

**CHARACTERIZATION OF A LONGITUDINAL CARE PLAN MODEL FOR  
MANAGING CHRONIC DISEASES: A CARE PLAN ONTOLOGY TO  
COMPUTERIZE PAPER- BASED CARE PLANS**

by

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for the degree of Master of Health Informatics

at

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DALHOUSIE UNIVERSITY  
FACULTIES OF COMPUTER SCIENCE AND MEDICINE

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## **ABSTRACT**

Chronic diseases are the largest cause of morbidity and mortality. Due to long course there is a need to plan longitudinal care for chronic disease. In this thesis, we aim to standardize the longitudinal care process for chronic disease in the form of Generic Care Plan Model. We adapted knowledge management approach and our research is guided by Methontology for developing formal knowledge model. This knowledge model is represented as Care Plan Ontology to facilitate the computerization of care plans. We instantiated our Care Plan Ontology using paper based care plans of chronic diseases generated during the research process. We evaluated our Care Plan Ontology in 4 phases (a) Using Pellet reasoner to ensure consistency (b) Instantiation of 3 new care plans for chronic diseases (c) Instantiation of patient specific case to ensure that model is capable to handle personalised information (d) Evaluation on the basis of Ontological design principles.

## **LIST OF ABBREVIATIONS USED**

CBC	Complete Blood Count
CDSS	Clinical Decision Support
COPD	Chronic Obstructive Pulmonary Disease
CP	Care Plan
CPG	Clinical Practice Guideline
CT	Computed Tomography
EMR	Electronic Medical Record
FBS	Fasting Blood Sugar
GPE	General Physical Examination
HBA1C	Haemoglobin A1C
MRI	Magnetic Resonance Imaging
MS	Multiple Sclerosis
OWL	Web Ontology Language
PACS	Picture archiving and communication system
PCP	Personalised Care Plan
RBS	Random Blood Sugar
RDF	Resource Description Framework
RR	Respiratory Rate
TOVE	Toronto Virtual Enterprise
UCE	Urea, Creatinine, Electrolytes
WBC	White Blood Count
WHO	World Health Organization

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# CHAPTER 1 INTRODUCTION

## 1.1) INTRODUCTION:

In health care, there are more support mechanisms for acute care in comparison to long term care for chronic illnesses [1, 2]. Chronic diseases refer to conditions that last for a period of more than 6 months. Some of the most common chronic diseases are diabetes, cardiovascular diseases, chronic kidney disease, COPD, Cancer, and Osteoporosis [1, 13 20]. One of the characteristic features of chronic diseases is that they not only exist for a longer period of time (i.e.  $\geq 6$  months) but, at the same time, they may also be accompanied with associated conditions called co-morbidities. Due to the complex nature and long course of the chronic diseases, there is a need to plan the long term care for a patient in a personalized and planned manner. The absence of a planned course of care for chronic patients leads to patient dissatisfaction, escalation of the disease, increased healthcare costs and most important deterioration of the patient's health, even leading to the early death of the patient [1]. We chose chronic diseases for our work mainly because of the rapid increase in number of people suffering with chronic illnesses since 1995 in North America. These statistics are shown in figure 1:

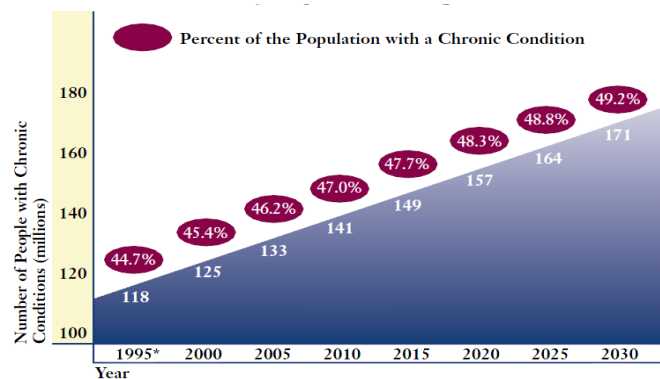


Figure 1 Rapid Increase in chronic illnesses from 1995-2030. Taken from [1]

The long term care process is multidimensional in nature and requires patient interaction with care provider teams which consist of physicians, nurses, etc. This interaction results in high quality chronic illness care consisting of a series of assessments, goal setting, self-management, education, support, therapy optimization, and follow up schedules in order to improve patient outcomes [2].

Care of the individual mainly depends on proper assessment and processes of care planning designed for each patient. Clinical care is streamlined through process-oriented plans called care plans and the overall process of care planning is defined in literature as:

“Number of strategies designed to guide health care professionals involved with patient care. Such plans are patient specific and are meant to address the total status of patient. Care plans are intended to ensure optimal outcomes for patients during the course of their care.” [3]

Care planning is a process of discussions and decision making which takes place between the patient and physician mainly for the management of chronic illnesses [8]. Care plans help in proper understanding of their disease by the patient, which results in patient satisfaction and improved quality of care. Although chronic diseases cannot be cured fully, proper management and regular follow up can provide life-saving information which is useful at the time of emergent situations. It helps in planning activities which are useful both for patients and physicians in the management of long term conditions. Care plans play an important role in saving physician’s time, and they are able to see more patients. Care plans are designed to track care provided to patients in long term conditions whether in hospitals, nursing homes and homes. With the help of these

dynamic route maps, patients can take better care of their long term conditions while staying at home. This helps in reducing their visits or admission to the hospital or, if admitted, reduces their length of stay. It is well said in literature that it is the right of the patient to get same amount of treatment planning information from their doctors as they get from travel agents about travelling. Just as a traveler is aware of any change or deviation from the expected route, the patient is also aware of his/her condition [4].

