

# **Creating Archetypes for Patient Assessment with Nurses to Facilitate Shared Patient Centred Care in the Older Person.**

A Thesis Submitted to University of Dublin, Trinity College for the  
Degree of Doctor of Philosophy

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## **Declaration**

I, the undersigned, declare that this work has not been previously submitted as an exercise for a degree at this or any other University, and that, unless otherwise stated, it is entirely my own work.

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Pamela Henry September 2010

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## **Summary**

The process of what information is captured in documenting patient care assessment and how it is summarised, communicated and interpreted by nurses across different healthcare services is the main focus of this thesis. Currently in Ireland, systems within the domain of healthcare are undergoing transformation. Existing practices where health information is collected at one local health organisation level and often duplicated across differing services will not support the strategic goals of the newly established clinical directorates. The political vision is simple: Ireland must move towards a nationally integrated electronic record to support patient centred care. Whilst the political vision may be simple, the process of implementation is not and forms the main topic of this thesis. Strategic goals to move nationally towards integrated electronic records are motivated by the global concerns of an ageing population associated with an increase in the prevalence of chronic illness and co-morbidity. The main objective of this thesis is to evaluate the impact of a pilot study which identified the semantic and syntactic clinical requirements for the testing and implementation of a shared discharge/transfer summary assessment record for persons over the age of 65. This summary record was designed in accordance with ISO 13606, the International standard for Electronic Healthcare Record (EHR) communication and is underpinned by ISO 18104, the international standard for Categorical Structures for Representation of Nursing Diagnosis and Nursing Actions in Terminological Systems. A participatory action research approach was adopted, using an exploratory mixed methods research study design. This translational study was completed in two local health organisation areas in Dublin with six service providers across the primary, acute and continuing

care services over a two year period. The qualitative element of the study involved 17 interviews, 7 focus group sessions with participants including policy makers and nurses from each of the participating services. Quantitative data included questionnaires from nurses (n = 14) and patients (n=5) evaluating the effectiveness of the summary record. The quantitative data also analysed information from a set of cumulative assessment records (n = 16) which were interpreted in tandem with the qualitative data and then analysed statistically. The shared discharge/transfer summary care record was piloted on 16 patients over an extended timeframe. The quantitative data showed a statistical significance commensurate with the qualitative data collected on patient participants. An evaluation of the pilot study produced qualitative data which was used to gain insight into the differing contexts that healthcare professionals practice within. This data was illustrated in graphical configurations to make evident to policy makers the various roles that nurses engage with in the course of their care delivery. Data collected from both the qualitative and quantitative analysis suggest that the test implementation of the record template was fit for purpose. Identification of the clinical requirements and testing of the summary record over a two year period was a labour intensive process which was logistically difficult to implement. One consequence of this study was the education of the nursing participants on gaining a common understanding of what needs to be measured in patient assessment to inform future theory testing for outcome based research. A second consequence was the empowerment of the nursing participants to develop archetypes for inclusion in future electronic healthcare records in Ireland. The prototype archetypes designed for assessment of the older person in this study are at present informing a number of practical applications within the nursing community in Ireland. Over the course of the

study the participatory action research design altered in its focus and emerged as a dominant qualitative mixed methods study.

## **Publications**

The publications relating to this thesis can be separated into research orientated publications and practice development publications, they are presented as follows:

### **Research**

Henry, P. 2010 National Council of Nursing and Midwifery Newsletter PARTNERS – incorporating “the essential tools of the trade” into EHR practice development. Autumn Newsletter Submitted and Accepted for Publication.

Henry, P. 2010 PARTNERS in Practice – Incorporating “the essential tools of the trade” into EHR development in Ireland Invited Guest Speaker for Plenary Session Canadian Health Outcomes for Better Information and Care Symposium, Toronto

Henry, P. 2010 PARTNERS an EHR Practice Development Initiative *Quality in Healthcare Journal with International Council of Nurses (ICN)* Submitted for publication May 30<sup>th</sup> 2010

### **Practice Development**

Henry, P., Spencer, A. PARTNERS website and suite of educational resources available online to view at [www.partnersct.com](http://www.partnersct.com)

Henry, P. International Classification of Nursing Practice C.Space – PARTNERS Group Online Resource

Henry, P. PARTNERS Interim Report 2008 Submitted to Health Services Executive June 2008

Henry, P. Sharpe, M. 2010 PARTNERS Evaluation Report submitted to Health Services Executive ISBN 1872327877

Spencer, A. Henry, 2010 PARTNERS and EHRland Documentary: PARTNERS in Practice.

## List of Abbreviations

<b>ADL</b>	Archetype Definition Language
<b>ANSI</b>	American National Standards Institute
<b>AMOS 5</b>	A statistical analysis tool used for structural equation modelling often used for outcomes based research analysis
<b>DICOM</b>	Digital Imaging and Communications in Medicine
<b>CDA</b>	Clinical Document Architecture
<b>CEN</b>	European Committee for Standardization
<b>C.HOBIC</b>	Canadian Health Outcomes for Better Information and Care
<b>CMO</b>	Context Mechanism and Outcome
<b>EHR</b>	Electronic Healthcare Record.
<b>EN</b>	European Standard
<b>ENV</b>	European Pre Standard
<b>FHCR</b>	Federated Healthcare Record
<b>GEHR</b>	Good European/Electronic Health Record
<b>HL7</b>	Health Level Seven
<b>ICT</b>	Information and Communication Technology
<b>IEEE</b>	The Institute of Electrical and Electronics Engineers
<b>ICNP®</b>	International Classification of Nursing Practice
<b>ISO</b>	International Organisation for Standardization
<b>IHTSDO</b>	International Health Terminology Standards Development Institute
<b>MDS</b>	Minimum Data Set
<b>NHS</b>	National Health Service
<b>NNN</b>	NANDA , NIC and NOC strategic alliance group established for formalised language
<b>RIM</b>	Reference Information Model
<b>RM</b>	Reference Model
<b>OID</b>	Object Identifiers
<b>TC251</b>	Technical Committee 251, the committee devoted to health informatics
<b>TILDA</b>	The Irish Longitudinal Study on Ageing <a href="http://www.tcd.ie/tilda/participants/">http://www.tcd.ie/tilda/participants/</a>
<b>TIGER</b>	The technology informatics guiding educational reform <a href="http://www.tigersummit.com/">http://www.tigersummit.com/</a>
<b>UML</b>	Unified Modeling Language
<b>WHO</b>	World Health Organisation
<b>XML</b>	eXtensible Mark up Language

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## 1. Introduction

A primary goal of healthcare for people who are aged, particularly those with chronic illness should be to optimise function and comfort rather than treat individual disease processes (Tinetti, Baker, and Gallo 2002; Vladeck 1994). The World Health Organisation describes health as a resource for everyday life and not the objective of living or the absence of disease (WHO, 1999). This suggests that health as a resource needs to be maintained on an ongoing basis, particularly for those individuals who are most at risk of losing it. Existing healthcare systems often succeed in meeting the short term needs of healthy people who experience acute illness and injuries i.e. those individuals who have temporarily lost their ability to maintain their health state. However, such systems can often fail patients who have multi-morbidity and complex care needs (Aliotta et. al., 2008). For such individuals maintaining health as a resource includes recognising a complex series of health patterns. For example in a patient who endures chronic pain this process will involve recognising symptoms such as pain, frequency, duration and intensity.

For individuals with complex care needs, healthcare practice is required to move beyond a predominately reactive acute care paradigm to a more holistic paradigm where patient care migrates from a lengthy inpatient episode of care to perhaps a day care case which will include management with continued appropriate primary care support in the community setting (Shortell and Kaluzny, 2006). Departing from the reactive acute paradigm to a more holistic paradigm in healthcare requires the adoption of two key principles; they are firstly integrated healthcare processes and secondly the notion of a patient centred care approach.

Integrated care, often called shared care can be defined as an organisational principle in which two or more healthcare providers jointly collaborate to provide healthcare services to a “subject of care” i.e. the patient for a continuing health issue (CEN, 2007). A health issue can be described as any problem with which a patient presents to a healthcare provider, one example being the symptom of back pain. Whilst patient centred care can be described as a change in focus from solely a disease orientation to include a patient’s feelings and experiences, it also integrates bio-psycho social factors in order to gain a deeper understanding of the patient’s illness (Hägglund, 2009). Patient centred care is also described by Stewart (2001) as taking into consideration the patient’s desire for information whilst accommodating a shared process of decision making on current and future illness management between the healthcare professional and the patient. In the example offered above, namely back pain, in a patient centred care approach the alternative options to understand the cause of the problem and the management of the back pain would be discussed with the patient and a shared decision would be made on how to progress with the care package for this individual patient with this particular health issue.

In addition, current global trends suggest that individuals are living longer and it is expected that in the future additional resources will be required for older persons to maintain independence in their homes (TILDA, 2010). This is of particular significance for those individuals who live with chronic illness, in an isolated home care environment. Such patients will need to manage symptoms of their illness and will require ongoing support in the home environment to avoid lengthy acute inpatient episodes of care or perhaps long term continuing care placement.

Of the twenty countries in the world with a highest percentage of older people per capita, eighteen are countries within the European Region (World Health Organisation, 2002). The old age dependency ratio in Europe which is the number of persons aged 65 years and over per one hundred persons aged 15 to 64 years, is anticipated to double by the middle of this century (United Nations, 2006; Lanzeiri, 2008). In Ireland the population of individuals who are 65 years or older is projected to increase significantly from a level in 2006 of 462,000 to 1.4 million by the year 2041. The population of over 80 years is set to rise more dramatically than the over 65 year's population showing a four fold increase (Central Statistics Office, 2008).

In June 2009 in Ireland a national principles based framework for the implementation of clinical directorates was launched (Department of Health and Children, 2009). The Irish Health Services Executive (HSE) describes the purpose of the clinical directorate as being one which seeks to achieve the best clinical outcome and experience for patients with the resources available. Significantly the framework identifies a number of pertinent factors which are required for the successful implementation of the new structure. Three of these factors are of relevance to this particular thesis. They are *clinical engagement*, and *effective decision making*, which the HSE insist will need to be underpinned by *valid timely and reliable data*. Such factors the HSE indicate are required for sound clinical judgement and decision making in effective patient care. It is also to ensure fiscal control is exercised on existing resources for current and future healthcare provision.

The focus of this study relates to clinical engagement by nurses. The process involves identifying the specific data requirements which are needed to enhance interagency communication across traditional service boundaries between healthcare professionals to support an

integrated model of patient centred care. It is anticipated that engaging in this process contributes to the delivery of reliable valid and timely data. The evidence suggests that there is an expressed need for integrated care i.e. collaborating in the care of patients across different health service providers particularly in care of the older persons (Bodenheimer, 2008).

The study also critiques how emerging technologies e.g. reference terminologies and health informatics standards can assist in the process of supporting older patient's health record requirements in order to achieve integrated patient centred care. By using standardised syntax and structure in documentation development, communication processes across service providers can achieve semantic integration. The word semantic relates to the study of meaning and in this study relates to a set of agreed clearly defined concepts and terms for inclusion in health assessment records. Electronic healthcare records are often identified as a vehicle to enhance interagency communication which enables integrated care provision (Garde, Knaup, Hovenga and Heard 2007a). In particular healthcare systems which are underpinned by Electronic Healthcare Record (EHR) standards can be perceived as being the catalysts for leveraging knowledge and promoting learning in the midst of migration from paper based records to electronic healthcare records (Delaney, Gonzales, Nagle, Maren, and Heimer 2006). Health informatics standards offer those individuals involved in software development of electronic healthcare records a set of formal guidelines, frameworks and models to guide the development process. Such methods enable syntactic interoperability to be achieved. Currently there are in existence several national and international standardisation 'projects' addressing the need to digitally represent clinical data for integrated care (e.g. EHRcom and OpenEHR). The EHRcom standard will be used in this thesis to

underpin the development of an integrated summary assessment record of care for persons aged 65 and over. The EHRcom standard is adequately suited for this purpose as it is solely concerned with an agreed approach to communicating extracts of information between EHRcom compliant electronic healthcare record systems which is seamless and secure.

The instrument used by EHRcom to communicate extracts of information is called an archetype. Within this thesis an archetype is defined by Kalra (2004) as follows:

*An **EHR archetype** is an agreed, formal and interoperable specification of the data and their inter-relationships that must or may be logically persisted within an electronic health record for documenting a particular clinical observation, evaluation, instruction or action* (Kalra 2004).

Interoperable specifications such as EHRcom can accommodate differing levels of integration and enable syntactic interoperability to occur. In brief this means that the EHRcom specification accommodates two or more systems to exchange information that has the same structure or syntax. It does not however necessarily assure that the meaning will be interpreted appropriately by all parties concerned, for example a healthcare professional that is receiving and interpreting data in a discharge letter. In order for the unambiguous meaning of the message or structure to occur one requires semantic interoperability (Hägglund, 2009).

By including semantic interoperability within the structures or syntax of system design the meaning of the structure can be unambiguously exchanged between all interested parties.

In order to achieve semantic interoperability the use of formalised terminologies is advised (Hoy, Hardiker and McNicholl, 2009). Therefore, to achieve complete integration and understanding of

records between service providers both syntactic and semantic interoperability are required (Mead, 2006).

Whilst achieving syntactic and semantic interoperability will accommodate shared and coherent records meaningful clinical engagement is also needed. Coiera (2003) identifies the merit of approaching system implementation from the socio technical perspective and suggests that the value of electronic health records can only be measured with reference to the social context in which the resource is used and by those stakeholders who utilise it. Early clinical involvement in system design is therefore advised in order to fully understand the context and expertise in which the system will operate.

For this research a decision was made by the author to review the aforementioned topics, and embark on a process of early engagement with clinicians as follows:

- To identify the documentation requirements and context for a summary assessment of the older person for integrated care.
- To validate the semantic interoperability of the identified information requirements.
- To test and evaluate a prototype paper based summary assessment record designed for future development as an archetype which will accommodate syntactic interoperability.
- To build a common understanding of what needs to be measured in patient assessment to inform future theory testing for outcome based research.

The EHRcom archetype framework will offer constraints which will accommodate syntactic interoperability.

The decision to select the older person as the focus for the study is twofold: firstly the increasing global trend of the aging population influenced the decision and secondly, the recognition in the literature base that tools to support integrated care for older persons are now required (Bodenheimer, 2008). In this research the author will utilise the expertise of experienced nurse practitioners to address the research question and objectives. Whilst the information requirements could have been identified by other clinicians the author has a background in nursing and would advocate that nurses are particularly appropriate to define information and communication requirements for patient centred care.

Nurses are described by O'Shea (2009) as the lynchpins of the success of the clinical directorate model in Ireland. If one considers the healthcare workforce in Ireland primarily viewing only those healthcare workers who are directly involved in patient care, i.e. excluding general services and administration roles, nursing and midwifery comprise of 48% of the total healthcare work force in Ireland (O'Shea, 2009, p.126).

### ***1.1 Research Objectives***

In order to deliver clinically appropriate records for integrated care which are underpinned by state of the art EHRcom archetypes and health informatics standards, the author has chosen to approach this thesis in the following way. To explore a number of clinical settings (n=6) which provide care to a purposeful sample of older patients (n=18) and identify key information and communication requirements to facilitate integrated patient centred care between those particular clinical care settings. The research process involves collaborating with a number of experienced nursing practitioners and patients across the acute, primary and continuing care settings in order to gain access to the contexts in which enhanced interagency

communication may occur. Following the completion of the identification of those information and communication requirements, a review of the available formalised concepts and terms will be completed and a taxonomy of the core concepts will be devised. A taxonomy can be defined as a classification of objects (in this case concepts and terms) according to presumed natural relationships among types and their subtypes (International Standards Organisation, 1999). The identified information requirements and the taxonomy will then be mapped to the most appropriate formal terminologies, for example ICNP®, to improve patient centred care and facilitate semantic interoperability.

A key element of this stage of the research process includes defining core concepts to determine a Model of Meaning and Model of Knowledge for future archetype development. This process will be completed in accordance with ISO EN 13606 (CEN, 2009) and is explained in Chapter 4 and Chapter 7. It is important to identify Models of Knowledge to determine future archetype creation which can inform development of EHR. In addition when implemented in clinical practice the archetypes can be used as vehicles for data collection which will inform the testing and development of theory led models for future patient outcome research. Effectiveness models can be used to identify statistical data which has the potential to demonstrate responsiveness to healthcare interventions and provide frameworks for valid and timely data collection; this is a key requirement for the newly formed clinical directorates (Doran et al., 2006; Hannah, White, Nagle and Pringle, 2009; O Shea, 2009). Finally existing health informatics standards and their associated technologies will be critiqued in order to deliver an integrated summary record for patient centred care of the older person. Potentially such data can also be used in partnership with older

persons to inform future health service planning and service provision.

The main research objectives of this study are:

1. To identify the interagency information requirements needed to provide an integrated summary record of care for older persons.
2. To categorise the core concepts (taxonomy) and develop and pilot test a prototype paper summary record to support shared patient centred care.
3. To map the above objectives to EN13606 and a reference terminology to achieve semantic and syntactic interoperability in the form of a set of archetypes.
4. To assist nurses to build a common understanding of what needs to be measured in patient assessment to inform future theory testing for outcome based research<sup>1</sup>.

The research questions are therefore;

Can nurses build a common understanding of patient assessment for future outcomes based research which can facilitate shared care in older persons using action research?

AND

Does an action research approach assist in the development of archetypes in accordance with EN13606?

In order to answer these questions, a mixed method study adopting action research principles of collaboration, education and participation with nurses and patients is used.

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<sup>1</sup> In theory led studies the researcher devises a theory and tests it e.g. what is the relationship between patient mortality and nursing care (see Aiken, Smith and Lake, 1994). Evidence based research does not always show strong relationships between specific sets of interventions and outcomes.

The author critiques a number of research strategies which are described in detail in Chapter 5. In the following section a brief outline of each of the chapters in the thesis is offered.

## ***1.2 Thesis Outline***

To achieve the study objectives outlined above the remainder of this thesis has been organised as follows:

### **Chapter 2**

This chapter offers an overview of information requirements process. It considers those issues and aspects of clinical engagement that need to be taken into consideration in the overall process of requirements and system analysis design in the socio technical context. It concludes with an introductory overview of the associated practice development projects which engaged and informed this study.

### **Chapter 3**

This chapter relates to semantics or meaning of language. It presents an overview of current state of health informatics concepts and terms. It focuses particularly on describing concepts and terms relevant to patient centred care and explores factors which influence healthcare outcomes. It introduces the reader to the bio psychosocial model of care and those related frameworks such as the patient centred care model. This section also offers an introductory overview of those terminologies classifications and datasets which are currently evolving within the sphere of healthcare and which are relevant to nursing and this particular thesis.

### **Chapter 4**

The chapter introduces the reader to syntactic interoperability and health informatics standards relating to Electronic Healthcare Record development. This chapter discusses a number of health informatics standards and those related international organisations which have directly influenced this thesis.

## Chapter 5

This chapter explores the study from an ontological and epistemological perspective. It offers a review of existing paradigms and theories used in healthcare research. It presents a review of current thinking on the merits of using specific ontological and epistemological approaches. It examines research methods and design frameworks from two viewpoints namely research design frameworks to assist in research utilisation and research methods for particular design approaches.

This chapter also includes a critical analysis of the literature reviewed on research and offers an illustration of key decision points relating to method and design as they evolved within this study.

## Chapter 6

This chapter offers an overview of the selected study design and methods. It presents a summary of the course of the action adopted and applied in this study. It explains to the reader the clinical engagement process and offers a brief chronological account of activities which were completed over a two year timeframe. It includes a sample of some of the tangible outputs which have been developed as a direct consequence of the study for example the taxonomy created in phase one of the study. It also highlights the challenges and opportunities that were an integral part of the research procedure and which informed the decision making process. This chapter is supported by two additional Appendices 3 and 4 which present the findings of the study from a practice development perspective.

## Chapter 7

This discussion chapter presents to the reader the draft Models of Meaning and Models of Knowledge for future archetype development in accordance with EN13606. These models will be used to present a graphical description of how the prototype

archetypes were developed in this study. The draft Models of Meaning and Models of Knowledge may be of particular interest to those stakeholders interested in future theory testing for outcome based research.

## Chapter 8

This concluding chapter is a summary of the research contribution made in this thesis. It explores how well the research questions have been addressed and whether the overall study objectives have been achieved. In this chapter the author will discuss the thesis from three particular viewpoints namely health research, practice development within nursing and health informatics particularly in regard to the implications for health informatics initiatives which involve the profession of nursing in the future.

This Chapter concludes with a brief summary of the research contribution that this thesis has made to the domain of nursing and offers a graphical representation of the thesis outline in Figure 1-1 which presents the thesis from the research objectives and outputs viewpoint.

### **1.3 Research Contribution**

#### **1. Nursing Role in Integrated Care**

This thesis offers important insights into existing roles that nurses perform in the acute primary and continuing care sector in Ireland. The conceptual models collated and presented in Appendix 3 and 4 of this study and the prototype archetypes developed identify specific contextual requirements of information for integrated care, which can assist in the delivery of safe and effective patient care for persons aged over 65.

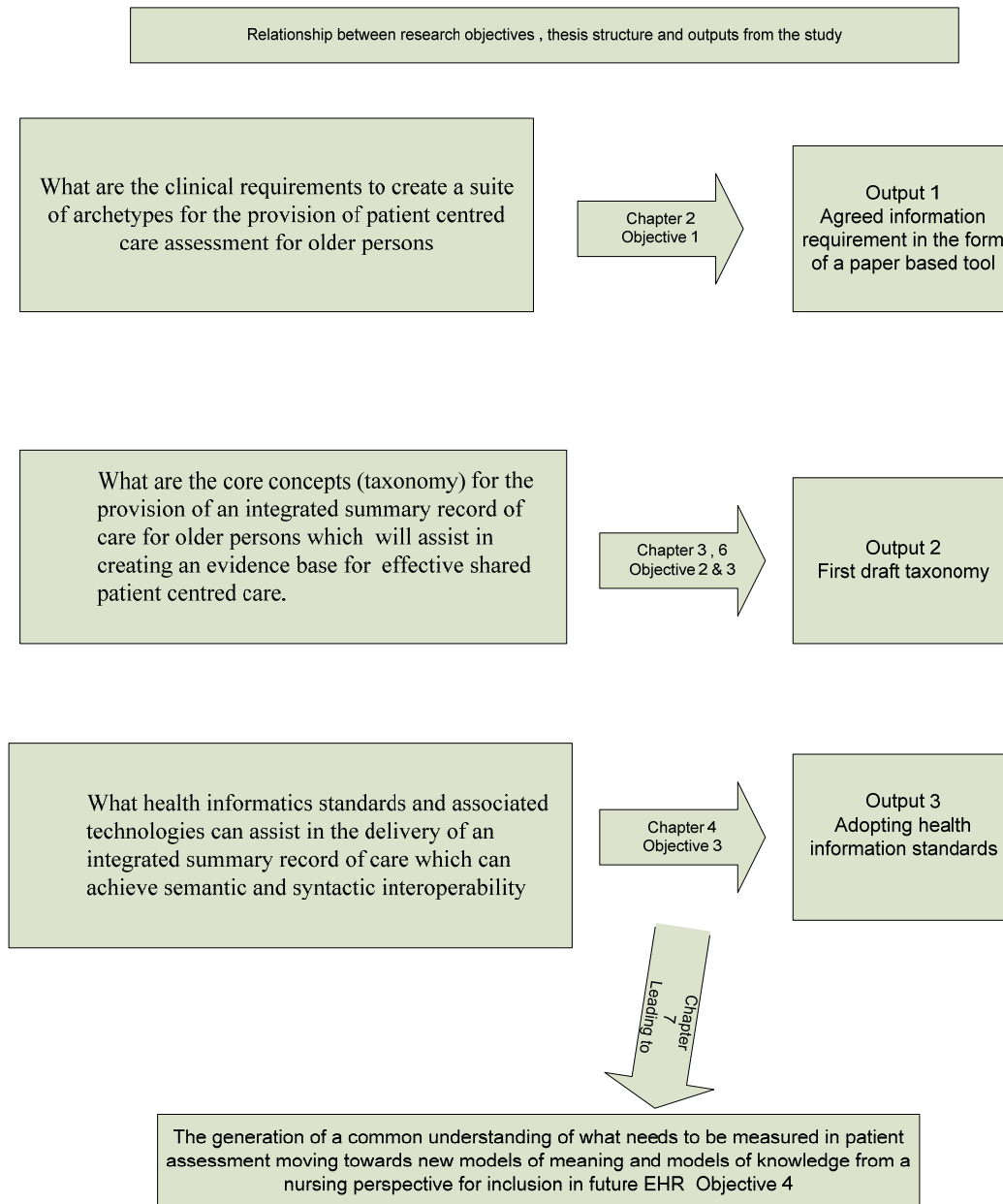
#### **2. The Practical Application of Prototype Archetypes**

The prototype archetypes developed in this thesis for patient assessment has been mapped to existing health informatics standards such as EN13606 and EN13940 and are available for future implementation. Practice development work is already underway in the primary care sector where the prototype archetypes developed in this thesis are to be used to inform core public health nursing assessment tools and patient care plans. A number of meetings have also been held with a national palliative care action research study group which will consider the integration of the archetypes into a palliative care pathway for patients who live with chronic illness.

#### **3. Models of Meaning and Models of Knowledge**

Theory led research is the most appropriate design method to study patient centred outcomes (Doran et al, 2006). In a theory led research study a hypothesis is conceived by the author and tested using quantitative data analysis on a number of coherent relevant factors (Cohen, Holzemer and Gorenberg, 2000). Conceptual models are often used to identify phenomena which can inform the researcher as to what the coherent relevant factors may be in a particular theory

led study. The draft Models of Meaning and Models of Knowledge created in this thesis will be used as conceptual models. Firstly to study outcome based research particularly in relation to patient centred health issues and needs (as opposed to service provision). Secondly the models will be used to educate and train nurses on health informatics specifically in regard to *intention to adopt* and *readiness* which have been identified by the Organisation for Economic Co-operation and Development as principal strategic drivers in successful ICT adoption (OECD, 2010).



**Figure 1-1 Thesis and Study Overview**

## **2. The Information Requirements Process**

### **2.1 Introduction**

The successful implementation of a software system depends primarily on how well it fits with the needs of its users and its environment (Nusieboth, and Easterbrook, 2000).

A basic premise in system design is to ask the question, what is the purpose of the system? It is often at this particular point that the problems start to arise. In order to create a system fit for purpose a clear understanding of the environment and the user's requirements is needed. Effective communication between users and system designers to define the environment and user requirements assists in development of a shared framework of reference from the outset of the development process. The language of the users work is transformed into an abstract formalism for communication purposes with system designers, implementers and users (Robinson and Robinson, 1991, p.224). Careful scrutiny is required in the early stages of planning and defining requirements to ensure that the initial scope and purpose of the system is maintained within the programme brief. Problems with moving beyond the initial scope of systems design can be described as *ontological drift* (Bossen, 2006, p.77).

To avoid such issues the requirements planning process should include key requisites such as persistent user participation, clear functional objectives, and a well defined context (Nytro, Sorby, and Karpati, 2009). A socio-technical approach can be used as it offers a broad framework which encompasses the complex inter-relationships of people and technology (Mate and Silva, 2005). Some authors engaged in defining the information requirements process contend that the knowledge stored in healthcare records is a matter of organisational relevance. Issues such as context, confidentiality and the informal manner in which information sharing occurs within

multidisciplinary teams are factors that are highlighted to require careful consideration (Hardstone, Hartswood and Rees, 2003). This theory is supported by Yamashita, Anda and Sjoberg, (2009), who maintain that contextual factors play an intrinsic role in system requirements design and future maintenance needs.

They suggest that individuals who wish to engage in effective systems design and development must possess a detailed understanding of the user's information needs in association with the context within which this system is proposed to operate.

From a socio-technical perspective the complexity and heterogeneity in clinical patient care suggests that healthcare systems which seek to support clinicians, such as nurses, are required to permit a certain degree of freedom. Such an approach ensures that different working styles and ideas can then be incorporated into the functional design of the clinical systems (van Bommel, 2006). For example in designing shared records such as discharge or transfer letters, users from different service providers may require different functional design elements, all of which will need to be included in the requirements analysis. Strategies to address the complexity of functional design requirements are well illustrated by Sorby, Melby and Seland (2005). One particular study which was found to be constraining and which failed to deliver anticipated benefits within a system was reported by Postle (2002). In this particular study electronic assessment records designed for inclusion in health information systems were reviewed and reported to fall short in their ability to collect information. In most cases the online templates were reduced to linear tick boxes with little or no ability to capture additional patient information.

Historically, within nursing the planning and implementation of information systems have taken limited account of nurses' existing ways of working with information in the information requirements gathering process (Ballard, 2006; Smith, 2000; Graves and Corcoran, 1998). In this chapter, which is illustrative as opposed to exhaustive, the core elements of identifying information requirements for practitioners such as nursing within healthcare are approached from two perspectives. Firstly, the contextual design which includes a review of requirements from not only an institutional view, but also an interpersonal perspective, and secondly the requirements engineering design. There is a degree of overlap between both of these perspectives as the requirements gatherer uses analysis models to help identify the requirements, and the system analyst uses the requirements to help model the functionality and data (Robertson and Robertson, 1999). This chapter will offer an overview of both of these approaches with some selected examples of relevant studies carried out within the healthcare domain included for demonstration purposes.

In section 2.4 of this chapter the author also introduces the associated practice development initiative associated with this particular study entitled PARTNERS and section 2.5 offers a brief conclusion.

## ***2.2 Contextual design***

Contextual design is defined as a “state of the art” approach to designing products directly from designers' understanding of how the customer (user) works in their individual workplace setting (Beyer and Holtzblatt 1999, p.32). In the healthcare domain knowledge is a matter of organisational relevance and therefore of understanding the context in which things are known.

For example, for a patient admitted to an acute care setting following a cerebral vascular event, the social circumstances impacting on the patient's ability to self care in the home will have a direct bearing on their discharge plan. Does this patient live alone? Or does this patient have access to a toilet downstairs? What is the patient's ability to manage his/her medications? Such knowledge needs to be captured and managed not only in a way that will make it accurate, available, accessible and usable, but must also address issues such as patient safety and data security across and between service providers (Hartwood et al, 2003). Clinicians work is characterised as being mobile and often this may involve access to information from a number of different locations. For example access to systems may be required during patient rounds, or at multidisciplinary meetings or at bedside or outpatient activities (Sorby, 2007, p.4). Nursing work is no exception to this particular rule. Contextual design is therefore an important element in nursing requirements analysis. It can offer a suite of tools to the project that can facilitate the collection and interpretation of those critical elements of user data. The contextual design process therefore can incorporate a number of methods which are exercised to gain a deeper understanding of what the user's real needs are. Contextual design deals with mainly front end design requirements and offers a useful framework to map the entire design process for all stakeholders engaged in system development (Beyer and Holtzblatt, 1999). Parts of contextual design include contextual inquiry, work modeling, consolidation, work redesign, user environment design and user mock up and end user testing. Each of these elements is now briefly outlined in the following sections.

### **2.2.1 Contextual Inquiry**

Contextual inquiry is a process engineered for understanding who the users are, and how they work on a daily basis. The contextual inquiry step usually involves one to one field interviews in the workplace environment to gain insight into the user's motivations and strategy for completing various working practices. Team interpretation sessions are also completed for the group to gain a more holistic overview of the working programme. During these sessions the team captures issues and draws work models to facilitate a shared view for all users' information needs and also to make evident just how the data is being shared and interpreted by all of the users involved in the programme (Ballard, 2006). A key element of the contextual inquiry process is devising lists of roles that users may assume when they are interacting with the system. For example what are the jobs of the people who might use the system; what other roles may they have? In nursing this may include ordering tests, reviewing test results and identifying where people will be located when they are interacting with an order communications system (Robertson and Robertson, 1999). This process is often referred to as elicitation in the requirements engineering process and this will be discussed further in the section 2.3.1.

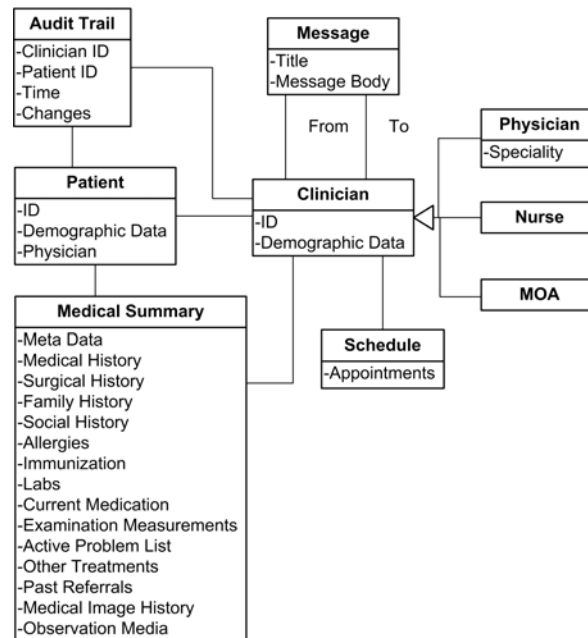
### **2.2.2 Work Modelling**

Work models are identified by a number of authors as a convenient and compact way to represent a user's work (Beyer and Holtzblatt, 1999; Yamashita et al, 2009). The notion of representing the information from a picture perspective facilitates the ability on the part of the reader to scan the information rather than read the textual data.

Such initiatives also assist in moving from knowing the work of the individual to understanding the structure for all of the stakeholders involved in the contextual design process. This information can then be used to offer guidance on designing an interface to support the task. Five different models are identified by Beyer and Holtzblatt (1999) for inclusion in work modeling:

- a) The flow model demonstrates communications and co-ordination.
- b) The cultural model shows culture and policy.
- c) The sequence model shows the detailed steps performed to accomplish the task.
- d) The physical model which depicts the physical environment.
- e) The artefacts model shows how artefacts' are used and structured in undertaking the work.

Figure 2-1 demonstrates a cultural model relating to stakeholder policy in regard to access to patient information by role definition which has been designed by Gurses et al (2005) to reflect cultural norms and access in one particular healthcare setting. The cultural model identifies each of the core concepts which have particular elements listed such as clinician identity (Clinician ID) and the arrow in the model depicts the relationships between the core concepts. For example one can see from the model that both nurses and physician have access to patient data and they are linked to an audit trail which includes clinician identification numbers.



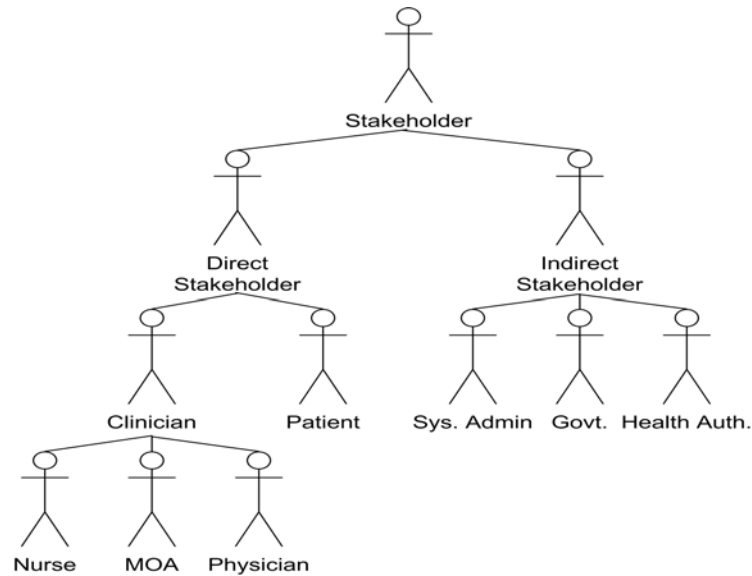
**Figure 2-1 Cultural Model Relating to Access by Role**  
 Source Gurses et al, 2005, p. 6

### 2.2.3 Consolidation

Consolidation collects data from all of the users so that all of the stakeholders involved in the contextual design development process can see the common patterns and structure without losing the individual variations identified in the modelling phase. This process usually includes an affinity diagram which maps issues and insights across all stakeholder groups, and a set of consolidated work model diagrams which offer a single view of how the system will function as a whole. Such diagrams are used to guide the overall system focus and include the business actions and delivery mechanisms in the system design (Beyer and Holtzblatt, 1999, p.36).

If the contextual design process is focused on a single task or element of a system, designing and building story boards is often a method used. Alternatively moving straight to paper prototypes is also suggested as an appropriate method. An example of a study which incorporates elements of the application of consolidation methods within the sphere of nursing is evident in the work of Ballard (2006a, 2006b). The identification of system requirements according to Ballard must work from the assumption that people's perception of the working world will vary and the preferences for addressing problems such as discharge planning needs will differ.

Ballard (2006a) approaches the discharge planning process from a system perspective and adopts a soft systems approach to the requirements analysis to address the complexity of human activity involved in the process of discharge planning. In this particular study the systems methodology supported the effective analysis of the requirements process and accommodated reasonable conclusions to be drawn through the development of rich pictures and conceptual systems development (Ballard, 2006a). Figure 2-2 illustrates stakeholder role taxonomy as a model diagram from the Gürses et al (2005) study which relates to the identification of confidentiality requirements for a particular healthcare project entitled Technology Assisted Practice Application Suite (TAPAS) from a Western Canadian Province.



**Figure 2-2 Stakeholder Role Taxonomy**

Source – Gürses et al, 2005, p. 106

In Figure 2-2 the confidentiality roles are arranged in taxonomy in order to facilitate the definition of confidentiality requirements (Gurses et al, 2005, p.106).

#### 2.2.4 Work Re-design

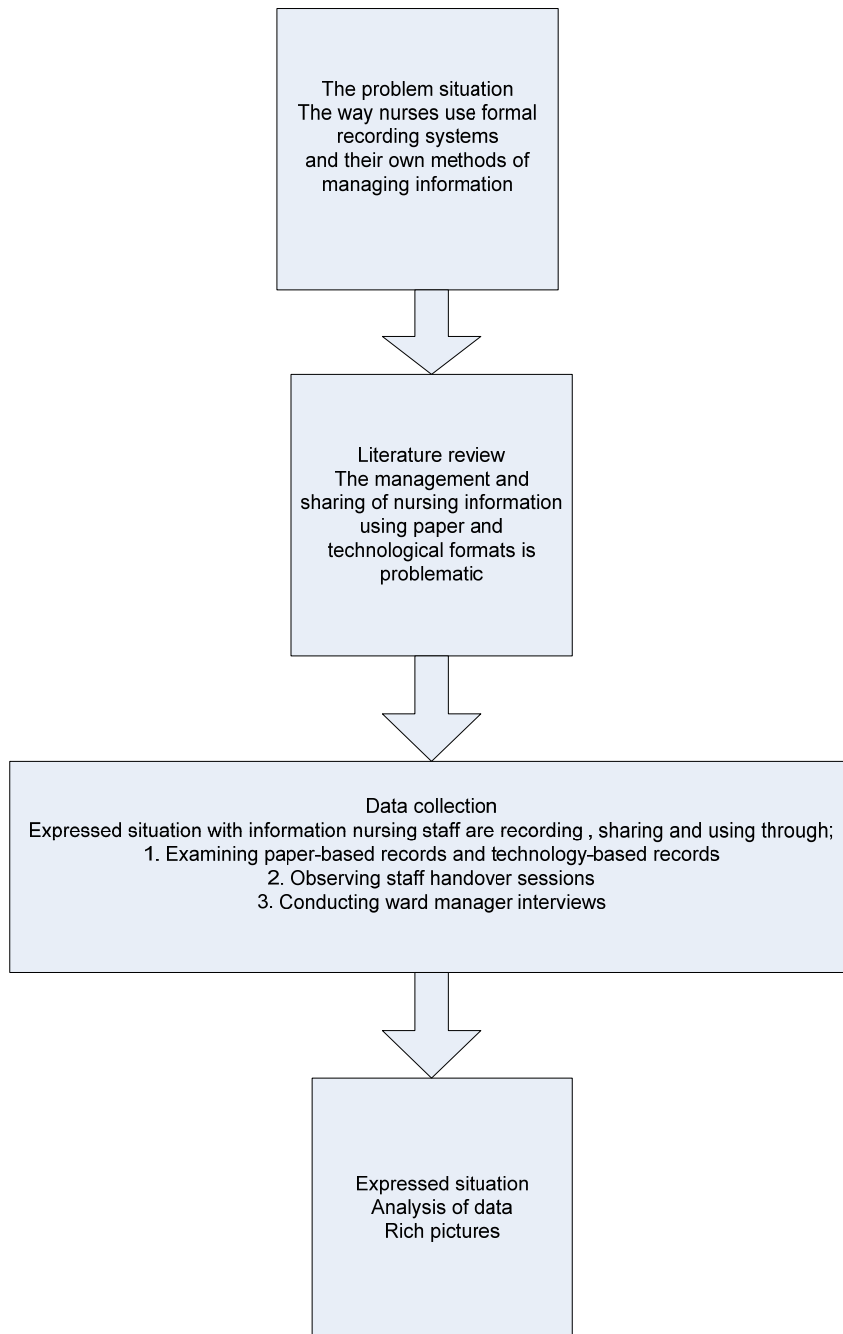
The work re-design focus is on improving working practices and not solely on delivering technology and ensures that the systems, business alliances and services fit into the users overall work practice. It also collects and integrates ideas on contextual design from the whole team. The work re-design process relates to considering how technology can improve the work and includes taking into consideration how the technology will impact on the user's working lives. One example of work re-design from the healthcare domain is the Quality Enhancement Research Initiative (QUERI) completed in the 1990s by the Department of Veteran Affairs (VA) in the United States of America which incorporated the Stetler Model (Stetler, 2001).

The practitioner orientated Stetler Model was first devised in 1976 but was refined in 1994 and is currently in use as an organising framework for evidence based research projects (Stetler, 2001; Stetler, McQueen, Demakis, and Mittman, 2008). Developing a clinical practice model which enhances the delivery of comprehensive, evidence based, collaborative and patient centred care is the stated main goal of the Stetler framework (Stetler, 2006). The QUERI programme devised a key operational structure with a guiding framework. The design brief was to enhance implementation of research for diagnosing and closing quality gaps and simultaneously advancing implementation science (Stetler et al 2008). QUERI was created as part of the transformation of the Veteran Affairs (VA's) healthcare delivery system. The re-design process involved a major reconfiguration of organisational structures and policies including implementation of innovative information technology and a new performance management accountability programme (Oliver, 2007). Three key contextual elements which informed the evidence based organisational framework and support work redesign to include information systems were:

- a) Cultural norms and values including the role of the researcher in evidence based quality improvement.
- b) Capacity amongst researchers and key partners to engage in the implementation research.
- c) Supportive infrastructures to reinforce expectations for change and to sustain new behaviors as part of the norm (Stetler et al., 2008).

### **2.2.5 User Environment Design**

The focus of the user environmental design process is to capture what the actual system does. It accommodates the planning process and maintains a focus on the entire system not just any one particular part of the system design process. It captures the structure, function and flow of the system often adopting methods such as use case and scenario building and analysis of existing documentation practices. However some authors suggest that this approach does not always capture the variations and the different contexts of use and advocate field studies including observation as the preferred alternative approach, particularly when designing socio-technical systems (Sorby, 2007). A socio-technical approach is defined by Mate and Silva (2005) as a complex inter-relationship of people and technology including hardware, software, data, physical surroundings, people, procedures, laws and regulations (Mate and Silva, 2005). For example in a study completed by Ballard (2004) the author identified that ward nurses continued to use established ways of working alongside a newly implemented computer systems rather than fully adapting working practices to computer systems in the workplace. To address such issues a further study in 2005 was completed by Ballard which is briefly discussed in this section (Ballard, 2006b). The 2005 study by Ballard adopts an action research methodology using a socio-technical approach to explore the complex organisational issues relating to the ways in which nurses work with information at ward level. Figure 2-3 offers a brief overview of the approach adopted which was adapted from Checkland (1981).



**Figure 2-3 Ballard's Framework Adapted from Checkland**  
Source – Ballard 2006b, p51

Figure 2-3 presents phase one of a soft systems approach adapted by Ballard from Checkland (1981) which establishes a space for discourse with nurses in which to consider how complex organisational issues can be enhanced using electronic information systems.

### **2.2.6 User Mock Up and Test**

The user mock up and test process finds and fixes errors in the new design before any commitment to large scale implementation has occurred. Within the domain of healthcare an example of user mock up and test process was reported by Boosen (2006a) when one region in Denmark tested an early prototype system which included a basic structure of an electronic healthcare record. A total of 120 clinicians (users) were given 12 hours training and then asked to test the prototype in one healthcare region in Denmark. Initially the prototype was recalled due to problems such as bugs and speed; however a second test period was carried out with 66 patient encounters later in the year. The clinician's findings of the mock up and test for the second phase of testing concluded that the prototype did not support daily practice. Issues such as fragmentation of patient cases and the process of balancing the co-ordination function and the accountability function led the clinicians to conclude that the system required further refinement. Beyer and Holtzblatt (1999) suggest testing a paper prototype prior to commitment to code is a useful method to test the structure of the new system in the user environment design. Furthermore it can facilitate testing of the initial user interface ideas prior to commitment to code. Paper prototypes support continuous iteration of the new system development and ensure that the design is faithful to the users needs.

