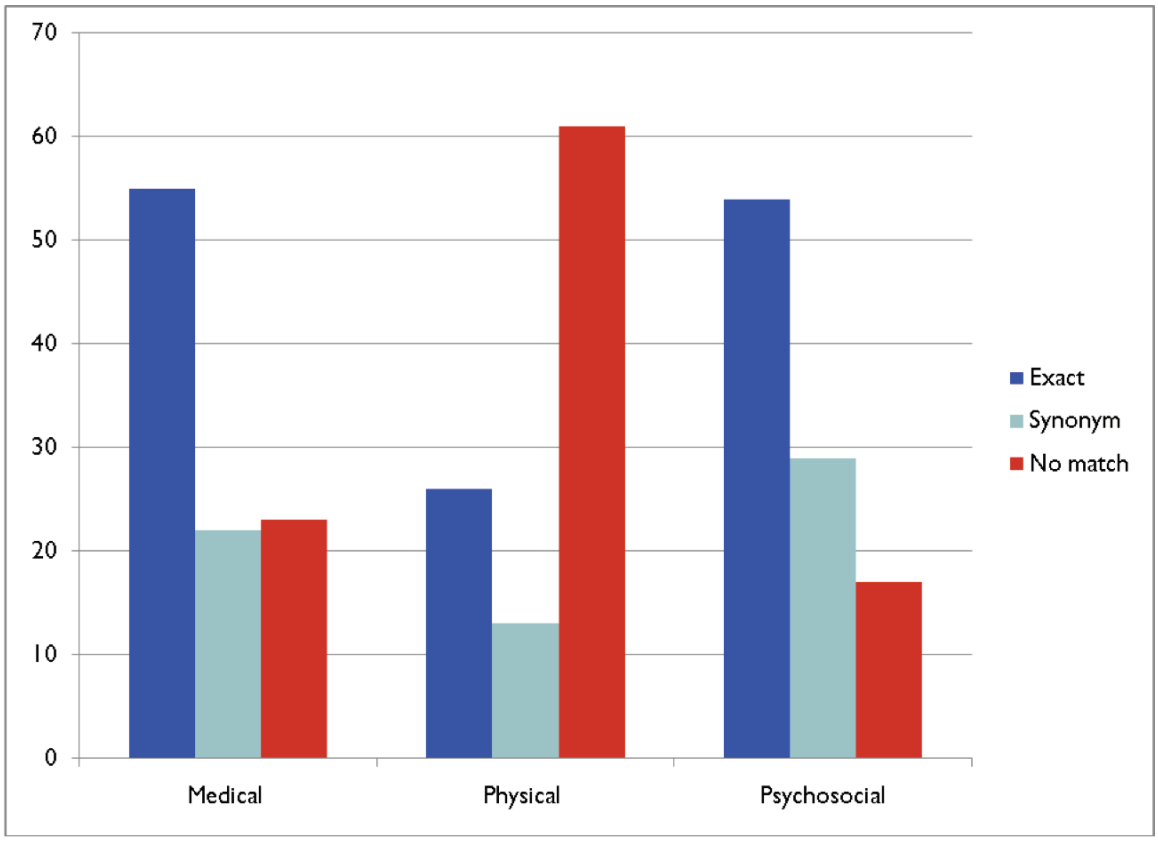

Figure 50 Percentage of exact, synonym and no match terms grouped under various areas of health focus in the chronic pain vocabulary.

Figure 50 shows that the psychosocial and medical categories had a high level of exact match terms compared to the physical category which had the highest level of "no match" terms (>60%). Based on the feedback from clinicians and a second round of review by researcher, additional related concepts were included in the controlled vocabulary; eighty four terms in the medical area, 14 in the physical and 12 in the psychosocial categories.

Table 15 Cohen's kappa score for missing terms for chronic pain by health discipline.

Health Care Discipline	**Cohen's Kappa for inter-rater reliability New term look up N = 2**
Nurse 1; Nurse 2	0.65
Occupational therapist 1; Occupational therapist 2	0.89
Physician 1; Physician 2	0.88

Based on the re-coding process, clinicians requested for additional terms. Cohen's kappa analysis for new term look up by health discipline was conducted. The kappa scores showed high correlation among all health disciplines as shown in Table 15 (< 0 as indicating no agreement and 0–.20 as slight, .21–.40 as fair, .41–.60 as moderate, .61–.80 as substantial, and .81–1). All cohen's kappa coefficients reached statistical significance but there is general agreement that a useful coefficient level start at 0.41.

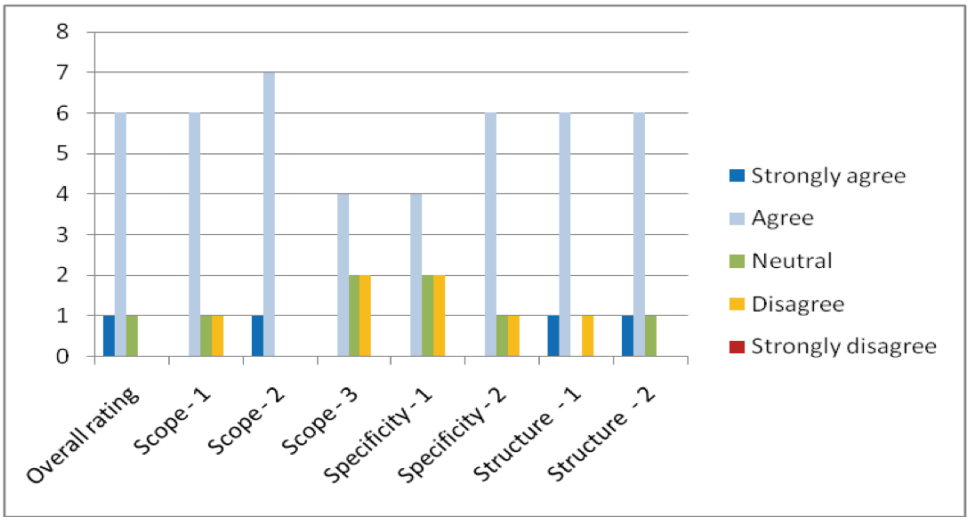

Figure 51 Feedback from the domain experts on the controlled vocabulary for chronic pain (y-axis shows the number of clinicians).

Eighty percent of the multidisciplinary clinicians (experts in the domain) agreed on the overall usefulness of the controlled vocabulary (Figure 51). The sub-categories also had an overall high level of agreement with the question on the use of terms familiar to the clinicians under the scope category getting the maximum level of agreement from the clinicians (90%). Questions under structure and specificity brought a level of disagreement from a small percentage of the clinicians. Cronbach's alpha analysis was conducted to determine the internal reliability of the survey questionnaire. A good level of internal consistency and reliability was obtained with a Cronbach's alpha score of 0.76 (alpha score > 0.7 is considered a good level of consistency by researchers).

Forty two clinicians in the community from various disciplines in health care participated in the study, nine physicians, seven psychologists, eight physiotherapists, six dietitians, seven nurses and five occupational therapists. They reviewed the patient charts in the old vocabulary and the new vocabulary. An overall agreement to the usefulness of the vocabulary was reached among the experts in most categories. Over 65% of clinicians agreed on the overall usefulness of the vocabulary (Figure 52). Over 50% of the clinicians were in agreement on all categories of the survey questionnaire with a small percentage of strong agreement and disagreement in most categories.

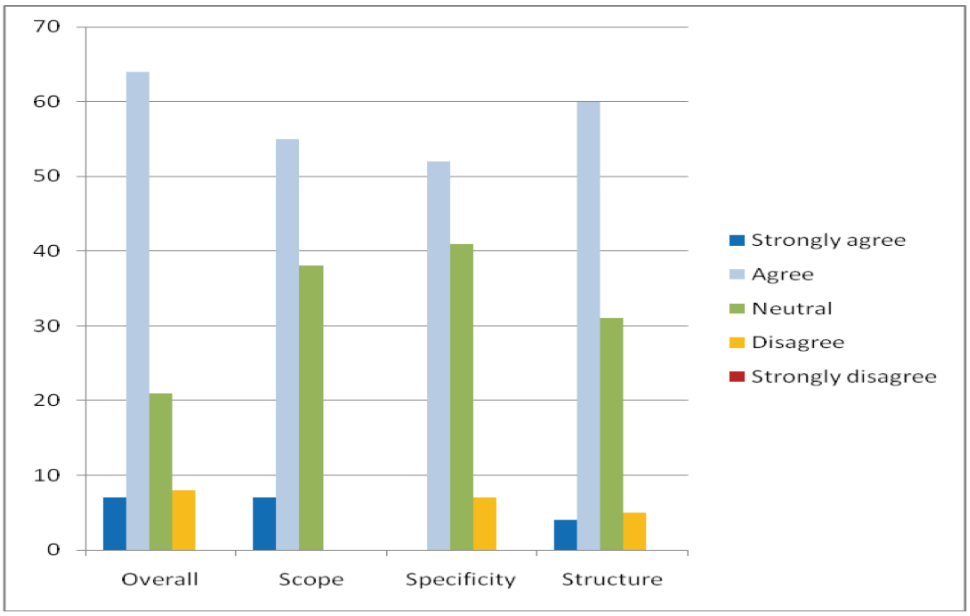

Figure 52 Feedback from clinicians in the community on the controlled vocabulary for chronic pain (y-axis shows the percentage of clinicians).

Figures 53 to 58 show the feedback obtained by disciplines of care on the usefulness of the controlled vocabulary.

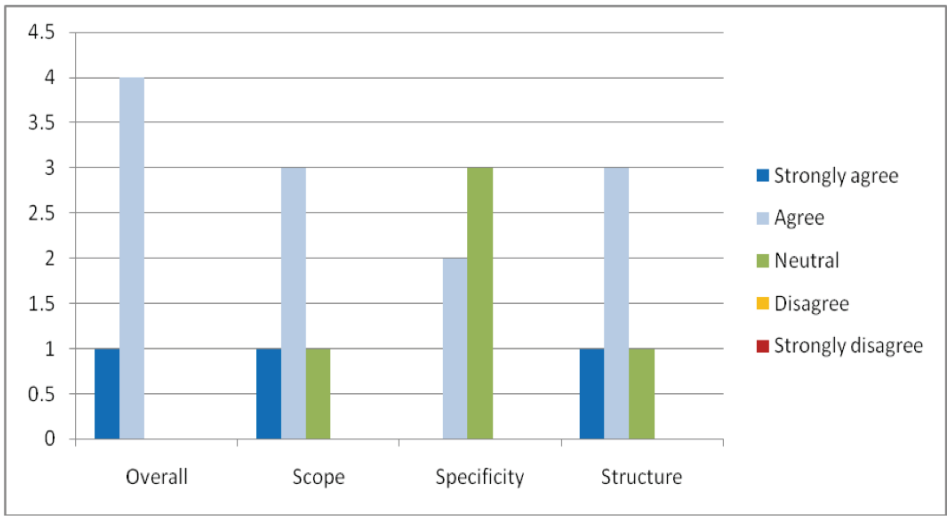

Figure 53 Feedback from the occupational therapists in the community on the controlled vocabulary for chronic pain (y-axis shows the number of clinicians, n=5).

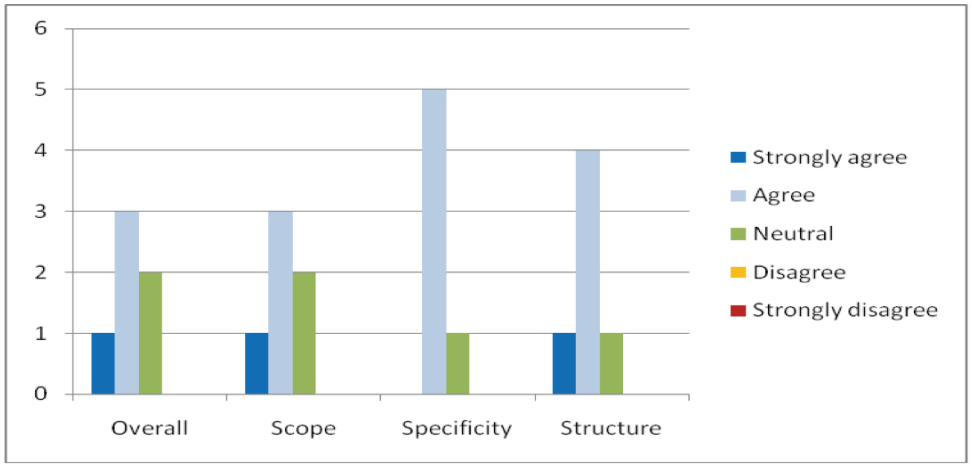

Figure 54 Feedback from the dietitians in the community on the controlled vocabulary for chronic pain (y-axis shows the number of clinicians, n=6).

The occupational therapists and dietitians were the most favourable to the new vocabulary with higher levels of agreement and strong agreement scores compared to other health disciplines as shown in figures 53 and 54.

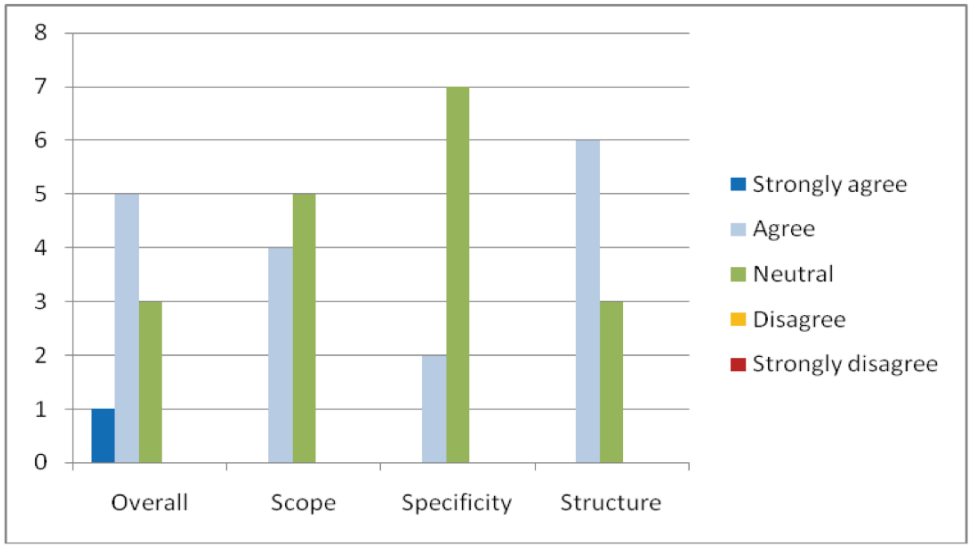

Figure 55 Feedback from the physicians in the community on the controlled vocabulary for chronic pain (y-axis shows the number of clinicians, n=9).

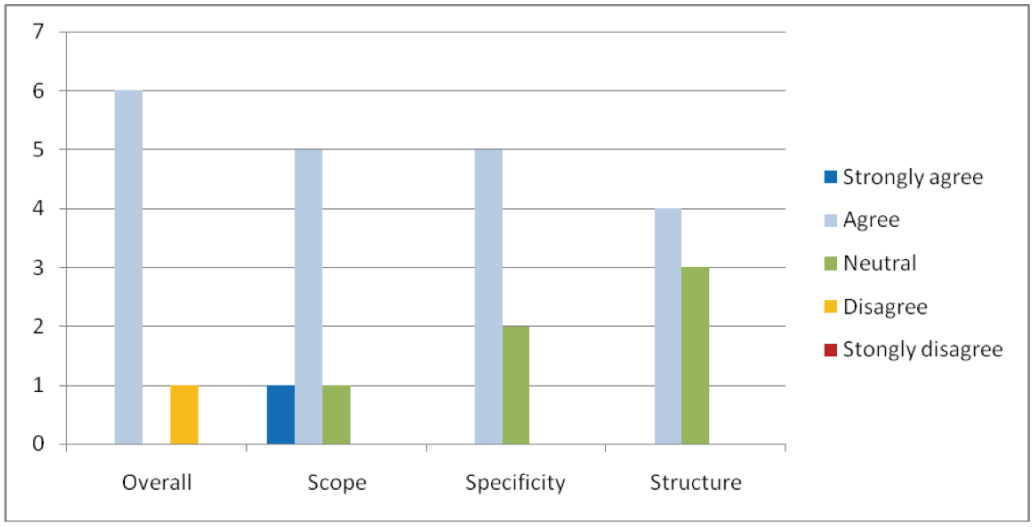

Figure 56 Feedback from the nurses in the community on the controlled vocabulary for chronic pain (y-axis shows the number of clinicians, n=7).

Figure 55 shows that the physicians were next in their overall acceptance of the new vocabulary in terms of a moderate level of agreement. However, as in the MCS evaluation, they showed a greater lean towards neutral rating in their evaluation of the vocabulary. Figure 56 shows the evaluation of the nursing discipline again with a favourable level of agreement towards the vocabulary. They had a high level agreement in the overall usefulness category. But a small level of disagreement was also demonstrated by this discipline of care. Figures 57 and 58 show the two health disciplines, psychologists and physiotherapists where the disagreement became more apparent, despite being a small percentage compared to the other health disciplines. This trend was similar to the feedback obtained in the MCS evaluation.