There are various synonyms used in literature for managing the long term care of patients. Some of the more prominent care planning concepts are:

**1) Process Mapping:** The best way to understand patient care processes is to map how patients proceed through the care delivery system [5]. Process mapping also helps in identifying constraints and unnecessary process steps during the treatment process. It is a useful way to understand real problems in the process of care from the patient's perspective. Helps in identifying steps which are duplicated or those which add no value to patient care. Also determines time taken by each step during the process.

**2) Patient Journey:** Patient journey is defined as:

“... all the sequential steps in providing a patient's clinical care; it includes the movement of a patient (from emergency department to ward or x-ray department) and the movement of a sample or document relating to the patient (e.g. Blood specimen, medical record, etc)” [9]



Sometimes the above two concepts are used together with care planning , but for our thesis work we are focusing on care planning rather than process mapping, and the term we will be using is care plans and care planning.

### **1.2) PROBLEM STATEMENT:**

In health care institutions, care plans are available in the paper based form. Although some existing care plans are available in an electronic format, they still cannot be readily utilized at the point-of-care. These care plans are static in nature, cannot be dynamically personalized to meet specific patient needs, not integrated with individual patient data, and do not conform to a standard representation template. The above limitations contribute to their under utilization at the point of care and hence they do not fully guide the care process from both the patient and physician perspectives.

We argue that the lack of standardized representation of care plan in terms of its function and components is one reason hindering their computerization in a manner that they can be adapted and applied to individual patients—i.e. to develop personalized care plans.

### **1.3) RESEARCH CHALLENGES:**

The research objective of this thesis is to develop a high-level knowledge model, representing the form and function of care plans for chronic diseases, in order to develop a standardized care plan representation template that can be used to computerize a range of care plans. The knowledge model is expected to have sufficient representational adequacy and consistency to systematically represent the elements of clinical knowledge

and clinical care process that are typically inherent in a care plan. The purpose of the care plan knowledge model is to computerize a range of care plans such that the care plans can be further adapted with respect to the patient's needs and preferences in order to yield a personalized care plan [6].

The development of the care plan knowledge model poses the following research challenges:

- 1) Abstraction of domain and care planning knowledge from paper-based care plans of chronic diseases.
- 2) Defining the structure of 'generic' and 'comprehensive' care plans in terms of a set of activities carried out during patient journey.
- 3) Representing the care plan structure in a formal knowledge model so that it can be used to computerize paper-based care plans. This involves developing a knowledge model, in this case as an ontology, to represent a care plan
- 4) Selection of methodology for building care plan ontology.
- 5) Developing care plan ontology through the process of knowledge modeling and ontology engineering.
- 6) Instantiation of a generic care plan model with selected care plans for chronic diseases.
- 7) Integration of care plans with patient specific data.
- 8) Execution of patient specific personalized care planning.

#### **1.4) SOLUTION APPROACH:**

We take a knowledge management approach for developing a care plan model and computerizing paper-based care plans. Our solution approach mainly focuses on the first 5 challenges outlined above.

There is currently no knowledge model available for representing care plans. Our approach is to abstract the structural knowledge, covering both the form and function of the different aspects of a care plan, from existing care plans and then representing the abstracted knowledge in terms of a knowledge model developed as a *Care Plan Ontology*.

Our solution approach is to understand and determine the basic structural components of paper based care plans in terms of practice-oriented knowledge. The next step will be to model this knowledge in the form of an ontological model to facilitate the computerization and execution of care plans.

Our approach is to use semantic web based ontologies to represent the care plan structure in terms of a Care Plan Ontology. To develop our Care Plan Ontology we plan to use a standard ontology engineering methodology—termed as methontology [7], as it allows the systematic explication and representation of knowledge in terms of classes, relationship among classes and restrictions. We believe that our solution approach will yield a generic care plan knowledge model suitable for most chronic diseases. Finally, to determine the efficacy of our care plan ontology (and knowledge model) we will instantiate the care plan model with four selected care plans for chronic diseases.

Our solution approach has following tasks:

- **Identification of Knowledge sources** : Since care plans are not readily available for a range of chronic diseases we will source care plans from a variety of sources such as:
  - a) Websites of different chronic disease associations.
  - b) Published literature for care planning.
  - c) Health and Social care data dictionary by NHS.
  - d) Care plans available on web.
- **Knowledge abstraction**: This step will involve formulating general concepts of care planning by abstracting them from existing care plans. In an inductive learning or reverse engineering manner we will abstract salient concepts from care plans of chronic diseases and relate them accordingly to realize a standardized care plan knowledge model—i.e. the care plan template. Knowledge will be abstracted in the form of clinical activities already defined in the structure of the care plan.
- **Ontology Engineering**: This step involves the development of a semantically-rich care plan ontology that models the care plan template in terms of concepts, their relationships and properties. The following steps will be undertaken:
  - 1) **Ontology specification**: To specify the purpose for which the ontology is built, and who will be its intended users.

- 2) **Ontology Modeling:** The key concepts of the abstracted knowledge were represented as classes and subclasses. The relationship between concepts is represented in the form of properties.
  - 3) **Instantiation:** We have selected a range of paper based care plans for chronic diseases that will be instantiated into our care plan ontology model. Selection of chronic diseases was done to cover wide range of care plan types.
- **Ontology Evaluation:** In this step we will evaluate our care plan ontology in four ways (1) to check for consistency of ontological framework (2) will computerize a set of new care plans to evaluate the representational adequacy of our care plan model/ontology. (3) Evaluation against the ontological design principles proposed by Bordneireder et al. (4) Instantiation of patient specific case of chronic disease to ensure that model is capable to handle personalised information and values.