Refining the design of a system with users gives designers a customer centred way to resolve disagreements and work out the next layer of requirements (Beyer and Holtzblatt, 1999, p.40). Furthermore users often prefer paper prototypes because they give them the opportunity to understand a new design and contribute to the design process throughout the course of the system development cycle.

### ***2.3 The Requirements Engineering Process***

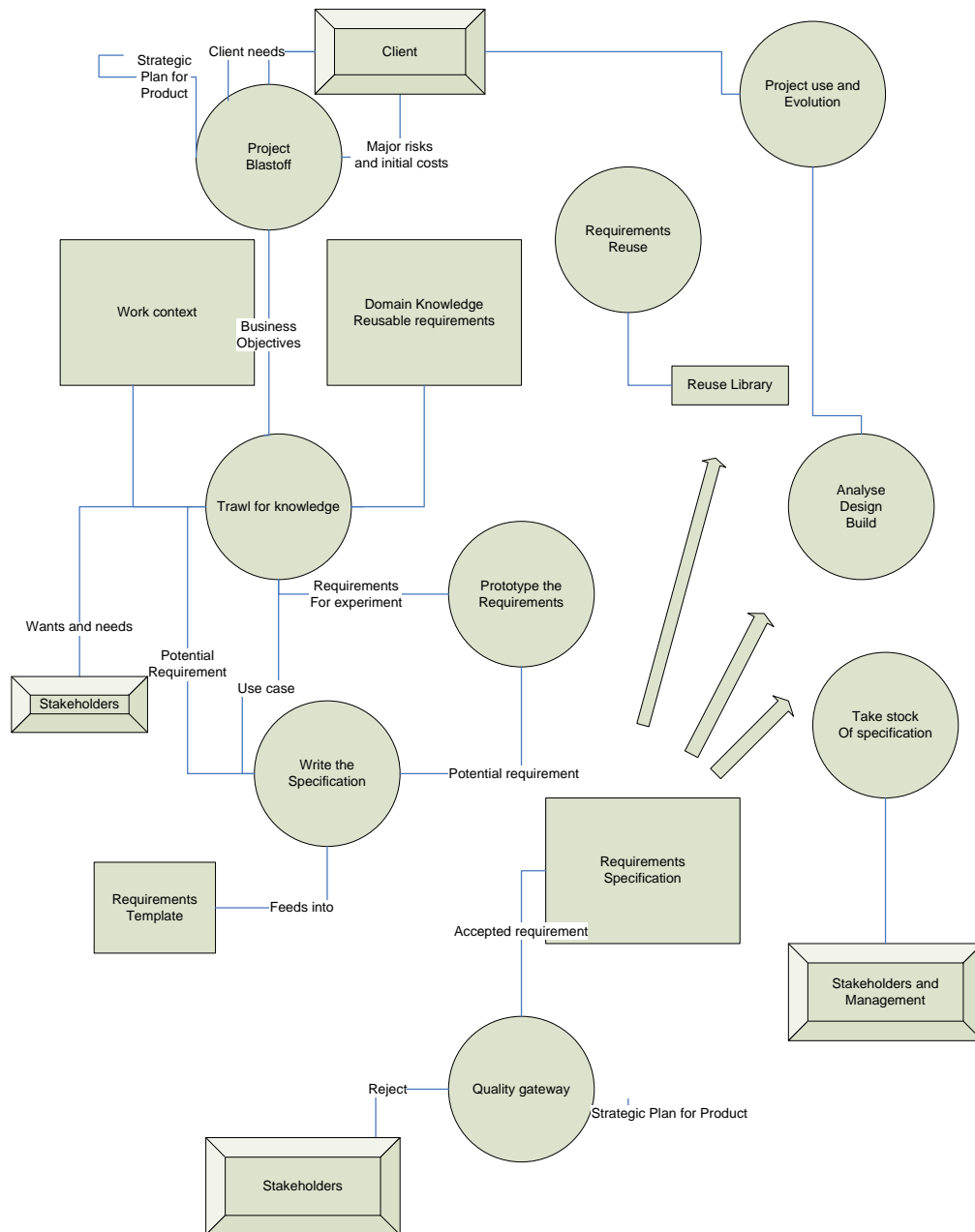
The requirements engineering process is defined by Robertson and Robertson (1999) as a method in which to find a way around the generic requirements gathering process. A requirement is something that the system must do or a quality that the product must have. Usually a requirement exists either because the type of system demands certain functions or qualities, or the client wants that requirement to be part of the delivered system (Robertson and Roberson, 1999, p.5). It is advised therefore that requirements engineering should include a set of functional and output based specification documents (Macaulay, 1994).

Requirements descriptions are also useful to include in the requirements engineering process, according to Cheng and Atlee (2007) they are ideally written entirely in terms of the environment and can offer descriptions of how the environment is to be affected by the proposed system implementation. Requirements descriptions (as opposed to technical specifications) offer a more simplistic explanation as they state what the requirements engineering is about by defining precisely the problem that the software is to solve. In the requirements analysis phase the process of refinement must progress from an ill defined notion of what the proposed system is to do to a single detailed technical specification.

There are therefore many options to consider and decisions to be made about requirements analysis progression and how to complete the process. Different authors can and do approach the process from different perspectives.

For example Robertson and Robertson (1999) recommend the Volere process identified in Figure 2-4 as an optimum method to determine gathering verifying and documentation requirements. This method is comprehensive in nature and involves a number of approaches to requirements definition which include stakeholder, business and technical perspectives. One interesting addition to the Volere process is the inclusion of a quality gateway to reject or accept additional requirements proposed by stakeholders. Garde and Knaup (2006) stress the importance of a domain driven methodology to systems requirements definition; this approach ensures that the domain model and overall design of the software system is developed iteratively using a grounded theory research method.

Alternatively a more formal approach is proposed by Cheng and Atlee (2007) who suggest that a classification structure be used in requirements engineering process. This approach is structured into 5 types of requirements tasks. These tasks are elicitation, modeling, requirements analysis, validation and verification, and requirements management. Interestingly Cheng and Atlee note that requirements engineering design should also include evaluation based research as an integral element of requirements engineering design process. To demonstrate the requirements engineering process each type of the requirement engineering process as described by Chen and Atlee (2007) will be discussed briefly in sections 2.3.1 to 2.3.5.



**Figure 2-4 Volere Requirements Process**  
 Source - Robertson and Robertson, 1999, p.11

### **2.3.1 Elicitation**

Requirements elicitation comprises of activities that enable the understanding of the goals, objectives and motives for building a proposed software system. The process of elicitation includes identifying the stated goals, objectives and motivations that the resulting system must satisfy in order to confirm that the requirements engineering process has been successfully accomplished. It can involve a number of techniques which are similar in nature to the contextual design process and for this reason there appears to be some overlap between these two processes. Cheng and Atlee (2007) identify the following list of techniques from the literature base:

- a) Identification of stakeholders impacted upon by the software implementation,
- b) Analogical techniques deep analysis to identify precise requirements,
- c) Contextual and personal requirements engineering techniques,
- d) Techniques for inventing requirements such as brainstorming or workshops,
- e) Feedback techniques which include model animations, simulations and storyboards.

Davis et al (2006) reported on a systematic review of empirical studies concerning the effectiveness of elicitation techniques, and the empirical evidence gathered from those studies. In this review the technique of interview, preferably structured, is noted to be one of the most effective elicitation techniques. Whilst think aloud or card sorting were reported upon they tended within the individual studies to be less effective.

Nytro, Sorby and Karpati (2009) advocate observation as a key method in requirements engineering and note that whilst it is often used in the early requirements elicitation process for domain modeling and stakeholder identification it can also be used as a source of domain knowledge during the iterative requirements engineering process. The authors suggest that a) observations without explicit design objectives may give answers to important design queries, b) non participatory observation may be used as an initial survey method, and for later iterative requirements development, and c) observations may be used repeatedly in iterative design by treating (new) software systems and prototypes as observable actors (Nytro, Sorby, and Karpati, 2009, p.70).

### **2.3.2 Modelling**

In the modeling phase of the requirements engineering process, data collected can assist in raising the level of abstractions in requirements descriptions. The requirements specification can be expressed in one or more models. The models devised in this particular stage of the requirements engineering process tend to be more comprehensive than in the elicitation process offering a tool to communicate the specific requirements to the development team. There are, as is the case in the elicitation process, a number of modeling techniques that can be used in the requirements engineering process; for example there are modelling strategies which provide guidelines for structural modeling such as RE reference models (Guntar et al., 2000). The reference model for requirement and specification documents deconstruct the requirements related descriptions into the stakeholder requirements, the specification of the proposed system, and assumptions made about the systems environment (Cheng and Atlee, 2007).

Alternatively, Yamashita et al (2009) suggest concept mapping is an effective method to incorporate contextual information in the development of software engineering constructs. By using expert judgment in the conceptual mapping process to identify different attributes and dimensions expert knowledge can provide more realistic interpretations of the technical requirements and properties of a system. Concept mapping is a method commonly used in social research to plan and evaluate programmes' overall effectiveness (Pawson and Tilley, 1997; Rossi et al, 2004). From a software engineering perspective the process involves a series of steps as outlined in Table 2-1.

**Table 2-1 Conceptual Mapping Requirements**

Source - Yamashita Anda and Sjoberg (2009)

<b>Conceptual Mapping in Requirements Engineering</b>	
Preparation	Selection of participants and definition of the conceptualization in order to generate statements about the domain.
Generation of statements	The development of a set of focused statements generated using focus groups and qualitative textual analysis.
Structuring of statements	The statements are given to the participants on cards and the participants arrange them in the most sensible arrangement according to the individual domain. Each statement is rated using a Likert Scale.
Representation of statements	In the representation stage the grouping and rating input is presented pictorially using statistical analysis such as 2 dimensional scaling and hierarchical cluster analysis.
Interpretation of concept maps	The facilitator works with the participants to assist them to deliver their own labels and interpretations for the different maps.
Utilisation of concept maps	The maps can be used as a visual framework to implement or evaluate a programme. They can also be used as a basis for developing measures and displaying results Each cluster can be seen as a construct and individual statements can suggest specific operations of that construct.
Outputs	Several artefacts are created from the concept mapping process.

### **2.3.3 Requirements Analysis**

In the requirements analysis phase the focus is on new or improved techniques to evaluate the quality of the recorded requirements. The analysis process seeks to identify errors in the stated requirements such as ambiguity or inconsistencies or incompleteness. Other analysis looks for unknown interactions amongst requirements or potential obstacles to requirements satisfaction (Cheng and Atlee, 2007).

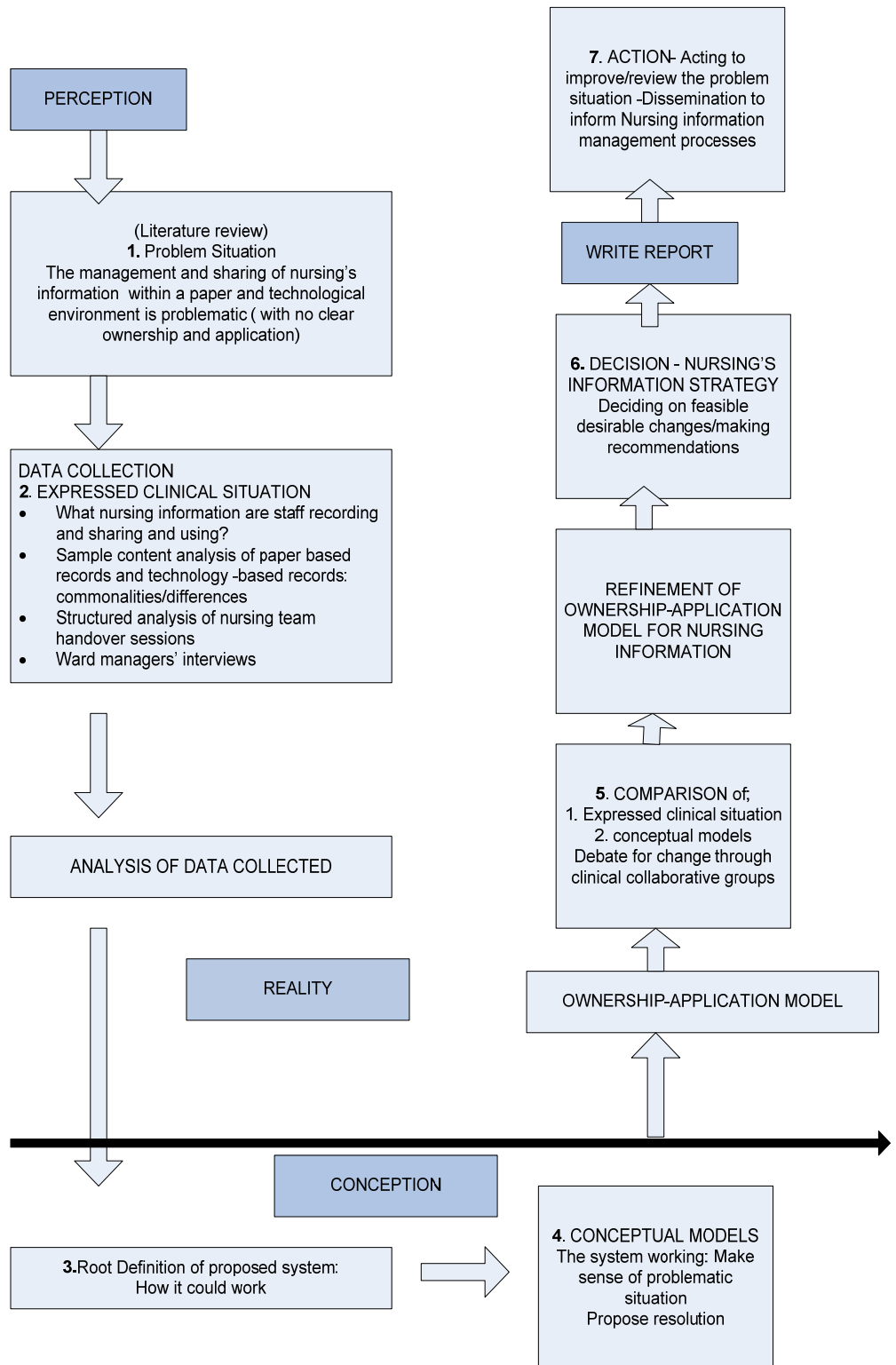
The requirements analyst is often described as the translator and must consider key talents such as observing and learning the work from the point of view of the user, interpreting the work and in some cases inventing better ways to do the work and recording the results in the form of a requirements specification and a series of analysis models (Robertson and Robertson, 1999, p.81). Observational studies are noted as an effective method for understanding clinical needs of users and to accommodate analysis of communication behavior amongst healthcare workers (Coiera and Tombs, 1998). An early non-participant observational study by Kennedy (1999) cited in Ballard (2006b) which explored communication during handover in a United Kingdom hospital ward reported that nurses continued to use pocket notes as an information resource to meet information management requirements relating to patients after a new system was implemented.

Ballard (2006b) suggested that migrating handover to electronic record keeping may address this issue of duplication and accommodate additional opportunities for information sharing.

In order to ensure the requirements for information management of a nursing environment were appropriately integrated into existing working practices Ballard (2006b) adopted a soft systems framework approach phase one of which is included in Figure 2-5.

Cheng and Atlee (2007) also recommend that the requirements analysis process should also include risk analysis and impact analysis. One approach that can serve to minimise risk whilst developing user-friendly system applications for the healthcare setting is to move towards a human centred design implementation process.

One of the key principles of a health informatics standard EN ISO 13407, 1999 entitled “human centred design” is to ensure the active involvement of users and a clear understanding of user and task environments (EN ISO 13407, 1999, p.2). Sorby et al (2006) demonstrates the use of this standard well by creating a purposeful framework for structuring and analysing scenarios and adopting a systems development approach through drama improvisation. The framework included field work which included observation identification of input and output attributes, creation of scenarios based on the initial observation study and a series of workshops with end users. The workshops were held in a simulated environment of a hospital ward, and doctors and nurses drama improvisation techniques were used to act out the scenarios. The net result of this process was a revised set of requirements for a mobile electronic patient record.



**Figure 2-5 Ballard's Exploring Nurses Environment**  
Source - Ballard, 2006b, p.50

### **2.3.4 Validation and Verification**

The validation and verification phase ensures that the models and documentation accurately express the stakeholders' needs. This process usually involves stakeholder's direct involvement in reviewing the requirements artefacts and may include simulations (Cheng and Atlee, 2007). A simulation can often involve a prototype which can assist users to play out the consequences of the requirements engineering process. Sorby's work discussed in section 2.3.3 is one example of using simulation as a validation and verification process through drama improvisation. However only a small number of scenarios can be used in a simulated environment and the author cautions on selection of sample users as representative of "average" users (Sorby et al, 2006, p. 72). Additionally, prototyping can be expensive and it is suggested that prototyping can be reserved for particular situations. For example in cases where a system has not existed before and it is difficult for the users to visualise or experience working with the system or the proposed technology this may be the preferred approach (Robertson and Robertson, 1999, p.203).

### **2.3.5 Requirements Management**

The requirements management technique is an umbrella activity that involves a number of tasks related to the management of the requirements including the notion of evolution of the requirements over time. This process includes techniques to ease and partially automate the task of identification and traceability links among requirements artifacts and downstream artifacts (Cheng and Atlee, 2007).

## **2.4 PARTNERS Project**

The research presented in this thesis has been conducted as part of a practice development initiative entitled PARTNERS. This study also informed a health informatics project entitled EHRland. The term PARTNERS is an acronym for Participatory Action Research To develop Nursing Electronic Resources. This title represents a group of practicing nurses who are employed in Dublin North East of the Health Services Executive (HSE).

To complete this study the author of this thesis was awarded funding from the National Council of Nursing and Midwifery to focus on defining the information requirements to enable inter agency communication across the acute, primary and continuing care sector. The study also included an exploration of how health informatics standards and formalised language, concepts and terms could assist nurses in facilitating shared care practice particularly in regard to clinical assessment for persons aged over 65. The focus of the EHRland study was to test a European standard for shared communication of electronic healthcare records (EN13606) entitled EHRcom. Central to this particular standard is the development of archetypes which are purposefully built templates that accommodate semantic and syntactic interoperability. An example of an excerpt from an archetype definition language is included in Chapter 4.

Figure 2-6 illustrates both the paper based prototype used in the pilot study and the electronic application designed in accordance with the archetype definition language for data collection. The examples presented in Figure 2-6 were used in this study in the following manner. The paper based prototype was used by the nurses participating in the study to collect patient assessment data across and between the different participating services.

The electronic data entry application and associated database was then used by the author of the thesis to retrospectively compile the data collected by the nurses for the duration of the pilot. The electronic application and associated database were held on a single laptop which was encrypted. This particular process of data collection was recommended by the Ethics Committee who approved the study. Analysis of the data collected in phase one of the study is used to refine the archetype tool development process.

Example Paper Based Form

10 Symptom Management A= 1 Assessment B= Return in repeat assessment C= Change in Status D= E= T/F out F= Routine Quarterly												
Assessment type	A											
Measurement Date	01/01/09											
Insert code for Fall in table below on Falls 1= Never 2= Rarely 3= Often 4= Risk for fall is high 5 Risk for fall is low												
Falls	2											
Risk for Falls is	5											
Insert code for Pressure ulcer / skin integrity PU 1= PU Stage 1 2= PU Stage 2 3= PU Stage 3 4= PU Stage 4 5= None 6= At risk												
Pressure Ulcer / Skin Integrity	6											
Insert code for continence below 1= None 2= Partial 3= Total 1= Intermittent C= Continuous												
Continence is	2											
Continence (Int or Cont)	1											
Insert codes for Constipation 1= None 2= Actual if actual 3= Partial 4= Total												
Constipation (problems with)	2											
Extent of Constipation	3											
Insert code for nutrition below 1= Nutrition in normality state 2= Abnormal state If abnormal then refer to dietary assessment												
Nutrition	1											
Fluid balance is 1= Normal state 2 Abnormal if 2 then select from following list 3= Deficit in fluid volume 4= Excess fluid volume 4= Fluid and electrolyte imbalance 5= Fluid retention												
Fluid Balance	1											
Abnormal status is	---											
Insert code for breath/days 1= Dyspnoea none 2= Functional Dyspnoea low 3= Functional Dyspnoea high 4= Resting Dyspnoea												
Breathing / Dyspnoea	3											
Insert code for Weakness and Fatigue 1= Fatigue none 2= Fatigue low 3= Fatigue Moderate 4= Fatigue high 5= Fatigue extreme												
Weakness / Fatigue	3											
Insert code for Nausea below 1= None 2= Low 3= Moderate 4= High 5= Extreme												
Nausea	1											

Example Data Entry Form

Assessment date:

Source of referral service detail

Remove Source of referral service detail

Source of referral

Remove Source of referral

Acute CIT ▼

Add Source of referral

Assessment type

Remove Assessment type

A - First Assessment ▼

Add Assessment type

Figure 2-6 Examples of Prototype & EHRLand Archetype

Key principles that the author wished to address from the outset were that the design brief of the archetype used a strong contextual design approach (research objectives 1 and 3). By conducting the study from this particular perspective the author could explore what the nursing information requirements are to enable shared care to occur whilst maintaining a patient centred orientation to the overall design.

The net result of this study and the interaction between the EHRland and PARTNERS projects was an action research programme which involved two action cycles and phases of development. Phase one devised a prototype summary assessment discharge/transfer template and pilot tested the prototype in paper format. In phase two of the study data from the pilot of the paper prototype and an evaluation of the pilot study was then used to inform the development of a set of archetypes for future electronic communication exchange to facilitate shared care. From a contextual inquiry and information requirements perspective a brief summary of the various methods adopted is now included in conclusion to this chapter.

## **2.5 Conclusion**

This study uses an adaption of Ballard's (2004; 2006a; 2006b) contextual design soft systems framework approach in phase one of the study. This includes exploration of the individual nurse's expression of their individual clinical situation, defining workflow processes, and the content analysis of paper based records currently in use. From a requirement engineering perspective the work of Sorby, Melby and Nytro (2005) is adapted, adopted and used as a model to test the initial requirements engineering of the tool. Figure 2-7 offers an image of the drama improvisation that was carried out by the PARTNERS group.



**Figure 2-7 PARTNERS Simulation Testing**

Beyer and Holtzblatts, (1999) contextual inquiry approach was used to pilot test the initial prototype tool in paper based format to accommodate continuous iterations of the new summary integrated record template. Appendix 1 demonstrates examples of outputs from this particular contextual inquiry and the requirements engineering process. Drawing on the work of Yamashita et al (2009) and Pawson and Tilley (1997), the planning and evaluation of the initial paper prototype was completed using conceptual models. This approach is noted as an effective method to incorporate contextual information in the development of software engineering constructs. In this study data analysis on focus group discussion with experts was used in the conceptual mapping process. This data was analysed in association with the patient assessment data collected from the paper prototype pilot study to inform the creation of a Model of Knowledge and Model of Meaning to inform future theory led outcome research and archetype development. The conceptual modeling process also provides the author of this thesis with more realistic interpretations of the technical requirements and properties of a system from the various individual nursing information contexts which were explored within the study.

### **3. Concepts, Terminology and Healthcare Outcomes**

#### ***3.1 Introduction***

The core topics which form the basis of this literature review relate to three key areas: firstly exploring 1) system requirements and contextual design, which has been discussed in Chapter 2, secondly 2) semantic interoperability and thirdly 3) syntactic interoperability. In chapter one of this thesis Mead (2006) identifies semantic and syntactic interoperability as key requisites to achieve complete integration and understanding of records between service providers. In this chapter the author considers issues relating to semantic integration which underpins the process of communicating shared documentation across and between differing healthcare settings. Syntactic interoperability will be discussed in Chapter 4. The word semantic relates to the study of meaning (Wordnet). In order to achieve semantic integration, the communication process that underpins electronic records development, needs to adopt a standardised structure and syntax of words in documentation. In this chapter semantic integration is critiqued from the perspective of formalised clinical concepts and terminology. As a key focus of this thesis is new Models of Meaning and new Models of Knowledge for future theory led research on patient centred outcomes, formalised concepts and terms that can be used to measure patient centred outcomes and support semantic interoperability will be explored. Section 3.2 addresses the research objectives of the thesis by considering what concepts and formal terminologies will assist in making evident shared patient centred care assessment criteria particularly in regard to the domain of nursing.

Section 3.3 will review data sets and in particular the role of the minimum data set within the sphere of nursing. Section 3.4, which is the largest section of this chapter, considers outcomes from three perspectives: 1) service process outcomes; 2) change and 3) maintenance outcomes; and finally section 3.5 reviews models and frameworks for outcomes data collection. As is the case in Chapter 2 there is a degree of overlap noted between the topics within the evidence base and this is apparent in the different sections.

### ***3.2 Concepts and Terminology***

An integral part of demonstrating the evidence base is the need for, and the importance of, consistency in data definitions and measurement tools. Such resources can facilitate the development of records for healthcare professionals which can provide reliable timely and valid data for clinical judgement and decision making (Hoy et al., 2009; Haberfeide et al., 2005). A pre-requisite for the delivery of valid reliable and timely data is therefore semantic interoperability which is underpinned with formalised concepts and terminology (Hoy et al 2009; Mead, 2006).

Early abstractions which were implicit in the development of concepts and terminology date back to the time of Plato's articulation of a perfect form. However it was Aristotle who introduced the notion that abstract concepts represent descriptions, or more properly definitions, of things that have been classified by describing their attributes (Chute, 2000, p.298). Classifications and nomenclatures can be regarded today as lying along a continuum. Classifications are developed in order to categorise concepts and to form a framework in which to aggregate language. Whilst nomenclatures have been devised to support classifications by introducing detailed descriptions of the concepts themselves (Chute, 2000, p298).

A classification is defined as the act of distributing phenomena into categories of the same type; for example the American Nursing Interventions Classification (NIC) consists of a comprehensive standardised set of interventions that nurses perform (McCloskey and Bulechek, 2000, p.3). A nomenclature is classified as a system of terminological phrases elaborated according to pre-established naming rules, to produce an explicit list of systematic names (CEN).

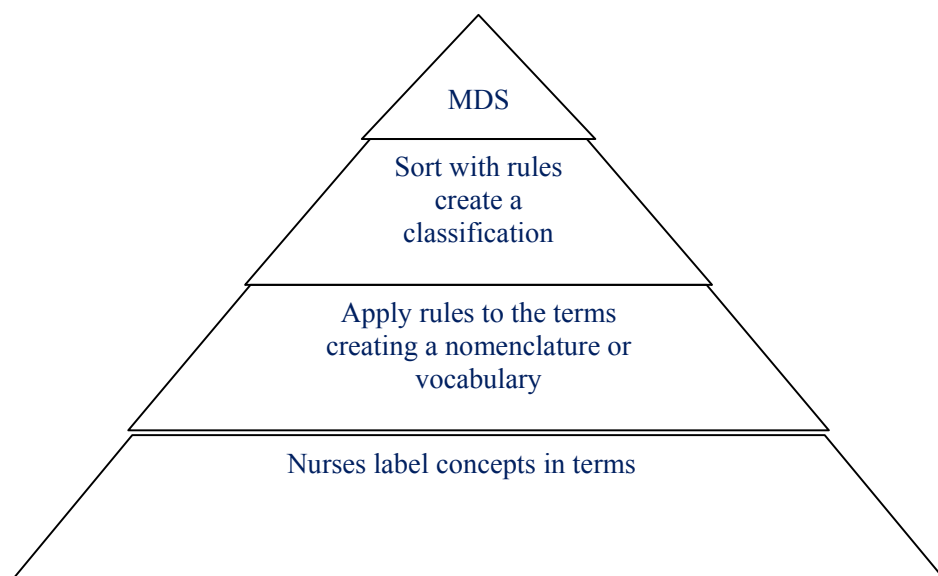
The most well known nomenclature is SNOMED which is an acronym for *Systematic Nomenclature of Human and Veterinary Medicine*. This resource is a general purpose computer process terminology which is meant to represent all of the events found in the medical record. SNOMED is multi-axial which infers that the concepts can be combined in numerous and various ways. SNOMED was originally developed by the College of American Pathologists and later merged with Read Codes in the United Kingdom to deliver a more comprehensive nomenclature.

Today the governing body which manages SNOMEDCT which contains an estimated 400,000 concepts is the International Health Terminology Standards Development Organisation (IHTSDO) (Oakes, 2007). According to Rolfe (2007) a review of classification systems and existing information systems deployed within nursing, whilst a useful set of resources, is failing to address the less tangible aspects of nursing work to date, such as decision making particularly in relation to the process of patient assessment. This has a direct bearing on overall quality of patient care. He notes that such information systems explored in a number of studies emphasise the importance of and classification of staff output and measurement of adverse patient outcomes. Rolfe (2007) suggests that direct line managers may very well be approaching the use of information systems from a negative orientation, for example planning and scheduling skill mix.

This may have an unconstructive impact on patients and staff alike particularly in regard to relationships concerning care provision. He maintains that the process of use of such information systems is a complex three way relationship between managers, clinical staff and patients (Rolfe, 2007 p. 471).

Within the profession of nursing, staff outputs are primarily measured according to patient care, although nursing is engaged in a number of indirect nursing interventions which relate to service provision e.g. supervision of students or stock ordering. The documentation procedures that nurses engage within are predominantly related to patient care. This documentation of patient care can be viewed as three discrete classes of information classified during the care process, namely diagnosis, interventions and outcomes (Hannah et al, 2009). In Ireland the nursing profession use a number of nursing models to document patient care, for example the Roper Logan and Tierney Model or the Orem model (MacNeela Scott, Treacey and Hyde, 2006), however a key element of the documentation process is to assess and record the current state of a patient's health over a series of particular time intervals. The use of classifications and nomenclatures within nursing models has been slow to evolve in Ireland. This may be partly due to the fact that the design of nursing models in their existing state does not fit well in EHR design and have been noted to be potentially problematic (Collins, 2009).

Figure 3-1 illustrates Clarke's (1999) depiction of nursing knowledge and science using a stratified structure to demonstrate the relationships between nursing concepts, nomenclature, classification and minimum datasets (MDS).



**Figure 3-1 Clarke Perspective on Nursing Phenomena**

Source Clarke 1999

There are many examples of classifications of nursing interventions that the nursing profession can access as resources to document nursing activity (McCloskey et al 2000; Martin and Scheet, 1992). The two most widely adopted intervention classifications globally are the Nursing Intervention Classification and the OMAHA System Intervention Scheme. The definitions of these two classifications are outlined below; a nursing intervention can be defined as:

*Any treatment, based upon clinical judgement and knowledge, that a nurse performs to enhance patient/client outcomes*

McCloskey et al., 2000 Nursing Intervention Classification p.xix

or as:

*An action or activity implemented by a nurse to address a specific client problem and to improve, maintain, or restore health or prevent illness. An intervention always includes a category and target(s); it usually includes client specific information.*

Martin, and Scheet, 1992 p.46

One leading stakeholder engaged in the development of concepts and terms to articulate the language of nursing is the International Council of Nurses (ICN). The ICN have developed a classification of terms entitled International Classification of Nursing Practice® (ICNP). This classification is a resource which presents a unified nursing language system as a reference point for nurses on an international platform. The classification is described by ICNP® as a compositional terminology for nursing practice that facilitates the development of and the cross-mapping among local terms and existing terminologies. The benefits of realising a unified nursing language system are to enable the articulation of the nursing contribution to wellbeing and healthcare globally. Formalised language can also assist in promoting harmonization between ICNP® with other widely used classifications and the work of standardization groups in health and nursing. The core elements of ICNP are nursing phenomena (often described as diagnosis), nursing actions and nursing outcomes.

The ICNP website [http://www.icn.ch/icnp\\_ben.htm](http://www.icn.ch/icnp_ben.htm) lists the following benefits that can be realised by the adoption of this formal terminology.

- a) Establishes an international standard to facilitate description and comparison of nursing practice.
- b) Serves as a unifying nursing language system for international nursing based on state-of-the-art terminology standards.
- c) Represents nursing concepts used in local, regional, national and international practice, across specialties, languages and cultures.
- d) Generates information about nursing practice that will influence decision-making, education and policy in the

areas of patient needs, nursing interventions, health outcomes, and resource utilization.

- e) Facilitates the development of nursing data sets used in research to direct policy by describing and comparing nursing care of individuals, families and communities world wide.
- f) Improves communication within the discipline of nursing and across other disciplines.
- g) Encourages nurses to reflect on their own practice and influence improvements in quality of care.

Source ICNP® ( [http://www.icn.ch/icnp\\_ben.htm](http://www.icn.ch/icnp_ben.htm))

A key tool that ICNP® offers nurses interested in working with concepts and formal terminologies is the ICNP® browser available at <http://browser.icn.ch/>.

This browser consists of a complete classification of terms organised in a catalogue for ease of access. Information held in this catalogue is collected within a seven axis model which includes the following sections: action, client, focus, judgment, location, means and time (ICNP). In June 2009 version 1.2 of ICNP® was released.

Within this research thesis a data dictionary was completed by mapping the terms identified for inclusion in the archetype by the nursing groups into ICNP® version 1.1 and this document has been disseminated to interested stakeholders on request. Successful implementation of formalised terminologies such as classifications and nomenclatures into clinical practice has been slow to evolve (Chute, 2000). The reasons for this are multifaceted; however Rector's (1999) noteworthy article on why terminology is so difficult to implement has been widely referenced over the past ten years.

As a consequence the grand view presented in Rector's paper is considered in this particular thesis as significant and a summary

analysis of the review completed on this chapter is included by the author in Table 3-1. Rector's paper interprets the implementation of formal concepts and terminology in healthcare as one of the grand challenges for medical informatics and a number of his theories are still applicable in current times (Rector, 1999, p.239). Despite this being the case some developments particularly in relation to the recently founded International Health Terminologies Standards Development Organisation (IHTSDO) are raising expectations.

In Table 3-1 the author reviews a list of challenges that Rector presents and offers a summary of development initiatives relating to clinical terminology that has evolved since the publication of Rector's article in 1999. For ease of reading some of Rector's listed challenges are on the left hand side of Table 3-1 and the authors comments on development initiatives in terminology are on the right. A number of acronyms are included in the table and these are identified in the list of abbreviations in this thesis.

**Table 3-1 Analysis of Rectors Comments**

Source Rector, 1999, p.241

<b>Rectors Comments</b>	<b>Summary of Critical Analysis</b>
The scale and multiplicity of activities tasks and users that terminology has to serve is vast; software needs to be developed and tested	Convergence of terminologies is now evident for example IHTSDO and archetypes development complements including and matching terminology to concepts.
The complexity of clinical pragmatics browsing and retrieval and testing	International organisations such as IHTSDO are developing and testing browsers to view terminology datasets. <a href="http://www.IHTSDO.org">http://www.IHTSDO.org</a> and ICNP®
Separating language and concept representation is difficult and has often been inadequate	Standards such as EN18104 and EN13940 have been devised to assist health informaticians on this particular issue.
Pragmatic clinical conventions often do not conform to general logic or linguistic paradigms	Education and training is required for appropriate application of formalised concepts and terminology. <a href="http://www.tigersummit.com/">http://www.tigersummit.com/</a>
Defining formalisms for clinical concept representation and populating them with clinical knowledge or “ontologies” is difficult	In IHTSDO all terms have a concept ID relationship ID and descriptor ID and there is a higher order set of terms for mapping. Also ICNP and the introduction of the ICNP C.Space. Application has seen some improvement in this area (Hoy et al, 2009).
Achieving the appropriate level of clinical consensus is hard and requires that the terminology be open ended and allow local tailoring.	This is an ongoing process and not necessarily one that relates solely to terminology but one which relates to agreed health information standards across the continuum of care e.g. ICNP®
The structure idiosyncrasies of existing conventional coding and classification systems must be addressed.	Strong reference information models such as ISO 13606 EHRcom are striving to address this issue (Hägglund, M. 2009)
Change must be managed, and it must be managed without corrupting information already recorded in medical records	This issue presents problems on a global or national scale and must be managed by strong principles and policy at national healthcare agency level (EU, Report 2010 A Digital Agenda for Europe)

### **3.3 Data Set and Minimum Data Set**

One tool which appears to be experiencing a resurgence of interest within healthcare, and particularly within nursing, is the minimum data set (MDS). A minimum data set can be defined as the least number of items of information with uniform definitions and categories concerning a specific dimension e.g. measuring the nursing contribution to patient care, which meets the information needs of multiple data users in the healthcare system (Mosby Medical Dictionary, 2009). As a resource tool the minimum data set in the past twenty years has been used in many areas of healthcare for many different purposes (Goosen et al., 1998; Malett 2003; MacNeela, et al, 2006).

The main purposes for using a nursing minimum data set could be described as:

- a) Articulating nursing contribution to care by capturing nursing intervention data
- b) Supporting efficient resource allocation by measuring patient outcome data and skill mix data which relates to the domain of nursing care.
- c) Promoting consumer interests through comprehensive and transparent documentation of care.
- d) Supporting electronic recording of patient data, thereby increasing the breadth and depth of available healthcare information.

The data elements within the minimum data set can be mapped to formalised concepts and terms, For example the Irish Nursing Minimum Dataset (INMDS) has been cross mapped by the author to the formal compositional reference terminology ICNP®. A key rationale for completing a mapping exercise of concepts to minimum datasets is to understand the relationship between nursing minimum

datasets and how they relate to interventions and outcomes. The exercise also applies design constraints as required on the data elements, thus providing a process to consider specific minimum data sets for inclusion in future EHR design planning.

Well designed minimum datasets can assist in demonstrating the nursing contribution to specific outcomes by direct and indirect interventions (Barriball and McKenzie 1993). This approach also offers the potential to demonstrate a clear understanding of the relationship between nursing interventions and patient outcomes, and provides researchers with an opportunity to inform nursing care and contribute to the evidence base for policy formation (Kreulen and Braden 2004).

Nursing Minimum Data Sets have been developed in a number of nations world wide such as USA (Werley et al, 1991), Belgium (Sermeus and Deleise 1994), Switzerland (Berthou and Junger 2003), the Netherlands (Goosen 2002), Canada (Hannah and Anderson 1993), Finland (Turtiainen et al, 2000), Sweden (Elo 1995), Brazil (Filho 2001), Thailand (Volrathongchai, Delaney and Phuphailbul 2003) and Japan (Shimanouchi et al 2000). In terms of resource allocation perhaps the most active minimum data set is in Belgium and is entitled Belgium Nursing Minimum Dataset (B-NMDS). Whilst some Nursing Minimum Datasets (NMDS) have been adopted internationally it is interesting to note that their uses at a national level differ in terms of aim purpose content and utilisation (MacNeela et al., 2006). The B-NMDS is used by the Ministry of Health since 1988 for mandatory registration of nursing data by nursing staff in all Belgium hospitals, leading to a database of over 13 million inpatient days referring to over four million patients in 2500 nursing units (Sermeus, Delesie and Van Den Heede, 2002; MacNeela, P. et al., 2005). Initial work was devised to develop an international nursing minimum data set i-NMDS (Goosen 2002).

This dataset was created in association with the International Council of Nurses and the International Medical Informatics Association Nursing Informatics Special Interest Group with a view to supporting developing and testing an international minimum dataset. However a recent review of the website <http://www.inmds.org> offers a brief posting stating that the website and the associated forum are no longer operational due to issues with hacking and security problems. Informal discussions with colleagues from the standards agencies suggest that the work of the International Minimum Dataset is currently on hold at the time of writing this thesis.

There is a strong relationship between minimum datasets and classification systems in nursing. In some instances large nursing classifications describe themselves as minimum datasets and minimum datasets can use elements of nursing classifications within them: this is demonstrated in the following section that introduces classifications relevant to the profession of nursing.

In some instances classifications systems such as North American Nursing Diagnosis Association (NANDA), the Nursing Intervention Classification (NIC), Nursing Outcomes Classification (NOC), the OMAHA System and the Home Healthcare Classification System (HHC) are integrated within the specific minimum datasets at different levels. For example the B-NMDS uses elements of the NIC in its dataset. Ryan and Delaney (1995) caution researchers engaged in data set development to recognise that the reliability and validity of the datasets should not be confused with the reliability and validity of the classification systems used within the minimum data set. Whilst it is reasonable to suggest that one set of validity and reliability criterion will impact on the other, it must be noted that they are still two very separate entities and validity and reliability of the minimum dataset must also be assured. Early publications by Goosen et al (1998) suggests that NMDS could provide the nursing profession with

significant benefits in regard to nursing effectiveness, quality assurance, mapping trends and nursing research.

However, Goosen et al (1998) also maintain that for minimum data sets to reach their full potential, issues such as access to specific population samples, abstraction and aggregation of data all needs to be addressed. One of the most successfully implemented minimum datasets is the Resident Assessment Instrument (RAI). This minimum data set has a number of modules relating to community care, mental health and continuing care for nursing homes. This instrument is particularly relevant in this thesis as the focus of this resource is on identifying those core data elements most relevant for inclusion in the provision of care for older persons aged over 65. The RAI developed in the United States is a multidisciplinary database that collects data on nursing assessment with a view to improving the care and outcomes for patients in nursing homes (Brunton and Rook, 1999). The focus of this instrument is to collect data on clinical practice, but the tool also assesses the patient holistically and fosters restorative and rehabilitative care (Hawes, Morris and Phillips., 1997). Content validity and reliability for the RAI dataset was achieved through communicating with a vast array of stakeholders including clinicians' administrators and consumer advocates. Within the study a series of three field tests were implemented and during the field testing and retesting the RAI tool underwent a set of 15 revisions (Hawes et al, 1997; Maleett, 1993). Findings indicated that 89% of the items had an intraclass correlation score of 0.4% or higher, and 63% had a score of at least 0.6 % (Hawes et al., 1997; Maleett, 1993).

Minimum datasets are developed for different purposes e.g the NMDS to capture and make the nursing contribution visible and the RAI to enhance delivery of care to the elderly. Goosen et al (1998) posed the question as to whether specific NMDS still have relevance in the healthcare environment.

He postulated that perhaps a more patient centred and more multidisciplinary orientated approach to data set development would be more appropriate. However it would appear from this review that the minimum dataset is experiencing resurgence in popularity again. This may in part be due to the fact that since 1998 there has been a significant advance in technology on the development of clinical data standards and a shift towards dual model approach to Electronic Healthcare Record development creating a space for archetype development.

The NMDS may offer the research and software development community a more functional set of data elements to include in identifying the clinical documentation requirements that are frequently used by nurses as a framework for development. In Ireland the Health Research Board funded the first national research project for nursing in 2002 –2007. This research programme comprised of a collaborative team of researchers from School of Nursing and Midwifery at University College Dublin (UCD) and the School of Nursing in Dublin City University. The research programme focused on clinical judgment and decision making; however, the Irish Nursing Minimum Dataset (INMDS) was one key deliverable from this research programme. The INMDS is an instrument designed to assist nurses in Ireland to articulate clearly the full contribution that they make to patient care. This dataset instrument comprised of a set of patient problems and nursing interventions with an associated 5 point measurement scale. It was defined as follows;

*The Nursing Minimum Dataset is a research tool designed to support a nurse to record all the major elements of care provided to a particular patient, while at the same time being relatively undemanding in terms of time. (INMDS Users Guide 2006 p. 5)*

The tool comprises of three main sections: patient problems, nursing interventions and activities, and background information.

In 2006 the National Council for the Professional Development of Nursing and Midwifery published a report entitled **Measurement of Nursing and Midwifery Interventions: Guidance and Resource Pack (2006)**, this report is available on line at <http://www.ncnm.ie> and is a two-part publication comprised of:

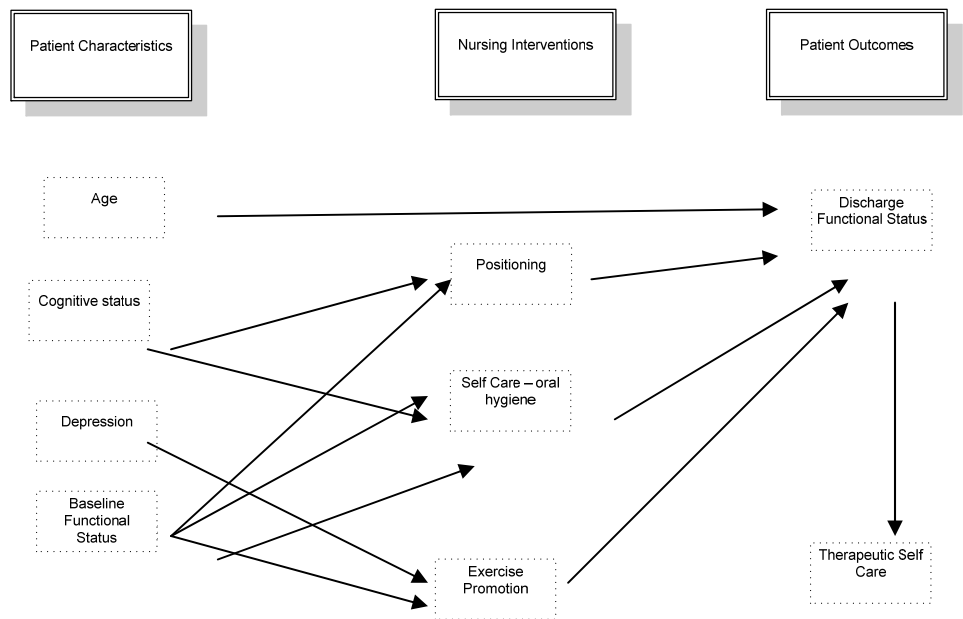
- A report of a study on the extent to which nurses/midwives in Ireland document their interventions.
- A report on the outcomes of these interventions and some preliminary guidance and assistance for nursing and midwifery in Ireland on the challenges of determining what interventions to select & assess in daily practice.