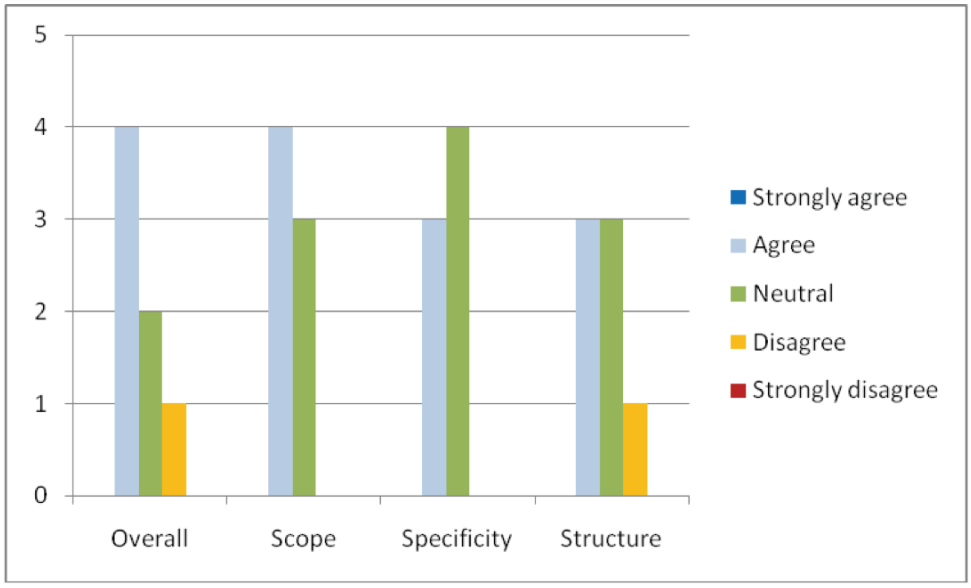

Figure 57 Feedback from the psychologists in the community on the controlled vocabulary for chronic pain (y-axis shows the number of clinicians, n=7).

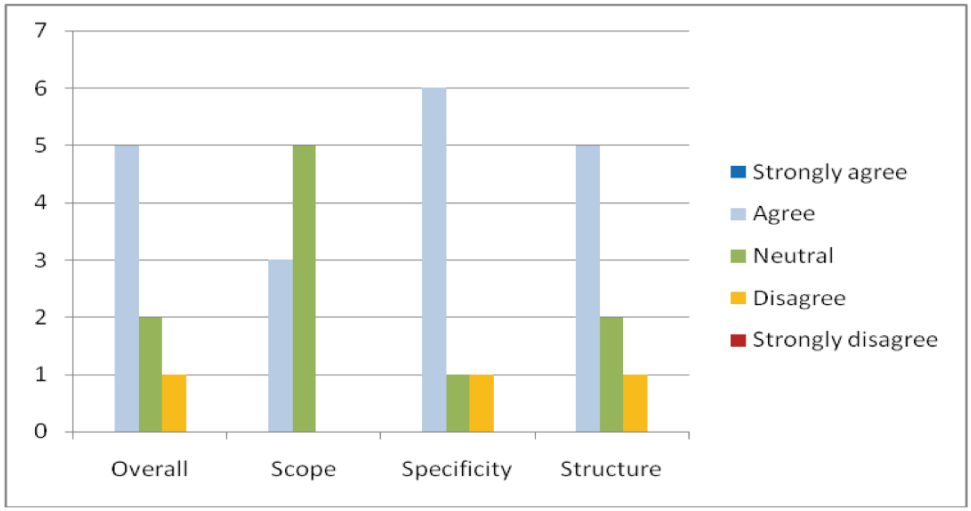

Figure 58 Feedback from the physiotherapists in the community on the controlled vocabulary for chronic pain (y-axis shows the number of clinicians, n=8).

Kendall's Tau was calculated at 0.6 with a moderate level of concordance among the 42 (multiple) raters with a p value of 0.03. Cohen's Kappa for the dietician's group showed the highest level of agreement with a score of 0.84. Cohen's Kappa for agreement across disciplines showed low agreement between physicians and dieticians (0.2) and a moderate level of agreement between physicians and physiotherapists (0.5).

Table 16 Kendall's Tau analysis for internal consistency of feedback questionnaire for chronic pain vocabulary.

Correlations for all pairs of data series with p-values			
pair	Pearson r	Spearman rho	Kendall tau
Overall;Scope	0.3147	0.3157	0.3082
p-value	(0.0424)	(0.0417)	(0.0432)
Overall;Specificity	0.4144	0.3997	0.3953
p-value	(0.0064)	(0.0087)	(0.0105)
Overall;Structure	0.4037	0.3905	0.3862
p-value	(0.008)	(0.0106)	(0.0124)
Scope;Specificity	0.4651	0.4471	0.4341
p-value	(0.0019)	(0.003)	(0.004)
Scope;Structure	0.3417	0.3236	0.3134
p-value	(0.0268)	(0.0366)	(0.0377)
Specificity;Structure	0.2885	0.3173	0.3107
p-value	(0.0639)	(0.0406)	(0.042)

Kendall's Tau was calculated between the categories in the survey questionnaire. All combinations reached statistical significance (<0.05) as seen in the table 16 showing good level of internal consistency in the questionnaire.

7.2 Profile Ontology For Chronic Pain

Outcome of the specification phase

The goal of the specification phase included identifying the concepts and terms that existed in the patient profile domain for chronic pain. The knowledge for the specification phase was derived from the controlled vocabulary which was developed through a retrospective chart audit process and feedback from domain experts. A total of 182 clinical terms were retrieved through the chart audit process out of which 137 concepts were standardized (75%) in SNOMED CT® through the manual string

matching technique. The terms were mapped using the normalized string matching technique. A total of 95 terms in the medical category, 16 terms in the physical and 28 terms in the psychosocial areas of health focus related to profile categorization was retrieved and standardized. The terms in the medical area of health focus were primarily related to diagnosis, patterns and sensations of pain, relevant symptoms and functional abilities. The physical area included terms related to functional abilities, activities of daily living and other relevant symptom categorization. Psychosocial area included terms related to psychological symptoms, life events, nutrition symptoms and trends and social profile categorization. A total of 77%, 67% and 80% terms were standardized in the medical, functional and psychosocial areas of health focus. Eighty percent of the multidisciplinary clinicians (experts in the domain) agreed on the overall usefulness of the controlled vocabulary (Figure 5). The sub-categories also had an overall high level of agreement with the question on the use of terms familiar to the clinicians under the scope category getting the maximum level of agreement from the clinicians (90%). Questions under structure and specificity brought a level of disagreement from a small percentage of the clinicians. Cronbach's alpha analysis was conducted to determine the internal reliability of the survey questionnaire. A good level of agreement was obtained with a Cronbach's alpha score of 0.76 (> 0.7 is considered a good level of consistency and reliability).

Description and organization of the knowledge in the domain

An important consideration of this phase was to develop consistency in the description of the knowledge in the domain. This was achieved through the development of the controlled vocabulary. The standardization offered another layer of clarity to assist in the organization of the knowledge in the domain. For instance the concept "radiating pain" can be interpreted as finding of pattern of pain. The intended clinical meaning relates to pain patterns observed in a patient who can now be tagged using a consistent terminology and a unique concept ID.

The controlled vocabulary was organized in a hierarchical structure with concepts being presented the way they were depicted or captured in the patient charts by the various health care disciplines.

Figures 59 to 61 show the organization of the controlled vocabulary under various areas of health focus.

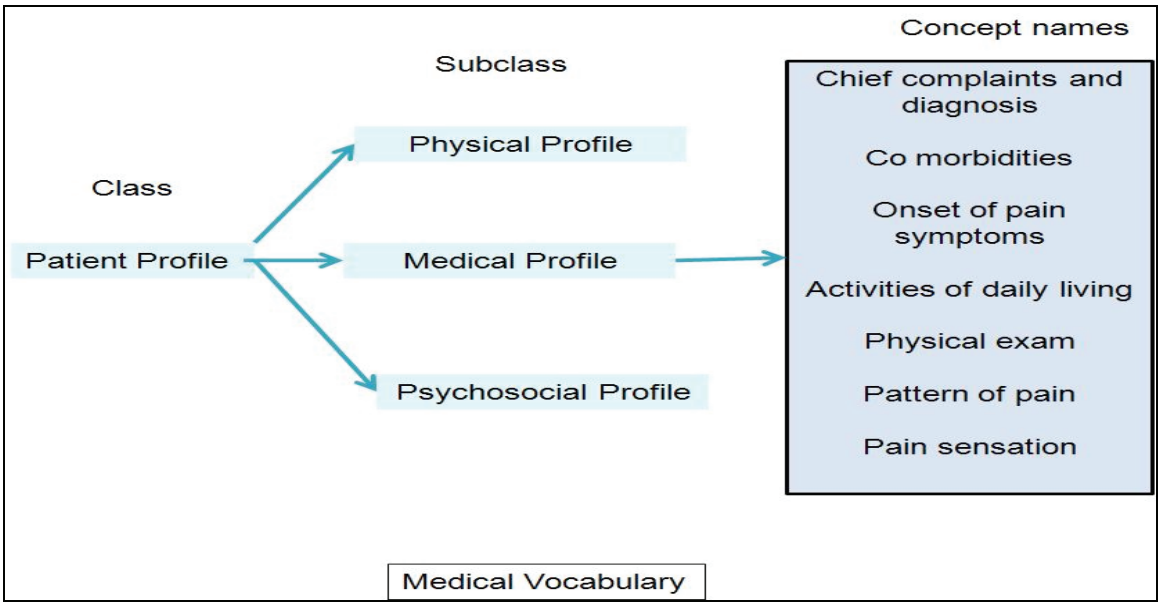

Figure 59 Medical profile in the chronic pain vocabulary.

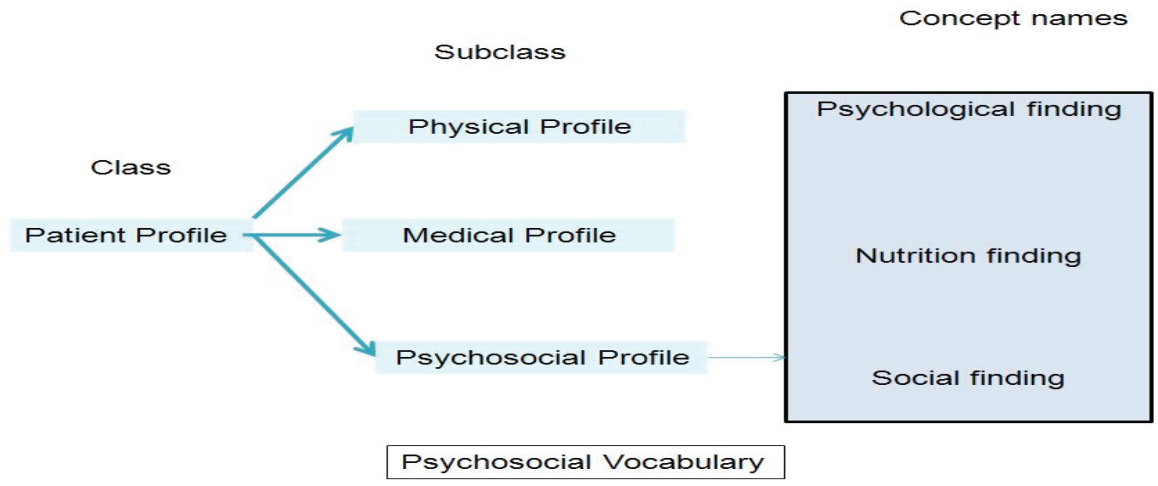

Figure 60 Psychosocial profile in the chronic pain vocabulary.

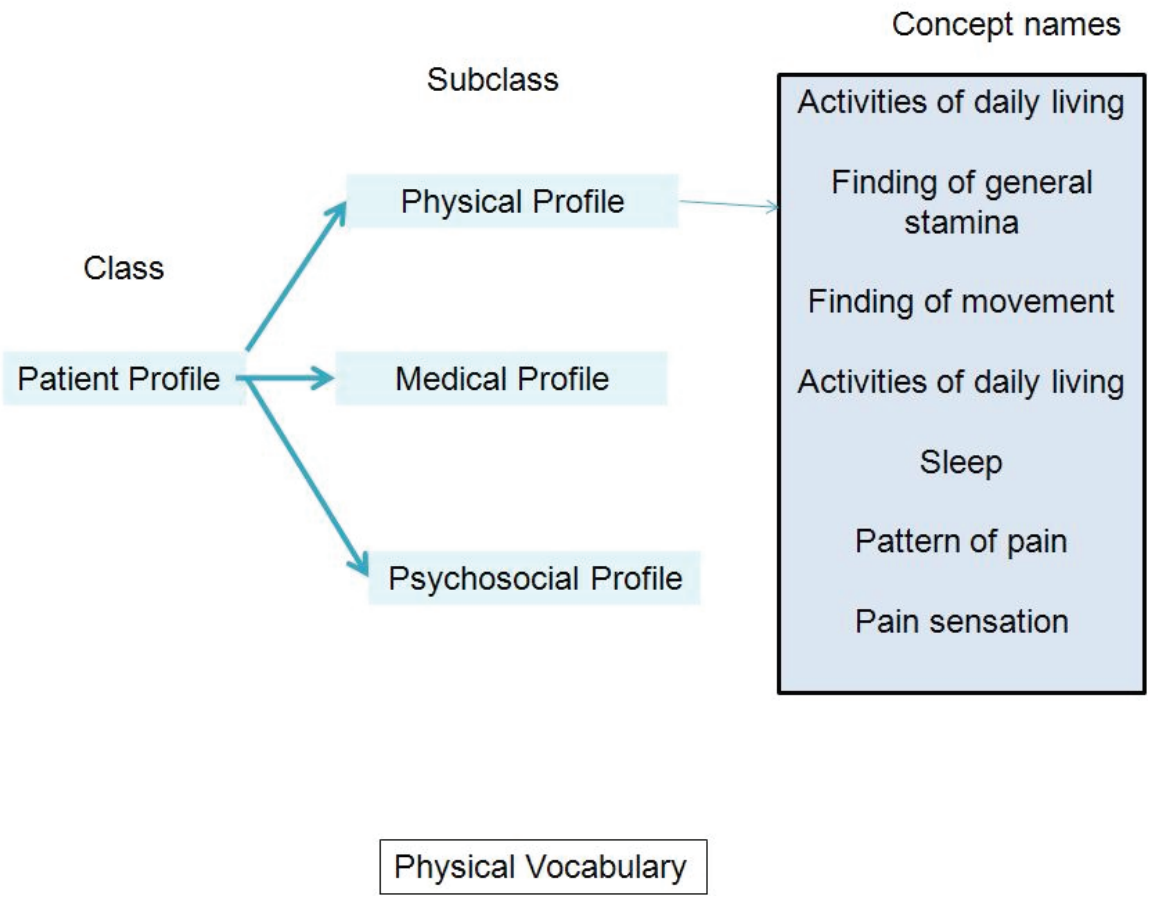

Figure 61 Physical profile in the chronic pain vocabulary.

Outcome of the conceptualization phase

Protégé 3.4.2 [36] was used to develop the ontology. The ontology presents a detailed taxonomic overview of the complex health condition domain. The ontology contained 345 classes describing the profile concepts for the condition of chronic pain. At the basic level there are three relevant super-classes under the primary areas of health focus identified for the condition of chronic: Medical, Physical and Psychosocial.

Figure 62 presents the Protégé tool displaying the relevant super classes from the ontology for chronic pain.

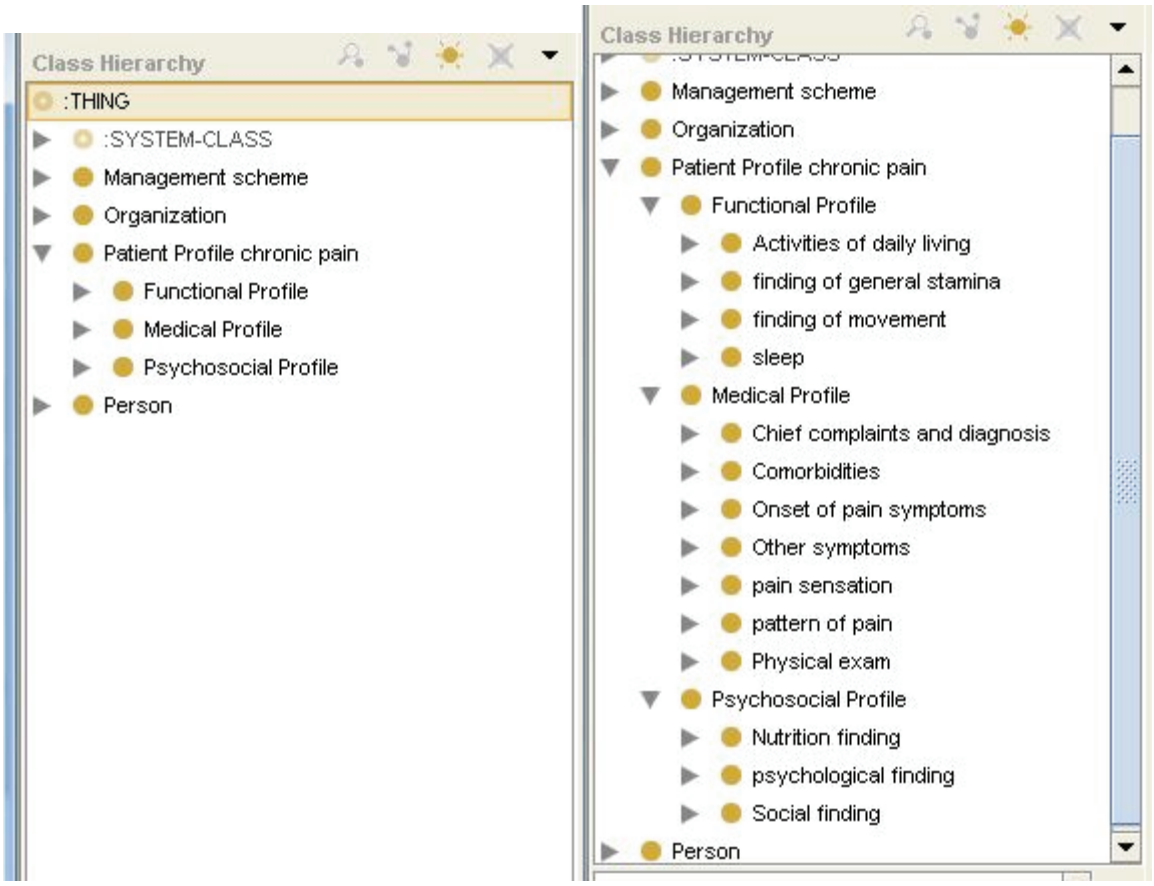

Figure 62 Profile ontology for chronic pain.