### 1.5) THESIS CONTRIBUTIONS:

This thesis makes the following contributions to the personalized care planning for chronic diseased patient.

- **Specification of a basic plan of patient journey for chronic diseases.**  
The specification covers the care episode that includes patient pre-hospital, in hospital and post hospital conditions. It is further categorized into assessment, investigation, patient status, treatment planning, discharge planning and follow up.

- **Abstraction of practice oriented knowledge from paper based care plans.**

After an extensive study of the paper based care plans four care plans were selected. From these selected care plans core knowledge elements were extracted in order to be used as operational knowledge in building the model.

- **Generic ontological model for care plans of chronic diseases.**

A generic model is built for care plans of chronic diseases. This simple but highly effective model captures and represents knowledge elements essential in long term care processes.

- **Instantiation**

Care plans for seven chronic diseases are instantiated in the ontological model. This instantiation will help in the execution of the model in the presence of an execution engine.

## **1.6) STRUCTURE OF THESIS:**

This thesis is organized into following chapters:

**Chapter 2** describes the global burden of chronic diseases on the healthcare system and its effect on patients. It also further explains the background of care plans, personalized care planning, use of personalized care planning, reasons for computerization of healthcare knowledge, and finally review of ontology and methods for ontology modeling.

**Chapter 3** describes the methodology we adapted for this particular thesis.

**Chapter 4** describes in detail the initial phase of the methodology which includes knowledge identification, knowledge abstraction from the paper based care plans. It also gives specifics about the care plan model based on knowledge abstraction.

**Chapter 5** describes ontology modeling of the care plan model proposed in chapter 4, the method we adapted for ontology engineering, and structure of our care plan ontology with one working example.

**Chapter 6** describes the results of our ontology evaluation. We evaluated our ontological model in four phases to check for care plan ontology modeling, consistency and representational accuracy.

**Chapter 7** describes the achievements and limitations of our thesis work; discusses the future scope.

## **CHAPTER 2: LITERATURE REVIEW**

### **2.1) INTRODUCTION:**

Chronic diseases are long term conditions that cannot be eradicated and can only be treated symptomatically. The impact of chronic disease is multi-axial on both the individual and community levels [1, 10, 12]. On individual level, the impact of chronic disease affects the quality of life which would ultimately affect the activities of daily living. The treatment of chronic diseases is longitudinal then episodic like in acute care [1]. An important aspect of this longitudinal care is the development of the care plan to treat the chronically ill patient. Care planning is an essential component of chronic disease management. In this chapter, we will present a review of the literature regarding chronic disease, its burden and impact on the community. Care planning, its components, benefits, and usage in chronic disease management, personalized care planning and various stages in the development of care plans will also be covered. Our goal here is to study in depth the process of care planning, to find out from where the process of care planning starts and what different stages involved in the care planning process.

### **2.2) CHRONIC DISEASES:**

Conditions that last for more than 6 months or more are referred to as chronic diseases. Chronic diseases not only have a major impact on the quality of life, but they also have adverse effects on families, communities, and societies [1]. Chronic diseases do not necessary kill a person, but they affect both patients and their communities in two ways:



a) Threaten the quality of life of patients with chronic disease by limiting their activities of daily living. The impact of this is multifaceted because sometimes the chronically ill patients are unable to perform their daily routine work by themselves and need assistance. This situation not only affects the patient's physical condition but also severely affects his/her psychological, economical, emotional and social life.

b) Consume a lot of healthcare services [6]. For example, unscheduled out-patient visits, admissions to emergency departments, costs of hospital and physician services.

The increasing burden of chronic disease is one of the greatest challenges that health systems will face globally in the twenty-first century [20, 7]. Chronic diseases are the largest cause of death in the world [9, 20, 31]. According to a report of WHO (2010) people diagnosed with chronic diseases form the largest community of patients that utilize healthcare services [20, 1]. It is estimated that about 72% of all physician visits and around 76% of hospital admissions are due to the patients with chronic disease [1]. Therefore, a large number of healthcare services are utilized for the management of chronic illnesses. Healthcare spending increases proportionally as the number of patients with multiple chronic conditions increase. It is being noted that healthcare spending for a person with a chronic condition is twice that of a person without any chronic condition [20, 31]. For a person suffering from 4 or 5 chronic conditions, healthcare spending is about 14 times greater than usual. According to a 1998 survey, patients with chronic disease utilize about 78% of healthcare spending [1] figure 2. Hoffman and Rice in 1996 found that almost 44% of patients with

chronic diseases had more than one chronic condition and it is expected that by 2020 81 million people will have more than one chronic condition [1].

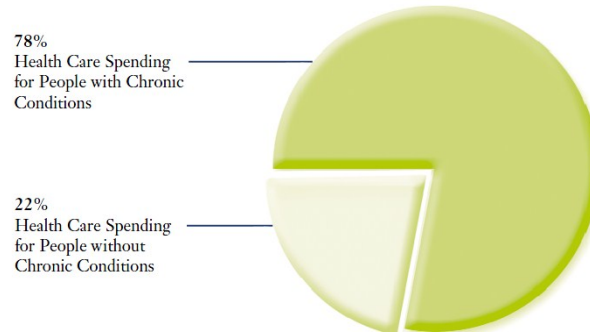


Figure 2 Utilization of Healthcare spending. Taken from [1]

The lives of many people have been cut short due to chronic disease. Chronic conditions not only affect the patient's physical and mental health but also affect their social life. 25% of people with chronic conditions have problems performing personal tasks such as dressing and bathing, for which they need assistance. These long-term conditions put stress on patients and also restrict their work opportunities.