As is the case with patient outcomes, patient characteristics also can have a direct bearing on nursing interventions processes (Doran, Harrison, Laschinger and Hirdes 2006a). The patient characteristic variables include age, cognitive ability, depression and status on the outcome variable on admission.

According to Packard Haberman, Woods and Yates, (1991) older age patients, patients with cognitive impairment, depression and lower health status on admission increase the need for nursing interventions and indicate that these factors increase illness demand (Packard et al. 1991). In Doran et al. (2006a) the research team selected a set of nursing interventions from the Nursing Interventions Classification Set, which would test the selected set of specific interventions in relation to specific nursing sensitive nursing outcomes. The outcomes selected were relating to functional status, and therapeutic self-care, and discharge status or readiness for discharge. Patient data was collected over a 6-month period from 2002- 2003 and patients were assessed on admission and discharge. Therapeutic self-care was only assessed on discharge, as the

researcher contended that the client would not be in a position to conceptualise their discharge functionality on admission.

Data analysis included descriptive statistics and inter-correlations amongst variables. Structural equation modelling was used in association with AMOS5, a statistical tool, to test the relationships amongst the variables (Doran, et al 2006a p.66). A brief over view of the findings is cited below from the Doran, et al 2006a article in Figure 3-2; however the actual figures demonstrating the inter-correlations are not included in this copy as is the case in the original article.



**Figure 3-2** Patient Characteristics SCM  
Source Self Care Model Doran et al, 2006a p.67

The findings demonstrated partial support for the hypothesized relationships between patient characteristics, nursing interventions and patient outcomes in accordance with the nursing reference effectiveness model, although one limitation was in relation to reliance on chart audit to collect data. For example interventions were either classed as present or absent in the patient record, thus the approach to measurement ignores the dose of the intervention. This makes it difficult to ascertain how much of a specific intervention is required to achieve a therapeutic effect (Doran, et al., 2006a, p.69).

The above study by Doran, et al., (2006a) is significant in informing the Model of Knowledge presented in Chapter 7. It will be considered further in section 3.4 in association with the work of Dickenson (2008) which critiques the literature from an outcomes perspective.

### **3.4 Outcomes**

The theory underpinning the development of healthcare outcomes is a broad and an extensive research topic. There are many factors which influence outcome studies, therefore a brief description of the factors affecting outcome research is included in Table 3.2 In this particular thesis the goal of reviewing the outcomes literature base is illustrative and therefore the review is not exhaustive. Mitchell (2001) found no references were evident when searching Medline from 1978 – 1989 using outcomes as a key word; however on completion of the same exercise from the years 1997-2000 over 700 references were listed. Doran, McGillis Hall and Sidani (2002), argues that this is primarily due to the fact that outcomes are increasingly becoming a key area of interest in health services research because accountability has become an important expectation of healthcare provision.

Over the past twenty years there are a number of typologies in existence with which to categorise outcomes. For example, there are those outcomes which have a negative orientation such as adverse events and complications due to hospitalisation (Lohr, 1985; Prescott, 1990), or those outcomes which are patient focused, provider focused or organisationally focused (Jennings, Staggers and Bosch 1999; Prescott, Phillips, Ryan and Thompson 1991). Dickenson (2008) suggests that outcomes can be categorised into service process outcomes, change outcomes and maintenance outcomes, Table 3.3 offers a brief summary description of this typology of outcomes by Dickenson, (2008). In the case of gerontology; the methodological process in devising healthcare outcomes has been noted to be fraught with difficulty (Hallberg, et al., 2004; Meyer 2004). In terms of nursing sensitive outcomes, Almost, Doran and McGillis Hall (2003) contends that there is still minimal theory linking patient outcomes and antecedent nursing factors. Most of the patient outcomes are empirically rather than theoretically driven and then tested (Doran, et al. 2002; Mitchell & Shortell, 1997).

However the Aiken et al. studies (2002; 2002a) are an exception as they have adopted a theory which links theory and adverse patient outcomes such as mortality (Doran et al, 2002). In the book on *Nursing Sensitive Outcomes State of Science* Almost, et al (2003) identify four factors which require careful consideration in relation to what is the strength of the primary research examining the relationship between the effects of nursing care on patients in regard to patient centred outcomes.

**Table 3-2 Factors Affecting Outcomes Research**

Source – Doran cited in Almost et al, 2003 p.8

<b>Factors Affecting Outcomes Research</b>
The availability of theoretical explanations to link various nursing inputs and processes to outcomes
The need for access to large samples to detect relationships that may be subtle or may exist only between sub-groups of patients and nursing factors
The ease of accessing these large samples
Appropriate measures that are congruent with the theory supporting the research and that have demonstrated reliability and validity

Early work completed by Donabedian offers a broad definition of healthcare outcomes as the effect of care on the health and welfare of individuals or populations (Donabedian, 1968). More recently Moorehead, Johnson and Maas (2004) redefined the concept of outcomes specifically in relation to nursing entitled Nursing Sensitive Outcomes. They devised a more comprehensive definition depicting a nursing sensitive outcome as an individual, family, or community state, behavior, or perception that is measured along a continuum in response to nursing intervention(s) (Moorehead, et al. 2004).

A broader definition is identified by Dickenson (2008) when she draws on the work of Nicholas et al (2003) and Smith (1996) suggesting that outcomes are the impact, effect or consequence of help received, thereby stating that outcomes are not just the direct products or services, but are the totality of the consequences of the actions of an organisation, policy, programme or initiative.

A simplified definition is that outcomes are the impact on society of a particular public sector activity (Dickenson, 2008, p.8).

Table 3-3 cited from Dickenson (2008) offers an illustration on how outcomes can be typified.

**Table 3-3 Outcomes by Type**

Source Dickenson, 2008, p.9

Outcome Type	Outcome description
Service Process Outcomes	Reflect the impact of the way in which services are delivered. This might include the degree to which service users are treated as human beings or feel that their privacy and confidentiality are respected or treated as people with the right to services.
Change Outcomes	Reflect the improvement (or disimprovement) made in physical, mental or emotional functioning. This includes improvement (or disimprovement) in a symptom or symptoms such as depression or anxiety that impair relationships and impede social participation, in physical functioning and in confidence and morale (Quereshi et al, 1998).
Maintenance Outcomes	Are those outcomes that prevent or delay deterioration in health, well-being or quality of life. This can include low level interventions and their outcomes such as living in a clean and tidy environment and having social contact.

Considering patient outcomes from a global perspective, the World Health Organisation (WHO, 2005) has emphasised the importance of organising present and future healthcare delivery processes towards the improvement of patient outcomes. Although, Wagner (2002) argues that whilst there is an emphasis on improving outcomes in terms of chronic disease management, the indications are that management of these diseases is sub-optimal. Wagner (2002) postulates that in many cases the fault may lie in our systems of care, rather than with the individual healthcare practitioners who are

engaged in chronic disease management. This review suggests that systems of care have included patient outcomes in their overall design brief. One early example is the system- process- outcome framework model by Donabedian (1968).

The work of Donabedian will be discussed further in section 3.5 under models and frameworks. The remainder of this outcomes section will review the evidence base from three key perspectives.

Firstly in Section 3.4.1 it will review those studies which seek to review outcomes from a service process orientation perspective; secondly, in Section 3.4.2 it will consider studies which relate to change and maintenance outcomes; and finally, models and frameworks for analysis of outcomes data will be discussed in Section 3.5.

### **3.4.1 Service Planning Outcomes**

Measuring patient outcomes for service planning purposes is strongly linked to quality of care and clinical effectiveness. Many authors advocate that measuring patient outcomes is an effective method of estimating the quality of patient care (Aiken, Clarke and Sloan . 2002; Kearney et al 2000; Needleman, Beurhaus and Mattke 2002; and Smith et al 2007). However there is much debate within the literature as to what specific measurement criteria should be adopted. This debate is specifically in regard to determining what precise patient outcomes will demonstrate the best indicators of quality patient care or indeed the absence of quality of patient care (Currell and Uruqhart 2003; Seago, Williamson and Atwood, 2006; and Van den Heede et al 2006). Also, in cases where more than one agency is collecting data relating to patient centred outcomes, the notion of attribution needs to be considered carefully (Dickenson, 2008).

In 2006, the International Congress of Nursing noted that a common challenge facing human resource managers is in determining the most effective mix of staff and skills needed for the delivery of quality and cost effective patient care. This is particularly important in light of rising demand for health services cost containment and shortage of nurses and other healthcare workers (ICN, 2005). The World Health Organisation (WHO) also recognises skill mix as a key dimension in effective use of healthcare provision (WHO, 2002). The WHO advise healthcare policy makers on the importance of building integrated healthcare systems that can address the ever-increasing burden of global chronic disease management (WHO 2002; TILDA, 2010). There is also a strong association on the topic of service planning outcomes and skill mix. This is demonstrated well by Lankshear, Sheldon and Maynard, (2005) who completed a systematic review of the international research evidence on nurse staffing and healthcare outcomes and found some interesting details particularly in regard to the research design of the studies critiqued in the review.

The authors reported on the relationship between the nursing workforce (level and skill mix), and patient outcomes (mortality, failure to rescue and complications) in the acute sector, whilst considering the relevance of the findings within each of the studies for policy development (Lankshear et al. 2005 p.163). In this study the authors found that because of the heterogeneity of the studies reviewed i.e. different outcomes and different measures of staffing and summarising of the association between the outcomes and staffing the team also needed to carry out a qualitative synthesis to explore patterns within the data. The authors suggested that this would also demonstrate possible explanations for inconsistencies in the study design, analysis context and setting (Lankshear et al. 2005 p.164).

The study concluded that the quality of methodological use and the range of research designs were poor using data from only one unit or hospital site whilst failing to control case mix variations. Likewise research settings and measurement criteria for staffing inputs and outcomes were varied and quite broad.

The authors recommended future research in this area to adopt a rigorous approach by using randomised control trials or quasi-experimental methods which would need to be accompanied with a rich qualitative organisational research evaluation. A key point noted was that the majority of the findings were cross-sectional as opposed to longitudinal. Lankshear, et al. (2005) recommended that if research is to measure the effect of nurse staffing on patient outcome, then patient outcomes should change in relation to variations in nurse staffing over time. Only two longitudinal studies met the inclusion criteria: Mark, Harless, McCue and Xu (2004) and Unruh (2003), and findings from these studies indicated that increases in registered nurses input over a period of time was correlated with reductions in patient mortality rates and patient complications (Lankshear, et al. 2005, p.171).

Tourangeau (2005) suggests that outcome research in nursing can be termed as "*atheoretical*". Whilst there is a significant amount of research evidence supporting patient mortality as an outcome, there is according to Tourangeau (2005) little discussion regarding theoretical models or nursing related determinants of mortality for hospitalised patients. As an indicator thirty day mortality is noted as an important quality outcome as it measures the full impact of hospitalisation without introducing many other competing risks (Jencks, 1988). Thirty day mortality as a measure relates to the fraction of patients that died within 30 days from the date of the first surgery. The monitoring of patient outcomes in studies which evaluate the relationship between nurse staffing ratios, patient

mortality and quality of care are prevalent in the literature base (Doran, Harrison and Laschinger, 2006b; Estabrooks, Cummings, Olivio and Squires, 2009; Kreulen, G. et al 2004; Lookinland, 2005).

Adverse outcomes in particular have been associated with the skilled nurse ratio mix and linked to mortality in the acute sector thus impacting upon organisational effectiveness (Van den Heede, 2006). A series of landmark papers demonstrate that nurse-staffing ratios levels in the United States of America have been linked to quality of care in hospitals, and in some instances patient mortality (Needleman et. al, 2002; Aiken, Clarke and Sloane, 2002a). Concerns within Europe are such that the findings from the aforementioned American studies have led to similar projects within the European Community (Pritchard and Gavin 2006). Research centres have now grown to include Germany, Switzerland and Belgium. Such studies, according to Buerhaus, Needleman Soeren and Stewart (2000) are required because of an insufficient body of credible evidence linking changes in the hospital nurse work force to potentially adverse effects on patient outcomes (Buerhaus, et. al, 2000, p.7). Two of these studies have been selected for discussion in this section as they demonstrate studies of international importance which are theoretically driven. The studies are completed by Needleman, et al., (2002) and Aiken et al., (2002a).

Needleman et al (2002) published an important paper relating to a large research study on nurse staffing ratios and their direct proportional relationship to the quality of care in hospital. This article used administrative data dating back to 1997 on 799 hospitals in the USA to review 5,075,969 discharge data records of medical patients.

The author sought to ascertain if there was a relationship between care provided by nurses in acute care and patient outcomes. Findings from this study yielded the following results for medical patients:

*In medical patients provision of care by registered nurses was associated with a shorter length of stay for patients ( $P = 0.01$  and  $P < 0.001$ ), lower rates of Urinary tract infections ( $p < 0.001$  and  $P = 0.003$ ) and lower rates in upper gastro intestinal bleeds ( $P = 0.03$  and  $P = 0.007$ ). Needleman, et al 2002, p.1715.*

These authors therefore concluded that this study provided strong empirical evidence that a greater number of hours of care by registered nurse per day are associated with better care for hospitalised medical patients.

In the same year a second study by Aiken et al. (2002a) examining the relationship between patient to nurse ratios, patient outcomes and nursing retention in the acute sector was published. This study completed a large scale cross sectional analyses of linked data from 10,184 staff nurses, surveyed in general, orthopaedic, and vascular hospital units. The study sample reviewed surgical patients discharged from hospital between April 1, 1988 and November the 30, 1999, and administrative data from 168 non federal adult general hospitals in Pennsylvania (Aiken et al. 2002a p. 1987). As was the case with Needleman the findings of this research were significant to the profession of nursing and are frequently referenced:

*In hospitals with high patient to nurse ratios, surgical patients experience a higher risk adjusted 30 day mortality and failure to rescue rates, and nurses are more likely to experience burnout and job dissatisfaction. (Aiken, et al, 2002a p. 1987).*

Sidani, Doran and Mitchell (2004) suggest that the recognition of outcome variability is influenced by multiple factors, which are inherent in the real world of clinical practice (Sidani, et al., 2004 p.61). As a consequence, a number of varying factors, can impact the findings of patient outcomes. Some authors maintain that the data used for studies such as Aiken et al 2002a and Needleman et al., 2002 use data that is primarily collected for quality assurance purposes such as incident reporting and may be subject to self report bias and or lack of awareness of the event (Seago, et al., 2006 p. 16). Tourangeau (2005) indicates that whilst death is an unpreventable outcome for some patients it is noted that persistent variation in risk adjusted rates across hospitals suggest that some portion of this outcome is excessive and preventable and is related to quality of care and random sources. As a consequence, registered nurses who are engaged in ongoing patient surveillance are best positioned to effectively identify (and prevent) patient complications that could lead to unnecessary patient deaths if not assessed or unresolved (Tourangeau, 2005, p.60).

This section of the chapter concludes with findings from Butler, Collins, Drennan, Halligan, Mathnu, Schultz, Sheridan and Villas (2008) who reported a Cochrane Systematic review which sought to critique issues in the organisation of health care, hospital staffing and patient and staff related outcomes. The findings suggest that in studies reviewed no evidence was found that replacing registered nurses with unqualified nursing assistants affects patient outcomes; however the addition of specialist nurses to nursing staff is likely to result in shorter inpatient hospital stay, and reductions in some preventable complications and pressure ulcers. Over 120 relevant studies had to be excluded from the review because of their design, most of the studies included were interrupted time series studies and all had fewer data points than usually expected.

### **3.4.2 Change Outcomes and Maintenance Outcomes**

Individuals who are elderly or who endure living with chronic diseases often have more than one condition. This is often referred in medical terms to as treating patients with multi-morbidity (Fortin, Dionne and Pinho 2006). Such individuals tend to have a poorer quality of life and loss of physical functioning (Smith, Allwight and O Dowd, 2007a). These debilitating conditions have an impact on both the lives of the individuals affected but also on utilisation of healthcare services. Therefore collecting data relating to monitoring change and maintenance of patient centred outcomes in such patients is a high priority (Parmelee, Thuras, Katz and Lawton 1995). Ideally patients who are elderly or who suffer with chronic illness and multi-morbidity live in a community setting with primary care support.

Within the context of the community setting, patient outcomes are not always immediately evident and it may take extended periods of time to fully understand the implications of partnership actions in terms of patient outcomes as opposed to outputs which are usually more apparent (Dickenson, 2008 p.11). One outcome study by Meyer and Sturdy (2004) which relates to care of the older person suggests that participative research methods are required to develop appropriate outcomes in care of the older person care advises researchers to use action research methodologies.

The justification for this approach is based upon the premise that the global growth in the older population is setting unprecedented demands on governments and societies to develop effective health and social systems of care (Meyer and Sturdy, 2004 p. 128). According to Smith, Soubhi, and Fortin (2007b), current healthcare system development does not necessarily address the issue of chronic disease management in relation to multi morbidity.

Smith et al (2007b) notes that such systems have a tendency to structure information into two broad categories; systems focusing on generic chronic care models of which there are examples to be seen in the United States, and national systems in the United Kingdom which focus on single chronic conditions (Smith et al. 2007b)

This notion is reiterated also by Dickenson in the following quote;

*Much of the western world has embraced a movement towards scientific –bureaucratic medicine ... nevertheless authors such as Netten et al. (2002) stress that social care outcomes in this new era of partnership are just as essential as health with the more sophisticated development of outcome measures in health:’ the benefit gains in social care could be easily overlooked or marginalised.* (Dickenson, 2008 p. 11)

Dickenson continues by quoting authors who have completed research studies which stress the importance of maintenance and change outcomes for patients (Clark, 1998; Gabriel and Bowling, 2004). It is important that change and maintenance outcomes are collected as indicators and are not subsumed by the more dominant medical model but that the two complement each other. This perspective underpins the expansion of the focus of this thesis to consider additional models of knowledge and meaning that can assist in understanding patient centred care record requirements.

The following section of this chapter will therefore offer a brief overview of the distinguishing criteria between the bio psychosocial model and patient centred care models that are in existence.

The bio psychosocial model of care (BPS) was originally presented by George Engel in 1978 as a more inclusive approach than the medical model that is based on general systems theory.

Engel describes the BPS model as one that *dispenses with the scientifically archaic principles of dualism and reductionism and replaces the simple cause and effect explanations of linear causality with reciprocal causal models. Health disease and disability thus are conceptualized in terms of the relative intactness and functioning of each component system on each hierarchal level* (Engel, 1978, p.175).

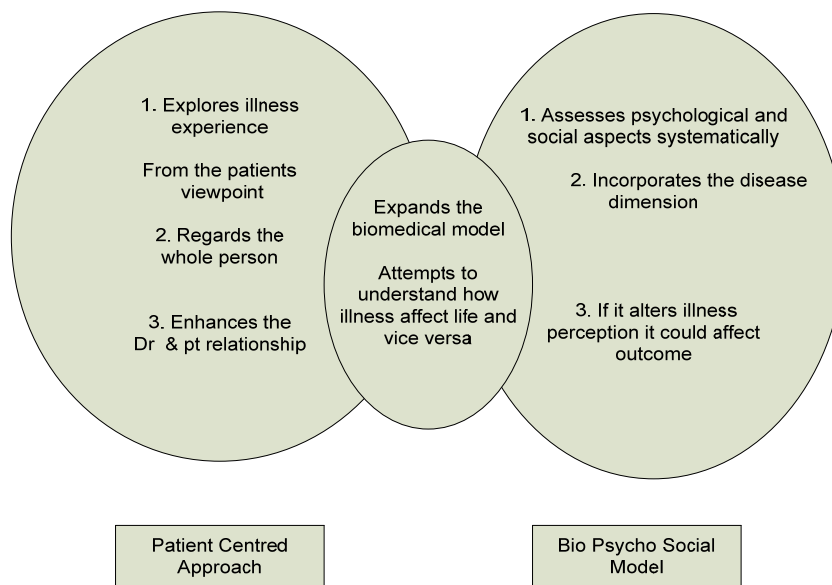
The BPS model differs from the medical model in that it is mainly used in the sphere of western medicine and offers a human dimension of illness, as opposed to the mechanical or scientific approach. It is described by Hallor (2009) as the socialized model of care. Engel argues the case that the key to optimal patient care is collaboration, and complementarities among all healthcare professions.

In order for this to be achieved the various disciplines must share in common a basic set of assumptions and principles. Otherwise the alternative is to inhibit collaboration create confusion and substitute competition for complementary approaches (Engel, 1978 p.175). This perspective is significant when one considers monitoring of change and maintenance outcomes for individuals who are elderly and potentially living with chronic illness or co-morbidity. A second related concept which is often associated or confused with the BPS is the patient centered approach. Mead and Bowers (2000) suggest that the patient centered model has been developed primarily to provide a framework for general practitioner (GP) training and to potentially provide a measurement for the quality of patient care in the primary care setting offer five dimensions of patient centeredness;

- a) A bio psychosocial perspective
- b) The patient as a person and the personal meaning of illness

- c) Sharing power and responsibility and recognition of patients needs and preferences
- d) The therapeutic alliance
- e) The doctor as a person

Creed (1998) considers if patient centered and bio-psychosocial approaches are actually compatible and suggests that one of the difficulties with the patient centered approach is that the model is not precise enough and may be used differently in various settings. Figure 3-3 offers an illustrative depiction of the associations between the patient centered model and the BPS model on what are the common and distinct components of the patient centred approach and bio psychosocial model.



**Figure 3-3 Patient Centred and BPS Model**

Source Creed, F. cited in Mead and Bowers 2000 p.1089

### **3.5 Models / Frameworks**

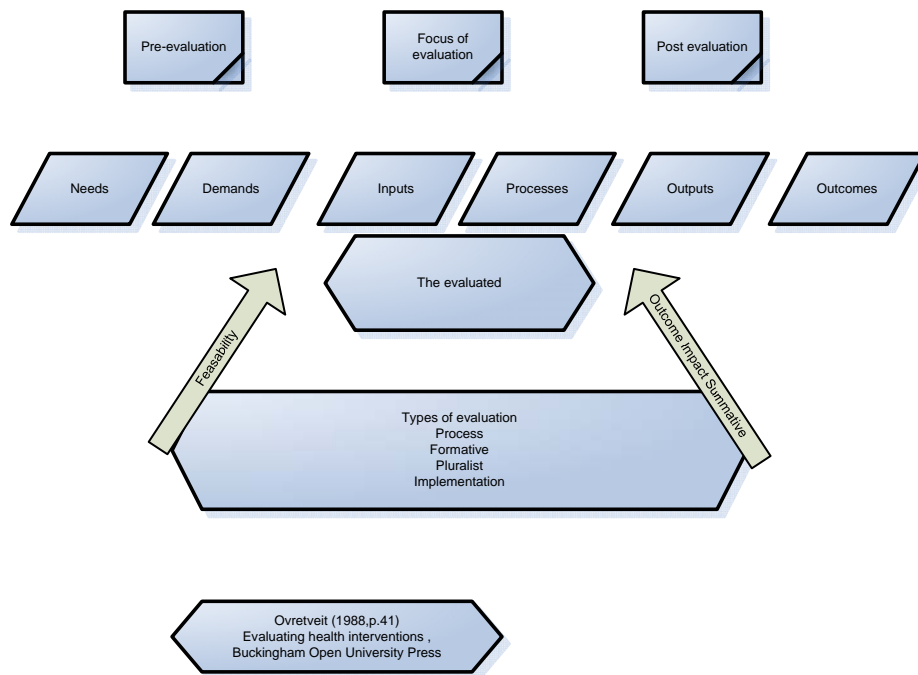
The theoretical explanations and frameworks to link inputs, processes and outcomes are noted in this chapter as key requisites when completing outcome studies. The evidence suggests therefore that measuring outcomes in an isolated fashion does not necessarily yield a realistic picture of clinical effectiveness in correlation to patient care (Sidani and Irvine, 1998). The use of a conceptual model, which includes a coherent demonstration of the relevant factors which must be taken into consideration in outcome measurement, is therefore seen as an important element of outcome measurement collection (Cohen, Holzemer and Gorenberg, 2000; Huber and Oberman, 1999; Irvine, et al., 1998). A model within this context can be described as a demonstration of the various elements which are required in the design of a mock up replica to measure

patient outcomes. Early recognition that a model of evidence was an intrinsic part of measuring effectiveness dates back to the days of the Crimean war and the practice of Florence Nightingale (Lang and Marek 1991). In more recent times however Donabedian (1968) developed a framework for evaluating the effectiveness of care. This framework included an explanation of contextualising the outcomes of healthcare interventions.

His model consists of three approaches. 1) *Structures*, which can be described as the care setting. 2) *Process*, the performance of care and 3) *Outcome*, the result of care. Likewise, Clarke (1999) supported this theory when she commented on the fact that the discovery of a beneficial outcome is of limited practical value unless one knows what factors are necessary for it to occur (structure) and how it was actually achieved (process). Similarly Griffiths (1999) commenting on Donabedian's work describes outcomes from process "care itself" and structure suggesting that if nursing has an impact on outcomes then the best way of evaluating quality in nursing is to demonstrate improvement in those outcomes that are influenced by nursing. If care is of a high quality it must surely result in better outcomes for patients (Griffiths and Evans, 1995). Today many researchers use adaptations and modifications of the previously referred to frameworks – structure, process and outcome to quantify clinical effectiveness (Irvine and Doran, 2002; Ovretveit, 1998). Griffiths, Harris and Richardson (2001) maintains that the process and structures that are validated by their relationship to outcomes are quite possibly the best quality indicators to critique and analyse since outcome data are so difficult to collect.

More recent literature suggests a more pragmatic approach, namely evaluation. The first step in empirically validating outcomes requires an evaluation particularly of the interventions (process) which may have had a direct or indirect impact upon the service provider or the

individual. Ovretveit (1998), whose primary domain of expertise is quality, offers an illustrative model on quality of care and evaluation. Figure 3.4 by Ovretveit 1998 offers a simple but well depicted conceptual overview of the various foci for different types of evaluation. Ovretveit uses the perspective of time to plot the particular stages of a programme across the continuum of the healthcare process. This is a useful diagram which can assist in determining which type of evaluation a particular programme is participating in and where the outcome data is positioned within the care process.



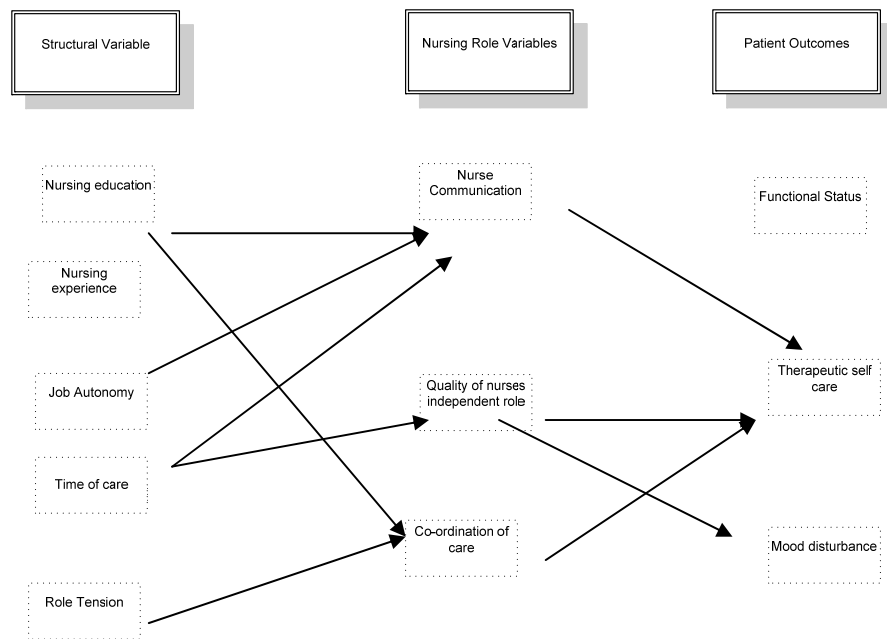
**Figure 3-4 Ovretviet Model**  
Source – Ovretveit, 1998.p.277

### **3.5.1 Nursing Role Effectiveness Model**

Expanding on the notion of quality and evaluation models, which can be used within the domain of nursing, it is evident that healthcare professionals do not tend to work in isolation, but work in an interdependent way to achieve a common goal of quality healthcare provision. Irvine et al (1998) have devised a conceptual model to explore the contribution of nursing within a healthcare system. As in previous studies this model (Figure 3-5) adopts the structure, process, outcome framework. The structure element of the model includes nurse, patient and nursing unit variables, which may impact upon the processes and outcomes of health care. The process element is comprised of independent, dependent and interdependent role and functions of the nurses. This model has had a significant impact on this thesis as it has shaped the author's initial thinking on the development of a taxonomy of core concepts and informed the ability of the researcher to design methods to collect information using a structure, process and outcome framework in association with Pawson and Tilley's (1997) context mechanism and outcome configurations which will be explained in Chapter 7. This model is entitled the Nursing Role Effectiveness Model (NREM).

Finally the outcome element is comprised of patient health status, patients' perceived health benefit from nursing care and the direct and indirect costs associated with nursing care (Irvine et al 1998). A second study by Irvine Doran D, Sidani, S. Keatings, M. Doidge, D (2002) completed empirical testing of the Nursing Role Effectiveness Model. This study adopted a cross sectional design to collect data relating to the individual structure, process, and outcome variables. The data collected included structured questionnaires, chart audits from 372 patients and 254 nurses.

The audits were undertaken in 26 general medical and surgical units in tertiary care hospital settings. Structural equation modelling was used to test the hypothesised relationships amongst selected variables. A number of the specific relationships between the three variables are demonstrated in Figure 3-5 below is cited from the study.



**Figure 3-5 Nursing Role Effectiveness Model**

Cited from Irvine Doran D, Sidani, S. Keatings, M. Doidge, D. 2002

p.35

Sidani et al 2004 offer some key elements for consideration within outcome-focused projects relating to nursing care. In brief they recommend that the researcher attends to factors that affect the delivery of care, the outcomes expected of care, and identify the aspects or processes of care believed to produce the expected outcomes. They also suggest that one should select outcomes that are sensitive to nursing care, measure the outcomes upon entry into and exit from a care episode and finally delineate the relationships among the factors, processes, and outcomes, to explain what contributes to the achievement of favourable outcomes as well as the relationships among them (Sidani, S. et al 2004 p. 64). Sidani and Braden (1998) classify the multiple factors into five categories in Table 3-4 as follows;

**Table 3-4 Factors Influencing Nursing Outcomes**  
Source Sidani and Braden (1998)

Number	Factors Influencing Outcome Measurement
1	Personal, socio cultural and health related characteristics of patients
2	Professional and personal characteristics of the professional caregiver
3	Physical and social features of the care delivery setting
4	The type dose and frequency of the care interventions
5	Nature and timing of the occurrence of outcomes

### **3.6 Conclusion**

This chapter offers an overview of concepts, terminology, specific frameworks and models which can be used in the domain of healthcare and within nursing to capture pertinent data relating to structure, process and outcome. The aging population projections, current economic climate and a drive towards clinical effectiveness in National, European and International health policy suggest that a patient centred approach adopting a bio psychosocial model of care is now required. As research into systems of care have extensively investigated the role of patient outcomes and nursing skill mix, future developments on patient outcomes will need to focus on the role of change and maintenance outcomes which can include social perspectives in their overall scope and design.

It is important when studying outcomes that the topic is not scrutinised in an isolated fashion. Measuring outcomes requires a deeper understanding of how nurses document patient care and also how formalised language and terms that are used in association with the measurement of outcomes namely nursing diagnosis and interventions can be mapped to each other. This chapter has therefore taken a broad focus on the topic and critiqued the literature on terminology, nomenclatures, and minimum data sets.

Recent publications by the European Health Consumer Index (2009) support this particular approach for Irish research and recommend that Ireland needs stronger patient participation in decision making on e.Health initiatives. The literature reviewed on patient centred outcomes completed by Almost et al (2003), and Dickenson (2008), and the nursing conceptual models such as Nursing Resource Effectiveness Model by Irvine et al (1998) are considered a suitable evidence base to inform this research process. There is a strong empirical base underpinning these studies, and the philosophical underpinnings of the authors are well aligned to this particular study. Core textbooks by Almost et al, 2003, and Dickenson (2008) and core studies by Irvine et al (2002) are therefore deemed instrumental in shaping decisions in this particular thesis. The detail of these texts will be used to inform new models of knowledge and new models of meaning, definitions of which will be introduced in chapter 4 of this thesis. Such models can evolve in order to inform an organic and progressive model of care for collection of patient centred outcomes across different healthcare settings with different nursing groups in the future.

In conclusion the final words of this chapter are cited from the work of Christopher Chute who suggested in the year 2000 that;

*The evolution of health terminology has undergone glacial transition over time, although the pace has quickened recently. The inescapable conclusion is that we are amidst a major revolution in the role and capabilities of health terminologies, entering an age of large scale systems for health concept representation with international implications.*

Chute 2000, p298

## **4. Syntactic Interoperability**

### **4.1 Introduction**

Chapters 2 and 3 of this review considered the literature base related to clinical requirements and semantic interoperability. In this fourth and final chapter the author will critique integrated electronic healthcare records from the perspective of syntactic interoperability and standardisation. Achieving syntactic interoperability between electronic healthcare record systems implies that two or more systems can exchange information that has the same structure or syntax, thus facilitating integration of records from different healthcare systems and environments (Hägglund, 2009). The focus therefore is not on what information is captured but on how the information is communicated and interpreted by users of information systems.

A recent report published by the European Union suggests that Europe is lagging behind other countries in the digital world and identified interoperability as a key inhibitor. The EU report suggests that the poor uptake of digital technology is directly attributable to fragmented markets, weaknesses in standard setting, and an overall lack of open platforms from which to operate. The EU report offers a statistical example which includes the fact that 30% of Europeans still have never used the internet. This Report entitled – A Digital Agenda for Europe (EU, 2010) maintains that a lack of interoperability and standards are curtailing open platforms which are required to achieve a digital Europe. A key action area marked for change within this report is Interoperability and Standardisation. A key objective of the action area is to create *effective interoperability between IT products and services to build a truly digital society* (EU, 2010, p.14).

From a healthcare perspective to achieve interoperability in electronic healthcare records (EHR) the development process must operate from a structured architectural perspective. The interoperable EHR requires an independent standardised information model which can support functionality such as access control and privacy management (Blobel, 2006). Such models can deal with not only communication *between* systems but also *inside* EHR systems and can accommodate scalability within EHR (Freriks and Schippers, 2008).

The architecture of an EHR will be explored in detail in Section 4.5 and Section 4.6 of this chapter in conjunction with the published standards of the International and European Standards Development Organisations (SDO) which relate to EHR development. Prior to the architectural and standards review, Section 4.2 will introduce the Electronic Healthcare Record (EHR) as an entity, define the EHR and discuss the core attributes that require careful consideration in relation to the healthcare process. Section 4.3 will discuss EHR implementation and present some examples of national policy publications and EHR development programmes within Ireland. Section 4.4 will consider interoperability as a process and introduce the health informatics standardisation agencies which are engaged in the development of standards particularly in regard to achieving interoperability in healthcare. Section 4.6 will review two core standards which have shaped the development of this study EN 13606 and EN 13940. This section will also demonstrate how these standards have been used within this thesis. Finally, Section 4.7 will offer a brief conclusion to this chapter.

## **4.2 Electronic Healthcare Record**

In many countries today the model for healthcare is moving towards integrated programmes of care which are supported by electronic healthcare records (Hannah et al. 2009). Nationally integrated electronic healthcare records are now an integral part of a wider political vision (Greenhalgh, Stramer and Brattan, 2010), and can be described as the heart of the application of information technology in healthcare (Grimson and Kugler 2000). Pre-defined stated requirements in EHR design include that EHR should be patient-centred, involve comprehensive stakeholder input both in design and use, and be capable of delivering an integrated distributed system for maximum returns on investment (Hannah et al, 2009).

The International Organization for Standardization (ISO) describes the EHR as an: "Integrated Care Electronic Health Record" (*EHR*) and defines it as *a repository of information regarding the health of a subject of care in computer processable form, stored and transmitted securely, and accessible by multiple authorized users. It has a commonly agreed logical information model which is independent of EHR systems. Its primary purpose is the support of continuing, efficient and quality integrated health care, and it contains information which is retrospective, concurrent and prospective.*" (International Standards Organisation, 2004).

EHR and their associated variants should therefore not be viewed as passive containers for information but rather as dynamic resources that actively shape and constrain healthcare processes (Greenhalgh et al, 2010).

OpenEHR is an international organisation conceived in Australia which supports the development and implementation of the EHR by assisting information and communication technology to effectively support healthcare, medical research and related areas. Within the OpenEHR community the following definition for EHR is adopted:

*An electronic longitudinal collection of personal health information usually based on the individual, entered or accepted by healthcare providers, which can be distributed over a number of sites or aggregated at a particular source. The information is organized primarily to support continuing, efficient and quality healthcare. The record is under the control of the consumer and is stored and transmitted securely* (OpenEHR, 2007).

The literature base suggests however, that implementation and progression of EHR to date has fallen short of expectations and although variants of EHR are now commonly used within the primary and acute care sectors, in many countries patient records are still local and departmentally orientated (Hardstone, Hartwood and Rees 2004). The International Standardisation Organisation (ISO) suggests that what is required is a comprehensive, multi-enterprise and longitudinal electronic healthcare record for patients which will require the linking of multiple clinical applications, databases and devices. An EHR designed in this manner can be tailored to the needs of individual conditions, specialties or enterprises, and most importantly not be viewed as a single monolithic system (ISO, 2005). Stakeholders who require access to EHR can therefore be framed from a macro, meso and micro process level.

Some of the key individuals and groups include members of the multidisciplinary team, the patients and carers, the hospital and primary care service providers. In addition there are those agencies which require access to particular elements of an integrated electronic record; these include pharmacy, nursing home providers, and those organisations, who are involved in financial reimbursement, accreditation and quality assurance agencies (Hannah et al, 2009).

In the past there was a clinical perspective that several clinicians were in a state of doubt as to whether the EHR is fit for purpose and in particular for widespread deployment (Goldschmidt, 2005; Hartwood et al 2003). They argued that important discrepancies existed between the presumptions of the role of EHR and the ways in which clinicians actually use and communicate information. A publication by Greenhalgh and colleagues supports this perspective (Greenhalgh et al 2010). They argue the case that people and technologies are linked in complex dynamic socio-technical networks. Such links, they contend, offer both possibilities and limits in regard to what is possible both materially and socially in particular situations and local contexts. Nohr (2007) reports on the diffusion of EHRs in different countries, as optimistic, suggesting that there is often a gap between the planning and actual development of useable and accepted systems.

What is required is a generalized approach to represent every conceivable kind of health record data structure in a consistent way (ISO, 2005). Beale and Heard (2007) suggest that *sustainability* is a key factor underpinning EHR design and development. They discuss the evolving nature of informatics suggesting that EHR development requires the inclusion of new specialist domains such as bio-informatics and genomics. Moving forward this will be particularly important in regard to fiscal matters relating to EHR (Hollar, Lozzio, and Lemak, 2005; Wadman, 2007). The debate as to whether the EHR can identify the subject of care as one person or a group of people or indeed both of these perspectives is also under review i.e. the family as a recipient of care. Another example in which this is evident is in the area of immunization in cases where individual subjects of care are viewed as a population group.

The ISO definition of an integrated EHR is *a repository of information regarding the health of a subject of care* (ISO).

Interestingly the OpenEHR definition is more ambiguous on this matter a *longitudinal collection of personal health information usually based on an individual*.

In the OpenEHR definition the text *entered or accepted by healthcare providers*, is an important phrase as it offers a broader scope relating to the autonomy of the patient and their chosen clinicians. This is reinforced in the final phrase of the definition by stating *the record is under the control of the consumer*. This approach endorses the view of the EHR as one which accommodates the subject of information to be seen as possessing an active role in maintaining health and presenting themselves as a consumer of a health service as and when is required. It also endorses the notion of interoperability as a requirement for the provision of shared healthcare processes across and between service providers. One of the challenges relating to EHR development is therefore to gain an unambiguous understanding of what the key core clinical requisites are to ensure systems are patient centred and, from a usability perspective, clinically appropriate in differing healthcare environments.

In effect the EHR must be able to support “electronic conversations” between both the subject of information or care and the health service providers who are delivering either single or multiple healthcare processes over extended periods of time.

In 2003 one hundred leading American healthcare professionals coordinated by the US Department of Health and Human Services agreed upon a suite of elements that are required for comprehensive EHR implementation in the United States (Hollar, et al 2005). The participating healthcare professionals suggested that an enterprise wide EHR programme would require public–private partnership and listed the following attributes as key elements in any EHR implementation:

- a) Data security.
- b) Common standards.
- c) A non proprietary nature.
- d) National scaling.
- e) Incremental growth,
- f) Simplicity in structure.
- g) Low entry barriers.
- h) Support of distributed systems.
- i) Flexibility and responsiveness.
- j) Use of internet protocols.

In the Netherlands, Spil and Katsma (2007) completed a study on EHR. They surveyed and interviewed a group of clinicians whom they defined as end users ( $n = 38$ ). They also engaged with a group of vendors, whom they define as suppliers ( $n = 8/12$ ), to ascertain what the end-users core processes and expected values would be for using an EHR in the Netherlands. Concurrently, the vendors were also asked to demonstrate their EHR products, in order to gain an insight into what they perceived their respective products could offer clinicians, particularly in terms of value for money. In this study the clinicians indicated that an EHR within their healthcare setting should accommodate: availability of information; less administrative work; analysis of information for research and management; uniformity of working processes and reliability. However Spil and Katsma (2007) concluded that five additional factors requiring closer consideration were also needed. This conclusion was based on discussions with physicians, and included additional factors such as direct contact with the patient, quality of care, collaboration with colleagues and time.

Interestingly the final factor “just being a good doctor” was raised in relation to the bureaucratically orientated process in which the clinicians operate within in the specific healthcare setting (Spil and Katsma, 2007, p.6). The authors’ research findings from the discourse analysis and the presentations of the vendors’ EHR projects were disappointing. Whilst some of the vendors possessed a good fit with patient logistics and freedom in the design process, there was limited decision support available in the EHR products presented with only one vendor offering a decision support facility in the EHR product. Spil and Katsma (2007) indicate that overall the systems were more descriptive than prescriptive, with the user input being time consuming and also the user interface resembling a spreadsheet.

A second and more recent evaluation study reported by Greenhalgh et al (2010) relating to shared electronic summary records development in England is also included in this section. Reporting on a mixed methods study, the findings indicated that creating individual electronic summary care records is a complex, technically challenging and labour intensive process. This large study included the development of 1.5 million electronic summary care records and the data collection processes included 416,325 quantitative cumulative encounters in participating primary care centers in England across three primary care sites.

From a qualitative perspective 140 interviews and 2000 pages of ethnographic field notes including 214 clinical consultation and documentary analysis on 3000 pages of documents were collected. Interestingly results from the study suggested that the main determinant of a summary care record access was the identity of the clinician. Access to the record varied from 0 to 84% of the time. When the summary care record was accessed by clinicians a better quality of care and an increase in clinician confidence was evident in

some encounters, although there was no direct evidence of improved safety, there was in a small number of cases, a significant positive impact witnessed on preventing medication errors. Greenhalgh et al (2010) concluded that the success or failure of the implementation at local service level was largely dependent on the interaction between multiple stakeholders from the various backgrounds who were noted to have different values, priorities and ways of working. Change agents were noted as instrumental in aligning conflicting logics and mobilizing of the implementation effort (Greenhalgh et al, 2010). The studies outlined above may offer some insight into clinical perspectives in relation to EHR implementation and design and can be supported in the literature by a number of authors who have critiqued the implementation process of EHR over the years (Avison and Young 2007; Heeks Mundy and Salazar 1999; Kaplan 1987).