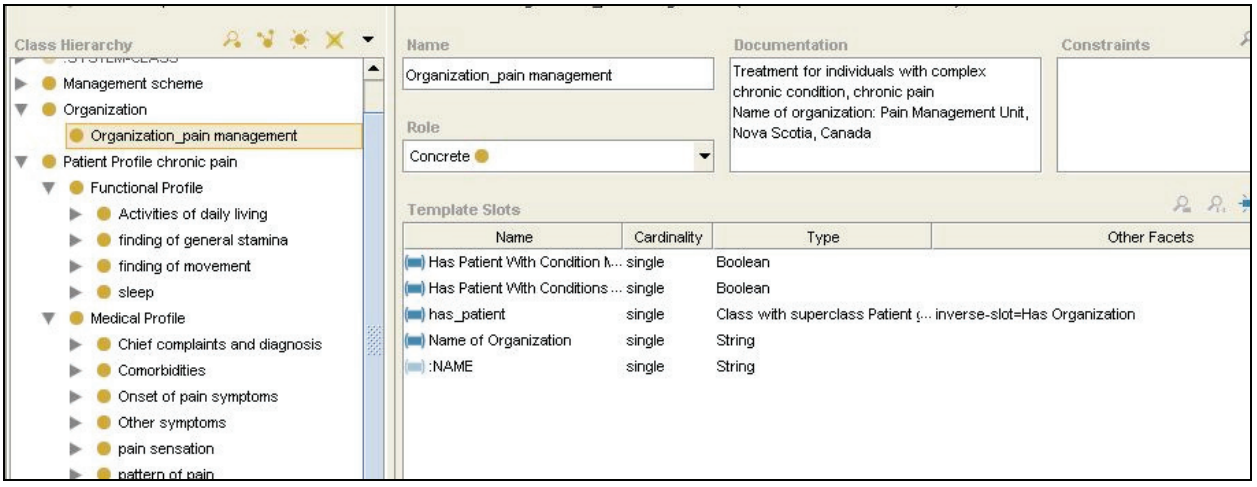

Figure 63 Pragmatic boundary of the chronic pain profile ontology.

The profile ontology for chronic pain contains explanation for all concepts included in the ontology such as the multidisciplinary nature of patient profile, the management scheme and the various concepts under each area of health focus.

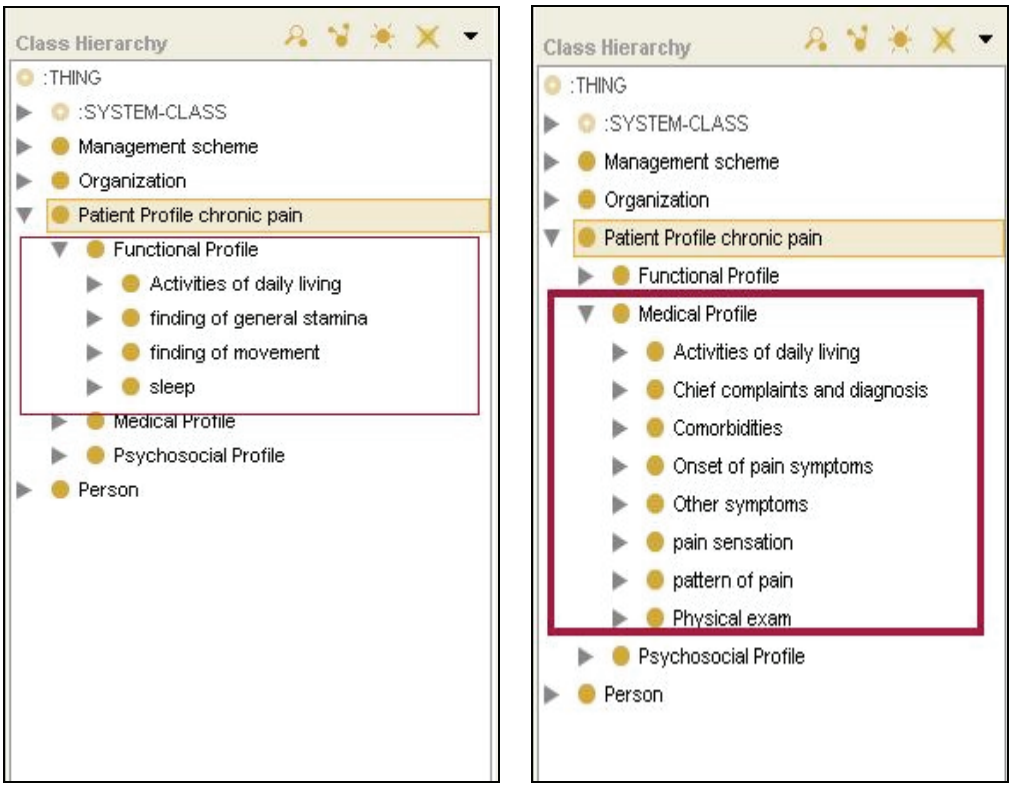

Figure 64 Functional and medical profiles in the chronic pain profile ontology.

Figures 64 and 65 show the organization of the domain knowledge based on the knowledge retrieved from the controlled vocabulary. The knowledge is organized under the key areas of health focus as organized in the controlled vocabulary and as retrieved from the patient charts.

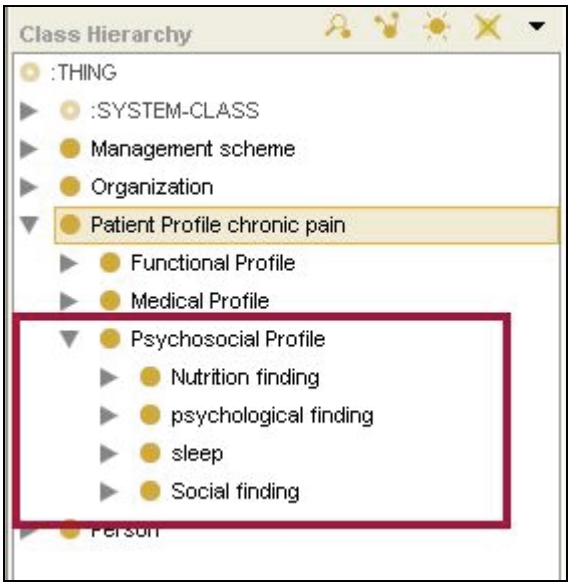

Figure 65 Psychosocial profile in the chronic pain profile ontology.

The properties in the ontology introduce relations among concepts. A patient *HasOrganization* and the organization is inversely linked to the class Patient by *HasPatient*. The class Profile is linked to the class Management Scheme by property *hasCollaborativeManagement*. The class Psychosocial Profile is linked to the management scheme by property *ManagementRequired* which has individual *dietitian_referral* or *physician_referral*. The profile ontology includes definitions of over 80 properties, with 51 data and 38 object properties.

The profile ontology is developed as a boundary object in this study to create a standard form and as a dynamic object that will allow knowledge to grow with the interaction and sharing of knowledge by multiple users.

The profile ontology contains standardized expression of concepts created in the controlled vocabulary to explicate the intended clinical meaning as seen by experts in the domain. Standardized concepts are specified with their SNOMED CT ID number (Concept Unique Identifier) and with a list of synonyms. Class *Lumbar spine - tender* has a SNOMED CT® concept ID of 298673002 with parent concept being *Finding of sensation of lumbar spine* with finding site as lumbar spine structure (Figure 66).

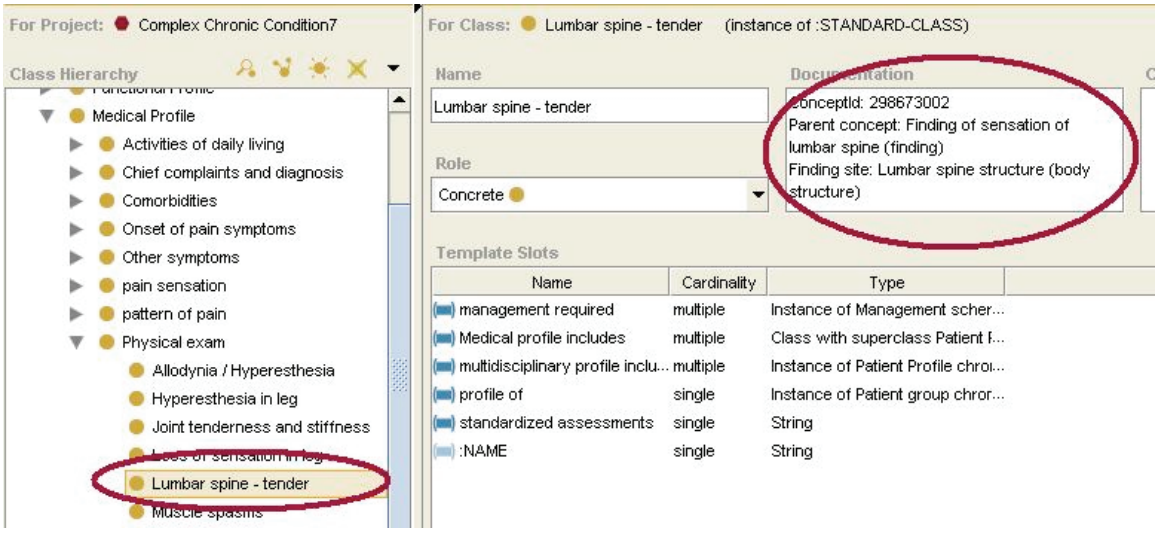

Figure 66 Standardized terminology and standard form of boundary object in the chronic pain ontology.

Individuals or instances are used in the profile ontology to present list of concrete concepts of relevance for each class. For example, the ontology contains 100 individuals with chronic pain in the class *Organization*. A patient has data properties such as education, marital status and object properties such as *HasProfile* and *HasOrganization* that link it to other classes in the ontology.

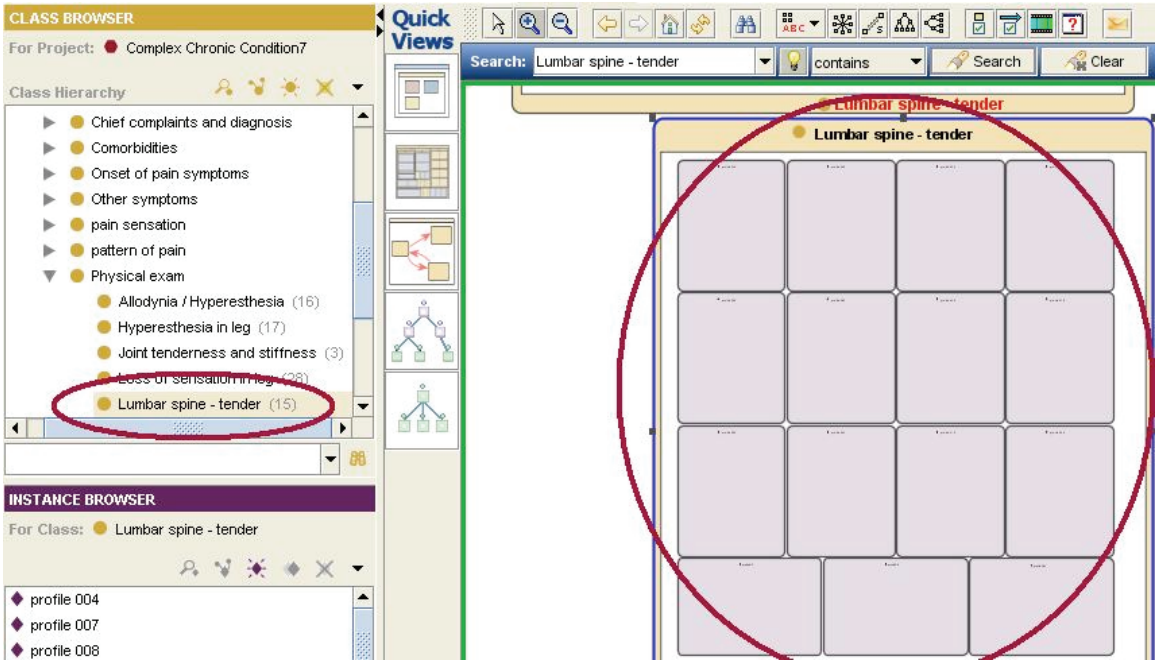

Figure 67 Query of a symptom in the chronic pain ontology.

The ontology also contains instances of 100 profiles for the class *Patient Profile*. Query of a symptom such as *Lumbar spine – tender* shows the number of patients with the symptoms and the super class of the concept in the ontology (Figure 67). The instances in profiles show the multifaceted nature of symptoms as substantiated under each area of health focus that exist in the domain of a chronic pain patient (Figure 68).

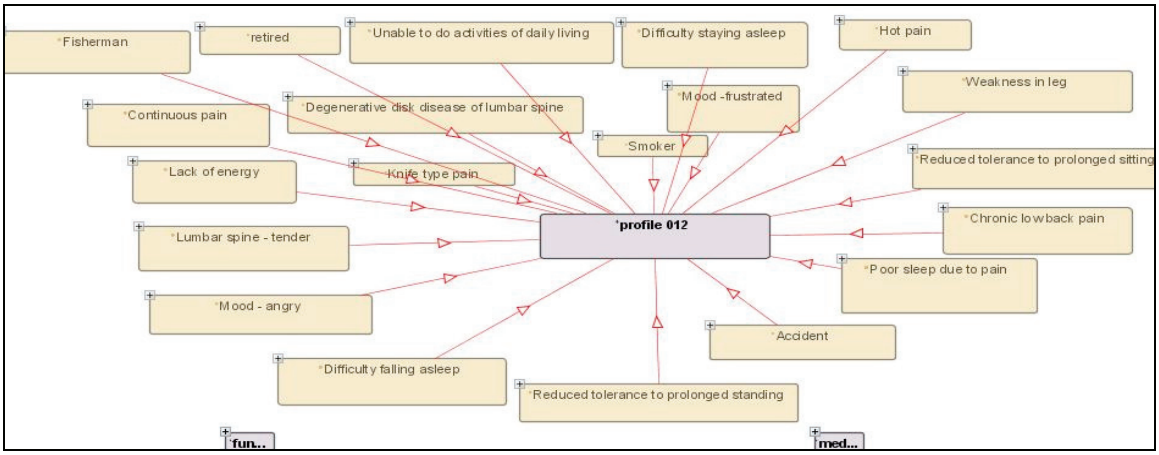

Figure 68 Multidisciplinary profile of a patient in chronic pain ontology.

The ontology can be queried to view the profiles of the 100 patients populated in the ontology. The ontology allows users to understand the complex nature of patient profile for individuals with chronic pain. The multidisciplinary profile shows the complex interactions in symptoms that exist in multiple areas of health focus: medical, functional and psychosocial. These include symptoms such as *mood – angry*, *difficulty initiating sleep*, *lack of energy*, *poor sleep due to pain*, *reduced tolerance to prolonged standing and sitting*, and *chronic low back pain*.

The ontology can also be queried to view the multidisciplinary interactions that exist in the management of the symptoms for individuals with chronic pain.