According to a study [10] conducted in US, in which functional status and well being of chronic disease patients were compared with those without any chronic conditions, patients with chronic conditions suffer from decreased physical and social functioning. They have disturbed mental health and also show more bodily pain in comparison to the control group of the study. The authors of [10] also commented that patients having multiple chronic conditions show a greater decrease in well-being than patients who only have one chronic condition.

**2.2.1) Chronic Diseases in Canada:** Chronic diseases are posing a major threat to healthcare services and resources. There are various reports which show that the leading cause of morbidity and mortality in Canada is chronic disease [11]. According to a report published in 2004, 153,000 Canadians die each year because of chronic diseases. They are the major cause of premature death and are also amongst the major causes for hospitalization [12]. In Canada alone, chronic diseases account for 89% of all deaths and their distribution is illustrated in figure 3:

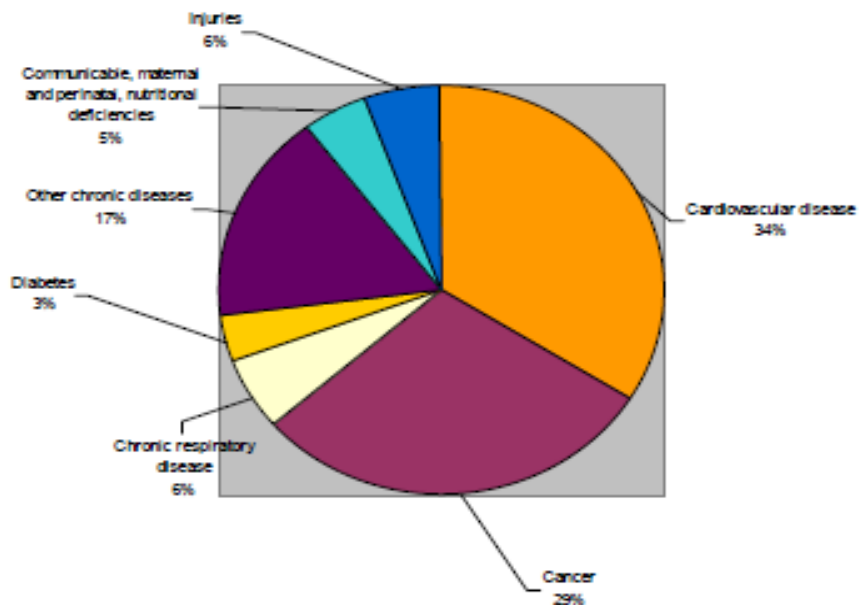


Figure 3 Causes of death in Canada in 2005, Taken from [1]

According to the WHO, over the next 10 years in Canada, more than two million people will die because of chronic diseases, which will result in a 15% increase in death [11]. Out of this 15% increase, diabetes will account for 44%. In Canada, around 57% of people have one chronic condition when they are below the age of 65 years. Because of a

continuous rise in patients having chronic conditions, the cost of medical care services in Canada for patients with chronic diseases is \$39 billion per year [12].

There are seven major categories of chronic illness which cause major utilization of healthcare services in Canada [13]. They are:

- 1) Endocrine disorders (especially diabetes).
- 2) Cardiovascular diseases.
- 3) Chronic obstructive pulmonary diseases.
- 4) Diseases of nervous system (multiple sclerosis, cerebral palsy etc.).
- 5) Cancers.
- 6) Musculoskeletal disorders (osteoporosis, arthritis).
- 7) Mental illness(Depression, Schizophrenia)

The direct cost of the management of the above seven diseases categories is \$38.9 billion per year in Canada which includes the cost of drugs, physician services, hospitalization, home care medicines and private medical expenditures [12, 13]. The indirect cost of the seven above mentioned diagnostic diseases is \$54.4 billion a year. This also includes loss of productivity due to the debilitating nature of chronic illnesses [13]. Combined these direct and indirect costs of these seven chronic diseases resulted in more than \$93 billion per year.

According to a survey conducted by Mathematic Policy Research in 2001[1], it was reported by physicians that the current healthcare system is not organized to treat chronic disease patients. It is hard for patients to access services at the time of need. Even if they are able to receive care for their chronic illnesses; this care is not well coordinated which results in (a) duplication of diagnostic tests, (b) nursing home placements, (c) unnecessary hospitalizations which eventually results in the misuse of services and an increase in the burden on the economy.

Patients with chronic diseases are frequent and long term users of health services [18]. Although people with long-term conditions account for only 31% of the population, according to 2009 report they occupy 52% of GP appointments and 65% of out- patient appointments [18]. Patients with chronic illnesses are not able to receive proper care through the current healthcare system [1]. For the treatment of chronic illness, most patients see more than one healthcare provider and they receive conflicting medical advice from different doctors, which results in a stressful situation for the patient. In some situations, they are even harmed by bad advice which enhances the progression of their disease. Some people may receive prescriptions that adversely conflict with each other, resulting in further deterioration of the chronic disease.

In order to save unnecessary hospital visits and to handle emergency situations at home it is important to involve patients in the management of their chronic illnesses. It is being noted that patients are usually seen by the healthcare provider when they develop any symptoms. However, it is recommended that patients with long-term conditions should have a care plan for their health [18, 19]. These care plans should help in

providing best countermeasures to prevent the progression of chronic diseases. For this reason care plans are generated in collaboration with patients to guide them in managing their long term conditions in a better and planned manner.