### **4.3 Electronic Healthcare Record Implementation**

In Ireland over the past ten years, there have been a number of national policy publications and developments in healthcare reform that relate to EHR development. Table 4.1 identifies a number of reports which relate to EHR within Ireland, followed by a brief discussion relating to factors influencing EHR progression in Ireland.

**Table 4-1 Policy Publications relating to EHR in Ireland**

<b>Publications and Developments</b>	<b>Type</b>
Quality and Fairness: A Health System for You (2001)	Report 2001
Strengthening Primary Care Primary Care Strategy	Report 2000-2005
The Prospectus Report (Organisational Reform)	Report 2003
The Brennan Report (Funding)	Report 2003
The Hanly Report ( Reform of acute hospital sector)	Report 2003
The National Health Information Strategy	Report 2004
Health Service Executive	Established 2005
Health Information and Quality Authority	Established 2007
Commission on Patient Safety and Quality Assurance	Report 2008
Transformational Programme 2007-2010	Report 2008
Building a Culture of Patient Safety	Report 2008

In Ireland the EHR has been identified as an integral part of the national healthcare strategy entitled Quality and Fairness (2004). The report Health Information a National Strategy was also published in 2004. The primary focus of this document was on health information rather than on defining a framework for the implementation of a national EHR. However it did recommend information and service planning process requirements in Chapter 7 of the report. The Health Information and Quality Authority are identified in the report as the agency responsible for the implementation of a national information standards framework. A suite of common indicator data sets and quality assurance frameworks are identified for development as a priority (Department of Health & Children, 2004 Action 21 p.98). A report published by the Commission on Patient Safety and Quality Assurance in July of 2008 however criticised the delay in implementation of the 2004 report this is evident in the following comment from the report published in 2008:

*The National Health Information Strategy (NHIS) which was published in 2004 and is still not fully implemented should be reviewed in order to clarify the roles and responsibilities of the Department of Health and Children, the Health Services Executive and the Health Information and Quality Authority Inter Agency Group. All agencies should ensure that these key bodies work together to progress the implementation of the Strategy as quickly as possible* (Building a Culture of Patient Safety Report, 2008, p.36).

A key inhibitor in moving the transformational programme forward in Ireland is the development and implementation of a unique patient identifier. At the time of this review a Health Information Bill is being drafted which will address this issue.

Whilst there is no national programme on the development of EHR at the time of writing this thesis, there are a number of projects engaged in the development of systems for use in future EHR in Ireland. Two programmes are included as examples of EHR projects that are in progress in Ireland. The first programme is a study which relates to chronic disease management in Ireland with a specific focus on epilepsy care (Fitzsimmons, 2009). This study funded by the Health Research Board is in progress within a large teaching hospital in Dublin, and focuses on establishing an information system which will underpin research and development in epilepsy in Ireland. The project adopts a web based modular architecture which has the capacity to support other chronic diseases in the future. On completion, this electronic patient record aims to support core business functions such as care and administration processes in the epilepsy department for staff including face to face and remote contact with patients. The system will also offer a consolidated or user-specific view of patient information and include a database for interrogation of information for clinical and research purposes.

The second programme worthy of note is the Mental Health Information System (MHIS) developed by clinicians in St John of Gods Mental Health Institution in Ireland. The MHIS is described as a comprehensive integrated electronic patient record (EPR) and patient administration system (PAS) designed to support care from referral to discharge within the Mental Health Services. The system incorporates both community and hospital based services and includes a number of core modules which include Patient Record, Case load and Service Management, Statistics and Reporting and Information Access.

Key design principles include a *three click* guideline – users have a minimum number of clicks to access pertinent information at the point of care. Other design features include simplicity in interface

design, as the MHIS hides the complexity of multi location and delivery detail to end users by defining an interface view of the system by individual role and context. Identification of the clinical requirements for the MHIS initially commenced in the 1970's however the development of the clinical based information systems commenced in 1995. Further information is available from <http://www.mhis.ie/index.htm>.

#### ***4.4 EHR Implementation Standards and Open Source***

There are a number of international partnerships in existence today striving to deliver an integrated EHR. These international partnerships have evolved over many years and have close associations with the two main health informatics standards agencies for health informatics, namely the International Standards Organisation TC 215 and CEN Technical Committee TC251. Further information is available from <http://isotc.iso.org> and <http://www.cen251.org>. Two more of these international partnerships which will be discussed in this chapter are OpenEHR and Health Level 7. They have been included in this thesis as they inform the critical debate on semantic and syntactic interoperability and are actively contributing to EHR development at an international level. The health information standard organisations and their associated roles are also introduced in this section.

From an Irish perspective standards development is defined by National Standards Authority of Ireland (NSAI) as: *the process of identifying what exactly is required to be performed - in either a manufacturing or service process - to ensure that the end product meets an agreed standard of performance* (NSAI, 2008). In the domain of health informatics the National Standards Authority of Ireland Health Informatics Standards Consortium (NSAIHISC) is the committee which monitors and contributes to the development of health information standards both nationally and internationally.

A key function of this committee on health information standards is to review and comment on emerging standards under development within the international standards community. The International Standards Organisation Technical Committee ISO TC 215 is the agency responsible for the development of health informatics standards internationally. The core function of the International Standards TC215 is to develop standards in a safe, efficient manner and to provide governments with a technical base for health, safety and environmental legislation. ISO TC 215 is organised structurally into 9 working groups which are listed in Table 4-1

**Table 4-1 ISO Working Groups**

<b>Group 1</b>	<b>Data structures</b>
Group 2	Data interchange
Group 3	Semantic content
Group 4	Security
Group 5	Health cards
Group 6	Pharmacy and medicine business
Group 7	Devices
Group 8	Business requirements for EHR
Group 9	SDO Harmonisation

The working groups are each led by a convenor and meet a number of times a year to develop and revise health information standards. All standards and outputs from the working groups meetings are available to download from the ISO portal at <http://www.iso.org/iso/home.htm>.

The European standards organisation responsible for the development, revision, and review of healthcare standards within Europe is CEN TC251. This group is sub divided into 4 working groups (Table 4.2), each one engages with the development of healthcare standards:

**Table 4-2 ISO TC251 Working Groups**

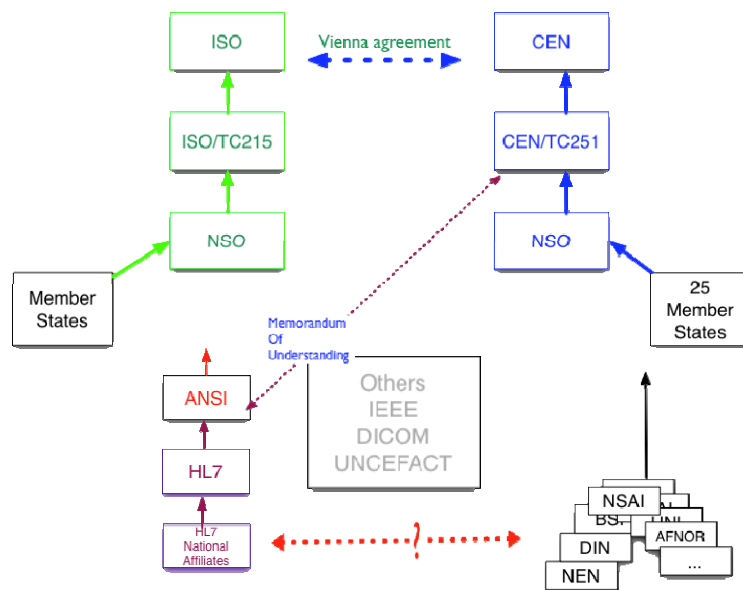
<b>Group 1</b>	<b>Communication information models messaging smart cards</b>
Group 2	Terminology
Group 3	Security, safety and quality
Group 4	Technology for interoperability (Devices)

A key focus for CENTC 251 is to achieve compatibility and interoperability between independent health systems, and to enable modularity by means of standardisation. This includes identification of the requirements on health information and structure to support clinical and administrative procedures. It also includes identifying technical specifications to support interoperability, as well as requirements analysis relating to safety security and quality of electronic healthcare records (Eichelberg, Aden and Reismeier, 2005, p.282). Interoperability can be defined as a state which exists between two application entities when one application entity can accept data from the other and perform the task in an appropriate and satisfactory manner, without the need for additional interventions by other parties (Hägglund, M. 2009).

Architecture in EHR is emphasized as a crucial element which underpins the entire development process, and which informs the structure for the overall system scope and design (Bossen, 2006a, p.69). Key aspects which require careful consideration within architectural frameworks include interfacing with potential legacy systems, the organisation of data, the data retrieval and search functions, and the response time to input and output data (Wozak et al, 2005). A technical requirements inventory which is provided by Blobel and Hasman (2007) suggests that what is required is a scalable, flexible, portable and secure design brief which includes an architecture based upon a component paradigm, model driven approach, and one which is capable of separating platform independent and platform specific models (Blobel, 2005, p.185).

To date research completed by software engineers includes extensive work in the area of concept model representation and information models for the various elements which embody the EHR. The standardisation working groups have made a number of attempts to tackle the issue of EHR interoperability. Some examples which have influenced EHR standards today include the Good European Health Record (GEHR) (Ingram, 1995) and the Synapses Programme (Grimson, Berry et al, 1998). Sharing new knowledge within the domain of health informatics standardisation is a key feature in progressing future EHR development. There is in existence a great deal of co-operation and sharing between the two standards agencies ISO TC 215 and CEN TC 251. One example of this co-operation is the Vienna Agreement which accommodates sharing of standards that are under development across and between the two agencies.

One output from this co-operation over many years is the establishment of international partnerships with the development of both formal and informal memorandums of understanding between both the standard agencies and international organisations with the associated member states engaged in the development of EHR. Organisations such as OpenEHR, Health Level 7 are two examples of organisations who are engaged in such agreements with the standards agencies. Figure 4-1 by Gerard Freriks (2010) has been included to demonstrate the hierarchical and networking structures that are currently in existence in relation to EHR and health informatics between the various SDO's and international organisations such as HL7. In Figure 4-1 the arrows depicts the relationships between the agencies that are collaborating to deliver on specific elements of EHR for example Dicom which is a international standard for Digital Imaging and Communications in Medicine. Figure 4-1 demonstrates how member state affiliates such as NSAI liaise with other non EU countries to co-operate, develop and implement health informatics standards internationally in the health care domain. The acronyms listed in the diagram are included in the abbreviations list in this thesis.



**Figure 4-1 Source Freriks Standards Agreement Chart**  
Source Freriks (2010) Semantic Interoperability EN13606  
Presentation EHRland Workshop

## 4.5 Standardisation, Information Models and Interoperability.

The key standard architecture in use today, relating to the subject area EHR is the European Standard for Electronic Health Record Communication EN 13606 (CEN TC251, 2009). This standard is often referred to as EHRcom. Other relevant work relating to EHR includes the work of the OpenEHR community and Health Level Seven Common Data Architecture (HL7 CDA) (Freriks, 2010). At the time of writing this review, a great deal of work is in progress to merge the work of the OpenEHR architecture and EHRcom. Whilst there are examples of OpenEHR and HL7 implementations parts 4 and 5 of EHRcom are still in development but almost complete (Freriks, 2010).

The Swedish Association of Local Authorities and Regions (SALAR) have recently published their decision to commit to the development of their national EHR using EN13606 (SALAR, 2008). Pilot work on archetype based conversion of EHR content models has been reported upon, and maintains that existing reference and archetype models are expressive enough to represent the existing clinical content models from the template based EHR systems tested (Chen et al, 2009). In the past ten years however in the industrial sector the main development architecture adopted has been HL7 CDA (Fernandez- Breis et al 2006, Toledo, Lallinde and Delpoz 2006). For the purpose of this review a brief overview of International Standards Organisation (ISO) and CEN the European standards relating to EHR and interoperability is now presented and discussed. The existing infrastructures of OpenEHR and HL7 relating to interoperability will also be expanded upon.

#### **4.5.1 EN ISO 18104 Informatics Standard for Nursing**

A key standard developed for nursing by ISO TC 215 Working Group 3 is ISO 18104. This standard developed and published in 2003 by the International Standards Organisation is entitled Categorical Structure for Representation of Nursing Diagnosis and Nursing Actions in Terminological Systems. The standard ISO 18104 is currently under review and the revised standard is scheduled to be published in the autumn of 2010. ISO 18104 offers a number of conceptual models to identify structures for nursing diagnosis and interventions which are supported by annexes in the standard. The key objective of this standard is to describe nursing in order to educate and inform students and other interested parties engaged in the development of electronic healthcare records relating to nursing documentation.

Nursing researchers can select concepts for inclusion in electronic records and map the selected concepts onto a constraint reference model. This ensures that the concepts and associated data elements are structured for inclusion in EHR and can be interpreted and analysed more efficiently in the future. The current revision sets out to include structures for patient outcomes however the 2003 version only relates to nursing diagnosis and interventions (ISO 18104:2003). This standard has not been explored in depth in chapter 3 as the current version of this standard does not include patient outcomes. It is however a significant standard for the profession of nursing particularly in regard to structuring concepts and terminology for future EHR use.

As the key principles underpinning this standard are also adopted in the International Classification of Nursing Practice® discussed in Chapter 3 this study would be compliant with ISO 18104 in its current form as the following example in Figure 4-2 demonstrates. The concepts focus and judgment are mandatory data elements for inclusion in nursing diagnosis. For example with a nursing diagnosis statement relating to a functional status concept such as a patient's ability to climb stairs independently is limited by the phrase – *Patient's ability to climb stairs is dependent partial* the standard would map the term as follows.

<p>&lt; Focus &gt; <i>mobility- climb stairs,</i></p> <p>&lt; Judgment is Degree &gt; <i>partially dependent</i></p> <p>&lt; Dimension is &gt; <i>ability.</i></p> <p>&lt; Subject of information is &gt; <i>patient</i></p> <p>&lt;site&gt; in this particular instance is not required.</p>
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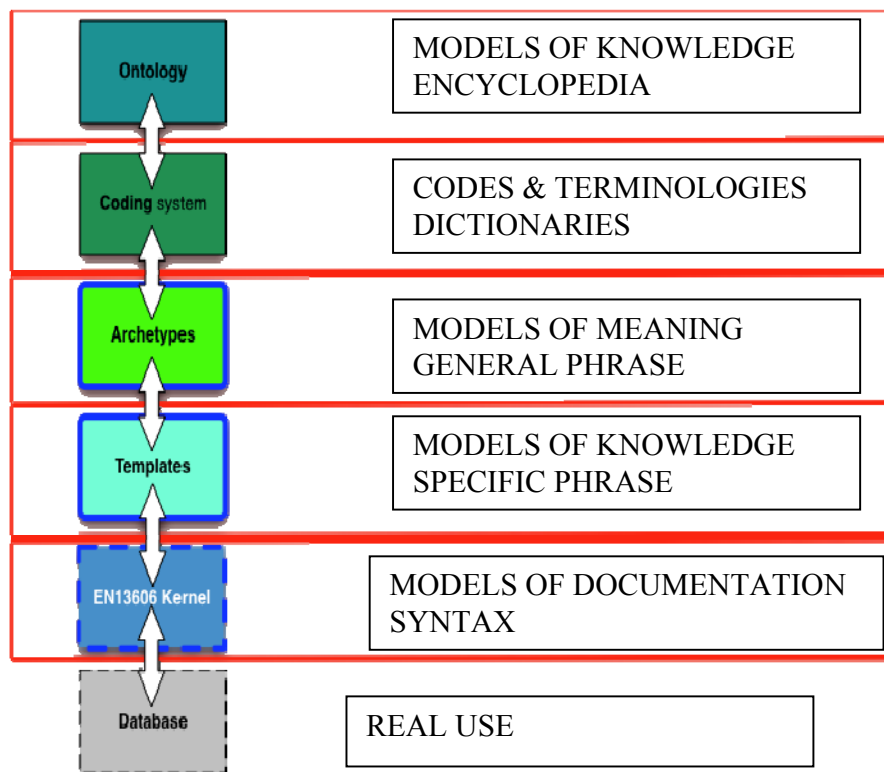
**Figure 4-2 Nursing Diagnosis ISO 18104**

#### **4.5.2 EN13606 EHRcom**

The CEN TC 251 standard for the EHR is EN13606 and has a standardised information model which is independent of EHR systems. The standard's primary function is to support continued efficient and quality integrated patient care. EN 13606 is a five part standard, parts 1, 2 and 3 are complete with parts 4 and 5 scheduled for completion by the end of 2010 (Berry, 2010) . The 5 parts of the draft standard are:

- a) The Reference Model,
- b) Archetype Interchange Specification,
- c) Reference Archetypes and Term lists,
- d) Security Features,
- e) Exchange Models.

EN13606 which has been developed over a twenty year time frame is based on two pre-standards ISO 18308 Requirements for an Electronic Healthcare Record Reference Architecture and ISO 22600 Privacy management and Access Control and has a strong architecture underpinning its development. Freriks (2010) created a semantic stack which illustrates the stages of development of resources relating to EN13606. As a focus of this thesis is to inform the development of archetypes which are compliant with EN13606, Freriks' (2010) semantic stack will be used in Chapter 7 to demonstrate key findings from this thesis. The semantic stack is therefore introduced in Figure 4.3 and offers a structured framework to depict the many dimensions that require careful consideration in the development of archetypes from how we know the world (ontologies) to how data can be presented and interpreted to ensure unambiguous meaning to both patients and healthcare professionals. In terms of the architecture of EN13606 the reference model and the archetype interchange specification detail will be discussed and described in greater detail in Section 4.6.



**Figure 4-3 Freriks Semantic Stack (2010)**

Source Freriks (2010) Semantic Interoperability EN13606 Presentation EHRland Workshop

### 4.5.3 Open EHR

The *OpenEHR* approach (<http://www.openEHR.org>) is defined as comprehensive open specifications for EHR systems. It was originally based on the results of the European Union's Good European Healthcare Record (GEHR) in the early 1990s (Garde et al 2007, p.2). Although the GEHR project developed via the third European framework in 1992, it was not until later that it continued under the name Good Electronic Healthcare Record with a strong participation from Australia (Eichelberg, Aden and Reismeier, 2005).

Today, it is maintained by the OpenEHR Foundation, as a non-profit organisation, defining itself as “*an international, on line community whose aim is to promote and facilitate progress towards electronic healthcare records of high quality, to support the needs of patients and clinicians everywhere*” (OpenEHR, 2008).

Beale et al (2007) promote a two tier approach, or dual model architecture, within the openEHR community, which is also integrated as part of EN 13606. This two tier architecture was formerly introduced in the Synapses project (Grimson, Berry et al, 1998). This approach introduces two distinct systems within the model, the domain and technical detail as follows (Beale, T. 2007):

- a. Domain concepts (which are described as the black box), are removed from the concrete software and database models, into independently managed and standardized vocabularies and libraries of domain concept.
- b. The Reference Object Model (ROM) system architecture, designed to process information by using externally supplied domain definitions.

Beale and Heard (2007) postulates that this approach tackles the various issues which have to date impeded the development of the electronic healthcare record. Issues such as the dynamic nature of the healthcare environment, and the ability for the record to evolve with the changing role of healthcare provision are possible, thereby facilitating and accommodating the development of scalable and adaptable models. Dual modelling adopts two main principles: 1) the separation of concepts in two levels, one defining the reference model and another defines the formation of archetypes (Fernandez-Breis, Vivancos and Tartosa 2006). Archetypes consist of three parts: *descriptive data, constraint rules, and ontological definitions*.

The descriptive data is comprised of a unique ID, and a machine readable code, which describes the concept modelled by the archetype, and its related metadata. This includes author versioning and purpose. As is the case with part 1 of EN13606 Reference Model, the constraint rules are the core of the archetype and define the structure, cardinality and content of the EHR component instances complying with the archetype. The ontological part defines the controlled vocabulary, which can be used in specific places in instances of the archetype (Eichelberg, Aden and Reismeier. 2005, p.280).

An extensive review of the work of the OpenEHR community is available on line at <http://www.openehr.org/>, however, for the purpose of this study, a brief overview of the archetype system and development process within *OpenEHR* and is outlined below.

An OpenEHR archetype is a computable expression of a domain content model in the form of structured constraint statements; based on some reference model (Beale and Heard, 2007); the archetype system is a framework for the development and use of archetypes and consists of two parts, namely the archetype authoring network and a dissemination mechanism. The archetype authoring network contains the following elements:

- Online repository,
- Collaborative authoring process,
- Querying and research tools,
- Quality assurance,
- Testing and approval processes.

The second part 2 consists of a dissemination mechanism for archetypes to be made available to production systems (Beale 2007 p.8). The archetype authoring environment follows a simple step by step process.

This includes development and review of the archetype, using the browsing and authoring tools which are depicted as the Clinical Knowledge Manager, and testing of the quality assurance of the archetype using the validation tools. For the purpose of this review, the author searched the OpenEHR Clinical Knowledge Manager. Key words for this search included *capacity, role nurse, assessment data, and outcome*. A total number of 286 archetypes were found on searching the Clinical Knowledge Repository. Key archetypes and associated templates found relating to this study are listed in Table 4.3 although this list is a representative sample only.

**Table 4-3 Open EHR Search 1 for Discharge Data Archetypes**

Archetype Title	Number of Archetypes Found
Role	6
Clinical synopsis	1
Evaluation	36

A review of the resource indicates that clinical synopsis and role archetypes are perhaps the most relevant to this thesis. The clinical synopsis archetype has one listed draft template in the resource. Other archetypes relating to evaluation referred to generic concepts such as archetypes relating to referral, device details or health events and to more specific archetypes and templates such as body fluid. The interface on the Clinical Knowledge Repository listed the following core elements presented in Table 4.4 in its architecture for both templates and archetypes relating to OpenEHR.

**Table 4-4 OpenEHR Architecture Elements**

OpenEHR Archetype	
	Cluster Composition Element
Entry	Action Evaluation Instruction Observation Admin
Section	Structure
Demographic model archetype	
	Address Capability Contact
Actor Role	Agency Organisation Party Group
Party Identity Party relationship	Cluster

The OpenEHR architectural elements in Table 4-4 whilst similar in nature to EN13606 are more comprehensive in the manner in which they are presented to the user in the Clinical Knowledge Repository. Table 4.4 will be discussed in more detail in the following section in order to make comparisons to EN13606.

The archetype clinical synopsis is now discussed as an example of an OpenEHR archetype. The archetype description suggests that the archetype clinical synopsis can be used to record a narrative, summary view of the patient's health. This archetype is defined as an unstructured summary which can include identified health issues; healthcare provided; associated interpretation; patient understanding; and enable communication about some of the softer, more subjective aspects of the patient's experience and journey.

The author of this archetype, (Heard, 2010) suggests that it may be most commonly used as a summary that is likely to be related to a specific health event such as a specific consultation or hospital admission, but may also be used to summarise the patient's health experience over varying time periods. It has been designed to create a meta observation that will complement the existing structured clinical record, allowing for expression of subtle, subjective or interpretive information about the patient that might not otherwise be obvious through structured data alone, providing balance and context to the EHR record. The archetype description offers an example of a Clinical Synopsis as one which can communicate a succinct summary of the patient's hospital admission as one component of a comprehensive and structured Discharge Summary document (OpenEHR online source).

Developments relating to EHR within the Health Level 7 community will now be reviewed. Health Level Seven (HL7) was founded in 1987 as a non-profit, ANSI accredited Standards Development Organisation. This HL7 community provides standards for the exchange management, and integration of data, which supports clinical patient care, and the management delivery, and evaluation of healthcare services (Eichelberg, Aden and Reismeier 2005, p.284). HL7 has an object orientated data model, which is called a Reference Information Model or RIM. The level 7 refers to the highest level of communication in terms of the International Standards Organisation Communications Model for open systems communication. HL7 is a protocol for data exchange and as such is not an actual standard. It defines the format and the content of the messages that applications must use when exchanging data with each other in various circumstances.

HL7 accommodates definitions of data to be exchanged, and supports functions, such as security checks, participant identification, availability checks, exchange mechanism negotiations and data exchange structuring (HL7 Organisation). The cornerstone of this communication is entitled the RIM, or Reference Information Model which is described by the HL7 organisation as:

*The Reference Information Model (RIM) is the cornerstone of the HL7 Version 3 development process. An object model created as part of the Version 3 methodology, the RIM is a large pictorial representation of the clinical data (domains) and identifies the life cycle of events that a message or groups of related messages will carry. It is a shared model between all the domains and as such is the model from which all domains create their messages. Explicitly representing the connections that exist between the information carried in the fields of HL7 messages, the RIM is essential to our ongoing mission of increasing precision and reducing implementation costs (<http://www.hl7.org/>).*

As this study does not use HL7 the author will not expand upon the architecture underpinning the HL7 in this chapter. It is interesting to note however that HL7's strength is in providing interoperability at a data level but not at a function level (Blobel, 2006, p. 187). Evidence suggests that HL7 version 2 is the health industry standard for communication and the most widely implemented protocol for healthcare information in the world today (Blobel 2006 p.187, Eichelberg, Aden and Reismeier 2005. Freriks (2010) maintains that HL7 cannot provide an effective platform for future EHR development as a stand alone resource.

The key rationale for this argument is based on the fact that the process of implementing message standards at an enterprise level is grossly time consuming and to achieve such an initiative at enterprise level using HL7 messaging would take many years and

the associated cost would be most prohibitive. Message standards are therefore inflexible and for this reason cannot support innovation in healthcare delivery (Freriks 2010). Considering this perspective in association with the cited studies by Greenhalgh et al (2010) or Beale and Heard (2007) who maintain innovation is a key catalyst to deliver a dynamic, scalable and flexible EHR, would suggest that stand alone messaging standards such as HL7 will therefore not be capable of delivering national EHR fit for purpose without a significant investment of time and money. One innovative method to deliver EHR with existing HL7 messaging is to develop a Detailed Clinical Models (DCM) which can assist in using messaging standards such as HL7 in association with more architecturally comprehensive EHR standards such as EN13606.

Developing detailed clinical models in healthcare is gaining momentum as it provides a structure for medical information, medical knowledge, data specifications and terminology in a combined construction to produce technical applications for EHR (DCM Foundation, 2010). Section 4.5.3 concludes with Table 4-5 developed by Freriks (2010) which illustrates how detailed clinical models are located between the existing HL7 message information model and EN13606. Table 4-5 has been modified to include only key elements of the HL7 and EN13606 from the original table by Freriks (2010) on the implementation process of EHR extracts. It is included to demonstrate the local adaptability of EN13606 over HL7.

**Table 4-5 Freriks comparison of HL7 and EN13606**

Source Freriks, 2010 EHR Systems Presentation EHRland Workshop

Exchange Message HL7		DCM	EN13606 Exchange		EN 13606 EHR System	
Exchange between databases not conformant with ISO 18308			EHR extract Reference Model conformant with ISO 18308		EHR Reference Model	
Not specified			Model describing how to make constraints	EN13606-2	Describe constraints	
		DCM	Describes what information gets documented		Describe concepts	
		EN13606 Representation Of DCM		Archetype	Definition of how topic is stored in database	
Message Reference Information Model RIM						
Model describing knowledge DMIM			Describes information needed in domain of exchange	Archetype Library	Domain Information Stored in Database	
Model of message scope CDA			Model describing local context , structure exchange	Template	Defines Content	
Technical standardized specification XML				EHR Extract		
Technical Representation IHE Profile					Not necessary	
Implementation vendors adopt software			Immediate implementation of extract and its archetype template		Immediate automatic implementation	
Local adaptability not possible			Possible		Possible	

#### **4.6 Standards ISO EN13606 and EN 13940**

Section 4.6 reviews two European standards which have had a direct bearing on this study. These standards are EN13606 the European standard for Electronic Healthcare Record Communication and EN13940 an emerging European standard entitled Systems of Concepts for Continuity of Care commonly known as Contsys. Both standards EN13606 Parts 1 and 2 commonly known as EHRcom and Contsys have shaped the course of this study over a two year period in the following way. The EHRland and PARTNERS projects have been engaged in defining the clinical requirements and testing of an EHRcom compliant archetype prototype as defined by EN13606 Part 1 and EN13606 Part 2. The identified clinical requirements for the summary assessment record in the PARTNERS study have then been used to develop a set of archetypes compliant with EN13606. Contsys describes a set of concepts for the development of information systems which can support continuity of care over time to facilitate integrated care from a high level perspective. The Contsys standard has been used to assist in the identification of concepts in a set of the archetypes developed by the PARTNERS and EHRland studies. For example one concept in Contsys which is of particular relevance to nursing is the concept of care planning. In this study a key priority is to develop clinically appropriate assessment tools for integrated care across different service providers. This study which seeks to support the continuity of care for persons aged over 65 years across and between 3 distinct domains of practice, namely the acute, primary and continuing care sector and has used Contsys as a reference framework to underpin the study. Two key outputs from this study relating to these standards are therefore:

a). A set of archetypes which includes contextually organised clinically defined data requirements to achieve integrated shared summary assessment records for transfer and discharge of patients across the acute primary and continuing care sector. The data definitions can be stored in future archetype repository. In this thesis the archetypes will be referred to in chapter 7 as Models of Meaning for General Use.

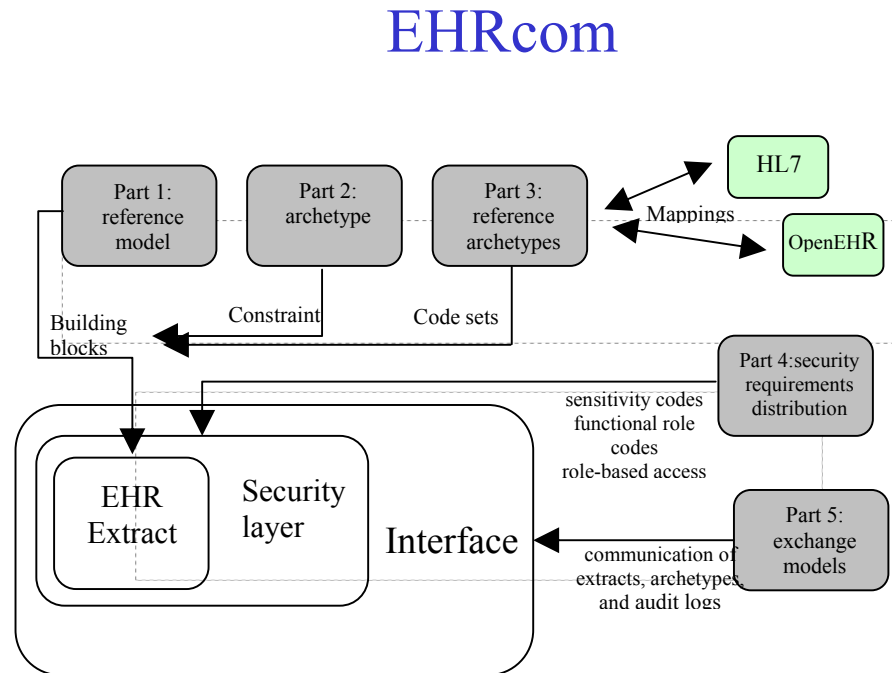
b) A draft archetype ontology framework to map existing nursing knowledge for use alongside other knowledge resources. In this thesis this resource will be referred to in chapter 7 as Models of Knowledge.

These outputs are stated as requirements in EN13606 part 2 in order to achieve optimal semantic interoperability. Both of these standards will be illustrated in the following section. The outputs from this study will be presented and described in detail in the discussion chapter of this thesis - Chapter 7.

#### **4.6.1 EN13606**

The primary goal of EN13606 is to define rigorous and stable information architecture for communicating part or all of EHR of a single subject of care. This will accommodate interoperability of systems and components which need to communicate data via electronic messages or as distributed objects (CEN, 2005, p 4). The standard states clearly that whilst EN13606 offers a set of practical and useful guidelines on how to design an EHR system it suggests that future EHR will be realised as a common set of external interfaces or messages which will be built on otherwise heterogeneous clinical systems (CEN, 2005,p.4). This approach supports the concept that EHR is longitudinal persistent individualised record which requires interfacing with multiple systems and service providers over an extended time period (Blobel,

2006; Hollar, et al 2005; Spil and Katsma, 2007). The graphical illustration Figure 4.4 demonstrates the key elements of EN13606.



**Figure 4-4 EHRcom**  
Source Camous et al, 2010 EHRland Workshop

#### 4.6.1.1 Part 1 The Reference Model

The Reference Model for EN13606 consists of four packages: The extract, demographics, access control and message, which collectively describe the various elements of the EHR, which are required for communication between systems. The mode of communication takes the form of an archetype which is the vehicle used to transfer information. The extract package defines the root class of the reference model and the data structures of the model. The demographics package provides a minimum data set, to define the various person's organisations, agents and devices that are referenced within the EHR extract. Access control package which is

part four of EN 13606 defines EHR access policies for disclosure of record detail. The message package which is part five of EN 13606 defines the EHR attributes required to communicate the EHR extract (Eichelberg, Aden and Reismeier 2005, p.283).

Part one of EN13606 defines the generic information (building blocks) for the purpose of exchanging patient detail within the electronic healthcare record. In part two the reference model is defined and is linked consistently across all five parts of EHRcom Part two defines the specification of the data interchange within the form of an archetype. Part two also depicts the mapping of the defined components from the reference model by defining the additional elements such as attributes and constraints, including linkage to the terminology and code lists. The logical building blocks of EHR in EHRcom are defined by Kalra (2004) as follows;

**EHR** – The electronic healthcare record for one person.

**Folder** – High –level organisation of the EHR e.g. per episode

**Composition** – A clinical care session, encounter or document

**Sections** – Clinical headings reflecting the workflow and consultation process

**Entries** – Clinical statement about observations, evaluations and instructions

**Clusters** – Nested multi-parts data structures (tables, interval, time series) e.g. audiogram

**Elements** – Leaf nodes with single data values e.g. reason for encounter, body weight

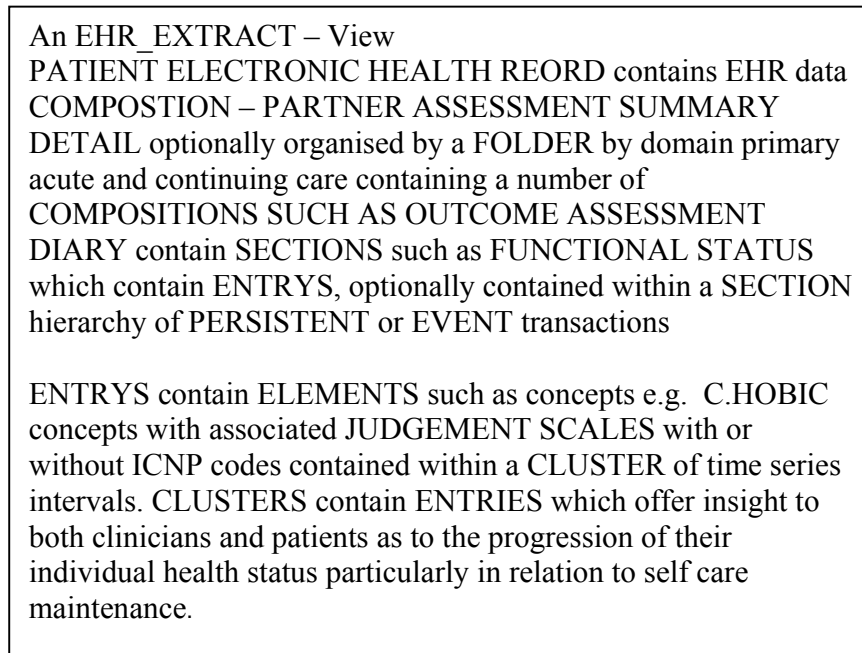
**Data values** – Data types for instance values e.g. coded terms, measurements with units

For the purpose of this review the building blocks are illustrated in Table 4.6 which offers a direct association between the reference model and how the PARTNERS tool links to the standard.

**Table 4-6 EHR Hierarchy and PARTNERS Tool**  
**Source Based on CEN, EN 13606\_1 2005, p.4**

Component Description		PARTNERS Example
EHR Extract Communication	Top level container. All EHR for a single subject of care. For EHR provider system and EHR recipient	Integrated Patient EHR
FOLDER Dividing into compartments	The high level organisation in an EHR (relating to care provided for a single condition by a clinical team or institution over a fixed time period e.g an episode of care	Examples include clinical pathway. Composition can also belong to certain folders and documentation session can be directed to different folders. PARTNERS has a series of folders for primary acute continuing care.
COMPOSITION	The set of information committed to one EHR by one agent as a result of one clinical encounter or record documentation session.	PARTNERS Summary Assessment Record review completed by one healthcare professional in one service environment. A number of compositions will need to be created.
SECTION	EHR data within a COMPOSITION that belongs under one clinical heading usually reflecting the flow of information during a clinical encounter structured	Persistent data transaction such as demographical data Or Event transaction such as functional status assessment detail from composition such as outcomes assessment diary
ENTRY	The information recorded into an EHR as a result of one clinical action observation, one clinical intention or interpretation	Functional status assessment clinical statement may indicate that functional status relating to ability to dress is impaired as patient dependent partial.
CLUSTER	This means organising nested multipart data structures such as time series	The time series of judgments created in assessment tool over a set time period and presented in table format
ELEMENT	The leaf node of the element of an EHR hierarchy containing a single node value	Functional status <ability to dress> Judgment scale = 3 – is dependent partial The data element is 3 or an ICNP reference code number.

In summary the PARTNERS tool maps to EN13606 reference model as presented in the following Figure 4-5.



**Figure 4-5 EHRcom and PARTNERS**

#### **4.6.1.2 Part 2 The Archetype Methodology**

In part 2 of the standard, archetypes accommodate specific clinical concepts to be built according to a prescribed constraint orientated system EN13606\_2. The process of development uses a formal description language entitled archetype definition language (ADL). This is the formal language used by EHRcom. Archetypes developed in accordance with the Reference Model defined in part one of EN13606 can then be used across differing clinical settings and for this reason are often described as forming the basic structure of semantic interoperability (Garde, Hullen and Chen, 2007). By using this formal structure (ADL), archetypes can be converted into HL7 refined messaging information models, which are called R-MIM's (Eichelberg, Aden and Reismeier, 2005, p.284).

This suggests that archetypes, as a data construct can be validated and queried by a multitude of differing healthcare systems. LinkEHR is a resource created in the University of Valencia by Cano (2010) which provides an ADL editor and Normalisation Platform. Cano (2010) has been using this resource to create a suite of archetypes as outlined in Chapter 7.

As is the case with the OpenEHR Clinical Knowledge Repository LinkEHR offers the user an interface which constrains the archetype development to subscribe to the reference information model building blocks in EN13606. So that the building blocks as defined by Kalra (2004) are used to define an EHR EN13606 compliant set of archetypes. The example in Table 4-7 compares the architecture between OpenEHR and EN13606 reference information model and demonstrates how Entry elements in OpenEHR offer the archetype developer a suite of options to select from. EN13606 as a Reference information model does not include templates and does not specify specific elements for inclusion in EHR other than the specifications detailed in Table 4-6. On review of the OpenEHR Clinical Knowledge Repository the author was impressed with the interface scope and detail included to inform users on how to create archetypes for development.

In particular the mind mapping facility demonstrates the detail of the existing archetypes in the repository well. The structures from a clinical perspective are intuitive in terms of entry components as they would reflect the existing documentation style of clinical recording procedures. For example, there are 36 individual evaluation type archetypes specified within the repository. The archetypes developed within both the OpenEHR Clinical Knowledge Repository and the EN13606 LinkEHR application will assist in advancing the integration of dual model architecture and in particular formalised language mapping into EHR in the future.

**Table 4-7 Comparison of Architecture Elements**

OpenEHR Archetype		EN13606
	Cluster Composition Element	Folder Composition
Entry	Action Evaluation Instruction Observation Admin	Entry Cluster Element
Section	Structure	Section
Demographic model archetype		
	Address Capability Contact	
Actor Role	Agency Organisation Party Group	
Party Identity Party relationship	Cluster	

In Table 4-7 columns 1 and 2 demonstrate the key components included in OpenEHR archetypes whilst column 3 lists the key components for an EN13606 archetype. It is evident from Table 4-7 that OpenEHR have included more detail in the archetype structure than EHRcom includes in the Reference Information Model. This may in part be due to the uptake and use of OpenEHR which assists in the development of definitions of elements for use within the OpenEHR archetype. One example of this is uptake is evident in the National E-Health Transition Authority (NEHTA). An Australian initiative NEHTA is engaged in the development of e.Health infrastructure and includes the development of a discharge summary

record which has been developed in consultation with a stakeholder group. NEHTA over a period of four years has gathered up to date intelligence and expertise on discharge summary records from participating clinical, administrative and analytical communities. This resource has been included in this particular chapter as it reflects the study topic under investigation and on review of the clinical core components of the tool it was noted that clinical synopsis role and evaluation archetypes from the OpenEHR community have been adopted to map to the Discharge Summary Structured Document Template. Appendix 2 in this thesis maps the data elements of the PARTNERS tool to the data elements of NEHTA and demonstrates the archetypes from the two tools in association with the archetypes created. This section concludes with an extract of an ADL Archetype code entitled Role created in LinkEHR in Figure 4-6. In this figure the individual constraints of the archetype are illustrated by the capital letters depicting the separate grouping of concepts within the archetype.

```

definition
  COMPOSITION[at0000] occurrences matches {1..1} matches { -- Role Encounter Record
    content existence matches {0..1} cardinality matches {0..*; unordered} matches {
      SECTION[at0001] occurrences matches {0..*} matches { -- Role Type
        members existence matches {0..1} cardinality matches {0..*; unordered; unique} matches
        {
          {
            SECTION[at0002] occurrences matches {0..*} matches { -- Role Identifier Healthcare
              professional
              members existence matches {0..1} cardinality matches {0..*; unordered; unique} matches {
                ENTRY[at0004] occurrences matches {0..*} matches { -- Public health nurse
                  items existence matches {0..1} cardinality matches {0..*; unordered; unique} matches
                  {
                    {
                      ENTRY[at0005] occurrences matches {0..*} matches { -- Clinical Nurse Specialist
                        items existence matches {0..1} cardinality matches {0..*; unordered; unique} matches
                        {
                          ELEMENT[at0008] occurrences matches {0..*} matches { -- Specify type
                            value existence matches {0..1} matches {
                              SIMPLE_TEXT[at0009] occurrences matches {0..1} matches { --
                                SIMPLE_TEXT
                                originalText existence matches {0..1} matches {/,*/; ""}
                              }
                            }
                          ENTRY[at0006] occurrences matches {0..*} matches { -- Community RGN
                            items existence matches {0..1} cardinality matches {0..*; unordered; unique} matches
                            {
                              {

```

**Figure 4-6 ADL Example Role**

#### 4.6.2 Continuity of Care - EN13940

A standard currently under revision by CEN Working Group 2 and which has direct implications for the electronic healthcare record is System of Concepts for Continuity of Care EN13940. As the name would suggest the core focus of EN13940 is in relation to the concept of continuity of care across and between healthcare providers. In February 2007 CEN TC 251 revised the standard EN13940:2001 and the pre standard prEN13940-1:2007 was prepared by the technical committee and submitted for formal vote. The document prEN13940 entitled System of Concepts to Support Continuity of Care has two parts: Part 1 basic concepts and Part 2 workflow. Part 1 of this pre-standard has now been accepted for approval and is in the public domain as EN13940\_1:2007. Part 2 of the document relates to issues regarding the effective transfer and linkage of data across and between services. Its core objective is therefore to describe workflow and it is currently under development. EN13940\_1:2007 sets in place a conceptual model that includes local management of information on a client in an individual healthcare setting, and also one which can facilitate information interchange between healthcare providers. Part 1 and 2 of this standard have the potential to contribute significantly to EHR development and design in the future.

EN13940 Part 1 introduces the basic concepts within the standard with key notions such as *health issue* and *health issue thread* as well as *time* related concepts. These are significant concepts within the domain of nursing practice as they offer an opportunity to define associations between health issues over an extended timeframe. This is often the case within individual patient care health records. Simply stated the patient or client has more than one problem and these problems are inter-related.

Contsys describes this process as follows:

*Continuity of care depends on the effective transfer and linkage of data and information about both the clinical situation and the healthcare provided to a subject of care, between different parties involved in the process, within the framework of ethical, professional and legal rules. The description and formalisation of continuity of care in information systems implies that the related concepts and descriptive terms be defined, so establishing a common conceptual framework across national, cultural and professional barriers* (CEN, EN13940\_1: 2009, p.6).