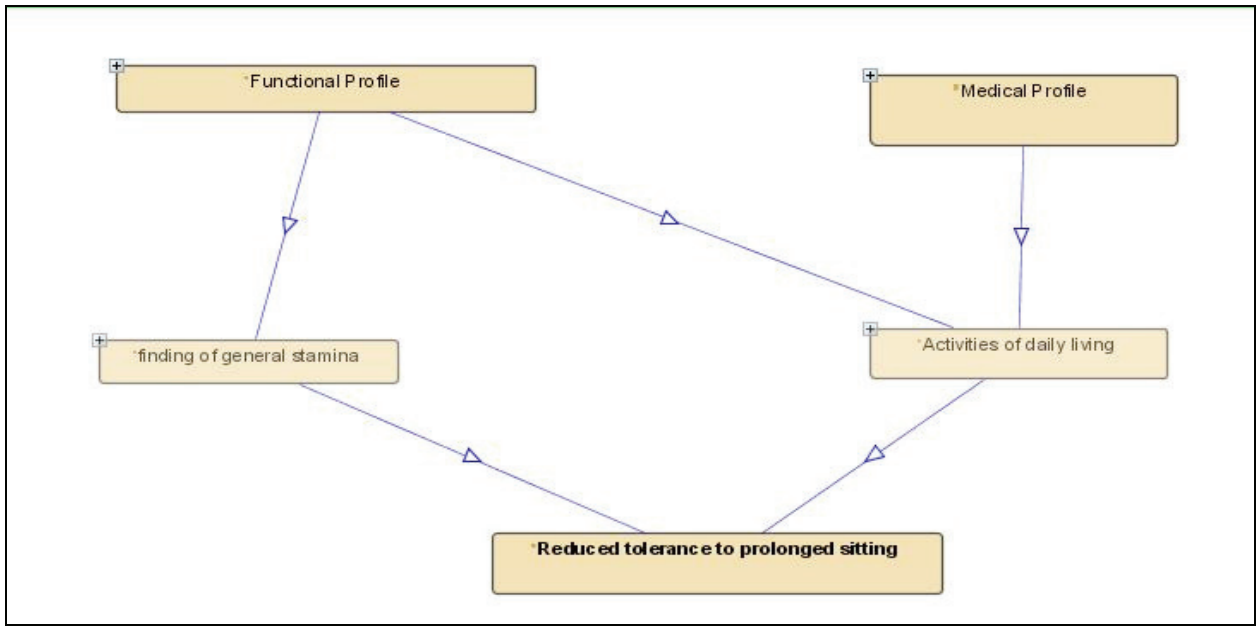

Figure 69 Multidisciplinary interactions in the categorization of a symptom, *Reduced tolerance to prolonged sitting* in chronic pain ontology.

For instance, the clinicians can view in a graphical interface the way a particular symptom or area of concern may play out as the focus of care for multiple disciplines. *Reduced tolerance to prolonged sitting* identified in the super class *Finding of general stamina* in SNOMED CT® can be a consideration for a physician and a physiotherapist or an occupational therapist (Figure 69).

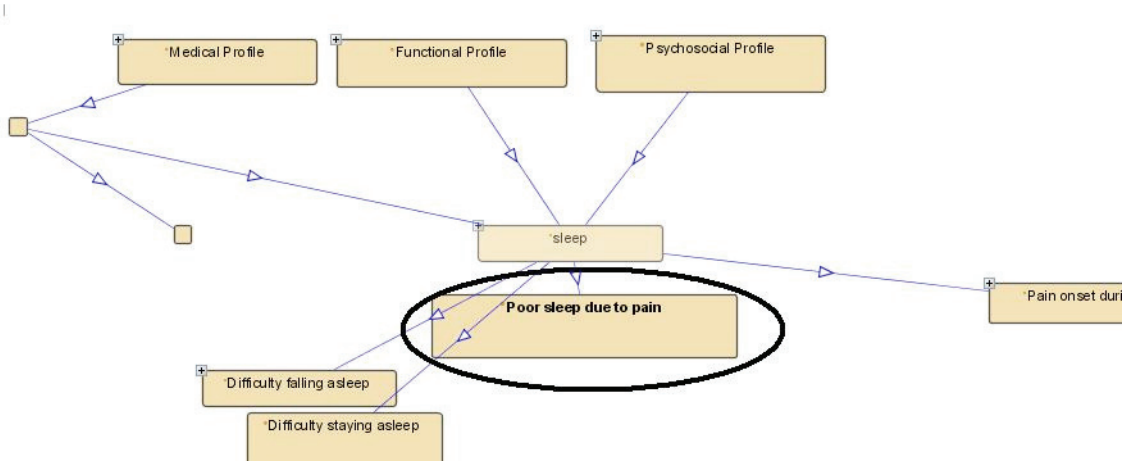

Figure 70 Multidisciplinary interactions in the categorization of a symptom, *Poor sleep due to pain* in chronic pain ontology.

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Poor sleep due to pain is another symptom that is of interest in the medical, psychosocial and physical areas of health focus as shown in figure 70.

Implementation phase – Pragmatic level, standard form and dynamic nature

Protégé 3.4.2 was used to do the consistency check for the ontology. There were no inconsistencies in the profile ontology.

An ontology evaluation was conducted by the domain experts checking the ontology for accuracy and completeness of knowledge representation. The clinicians also explored the multidisciplinary interactions and multidimensional concepts available in this comprehensive ontology. Three browsing tools were explored to determine the format that was most suitable and user friendly for the study on hand. Google ontology browser was preferred over TGViz and OwlSight.

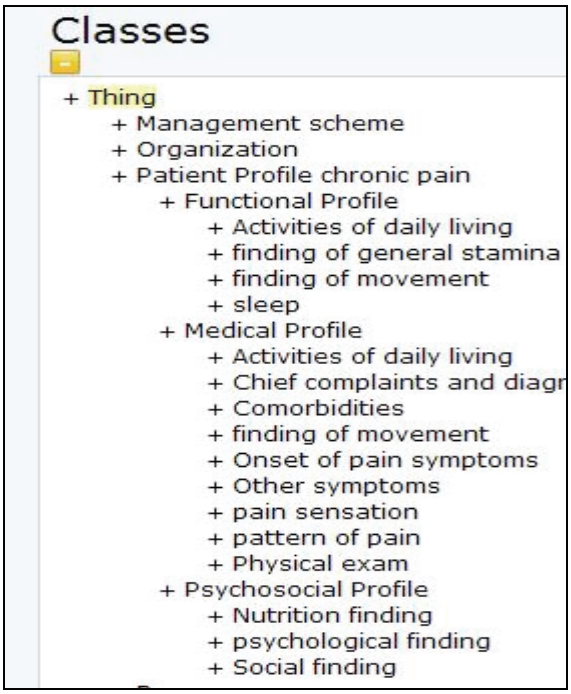

Figure 71 Chronic pain ontology using Google ontology browser.

Figure 71 shows a view of the chronic pain ontology in the Google ontology browser. The figure displays the top classes in the ontology to the left in the browser window and a view of the properties included in the ontology in the right window.

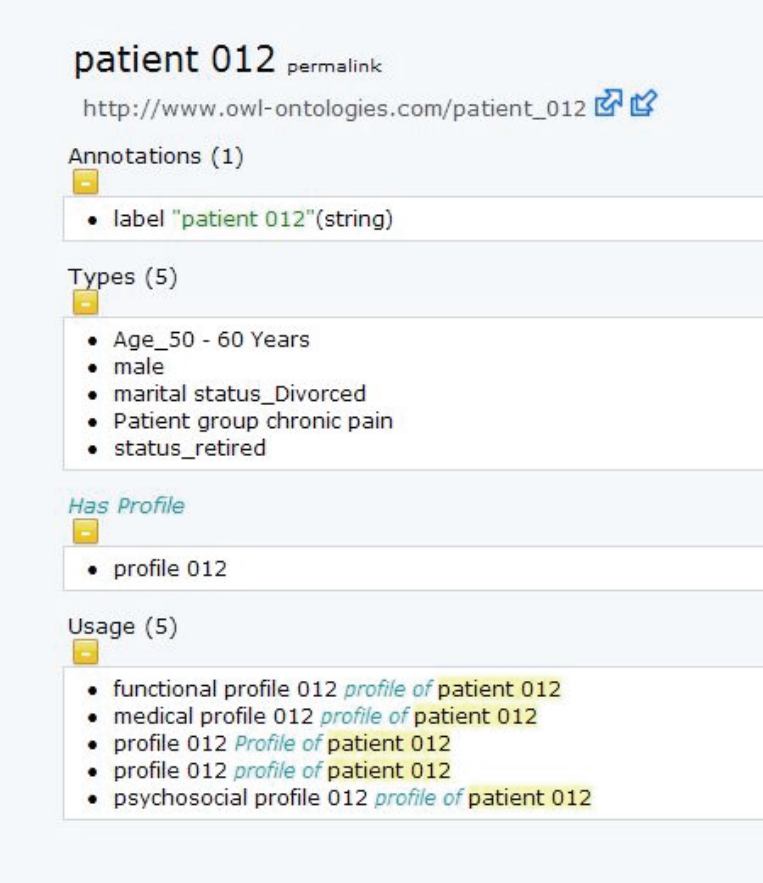

Figure 72 Profile of patient 012 using Google ontology browser.

Figures 72 to 74 show the various levels of querying that is possible while viewing the profile of a patient, patient 012 in the ontology browser. At the base level of query, the browser displays background information on the patient as shown in figure 72. User can query various aspects of the background information that include the multidisciplinary profiles for the patient.

Figure 73 shows a view of the functional profile for patient 012. The functional profile shows the symptoms of relevance in this category along with the required management scheme.

Figure 73 functional profiles of patient 012 using Google ontology browser.

A symptom can then be queried further in the functional profile (figure 74). This allows the user to view details of the symptom that include the standardization information and in this case the term was a "no match" in SNOMED CT® and hence a non-standardized term. It has been included in the vocabulary as clinicians determined an important concept in the profile categorization for chronic pain.

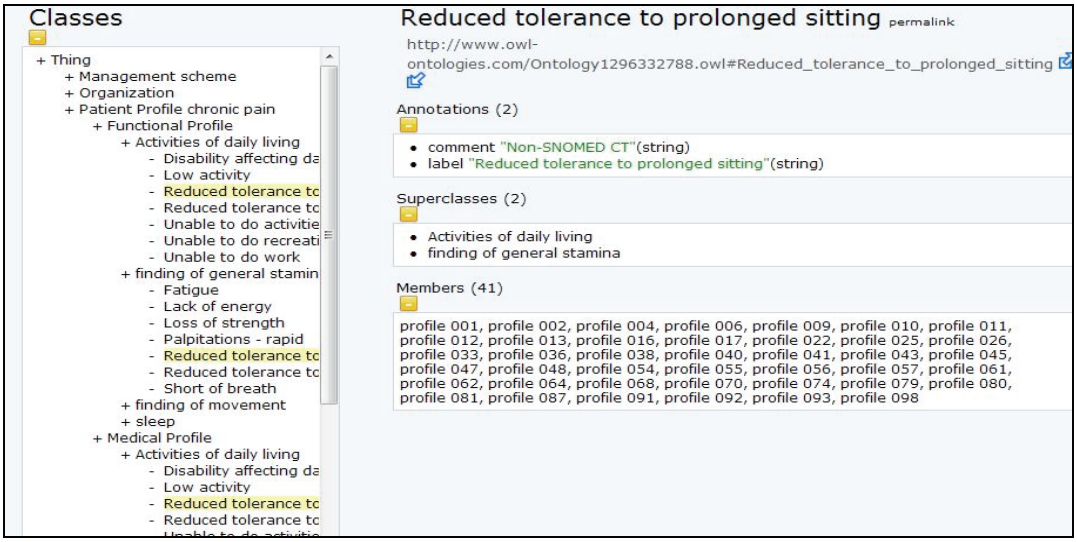

Figure 74 Query of a symptom in the functional profile of patient 012 using Google ontology browser.

The user can also view the number of patients that have this symptom and the multidisciplinary interactions in the management of this symptom.

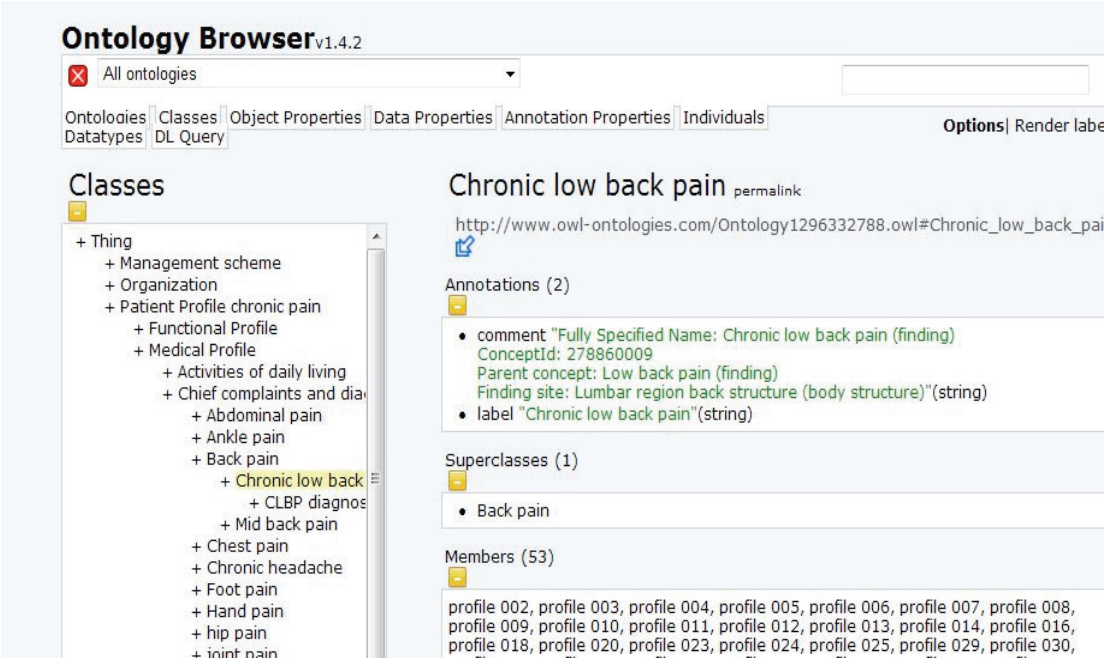

Figure 75 Query of a symptom *chronic low back pain* using Google ontology browser.

Shown in figure 75 is a standardized term in SNOMED CT®, symptom *chronic low back pain*.

Six domain experts were recruited to participate in the review of the ontology. Clinicians used the user friendly Google ontology browser to navigate through the ontology and were given an option to query the multidisciplinary interactions and the patient profile knowledge that exists in the populated instances of the ontology. Clinicians then used a survey questionnaire to provide feedback on the usefulness of the ontology. They provided feedback on the overall usefulness of the ontology, relevance of the ontology to their health discipline, usefulness of viewing information generated from other health disciplines and the usefulness of viewing multidisciplinary interactions.

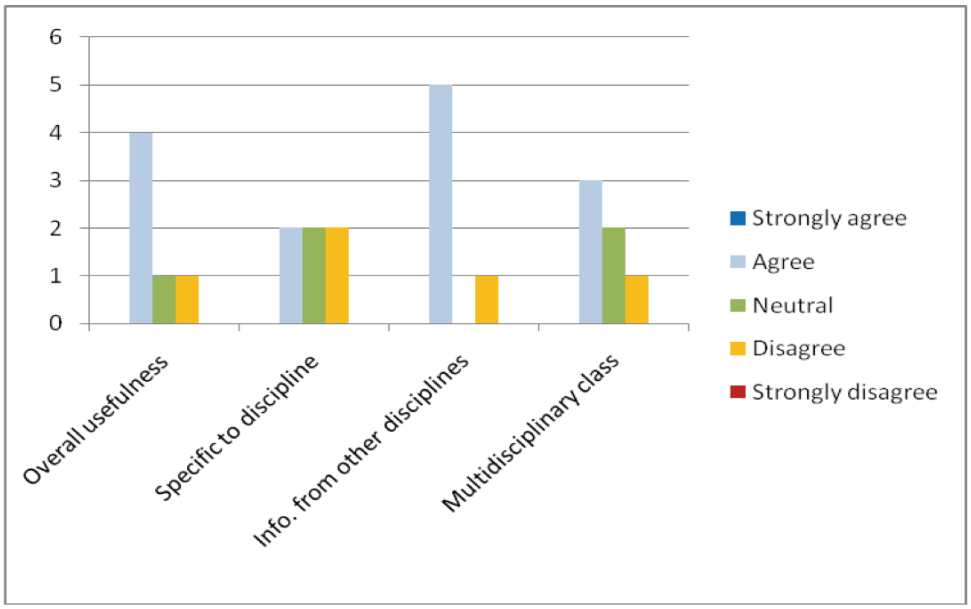

Figure 76 Feedback from the domain experts on the chronic pain profile ontology using a survey questionnaire.

Sixty-seven percent of clinicians agreed on the overall usefulness of the ontology as a boundary object. Highes level of agreement (83%) was reached on the usefulness of the ontology to view the information generated from other health disciplines in the categorization of a patient profile (Figure 76).

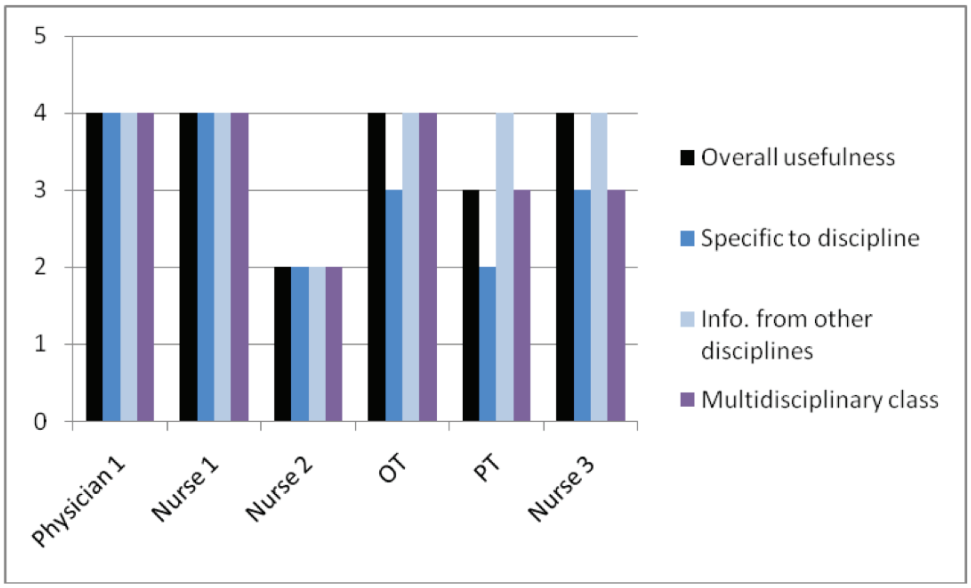

Figure 77 Feedback on the chronic pain profile ontology by disciplines of care.