### **2.3) DEFINITION OF CARE PLANS:**

There are a number of definitions of care plans, such as

*“Number of strategies designed to guide health care professionals involved with patient care. Such plans are patient specific and are meant to address the total status of patient. Care plans are intended to ensure optimal outcomes for patients during the course of their care.”*[3]

*“Care planning can usefully be seen as a dynamic route map, developed in collaboration between the individual and the professionals involved, and guiding all those involved through the process of care.”*[8]

#### **2.3.1) Key Stages of Care Plan**

According to National Health Service [8], key stages identified in care planning procedure include:

- a) Patient entry into the health care system: starting point of the care planning process, in which patient with chronic disease enters into the hospital.
- b) Initial assessment: to know the current state of the chronic disease, patient’s initial assessment is done which is based on physical examinations and investigations.

c) Development of a care plan: treatment plan is developed on the basis of results of the assessment and the investigations.

d) Care plan implementation: treatment plan implemented to treat patient either as in-hospital or out-hospital based on condition.

e) Review of patient's condition: patient's condition is reviewed after few days to check for any changes in the care plan. If their condition worsens, the patient is sent again for reassessment, or if the patient is getting better, he/she will be discharged from the healthcare facility with discharge plan having home based procedures.

f) Exit/Re-entry into the system: This is the decision point in the care planning process where patient is either sent for reassessment or is discharged from the hospital.

Above mentioned stages are illustrated in following Care plan model figure 4:

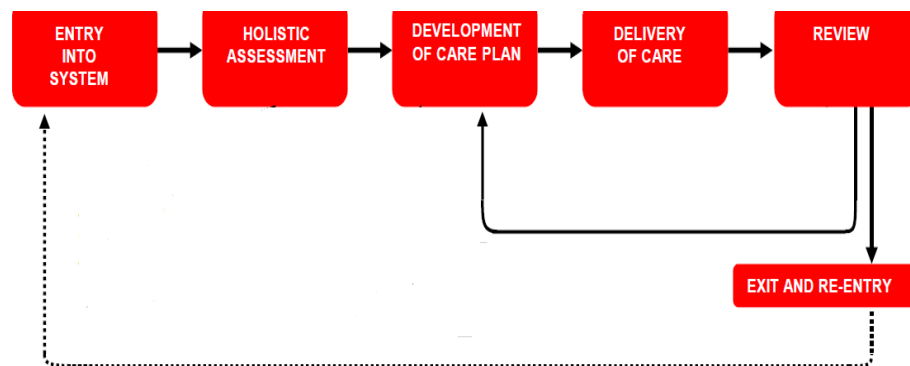


Figure 4 Stages of Care planning model for long-term care. Taken from [8]

### 2.3.2) Types of Care Plan.

There exist different types of care plans as follows:

- a) *Nursing Care Plan*: It is basically a written plan of patient care based on nursing diagnosis. It helps to provide appropriate care to patients and to keep track of their progress. [21]
- b) *Patient Care Plan*: Plan generated according to the needs of the patient by the health care provider.
- c) *Advance Care Plan*: Planning of health related decisions in advance. For example: Who will take care of the health related decisions when a person cannot do so?
- d) *Multidisciplinary Care Plan*: Plan involving health care providers from multiple disciplines to provide comprehensive care to patients and also to fulfill other needs of patient.

From the above mentioned list, the nursing care plan is the most commonly used care plan and this may largely be since there are many publications and care plans for nurses.

Care planning is useful for long term conditions specifically because patients with chronic conditions need regular assessment and follow up. In most long term conditions, the goal of healthcare provider is to improve the quality of life of chronically ill patient [22]. To provide patients with standard care at all the stages of the chronic disease, it is necessary to follow a proper treatment plan recommended at each step. For this reason, care plans are developed based on specific patient condition which carries information for in-hospital and post hospital interventions. Care plans include lists of tasks related to the



management of chronic disease for patients as well as physicians. Care plans also record the outcome of discussions at each meeting between the patient and the health care professional. It includes the results of assessment, investigation and goals for the each visit. It helps in identifying the patient's current status and how he/she should be managed in future for example, as an out-patient or whether they need to be admitted or referred to other healthcare facility. Care plans can be generic without any details and complexities or they can be detailed and individualized depending on the complexity of a chronic disease. For example, Care Plan for an elderly patient having multiple chronic conditions like asthma, diabetes and arthritis would have more complex details of medications, lists of procedures to perform at home and in addition would also include tasks to handle emergency situations . On the other hand care plan of a patient who is young and fit with asthma would only include how to use inhalers, goals to quit smoking, and referral to places where health care workers can help to quit smoking [18].

**2.3.3) Personalized Care Planning:** When a patient with a chronic disease enters into the healthcare system, his/her care plan is generated based on the current state of the disease [6]. This patient specific care plan is known as a personalized care plan [6]. A personalized care plan includes (1) health profile (2) description of the patient's present health condition (3) details of risk assessment and (4) interventions or procedures required for the management of chronic disease specific to the particular patient. It mainly focuses on individual needs and it encapsulates the elements shown in figure (5) and explained below:

- a) Patient's health record. This includes the details of patient specific information related to the patients past medical and surgical history. It also includes records of previous diagnostic and therapeutic procedures and details of previous health encounters.
- b) Clinical care activities recommended by clinical guidelines for patient's current health situation. For example, (1) Send Investigations for urea, creatinine and electrolytes (2) Perform general physical examination to record vitals and non-vitals.
- c) Sequence of medical events as they occur during the process of the chronic illness care. For example: Assessment -> Investigations -> Treatment -> Follow up.
- d) Patient's diagnosis and prognosis based on the evidence based knowledge. This evidence based knowledge would merge into the care plan from the disease specific guidelines as shown in the figure (5). These guidelines are used in clinical practice and published by the various institutions after the joint agreement of different healthcare professionals.
- e) Patient specific education and the record of self monitoring interventions required for chronic illness care. For example: In case of diabetic patient, (1) it is recommended to keep their Fasting glucose level below 100 mg/dl. (2) Control weight gain (3) Regular exercise for at least 5 days per week.
- f) Specification of tasks, the person responsible for each task and the location of action/event i.e. in-hospital or post hospital. Some procedures are performed within the hospital for example: (1) aspiration of pus in case of abscesses (2) surgical removal of a cyst or tumor. For the better management of chronic diseases, patients have many tasks to

perform at home and record the results of home care procedures. These results would help physicians in future visits to assess the current stage of disease and to make any specific changes in the care plan.

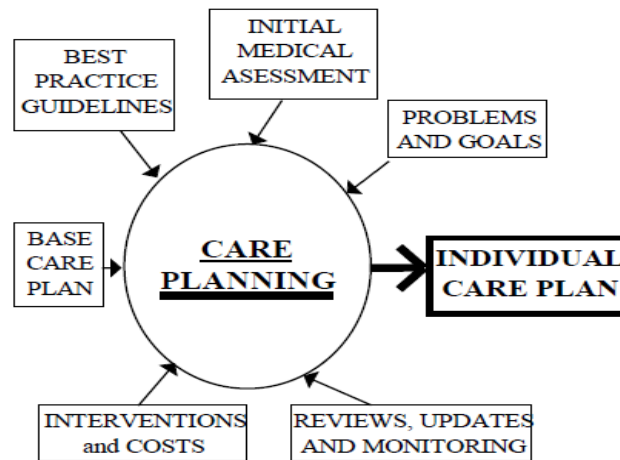


Figure 5 Generation of individual care plan. Taken from [19]

Having a personalized care plan for chronic diseases is useful in understanding a patient's current situation in short time period by the health care provider. It helps the patient in managing their illnesses through the support of their health care provider. Studies have shown that patients having information about their disease state results in higher satisfaction, higher quality and greater continuity of care [18, 23]. Co-ordinating care of chronic illnesses has also resulted in favourable clinical outcomes and reduced cost of health care services utilized [18].

**2.3.4) An example of Personalized Care planning is provided for managing diabetes:** Personalized care planning is especially important for diabetes because in diabetes the message is loud and clear that “no two people are exactly alike” [24].As it is

an endocrine disorder, it involves hormone action which is different for each individual. This hormonal action, different human behaviour and different diabetes complications causes a variety of responses to diabetes. Moreover patient's preferences are different for treatment resulting in a need of individualized plan.

According to the Department of the Health (2006) [30] for a diabetic patient care planning is:

“A process which offers patient's active involvement in deciding, agreeing and owning how their diabetes will be managed. It aims to help patients with diabetes achieve optimum health through a partnership approach with health professionals in order to learn about diabetes, manage it and related conditions better and to cope with it in their daily lives.”

According to the study conducted in England (2004) [25] by Burn Brae medical group, it was seen that care planning encourages patients to play a central role in managing their chronic condition. The period of study was 6 months and it involved 30 diabetic patients, and the aim of the initial trial was to gather patients' views about care planning and implementing interventions which could help them to manage their condition more effectively. This study was successful in helping patients to manage their health. Suggestion made during this study were that patients should be able to see their tests results before the next scheduled appointments with nurses so that they ask relevant questions related to their investigation results. One of the comments from a patient was that “It gave me a chance to think about my diabetes and what I could do to improve it.” Later in 2008, the effect of care planning on diabetic patients was tested at three sites in

England [25]. The care plans were generated by nurses in collaboration with the patients. Every patient taking part in the pilot had an annual review. Additionally, these patients were offered a review after six or even three months if they are concerned about their health. During these reviews, patients have a chance to discuss about their care plans. Each review consists of two appointments, during the first appointment the health care provider collects blood and urine samples for investigations. The second appointment is to discuss the results of the investigations and address any concerns which the patient might have regarding his/her health. The results of the tests were sent to the patients before they appeared for the second appointment. Along with the latest results patients also receive their previous test results which helped them to compare the two results. During the second appointment, the nurse worked with patients to generate a care plan for managing diabetes in the coming year. The care plan contained the information for self care at home and suggestions for referral to another healthcare facility or other health care provider. For example: smoking cessation services, other community services, a dietician or a physiotherapist. The results of the study indicated that the number of unscheduled appointments was reduced and patients had fewer problems between the scheduled reviews.

**2.3.5) Benefits of care planning:** According to the study conducted in the year 2010 by Dr Shahid Ali *et al* [26], care planning has a clear and positive impact on patients with long term conditions. This study involved 3,600 patients who had one or more than one long term condition. They were placed into groups of one, two, three, four or more depending on the number of chronic conditions they had. These patients were offered care planning consultations. The results of the study were analyzed and compared both

before and after the provision of care planning. Services taken as performance measures include outpatient visits, accident and emergency attendances, acute admissions and practice clinical contacts. The results showed reduction in the utilization of services in all cases except for one patient. (See charts in figure 6). There were reduced out-patient visits after care planning implementation and also reduced number of emergency visits. So we can say that the impact of care planning in reducing the use of these services is twofold (a) Care planning reduced the cost of healthcare services for chronic diseases by reducing the number of visits and (b) The concept of patient education and home based care provided by care plans empowered the patient with useful material that enables them in to understand their conditions and helped them in problem solving on their own, without using the healthcare services.