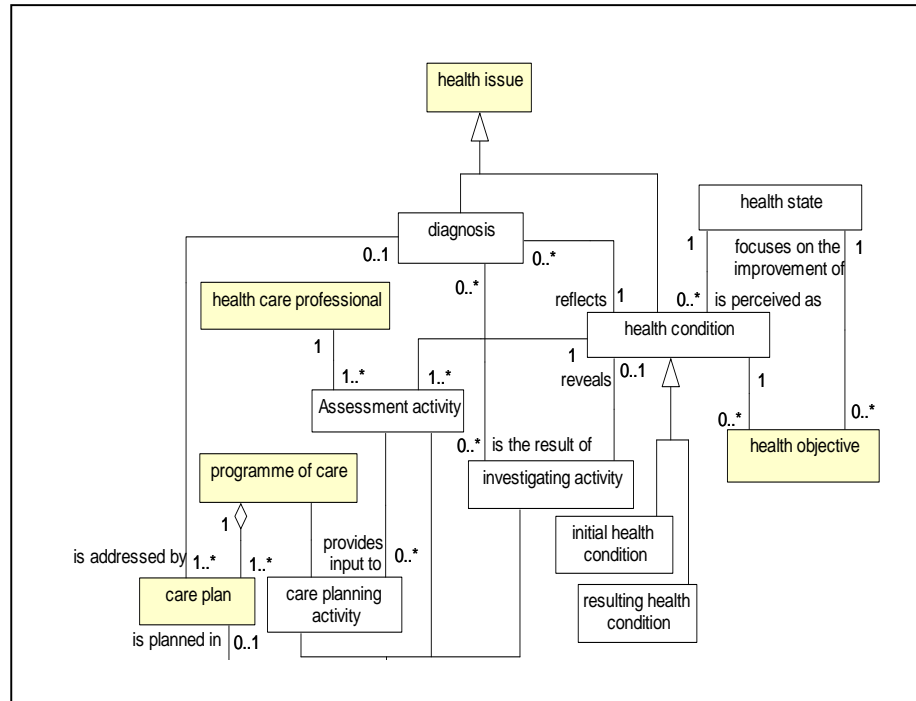
Health issue and health issue thread can be viewed as concepts which can be used to label and cluster information in an EHR which have a known association or relationship. The difference between a health issue and health issue thread is that one or more health issues can be linked together to make a health issue thread. This offers the clinician an alternative method to view patient or population data which complements the existing programmes of care which are in existence in the healthcare setting today. Existing healthcare record programmes generally are used to view clusters of information including diagnostic patterns by episodes of care. Goldschmidt (2005) refers to existing healthcare record programmes which offer clinicians *functional views assembled when needed from data stored in various geographic locations*. He explains that such views are constructed due to interoperability among EHR systems and often use intelligent agents to knit together data obtained from disparate sources into a single coherent record (Goldschmidt, 2005 p.71).

The implications of how data can be viewed and clustered within current health information systems and integrated into the design of future EHR are noteworthy and will play a significant role in the

uptake and use of EHR in the future. Clinicians require access to data at the right time and at the right place in order to inform clinical decision making for patient care. Clinical concepts (such as those identified in Contsys) can be used to create representations of information into coherent expressions which have the capacity to impact significantly on the how health professionals (and other interested 3<sup>rd</sup> parties such as health insurance companies) will source, view and indeed document information relating to care for a subject of information. There is no doubt that the EHR record will need to accommodate shared care not only to the patient, but also to many healthcare providers charged with providing the care process but ethically there are a number of issues that require careful analysis for example issues relating to assessment of social capacity for chronically ill patients to maintain independence and manage symptoms in the home, issues relating to allocation of resources for provision of care packages will need to be carefully considered. From the clinical perspective the EHR will require a more complex view of patient specific health issues that can be clustered into threads and monitored over time.

Such clusters or threads can be viewed over time to ascertain if they have a direct bearing on the impact of care or on the overall physical social and psychological health state of the patient. Examples of health issues identified in this particular thesis which have been highlighted by nurses to impact on nursing interventions include medication mismanagement and social isolation. Both of these identified health issues have a direct impact on individualized patient centred care and have a direct bearing on fiscal resources for future health service provision. The health issues impact upon the patient's ability to maintain independence in the primary care setting resulting in frequent readmission to the acute services.

Figure 4-7 offers an excerpt from Contsys and demonstrates the associations between concepts, health issue, care plan, assessment activity and healthcare professional.

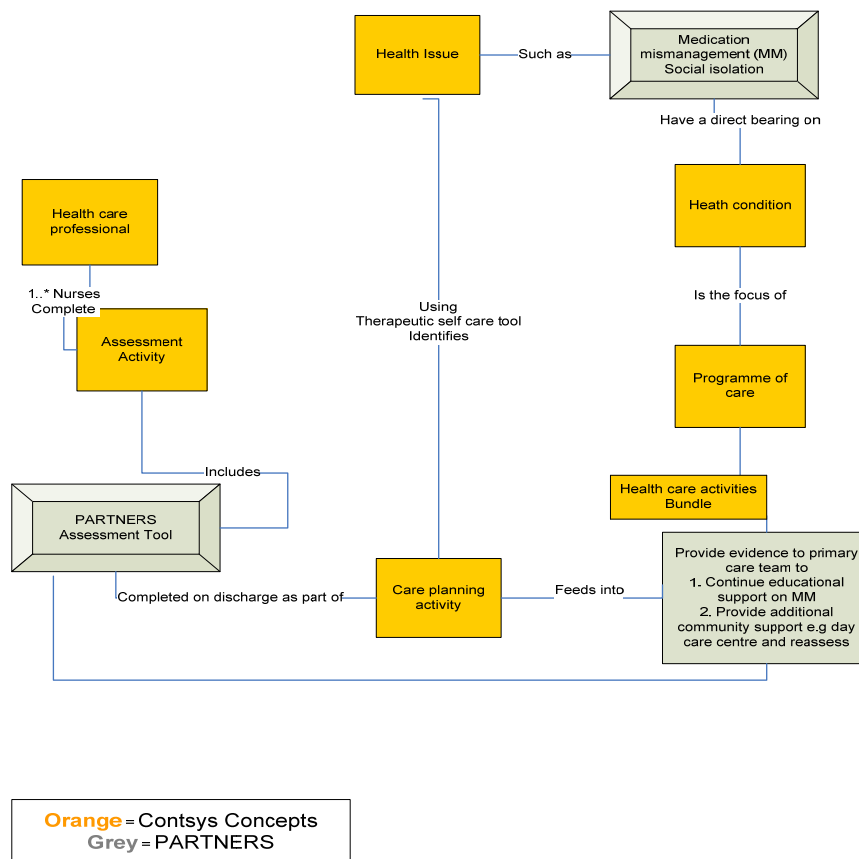


**Figure 4-7 Contsys Core Concepts**  
Source EN13940 part 1 CEN 2009

In the examples mentioned in this study in cases where there is a particularly higher incidence of readmissions there may be an extended delay in the identification of health issues such as social isolation and medication mismanagement particularly in cases where there are a number of services involved. By labeling the health issues as defined in EN13940 within an EHR all practitioners involved in the patient's programme of care can recognise the specific health issues which are causing readmission to acute services. Documenting the health issues in the care plan and providing care planning activity (interventions) to address the health issues will save time and energy.

It will focus primary care team interventions on the identified patient documented needs and the assessment activity will indicate whether the interventions are addressing the identified problems.

In Figure 4.7 the concepts which are shaded in yellow – assessment activity are used to inform the development of care plan that identifies care planning activities which when reassessed will inform the overall plan of care for the subject of information. These core concepts are now demonstrated in Figure 4-8 with an example.



**Figure 4-8 Contsys Concepts and PARTNERS**

Figure 4-8 demonstrates the work flow process of a case example in the following manner. A healthcare professional completes an assessment activity including one or many PARTNERS selected

archetypes such as readiness for discharge (therapeutic self care tool) and identifies one or more health issues. The health issue in this particular case example is the patient's ability to perform medication management. This is completed as part of the discharge summary record of a patient from a service in the care planning activity element of programme of care. The healthcare professional records the assessment of two health issues: one, that the patient has a health issue relating to medication management and two, that the individual lives alone and will require social support to manage their medications on discharge from the service. Interventions relating to education on medication management are included as part of the planned healthcare activities bundle in the programme of care and then a referral is sent to the primary care team.

The programme of care is evaluated and the health condition of the patient is assessed on discharge and again by the primary care team over a series of time intervals. At a time when the patient is competent with medication management the health issue is updated on the record as addressed and no longer an active health issue for this particular patient. In Figure 4.8 this example is demonstrated from a Contsys perspective with the concepts shaded in orange and from this study's perspective with the concepts shaded in grey.

## 4.7 Conclusion

In this chapter the literature has been critiqued from the perspective of syntactic interoperability. The author has focused primarily on EHR and those health information standards that can assist in the process of achieving syntactic interoperability.

Health information standards agencies and key principles required for effective implementation of EHR have also been discussed. EN13606 and EN13940 have been explored in order to inform this particular study. A series of figures and tables were used to demonstrate the standards in context. CEN the European standards agency is at the time of writing this review drafting a New Working Item Proposal (NWIP) within CEN to review how well the Electronic Healthcare Record Standard EN13606 Part 1 and Consys EN 13940 Part 1 will interface with each other in future development of EHR. In terms of specific characteristics of the EHR the Spil and Katsma (2007) definition of EHR, reflects the Consys principles offering accessibility to *complete and accurate patient data*. The participation of the Standards Development Organisations in tandem with the International organisations such as OpenEHR are making a significant contribution to EHR progression one example of enterprise development being NEHTA an Australian initiative, NEHTA is actively using archetype templates such as clinical synopsis in their stated core information reports. Spil and Katsmas (2007), in relation to aspects of OpenEHR, highlight important features of EHR such as *sink and source* and *push and pull* which offer a descriptive and salient analysis of the functional requirements of future EHR. With the current economic trends in population health this view is becoming a key priority within the healthcare information technology domain (Kilic and Dogac 2007).

For this reason the author would suggest that the review of EN13606 reference model and how it integrates with EN13940 is a timely, worthwhile and perhaps cost effective exercise in order to consider how these standards and the fledgling EHR's may impact upon quality of patient care in the future.

## **5. Research Theory Design and Methods**

### **5.1 Introduction**

In order to address rigour within a research design the investigator must carefully consider not only the methodology but also the philosophical intent of the study. Selection of a philosophical viewpoint within a study offers the reader evidence which can assist in judging the particular merits of a chosen methodology (Wilson and McCormack, 2006). The decision to select a particular research design is also a crucial element of the research process and according to Bryman (2004) is an important framework for the generation of evidence. Research design can also assist in providing linkage of specific criteria to the research question (Bryman, 2004, p27). Cresswell and Clark (2007) support this notion suggesting that a rigorous review of design methods is essential in order to inform and guide the decision making process. Research design can assist in locating the logic by which interpretations are made by the investigator in the study analysis. Critical analysis however suggests that evidence of the decision making process can often be absent from reported research (Clark, Lissel and Davies, 2008). The literature base indicates that within the realm of the social sciences the process of doing the study and considering the science of the paradigm is alluring; however the procedure of research design and method is often undertaken without wanting or needing to strongly question its philosophical underpinning (Wilson and McCormack, 2006, p.46). Clark et al (2008) maintain that failing to critique the research questions and objectives with a particular research design processes and method and relying on only common sense approaches during a study can result in a thesis which lacks wider credibility, is inadequately justified, or lacks internal coherence (Clark et al 2008, p, 67).

It is therefore important to restate the research questions and objectives at the outset in this research design and methods chapter which are as follows;

In this study the research questions under investigation are;

Can nurses build a common understanding of patient assessment for future outcomes based research which can facilitate shared care in older persons using action research?

AND

Does an action research approach assist in the development of archetypes in accordance with EN13606?

The research objectives of this study are:

1. To identify the interagency information requirements needed to provide an integrated summary record of care for older persons.
2. To categorise the core concepts (taxonomy) and develop and pilot test a prototype paper summary record to support shared patient centred care.
3. To map the above objectives to EN13606 and a reference terminology to achieve semantic and syntactic interoperability in the form of a set of archetypes.
4. To assist nurses to build a common understanding of what needs to be measured in patient assessment to inform future theory testing for outcome based research

Lipscomb (2008) proposes that three key elements must be addressed within the research design and methods chapter and logical connections must be made in the research process between:

- The ontological premises.
- The epistemological premises.
- The methodological premises.

Understanding that these three chains of reasoning exist and that they are logically connected within the study process is important as it assists students embarking on research to maintain lucidity in the design progression and the overall implementation and reporting of the study. Lipscomb (2008) maintains that in addition *such an approach pays greater heed to the conceptual linkages as it can also demonstrate argumentative coherence and validity as logical relations tend to exist between ontological epistemological and methodological concepts irrespective of their acknowledgment or recognition within research studies* (Lipscomb, 2008, p.33).

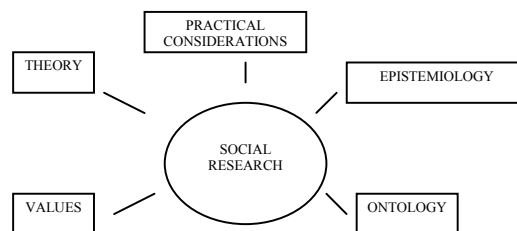
This chapter will therefore review such concepts and conclude with a critical analysis of the literature reviewed and the implications for this particular study.

In this Chapter Section 5.2 considers the ontological - the overall outlook by which the investigator views and articulates the study. This is often described as a worldview or paradigm. This section will also consider the epistemological view point the theories of knowledge which are in existence and which are commonly in use today within health and social healthcare research. Section 5.3 considers research design methods and frameworks that are particularly relevant to nursing practice and development, whilst Section 5.4 critically explores the literature base to search for the most appropriate design and method for this particular study.

This process is completed in order to ensure logical connections are made between the ontological, epistemological, and the methodological premises that underpin the author's work.

## **5.2 Worldviews and Paradigms**

All investigators need to consider a foundation for their inquiry and need to be aware of the implicit world views that they bring to their studies (Bryman, 2004; Cresswell and Clarke, 2008; Melynck and Fineout-Overholt, 2005). Arguments which are solely based on reason or which emphasised the existence of universal law do not tend to sit well with many researchers in the health and social care setting (Clark et al , 2008). There are many factors which influence social research and these are illustrated by Bryman (2004) in Figure 5-1:



**Figure 5-1 Bryman Conceptual Research**

Source Bryman 2004, p. 21

Creswell and Clark (2007) suggest that all researchers need a foundation for their inquiry in order to articulate and identify which particular world view they bring to their individual study. They offer a framework which includes four core world views that can be considered for use in mixed methods research.

They are post positivism, constructivism, advocacy or participatory and pragmatism.

Whilst Melynk and Fineout-overholt (2005), and Creswell and Clark (2007), offer a more summative view of the research process, by considering research from the perspective of a series of differing paradigms. They define the concept of paradigm as a world view or set of beliefs, assumptions, and values that guides all types of research by identifying where the researcher stands on issues related to the nature of reality (ontology), relationships of research to the researched (epistemology), role of values (axiology), use of languages (rhetoric) and process (methodology) (Melynk and Fineout-Overholt, 2005, p.591). Parahoo (2006) suggests that paradigms influence the nature of the study, the way in which the phenomena can be studied and the design methods which are most appropriate to answer research questions (Parahoo, 2006, p.38). From a nursing perspective Clark et al (2008) advocates the use of theory adoption to underpin research and argues that understanding complex patterns should be a priority for nursing research as it seeks to addresses key present and future healthcare challenges. This they argue needs to be underpinned with a sound and articulated ontology (Clark et al 2008, p.78).

Lipscomb (2008) stresses the need to acknowledge philosophical affiliation with theory and research practice in nursing and acknowledges a number of authors who offer a range of perspectives on why nursing research must address philosophical viewpoint in order to validate their research topic (Lipscomb, 2008, p.35). Positivism as an alternative paradigm to relativism has influenced much research and focuses on the positive sciences – that is on tested and systemised experience rather than on undisciplined speculation. Positivists take a realist view of social phenomena and maintain that the world has an existence independent of our perception of it.

There is an objective way of knowing what *it* (the focus of the study) is. Those individuals who ascribe to the notion of positivism support a separation between the researcher and their object of inquiry.

Alternatively, Creswell and Clark (2007) support the notions of advocacy and participatory worldviews which are often associated with qualitative approaches and focus on a need to improve our society. They tend to focus on empowerment and issues which affect marginalised groups. The focus of their attention is change of the social world for the better. Whilst pragmatism is more often associated with mixed methods research and the focus is more complex, with the primary emphasis on the consequences of the research. It also tends to adopt multiple methods of data collection to inform the problems under study. It is therefore pluralistic and orientated towards what actually works and the practice domain (Creswell and Clark, 2007, p.22).

Pragmatism is often described as a set of ideas articulated by many people from historical figures such as Dewey, James and Pierce to contemporaries such as Cherryholmes (1992), Murphy (1990) and Rorty (1990). It draws on many ideas including employing “*what works*” using diverse approaches and valuing both objective and subjective knowledge. Recently Tashakkori and Teddlie (2003) linked pragmatism to mixed methods research and offered the following key arguments for consideration. They contend that both qualitative and quantitative research methods may be used in a single study, and that the research question should be of primary importance – more important than either the method or the philosophical worldview that underlies the method. Finally they suggest that practical and applied research philosophy should guide the methodological choices (Creswell and Clark, 2007, p.27).

Bryman (2004) argues that the practice of social theory does not operate in a bubble and notes that methods of research are closely tied to visions of reality which he describes as theories.

Within the domain of nursing some authors suggest that the outputs of nursing research should have immediate consequences for patient care (Newell and Burnard, 2006, p.4), and research should connect to a wider social and scientific enterprise (Bryman, 2004). Early writings by Bhaskar supports this approach when he argues that the world in which we live and in which healthcare operates is complex, and could not be described even in principle as reducible to the conditions of a laboratory in which experimental studies may be contrived (Bhaskar, 1975).

Theories within the realm of social research can vary in range from grand theory to middle theory and whilst they may not offer the researcher indications as to how to guide or develop the research study, they are nevertheless influential in making evident the significance of the findings of the research. This is achieved by the manner in which the object of the study links with and between the research and theory. Some examples of grand theories include but are not restricted to structural functionalism, symbolic interactionism and critical theory (Bryman, 2004, p.4). An alternative method with which to view theory is to consider theory as something that occurs after the collection and analysis of the data associated with a project. In this case it is often referred to as deductive or inductive theory. Deductive theory considers what is already known in a particular domain and the researcher then deduces a hypothesis or hypotheses that must be subjected to empirical scrutiny and often uses quantitative research methods for the testing of the generated theory. Whilst inductive theory offers an alternative strategy for linking theory and research, it can also often contain a deductive element.

### 5.2.1 Action Research

The origins of action research date back to the pioneering work of Kurt Lewin (1890-1947). Elden and Chisholm (1993) argue that although the exact origins of it are open to dispute action research has been a distinctive form of inquiry since the 1940's when Kurt Lewin introduced the term as a way of generating knowledge about a social system while, at the same time attempting to change it (Elden and Chisholm, 1993,p.121)

Hart and Bond (1996) advocate that action research has developed from an Americanized form of rational social management to a more robustly democratic and empowering approach to change (Hart and Bond, 1996, p.13). Within the discipline of nursing Meyer (1993) maintains that the process of action research involves a four step framework of planning, acting, observing and reflecting which derived from Lewin's work and forms the basis for a modern day definition of action research (Meyer, 1993, p.1066). Participatory action research emerged in the later half of the 21<sup>st</sup> century. Paolo Freire (1970) a leading educationalist wrote the classic text *Pedagogy of the Oppressed* and broke away from the traditional process of carrying out research *on* people to instead carrying out research *with* participants thereby offering participants an opportunity to transform themselves. Freire argued that every person no matter how impoverished or illiterate can develop self awareness, which will free them to be more than passive objects in a world in which they have no control (Koch, T and Kralik, D. 2006, p.13). In considering health as a topic we must consider health within the context of community and its dependency on environmental factors such as attitudes and beliefs, qualities of relationships and well as bio-medical factors.

To understand our health we must see ourselves as interdependent with human and non-human elements in the systems in which we participate (Hughes, 2008 p.382).

By approaching health in such a holistic manner we include the context in which people exist. Health professionals, clients and communities are all part of a larger system of research which offers individuals an opportunity to help shape and influence communities. In order to achieve this action research requires people to be inquisitive about the relationships and forces between circumstances, actions and consequences in their lives (Koch, T and Kralik, D.2006 p. 41). This development occurs through a process of action, research and growth. Winter (1998) describes this process as voices, from which participants can share experiences with others, learn from each other whilst concurrently collaborating in the formation of new knowledge. A key element of the data collection process within action research studies involves a process entitled triangulation. The procedure of triangulation involves sourcing more than one method (usually three sources) of data collection. The method of triangulation was originally conceptualised by Webb, Campbell, Schwartz, and Sechrest (1966) as an approach to create measures of concepts whereby more than one method would be employed in the development process of measures. Therefore leading to greater confidence in the overall findings of studies which use triangulation as a data collection method.

Within the domain of healthcare there is an extensive diverse literature base available which adopts action research as the preferred research design. Koch and Kralik (2006), advocate that participatory action is in itself a useful process within everyday healthcare practice.

*Ideally healthcare is organised within an integrated team and supported by a community network that includes partners not only the healthcare workers and service providers but also the community itself* (Koch and Kralik 2006, p.89).

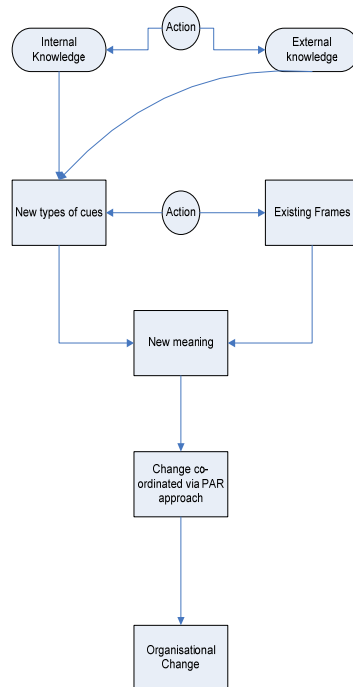
According to Kemmis (2001) action research is rooted in participation which in turn supports key values of purpose.

Heron and Reason (2001) describes the process as a situation in which all those involved can contribute both to the thinking that informs the inquiry and to the action which is its subject (Heron, and Reason, 2001). Examples of studies which adopt an action research design include those which seek to address educational requirements on HIV/AIDs in Tanzania (Mabala and Allen, 2002), or projects which seek to improve care in nursing homes in Australia (Street, 1999). Systematic reviews note an increased use of participatory action research in public and community healthcare (Viswanathan, Ammerman, Eng, Garlehner, Lohr and Griffith, 2004), and also in health promotion (Green, George and Daniel, 1995). Hughes (2008) argues the case that there is an increase in community based participatory health research in the USA and that systematic reviews demonstrate that half of all studies meeting this criteria have been published after 2000 (Hughes, I. 2008, p.382). One method, which draws on action research design and is used in the development of information systems, is Dymeks Action and Sense making Model (2008). According to Dymek (2008), considering existing and new frames in relation to work practices is the first step of an action cycle. Drawing on social science work and interpretive schemes such as Argyris and Schon, 1978, Hedburg, 1981 Dymek argues the case that fundamental change in organisation's thinking and doing requires schemata change. By linking this course of action with

informatics, Dymek (2008), advocates that this practice provides a key element in developing and implementing information systems. This is demonstrated in the following quote;

*In large IT projects, where many departments are affected, there are typically wide variations in views about how best to implement the new systems. These views result in part, from different schemata or frames held by members of different departments of an organisation. Moreover power issues come into play with IT projects- the powerful voices typically hold sway around what gets implemented.*  
(Dymek, 2008, p. 576).

He maintains that reconciling diverse frames and power bases in IT projects has been accomplished in action research project completed by McDonagh and Coghlan (2006). He proposes adoption of an action sense making model. The cycles of action and reflection offer an opportunity for group learning and are useful during the action process required in development of new systems. This perspective is offered in a conceptual framework in Figure 5-2. Through a process of critical reflection internal knowledge possessed by individual participants is merged with new knowledge gleaned from a variety of sources accommodating opportunities to create new meaning.



**Figure 5-2 Dymek Sense Making Model**

Source Dymek, 2008, p.576

Feminist theory is linked to participatory action research and is described as;

*A conscious raising experience which provides a way in which a greater awareness is achieved and results in action as the researcher and participants engage in mutually educative and liberating encounters.... a leading goal of feminist research is empowerment of the people participating in the research through the co-construction of knowledge.* Koch and Kralik 2006, p.15

### 5.2.2 Feminist Theory

Feminist theory adopts a standpoint of exploring the everyday. This attention to detail can yield significant knowledge which assists us to understand the problems under investigation. This is best articulated by Smith (1996) in the following text;

*Our everyday worlds are in part our own accomplishments, and our special expert knowledge is continually demonstrated in their ordinary familiarity and unsurprising ongoing presence.*

(Smith 1996, p.111)

Feminist theory has also been linked to change management. In the case of technology implementation there is also evidence to suggest that practitioners often need to be empowered to carry out such change processes as system design and development. Suchman (1994) also offers a strong argument based on a feminist reconstruction of objectivity for the development of alternative practices of technology production and use. In her paper *Located Accountabilities in Technology Production*; she argues the case that just as the term “designer” opens out on closer inspection, onto an extended field of alliances and contests, so does the term *user*. Organizations comprised of multiple constituencies each with their own professional identities (Suchman, 1994 p. 8). So in terms of giving a voice to specific professionals in the design and implementation of effective and efficient technologies there is some credence in considering the feminist theory perspective. Kralik (2005) notes that action is the political side to feminist research; it is the side which states “let us not simply observe and analyze these systems, but facilitate the action necessary for change to occur”.

### **5.2.3 Social Constructivist Theory**

The phrase, social construction, typically refers to a tradition of scholarship which traces the origin of knowledge, meaning or understanding to human relationships. Likewise the term constructivism is sometimes used inter-changeably, however most scholars associate the term constructivism with the individual mind as opposed to human relationships (Gergen et al, 2003, p160). Often whilst social constructionism is linked to Vico, Nietzsche and Dewey it is Berger and Luckmann's (1966) work that is often most associated with the emergence of the theory. The process of action inquiry has from its very inception laid stress on processes of collaboration. Heron and Reason (2001) specifically emphasize action research as a practice of co-operative enquiry in a domain of practice which carries out research *with* people rather than *on* people. An action research methodology therefore places the emphasis on participation of the excluded in knowledge construction itself, and has come to influence the thinking of policy makers and the development of professionals (Brown and Tandon, 2008 p.228)

### **5.2.4 New Institutional Theory**

Dickenson's (2008) worldview of research can be seen through the lens of organisational theory. Organisations are typically arranged in one of three ways: markets, hierarchies, and networks. The notion of networks, she suggests tend to be characterised by actors recognising complementary interests and developing interdependent relationships based on trust, loyalty and reciprocity to enable and maintain collaborative enquiry. This trust reduces transaction costs without creating the same formal structures associated with hierarchies.

Drawing on the work of Sullivan and Skelcher (2002), Dickenson offers a framework which incorporates a range of approaches to understanding research that involves collaboration and which builds upon the aforementioned theories but offers a more pragmatic perspective which supports partnership and promotes social capital. She also argues that in reality organisations do not tend to exist in essential forms, but rather work collaboratively to achieve mutual goals. Table 5-1 provides an insight into the key realist theories of collaboration (Dickenson, 2008 p. 38).

**Table 5-1 Organisational Collaboration Dickenson**  
Source Dickenson 2008, p.38

	<b>Optimist</b>	<b>Pessimist</b>	<b>Realist</b>
Why collaboration happens?	Achieving shared vision: collaborative empowerment & Regime theory Resource Maximization Exchange theory.	Maintaining / enhancing position: Resource dependency theory.	Responding to new environments: Evolutionary theory.
What form of collaboration is developed and why	Multiple relationships: Collaborative Empowerment theory.	Inter organisational network: Resource dependency theory.	Formalised networks Evolutionary theory Policy networks - governance instruments: Policy network theories including New institutional theory.

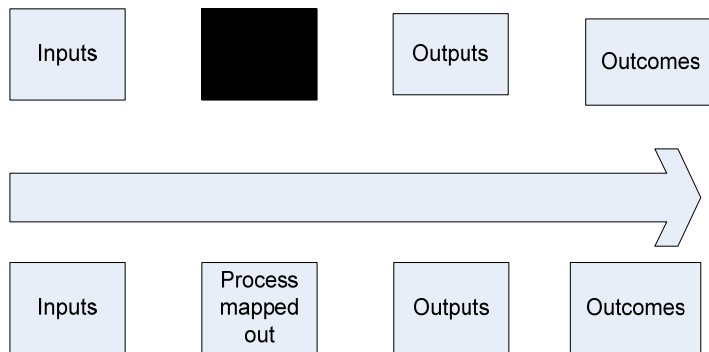
The realist perspective suggests that individuals collaborate in response to a wider agenda that incorporates and accommodates the co-existence of both altruism and individual gain.

New institutional theory examines why organisations might wish to collaborate. New institutional theory suggests that organisations take on particular characteristics or initiatives not because they have necessarily demonstrated that they are most effective, but because the institutional environment values these behaviors. In the past twenty years there has been a renewed theoretical attempt to establish an independent role for social actors and their contribution to social change (Fligstein, 2001). Furthermore the notion of partnership is growing in popularity and the mechanism of partnership may in itself become a driver for change.

Dickenson (2008) maintains that because policy has not been specific about what partnership should achieve whilst simultaneously reiterating the importance of partnership, the concept is seen as a potential solution to a number of the challenges currently facing communities dealing with health and social care (Dickenson, 2008, p.46).

#### **5.2.5 Theories of Change, Evaluation and Complex Realism**

Dickenson (2008) indicates that when evaluating outcomes the theory adopted within particular studies is a key factor. She identifies a number of various research methods and theories in her book on evaluation of *outcomes* in health and social care. She advocates that by simply looking at inputs, outputs and outcomes of a study may lead to an incomplete picture. This she refers to as a “black box” evaluation. Figure 5.3 is cited from her book



**Figure 5-3 Black Box Dickenson**

Source Dickenson, 2008, p. 69

Clear box evaluation: processes mapped out, can make statements about causality with more certainty (Dickenson 2008, p.54)

For the purpose of this particular study it is relevant to mention that randomised control trials and non-randomised comparative design are identified as failing to unlock the “black box”. Whilst qualitative methods were depicted as quite labour intensive and often present difficulties in generalising the results. The approach which appears to suit this particular study was the multi-method approach. This method combines both quantitative and qualitative approaches and often involves the researcher swapping between epistemological bases and various frameworks. The strengths of this approach facilitate the perspectives of all stakeholders and accommodate the complexity of the phenomena under study (El Ansari and Weiss, 2006, p178 cited in Dickenson 2008, p.58).

Theories which support clear box evaluations are Theories of Change and Realistic Evaluation. These are theories which accommodate multi-method approaches which incorporate both qualitative and quantitative design. Rather than inferring causation from the input and outputs of a project theory led evaluation aims to map out the entire process (Pawson and Tilley, 1997).

The author considers Dickenson's perspectives outlined in this section as significant for this particular study. As a key requisite in this thesis is to understand the local context and expertise of the participants in order to design a clinically appropriate archetype for future use, key principles will be adopted in the study.

<b><i>DECISION POINT</i></b>	<i>Use Clear Box Evaluation Approach Consider either Theories of Change or Realistic Evaluation as theory of choice to underpin the study.</i>
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This author offers Table 5-2 and Table 5-3 as a summary of the various methods, which can be used for individual studies.

Source Dickenson, 2008, p.62

Table 5-2 Theory of Change

<b>Approach</b> <b>Theories of change</b>	<b>Strengths</b>	<b>Limitations in Practice</b>
<p>A systematic and cumulative study of the links between activities, outcomes and contexts of the initiative. This approach involves stakeholder's surfacing the theories underpinning how and why a programme will work in as fine a detail as possible and identifying all the assumptions and sub-assumptions built into this process.</p>	<p>By specifying what will happen in terms of short, medium and long term outcomes of the interventions</p> <p>ToC seeks to overcome issues of attribution.</p> <p>Assists in planning and implementation of an initiative</p> <p>in-depth analysis of internal process issues.</p> <p>Multiple stakeholder involvement</p>	<p>External evaluation teams are rarely party to planning discussions in practice, so surfacing activities are unable to take place at this point.</p> <p>ToC demands that one theory should prevail , but this is often not appropriate in practice</p> <p>National evaluation of Health Action Zones (Barnes et al , 2005)</p>

**Table 5-3 Realistic Evaluation**

<b>Approach Realistic Evaluation RE</b>	<b>Strengths</b>	<b>Limitations in Practice</b>
<p>RE suggests outcomes are characterised by the equation of (C) Context + (M) Mechanism = (O) Outcome. Pawson and Tilley (1997) argue that no individual level intervention works for everyone and no institution level intervention works everywhere. RE seeks to discover what mechanisms work for whom and within which contexts.</p>	<p>Overcomes issues of attribution by uncovering micro-level theory identifies which mechanisms work for which individuals, and in which contexts. Cumulative potential of knowledge with CMO configurations</p>	<p>Problems in identifying the outcomes of partnership working Problems in identifying mechanisms Pawson and Tilley (1998) suggest these are often micro level psychological processes, but they have often been interpreted as grander theories in practice.</p>

Realistic evaluation and Theory of Change have also been linked to the notion of complex critical realism which is emerging as a competent basis from which to theorize the human sciences as well as the profession of nursing (Clark et al 2008). Complex critical realism as a research framework is described by Clark et al (2008) as a wider attempt to harness the strengths and address the weakness of positivism, idealism and relativism. It acknowledges the possibility of science but recognises the social dimensions of humans and science in a manner that does not fall into problematic versions of relativism or positivism (Clark et al, 2008, p.68). In their paper on complex critical realism Clark et al (2008) identify a particular worldview of specific complex critical realism which they summarise as follows:

- a) The existence of independent social and physical reality:  
This notion relates to the reconciliation of the objective and subjective values. In brief, human social processes and perceptions (including science as with physical phenomena) are fallible and perspective; therefore, judgements made relating to discourse in regard to social phenomena should be considered with other objective available data.
- b) A stratified emergent generative ontology: Bhaskar (1998) advocated that for experiments to be possible, underlying structures, powers, and processes must act together under certain circumstances to influence observable events. Clark et al (2008) argues that the underlying phenomena are as real as the observable effects and outcomes they cause. Therefore reality is divided into three domains a) the actual b) the real and c) the empirical. These domains must be considered with the

notion of transfactuality (the frequent misalignment of the actual, real and empirical as human perceptions in the empirical domain are fallible representations of the real and actual domains), and emergence. Complex critical realism offers emergence as a relationship between two features or aspects such that one arises from the other. However Clark et al (2008) stresses that in practice this suggests that entities can be classified hierarchically into strata at a micro and macro levels.

- c) An explanatory focused open-systems view: This perspective relates to understanding deep causation in a complex world. In this frame the authors advocate that social phenomena occur in open systems rather than in artificially controlled closed systems such as laboratory experiments. Drawing on the work of Sayer (2000) the research paradigm must acknowledge the open nature of the social world in which numerous factors are present and interact in highly complex and variable ways over time and context. Understanding the causes and mechanism is crucial to the research process specifically in terms of outcomes based research as the following quote demonstrates; *To understand outcomes and patterns, researchers still need to examine regularities in the world but search for explanations beneath these patterns to account for why they did or did not occur* (Clark et al , 2008, p.71)
- d) Recognition of complex agency and structure interactions: In this point Clarke acknowledges complex critical realism and draws on the side of caution advising the investigator to ensure that their conceptions actually minimise the distortion of the actual domain. This can be

achieved by careful scrutiny on modes of extraction of the data.

- e) Methodological eclecticism and post disciplinary stud. In this section Clark et al (2008) advocate that all phenomena cannot be quantified and advises the investigator to carefully scrutinise the research design method and the applicability to the study. They also advocate the notion of moving beyond single disciplinary research thus avoiding *disciplinary imperialism*
- f) Using complex critical realism to inform research questions. In this final point Clark and his colleagues advocate that although complex critical realism has some methodological and theoretical implications it does not in itself constitute a method (Clark et al, 2008, p73). The areas identified are health outcomes explaining events in context, understanding and improving interventions, and towards integrative programs of nursing research such as understanding bio psychosocial pathways (Clark et al 2008, p73).

The preceding summary points identified by Clark et al (2008) presents the author of this thesis with a set of guiding principles which can inform this study. By adopting Clarke et al (2008) complex critical realism principles, the author can consider the study objectives from a particular viewpoint. For example understanding the specific cause and mechanisms relating to complex agency and communication patterns will assist in identification of interagency information requirements (Objective 1). This approach will also assist both the author and participants in building a common understanding of what needs to be measured for outcomes based research (Objective 4)

Complex critical realism offers a deeper understanding of causation in the complex and dynamic world of healthcare. The environment in which this particular study is carried out involves a number of participants from differing agencies and complex critical realism will accommodate investigating this environment as an open system which is not easily controlled or understood. Explanations can therefore be sought by the researcher for causation and mechanisms to inform the research process. Clark et al (2008) do however maintain that complex critical realism does not in itself offer a research method. Nor does it advocate use in studies which are specific to only one particular domain (disciplinary imperialism), which in this study is the case. Therefore in section 5.3 the author will consider particular research methods which could be considered appropriate to link with a complex critical realism approach.

### ***5.3 Research Design Methods***

This section reflects upon methodology relating to the development of this thesis and its associated tangible outputs. It is divided into two sub sections; first Section 5.3.1 will offer a selection of broad research utilisation frameworks currently in use in practice development within the sphere of nursing. The justification for including these frameworks is based on the fact that this research is underpinned by complex critical realism and is practice-orientated. The literature base suggests that new implementation methods and frameworks are required in order to support implementation of evidence based clinical practices within healthcare (Clark, et al., 2008; Stetler, et al., 2008). Subsection 5.3.2 of this chapter focuses on specific research design methods for data collection and analysis.

### 5.3.1 Research Frameworks Relevant to Nursing

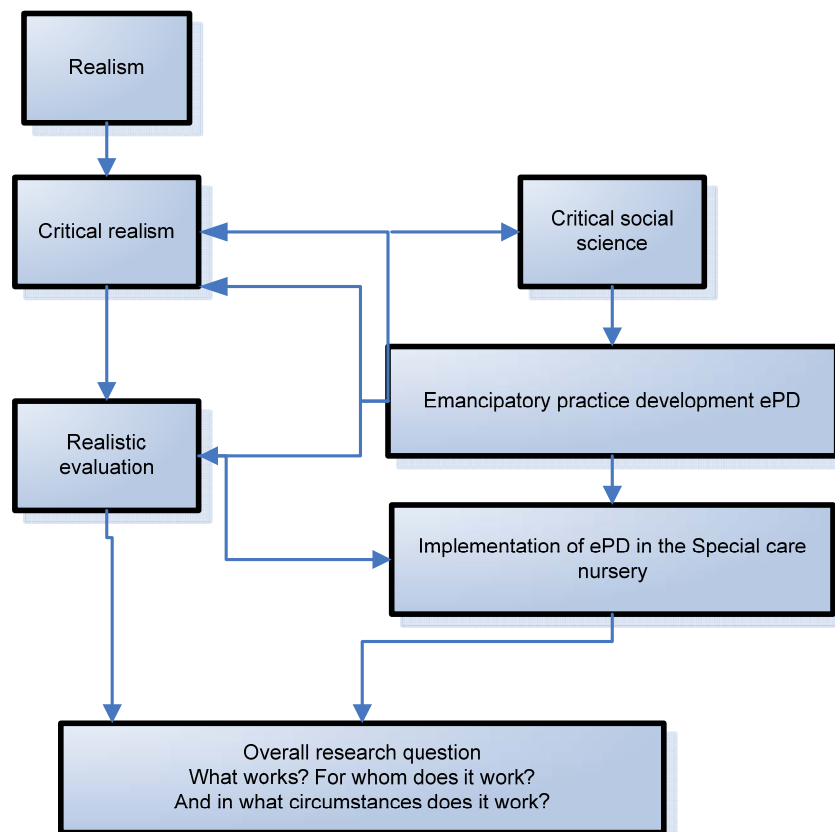
A number of frameworks were critiqued in this review, however only a small number have been shortlisted for closer inspection. The author will therefore only discuss the most relevant frameworks, and refer briefly to those frameworks which were considered and discounted during the study programme. The frameworks included in this chapter are often titled implementation methods and can assist in the timely adoption of evidence based clinical practices. They can also offer clinicians in practice a strong and illustrative overview of the decision making process within research studies. One framework by Wilson and McCormack (2006) identifies emancipatory practice development (ePD). This framework is described as a vehicle for programmes of research aimed at promoting the empowerment of nursing staff, whilst utilising staff knowledge and expertise to identify the need for change. The process of ePD encourages reflection on and in practice, whilst supporting staff to challenge themselves and each other (Wilson and McCormack, 2006, p. 49). Based on a theory of critical social science the ePD approach to practice development differs from a more technical approach to practice development in that it seeks to develop the individual rather than assist in the development of technical knowledge and skills for the individual practitioner. It consists of three phases: enlightenment, empowerment and emancipation. Phase one draws on the notion of emancipatory intent linking to transformative action and in turn transforming the culture in which practice takes place. Integral to this process is *enlightenment* in order for practitioners to become aware of the changes that are required. Once enlightenment has been achieved practitioners need to act upon this information in order to achieve

more effective patient centred care or as Wilson and McCormack suggest they are *empowered* to act (Wilson and McCormack, 2006, p.49). The final phase is achieved when the enlightened and empowered practitioner takes action which results in transformation in the practice setting – resulting in emancipation. As a framework the process of ePD links well with realistic evaluation as defined by Pawson and Tilley (1997) and the notions of complex critical realism. According to Wilson and McCormack (2006) issues such as power relationships suits the domain of nursing practice. This is evident in the following quote from Wilson and McCormack:

*Previous evaluations of practice developments in nursing have tended to either focus on evaluating outcomes using experimental designs or emancipatory approaches where an in-depth understanding of the effectiveness of processes in a particular context is developed.*

(Wilson and McCormack, 2006, p.50).

Pawson and Tilley suggest that such approaches accommodate transferability *of sets of ideas between cases rather than lumps of data* (Pawson and Tilley, 1997, p.120). A conceptual framework of how this process can be viewed in a particular ePD project by Wilson and McCormack is presented in Figure 5-4.



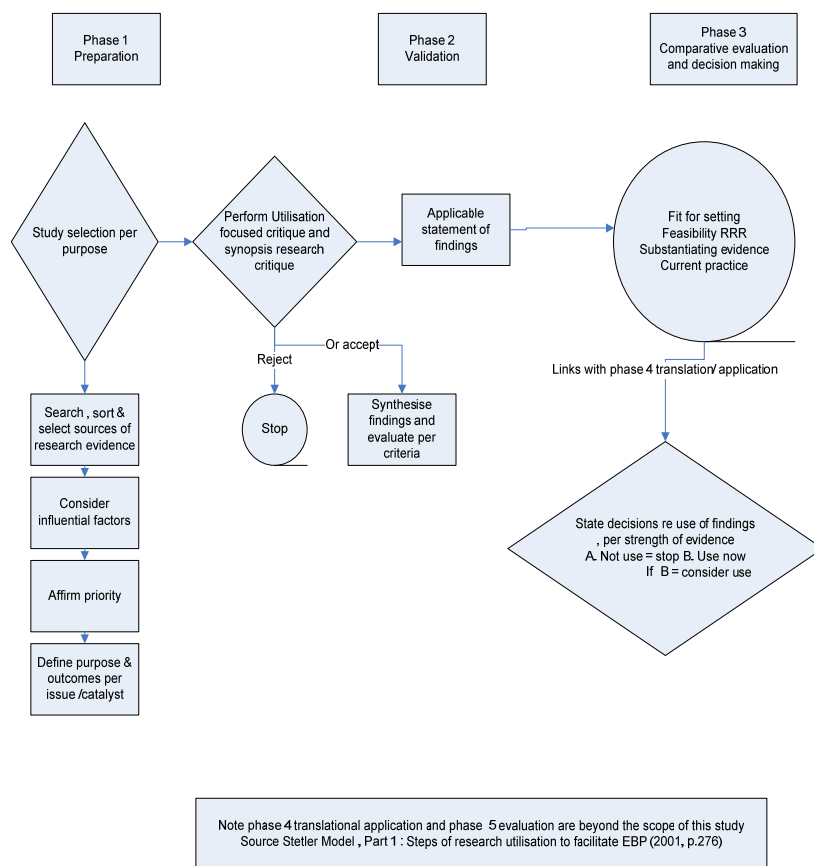
**Figure 5-4 ePD by Wilson and McCormack**

Source Wilson and McCormack, 2006, p.52

An alternative framework considered for use in the study of practice development initiatives is the Stetler Model which is linked to the Quality Enhancement Research Initiative (QUERI) completed in the 1990's by the Department of Veteran Affairs in the United States of America. The practitioner orientated Stetler Model was first devised in 1976 but has been refined in 1994 and is now used as an organising framework for evidence based research projects (Stetler, 2001; Stetler, McQueen, Demakis, and Mittman, 2008).

This framework discussed briefly in chapter two of this thesis develops a clinical practice model which enhances the delivery of comprehensive, evidence based, collaborative and patient centred care research (Stetler et al, 2008). According to research practice team both research products and research as a process come into play in the Stetler Model of research utilisation (Stetler, 2001, p.272).