Figure 77 shows the feedback obtained by discipline of care. There were no specific differences or specific trends identified between disciplines of care. Overall, the sample size in the study did not allow drawing higher level of conclusions in this category. In general, the participants showed a reasonable level of agreement on the usefulness of the ontology.

CHAPTER 8 COMPARATIVE ANALYSIS FOR MCS AND CHRONIC PAIN GROUPS

8.1 CONTROLLED VOCABULARIES

Table 17 Summarization of controlled vocabulary results for MCS and chronic pain.

CATEGORIES	*MCS*	*CHRONIC PAIN*
Number of charts reviewed	100	100
Number of participating multidisciplinary clinicians	9	8
Total number of concepts retrieved in chart audit process	512	182
Total number of terms standardized	82%	75%
Medical - standardized	63%	77%
Physical - standardized	69%	67%
Psychosocial - standardized	68%	80%
Nutrition - standardized	75%	-
Rehabilitation - standardized	62%	-
Number of participating Clinicians in the community	36	42
Cronbach's alpha for internal consistency (experts)	0.84	0.76
Overall usefulness of the vocabulary (experts)	83% - agree; 17% - neutral N=12	14% - strongly agree; 72% - agree and 14% - neutral N=7
Overall usefulness of the vocabulary (clinicians in the community)	67% - agree; 33% - neutral N=36	7% - strongly agree; 64% - agree; 21% - neutral; 8% - disagree N=42
Order by level of agreement among disciplines of care	Dietitians, OTs, Nurses, Physiotherapists, Psychologists, Physicians	OTs, Dietitians, Nurses, Psychologists, Physiotherapists, Physicians

Table 17 shows the comparison in the two groups considered in this study, MCS and chronic pain. A discussion of the comparison is presented below.

Participants: The groups were similar in the number of participants: patients, domain experts and end users. The difference among the two groups was in the number of the participating health discipline in the domain experts category. MCS had a representation

from six health disciplines while chronic pain had representation from four health disciplines.

Chart audit terms: There were five identifiable global categories in the domain of MCS in the patient charts and they were medical, physical / functional, psychosocial, nutrition and rehabilitation / vocational. There were three identifiable categories in the domain of chronic pain in the patient charts and they were medical, physical / functional and psychosocial which included concepts from vocational and nutrition areas of health focus.

A significant difference was in the number of terms retrieved for the two conditions in the patient profile domain from the patient charts. A total of 512 terms were retrieved in the five identified categories for MCS and a total of 182 terms retrieved in the three identified categories for chronic pain. This could be interpreted in more than one way. It could be indicative of a more comprehensive nature of assessment for MCS in the expert group with more health disciplines involved in the intake assessment. It could also mean that perhaps chronic pain has more definition in its domain categorization than MCS. A more plausible reason is that the multiple disciplines involved with MCS had several overlapping terminologies in use for categorizing patient profiles.

Standardization: There was a close match between the overall number of terms standardized for MCS (82%) and for chronic pain (75%). Both conditions had a reasonable coverage of required terms in SNOMED CT® . The difference in coverage for MCS was experienced in terms of direct relevance to the condition that was not found in SNOMED CT® such as the term *Multiple Chemical Sensitivity*. For chronic pain, the number of "no match" terms in the physical / functional profile category was high. This trend was seen for MCS as well.

Re-coding: The Cohen's kappa and Cronbach alpha scores for both groups were in the moderate to excelled level of agreement and consistency. The level of agreement in the usefulness of the vocabulary among experts in the two domains and among the end users

in the two domains was closely matched and in the high agreement level category. The trends shown in the order of agreement shown by disciplines of care in the end users group bore a great deal of consistency for the two health conditions with the dietitians and occupational therapists showing the highest levels of agreement on the usefulness for both conditions and the psychologists and physiotherapist ranking in the lower agreement order.

Table 18 shows the Kendall's tau values for the two groups. Again, there was a good level of agreement in the overall internal consistency of the instrument. The specificity and structure did not reach significance for the MCS group but did reach significance (>0.05) for the chronic pain group.

Table 18 Summarization of Kendall's Tau values for MCS and chronic pain (red highlights indicate values that did not reach significance of <0.05).

Kendall's tau	MCS	Chronic pain
Overall;Scope	0.4243	0.3082
p-value	(0.0104)	(0.0432)
Overall;Specificity	0.5725	0.3953
p-value	<0.001	(0.0105)
Overall;Structure	0.485	0.3862
p-value	(0.0037)	(0.0124)
Scope;Specificity	0.2776	0.4341
p-value	(0.0937)	(0.004)
Scope;Structure	0.3191	0.3134
p-value	(0.0511)	(0.0377)
Specificity;Structure	0.2537	0.3107
p-value	(0.1286)	(0.042)

Evaluation of the vocabulary:

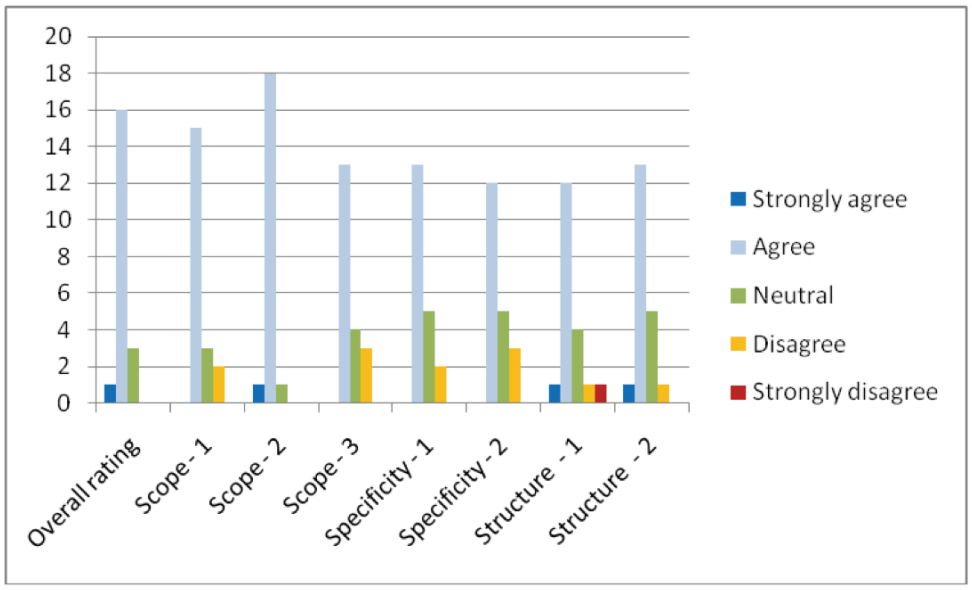

Figure 78 Combined graph for controlled vocabulary: (n=20) Experts

Figure 78 shows the overall feedback obtained on the usefulness of the controlled vocabulary from the domain experts in the two groups. The overall acceptance on the usefulness of the vocabulary as a boundary object was quite high with over 80% showing agreement. The categories of specificity and structure brought a small percentage of disagreement among clinicians. These categories had questions related to completeness and accuracy of the standardized and controlled vocabulary and the general organization of the vocabulary. The vocabulary did undergo three rounds of revisions for the MCS group and two rounds of revisions for the chronic pain group based on the feedback from the clinicians.

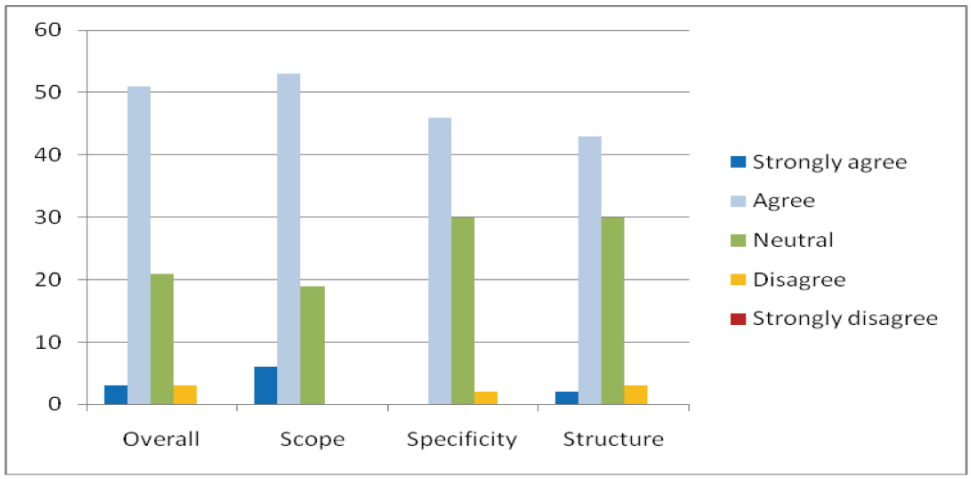

Figure 79 Combined graph for controlled vocabulary: (n= 78)

Figure 79 shows the combined feedback from the end users (clinicians in the community) on the usefulness of the vocabulary as a boundary object. Over 60% of the clinicians showed agreement on the overall usefulness of the vocabulary as a boundary object. The categories of specificity and structure brought more neutral scores and a level of disagreement among clinicians.

8.2 PROFILE ONTOLOGIES

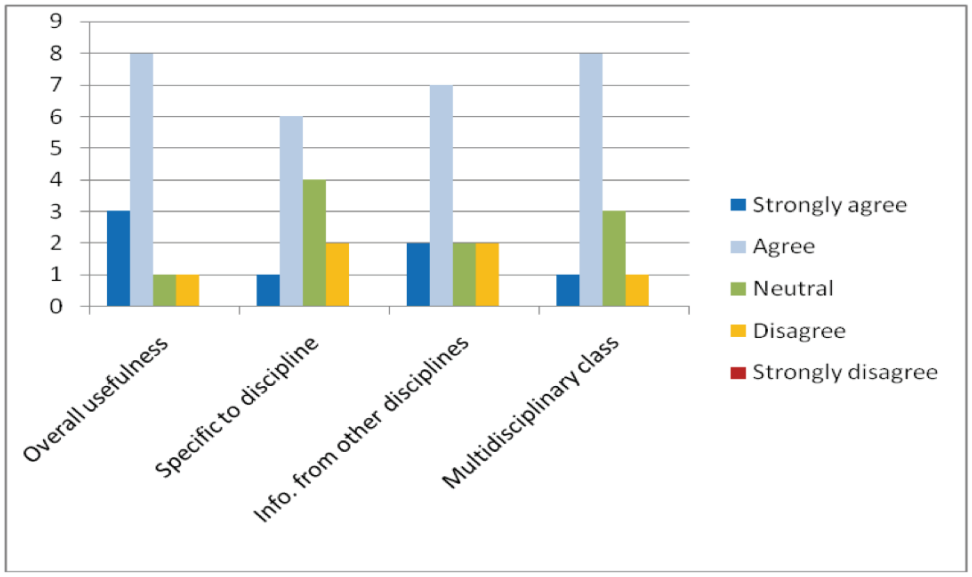

Figure 80 Combined graph for ontology (n = 13)

Figure 80 shows the evaluation of the ontology as a boundary object by the domain experts of both groups. The ontology had > 80% of agreement from the experts on its usefulness as a boundary object. The ontology also had a consistently small to moderate percentage of clinicians showing strong agreement on its usefulness on all categories of the questionnaire. The ontology also had a very small percentage of disagreement on all categories of the survey questionnaire.

Table 19 Summarization of results for MCS and chronic pain - Ontology.

Survey questions	Responses	
	Multiple Chemical Sensitivity n = 7	**Chronic pain n = 6**
How many patient profiles viewed?	**3 profiles - 4** 4 profiles - 0 >5 profiles - 3	**3 profiles - 4** 4 profiles - 1 >5 profiles - 1
I would be interested in using the ontology for the following reasons?	When seeing a patient - 0 Team conference 2 Options 1 &2 1 Knowledge enhancement 0 **All of the above- 4** None of the above - 0	When seeing a patient 1 Team conference 0 Options 1 &2 0 Knowledge enhancement 1 **All of the above 3** None of the above 1
When browsing the ontology, I browsed profiles	Only under my specialty 0 Closely related to my specialty 1 **All specialties 6**	Only under my specialty 0 **Closely related to my specialty 3** **All specialties 3**

Table 19 shows over 50% of clinicians in both groups viewed the 3 profiles provided by the researcher. The results also show that 50% and over considered the usefulness of using the ontology while seeing a patient, in a team conference and to enhance their personal knowledge. Over 85% of MCS clinicians provided feedback that they viewed profile information related to all specialties in the ontology and 50% in the chronic pain group said they viewed profile information related to all specialties in the ontology.

CHAPTER 9 CONCLUSION

In this chapter, a discussion of the methodology used and the results is presented, the main contributions of this thesis are outlined following which conclusions and directions for future work are presented.

9.1 DISCUSSION

A novel methodology and model has been presented in this research for the development of boundary objects in heterogeneous knowledge domain. The broad objective of the research was to enhance communication in the multidisciplinary care management of chronic, complex and lesser known health conditions. Through the problem description and the literature review, it was established that there exist communication gaps in the management for these conditions which can result in poor care experiences, medical errors and poor collaboration among clinicians. It was also established the domain knowledge for these complex conditions was heterogeneous. The heterogeneity in this research has been defined by poor categorization, multidisciplinarity, inconsistency and lack of standardization in the domain knowledge. The boundary objects approach [27] was selected to develop consistency, standardization and organization of domain knowledge with the broad goal of improving collaboration and communication for multidisciplinary clinicians involved in the care of patients with complex chronic conditions [40,41].

The boundary objects developed in this study had to maintain the following three characteristics of relevance to the proposed objectives: pragmatic boundary [26], dynamic boundary object [32] and standardized form [94].

To satisfy the above requirements, a two-staged approach was used to develop the boundary objects in this study in terms of creating organization and standardization in the heterogeneous knowledge: First, a controlled vocabulary was developed as a boundary

object to develop consistency and standardization and second, an ontology was developed as a boundary object to develop a pragmatic boundary that allows future knowledge to grow and be flexible (dynamic). The purpose of the controlled and standardized vocabulary has been to bring consistency and pragmatic interoperability to the unstructured and inconsistent vocabulary in the communication clinicians. It was anticipated that the clinical vocabulary will be used by multiple health disciplines in the management of complex conditions, experts and non-experts in the field. Therefore, a widely accepted, well recognized reference terminology, Systematized Nomenclature of Medicine – Clinical Terms that is considered to be the most comprehensive source of clinical terminology in the literature has been applied for standardization [45].

The methodology included the involvement and feedback from domain experts and clinicians in the community [48], elements of the Delphi [118] and Nominal Group techniques [119]. This was important to ensure the accuracy, pragmatic level of interoperability and flexibility of the boundary objects to accommodate multiple view points and levels of expertise. Overall, it was essential to test the usefulness of the boundary objects in clinical practice.

The results from the study show a good level of agreement among domain experts and end users (clinicians in the community) for both complex conditions on the usefulness of the controlled clinical vocabulary as a boundary object. The ontology received a more favourable response from the domain experts on the usefulness as a boundary object in collaborative work.

The evaluation from the study show that the methodology developed has good potential to enhance collaborative work by creating an understanding at a pragmatic level, being flexible to allow dynamic nature of knowledge growth and by creating standardization in the domain knowledge. The study has also established that it is possible for clinicians to apply the boundary objects in a clinical environment from the feedback offered by the clinicians in the evaluation of the boundary objects.

9.2 SUMMARY OF CONTRIBUTIONS

As stated in section 1.4, the ultimate goal of this research is to solve communication and collaboration problems in the heterogeneous domain of complex, chronic and lesser known health conditions.

The existence of knowledge heterogeneity and communication gaps in the collaborative management of complex health conditions has motivated our research of boundary objects in heterogeneous knowledge domains. The ultimate goal of this research is to solve the problem of collaborative communication and thus enabling syntactic, semantic and pragmatic level of operability among multidisciplinary clinicians involved in the care of complex chronic health conditions. More specifically, the aim is to develop a generic methodology to develop boundary objects in heterogeneous knowledge domains. This is because creating boundary objects in heterogeneous environments can reduce communication gaps in many complex and dynamic collaborations which has drawn the attention of many researchers [40,41].

The global objective of this research is to enable a pragmatic layer of knowledge development in the heterogeneous domain of complex chronic health conditions. We developed a controlled vocabulary and a profile ontology as boundary objects. The main contribution of our work was the development of a methodology to generate boundary objects in heterogeneous knowledge domains. We have used the boundary objects approach and developed a two-staged layer of interoperability in the multidisciplinary care management of complex chronic health conditions.

1. Development and validation of a methodology for the creation of boundary objects in heterogeneous knowledge domain.
2. Development of boundary objects that have the following characteristics: pragmatic level of interoperability, dynamic and standardized forms
3. Development of a standardized and controlled vocabulary and a profile ontology for MCS.