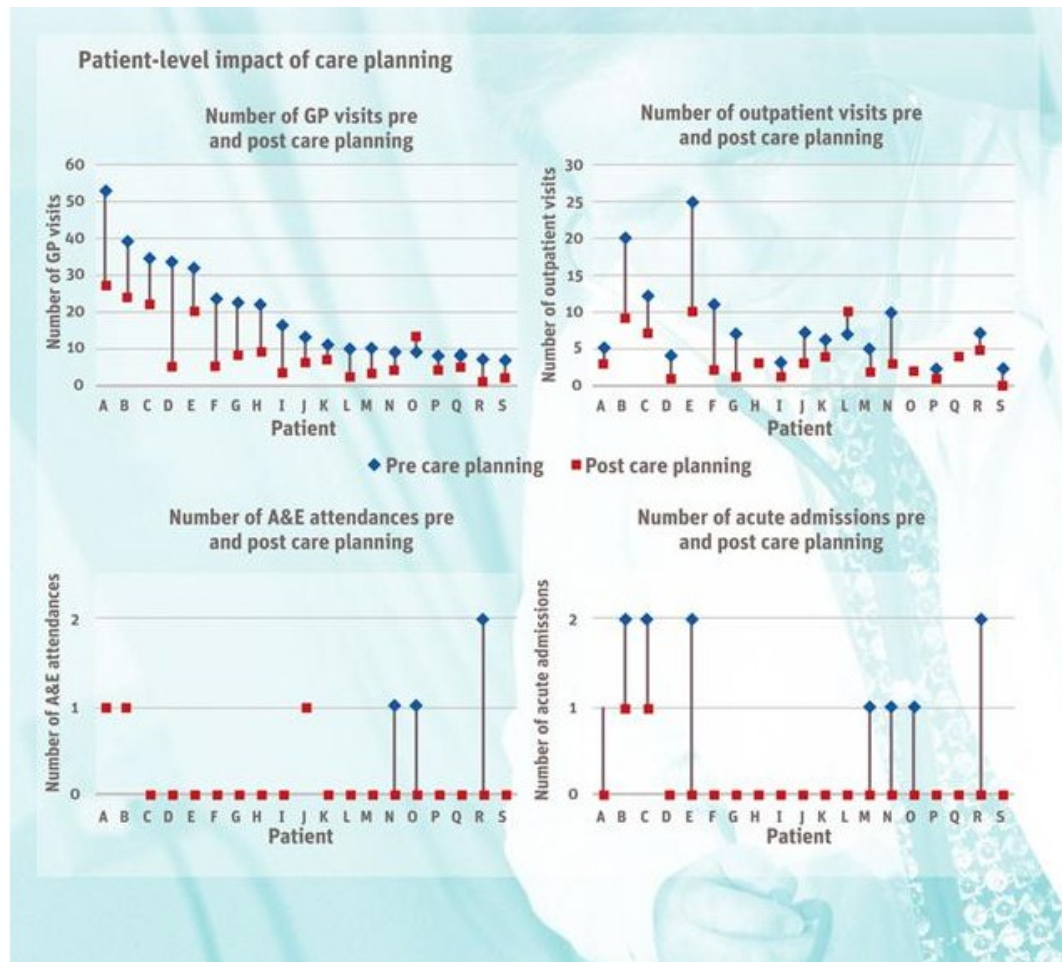


Figure 6 Utilization of healthcare services pre and post care planning. Taken from [26]

Good care planning can result in benefits to the professionals providing care and also to the individuals receiving care. Some of the important benefits mentioned in the literature [22, 8] include:

- 1) Continuity of care: Care planning helps in continuity of care through the improved communication between individuals and professionals. As the management of chronic disease involves patient as the major share holder, the improved communication helps the

patient in better understanding of their long term condition. This results in favourable clinical outcomes due to improved preventive care [27] .

2) Risk Assessment and Management: Care planning helps in identifying risk associated with patient's condition. Through proper care planning these risks are managed timely in a structured and co-ordinated manner. Regular risk assessment helps in early diagnosis of any major problems.

3) Support self care management: Depending on the circumstances, care planning can help in providing support for self care management. This in turn results in reducing pressure on the healthcare resources. For example: it can reduce the number of unscheduled visits to the General practitioner by 40% especially for the high risk groups [28].Patients will have more control over their health and it reduces hospital admissions by 50% [29].

#### **2.4) DISCUSSION:**

After thorough literature review of care plans and personalized care planning, most of the studies show that care planning for chronic diseases is longitudinal care process and starts with patient entry into the healthcare system [6,8]. Our goal is to capture the longitudinal care planning process of chronic disease management and our research suggests that proper care planning starts from the time when patient with the chronic disease enters into the healthcare system [6].We aim to present the standardized representation template capturing the sequential flow of activities involved in the chronic disease management. Our generic model starts with the patient encounter and represents a guide for both



healthcare provider and patient. As our aim is to develop knowledge model for chronic disease management, our generic model should include each piece of information generated during the care process. By capturing all the information, the knowledge model functions in a multifaceted manner which is (a) helping healthcare providers in their decision making process and (b) helping the patient to attain control on their condition by receiving patient education, which makes the model patient centric. Although it is suggested through studies that care plans can be generated in collaboration with a single health care professional [10], to get the real benefit of care planning it should involve multiple health care providers for example, GPs, nurses, surgeons, chemotherapists, radiotherapists, social workers and even family members.

**2.5) COMPUTERIZATION OF CARE PLANS:** According to the literature review, most of the work done concerns the computerization of nursing care plans with the intention of saving time, tracking patient information, reducing excessive paper work and improving efficiency and workflow.