In Stetler et al, (2008) the authors suggest that for nursing related problems a mix of research can provide valuable insights, at times along with other types of information such as consensus guidelines, however they suggest that research groups are required to differentiate between different sources of information and select appropriately. A central tenet of this framework is to optimise understanding of the existing evidence base and ensure optimum research utilisation occurs within the practice setting. To tackle the challenge of the adoption of evidence based clinical practices within healthcare the United States Department of Veteran Affairs decided to create the Quality Enhancement Research Initiative (QUERI) in the late 1990's. The QUERI programme devised a key operational structure with a guiding framework designed to enhance implementation of research for diagnosing and closing quality gaps and simultaneously advancing implementation science (Stetler et al 2008). The research utilisation model is presented in Figure 5-5



**Figure 5-5 Research Utilisation Model**  
Source Stetler, 2001, p.276

The revised Stetler Model of 2001 involves a deliberate and systematic continuous evaluation process throughout the entire implementation procedure. The internal evidence is identified collected, fed back to users and used to enhance the application of the translated findings.

Analysis of the frameworks by the author discounted the ePD and the Stetler model for use in this particular study. Both frameworks were considered as appropriate alternatives from which to develop the research study, however they were discounted primarily for two reasons. The first was the issue of resources, both of these frameworks would ideally require a large sample for data collection in the healthcare setting. The existing resources available to this particular study did not suffice to complete a large scale research programme.

Secondly, the existing clinical context in which the study is to be completed is in the midst of a transformational programme with associated economic constraints. The PARTNERS team therefore had no mandate to progress the research associated with this thesis into to a large practice development initiative. The PARTNERS practice development initiative and the associated study reported upon in this thesis has therefore opted to complete a participatory action research underpinned by critical realism principles and to complete a realistic evaluation as defined by Pawson and Tilley (1998) on the initial pilot of a integrated shared assessment summary of care. A key principle of realistic evaluation is to iteratively complete a series of phased evaluations over time on social programmes and their effectiveness in differing settings with different stakeholders. By completing this study in this way the author will provide evidence for a similar and larger practice development initiative in the future. In Section 5.3.2 specific research design methods are now considered for data collection purposes for the study.

<b>DECISION POINT</b>	<i>Use Participatory Action Research –Dymeks Sense Making Model</i>
	<i>Complete Realistic Evaluation on Pilot Study</i>

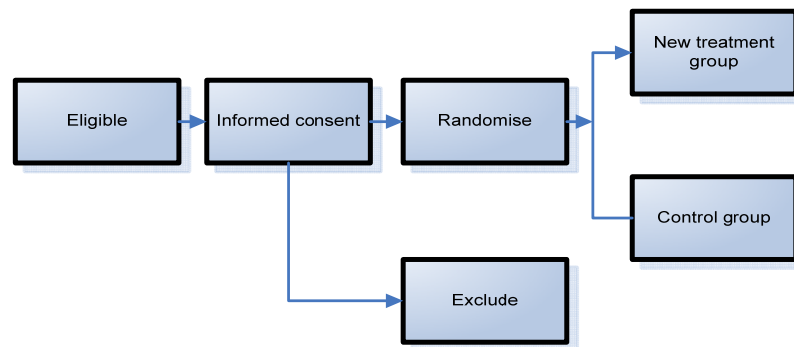
### **5.3.2 Research Design Methods**

The choice of a particular design method is a fundamental decision which can often assist the investigator in making evident the hypothesis which is to be tested or the causation which can be implied (Peat, Mellis, Williams and Xuan, 2002) Within this section prominent research designs and their associated methods are explored which are noted by Bryman (2004) and Creswell and Clarke (2007) to be widely adopted within realm of social research.

- a) Experimental and related designs such as quasi experimental
- b) Cross sectional design, the most common form of which is survey Research
- c) Longitudinal design and its various forms e.g. the panel study or cohort study
- d) Case study design
- e) Comparison design
- f) Mixed methods design (Bryman, 2004, p. 27; Creswell and Clarke, 2007).

#### **a) Experimental and quasi experimental**

The first of these research designs, experimental design is often used to test the effects of an intervention or treatment on patient outcomes. This design is often associated with a randomised control trial and is associated with testing of a cause and effect relationships. A randomised control trial is a study in which the subjects are randomly allocated to a new treatment, to a control group or to an existing treatment group. The overall basic design and method is demonstrated by Peat et al (2002) in the following Figure 5-6.



**Figure 5-6 Experimental Design**

Source Peat et al, 2002, p. 22

In randomised control trials the results are made evident by comparing the outcomes of the study groups. However whilst experimental research design such as randomised control trials are seen as a yardstick from which to gauge causal findings it can according to Melynk and Fineout-Overholt (2005) be difficult to use within the realm of patient care. This is due to the fact that strict criteria relating to the variables must be established. For example the intervention which may be labelled as the *independent* variable must be able to measure that it has impacted or not upon the *dependent* variable for example in this case the patient outcome. Two groups are formed and tested one group receives the experimental intervention whilst the other group the control group are not given the experimental intervention and both groups are tested for outcomes. The sample which is selected for the investigation also requires that the patients are randomly selected.

For ethical and practical reasons a quasi experimental research design method is often a preferred option within the domain of nursing. A quasi experimental research design is similar to the experimental design, however the criteria are often less strict and for this reason this research design is less difficult to implement.

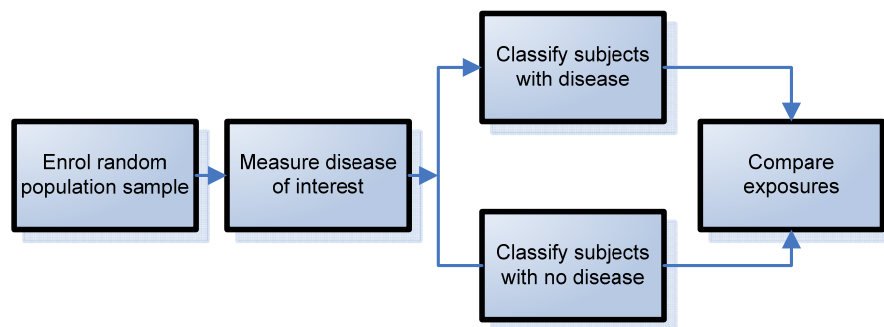
For example in quasi experimental design the variables are still manipulated however the sample is not required to be random Melynk and Fineout-Overholt (2005).

<b>DECISION POINT</b>	<i>Experimental and quasi experimental design will not be used in this particular study. Sample and selection process not suitable.</i>
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### **b) Cross Sectional Design**

Cross sectional design can be defined as the collection of data on more than one case and at a single point in time in order to collect a body of quantifiable data in connection with two or more variables which are then examined to detect patterns of association. It usually involves a number of cases and a number of variables (Bryman, 2004, p.41). It is often associated with survey research. In cross sectional studies large random selections of subjects who are representative of a defined population are enrolled and their health status, exposures, health related behaviour; demographics and other relevant information are collected and measured.

As the data is collected at the same time no inference of which came first can be made, however this type of study is often used for collecting initial ideas of association, or for making an initial investigation into hypothesis about causal pathways (Peat et al, 2002, p.50). It is defined by Melynk and Fineout-overholt (2005) as a study designed to observe an outcome or variable at a single point in time , usually for the purpose of inferring trends over time (Melynk and Fineout-overholt ,2005, p.586). The overall design of a cross sectional study is outlined by Peat et al (2002) in the following Figure 5-7



**Figure 5-7 Cross Sectional Design**  
Source Peat et al 2002, p. 50

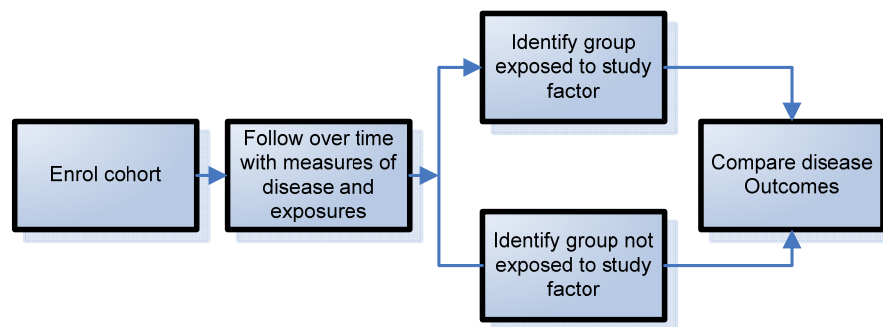
<b>DECISION</b>	<i>Cross sectional design will not be used in this study</i>
<b>POINT</b>	<i>Not appropriate due to time point of data collection and sample size</i>

### c) Longitudinal design

Longitudinal design is a distinct form of research often associated with social science subjects associated with sociology or human geography. It is quite expensive and requires

a great deal of time and for this reason it is not often used in nursing related research. It is usually an extension of survey research based on self completion questionnaire or structured interview. There are two types of longitudinal study, the panel study and the cohort study. The data in a panel study tends to collect data from a particular study framework for example households or organisations, whilst the cohort study either selects an entire cohort of people or a randomly selected sample of them (Bryman, 2004, p.46).

Cohort studies are sometimes referred to as prospective studies and are used to describe “what happens next” to a group of subject; they are identified by Peat et al (2002) in Figure 5-8.



**Figure 5-8 Longitudinal Study**

Source Peat et al 2002, p. 50

**DECISION POINT** *Consider inclusion of elements of longitudinal study however Costing as a factor may be an issue.*

#### **d) Case study**

Case studies are often used in qualitative inquiry. However Stake (2000) argues that case study research is neither new nor essentially qualitative. Bryman (2001) supports this perspective and advocates that case study research tends to favour qualitative methods such as participant observation and unstructured interviewing. He does however maintain that in quantitative studies it is often difficult to ascertain if the study is best suited as a case study design or as a cross sectional research design (Bryman, 2004, p.49). Stake however cautions researchers that case study is not a methodological choice but rather a choice of what is to be studied (Stake, 2000, p.443). Cases may be simple or complex and involve a single individual or involve a group of people. Stake (2000) identifies types of case study, namely the intrinsic case, the instrumental case and the multiple case studies or collective case study.

The intrinsic case study is considered the correct choice if the investigator wishes to gain a deeper understanding of this particular case and in this situation the case in all its particularity and ordinariness is in itself the key focus of interest. The instrumental case is the selection of choice when the particular case is examined mainly to provide insight into an issue or to redraw a generalisation.

DECISION POINT	<i>Consider inclusion of elements of instrumental collective set of cases</i>
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In this situation the case plays a secondary and supportive role which facilitates our understanding of another phenomenon. When there is less interest in one particular case, a number of studies may be required to be investigated jointly. The multiple case study or collective case study is an instrumental study extended to several cases where the researcher believes that studying them collectively will lead to a better understanding and perhaps a better theorising of the subject under investigation (Stake, 2000, p.446)

#### **e) Comparison design**

A comparative design uses identical methods to examine two or more contrasting cases and embodies the logic of comparison within the study. The central thesis for this type of research design is for the investigator to understand the social phenomena under investigation better when a comparison in relation to the two or more meaningfully contrasting cases or situations are explored in the context of either qualitative or quantitative research (Bryman, 2004, p.53).

It is often used in cross cultural research cases from different socio cultural settings in order to seek explanation for similarities and differences and to gain a deeper insight into social reality in different national contexts (Hantrais, 1996).

<b>DECISION POINT</b>	<i>Not appropriate as project occurring in one healthcare area and limited resources</i>
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#### **f) Mixed Method Research**

Mixed method research is described by Creswell and Clarke (2007) as practical, as the researcher is free to use all methods possible to address a research problem. By using both numbers and words one can combine both inductive and deductive thinking (Creswell and Clarke, 2007, p.10). Mixed method research can often be titled Multi-method research or mixed world views research, however the distinction lies in the fact that multi-method research is based on multiple qualitative or quantitative methods and datasets. Mixed method research is often the research design of choice if a problem exists where qualitative research can provide only part of the exploration of a problem, and the study also requires quantitative research to understand the topic in its entirety (Creswell and Clarke, 2007, p. 34.) The qualitative data provided the variables constructs and taxonomies and theories to test as well as aid in the identification of items and scales to help develop a quantitative instrument see Kutner et al (1999). There are a number of research design methods that one can use in mixed method design. They are listed in Table 5.4 and are cited from Creswell and Clark (2007).

It is interesting to note that each of these research designs uses a different set of procedures and processes of blending quantitative and qualitative data.

**Table 5-4 Mixed Methods Design**  
Source Creswell and Clark 2007 p. 71

<b>Triangulation design</b>	<b>Embedded design</b>	<b>Explanatory design</b>	<b>Exploratory design</b>
Convergence model	Embedded design procedure	Follow up explanation model	Instrument development model
Data transformation model	Experimental model	Participant selection model	Taxonomy development model
Validating quantitative data model	Co relational model		
Multilevel model			

#### **i. Triangulation Design**

The validating quantitative model is used when researchers want to validate and expand upon quantitative findings from a survey by including a few open ended qualitative questions. Whilst the qualitative open ended responses do not result in rigorous qualitative data, they do provide results which can assist in validating and embellishing the quantitative survey findings (Creswell and Clark, 2007)

**ii. Embedded Design key points for this study**

Within mixed methods research the embedded design is particularly useful for experimental or correlational design. It is often used to develop a treatment, to examine the process of an intervention or the mechanisms that can relate variables to each other (Creswell and Clark, 2007, p.67). The embedded experimental model is often used to have qualitative data embedded within an experimental design for example in an experiment or quasi-experimental design. In this particular process the qualitative data is subservient to the overall quantitative dataset. The design can be either completed in one or two phases depending on the actual purpose for the qualitative data.

**iii. Explanatory Design**

The overall purpose of the explanatory design is that the qualitative data assists the study in building upon the initial quantitative results (Creswell, 2003). This method is particularly useful when a researcher wants to explain significant (or non-significant) results. There are two key methods available the explanatory sequential design procedure and the variants of the explanatory design. The two methods differ as follows;

*Although both models have an initial quantitative phase followed by a qualitative phase, they differ in the connection of the two phases, with one focusing on results to be examined in more detail and the other on the appropriate participants to be selected. They also differ in the relative emphasis often placed on the two phases (Creswell and Clark, 2007, p.72).*

The strengths of the explanatory design are that the process is straight forward to implement it can be conducted in phases collecting data one phase at a time thereby accommodating a single researcher study.

**iv. Exploratory Design**

A decision to adopt an exploratory design framework as a research methodology is usually based on the premise that measurements or instruments are not available, the variables are unknown or that there is no guiding framework or theory (Creswell and Clarke, 2007). It is often the method of choice when the researcher wishes to develop and test and instrument because one is not available (Creswell, 1999). It is also useful to test aspects of an emergent theory or classification or to explore a phenomenon in depth and measure its prevalence (Creswell and Clark, 2007; Morgan, 1986). There are two variants listed by Creswell and Clark (2007) , the instrument development model and the taxonomy development model. The instrument development model is used when a researcher wishes to develop a quantitative tool based on qualitative findings. The emphasis is on the development of the quantitative tool and the qualitative phase is usually undertaken with a small number of participants. In this variant the qualitative and quantitative elements are connected through the development of the instrument items. In the taxonomy variant the initial qualitative phase of the study is conducted to identify important variables, develop a taxonomy or classification system or develop an emergent theory and the second phase of the study tests or studies these results in more detail.

Unlike the instrument development model the taxonomy model focus is on qualitative phase of the study using the quantitative phase only to verify the results (Creswell and Clark, 2007, p.77)

**DECISION POINT** *Consider mixed methods exploratory design using taxonomy model*

It is important when considering research design and methods to take time to consider the actual sample that is under consideration for data collection. For this reason section 5.3.4 briefly discusses the topic of research sampling.

### **5.3.3 Sampling**

Selecting and choosing a sample for a particular study is an important factor to consider in research design. External validity and generalisability are influenced by sample selection therefore it is important to consider selecting a representative sample of the population under investigation; this however can be a complex and challenging task. Melynk and Fineout-Overholt, 2005 identify a number of protocols that can be used in sampling selection and a brief summary of these are identified below.

- a) Random sampling – every potential subject has an equal chance of being selected. This is an efficient way to identify a representative sample however problems may arise in ensuring that a true representative sample is selected and the selected sample may emerge as being atypical.
- b) Stratified sampling can be adopted to avoid atypical samples being selected. The investigator divides the potential sample groups into two, for example male and female, sub groups

and then selects a specific number from each sub group in order to ensure both female and male participants are include

- c) Cluster (Area) Random Sampling is used in studies which are spread over a wide geographic area. Cluster random sampling divides the subjects into clusters or regions and from these groups a random selection is adopted using the same sampling frame and strategy within each cluster.
- d) Non probability or purposive samples are used when it is not feasible to use random sampling although every effort should be made to employ a systematic approach that can be well described in order to justify this type of sampling selection.
- e) Modal instance sampling is used when you sample the most frequent or modal case. This type of sampling can be used when the treatment or intervention is being applied to a particular region or clinic in order to select a sample that is a reasonable reflection of the sample that is under study.

<b>Decision point</b>	<i>Consider systematic approach to non probability purposive sample</i>
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## ***5.4 Critical Analysis of Design***

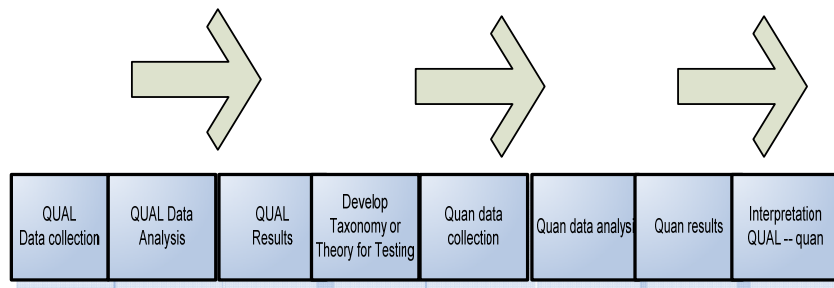
Health informatics research is often shaped by a vision of change and the ability of the research team's capacity to succeed or fail is dependent on a number of factors. Key factors include the veracity and passion of that vision and the testing of the underlying programme theories in the field of practice. Critically exploring ontological epistemological and methodological frames and their associated linkage within Chapter 5 of this thesis has proven to be a time consuming process.

In some cases associations have been made and on further review discounted as not appropriate for use within this particular study. This challenge is compounded by the fact that the study has adopted a participatory approach which has led to two distinct phases in this study. Over the course of the research the author drew upon different epistemologies and research methods at different times. For example for phase one of the study participatory action research and particularly Dymeks Sense making model was used as it offers a strong framework to demonstrate the research process in action to the participants. As this study is grounded in practice development, Stetler's Model and Theories of change was considered carefully but discounted given the limited resources in this study.

Phase two of the study requires the author to draw on theory driven evaluation using a realist evaluation framework. This approach sits well with outcomes based research and is referenced in the literature base as the optimal approach for future outcomes based research studies. From an ontological and philosophical perspective the study could be located between alternative world views namely *advocacy & participatory* from the action research perspective whilst the data collection and analysis will be grounded in critical realism, drawing data from both from qualitative and quantitative perspectives. The research inquiry is actively collaborative and involves all participant's views at all stages of the study.

The focus of this study is very much change orientated and seeks to empower nursing and in the longer term support patient groups through a process of collaboration. The study adopts a mixed method approach using both qualitative and quantitative data drawing on both formal and informal writing styles to inform the process of inquiry. The study design and method were also informed by Dickenson (2008) who supports the different approaches to partnership in evaluation, and suggests that theory led approaches (as

opposed to method led) are useful in research design. A review of the classification of mixed methods research suggests that the study is best located in an exploratory design framework. However a decision as to whether the research was orientated towards a taxonomy development model rather than the instrument development model took time to determine however the taxonomy model appeared to be the more relevant of the two approaches. The principal rationale for the final decision was based on the fact that a significant proportion of the time invested in this inquiry was directed towards understanding the clinical requirements from the local context and expertise of nurses engaged in the care of the older person in the acute primary and continuing care sector. The requirements when identified formed the basis for the development of a set of archetypes. It is possible that future studies relating to the outputs of this thesis will be directed solely towards the instrument development model. In order to complete an experimental study or a randomised control trial the author would have required additional resources which at the time of writing this thesis were not available. Therefore a mixed method approach with a strong emphasis on qualitative collection of data with some quantitative analysis in phase two of the study is the research design and method of choice. This is demonstrated by Creswell (2007) in Figure 5-9.



**Figure 5-9: Creswell and Clark Mixed Methods**

Source: Creswell and Clark 2007, P.76.

Data collection in the pilot study was analysed using a realistic evaluation/ critical realism framework as it is useful to view the data from this perspective in order to gain a deeper understanding of both the context and the recorded patient outcomes, data can also be then used for optimising future interventions and researching bio psychosocial pathways (Clark et al, 2008). Critical realism is recognised as a rational approach to the evaluation of public health interventions (Connolly, 2001) and is the preferred solution to evaluation and interpretation of complex health and social care partnerships (Dickenson, 2008). However it is recognised that for those researchers engaged in the social sciences, interpretation of the outputs from this inquiry through a realist framework presents the author with both practical and theoretical difficulties in relation to discovering and predicting social phenomena (Connolly, 2001). Despite this being the case, the capacity to reconceptualise social and human sciences from a realist philosophical viewpoint is required in order to explain the regularities of the social world whilst avoiding the dead ends of positivism (Bhaskar, 1989, Connolly, 2001).

In conclusion Chapter 5 has reviewed the research literature base from three distinct vantage points ontological, epistemological and methodological perspectives.

The author has endeavoured to consider the study from each of these perspectives. Table 5-5 initially created by Peat et al 2002 has been included to demonstrate a summary of the author's decision making in relation to research design and method.

**Table 5-5 Summary of Research Design and Method**

<b>Study</b>	<b>Strengths</b>	<b>Limitations</b>	<b>Decision</b>
RCT	Scientifically provides the most convincing evidence	Expensive and difficult to conduct Generalisability may be poor May not be ethically feasible	Not appropriate due to limited resources and ethical implications for this particular study
Cohort study	Can document progression of disease Reduce effects of recall bias Can be used to measure incidence	Expensive to conduct Follow up may be impossible Requires large sample size Exposure may be linked to unknown confounders	Not appropriate due to limited resources. This study focuses on collecting evidence on patient outcomes over a period of time this is not a suitable design for the study
Non Random clinical trial	Can answer important clinical questions	Evidence is only supplemental to RCT	This research design whilst suitable for this particular study requires large resources
Case control studies	Easy to conduct and provide rapid results Large sample size not required	Difficult to control for bias May be difficult to recruit suitable controls Information on exposure relies on subject recall	This design is not suitable for this study as the focus is on disease and exposure not on patient outcomes
Cross sectional studies	Fast and easy to conduct Can provide accurate evidence of prevalence	Random sample may be difficult to recruit. Prone to bias if response rate is low Effect of timing of exposure cannot be estimated	Not suitable for this study the focus is on individual patients not disease prevalence related outcomes.
Mixed Method study	Offers a practical approach to research Can be used for inductive and deductive thinking	More complex and timely to complete Requires scrutiny which mixed method framework best meets the terms of reference of the study	Preferred design approach. Offers a sequenced approach to the collection of data & can be used in a critical realism framework

## **6. Presentation of Research Findings**

### ***6.1 Introduction***

Chapter 6 is a presentation of findings of this research study. The findings of this study are presented from two perspectives, firstly from a research perspective and secondly from a practice development perspective. The results of the study from the practice development perspective have been reported upon in an evaluation report which includes full transcripts of the qualitative data; these are included as Appendices 3 and 4 of this thesis. As a participatory action research study a key action has been to circulate the findings from the evaluation of the pilot study of the paper prototype created in phase one of the study to a wider audience including key stakeholders in the health service domain. A summary of the evaluation report has also been published and is available to download from the PARTNERS website at [www.partnersct.com](http://www.partnersct.com). The core research findings of the study are therefore presented in this chapter as follows. Section 6.2 offers a summary of the study aims objectives and mixed methods adopted and introduces the reader to design participants and the setting in which the study was completed. A summary of the key data identified for the taxonomy for the archetype development from phase one of the study is included in section 6.2 from Tables 6.2 through to Table 6.8. Also included are some explanations of the decisions made and route adopted from phase one of the study. Section 6.2 concludes with a summary Figure 6.3 which illustrates the two phases of this study demonstrating the triangulation of data sources in the action cycles included in this study.

Section 6.3 expands upon the theoretical approach and discusses the implications of drawing upon Pawson and Tilley's evaluation methods. In Section 6.3 the author explores how this study has been located between the realm of critical realism and pragmatism and offers the reader some insights into the author's experiences particularly in regard to case 1 which is used as an example. Sections 6.4 and Section 6.5 offer a summary of the qualitative and quantitative findings of the study respectively. The results of the findings from this study are used to inform new Models of Knowledge and new Models of Meaning using Freriks' (2010) semantic stack as an analysis framework. Freriks' (2010) semantic stack framework has been previously described in Chapter 4 of this thesis and will contribute to the discussion section of this thesis presented in Chapter 7.

## ***6.2 Study Method and Design***

The key subject matter of this thesis has been to define the clinical requirements to create a core set of concepts (taxonomy) for integrated care across and between the primary, continuing and acute care services. The core requirements are to be defined by nurses based on expressed need within the clinical domain. A key motivation of the study is to build on existing networks of shared care using new systems to enhance integrated patient centred care for persons aged 65 and over. On identification of the clinical requirements and the identification of taxonomy of core concepts the author proceeded to engage with the EHRland project to inform the development of syntactical and semantically appropriate set of archetypes for future development. In order to achieve the research objectives the PARTNERS group was established to collaborate with experienced nurses and recruit a sample of nurses to engage in the study over the two year timeframe. As an action orientated project

the PARTNERS group were keen to disseminate information on progress of the study from a practice development perspective.

The PARTNERS group adopted the word PARTNERS as the title as it is an acronym for Participatory Action Research To develop Nursing Electronic Records. The EHRland project introduced in Chapter 1 of this thesis is a health informatics programme which has been funded to develop and test archetypes compliant with the International Standards Organisation (ISO) standard for Electronic Healthcare Record EN13606. The main research objectives of the PARTNERS study are therefore to:

- a) To identify clinical requirements to create a suite of archetypes for the provision of an integrated summary assessment record of patient centred care for older person
- b) To categorise the core concepts (taxonomy) required for the provision of integrated summary records of care for older persons between the acute primary and continuing care sector.
- c) To map the above objectives to EN13606 to achieve semantic and syntactic interoperability.
- d) To assist nurses to build a common understanding of what needs to be measured in patient assessment to inform future theory testing for outcome based research.

The research questions for this study are

Can nurses build a common understanding of patient assessment for future outcomes based research which can facilitate shared care in older persons using action research?

AND

Does an action research approach assist in the development of archetypes in accordance with EN13606?

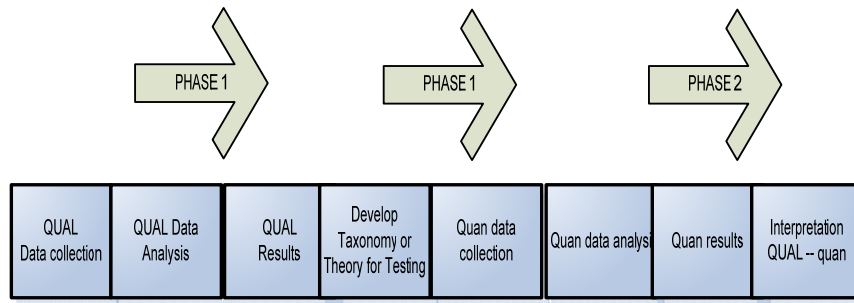
### **6.2.1 Design Process and Method**

Drawing on the work of Bryman (2004) this research study considers a number of factors in its selection of a particular research design process. These factors include practical considerations and the appropriate selection of epistemological and ontological values which adequately reflect both the participants and the author in this study. The setting in which the study has been undertaken includes 6 practice settings over three distinct care domains namely acute, primary and continuing care. Participants who engaged in the study had two key roles, namely registered nurses from the acute primary and continuing care services and a purposeful selection of patients aged 65 or over who were both well and unwell. As the study is dealing with a vulnerable population a decision was made by the nursing participants to recruit a purposeful sample of both well and unwell patients from the three practice domains. The participants are presented in Table 6-1 as follows;

**Table 6-1 Participant Numbers in the Study**

<i>DOMAIN</i>	<i>ACUTE SERVICE (AS)</i>		<i>PRIMARY CARE SERVICE (PCS)</i>		<i>CONTINUING CARE SERVICE (C.C.S.)</i>		
	AS	AS	PCS.	PCS.	C.C.S.	C.C.S.	C.C.S.
Service provider	1	2	1	2	1	2	3
Cases	4	1	4	4	2	2	1
Participant	3	2	5	3	2	2	1

A participatory action research methodology was used in this study from the outset. Participants focused on addressing everyday clinical challenges. The PARTNERS group sought strategies to improve existing practices such as interagency communication and the author endeavoured to empower the study participants to bring about change to enhance practice in their individual clinical domains. Evidence of practitioner empowerment is visible in the decision making processes that occur particularly in the selection of study design methods. Practitioners in the PARTNERS group opted to move from a solely qualitative study using a sense making model (Dymek, 2008) to using Creswell and Clarke's (2007) mixed methods design. So that the study could include a quantitative data collection process in the study research design. A number of mixed method frameworks were considered but the final selection chose a mixed methods study with a dominant exploratory qualitative approach for the development of a taxonomy for theory testing in the future. The method adopted is presented in Figure 6-1 and explained thereafter.

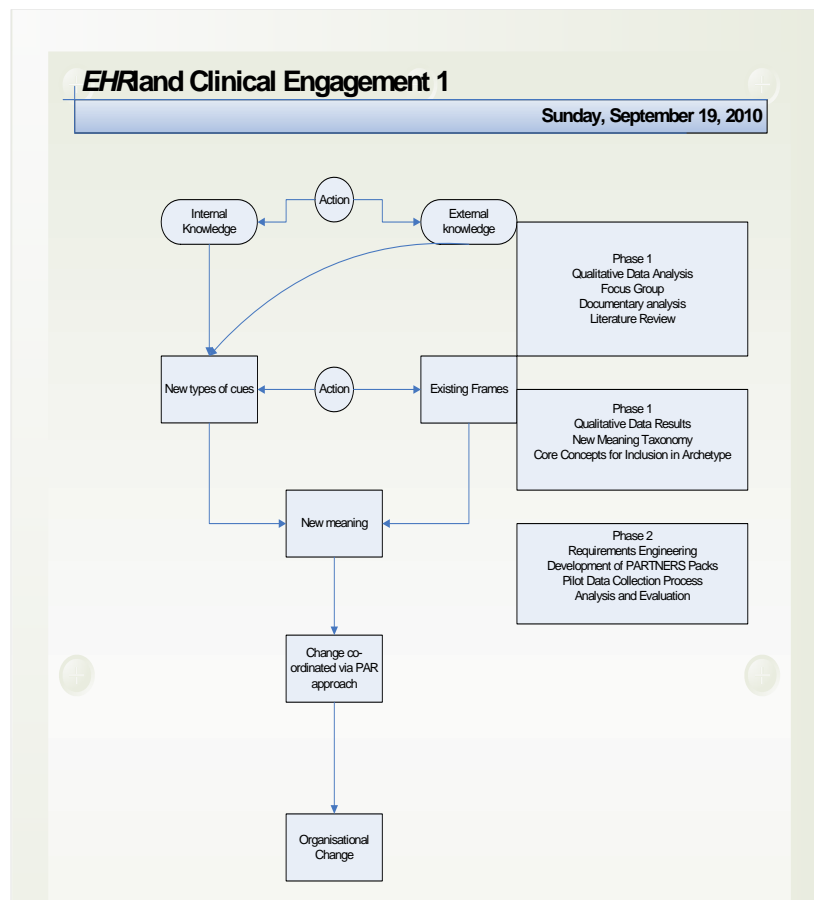


**Figure 6-1 Creswell and Clarke 2007 Qual Mixed Method**

Phase one of the project was primarily qualitative data collection and involved a series of focus group interviews over a one year time period. Initial focus group discussions centred on considering what the core concepts and stated clinical requirements were for a shared summary assessment record of care to collect patient centred outcomes on older patients. In parallel to these discussions a group documentary analysis was completed on the services and an extensive literature review was completed by the author. Findings from the literature review (Chapters 2, 3 and 4) and the documentary analysis were discussed in meetings  $n = 24$  which were hosted in the clinical services over a two year timeframe.

Drawing on social science research and interpretive schemes such as Argyris and Schon,(1978), Hedburg, 1981, Dymek's "Action and Sense Making Model" (2008) in Figure 6.2 was used for phase one of the study, although the group opted to adopt Creswell and Clarkes (2007) exploratory mixed method design for phase two of the study. Dymek (2008) argues the case that fundamental change in organisations' thinking and doing requires schemata change and by linking this course of action with informatics,

Dymek (2008), advocates that this practice provides a key element in developing and implementing information systems. The interpretation of Dymek's Sense Making Model as used by the PARTNERS group to frame the phase one of the study is presented in Figure 6-2



**Figure 6-2 Dymek's Sense Making Model**

As illustrated in Figure 6-2 the net result from the qualitative data results led to the development of a taxonomy of core concepts that could be shared by the participants.

Table 6.2 to Table 6.8 offer a summary of the taxonomy created from phase one of the PARTNERS project. For ease of reading the triangulation completed over phase one and phase two of the study is also included in Figure 6.3. The process of triangulation involves using more than one method or source of data (Webb et al, 1966), which in this study included two phases of data collection. Phase one and two action cycles provides data which assists the author to create new meaning as described by Dymek (2008). From a knowledge performance indicator perspective it is anticipated that the domains affected by this particular data set would include effectiveness of care, patient centredness, and patient safety (HIQA, 2010)

**Table 6-2 Role Encounter Record Version 1**

<b>Taxonomy Headings, Concepts and Terms</b>	<b>Definitions</b>
<b>1 ROLE ENCOUNTER RECORD</b>	
Subject of Information	Subject of record (SNOMED CT)
UHI Number	Currently under development
Name First	A language unit by which a person or thing is known (Wordnet)
Name Last	A language unit by which a person or thing is known (Wordnet)
Address	The place where a person or organization can be found or communicated with (Wordnet)
General Practitioner	The General Practitioner with whom the patient is registered with (PARTNERS)
Date of Birth	The day the month and the year that a person is born (Wordnet)
Gender	Social aspects of being male or female (Wordnet)
Ethnicity	Status with the specific characteristics: Documentation and classifications of individuals by nation, heritage, customs and language of individuals (ICNP)
Next of Kin	The person who is (or persons who are) most closely related to a given person (Source Wordnet)
Service Status	The patient's current position within a particular service (PARTNERS)
Assessment Type	The act of judging (estimating) or jointly appraising a person's health or social situation or event against a pre determined set of criteria at first or repeat stages in the partnership. The purpose of the assessment encounter is to facilitate evidenced based health care by creating a set of documentation to record the identified needs and corresponding care responses for individual clients (PARTNERS)

Existing Support	Resource utilisation of health and social infrastructure (PARTNERS)
Date of Last Assessment	The most recent clinical contact/interaction/episode (PARTNERS)
UHI- Practitioner Code = Nurse Practitioner	Currently under development
UHI -Org	Currently under development
Professional Role Type (Assigned Practitioner)	Care provider role (ICNP®)
DED	It is the smallest administrative area for which population statistics are published by the Central Statistics Office. There are 3440 DEDs in the state - Example 073= Mountjoy A (PARTNERS)
PHN Case Load Number	A designated two digit number allocated to any Public Health Nurse which identifies that nurse as the manager of a particular geographic case load. The number is assigned to the case load as opposed to the actual nurse. (PARTNERS)
Record Type	Assessed nurse practitioner focus (SNOMED CT)
Record Date	DD/MM/YYYY
Local Health Organisation	Defined geographic area within one of the four administrative regions which is governed by the Health Services Executive through primary community and continuing care services (PARTNERS)
Local Health Centre	A designated health service executive building which houses members of the primary care team and which is used for both administrative and for clinical functions, or an acute health care provider (PARTNERS)

**Table 6-3 Health Findings Version 1**

<b>2 HEALTH FINDINGS</b>	
Height / Length	Observable entity - Height measured in metres without shoes (SNOMED CT)
Weight	Observable entity -Weight measured in kilograms taken without shoes or outdoor clothing.(SNOMED CT)
Allergy Type	Intolerances or adverse reactions that have been activated (SNOMED CT)
Temperature	Observable entity - A record of the patient's general body temperature measured in degrees centigrade (SNOMED CT)
Pulse Rate	Observable entity - The frequency of the pulse measured in a peripheral artery recorded as beats per minute (bpm) (SNOMED CT)
Respiratory Rate	Observable entity -The number of breaths per minute measured when the patient is at rest (SNOMED CT)
Infection Status	Pathological process with specific characteristics: Invasion of the body by pathogenic microorganisms that reproduces and multiplies, causing disease by local cellular injury, secretion of toxin or antigen-antibody reaction (ICNP)
Medical Diagnosis	Identification of the cause or nature of some phenomena (SNOMED CT)

**Table 6-4 Social Circumstances and Support Version 1**

<b>3. SOCIAL CIRCUMSTANCES AND SUPPORT</b>	
Health Issue / Patient Need	A subjective comment or indication made by the client or care giver relating to their individual perception of their priority of needs. An unmet need exists when an individual is not receiving the appropriate level of assessment, assistance or care. This need is based on the assessment made by the client the caregiver the professional or a maybe a combination of all members of the partnership. Example a patient requires structural changes to residence in order to achieve independence, a quality of life measure in itself (Xenitidis et al 2000)
Ability to Address Health Issue	A definition of need that incorporates the notion of an intervention has the potential of being able to separate needs into those that are presently met and those that are not met. A met need would be defined as a situation in which the individual has difficulties in a particular area but these difficulties are being adequately provided for. An unmet need would then exist when they are not receiving the appropriate level of assessment or care (Hancock, G, Orrell, G., 2004, p.2)
Home Assessment	Procedure -Assessment of main residence of the patient (SNOMED CT)
Toilet and Bath Facilities	A plumbing fixture for defecation and urination and washing (Wordnet)
Living Areas	Address at which subject of information dwells more than temporarily (Wordnet)
Steps and Stairs	Support consisting of a place to rest the foot while ascending or descending a stairway (Wordnet)

Cooking and Safety	Equipment and environment for food preparation (Wordnet)
Heating and Safety	Equipment and environment for maintaining adequate body temperature (Wordnet)
Security	Environment that is free from danger or inquiry (Wordnet)
PHN	Public Health Nurse - Role (PARTNERS)
Home Care Support	Home Carer Support - Role (PARTNERS)
PCCC	Primary community and continuing care service provider (PARTNERS)
Meals on Wheels	Home support - Role
Family	Primary social group
Day Centre	A designated community service which houses members of the primary care team and which is used for both administrative and for clinical functions, or an acute health care provider (PARTNERS)
Day Hospital	A designated health services executive building which houses members of the primary care team and which is used for clinical functions for patients aged over 65 (PARTNERS)

**Table 6-5 Psychological Capacity Version 1**

<b>4. SUBJECT OF INFORMATION CAPACITY PSYCHOLOGICAL</b>	
Thought and Cognition (Ability)	Difficulty or impairment with perceptual functions and or belief systems Cognition with specific characteristics (INMDS)
Comprehension	An ability to understand the meaning or importance of something (or the knowledge acquired as a result (Wordnet)
Decision Making	The cognitive process of making your mind up about something (Wordnet)
Verbalise Understanding (Communicate)	Ability total or partial to interact with others (INMDS)
Memory Function	Psychological Process with the specific characteristics: Mental acts by which sensations, impressions and ideas are stored and recalled; mental registration, retention and recall of past experience, knowledge, ideas, sensation, and thought (ICNP).
Anxiety (Finding)	Anxiety or fear linked to current stressors Feeling of apprehension or dread, associated with the anticipation of threat or danger (INMDS)
Motivation	Any problem with the persons arousal to action towards a goal and or whereby there is a low level of purpose and direction to behaviour (INMDS)

**Table 6-6 Physical Sensory &Functional Status Version 1**

<b>5 CAPACITY PHYSICAL SENSORY</b>	
Hearing (Finding)	Perception with the specific characteristics: Faculty of hearing due to responses to stimuli from auditory organs, capacity to hear (ICNP)
Vision (Finding)	Perception with the specific characteristics: Faculty of seeing due to responses to stimuli from visual organs, capacity for sight (ICNP)
<b>6. SUBJECT OF INFORMATION FUNCTIONAL STATUS</b>	
Ability to Perform Hygiene	Ability to perform or complete bathing/washing (INMDS)
Ability to Dress and Groom	Ability to perform or complete dressing and grooming activities for oneself (INMDS)
Ability to Mobilise	Assessing patient's performance to locomote (C-HOBIC)
Ability to Walk	Assessing patient's performance to locomote on and off units walk in room corridors (C-HOBIC)
Ability to Transfer (Chair /Bed)	Assessing patient's performance to transfer on and off chair or bed and walk in room corridors or locomote staircase (C-HOBIC)
Ability to Walk in Room	Assessing patient's performance to locomote on and off units, transfer on and off chair or bed and walk in room corridors or locomote staircase (C-HOBIC)
Ability to Walk in Corridor	Assessing patient's performance to locomote on corridors (C-HOBIC)
Ability to Climb Steps/Stairs	Assessing patient's performance to locomote staircase (C-HOBIC)
Ability to Get on Toilet (Self)	Assessing patient's performance to locomote to and transfer on and off toilet (C-HOBIC)

Ability to Use Toilet	The process of discharging waste matter from the body (INMDS) Body Process with specific characteristics , movement and evacuation of waste as excretion (ICNP)
Ability to Feed Self	The act of consuming food (Wordnet)
Change in ADL / Risk Assessment	A cumulative score assigned to patient in relation to progress or deterioration status (PARTNERS)

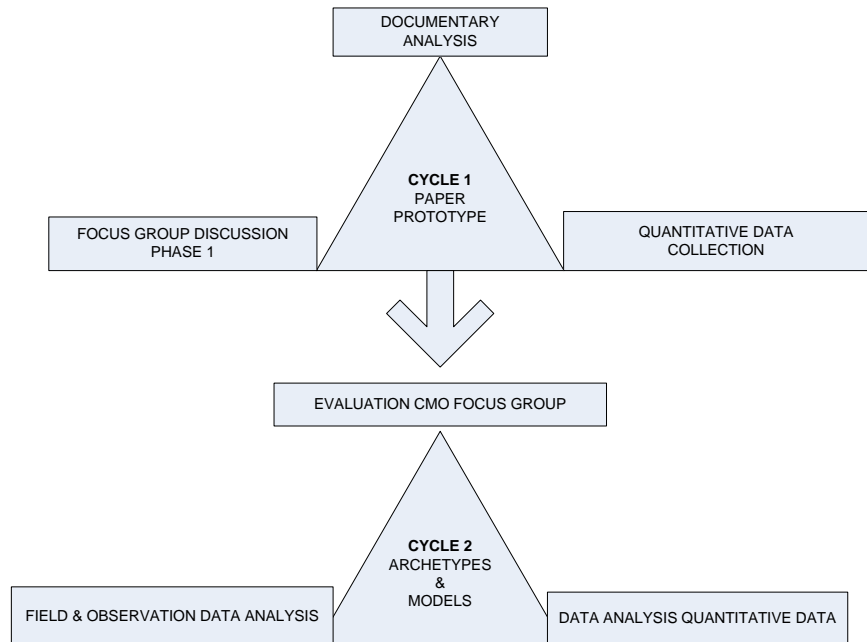
**Table 6-7 Symptom Management & Discharge Version 1**

<b>7 SYMPTOM MANAGEMENT</b>	
Incontinence Urinary	Finding -Voluntary control over urinary discharge (SNOMED CT)
Incontinence Faecal	Finding - Voluntary control over fecal discharge (SNOMED CT)
Nutritional Status Fluid and Food Intake	Process relating to ingestion absorption and digestion of food and during nourishment of body with food and fluid. This includes the processes by which food is used to provide energy, maintenance and growth (Omaha,2002)
Falls Occurrence Event	Falling – A Self Performing Activity with the specific characteristics: Rapidly decent of body from a higher to a lower level due to disturbed balance of the body or reduced capacity to bear weight of body in different positions (ICNP – Falling)
Fluid Balance	Problems refer to inadequate fluid volume, excess fluid volume or the risk of fluid volume imbalance (INMDS)
Skin Integrity / Pressure Ulcer	Observable entity - Altered epidermis and or dermis (SNOMED CT)
Breathing and Dyspnoea	The bodily process of inhalation and exhalation or the process of gaseous exchange from the body (INMDS)

Weakness and Fatigue	Weakness: A generalised feeling of exhaustion / lethargy or a lack of strength in one part of the body Fatigue: An overwhelming sustained sense of exhaustion and decreased capacity for physical and mental work at a usual level (INMDS)
Nausea Finding	Finding - a state that precedes vomiting (Wordnet)
Pain as a Sign or Symptom	Perception with the specific characteristics: Sensation of feeling sick with an inclination to vomit, unpleasant sensation vaguely referred to the epigastrium and abdomen, offensive to taste or smell (ICNP)
<b>8.READINESS FOR DISCHARGE ( TSC C-HOBIC)</b>	
Understand the purpose of the medication	The person or carer is not aware of or does not fully understand, or is seeking information on certain or all aspects of their illness / diagnosis / prognosis or treatment (Source INMDS)
Ability to take medications as prescribed	C-HOBIC
Understanding why you experience symptoms	C-HOBIC
Recognition of changes in your body (symptoms)	C-HOBIC
Knowledge of what to do to control these changes	C-HOBIC
Ability to carry out the treatments or activities	C-HOBIC
Ability to do things or activities maintain your health	C-HOBIC
Ability to perform regular activities	C-HOBIC
Ability to adjust your regular activities	C-HOBIC
Knowledge of whom to contact to get help	C-HOBIC
Knowledge of who to contact in emergency	C-HOBIC

**Table 6-8 Devices & Medication Management Version 1**

<b>9 MEDICAL DEVICES ( ABILITY TO USE)</b>	
Medication and Medical Devices	A medication, or treatment regime as prescribed or advised by the health care professional INMDS
	Medical devices include oxygen, personal alarms , bed, pill boxes , inhalers, walking frames, wheelchair
<b>10 MEDICATION MANAGEMENT</b>	
Medication	Drug substance (SNOMED CT)
Dose	Qualifier value - unit of drug administered (SNOMED CT)
Frequency	Attribute - the number of occurrences within a given time period (SNOMED CT)
Route	Qualifier value - route of administration (SNOMED CT)
Prescribed	Observable entity - prescribed activity (SNOMED CT)
Start date	Qualifier value - start time (SNOMED CT)
Adherence comment	Observable entity - medication compliance (SNOMED CT)
D/C date	Qualifier value - discontinue dosing instruction imperative (SNOMED CT)



**Figure 6-3 Triangulation of Data Sources**

Outputs of Table 6.2 to Table 6.8 are described by Dymek (2008) as new meaning. Drawing on the socio technical notion of change, a decision was made by the PARTNERS and EHRland groups to proceed with piloting this taxonomy as a draft summary assessment tool in paper format to evaluate whether it was fit for purpose i.e. clinically practical. At this time the participants in the study were considering the option of adopting the concepts within the taxonomy as a resource to underpin a discharge summary assessment electronic record. This process involved gaining ethical access to the six services to pilot the identified core concepts in the taxonomy over a six month period as a prototype paper record. A number of key decisions made by the PARTNERS and EHRland group relating to the pilot study are presented in Figure 6-4

- The workflow of the data collection process was new to the services. As a consequence this study may directly impact on patient care therefore the data collection process would be completed as a duplicate recording process over a six month period.
- A draft data collection tool would be developed.
- Prior to piloting the data collection tool in the practice setting a requirements engineering process would be completed to act out everyday working situations using virtual cases in a simulated environment.
- Taking into account logistic ethics and existing clinical practice routines a paper based pilot was the most sensible approach.
- Data collection in pilot study would be retrospectively recorded into an encrypted database developed by the EHRLand research programme.
- The quantitative data would be analysed and presented back to key stakeholders in the health services.
- The Canadian Health Outcomes for Better Information and Care would be used to underpin the collection of patient centred outcomes.
- The patients who engaged in the study would be given the option of holding their own record.
- Additional data used by service providers was to be included in the data collection process for example the mini mental score examination record.