4. Development of a standardized and controlled vocabulary and profile ontology for chronic pain.

9.3 Concluding Remarks

The results from the study are promising in two important areas of research: collaboration in the management of complex health conditions through the application of boundary objects and boundary objects in heterogeneous knowledge domains. A novel methodology has been presented to address the gaps in the literature towards the two areas of research. The methodology includes several key components or criteria that were identified in past research such as acknowledging the heterogeneous nature of the domain knowledge, involving clinicians (experts and non-experts) in the process of development and evaluation and exploring the potential of the study by testing it in clinical workflow. However there are several limitations to this research such as the scope being limited to the domain of patient profile information, a convenience sample of participants, size of the sample, the fact that the potential of the boundary objects in improving communication or collaboration among clinicians or the impact on patient care was not explored. The results do indicate that this direction of research has significant potential and requires further exploration.

9.4 Future Work

The future directions for this research stem from the identified limitations of this research.

1. The research used a convenience sample approach. The knowledge on the condition MCS and chronic pain was explored from the view of one expert group. There is a possibility that other expert groups may have additional terms which may lower the expectation for finding multidisciplinary terms in Systematized Nomenclature of Medicine – Clinical Terms, SNOMED CT®. It is important to

expand the scope of the research to other expert groups and explore the potential of the robustness of the methodology and the research objectives for a larger and more inclusive sample of participants. This exploration should also include examining the methodology in other health conditions with similar domain characteristics.

2. The post coordination of terms [139] developed in the study for MCS was not reviewed by the experts for accuracy and completeness. This can be viewed as another important step in the methodology for developing standardization for complex conditions by improving coverage of terms and concepts that are relevant and important to these conditions in SNOMED CT®. This step would raise the expectation on the involvement and time commitment from domain experts in reviewing post coordination terms for accuracy and completeness and in requesting new terms in SNOMED CT®. This could also lend itself to an exploration of other reference terminologies and comparing the coverage of terms with SNOMED CT®.
3. While the controlled vocabulary received an overall level of agreement from the clinicians, it is not known whether using the vocabulary will in fact improve communication or enhance patient care experience. However, it must be stated that this study conducted an evaluation of the boundary object in a clinical setting. Clinicians used the controlled vocabulary to re-code patient profiles and offered feedback on the usefulness of the controlled vocabulary as a boundary object. It is important to explore the usefulness of the vocabulary in clinical practice by conducting an evaluation for a reasonable period of time. The evaluation process should include the opportunity for clinicians to continue requesting new terms and reviewing the possibility of standardization of the terms or conducting post coordination when standardization is not possible. This will maintain the flexibility in an evolving domain of knowledge.
4. The ontology has the potential to get richer as more users contribute new knowledge and as more patient instances are populated in the ontology. They can become decision support tools. The profile ontology developed in the study is at a very basic level of explication of knowledge in the domain of complex health

conditions. There are many layers of knowledge that needs to develop in the ontology for it to reach the level of being a decision support tool. Also, the knowledge developed from a convenience sample of experts. It is important to expand the scope of the research to publish the ontology and invite other groups with similar interest to contribute to the knowledge in the ontology. Also, continuing to populate patient instances for a longer period of time may add additional relations to the concepts in the patient profile domain. Furthermore, the ontology has the potential to develop into a decision support system. Having experts continue to contribute to the knowledge in the ontology by building a user friendly interface would allow the knowledge in the treatment domain to grow as well which can in turn lend itself to the ontology becoming a decision support system at some point.

5. The scope of the research did not allow an exploration of the dynamic nature of the boundary object to its full potential. The dynamic nature within the scope of this research was considered in the testing of the vocabulary where multiple disciplines used the vocabulary and in the review of the ontology by experts where multiple disciplines appreciated the knowledge contributed by other disciplines. However, the dynamic nature of these boundary objects can be explored by evaluating the interactions over a period of time and examine the changes in the objects and the interacting communities.

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APPENDIX A Terms and concepts for MCS

PATIENT DEMOGRAPHICS N = 100	Percentage of occurence %
AGE GROUP	
Age group 30 - 40 years	8
Age group 40 - 50 years	68
Age group 50 - 60 years	18
Age group 60 + years	6
SEX	
Male	11
Female	89
EMPLOYMENT	
Employed	45
Unemployed (stopped work / retired / disability)	55

Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
MEDICAL		
Chronic Fatigue Syndrome	Exact	SNOMED Concept ID: 52702003 Parent concept: Mental disorder and Multisystem disorder Synonym: Iceland disease, Akureyri disease
Chronic pain syndrome	Exact	SNOMED Concept ID: 373621006 Parent concept: Disorder characterized by pain
Fibromyalgia	Synonym	Fibromyositis SNOMED Concept ID: 24693007 Parent concept: Myositis Synonym: Fibromyalgia, myofascial pain syndrome, fibrositis
Multiple Chemical Sensitivity	No match	
Comorbidities		
Arthritis	Exact	SNOMED Concept ID: 3723001 Parent concept: Inflamed joint; inflammation of specific body organs; inflammatory disorder of musculoskeletal system; arthropathy Finding site: Joint structure
Osteoarthritis	Exact	SNOMED Concept ID: 396275006 Parent concept: Degenerative disorder of musculoskeletal system; arthropathy Finding site: Joint structure
Urticaria	Exact	SNOMED Concept ID: 126485001 Parent concept: Edematous skin

Chart audit terms	**Term availability in SNOMED CT** **Exact match / synonym / no match**	**Standardized terms using SNOMED CT**
Tension-type headache	Exact	SNOMED Concept ID: 398057008 Parent concept: Headache disorder;
Irritable Bowel Syndrome	Exact	SNOMED Concept ID: 10743008 Parent concept: Disorder of colon Finding site: Colon structure
Chronic low back pain	Exact	SNOMED Concept ID: 279040009 Parent concept: Low back pain Finding site: Lumbar region back structure
Chronic headache	Exact	SNOMED Concept ID: 431237007 Parent concept: Headache disorder; chronic disorder Finding site: Head structure
Migraine	Exact	SNOMED Concept ID: 37796009 Parent concept: Vascular headache Finding site: Vascular structure of head
Chronic diarrhea	Exact	SNOMED Concept ID: 236071009 Parent concept: Diarrheal disorder Finding site: Gastrointestinal tract structure
Chronic kidney disease	Exact	SNOMED Concept ID: 236425005 Parent concept: Chronic disease of genitourinary system; Finding site: Kidney structure

Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
Angina	Exact	SNOMED Concept ID: 194828000 Parent concept: Disorder characterized by pain; Ischemic heart disease Finding site: Heart structure
Sleep Apnea	Exact	SNOMED Concept ID: 73430006 Parent concept: Sleep disorder
Obstructive sleep apnea	Exact	SNOMED Concept ID: 78275009 Parent concept: Breathing-related sleep disorder, respiratory obstruction, sleep apnea
Hyperthyroidism	Exact	SNOMED Concept ID: 34486009 Parent concept: Disorder of thyroid gland; Finding site: Thyroid structure
Asthma	Exact	SNOMED Concept ID: 195967001 Parent concept: Disorder of respiratory system; Finding site: Structure of respiratory system
Bronchitis	Exact	SNOMED Concept ID: 32398004 Parent concept: Inflammatory disorder of lower respiratory tract; Disorder of bronchus; Finding site: Bronchial structure
General Anxiety Disorder	Exact	SNOMED Concept ID: 21897009 Parent concept: Anxiety disorder;
Post traumatic stress disorder	Exact	SNOMED Concept ID: 47505003 Parent concept: Anxiety disorder;
Diabetes	Synonym	Diabetes mellitus SNOMED Concept ID: 73211009 Parent concept: Disorder of glucose metabolism; disorder of endocrine

		structure Finding site: Endocrine pancreatic structure
Chart audit terms	**Term availability in SNOMED CT** **Exact match / synonym / no match**	**Standardized terms using SNOMED CT**
Depression	Synonym	Depressive disorder SNOMED Concept ID: 35489007 Parent concept: Mood disorder;
Hypertension	Synonym	Hypertensive disorder SNOMED Concept ID: 38341003 Parent concept: Systemic arterial finding; Disorder of artery; Finding site: Systemic arterial structure
COPD	Synonym	Chronic obstructive lung disease SNOMED Concept ID: 13645005 Parent concept: Chronic disease of respiratory system; disorder of lungs; bronchiolar disease Finding site: Lung structure
Interstitial cystitis	Synonym	Chronic interstitial cystitis SNOMED Concept ID: 197834003 Parent concept: Disorder of connective tissue; chronic cystitis Finding site: Structure of interstitial tissue of urinary bladder
Onset of illness		
Unknown onset	No match	
Undetermined onset	No match	
Exposure in workplace	No match	
Post pregnancy	No match	
Multifactorial causation	No match	
Chief complaints		
Fatigue	Exact	84229001
Lightheadedness	Exact	386705008

Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
Chronic pain	Exact	82423001
Headache	Exact	25064002
Musculoskeletal pain	Exact	279069000
Dizziness	Exact	404640003
Nasal congestion	Exact	68235000
Tight chest	Exact	23924001
Cough	Exact	49727002
Abdominal bloating	Exact	116289008
Difficulty sleeping	Exact	301345002
Poor sleep patterns	Exact	314938000
Anxiety	Exact	48694002
Throat irritation	Exact	162400007
Chest pain	Exact	29857009
Muscle pain	Exact	68962001
Fluttering heart	Exact	161969004
Light sensitivity	Synonym	Light intolerance 62481005
Noise sensitivity	Synonym	Heightened auditory perception 247713003
Odour sensitivity	Synonym	
Heightened reactivity	Synonym	Heightened perception 247712008
Heightened sensitivity	Synonym	Hyperesthesia of special senses 289174003
Balance problems, poor balance	Synonym	Impairment of balance 387603000
Tiredness with small exertion	Synonym	Tiredness on least exertion 248269005
Irritability	Synonym	Feeling irritable 55929007
Forgetfulness	Synonym	Forgetful 55533009
Abdominal pain	Synonym	Generalized abdominal pain 102614006
Depression	Synonym	Symptoms of depression 394924000
Heat intolerance	Synonym	Intolerant of heat 69215007
Reduced tolerance to cold	Synonym	Intolerant of cold 80585000
Feeling feverish	Synonym	Feels hot / feverish 373904004
Shortness of breath on exertion	Synonym	Dyspnea on exertion, 60845006
Weakness in muscle	Synonym	Muscle weakness, 26544005
Irregular heartbeat	Synonym	Heart irregular, 24865006
Medical history is not significant	Synonym	No significant medical history
Unclear medical history	Synonym	Past medical history unknown

Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
Problems related to work	Synonym	Medical problems at work finding
Number of symptoms	Synonym	Multiple symptoms finding
Symptoms are severe	Synonym	Symptom very severe
Moderate level of symptoms	Synonym	Symptom moderate
Mild symptoms	Synonym	Symptom mild
Poor memory	No match	
Stuffy or full sinuses	No match	
Eye irritation	No match	
Itchy eyes	No match	
Burning eyes	No match	
Burning mouth	No match	
Non-restorative sleep	No match	
Unrefreshed by sleep	No match	
Childhood abuse	No match	
Health problems as a child	No match	
Burning mouth	No match	
Cold extremities	No match	
Skin irritation	No match	
Metallic taste in mouth	No match	
Shortness of breath	No match	
Mouth symptoms	No match	
Purplish finger tips	No match	
Difficulty concentrating	No match	
Cognitive difficulties	No match	
Unable to say the right words	No match	
Brain fog	No match	
Increasing reactivity	No match	
Increase in symptoms with exposure	No match	
Unable to do activities of daily living	No match	
Pain onset with exposure	No match	
Exacerbation of symptoms with exposure	No match	
Multidisciplinary finding in the medical category		
Employed	Exact	
Self-employed	Exact	
Stopped work	Exact	
Unemployed	Exact	

Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
Retired	Exact	
Semi-retired	Exact	
Retirement problems	Exact	
Works after retirement	Exact	
On leave from work	Exact	
On sick leave from work	Exact	
On unpaid leave	Exact	
Leaving job	Exact	
On secondment from work	Exact	
Returned to work	Exact	
Unfit to return to work	Exact	
Returned to work after illness	Exact	
May not be able to return to work due to mental health	Synonym	Mentally unfit to return to work
May not be able to return to work due to physical capacity	Synonym	Physically unfit to return to work
Requires accommodation at work	Synonym	Fit to return to work after restrictions
Works from home	Synonym	Works at home
Seasonal work	Synonym	Works irregularly
Is unhappy	Synonym	Unhappy environment
Living alone	Synonym	Lives alone
Has a partner	Synonym	Lives with partner
Living with parents	Synonym	Lives with parents
Dampness in the basement	Synonym	Lives in damp conditions
	Synonym	Living in residence with poor sanitation
Exposure to chemicals	Synonym	Exposure to chemical pollution (event)
Exposure to chemicals at workplace	Synonym	Exposure to chemical pollution, occupational (event)
Financial problems	Synonym	Finding of financial circumstances
Poor finances	Synonym	Financially poor
Income issues	Synonym	Finding of income details
Does not have any income	Synonym	No income
Income is low	Synonym	Low income
Benefit entitlement	Synonym	Finding of benefit status
Unhappy as a child	Synonym	Unhappy childhood finding
Tension in the family	Synonym	Family-tension finding
School bullying	Synonym	Bullied at school finding
Not well educated	Synonym	Lack of education finding

Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
School performance deteriorating	Synonym	Deterioration in school performance finding
Requires special care in school	Synonym	Finding related to special school needs
Unable to adjust to school	Synonym	School maladjustment
Unable to adjust or cope socially	Synonym	Social maladjustment
Unable to adjust to work	Synonym	Occupational maladjustment
Feels isolated	Synonym	Sensory isolation
Feels isolated socially	Synonym	Social isolation
Clutter at home	Synonym	Cluttered living space
Catastrophization	No match	
Perceived injustice	No match	
Job accommodation / duty to accommodate	No match	
Wrongful termination	No match	
Easeback /graduated return to work	No match	
Work refusal	No match	
Workplace bullying / harassment	No match	
Fatigue in muscles	Synonym	Muscle fatigue
Feels sleepy all the time	Synonym	Sleeps too much
Disrupted patterns in sleeping	Synonym	Abnormal sleep pattern finding
	Synonym	Ataxia
Balance has decreased	Synonym	Decreased balance
Reduction in strength	Synonym	Decreased strength
ROM is abnormal	Synonym	Abnormal ROM
Pain in back	Synonym	Back pain
Pain in neck	Synonym	Neck pain
Pain in shoulder	Synonym	Shoulder pain
	Synonym	Hip pain
Pain in respiratory	Synonym	Pain of respiratory structure
Pain in cardiovascular system	Synonym	Pain of cardiovascular structure
Socially isolated	Synonym	Social withdrawal
Panic attack	Exact	
Stress incontinence	Exact	
Inability to cope	Exact	
Difficulty coping	Exact	
Avoidance coping	Exact	
Difficulty coping with pain	Exact	

Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
Suppresses emotions	Synonym	Suppressed emotion
Emotional disconnect	Synonym	Emotionally subdued
Problems in interpersonal relationships	Synonym	Interpersonal problem
Reduced tolerance to activity	Synonym	Activity intolerance
Hypervigilance	Synonym	Hypervigilant behaviour
Abnormal sitting pressure	Synonym	Sitting blood pressure abnormal
Sitting heart rate abnormal	No match	
Sitting arterial pulse pressure abnormal	No match	
Respiratory rate abnormal	No match	
Peak flow abnormal	No match	
Low step count	No match	
Low activity level	No match	
Low activity tolerance	No match	
Gait abnormal	No match	
Antalgic gait	No match	
REHABILITATION		
Education and school finding		365458002
Bullied at school finding	Exact	313168004
Deterioration in school performance finding	Exact	315245004
Finding related to special educational needs	Exact	302141000
Poor education	Exact	105422001
Lack of education	Exact	361063004
School problem	Exact	161155000
Finding of school attendance	Exact	365467002
Irregular attendance at school – synonym of school attendance poor	Synonym	161133008
Employment finding	Synonym	302768007
Employed	Exact	224363007
Self-employed	Exact	160906004
Stopped work	Exact	160895006
Out of work – synonym of Unemployed	Exact	73438004
Retired	Exact	105493001

Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
Semi-retired	Exact	224379008
Retirement problems	Exact	266965008
Works after retirement	Exact	160902002
On leave from work	Exact	224456008
On sick leave from work	Exact	224459001
On unpaid leave	Exact	224461005
Leaving job	Exact	224472000
On secondment from work	Exact	307112004
Returned to work	Exact	266962006
Headache	Exact	25064002
Abdominal pain	Exact	21522001
Nausea	Exact	422587007
Nasal congestion	Exact	68235000
Unfit to return to work	Synonym	225888002
Returned to work after illness	Synonym	276062005
Fit to return to work	Synonym	302120006
Mentally unfit to return to work	Synonym	225890001
Physically unfit to return to work	Synonym	225889005
Fit to return to work after restrictions	Synonym	225893004
Suspended from work	Synonym	385655000
Works at home	Synonym	224407007
Works irregularly	Synonym	224376001
Environment finding		
Unhappy environment	Synonym	285135001
Unfriendly environment	Synonym	224802008
Lives alone	Synonym	105529008
Lives with partner	Synonym	408821002
Lives with parents	Synonym	224137008
Lives with husband	Synonym	408820001
Lives with wife	Synonym	
Lives with family	Synonym	224133007
Lives in damp conditions	Synonym	397756006
Living in inadequate housing	Synonym	105528000

Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
Living in residence with poor sanitation	Synonym	105527005
Exposure to chemical pollution (event)	Synonym	102435003
Exposure to chemical pollution, occupational (event)	Synonym	102436002
Injury to chemical exposure (disorder)	Synonym	371704001
Finding of financial circumstances	Synonym	365550006
Financially secure	Synonym	224165005
Financially poor	Synonym	11403006
Victim of financial abuse	Synonym	225827005
Finding of income details	Synonym	365552003
No income	Synonym	425111004
Variable income	Synonym	224187001
Low income	Synonym	424860001
Finding of benefit status	Synonym	365558004
Application of benefit status	Synonym	228162002
Entitled to benefits	Synonym	161040006
No benefits received	Synonym	161039009
Finding of life event	Synonym	365574009
Disturbance in life pattern associated with work	Synonym	67197000
Disturbance in life pattern associated with family	Synonym	12347001
Sleep pattern disturbance	Synonym	26677001
Divorce, life event	Synonym	63234004
Life crisis, life event	Synonym	162318009
School maladjustment	Synonym	67591007
Social maladjustment	Synonym	67564005
Occupational maladjustment	Synonym	7584007
Victim of abuse	Synonym	386702006
Victim of sexual abuse	Synonym	225826001
Victim of physical abuse	Synonym	225824003
Victim of child abuse	Synonym	397940009

Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
Lacking belief in own ability	Synonym	286650004
Social context finding	Synonym	
Sensory isolation	Synonym	113156005
Social isolation	Synonym	422650009
Interpersonal relationship finding	Synonym	225706007
Obsessive-compulsive personality trait (finding)	Synonym	112091009
Unhappy childhood finding	Synonym	276101003
Family-tension finding	Synonym	105485001
Job accommodation	No match	
Duty to accommodate	No match	
Wrongful termination	No match	
Easeback	No match	
Graduated Return to Work	No match	
Work refusal	No match	
Workplace bullying / harassment	No match	
Variable income casual	No match	
Variable income seasonal	No match	
CPP	No match	
Income Assistance	No match	
WCB	No match	
Cluttered living space	No match	
Legal problem	No match	
Legal problem with divorce	No match	
Legal problem at workplace	No match	
Catastrophization	No match	
Perceived injustice	No match	
Under the care of occupational therapist	Synonym	
Under the care of physician	Synonym	
Under the care of vocational counsellor	Synonym	

Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
Seen by Occupational Therapist	Synonym	
Seen by vocational counselor	Synonym	
Seen by physician	Synonym	
PSYCHOSOCIAL		
Depressive disorder	Exact	35489007
Anxiety disorder	Exact	197480006
Postpartum depression	Exact	58703003
Chronic pain	Exact	82423001
Somatic pain	Exact	48429009
Somatization disorder	Exact	397923000
Delusional pain	Exact	231488009
Hypertensive disorder	Exact	38341003
Night pain	Exact	36163009
Palpitations	Exact	80313002
Chest pain	Exact	2985009
Heart irregular	Exact	248650006
Fluttering heart	Exact	161969004
Stress	Exact	73595000
Psychological symptom	Exact	81659004
Difficulty adjusting to work situation	Exact	10139004
Difficulty coping	Exact	18232000
Maladaptive behaviour	Exact	284499009
Marital problems	Exact	65118005
Malingering	Exact	23268009
Tight chest	Exact	23924001
Inadequate social support	Exact	425022003
Social withdrawal	Exact	105411000
Symptom checklist (assessment scale)	Exact	273859002
Beck depression inventory (assessment scale)	Exact	273306008
Beck anxiety inventory	Exact	304711006
Panic attack	Exact	225624000
Stress incontinence	Exact	
Inability to cope	Exact	47695004

Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
Difficulty coping	Exact	18232000
Avoidance coping	Exact	16735006
Difficulty coping with pain	Exact	16399001
Suppressed emotion	Exact	247792007
Emotionally subdued	Exact	225650001
Withdrawn behaviour	Exact	276249004
Interpersonal problem	Exact	2863003
Financially poor	Exact	11403006
Financial problem	Exact	160932005
Activity intolerance	Exact	77427003
Depression	Exact	41006004
Anxiety	Exact	48694002
Hypervigilant behaviour	Exact	423752000
Sensory intolerance	Exact	277841004
Lives alone	Exact	105529008
Lives with partner	Exact	408821002
Lives with parents	Exact	224137008
Lives with family	Exact	224133007
Lives in damp conditions	Exact	397756006
Seen by Psychologist	Exact	310348003
Seen by Psychiatrist	Exact	305693007
Lack of feeling	Synonym	
Loss of capacity to feel emotions	Synonym	
Feeling guilt	Synonym	7571003
Impairment of balance	Synonym	387603000
Difficulty adjusting to work situation	Synonym	10139004
Unhappy childhood finding	Synonym	276101003
Family-tension finding	Synonym	105485001
Bullied at school finding	Synonym	313168004
Detrioration in school performance finding	Synonym	315245004
Poor education	Synonym	105422001
Lack of education	Synonym	361063004
On sick leave from work	Synonym	224459001

Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
Mentally unfit to return to work	Synonym	225890001
No income	Synonym	425111004
Low income	Synonym	424860001
Finding of life event	Synonym	365574009
Disturbance in life event associated to work finding	Synonym	67197000
Disturbance in life event related to family finding	Synonym	12347001
Sleep disturbance	Synonym	44186003
Sleep pattern disturbance	Synonym	26677001
Life crisis	Synonym	162318009
Social context finding	Synonym	108329005
Victim of abuse	Synonym	386702006
Victim of sexual abuse	Synonym	225826001
Victim of physical abuse	Synonym	225824003
Victim of child abuse	Synonym	397940009
Lacking belief in own ability	Synonym	286650004
Sensory isolation	Synonym	113156005
Social isolation	Synonym	422650009
Interpersonal relationship finding	Synonym	225706007
Obsessive-compulsive personality trait (finding)	Synonym	112091009
Fatigue	Synonym	84229001
Pain	Synonym	
Muscle pain	Synonym	
Abdominal pain	Synonym	
Low energy	Synonym	84229001
Lack of energy	Synonym	84229001
Abdominal cramps	Synonym	
Low activity	Synonym	
Dystonic	No match	
Syntonic	No match	
Lack of awareness	No match	
Repression of emotions	No match	
Emotional eating	No match	

Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
Internally focussed	No match	
Externally focussed	No match	
Teary	No match	
Somatization	No match	
Lack of awareness of body mind connection	No match	
Trauma – early childhood, sexual	No match	
Perceived injustice	No match	
PHYSICAL		
Finding of movement	Synonym	298325004
Abnormal flexion	Synonym	123623009
Decrease flexion	Synonym	46575009
Muscle rigidity	Synonym	16046003
Shortness of breath	Synonym	
Shortness of breath on exertion	Synonym	
Cognitive difficulties	No match	
Unable to say the right words	No match	
Muscle pain	Exact	
Muscle weakness		
Abdominal pain	Exact	
Abdominal bloating	Exact	
Nausea	Exact	
Diarrhea	Exact	
Constipation	Exact	
Employment finding	Exact	
Employed	Exact	
Self-employed	Exact	
Stopped work	Exact	
Out of work – synonym of Unemployed	Exact	
Retired	Exact	
Semi-retired	Exact	
Retirement problems	Exact	
Works after retirement	Exact	

Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
On leave from work	Exact	
On sick leave from work	Synonym	
On unpaid leave	Synonym	
Leaving job	Synonym	
On secondment from work	Synonym	
Returned to work	Synonym	
Unfit to return to work	Synonym	
Returned to work after illness	Synonym	
Fit to return to work	Synonym	
Mentally unfit to return to work	Synonym	
Physically unfit to return to work	Synonym	
Fit to return to work after restrictions	Synonym	
Suspended from work	Synonym	
Works at home	Synonym	
Works irregularly	Synonym	
Unhappy environment	Synonym	
Unfriendly environment	Synonym	
Lives alone	Synonym	
Lives with partner	Synonym	
Lives with parents	Synonym	
Lives with husband	Synonym	
Lives with wife	Synonym	
Lives with family	Synonym	
Fatigue	Synonym	
Impairment of balance	Synonym	
Chronic pain	Synonym	
Headache	Synonym	
Migraine	Synonym	
Dizziness	Synonym	
Tires quickly	Synonym	
Lightheadedness	Synonym	
Abdominal bloating	Synonym	
Generalized abdominal pain	Synonym	

Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
Non-restorative sleep	Synonym	
Unrefreshed by sleep	Synonym	
Difficulty sleeping	Synonym	
Stress	Synonym	
Dyssomnia	Synonym	
Hypersomnia	Synonym	
Chronic constipation	Synonym	
Chronic Diarrhea	Synonym	
Asthma	Synonym	
Obstructive Sleep Apnea	Synonym	
Depressive disorder	Synonym	
Anxiety disorder	Synonym	
Hypertensive disorder	Synonym	
Hypothyroidism	Synonym	
Hyperthyroidism	Synonym	
Arthritis	Synonym	
Reactive Airways Dysfunction Syndrome	Synonym	
Postpartum Depression	Synonym	
Food intolerance	Synonym	
Finding of movement	Synonym	
Abnormal flexion	Synonym	
Decrease flexion	Synonym	
Muscle rigidity	Synonym	
Lack of stamina	Synonym	
Energy and stamina finding	Synonym	
Exhaustion	Synonym	
Tires quickly	Synonym	
Exhaustion due to excessive exertion	Synonym	
Exhaustion due to exposure	Synonym	
History taking (procedure)	Synonym	
No significant medical history	Synonym	
Past medical history unknown	Synonym	

Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
Medical problems at work finding	Synonym	
Chief complaints finding	Synonym	
Multiple symptoms finding	Synonym	
Symptom very severe	Synonym	
Symptom moderate	Synonym	
Symptom mild	Synonym	
Muscle fatigue	Synonym	
Malaise and fatigue	Synonym	
Sleeps too much	Synonym	
Sleep pattern finding	Synonym	
Musculoskeletal hypomobility	Synonym	
Musculoskeletal immobility	Synonym	
Ataxia	Synonym	
Decreased balance	Synonym	
Decreased strength	Synonym	
Abnormal ROM	Synonym	
Back pain	Exact	
Chronic back pain	Exact	
Neck pain	Exact	
Shoulder pain	Exact	
Elbow pain	Exact	
Hip pain	Exact	
Pain at anatomical site	Synonym	
Ankle pain	Exact	
Foot pain	Exact	
Musculoskeletal pain	Exact	
Pain of respiratory structure	Synonym	
Pain of cardiovascular structure	Synonym	
Chest pain	Synonym	
Sitting blood pressure abnormal	Synonym	
Sitting heart rate abnormal	No match	
Sitting arterial pulse	No match	

pressure abnormal		
Chart audit terms	**Term availability in SNOMED CT** **Exact match / synonym / no match**	**Standardized terms using SNOMED CT**
Respiratory rate abnormal	No match	
Peak flow abnormal	No match	
Low step count	No match	
Low activity level	No match	
Low activity tolerance	No match	
Gait abnormal	No match	
Antalgic gait	No match	
Reduced activity	No match	
Unable to do activities of daily living	No match	
Low functioning	No match	
Abnormal grip strength	No match	
Abnormal gait	No match	
Unable to do housework	No match	
Unable to work	No match	
NUTRITION		
Chronic constipation	Exact	
Chronic diarrhea	Exact	
Irritable bowel (with diarrhea)	Exact	
Irritable bowel (with constipation)	Exact	
Anorexia Nervosa	Exact	
Food sensitivity	Exact	
Abnormal weight loss	Exact	
Unexplained weight loss	Exact	
Abnormal weight gain	Exact	
Unexplained weight gain	Exact	
Excessive weight loss	Exact	
Excessive weight gain	Exact	
Generalized abdominal pain	Exact	
Nausea	Exact	
Diarrhea	Exact	
Constipation	Exact	
Bloating symptom	Exact	

Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
Reflux	Exact	
Migraine	Exact	
Incontinence	Exact	
Bladder problem	Exact	
Energy and stamina finding	Exact	
Fatigue	Exact	
Exhaustion	Exact	
Light-headedness	Exact	
Tires quickly	Exact	
Body measurement finding	Exact	
BMI > 25	Exact	
Finding of food and drink intake	Exact	
Food intake abnormal	Exact	
Food intake inadequate	Exact	
Drink intake abnormal	Exact	
Drink intake inadequate	Exact	
Sugar intake excessive	Exact	
Overweight	Exact	
Obese	Exact	
Underweight	Exact	
Back pain	Exact	
Chronic back pain	Exact	
Neck pain	Exact	
Shoulder pain	Exact	
Elbow pain	Exact	
Hip pain	Exact	
Depression	Exact	
Anxiety	Exact	
Cough	Exact	
Fried food intake excessive	Synonym	
Sweet intake excessive	Synonym	
Salt intake excessive	Synonym	
Processed food intake excessive	Synonym	
Coffee intake excessive	Synonym	

Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
Alcohol intake excessive	Synonym	
Finding related to ability to eat	Synonym	
Does not eat	Synonym	
Always eating	Synonym	
Unable to eat	Synonym	
Inappropriate snacking	Synonym	
Skips meals	Synonym	
Nighttime eating	Synonym	
Polyphagia	Synonym	
Polydipsia	Synonym	
IBS	Synonym	
Food intolerance	Synonym	
Starchy food intake	Synonym	
Vegetable intake	Synonym	
Dairy food intake	Synonym	
Meat intake	Synonym	
Vitamin intake	Synonym	
Fiber intake	Synonym	
Milk intake	Synonym	
Water intake	Synonym	
Juice intake	Synonym	
Food allergies	Synonym	
Nut allergy	Synonym	
Allergy to chocolates	Synonym	
Milk allergy	Synonym	
Wheat allergy	Synonym	
Emotional eating	No match	
Low activity level	No match	
Low activity tolerance	No match	
Gluten free diet	No match	
Increasing reactivity	No match	
Increase in symptoms with exposure	No match	
Unable to do activities of daily living	No match	
Increasing sensitivity to food	No match	

APPENDIX B Terms and concepts for chronic pain

PATIENT DEMOGRAPHICS N = 100	Percentage of occurence %
AGE GROUP	
Age group 30 and under	10
Age group 30 - 40 years	18
Age group 40 - 50 years	25
Age group 50 - 60 years	35
Age group 60 + years	12
SEX	
Male	44
Female	56
EMPLOYMENT	
Employed	53
Unemployed (stopped work / retired / disability)	57

Items	Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
MEDICAL			
1	Mechanical low back pain	Exact	SNOMED Concept ID: 279040009 Parent concept: Low back pain Finding site: Lumbar region back structure
2	Chronic low back pain	Exact	SNOMED Concept ID: 279040009 Parent concept: Low back pain Finding site: Lumbar region back structure
3	Chronic headache	Exact	SNOMED Concept ID: 431237007 Parent concept: Headache disorder; chronic disorder Finding site: Head structure
4	Migraine	Exact	SNOMED Concept ID: 37796009 Parent concept: Vascular headache Finding site: Vascular structure of head
5	Complex regional pain syndrome	Exact	SNOMED Concept ID: 128200000 Parent concept: Disorder characterized by pain; disorder of the peripheral nervous system Finding site: Peripheral nervous system structure
6	Arthritis	Exact	SNOMED Concept ID: 3723001 Parent concept: Inflamed joint; inflammation of specific body organs; inflammatory disorder of

			musculoskeletal system; arthropathy Finding site: Joint structure
Items	**Chart audit terms**	**Term availability in SNOMED CT** **Exact match / synonym / no match**	**Standardized terms using SNOMED CT**
7	Osteoarthritis	Exact	SNOMED Concept ID: 396275006 Parent concept: Degenerative disorder of musculoskeletal system; arthropathy Finding site: Joint structure
8	Spinal stenosis	Exact	SNOMED Concept ID: 76107001 Parent concept: Disorder of spine Finding site: Spinal canal structure
9	Lumbar spinal stenosis	Exact	SNOMED Concept ID: 18347007 Parent concept: Disorder of abdominal wall; spinal stenosis Finding site: Structure of lumbar spinal canal
10	Thoracic spinal stenosis	Exact	SNOMED Concept ID: 41341006 Parent concept: Disorder of thorax; spinal stenosis Finding site: Structure of thoracic spinal canal
11	Radiculopathy, nerve root disorder	Exact	SNOMED Concept ID: 72274001 Parent concept: Disorder of soft tissue; neuropathy; disorder of peripheral nervous system Finding site: Nerve root structure
12	Reflex sympathetic dystrophy	Exact	SNOMED Concept ID: 128079007 Parent concept: Disorder of peripheral autonomic nervous system; complex regional pain syndrome Finding site: Autonomic nerve structure

Items	Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
13	Vulvodynia	Exact	SNOMED Concept ID: 238968009 Parent concept: Disorder of vulva; disorder characterized by pain; Finding site: Vulval structure
14	Chronic psychogenic pain	Exact	SNOMED CT ID: 441711008
15	Chronic pelvic pain syndrome	Exact	SNOMED CT ID: 426135001 Parent concept: Chronic pain syndrome; chronic prostatitis
16	Chronic painful diabetic neuropathy	Exact	SNOMED CT ID: 193184006 Parent concept: Chronic pain syndrome; diabetic neuropathy
17	Mixed soft tissue disorder	Synonym	Soft tissue disorder SNOMED Concept ID: 19660004 Parent concept: Disorder by body site; general finding of soft tissue Finding site: Soft tissues
18	Neuropathic regional pain	Synonym	Neuropathic pain SNOMED Concept ID: 262522002 Parent concept: Neurogenic pain Finding site: Anatomical or acquired body structure
19	Cervical strain injury	Synonym	Injury of cervical spine SNOMED Concept ID: 279040009 Parent concept: Disorder of cervical spine; spinal injury; injury of neck Finding site: Cervical spine structure
20	Fibromyalgia	Synonym	SNOMED Concept ID: 24693007 Parent concept: Myositis