**Figure 6-4 Decisions Made in Study**

The pilot study of the paper prototype assessment using the taxonomy concepts was completed over a six month period and adopted the following implementation process. A draft data collection tool was devised and tested in a simulation exercise using virtual cases. Sorby, Melba and Sealand (2005) requirements engineering drama improvisation method was used for this exercise. The documentation was collated and presented in a purpose built pack which was tested and refined. The final result was a PARTNERS final pack (Figure 6-5) containing a set of key documents which included the following resources;

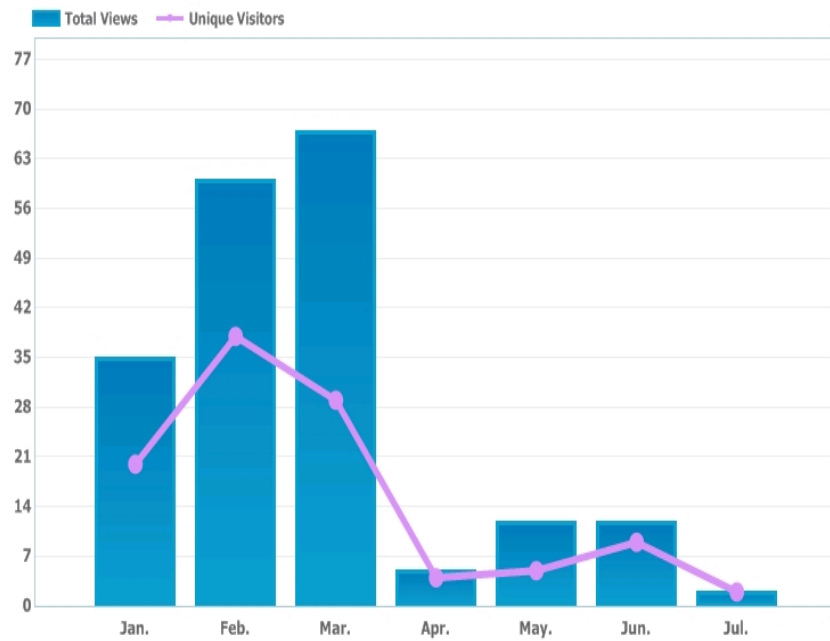
- A lay person description and explanation of the study aims objectives and a patient consent form.
- A paper based assessment tool devised by the PARTNERS group and based on existing documentation with the additional identified core concepts for the taxonomy.
- Instructions for nurses on how to use the information pack and collect patient data over an extended time frame.

These documents are included in Appendix 4 of this thesis. As the pack was introduced in three different domains, i.e. acute, primary, and continuing care the time and frequency of collection of data was identified in each of the domains by the nurses engaged in the PARTNERS group. For example the public health nurses routinely assessed patients in the primary care services monthly. Over a six month period the six services in the three domains were introduced incrementally to the data collection process. A short training programme was offered to nurses who participated in the data collection process. The author of this thesis acted as a project manager and recruited patients with the nursing participants in each case.

A web based educational and training resource was provided online as an additional source of information. Figure 6-5 offers an image of the pack and Figure 6.6 illustrates the statistics on individuals who have accessed the online educational resource.



**Figure 6-5 Image of PARTNERS Pack**



**Figure 6-6 Access Figures Educational Resource**

As was the case with phase 1 Figure 6-7 presents a summary of the key challenges encountered and decisions made during the pilot data collection process.

- The PARTNERS pack was incompatible with existing organisational routines and practices.
- Service boundaries were fixed and discussion with staff who were not active members of the PARTNERS group suggested that roles were grounded in a set of controlled routines e.g. medication rounds, observation of vital signs and blood results and group activity. Staff did not display any degree of interest or motivation to engage in shared documentation practices across their respective service boundaries such as the PARTNERS pack. In one case the pack was lost when the patient presented the pack from the primary care to the acute care service for an acute admission.
- Some typing errors were noted in the PARTNERS pack e.g. continence should have been incontinence and some of the judgement scales used in the pack were inconsistent again causing some degree of confusion to the participants.
- Patients who attended the day care services and who had mobility issues did not like the idea of having to bring the pack with them to the day care service. They opted to leave the pack with the nurses in the day centre.

**Figure 6-7 Challenges Experienced in Pilot**

### ***6.3 Theoretical Approach***

As discussed in Chapter 2 defining the clinical requirements for clinicians is a complex process (Beyer and Holtzblatts, 1999; Ballard, 2006a). There is an increasing realisation that people and technologies are linked in complex dynamic social technical networks which require close examination to maximise the benefit of return on investment (Greenhalgh, 2010). This study drew on the work of Pawson and Tilley (1997) and Dickenson (2008) who recognise that social technical research programmes do not operate

in an isolated fashion but require iterative evaluation across the spectrum of contexts in which they are required to operate. The presentation of the findings of this particular study is therefore stratified into three distinct sections. Firstly to evaluate the clinical usefulness of the taxonomy identified by the practitioners to underpin a summary assessment tool for future use as a set of archetypes in an Electronic Healthcare Record. This data is identified in a reasonably straightforward manner and for the sake of interpretation of the research findings in this thesis this data will be classified as *Level 1* data. An example of Level 1 data is functional status – ability to mobilise.

The second and perhaps more subtle type of data for analysis from the study is the knowledge and information collated from a socio technical perspective of the practice setting. This information can have a strong influence on the implementation and uptake of a summary assessment tool for shared care. Such information includes data on cultural aspects of the implementation process of the pilot study which may inform future clinical requirements process engineering. This data, the author would argue, is less straightforward to identify particularly if one is moving across different domains and not using the popular medical model. For the purpose of interpretation of data in this study the author will classify this as *Level 2* data. Two examples of Level 2 data are the District Electoral Division which is a key identifier used by public health nurses in identifying catchment areas, or to ascertain on the assessment tool if the patient is registered with the public health nurse prior to admission to an acute service.

The third set of data detail relates more to outcomes measurement and lends itself in the future to theory led research. It requires the investigator to gain a more comprehensive understanding of the data in context and involves a process of interpretation and deductive

reasoning. It is commonly described as the black box by a number of authors including Dickenson (2008) and has been discussed in Chapter 5. This data in this study will be classified as *Level 3* data and will be discussed in greater detail in the discussion Chapter 7 as it informs the development of a set of archetypes. An example of Level 3 data would be the concept of capacity i.e. individual or community capacity which has a direct bearing on patient outcomes. The concepts and associated terminologies identified in existing archetypes in Chapter 4 from OpenEHR are presented and structured in a particular manner primarily for the provision of acute and primary care services. As the newly formed clinical directorates implement care pathways, formal interagency communication will be a priority and archetypes can offer a vehicle to achieve such communication practices. These pathways will be implemented according to a medical model by diagnosis e.g. stroke pathway, diabetes care. Based on existing health policy and projected business plan objectives this approach could be described as the core business of processing of healthcare data in Ireland in the future. The author of this thesis is keen to explore how compositions in EN13606 and concepts in EN13940 can be actively merged to create more intuitive archetypes for integrated shared patient centred care. In particular the author will explore in Chapter 7 what new presentation style (if any) is possible, and also to enquire if the EHR can offer enhanced views of information in context to patients and their associated care providers who endure chronic illnesses and who are aged 65 or over. Pawson and Tilley (1997) articulate this perspective well when they describe the research process as follows:

*What are the mechanisms for change triggered by a programme and how do they counteract the existing social processes? It is not the programmes' that work but the programmes ability to break into existing chains of resources and reasoning in specific contexts.*  
(Pawson and Tilley 1997, p.15)

In order to contribute to the body of knowledge and bring about effective change it is therefore necessary to evaluate the theory (research questions) using a stratified approach for each group of participants involved in the programme.

This tenet would support a recent OECD publication (2010) which advocates that intention to adopt and readiness to adopt are key states which require careful consideration in ICT implementation in healthcare (OECD, 2010, p.117).

From an ontological perspective Pawson and Tilley argue that a post-empiricist view is required as this approach focuses on a process of explanation, and is therefore not a technique which is solely driven by method and measurement. Research programmes which are practice orientated can often offer a more extensive role for theory or the generation of theory. By adopting a realist exploratory approach to the programme which informs the research method one is not completing research solely for the benefit of science, but rather a research method to inform the thinking of policy makers, practitioners, programme participants and the public in general (Pawson and Tilley, 1997, p158).

As the full evaluation reports are included in this thesis a summary of Level 1 and Level 2 data from this evaluation will be presented in the following section. Level 3 data will be presented in Chapter 7. In conclusion of this section case 1 and case 15 are presented as an explanation of what occurs in the practice domain.

Case 1 is offered as an example used by the participants to study specific issues and problems in a more detailed context in order to provide an explanation supported by patterns;

- Case 1 had repeated readmissions to the acute services relating to medication mismanagement - informal discussion suggested that discharge records for this patient were not up to date in the primary care sector. This particular service did therefore not know that the patient had been discharged from the acute service for follow up on medications management by the community services.
- Difficulty in contacting the assigned public health nurse in relation to Case 1, it transpired that the public health nurse was on annual leave followed by an episode of sick leave.
- Additional issues identified by the acute community services included patient experiencing problems with dyspnoea and self administration of nebulizer machine (to assist breathing) which although the machine was fully operational was not in use by Case 1 as there was no nebuliser solution available in the home.
- Case 1 was also not taking his medications as prescribed and this was leading to significant health problems with his ability to maintain a stable blood clotting time (INR).

In an attempt to seek a clear understanding of the explanations underpinning this particular case, the detail of Case 1 and Case 15 will be discussed further. As suggested by the literature base, one needs to look *beneath these patterns to account for why they did or did not occur* (Clark et al, 2008, p.71).

In this particular case the study participants concluded that social isolation was a major contributory factor in Case 1's ability to self care. The daily visits from the health service provider offer Case 1 some degree of social contact with the outside world which Case 1

may not have otherwise had. Likewise Case 1's frequent readmission to the acute services offered a recess from the existing life of social isolation. In summary Case 1 was lonely and the interaction with the health service providers gave him some comfort and support. The patterns identified in this case would suggest that future care plans for Case 1 should include social integration in local community organisations and that existing discharge documentation between the acute and primary care services be reviewed for critical incident analysis. The author of this study would recommend using the critical realism approach in the future as it was useful in the identification of health outcomes and explaining events in context (Clark et al, 2008, p73). In particular the evidence of maintenance outcomes was prevalent in the community. The lack of the public health nurse presence in Case 1's management is perhaps a good example of how maintenance outcomes form a critical element of the role of the community nurse particularly in case management and in public health nursing. Ensuring support is accessible to the right people under the right circumstances is also a key issue that requires further consideration.

In a second case included here for discussion is the example of Case 15. In Case 15 there were two primary care services and one acute care service involved in this individual's care. Observation notes would suggest that one or all of these services could have individually provided the care required for this individual case.

The cause for this overlap of service provision related to the roles of the individual nurses in each of the services e.g. one service did not administer intravenous fluid therapy, therefore all of the services who were involved to attend to this patient were given different tasks to complete. For example, one nurse did a dressing, a second nurse gave intravenous medication and the third nurse was engaged in mobilising the individual. As an observer it was intriguing to watch

the number of nurses from different services attending to one patient in one residential setting. At no point did any of these nurses make a clinical judgment to hand over the core tasks to be completed to the nurses who were trained to administer intravenous fluid therapy. Instead they opted to wait and individually complete each task as they were assigned.

On questioning the individual nurses on this particular matter it became apparent that a key motivation for this behaviour is located at local service boundary and policy implementation level. Fragmentation of the service delivery process with different services providing different tasks has led in this particular case to inefficiencies of health service provision.

## ***6.4 Summary of Qualitative Data Analysis Phase 2***

The qualitative analysis process involved focus group interviews with both patients  $n = 16$  and nurses  $n = 14$  who participated in the study. Context mechanism and outcome (CMO) configurations were used to refine core concepts to inform a model of knowledge (ontology) of clinical context and social reality that the individual participants lived in. In considering the various methods that could be used to complete this work the group opted to use a visual framework in the form of a conceptual map to represent the core concepts under consideration. By adopting this approach each of the service requirements to facilitate shared care were identified in order to enable inter agency communication to occur. Yamashita et al (2009) suggest concept mapping is an effective method to incorporate contextual information in the development of software engineering constructs. By using expert judgment in the conceptual mapping process to identify different attributes and dimensions

expert knowledge can provide more realistic interpretations of the technical requirements and properties of a system.

Concept mapping is a method commonly used in social research to plan and evaluate programmes' overall effectiveness (Pawson and Tilley, 2007; Rossi et al, 2004). A second advantage of adopting this particular approach will be to use the articulated conceptual models for training and education of nurses in future initiatives.

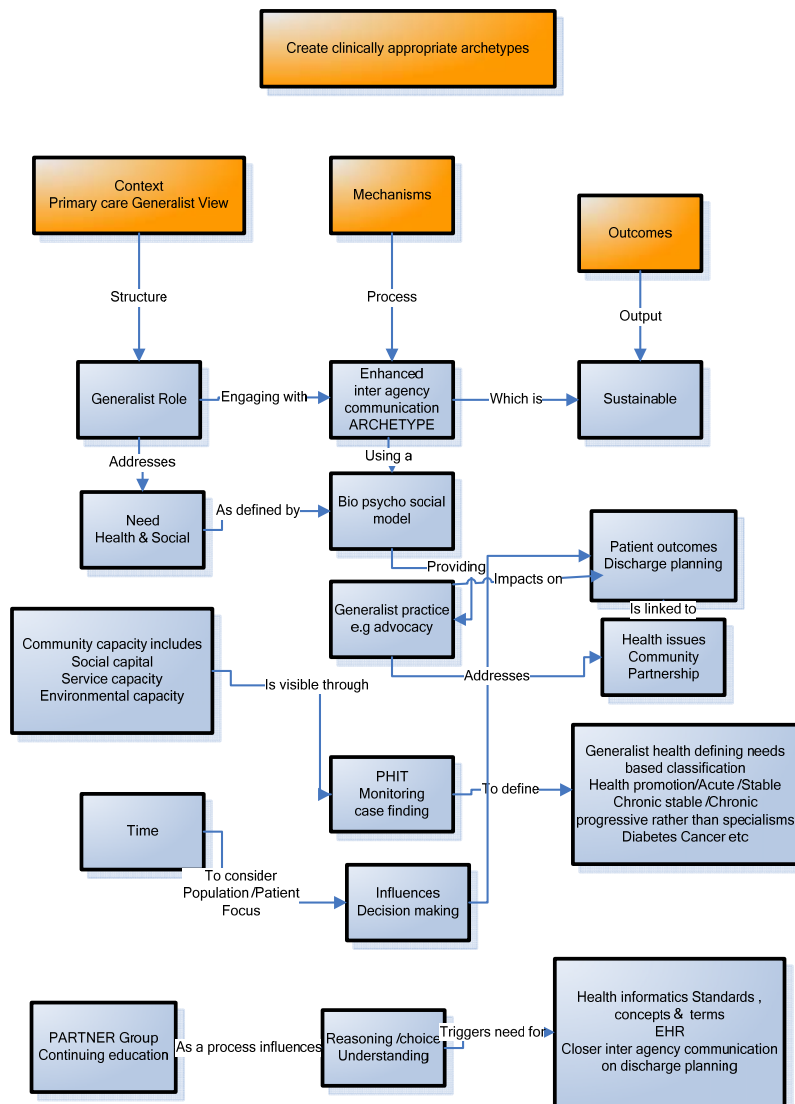
The process of creating a conceptual model includes asking participants to evaluate a programme with the author adopting a teacher learner approach. Pawson and Tilley (1997) reject the notion of pre determined questions arguing that this leads to limited understanding of theory under investigation.

Rather they suggest that a relationship between the evaluator and the informant must develop in which the evaluator explains the theory using a model and the informant assists the evaluator to refine the model in such a manner as the evaluator learns the informants view of the theory from an insiders perspective of the programme. The authors offer a model which they describe as a context mechanism outcome configuration (CMO configuration) as the following quotes explains:

*In order to develop transferable and cumulative lessons from research, evaluators need to orientate their thinking to context-mechanism – outcome pattern configurations (CMO configurations). The CMO configuration is the starting point from which to start an evaluation and the refined CMO configuration is the finding of an evaluation.*

Pawson and Tilley 1997, p.21

An example of a CMO configuration is included as Figure 6-8



**Figure 6-8 CMO Configuration**

The CMO configuration in Figure 6-8 above can be read from left to right. The PHIT monitoring and case finding in Figure 6.8 relates to the Population Health Information Tool (PHIT) which is a purpose built register used by Public Health Nursing in Ireland. The PARTNERS concepts link into the PHIT to create an alternative classification of patients based on patients' acute or chronic illness state.

This CMO configuration offers an alternative viewpoint from the business orientated medical models which have been discussed previously and which are currently in development in the Irish healthcare domain. The qualitative data collection also included a reflective diary which the author maintained for the duration of the pilot study. This diary was used to reflect upon particular issues as they arose in the field during the pilot study. Excerpts from the diary were included in the evaluation report to highlight particular key points raised within the study. Figure 6-9 offers an excerpt from the author's diary relating to inter agency communication.

**08/07/2009**

I have tried to contact the public health nurse (PHN 1) over the past couple of days to discuss case 1. Today one of the PHN's (PHN 2) from the local healthcare organisation team rang me to explain that PHN 1 who is allocated case 1 has been on annual leave and subsequently on leave due to illness for 2 weeks and will be returning to work tomorrow. An initial review of the existing PHN 1 records on case 1 would appear that the PHN 1 records were not up to date, the last record indicated that he was admitted to the acute teaching hospital. Although the actual home care package was still in progress i.e. home help etc this would partly explain the lack of home visits by the PHN 1. PHN 2 agreed to update PHN 1 and also to request that she make contact with me on return from leave.

**Figure 6-9 Excerpt from Diary 1**

## **6.5 Quantitative Analysis**

The quantitative analysis framework had a number of different strands which were used to source and analyse data. The framework included;

- a) Quantitative analysis of patient individual data.

- b) Cumulative quantitative analysis of patient data over 6 services.
- c) Matrix data on both patients and nurses who participated in the study.

Findings from the cumulative quantitative data collected over the 6 services demonstrated a statistical significance in a number of particular data fields included in the pilot tool within this study.

The key aim of the quantitative analysis of the patient data collected in cycle one of this study has been to test the concepts collected by the nurses in the paper prototype tool. This process was completed in order to demonstrate what patient outcomes can be collected over extended time intervals when using a shared assessment record. Such data articulates the nursing contribution to patient care across the acute, primary and continuing care services. Such data also demonstrates patient centred outcomes that can have a direct bearing on patient safety for example medication management and maintenance outcomes of symptom management.

The small scale quantitative pilot study which was completed on grouped data showed statistical significance with a p value of  $p = 0.018$  for functional status improvement and a p value of  $p = 0.002$  for functional status deterioration. Combining figures for ability to perform the main tasks of everyday living with falls and risk for falling, skin integrity and symptom management such as breathing and dyspnoea, weakness and fatigue, nausea and pain and completing a t test gave a significant difference of  $p = 0.03$ .

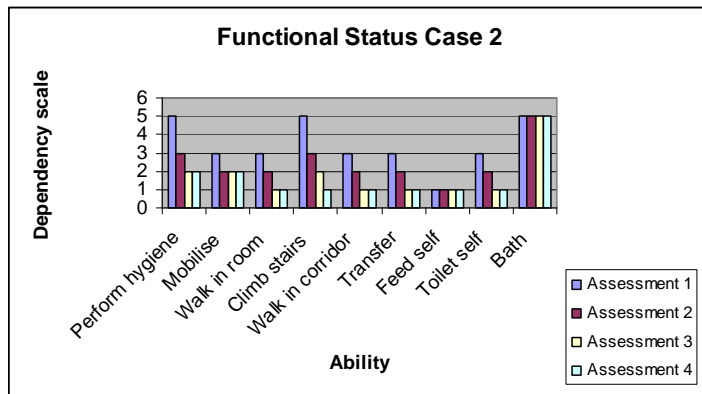
These findings correlated to the qualitative data collected on patients and the individual patient centred outcomes identified for individual cases. An example of the grouped and individual case data is provided in Table 6-9. This data identifies significant changes in patient's ability to maintain functional independence in activities of daily living and key symptoms which directly impact on the patient's ability to maintain independence and self care. The observation data

collected by the author over the six month pilot study noted that there were six patients that showed a general improvement, six patients that showed a general deterioration and four patients that maintained their existing health state particularly in relation to patient centred outcome. The quantitative data presented in Table 6-9 endorses the observation data. Episode 1 and Episode 2 represent two time intervals that the data was record on.

**Table 6-9 Grouped Data Functional Status and Other Criteria**

<b>Functional Status</b>	<b>Episode 1</b>	<b>Episode 2</b>
Ability to perform hygiene	0.875	0.8125
Ability to dress	0.625	0.6875
Ability to groom oneself	0.625	0.625
Ability to bath	1.625	1.6875
Ability to mobilise	1	1.25
Ability to walk	0.875	1.125
Ability to transfer chair or bed	0.6875	0.625
Ability to walk in room	0.625	0.8125
Ability to walk in corridor	0.75	0.9375
Ability to toilet oneself	0.625	0.5
Ability to feed self	0.25	0.25
Falls Frequency	0.5	0.5
Falls Risk	1.5625	4.5625
Pressure Ulcer & Skin Integrity	3.875	3.6875
Breathing & Dyspnoea	0.6875	0.875
Weakness & Fatigue	1.3125	1.5
Nausea	0.125	0.1875
Fluid Balance	0.125	0.25
Pain Frequency	0.625	0.625
Pain Intensity	0.3125	0.5

Figure 6-10 offers an example of a view of patient outcomes on one single patient who was assessed four times during the data collection process.



**Figure 6-10 Functional Status Case 2**

This viewpoint demonstrates to the patient and the nurse the impact of particular interventions on the patient's health state. For patients who endure chronic illness or who are elderly and are striving to maintain independence such graphical representations are important to promote motivation and self caring strategies over extended periods of time. In this particular Case 2 the patient had a Guillain-Barre Syndrome, a neuro muscular disorder which affected her functional status. Data collection commenced on discharge from the acute services and continued over 4 months. The data presented in Figure 6-10 demonstrates a significant improvement in functional status and a decrease in her overall dependency level over the 4 month period. As Case 2 had no down stairs toilet facilities ability to climb stairs was a significant milestone for her to achieve in her care plan.

The matrix data which could be described as level 2 data collected on both the patients and the nurses was a small sample due to the nature of the study. A decision was made on ethical grounds to only request information on this element of the study from patients who were capable of completing the process competently and with ease. The purposeful sample of patients over 65 (n=18) included individuals who were vulnerable, and it was the intention of the researcher not to impose any degree of undue stress on such

individuals who agreed to participate in the study. For this reason only 5 patients completed the matrix and their results are included in Table 6-10 below

Table 6-10 Patient Matrix

<u>Participant Question</u>	Case 12	Case 14	Case 3	Case 4	Case 16
<b>I think that the PARTNERS pack</b>					
Captures information on my health needs	4	4	3	4	4
Helps me understand my plan of care	2	4	4	3	3
Helps with communication between services taking care of me	4	3	4	4	3
Helps me see if my health state is improving or not	4	4	3	4	4
Helps me access information previously not easily available to me	4	2	4	3	3
The assessment is more focused on me and my needs to maintain independence	4	4	3	2	3
I liked the idea of holding my own record	4	4	4	4	4
Legend 4= To a considerable extent 3= To a moderate extent 2= To a slight extent 1= Not at all					

The nursing participants also completed a matrix which is presented in Table 6-11 followed by a summary of the findings in Table 6-12

Table 6-11 Nursing Participant Matrix

<b><i>PARTNERS MATRIX</i></b>				
	To a	To a	To a	Not

<b>The PARTNERS Archetype</b>	Considerable Extent	Moderate Extent	Slight Extent	at all
Captures patient centred outcomes				
Improves patient care processes (care planning)				
Helps Formal Interagency communication (Documentation)				
Helps Informal Interagency communication				
Helps Access Information previously not easily available				
Increases focus during assessment to the individual patients requirements to maintain independence				

A summative table of the data collected from this matrix is presented in Table 6-12

**Table 6-12  
Findings from  
Nurse Practitioner  
Matrix**

		Capture Patient Centre Outcom
N	Valid Missing	
Mean		3.71
Median		4.00
Mode		4
Std. Deviation		.468

## 6.6 Conclusion

A key focus of this pilot study has been to evaluate the effectiveness of a taxonomy of concepts devised by practitioners in phase one of the study (see Table 6.9). This taxonomy can then be used to inform the development of a set of archetypes for discharge summary assessment in the future. Although the sample is small, the author would suggest that the data collected in phase two of the study has demonstrated a taxonomy of concepts which is fit for purpose. This Level 1 data is best demonstrated in the quantitative cumulative and individual patient data presented in Table 6-9 and Figure 6-10. The Level 2 data which seeks to explore the socio-technical aspects of

the implementation of the pilot study may inform future clinical requirements process engineering. Level 2 data is perhaps best presented in the qualitative data collected in the study. For example the CMO configurations and the reflective diary offer examples which are presented in Figure 6-8 and Figure 6-9 of this chapter. As this level 2 data is less tangible to summarise and refers to the more subtle research findings of the study the full transcripts are included for review in the practice development evaluation report Appendices 3 and 4. Whilst the participant matrices Table 6-10 and Table 6-11 are useful to gauge how the PARTNERS practice development initiatives have been received the author would argue that they do not add any great deal of significance to the research finding process under discussion in this chapter. Finally the Level 3 data which relates more to outcomes measurement and lends itself in the future to theory led research will be discussed in chapter 7 of this thesis. A summary review of the qualitative and quantitative methods adopted in the study is presented in Table 6-13. This table considers the research design methods critically in regard to overall general approach and the adopted strengths and limitations of the particular approaches used within the study.

**Table 6-13 Summary of Methods Adopted**

<b>Approach</b>	<b>Strength</b>	<b>Limitations</b>
CMO Configurations.	Created a productive space for discussion with practitioners. Offers readers concise mind map of narrative process with supporting transcripts. Useful resource for education and training. Useful resource for interfacing with external stakeholders to demonstrate different roles and opinions.	Over simplified mind map of the reality of practice – need to ensure transcripts are reviewed in tandem with CMO configuration. Because of sample size not generalisable data only useful for micro level theory testing.
Reflective diary.	Useful resource for author of thesis to reflect upon events as they transpired. Offers more factual data of events that occurred as diary completed during field study.	Time consuming exercise. From an ethical perspective some detail in the diary not suitable for inclusion in study.
Quantitative analysis of patient individual data.	Useful resource to demonstrate to practitioners and service managers the notion of patient centred outcomes.	Time consuming process as ICT infrastructure not in place at time of pilot. Data transcribing increased risk of error.
Quantitative analysis of patient data grouped.	Useful resource to demonstrate to managers the potential power of statistically significant data for export to HSE dashboard. Assisted in development of Draft Knowledge Model for future archetype creation.	Because of sample size not generalisable data only useful for micro level theory testing.
Matrix data on patients.	Inclusive - Offers opportunity to patients to contribute to the study findings.	Not effective method to collect information from older patients.
Matrix data on nurse participants.	Offered opportunity for staff to individually contribute to the evaluation process and include comments.	Because of sample size not generalisable data only useful for micro level theory testing.

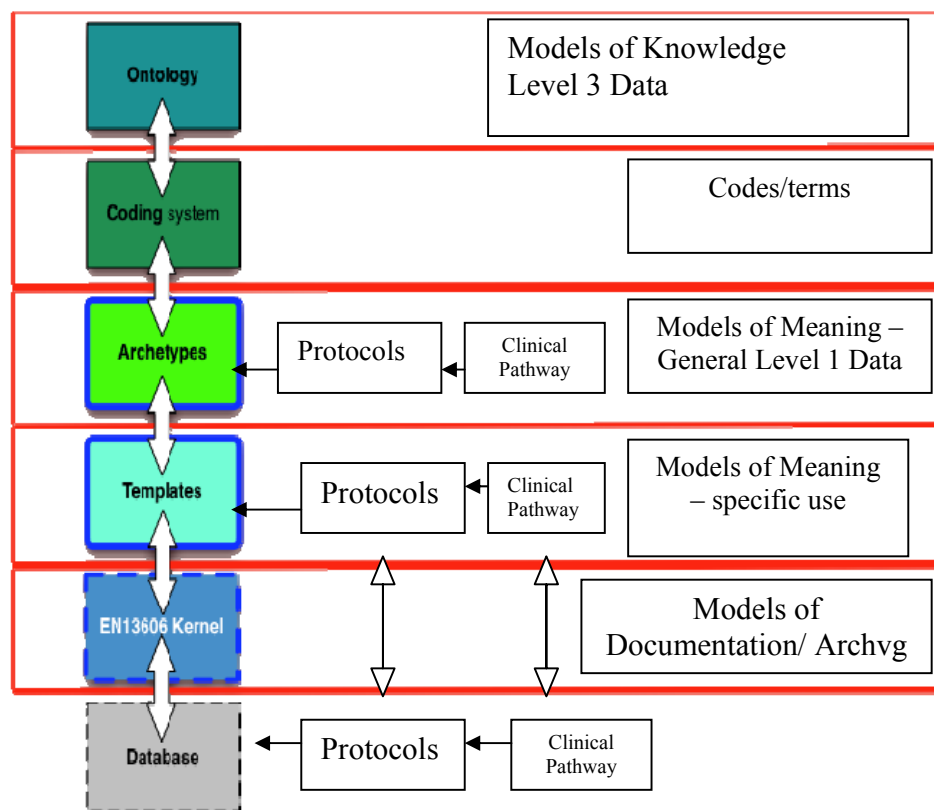
Chapter 7 will now present a synthesis of the findings of this study from a health informatics perspective and will offer some insight into new knowledge gained relating to the development of a set of archetypes for integrated care for older persons aged 65 and over. This is described by the author as Level 3 data collection.

## **7. Discussion**

### ***7.1 Introduction***

Chapters 3 and 4 have explored semantic and syntactic interoperability as the two key requirements of clinical information systems in order to deliver information in context to create shared meaning and knowledge to healthcare professionals for current and future interpretation. Interoperability and standards are key requirements to deliver patient efficiency and effectiveness particularly in the digital society in which we now live. It is therefore not surprising that improving ICT standard setting, promoting better use of standards and enhancing interoperability through co-ordination have been recently prioritised as key action areas for the digital agenda in Europe (EU Digital Agenda, 2010). In this study a number of European and International standards have been reviewed (EN13940, EN13606, ISO 18104, ISO 11179). Two European standards that were instrumental to this study and which were discussed in Chapter 4 are EN13606 or EHRcom and EN13940 Systems of Concepts for Continuity of Care. The standard EN13940 could be described as offering an ontological viewpoint of core concepts for continuity of care, and given the topic for this study the standard has proven to have been a useful resource to consider in conjunction with EN13606. By critiquing these two health information standards and linking them where appropriate to the identified clinical requirements for shared care, a model of knowledge for future theory testing can be considered. This the author describes as Level 3 data in Chapter 6. Models of Knowledge are required to maximise patient care effectiveness and from a health informatics perspective such frameworks can inform the future development of a detailed clinical model (DCM).

Developing DCM's in healthcare is gaining momentum and popularity as it provides a structure for medical information, medical knowledge, data specifications and terminology in a combined construction to produce technical applications for EHR (DCM Foundation). The semantic stack (Freriks, 2010) was introduced in Chapter 4 and is shown in Figure 7-1. It is used in this chapter to present the analysis. Freriks (2010) semantic stack demonstrates the relationships between Models of Knowledge (Level 3 data) and Models of Meaning (Level 1 data) in accordance with EN13606 and offers a scaffold to demonstrate the new knowledge in health informatics generated from this thesis. The semantic stack and Models of Meaning and Models of Knowledge are presented here as an analysis framework only. The key focus of using the semantic stack as an analysis framework assists the author to synthesise both the qualitative and quantitative data collected into Models of Meaning and Models of Knowledge which relates to objective 3 and objective 4 of the study.



**Figure 7-1 Gerard Freriks Semantic Stack**

Source Freriks (2010) Semantic Interoperability EN13606 Presentation EHRLand Workshop

This scaffold for analysis is defined by Freriks (2010) as a semantic stack and this framework clearly defines the elements of EN13606 from the perspective of the healthcare professional EHR view. This chapter contains critical analysis of this semantic stack in Figure 7-1 to draw together the differing elements of the data collected in the study from the perspective of the author's research experience.

This chapter presents the author's interpretation of the study and sets down a narrative for further health informatics research in the future. Specifically this chapter will demonstrate the framework created to represent both Models of Knowledge (ontology) and Models of Meaning (semantics). In order to illustrate these models the author has created a series of detailed figures with examples from a set of

archetypes designed for shared care of persons 65 or over which has been a key objective in this study. The remainder of this chapter is structured as follows. Section 7-2 offers a brief outline of core elements which have emanated from the evaluation process. To present this data the author has selected a number of cross cutting themes which have emanated from both the quantitative and qualitative elements of this mixed methods study. The cross cutting themes are used to describe how the elements have been combined to include the knowledge generated from this study which is now presented from a sense making and clinical interpretation perspective. This resource represents the ontology – the agreed core concepts that are required to formally represent the world in which the practitioners exist. The ontology described in Section 7.2 is summarised in Figure 7-2 and Figure 7-3 and describes the Model of Knowledge created in this study and relates to Level 3 data. Section 7-3 describes the codes and terms that can be used in order to map the selected concepts used in the archetype to a formalised reference terminology server.

This process accommodates semantic interoperability ensuring that the meaning of the EHR extract is preserved in the transfer of data across and between service providers. In this study a compositional reference terminology International Classification of Nursing Practice (ICNP) version 1.1 was used. This compositional reference terminology was adopted to create a data dictionary in accordance with ISO 11179 the Metadata Registry standard. Figure 7-5 offers an example on the term *allergy* from this data dictionary in section 7-3. The following section 7-4 describes the first draft of the Model of Meaning and describes the Level 1 data created in this study. The information contained in this framework is presented in a formal aggregation linking to the ontology (Figure 7-2) and can be presented in an EHR viewer to nurses and patients across the

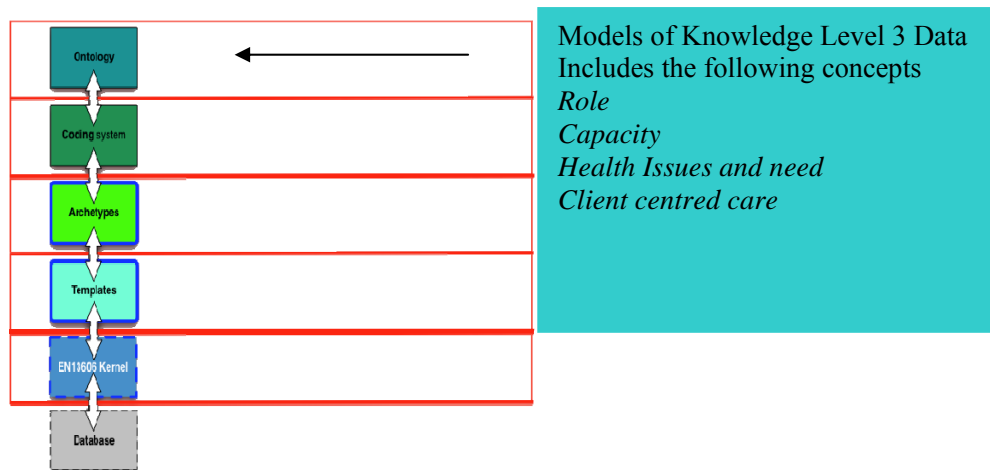
differing healthcare settings. The Model of Meaning Figure 7-7 presents a summary of the archetype compositions created for general use.

The individual sections on the Model of Meaning can be selected by service users in tandem or separately. Figure 7-7 considers carefully the structure of the content for presentation back to healthcare professionals both in a clinically pragmatic view (individual patient and service provider) but also one which is cognisant of the cross cutting themes identified in this study such as role capacity and patient need as a health issue.

This Model of Meaning does not include the administration or business requirements for EHR but rather focuses on what key information is required for nurses to care for patients safely across and between services with the most up to date information available. Therefore the Model of Meaning described in Figure 7-6 and Figure 7.7 would require clinical protocols in order to operationally implement the archetype compositions for general use.

Section 7.5 demonstrates Model of Meaning for specific use and describes examples of archetypes templates created using an archetype editor application LinkEHR; this is also representative of Level 1 data. The Reference Information Model (part 1) and ADL (part 2) of EN13606 are used to inform this particular process with some supporting examples relating to this study. Examples of excerpts of the archetype editor and the archetype editor views in XML and ADL are included to demonstrate the LinkEHR archetype editor functional outputs. This section concludes with a brief view of the data as it would be presented to the practitioner as a user summary report view in Figure 7-12. Finally section 7.5 concludes this chapter with discussion of the existing challenges experienced in this study in relation to archetype development.

## 7.2 A Model of Knowledge



**Figure 7-2 Models of Knowledge**

Source Freriks (2010) Semantic Interoperability EN13606 Presentation EHRLand Workshop

A number of core concepts were identified in the context mechanism and outcome configurations in this study. Examples of these concepts are presented in chapter 6 and the full transcript of the evaluation report from the stakeholders is included as Appendices 3 and 4 in this thesis. A series of cross cutting themes have been prevalent within the transcript analysis, informal observations in patient care, and documentary analysis. Concepts which were identified by all of the stakeholders as key to patient care effectiveness are summarised in Figure 7-3. These concepts relate to role capacity and health issues and are expanded upon in this section. The decision to include these concepts is based on the triangulation of data from different sources in action phase one and two of this study illustrated in Chapter 6 (see Figure 6.3 p.212). The triangulation process which is defined by Webb et al (1966) as an approach to the development of measurement of concepts using

more than one method of measurement results in greater confidence in findings and has been used in this study to validate decisions made for Figure 7.3 and 7.7 relating to research objectives 3 and 4 in this study.

The role of the nurses who participated in the study was varied. This variation in role is viewed as quite significant across the acute, continuing care and primary care service providers. A key difference in role is that nurses in the acute services tended to focus on the particular episode of care and the interventions that were required for that patient with one or more health issues. This could be described as care pathway orientated. Whilst the nurses in continuing care were more focused on clients reaching and maintaining independence over a more extended timeframe.

The primary care and community nurses had a broader remit to their role. The primary and community care nursing role appeared to be all encompassing and required a diverse suite of roles to be adopted depending on the actual patient. This included caring for individual patients or caring for individual patients and families to considering individual populations in particular areas often from very diverse cultures and backgrounds. This broad focus of role for community nursing is perhaps best described as facilitating, promoting, and maintenance of health for individuals and families, by preventing and minimising the progression of disease, and improving the overall quality of life St John & Keleher (2007). This is often described by Public Health Nurses in Ireland as case management and surveillance. The following quotes are included as summary examples from the evaluation report in Box 7.1.

*Role is important (Continuing care 1)*  
*I suppose our role and time that's very important (Primary care 1)*  
*Part of our role is to inform people of their rights (Pop Health)*  
*Our role is advancing (Acute service 1)*  
*Understanding our role is key (Primary care 2)*  
*The role is very different than an RGN or PHN (Continuing care 2)*

**Box 7-1 Evaluation Focus Group 1**

As *Role* is considered important by participating nurses in this study and is mentioned frequently it has been identified for inclusion within the detailed knowledge model Figure 7-3. The role of nurse seen in this study included a wide spectrum of activities and environments, and in some cases nurses often assumed a number of different roles. Role encounter record is therefore created as an archetype so that templates can be created and tailored locally to meet clinical requirements and to accommodate shared record views of patients by role.

Capacity is also mentioned frequently in the transcripts, the notion of capacity presents a particular challenge for those nurses engaged in primary care. It also has a direct bearing on effective discharge to the community. Capacity can be further considered as four core sub themes namely individual patient, family or carer's capacity. The available service capacity in a particular setting which can be linked to social deprivation or accumulated wealth and the overall community capacity is a key indicator for patient centred outcomes. This is summarised well in the following quotes in Box 7.2.

*You need to consider that the capacity or environment in one community might be better than in another environment. We need to think about the community environment and the social capital as well, there are huge supports in a hospital but this is often not the case in the community. Often with elderly people the longer that they are in hospital the more their ability to be independent is lost. Their self confidence to live on their own is gone (Primary care 1) The patient in the context of their home versus the patient in the context of the hospital is totally different and that's what we need to capture (Primary care 2)*

**Box 7-2 Evaluation Focus Group 2**

The notion of capacity is also included in the knowledge model Figure 7-3 for further consideration and is linked to the individual's health findings and assessed subject of information capacity record.