			Finding site: Skeletal muscle structure
Items	**Chart audit terms**	**Term availability in SNOMED CT** **Exact match / synonym / no match**	**Standardized terms using SNOMED CT**
21	Chronic cervical pain	No match	
22	Degenerative disk disease of lumbar spine	No match	
23	Mechanical pain of shoulder	No match	
24	Post traumatic low back pain	No match	
25	Neuropathic maxillary facial pain	No match	
26	Chronic back pain with musculoskeletal and neuropathic	No match	
Co morbidities			
27	GERD	Exact	SNOMED Concept ID: 235595009 Parent concept: Disorder of stomach; disorder of esophagus Finding site: Cardioesophageal junction structure
28	Platelet disorder	Exact	SNOMED Concept ID: 22716005 Parent concept: Disorder of hemostatic system; Finding of cellular component of blood;
29	CFS	Exact	SNOMED Concept ID: 52702003 Parent concept: Multisystem disorder; Mental disorder;
30	Diverticular disease	Exact	SNOMED Concept ID: 397881000 Parent concept: Disorder of gastrointestinal tract Finding site: Gastrointestinal tract structure
31	Hyperlipidemia	Exact	SNOMED Concept ID: 55822004 Parent concept: Disorder of lipoprotein storage and metabolism
32	Dyslipidemia	Exact	SNOMED Concept ID: 370992007 Parent concept: Disorder of lipoprotein AND/OR lipid metabolism

Items	Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
33	IBS	Exact	SNOMED Concept ID: 10743008 Parent concept: Disorder of colon Finding site: Colon structure
34	Chronic diarrhea	Exact	SNOMED Concept ID: 236071009 Parent concept: Diarrheal disorder Finding site: Gastrointestinal tract structure
35	Chronic kidney disease	Exact	SNOMED Concept ID: 236425005 Parent concept: Chronic disease of genitourinary system; Finding site: Kidney structure
36	Angina	Exact	SNOMED Concept ID: 194828000 Parent concept: Disorder characterized by pain; Ischemic heart disease Finding site: Heart structure
37	Sleep Apnea	Exact	SNOMED Concept ID: 73430006 Parent concept: Sleep disorder
38	Hyperthyroidism	Exact	SNOMED Concept ID: 34486009 Parent concept: Disorder of thyroid gland; Finding site: Thyroid structure
39	Asthma	Exact	SNOMED Concept ID: 195967001 Parent concept: Disorder of respiratory system; Finding site: Structure of respiratory system
40	Bronchitis	Exact	SNOMED Concept ID: 32398004 Parent concept: Inflammatory disorder of lower respiratory tract; Disorder of bronchus; Finding site: Bronchial structure

Items	**Chart audit terms**	**Term availability in SNOMED CT** **Exact match / synonym / no match**	**Standardized terms using SNOMED CT**
41	General Anxiety Disorder	Exact	SNOMED Concept ID: 21897009 Parent concept: Anxiety disorder;
42	Pituitary tumor	Exact	SNOMED Concept ID: 127024001 Parent concept: Disorder of pituitary gland; Finding site: Pituitary structure
43	Post traumatic stress disorder	Exact	SNOMED Concept ID: 47505003 Parent concept: Anxiety disorder;
44	Diabetes	Synonym	Diabetes mellitus SNOMED Concept ID: 73211009 Parent concept: Disorder of glucose metabolism; disorder of endocrine structure Finding site: Endocrine pancreatic structure
45	Depression	Synonym	Depressive disorder SNOMED Concept ID: 35489007 Parent concept: Mood disorder;
46	Hypertension	Synonym	Hypertensive disorder SNOMED Concept ID: 38341003 Parent concept: Systemic arterial finding; Disorder of artery; Finding site: Systemic arterial structure
47	COPD	Synonym	Chronic obstructive lung disease SNOMED Concept ID: 13645005 Parent concept: Chronic disease of respiratory system; disorder of lungs; bronchiolar disease Finding site: Lung structure

48	Interstitial cystitis	Synonym	Chronic interstitial cystitis SNOMED Concept ID: 197834003 Parent concept: Disorder of connective tissue; chronic cystitis Finding site: Structure of interstitial tissue of urinary bladder
Items	**Chart audit terms**	**Term availability in SNOMED CT** **Exact match / synonym / no match**	**Standardized terms using SNOMED CT**
49	Wharton's Neuroma	No match	
50	MCS	No match	No match in SNOMED CT
51	PHYSICAL		**Pain finding at anatomical site – parent concept in SNOMED**
52	Low back pain	Exact	279039007
53	Chronic low back pain	Exact	278860009
54	Chronic back pain	Exact	134407002
55	Neck pain	Exact	8168005
56	Shoulder pain	Exact	45326000
57	Foot pain	Exact	47933007
58	Heel pain	Exact	2733002
59	Headache	Exact	25064002
60	Chest pain	Exact	29857009
61	Radicular pain	Exact	11679003
62	Hip pain	Exact	49218002
63	Joint pain	Exact	57676002
64	Muscle pain	Exact	68962001
65	Onset of pain		
66	Accident	Exact	55566008
67	Pattern of pain		**Finding of pattern of pain - parent concept in SNOMED**
68	Diffuse pain	Exact	2134003
69	Radiating pain	Exact	9972008
70	Constant pain	Exact	426206001
71	Intermittent pain	Exact	314642004
72	Mechanical pain	Exact	9626006
73	Localized pain	Exact	112104007
74	Squeezing pain	Exact	428557006
75			**Pain by sensation quality - parent concept in SNOMED**
76	Burning pain	Exact	36349006
77	Stabbing pain	Exact	55145008
78	Throbbing pain	Exact	29695002

Items	Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
79	Sharp pain	Exact	8708008
80			
81	Hot pain	Exact	36349006
82	Tingling	Exact	62507009
83	Pins and needles	Exact	62507009
	Physical Exam		
84	Weakness in legs	Exact	Weakness of leg, 249945007, monoparesis – leg
85	Weakness in arms	Exact	Weakness of arm, 249944006, monoparesis - arm
86	Fatigue	Exact	84229001, tiredness, weariness
87	Light-headedness	Exact	386705008
88	Difficulty staying asleep	Exact	67233009
89	Antalgic gait	Exact	67141003
90	Limited range of motion	Exact	70733008
91	Shortness of breath	Exact	267036007
92	Palpitations	Exact	80313002
93	Right lower limb pain	Synonym	Pain in lower limb, 10601006
94	Right shoulder pain	Synonym	Pain radiating to right shoulder, 426142001
95	Stomach pain	Synonym	Abdominal pain, 21522001
96	Motor vehicle accident	Synonym	Motor vehicle traffic accident, 242089005
97	Surgery related	Synonym	Postoperative pain, 231299007
98	Work injury	Synonym	Accident at work, 17542004
99	Compression fracture	Synonym	
100	Achiness	Synonym	Aching pain, 27635008
101	Soreness with pain	Synonym	Soreness, 71393004
102	Pain sensation	Synonym	**Observation of sensation - parent concept**
103	Tenderness in thoracic spine	Synonym	Thoracic spine - tender, 298578004
104	Tenderness in lumbar spine	Synonym	Lumbar spine - tender, 298673002
105	Tenderness over knee joint	Synonym	Knee joint - tender, 299372009
106	Right scoliosis of the lumbar spine	Synonym	Lumbar spine scoliosis - 298591003
107	Lumbar lordosis	Synonym	Loss of lumbar lordosis, 29859002
108	Sensitivity to light	Synonym	Light intolerance, 62481005
109	Sensitivity to sound	Synonym	Noise intolerance, 247994001
110	Difficulty initiating sleep	Synonym	Difficulty falling asleep, 5905008
111	Unable to do activities of	Synonym	Disability affecting daily living,

	daily living due to pain		413298002
Items	**Chart audit terms**	**Term availability in SNOMED CT** **Exact match / synonym / no match**	**Standardized terms using SNOMED CT**
112	Unable to do housework due to pain	Synonym	Unable to do do-it-yourself activities, 300830007
113	Pain during sleep	Synonym	Pain onset during sleep, 429038000
114	Mid back pain	No match	
115	Right lower sided back pain	No match	
116	Continuous pain	No match	
117	Knife type pain	No match	
118	Numb pain	No match	
119	Pressure with pain	No match	
120	Hyperesthesia in leg	No match	Hyperesthesia, 14151009
121	Hypoesthesia in the lower lumbar region	No match	Hypoesthesia, 397974008
122	Loss of sensation in leg	No match	
123	Tenderness in the paraspinous area	No match	
124	Tenderness at the bilateral SI areas	No match	
125	Tenderness over Ischial Tuberosity	No match	
126	Decreased sensation over lateral calf and foot	No match	
127	Hyperalgesia at the right posterior chest	No match	
128	Mechanical and light touch allodynia	No match	
129	Bilateral myofascial tenderness of trapezius	No match	
130	Sensation to sharp and dull	No match	
131	Sensation to cold and hot	No match	
132	Low energy	No match	
133	Poor sleep due to pain	No match	
134	Daily headaches	No match	
135	Low activity	No match	
136	No exercises	No match	
137	Loss of strength	No match	
138	Unable to do recreational activities due to pain	No match	
139	Unable to do work	No match	
140	Ambulation slow, guarded	No match	
141	Limited extension, rotation and bending	No match	

Items	Chart audit terms	Term availability in SNOMED CT Exact match / synonym / no match	Standardized terms using SNOMED CT
142	Deconditioning	No match	
143	Pain with range of motion	No match	
144	Restricted cervical range of motion	No match	
145	Reduced tolerance to prolonged standing, sitting and bending over	No match	
	Psychosocial		
PSYCHOSOCIAL			
	Psychological		
146	Anxiety	Exact	48694002
147	Difficulty coping with pain	Exact	16399001
148	Difficulty coping	Exact	18232000
149	Mood - frustrated	Synonym	Feeling frustrated, 224973000
150	Mood - angry	Synonym	Feeling angry, 75408008
151	Depression	Synonym	Depressive disorder
152	Difficulty in concentration related to pain	No match	
153	Childhood trauma	No match	
154	Low mood	No match	
	Social		
155	Employed	Exact	224363007
156	Unemployed	Exact	73438004
157	Disability	Exact	29695002
158	Married	Exact	87915002
159	Single	Exact	125725006
160	Divorced	Exact	20295000
161	Common law	Exact	14012001
162	Widow / widower	Exact	3071008 / 78061006
163	Smoker	Exact	77176002
164	Financial stressors	Synonyms	financially poor, financial circumstance finding, finding of benefit status, economic problems
165	Family support stressors	Synonym	Home problem, 266949007;
166	Difficulty working related to illness	Synonym	Temporarily unable perform work activities due to medical condition, 440337002; Permanently unable to perform work activities due to medical condition;
167	Does not have sufficient	Synonym	Inadequate social support,

	social support		425022003
Items	**Chart audit terms**	**Term availability in SNOMED CT** **Exact match / synonym / no match**	**Standardized terms using SNOMED CT**
168	Marijuana for pain	No match	
169	Stopped work	No match	
	Nutrition		
170	Weight gain	Exact	8943002
171	Weight loss	Exact	89362005
172	Abdominal pain	Exact	21522001
173	Nausea	Exact	422587007
174	Diarrhea	Exact	62315008
175	Constipation	Exact	14760008
176	Food intolerance	Exact	235719002
177	BMI > 25	Synonym	BMI 25-29 overweight, 162863004
178	Obese	Synonym	BMI 30+ obesity, 162864005
179	Loss of appetite due to pain	Synonym	Loss of appetite, 249469002
180	Difficulty maintaining weight	No match	
181	Food allergies	No match	
182	Increasing sensitivity to food	No match	

APPENDIX C Related Publications

1. Sampalli T, Shepherd M, Fox R. Boundary objects in the multidisciplinary care management of chronic conditions: multiple chemical sensitivity. Stud Health Technol Inform. 2009;143:534-9

Abstract:

Chronic conditions such as Multiple Chemical Sensitivity (MCS) are a significant challenge to the health care system as they are poorly understood, poorly documented and lack accepted or standardized treatment strategies. Research has shown that the successful management of patients with such conditions requires a multidisciplinary team of clinicians and the comprehensive assessment of factors contributing to the ill health. Results from two studies that have shown reduction in health care costs and improvement in symptoms for patients with MCS are presented. We explore the use of a controlled clinical vocabulary as a boundary object in care documents to facilitate collaborative management of patients with MCS.

2. Sampalli T, Shepherd M, Duffy J, Fox R. An evaluation of SNOMED CT in the domain of complex chronic conditions. Int J Integr Care. 2010 Mar 24;10

Abstract
Objective: To determine the content coverage in SNOMED CT to represent the multidisciplinary terms and concepts in the domain for complex chronic conditions.
Methods: An evaluation of the coverage of multidisciplinary health factors in SNOMED CT for the complex and chronic condition, multiple chemical sensitivity (MCS) is conducted in the study. The methodology included a retrospective audit of patient charts and feedback from multidisciplinary clinicians in the creation of a controlled vocabulary used in the generation of patient profiles for MCS. Clinicians and experts in the field reviewed and tested the vocabulary for its usefulness (scope, specificity and structure) by re-coding three patient profiles using the vocabulary. Cohen's kappa analysis was conducted to determine inter-rater reliability. Cronbach's alpha analysis was conducted to determine the internal reliability of the survey questionnaire.
Results: One hundred patient charts and nine clinicians from varying health disciplines participated in the study. SNOMED CT was shown to capture nearly 82% of the concepts spanning multidisciplinary areas of health focus. The nutrition area of health focus had the highest level of exact matches. Furthermore, post-coordination was applied in an attempt to improve coverage of concepts to 75% (23 terms) of the missing terms in SNOMED CT. Seventy-five percent (n=9) of the clinicians agreed on the overall usefulness of the vocabulary.
Conclusion: SNOMED CT had a reasonable coverage of the multidisciplinary health concepts required to describe a complex and chronic condition. Standardizing the multidisciplinary vocabulary with reference tag to a widely used reference terminology, such as SNOMED CT to discuss the terms and concepts used may improve the understanding across disciplines and communities of practice. Overall, based on the

availability of concepts in SNOMED CT and the feedback from clinicians, the approach looks promising and should be further explored.

3. Tara Sampalli, Michael Shepherd, Jack Duffy, "A Patient Profile Ontology in the Heterogeneous Domain of Complex and Chronic Health Conditions," hicss, pp.1-10, 2011 44th Hawaii International Conference on System Sciences, 2011

Abstract:

There is growing interest in recent years in applying ontologies to represent disease concepts because they have the ability to depict the domain knowledge with a superior level of expressiveness and precision. Ontologies have been predominantly used to represent well-categorized disease concepts. However, there are challenges in representing the domain knowledge for heterogeneous and poorly categorized systems. In this study, a methodology to create an ontology to represent the domain knowledge for complex and chronic health conditions is explored. The domain of complex chronic conditions can be viewed not only as heterogeneous but also as dynamic with new knowledge continually evolving. The methodology includes the development of a controlled vocabulary to create the first layer of semantic interoperability. The controlled vocabulary is then converted into a patient profile ontology to add deeper semantics, conceptually and relationally in the heterogeneous domain knowledge.

4. Sampalli T, Shepherd M, Duffy J: A standardized and controlled clinical vocabulary in the multidisciplinary care management of a complex and chronic condition: Multiple Chemical Sensitivity. J Multidiscip Healthc. 2011 Apr 7;2:53-9

Abstract:
Purpose: Research has shown that accurate and timely communication among multidisciplinary clinicians involved in the care of complex and chronic health conditions is often challenging. The domain knowledge for these conditions is heterogeneous with poorly categorized, unstructured and inconsistent clinical vocabulary. The potential of boundary object as a technique to bridge communication gaps is explored in this study. A standardized and controlled clinical vocabulary was developed as a boundary object in the domain of a complex and chronic health condition, namely, Multiple Chemical Sensitivity (MCS) to improve communication among multidisciplinary clinicians.
Patients and methods: A convenience sample of patients (n=100) with a diagnosis of MCS, multidisciplinary clinicians involved in the care (n=9) and clinicians in the community (n=36) participated in the study.
Results: Eighty two percent of the multidisciplinary and inconsistent vocabulary was standardized using Systematized Nomenclature of Medicine – Clinical Terms, SNOMED CT as a reference terminology. Over 80% of the multidisciplinary clinicians agreed on the overall usefulness of having a controlled vocabulary as a boundary object. Over 65% of clinicians in the community agreed on the overall usefulness of the vocabulary.

Conclusion: The study was conducted as a preliminary analysis for developing a boundary object in a heterogeneous domain of knowledge. The results from this study are promising and will be further evaluated in the domain of another complex chronic condition, chronic pain

APPENDIX D Ethics Approval Letter

CDHA-RS/2009-090 Ethics Board Approval Number – Capital District Health Authority Ethics Committee