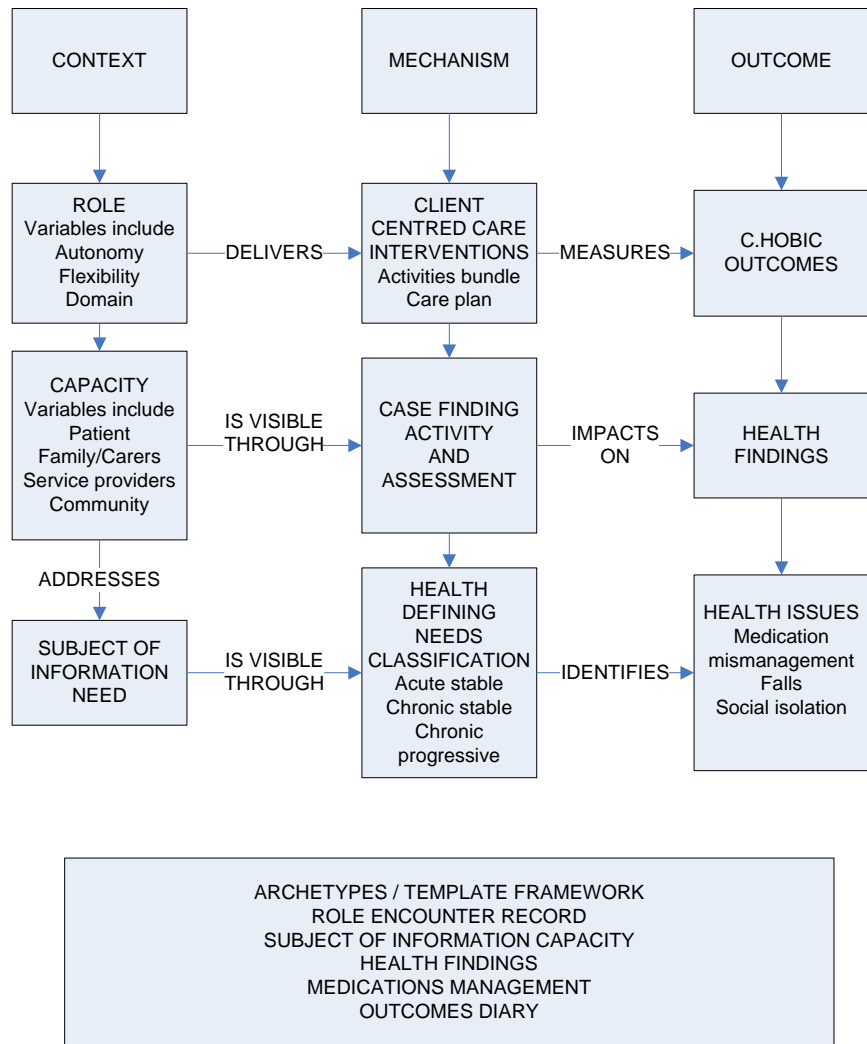
A number of participants within the study expressed the concept relating to patients' expressed need. Concerns were articulated in particular to the absence of expressed patient need in existing records, this concern was linked to the increase in resources being tailored around specific medical conditions such as diabetes or cardiac care. Such approaches may limit the holistic care view for patients with co-morbidity issues. Box 7.3 demonstrates this particular issue.

*We should perhaps consider systems based on urgency of need (Pop health)*  
*They may need an occupational therapist or a physiotherapist or they may need something else in the house as well (Primary care 1)*  
*Decreasing the need of the patients is important (Primary care 2)*  
*See how they are progressing and inform us what their needs are (Cont Care 2)*  
*Patient needs in context is important (Continuing care 1)*  
*Like hospital in the home but more holistic (Acute 1)*

**Box 7-3 Evaluation Focus Group 3**

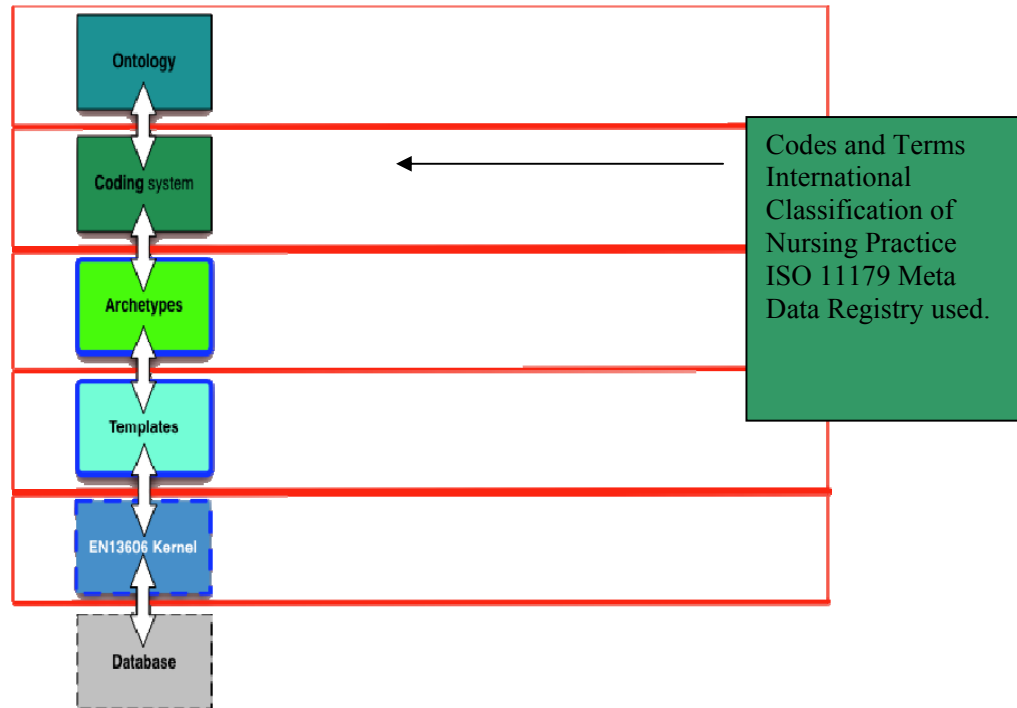
The study explored the concept of patient expressed need and identified a number of patient needs which it links to the concept of health issue from EN13940. The two most prevalent health issues that the nurses articulated in relation to patient care effectiveness were falls and medication mismanagement. A decision to link health issue with patient need to patient outcomes in the knowledge model was made. The final concept that is included on the knowledge model relates to organisational structures, this is included on the knowledge model as an underpinning structure to accommodate access to records using archetype templates to facilitate both syntactic and semantic interoperability. This concept is linked to health findings record and subject of information capacity record, and there should be an association between health issue and role encounter record so that this data can be viewed collectively.

Figure 7-3 demonstrates the core elements of the knowledge model and the linkage



**Figure 7-3 Knowledge Model version 1**

### 7.3 Coding System and Terms



**Figure 7-4 Coding System and Terms**

Source Freriks (2010) Semantic Interoperability EN13606 Presentation EHRland Workshop

The coding system used in this particular study is based on the International Classification Nursing Practice (ICNP®) which adopts the standard from nursing EN18104 as the reference standard for categorisation of nursing diagnosis and interventions. Mapping of the taxonomy and paper prototype was completed in accordance with an ISO standard ISO 11179 Metadata Registry. An example of this mapping using the concept allergy is included in Figure 7-5 for demonstration purposes. Using ISO 11179 to create a data dictionary requires the inclusion of a data definition, data synonyms and any particular key notes to the author on the concepts.

In this case the note relates to the concepts allergy and is in regard to generating evidence post exposure to a medication allergy.

### Concept - Allergy

#### Definition

Intolerances or adverse reactions that have been activated

#### Note

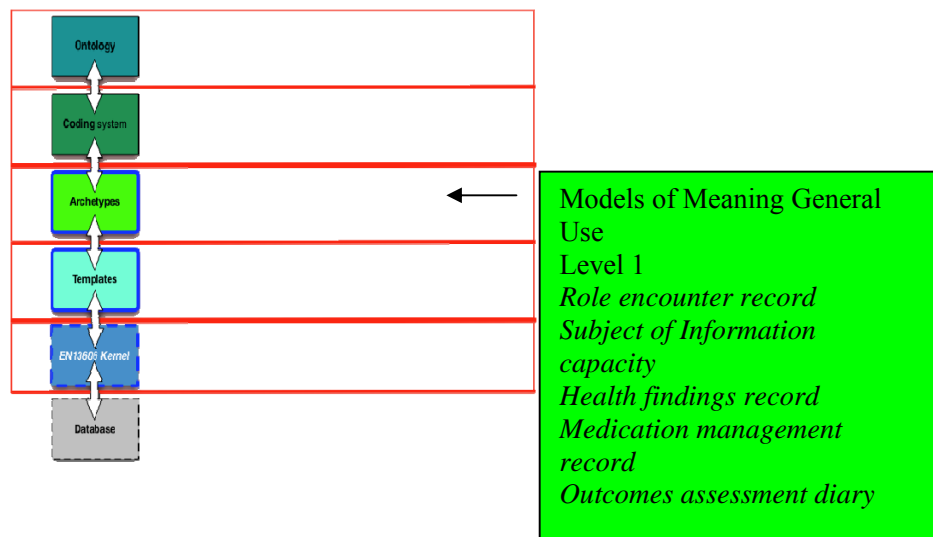
Evidence should be confirmed following exposure e.g. antibiotic or warfarin allergies, often not true allergies i.e. or allergies to food.

**Example** Latex Allergy      **Synonym** Reaction    Sensitivity

ICNP Code	ICNP Term
10002163	Allergy
10013253	Judgment
10000420	None
10008091	Actual
10010307	Food Allergy
10011185	Insect Bite Allergy Latex Allergy
10011878	Medication Allergy

**Figure 7-5 Example of ICNP Mapping ISO 11179**

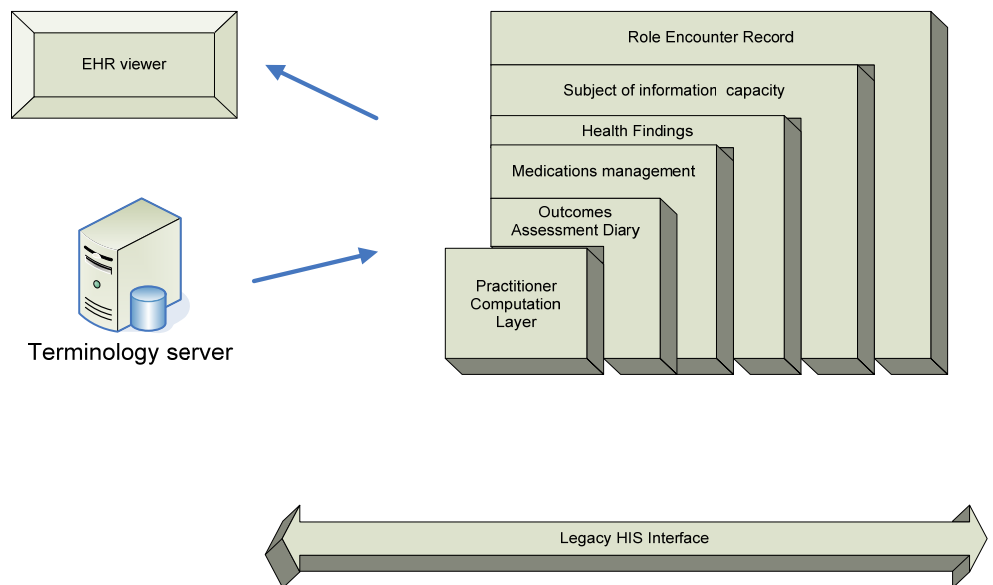
## 7.4 Model of Meaning - General



**Figure 7-6 Models of Meaning**

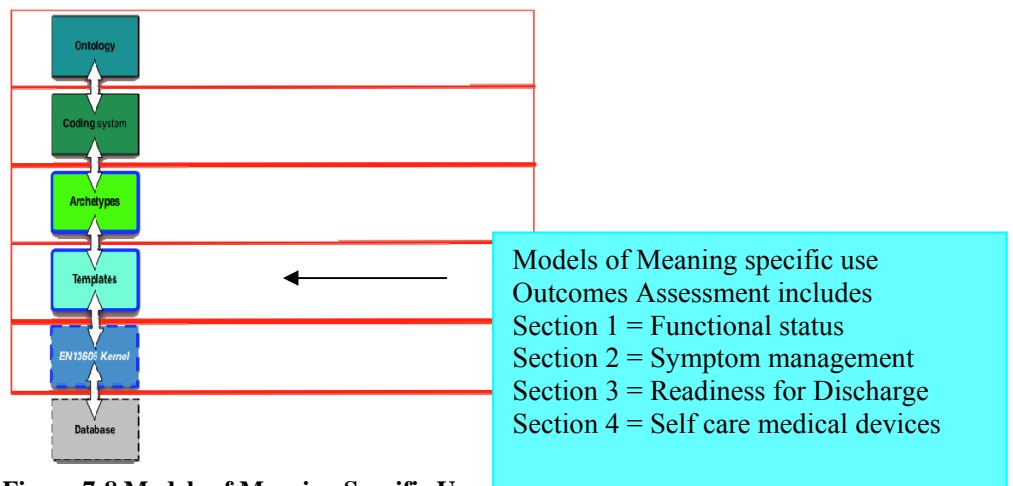
Source Freriks (2010) Semantic Interoperability EN13606 Presentation EHRland Workshop

The Model of Meaning for general use is presented here in Figure 7-6 to illustrate the creation of an archetype model designed in accordance with the Model of Knowledge version 1 Figure 7-3. This Model of Meaning offers a high level view of the compositions in the archetype resource. It is envisaged that within the EHR extract a number of compositions are created which are presented in Figure 7-7. In this figure the compositions would be seen by healthcare professionals via an EHR viewer. All data elements contained in the compositions would be mapped to a terminology server and would have the capacity to interface with legacy hospital information systems via an application programming interface. Each of the compositions has a number of structured sections with associated entries that healthcare professionals can view the data from and which is context specific. Examples of compositions with their associated sections are presented in the following Section 7.5.



**Figure 7-7 Archetype Compositions**

## 7.5 Model of Meaning - Specific

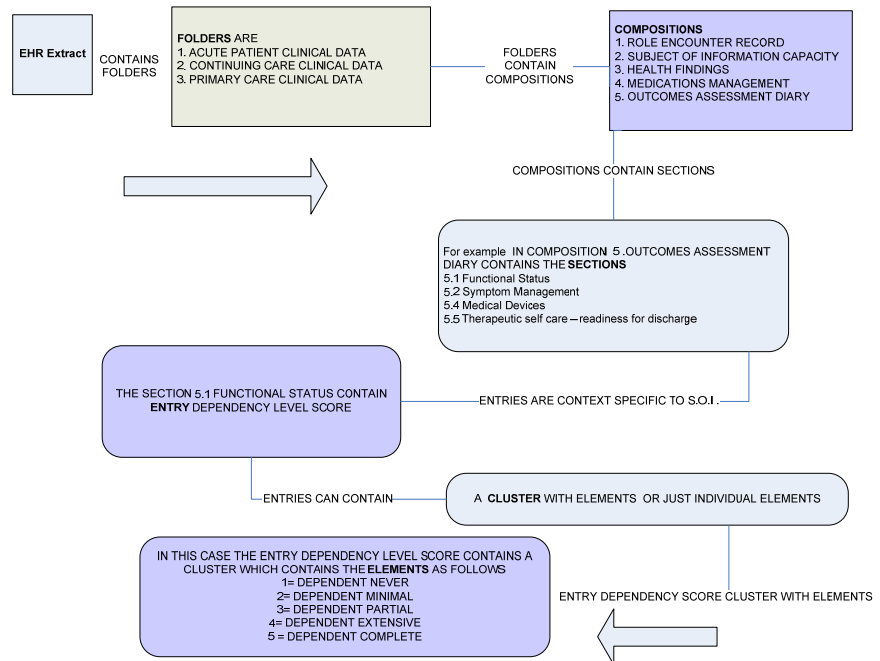


**Figure 7-8 Models of Meaning Specific Use**

Source Freriks (2010) Semantic Interoperability EN13606 Presentation EHRland Workshop

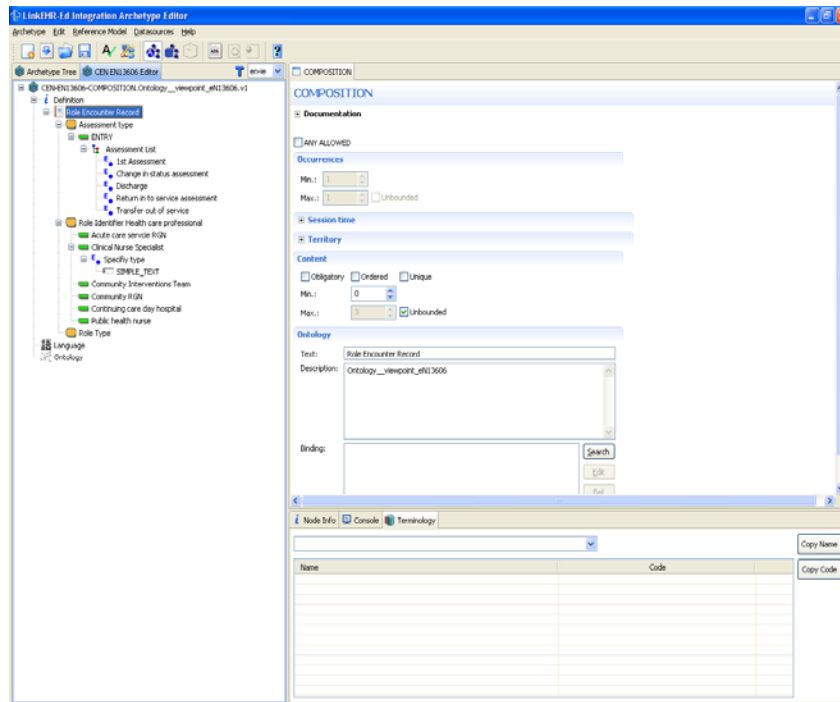
The Model of Meaning for specific use Figure 7.8 illustrates the use of the content of a section of the reference information model of EN13606 for this particular study. Models of meaning for specific use illustrate sections that are contextually relevant to the nurse who will be using the archetype in the practice domain and presents how information will be viewed in a summary format by the nurse. It is envisaged that templates can be configured from the archetypes in the future; such templates could be configured by role. For example archetype templates could be created for specific environments such as primary, acute and continuing care based on patient type such as acute or chronic stable patients or chronic progressive patients.

A more detailed view is presented in Figure 7-9 which demonstrates how this EHR extract detail can be arranged in an archetype using part one of the standard relating to the reference information model. In this particular case the *composition* – Outcomes Assessment Diary contains a section entitled Functional Status. The section Functional Status is used to demonstrate how an *entry* called dependency level score can be used in a *cluster* of *elements* from 1-5 with 1= Dependent never and 5= Dependent complete.



**Figure 7-9 Detailed View of Archetype RIM**

This work is then entered into an archetype editor (in this case Linked EHR was used) and the information is presented in a structured framework as Figure 7-10 demonstrates;



**Figure 7-10 LinkEHR Interface**

Once the data has been entered as an archetype using the constraint reference information model in LinkEHR the archetype or set of archetypes can then be converted and exported for use with other legacy health information systems. The following Figure 7-11 demonstrates the archetype templates converted and exported into ADL. This work was completed as part of this study and in this particular example the concept relates to Role Encounter Record. This example is included as a representative sample of the ADL code and is therefore not the complete template for Role Encounter Record.



<b>Patient Summary</b>			
<b>Patient Clinical Data</b>			
Subject of Information Biographical Detail			
First Name	John		
Last Name	Smith		
Age	67		
Sex	Male		
Subject of Infor. Capacity	ICNP ID Code	Date Assessed	Current status
Individual		01/06/2010	
Lives alone	10022753		Current status
Environmental			
Steps and Stairs	10000340	01/06/2010	Complex issues with facilities
Social			
Meals on wheels	10004808	01/06/2010	Daily
Public Health Nurse	10027359	01/06/2010	Weekly
<b>Active Health Issues List</b>			
Outcomes Assessment Diary	ICNP ID Code	Date Onset	Current status
Functional status	10018786	01/06/2010	Active
Functional Status	ICNP ID Code	Date Assessed	Judgement
Ability to bath	10028224	01/06/2010	Dependent minimal
Ability to dress	10000145	01/06/2010	Dependent minimal

**Figure 7-12 Example of EHR viewer**

## 7.6 Conclusion

A key inhibitor in the development of this study has been the lack of a unique identifier in Ireland during the course of the archetype development process. Throughout Part 1 and Part 2 of EN13606 identifiers are noted as key elements of the standard to facilitate safe integrated records of care. In EN13606, for example there are object identifiers (O.I.D.'s) and instance identifiers (I.I.) which need to be included in each data element of EN13606.

Current thinking on this particular issue suggests that a technical specification document by ISO /PDS 2220 Identification of Subjects of Healthcare may offer some guidance on this particular challenge in the short to medium term.

The composition *Role Encounter Record* identified in Figure 7-11 will require input on specific data elements such as healthcare professional ID and subject of information ID in order to progress the Model of Meaning for future use. Governance issues relating to the processing of data on the archetype templates in a practice environment were not addressed in this study. To ensure the integrity of the data input, viewing and analysis of the terms of reference relating to data collection and viewing of data will be required. For example what is the agreed frequency and time for data collection? Who should input data? Who is responsible for the delivery of appropriate training and education of practitioners to facilitate inter rater reliability? All of the above questions will require careful consideration in the drafting of clinical guidelines and protocols for future implementation in practice. Some of the outputs from this particular study relating to clinical requirements engineering included in Appendix 1 may inform some of the processes for the archetypes developed in this particular thesis. Determining who is able to access particular patient record detail will also need to be considered at both local and regional level.

## **8. Conclusions and Future Research**

### ***8.1 Introduction***

In this final chapter the study is discussed from a health informatics, research and practice development perspective as follows. Section 8.2 will consider the study from a research perspective, Section 8.3 will consider the study from a practice perspective and Section 8.4 will explore the study from a health informatics perspective. The epistemological, theoretical and ontological perspectives are considered in this Chapter and some examples are offered from the study design and overall findings in order to identify and illustrate the complex interdependencies that this study has come to recognise over a two year timeframe. The overall aim of this study has been to create a shared nursing assessment record of care using state of the art technology for persons aged over 65 which could enhance interagency communication whilst improving patient safety. The key research outputs from this study will be explored for their usefulness in supporting the creation of new knowledge, for example the Models of Meaning and Models of Knowledge devised for future archetype and outcomes framework development.

The findings of the study are drawn together in this concluding Chapter and presented in a final summative illustration presented in Section 8.3 as Figure 8-1. At the outset however the main areas in which this thesis has contributed to the area of health informatics are presented in section 8.1.1. As this study was underpinned by participatory action research where appropriate the actions delivered upon will also be articulated in the text.

### 8.1.1 Research Contribution

In health informatics terms the existing environment already described in this study could be summarised as follows:

- The existing health system of care is not sufficient to address the growing aging population (CSO, 2008).
- Current health policy e.g. The Transformational Programme in Ireland has recommended to the recently established clinical directorates to implement shared pathways of integrated care which foster a patient centred approach to healthcare (O'Shea, 2009).
- There is to be a more specific focus on delivery of healthcare services in primary care which can address chronic illness such as diabetes. (O'Shea, 2009).
- Information and communication technology (ICT) is to be used as an enabler to underpin the shared pathways of healthcare and enhance interagency communication (DoHC,2009)
- An important issue to be addressed in order to enable the delivery of ICT in Ireland is the adoption of health informatics standards, standardised information models and standardised terminologies which have yet to be evaluated in the Irish context (Berry, 2010).

The key contribution that this study offers the health informatics research community in Ireland can be summarised as follows:

- As a consequence of engaging in the PARTNERS study, the participating nurses have a common understanding of each others respective roles across the healthcare services, and have established a core set of assessment data for shared

patient centred care. This creates an opportunity for future practice development initiatives in line with the stated transformational programme requirements initiative. This contribution relates to objective one and four of this study. Key Action – Empowerment of nursing participants, nurses have gained a deeper understanding of the different contexts that they practice within i.e. acute primary and continuing care.

- A set of archetypes relating to patient assessment in the older person have been pilot tested and are deemed fit for purpose offering practitioners some practical applications for future use which accommodate semantic and syntactic interoperability. This contribution links to objective 2 and 3 of this study. Key Action –Engagement with individual groups delivering focused education and training on preparation for EHR deployment this is described as a *readiness* and *intention to adopt* for future ICT implementation (OECD, 2010, p. 115).
- The emerging Models of Meaning and Models of Knowledge offer the author a framework for future theory led outcomes research on patient centred care. This contribution links to objective 4. Key Action – Research based teaching involving the development of a Conceptual Model for future health Informatics research and education.
- The PARTNERS and EHRLand project demonstrate practical application of health informatics standards such as EN13606. The studies also identify discrepancies and issues in testing and implementing of the standardised information models which are informing future development of health information standards in CENTC251. To some extent this contribution was unexpected and not identified in the initial

study objectives. Key Action – Active engagement in the European Task Force on Continuity of Care. The author has participated in the development of EN13940\_2 based on outputs from this study e.g. the role of social capacity in primary care setting and its affect on health outcomes.

- Demonstrate use of standardised reference terminologies such as ICNP which are slow to evolve in Ireland: The PARTNERS project offers a practical example of the benefits and disbenefits of using such terminologies which have yet to be evaluated in the Irish context. This contribution links to objective three in this study.
- The Web 2.0 technologies, publications and reports offer scope for the education and training of nurses on health informatics in the future see [www.partnersct.com](http://www.partnersct.com). This contribution links to objective four of this study.

Key Actions – Research based education and training of nurses in Ireland on clinical concepts and terminology, health information standards and EHR *readiness* and intention to *adopt* (OECD, 2010).

## **8.2 Research Overview**

The main research questions identified in this thesis is:

Can nurses build a common understanding of patient assessment for future outcomes based research which can facilitate shared care in older persons using action research?

AND

Does an action research approach assist in the development of archetypes in accordance with EN13606?

The author would contend that this study has to some extent assisted nurses to build a common understanding of what is required for shared patient assessment, and has delivered archetypes which are fit for purpose to facilitate shared care. This study has provided important contextual case information on the various roles in which nurses engage in the different services, which is a key functional requirement for safe and efficient continuity of care. A suite of archetypes based on identified requirements has also been developed and piloted which the participating nurses articulate in the evaluation is fit for practical application. The patient centred outcome data collected from the pilot assessment tools over a six month timeframe offers significant statistical evidence which although not generalisable was also validated by the qualitative data collected on the patients who participated in the study.

In summary the author would contend that the research objectives were reasonably well achieved however in Section 8.2 and Section 8.3 the author will discuss in more detail the more subtle contextual information relating to this study that the author has become familiar with and which may inform similar projects in the future to facilitate best practice.

The stated research objectives were:

1. To identify the interagency information requirements needed to provide an integrated summary record of care for older persons.

The author would contend that this objective was achieved, Documentary analysis of existing assessment records from the participating services was reviewed and focus group interviews delivered the requirements engineering data for each service provider. This data was presented back to the services in the form of an Interim Report which was launched in June 2008 in the health services. The data collected was then used to create a prototype assessment form which was tested with the participants using simulation on anonymised patient cases from the respective services. The data collected in the evaluation report of the pilot study suggests the prototype assessment form would, when properly implemented, meet their individual communication needs (see Table 6.5 and Appendix 3 p.48).

2. To categorise the core concepts (taxonomy) and develop and pilot test a prototype paper summary record to support shared patient centred care.

The author would contend that this objective was not so well achieved due to external factors particularly in relation to access to and from one of the participating services. The main objective was achieved in the sense that the taxonomy of core concepts was drawn together from a strong evidence base such as Canadian Health Outcomes for Better Information and Care and the Irish Nursing Minimum

Dataset studies (Hannah, et al, 2009, MacNeela et al 2006) and mapped to the core data requirements identified from the existing assessment documentation that the nurses were using. The draft assessment tool was also then created and pilot tested over a six month period from June to September 2009 in six healthcare service areas with eighteen patients. The author must concede however that whilst the prototype pilot assessment record was fit for purpose the external factors relating to access in one care setting created a series of chain events to hamper the interagency communication.

Failure to access this service was directly related to gaining ethical approval from one services ethics committee who requested three specific changes to be made to the PARTNERS prototype documentation over a four month period. The specific issues relating to access is discussed in detail in Appendix 3 of this thesis.

3. To map the information requirements and taxonomy to EN13606 and a reference terminology to achieve semantic and syntactic interoperability in the form of a set of archetypes.

The author would contend that this objective was achieved. The concepts identified in the assessment tool were mapped to ICNP and a data dictionary was completed in accordance with ISO 11179 the International Standard for Meta Data Registries.

The author engaged with the EHRland team and delivered a prototype application and database in accordance with EN13606 to assure both semantic and syntactic

interoperability was possible. Following the evaluation of the pilot study the author proceeded to consolidate both the experience of engaging in the pilot with the qualitative and quantitative data derived from the study to create Models of Meaning and Models of Knowledge. These conceptual frameworks were based on Freriks (2010) presentation on interoperability using a semantic stack and LinkEHR an ADL editor and Normalisation Platform created by Cano (2010).

4. To assist nursing participants to build a common understanding of what needs to be measured in patient assessment to inform future theory testing for outcome based research.

This objective the author would maintain was also achieved. Nurses who participated in this study have articulated to the author that a key output from this study for them has been learning about the other roles that the participating nurses perform in the different services. The new knowledge that they have acquired is directly impacting on practice development programmes within the primary and acute healthcare setting. For example public health nurses participating in this project are devising a core assessment tool for primary care which is currently under development for national implementation.

The selected research design and method evolved over the course of the study. This was a direct result of discussions with the nursing participants in the study. As the nursing participants became more empowered by the practice development initiatives associated with the study, they had a more vocal opinion on how the study design was to be implemented.

Critical analysis of the evidence base relating to outcomes based research also suggested that a mixed methods research approach was a good fit to the practice development initiative associated with this study – PARTNERS. From an ontological viewpoint randomised control trials and non-randomised comparative design were identified as failing to unlock the “black box” (Dickenson, 2008). Therefore a dominant qualitative mixed method design, although more labour intensive and presenting difficulties in generalising the results, was the preferred choice using an exploratory design. The strength of this approach included the facilitation of the perspectives of all stakeholders who engaged in the study and although the data analysis was more difficult for the author it presented to the reader the complexity and often subtle tensions of the phenomena under study. Using different methods for data acquisition is also considered as a key research method in action research, the term used for this process is triangulation (Reason and Bradbury, 2008). El Ansari and Weiss, (2006) also support this approach and recommend that under such circumstances it is best to adopt a stratified evaluation as identified by Pawson and Tilley (1997). The evaluation framework entitled realistic evaluation used within this study sought to explore micro level theory only. Byng et al (2005) cautions researchers on using realistic evaluation and their associated findings for interpretation of grander theories in the practice domain. Investigators recognise that for research engaged in social sciences, the interpretation of outputs from such studies creates practical and theoretical difficulties in regard to discovery and prediction (Connolly, 2001).

For micro theory testing however realistic evaluation facilitates the potential to create a space for cumulative knowledge development within the context mechanism and outcome configurations (CMO). The author’s interpretation of the CMO configurations in this

particular study led to the Models of Meaning (Figure 7-8) and Models of Knowledge (Figure 7-3) as identified in Chapter 7. Clarke et al (2008) describes this process as follows;

*To understand outcomes and patterns , researchers still need to examine regularities in the world but search for explanations beneath these patterns to account for why the did or did not occur (Clark et al , 2008, p.71).*

## **8.2 Practice Development Overview**

During this study the degree of participation and commitment to the practice development process by the participants occurred with varying levels of dedication and enthusiasm. Whilst participatory action research creates a situation in which all those involved can contribute both to the thinking that informs the inquiry and to the action which is its subject (Heron and Reason, 2001.p.106) the participants' clinical workload can have a direct bearing on what is feasible and what can be achieved with the resources available.

The element of trust between the three domains of practice could also be described as fragile during the timeframe in which the study was completed. This was evident by their expressed *ways of working* which in some cases directly led to difficulties such as local tension in ability to co-ordinate care amongst the different services. For some of the participants the process of engagement was straightforward: a clear understanding of the fact that practice particularly in the community could no longer continue in its former state. The perceived benefits to actively shape the study were seen as a positive initiative. For others this was not necessarily the case, they operated in a practice domain which was self contained and the traditional and financial boundaries were fixed. There was no apparent threat or risk to the organisation at this time and participation in the project was not a high priority. Local institutional projects were a higher priority.

As the study progressed, two key elements influenced group participation particularly with the late adopter's. Firstly national policy agendas and publications particularly in regard to the establishment of clinical directorates were realised. The notion of shared care across the primary and acute sectors with shared funding was now emerging as a reality.

This suggested to some of the participants that the study profile was now a higher priority than was originally thought. Contributing to this belief was the expertise of the EHRland project team.

Secondly the author would advocate that working closely with the participants over a two year period and fostering a reflective and analytical approach had an effect on their co-operation with the project. The close involvement of the author with the participants may also have influenced the results thereby limiting the generalisability of the study.

Winter (1998) describes this process as voices, from which participants can share experiences with others, learn from each other whilst concurrently collaborating in the formation of new knowledge (Winter, 1998, p.106).

### ***8.3 Health Informatics Overview***

EN13606 and EN13940 have been demonstrated in this study as useful tools in the generation of EHR variants for integrated care across and between service providers. Developing EHRcom compositions and sections using archetype definition editors such as LinkEHR can assist healthcare practitioners with an interest in health informatics in the creation of Detailed Clinical Models (DCM's). Such clinical models may wish to consider cross cutting strands such as context culture and care to design and deliver appropriate Models of Meaning and Models of Knowledge for future theory testing of patient centred outcomes. Archetypes which include C-Hobic datasets and terms offer pragmatic statistically sensitive tools to healthcare providers engaged in such work in integrated summary records of care. In the current healthcare and economic climate such tools may become the yardstick in which the profession of nursing's contribution to patient centred care may be measured.

The development and implementation of EHR at an enterprise level in Ireland has yet to be realised. There is much to learn from neighbouring countries who have initiated the process and who have come to known as the early adopters. A critical analysis of EN13606 and EN13940 completed in this study suggest that the building blocks to create syntactic and semantic records are now achievable.

What is perhaps most encouraging is that by using the reference model in EN13606 scalable archetypes can be created accommodating future additional entries as required. This is particularly important to the profession of nursing as specialist nursing roles evolve and their individual contribution will need to be evident in records to be measured particularly from a skill mix perspective.

The absence of the design feature of scalability in the past has proven to impede the development process of EHR (Garde et al, 2007) and could arguably be presented as one of the most attractive design features of EN13606. The existing developments in OpenEHR archetype and associated template creation in the clinical knowledge repository suggest that the dual model approach has achieved significant interest and active engagement from the clinical community in the identification of the clinical requirements for shared integrated records of care. It would appear that there is some degree of overlap of concepts and terms between the OpenEHR templates in the National Electronic Health Transition Authority (NEHTA) for example *Clinical Synopsis* and *Role* are both listed archetypes in the resources.

A key finding from the mapping of OpenEHR to NEHTA and the outputs from this study suggest that the administrative orientated elements of the Enterprise EHR variants are significant and numerous in size.

As the Health Information Bill is in process in Ireland administration of unique organisational and patient identifiers will need to be considered and critiqued carefully. The technical specification document by ISO /PDS 2220 Identification of Subjects of Healthcare with approved legislation relating to the unique patient identifier will assist in advancing this process. From EN13606 the LinkEHR application is a powerful resource which offers clinicians a framework to devise archetypes which in this study have been described as Models of Meaning. In this study the Models of Meaning are labelled as Level 1 data.

Freriks (2010) semantic stack and associated resources were found to be useful tools to demonstrate in context the new knowledge emerging from this particular study described in Chapter 7 as Models of Knowledge or Level 3 data (Figure 8.1). At a national level limited understanding of the Standards Development Organisations relating to health informatics particularly within nursing is evident.

One example of a key standard published for the profession of nursing is ISO 18104 Categorical Structure for Representation of Nursing Diagnosis and Nursing Actions in Terminological Systems. This standard has yet to be formally endorsed or recognised in Ireland and is a key requirement in the migration process of nursing documentation from paper based records using nursing models of care to enterprise adoption of EHR for more effective patient care in Ireland in the future.

A key output from this research which has not been discussed in any great detail within this thesis is the website and educational resources which have been developed over the two years. Addressing issues such as culture, context and change are fundamental to effective EHR implementation, and are often described as *readiness* and *intention to adopt* (OECD, 2010).

The final resource developed and scheduled for publication in December, 2010 is a documentary based on EHR particularly in relation to PARTNERS integrated summary assessment records of care. This documentary which offers a voice to the nursing participants in this study demonstrates to nurses and patients how practice development initiatives like the PARTNERS and EHRland programmes work to meet the information requirements in a contextually appropriate manner. The contribution of the profession of nursing towards effective and efficient patient healthcare is often most prevalent by its absence. A deficiency of identified clinical requirements in EHR design brief could prove not only to be damaging to the profession of nursing in terms of skill mix but also harmful for patients.

In Figure 8-1, the author attempts to illustrate how the various elements of the study can be integrated together and located within the domain of health informatics. Figure 8-1 could therefore be described as a summary of the author's interpretation of the key elements and evidence required to create an organic progressive model which can evolve to meet the future needs of effective integrated patient health care. Figure 8-1 illustrates the interaction between the three core elements of health informatics; computer science, health science and information science and demonstrates where this thesis locates the outputs from this study. This illustration has been created to offer the reader a macro view of the study and to demonstrate how the information and knowledge generated is located within the domain of health informatics.

By categorising and classifying the various types of information required in such studies healthcare professionals can see clearly the intersection points of how different levels of data are required. Figure 8.1 demonstrates the iterative nature of the cycle of semantics of language and meaning and illustrates how the new Models of Meaning and Knowledge can be located using cross cutting strands of health informatics i.e. computer science, information science to create new Models of Knowledge that can be adopted in health science to develop an evidence base for effective patient centred care. The semiotic triangle originally introduced by Ogden and Richards (Ogden and Richards, 1923) has influenced the development of language upon thought and the science of symbolism. The semiotic triangle is very much a landmark figure in the education of language and semantics. Figure 8.1 locates the semiotic triangle in the centre of the diagram and demonstrates how the various levels of data can be plotted onto a circle in the following manner.

Individuals create thoughts which can be described as referent thoughts on the semiotic triangle. In the case of Figure 8.1 the Standard Development Organisations have created EN 13606 which has a reference information model (RIM). This RIM is used to develop concepts for those individuals engaged in computer science in order to create EHR or variants of EHR. An example of this is included in Figure 8.1 as Gerard Freriks Semantic Stack (2010) discussed in detail in Chapter 7. Those health informaticians engaged in the process of clinical requirements identification explore notions of culture context and change management processes to create new Models of Meaning from the referents on the semiotic triangle. The Models of Meaning are then created as the stated clinical requirements for to build EHR or variants of EHR based on information science. They have been labeled as Level 1 and Level 2

type data in this thesis. The outputs from this process could be referred to as symbols on the semiotic triangle.

The computer science and information science combined offer health science professionals new Models of Meaning archetype templates for use in healthcare which are implemented over a number of settings and contexts. The data stored from these systems is then interpreted to ascertain which interventions best achieve the most effective patient outcomes and inform the creation of new Models of Knowledge.

These new models of knowledge epitomize the most up to date Level 3 data on healthcare processes. Such data are required to inform models of thinking i.e. clinical judgment and decision making. An example of new knowledge emanating from this thesis is the need for archetypes to be created from the perspective of Role Encounter Record and Outcomes Assessment Diary in order to depict the contribution that nurses make in differing roles to maintain continuity of care for patients. Figure 8.1 illustrates this process and can be used to make important comparisons on differing levels of data and to create an educational resource for future use with healthcare professionals to achieve readiness and intention to adopt ICT programmes in the future (OECD, 2010).

The Figures created in Chapter 7 are included in the model to demonstrate to the reader how the different research outputs from this study can be plotted on to the progressive organic model. The author would conclude by suggesting that this study offers some insights into the specific needs and requirements for integrated summary records of care for patients aged 65 and over

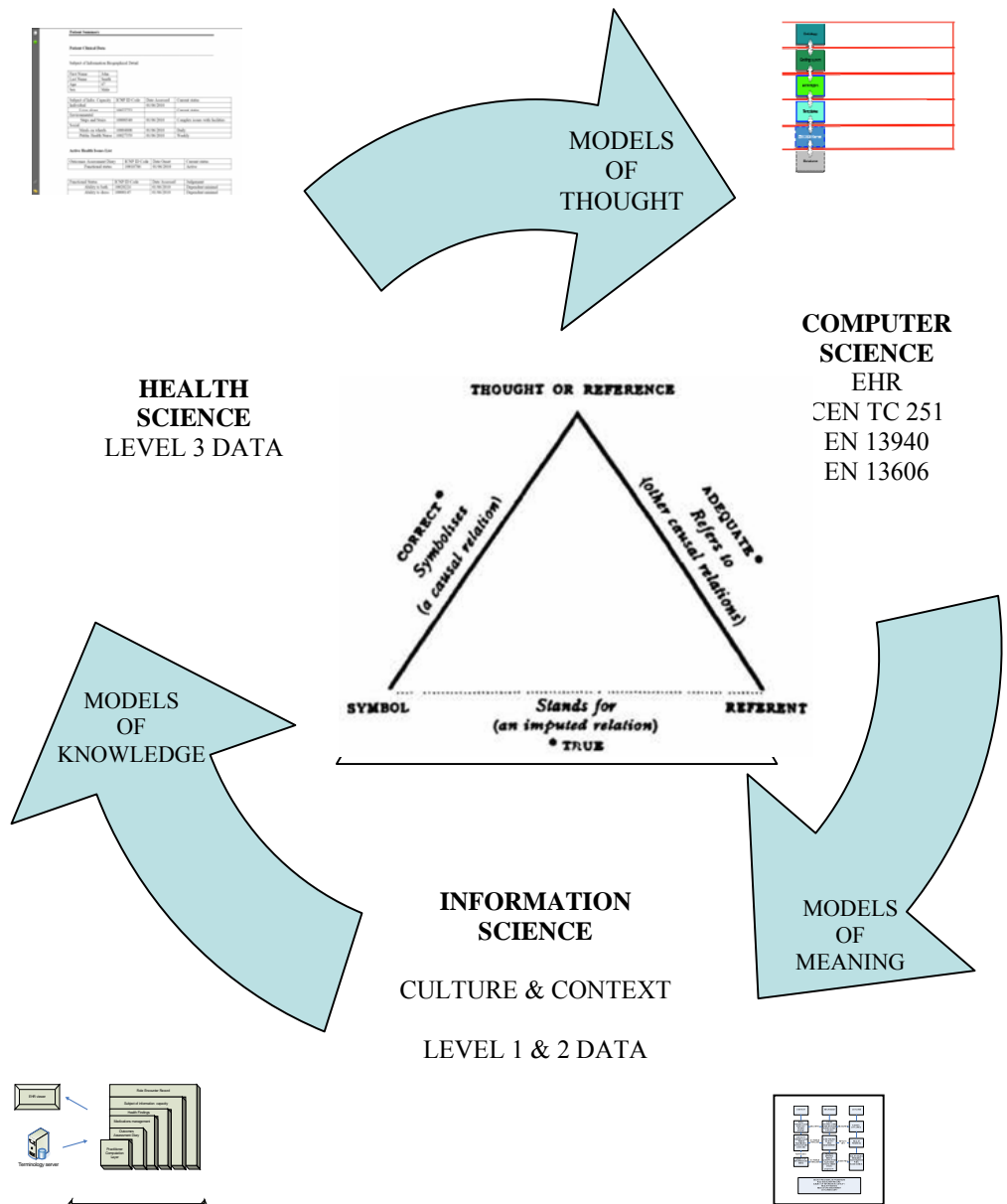


Figure 8-1 Progressive Organic Model

## **8.4 Future Research**

Throughout the course of completing this study the author has recognized the need for a model which drew together the key findings identified in this study. Categorising the data into 3 different levels facilitated the author distinguishing and locating information presented in this thesis across the domain of health informatics. The author would suggest that illustrations such as Figure 8.1 are required for effective EHR development and implementation and offer a roadmap for future research.

The pilot study indicated that the paper prototype was clinically pragmatic and was fit for purpose. Although future similar projects in this domain may wish to consider that the existing organisational practice routines within nursing, particularly in the acute care sector, did not demonstrate a readiness for integrated programmes of care across and between services. The author would contend that additional incentives such as education and training or indeed practice orientation in a community setting would assist nurses practicing in the acute services to engage in a more effective manner with such studies in the future.

The author concludes that EN13606 using LinkEHR is a suitable tool to create summary assessment records; however a unique identifier is required to deliver archetypes in the practice setting. Finally the outputs from this study will be used to inform two practice development initiatives, one in the primary care setting and one in the acute care setting. There is still much work to be done in this area; a recent survey of sick adults in Australia, Canada, Germany, New Zealand, the United Kingdom and United States indicates that when discharged from hospital, a sizeable share of patients in all six countries were not told what symptoms to look out

for and or had no follow up visit arranged (Schoen and Olsen., 2009). The author of this thesis will continue in an action research capacity to create archetypes which are fit for purpose to improve patient care.

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**Appendix 1 Requirements Engineering**

**Appendix 2 Archetypes Mapping Chart**

**Appendix 3 Report to Services**

**Appendix 4 Transcript Report to Service**

Please Note

All appendices available to view on attached CD