The concept of computerizing nursing care plans started in late 60's. In the past, the two approaches used for computerizing purposes were a) forms which are computer readable, in this approach actions listed on the forms are indicated by the nurses and b) Computer generated standard care plans which are adjusted by the nurses for each patient [31]. System based on second approach was developed in California hospital and was named as Technicon [31].

Several computer assisted systems were developed at hospitals in Arizona, Texas and North Carolina which were built on databases [62]. All of these systems had nursing care

plans stored in them which nurses could print out according to the specific needs of the patient. Later in the 80's several other systems were developed for computerization of nursing care plans, one of the examples included 1) Computerized care plan system for critical patients in ICU, which printed a care plan for a specific individual based on information inputted by nurses to the system [32].The main emphasis was to generate personalized care plans. The majority of the systems developed for computerization of nursing care plans were rule-based systems [33].According to the authors of [34] computerization of care plans can lead to more effective use of nursing skills. They also mentioned that computerization can enhance the speed of creating patient specific personalized care plans.

In the literature, we found ontology based computerization [36,70, 71 ] of care plans. It is noted that the computerization of care plans will encourage the communication between patient-physician and also among different health care providers [35] and facilitate the shared decision making process. This sharing will help in co-ordinated patient care and will result in improved patient outcomes [30].

Currently computerized systems available for managing chronic conditions include K4 healthcare model [70, 71] for providing home care services for elderly patients with long term conditions. K4 is an ontology based system and helps in providing a life cycle of personalized care planning process in home care. Our proposed work differs from the K4 care model in having a sequence of clinical activities involved in chronic disease management for individuals of any age, taking place in hospital, home or nursing homes,

where as the K4 healthcare model is specially designed for assisting elderly patients at home [70].

**2.6) CONCLUSION:** Longitudinal nature of chronic disease management features several important aspects that need to be considered during the care delivery process. For proper care of the chronic illnesses, it is necessary to have proper care planning for treatment with regular follow up procedures. Key principles to improve the outcome of chronic illnesses depends on collaborative management between the patient and provider, goal setting and planning, self-management training and support services, and last but not least active follow up. Capturing these vital steps of chronic disease management and developing a general care plan model must have positive effects on the outcome of chronically ill patient. This conceptual model should act as a common ground to fulfil important functions such as (a) capture the important aspects of a care plan for chronic diseases. (b) there should be a sequential flow that is capable to guide the care process. (c) the proposed model can be used for computerization of paper based care plans.

## **CHAPTER 3: RESEARCH METHODOLOGY**

### **3.1) INTRODUCTION:**

The goal of this research is to develop a high level knowledge model of care plans for chronic diseases. This model not only represent the form and functions of care plans for chronic diseases but at the same time the intent is to use it to computerize a range of for care plans chronic disease management. Semantic web technologies, in particular ontologies, have been demonstrated to represent and execute medical knowledge [61, 62, 63]. In our research, we therefore aim to develop a formal ontological model for capturing knowledge pertaining to the care plans for chronic diseases.

In this chapter we present our research methodology for developing an ontological model for representing care plans. Our research methodology for knowledge modeling is guided by the Methontology methodology for developing an ontology-based knowledge model [51, 52, 55, 60]. We present an overview of the Methontology and discuss its adaptation and application towards our research methodology.

### **3.2) OVERVIEW OF METHODOLOGIES:**

There exist several methodologies for developing ontologies, features of some methodologies are explained as follows:

**1) Kactus Methodology:** This methodology for ontology development was proposed by Beneras et.al in 1996 and recommends an application based ontology development [51]. It uses top-down approach for identification of concepts and mostly used in developing ontologies with the domain of electrical networks [52]. Ontology developed using this approach offers very little details and does not provide specific techniques for the development process [51].In addition in requires double effort as every time it requires

the user to pass through certain steps which include: 1) Specification of the application .2) Searching of preliminary design to be used in the new application. 3) Refinement and structuring of the ontology in order to achieve particular design [52, 53].

**2) Sensus Methodology:** This methodology was developed by Information Science Institute in order to provide conceptual structure for machine translators [52]. Sensus methodology uses the bottom up approach as the most important concepts are identified first, and it is not dependent on application as compared to the Kactus approach [53]. Sensus methodology helps in promoting knowledge sharing because base ontology is reused several times to develop ontology in specific domain [54]. Ontologies developed using this approach include domain of military campaign. Although this approach has many advantages over other methods but it does not provide a life cycle for developing ontology [52].

**3) Tove project Methodology:** This methodology was proposed by Grugner and Fox in 1995 and based on development of Tove project ontology mainly for the activities of business domain [52]. This methodology has its own terminology which helps in ontology development from scratch but requires informal competency questions as the initial starting point of ontology development [56]. Additionally this methodology does not provide any details for carrying out specific activities during the development of ontology. There is no proposed life cycle, and also it does not provide any description of techniques [52]. Since, it requires the initial set of competency questions we can say that it is semi-dependent approach which can also act as a bottle neck. More over it doesn't provide any guidelines for reusing other ontologies.

**4) Methontology Methodology:** This methodology developed in Artificial Intelligence Lab of Madrid to build ontologies either from scratch or to use other ontologies [55]. methontology provides the framework for ontology development at the knowledge level. It proposes a life cycle of the ontology development process (illustrated in figure 7) i.e. specification, conceptualization, formalization, implementation and maintenance [7]. The methodology provides specific techniques to perform each activity during the ontology development .The main phase identified by this methodology in the ontology development process is the conceptualization phase because the objective of this phase is to organize the acquired knowledge independent of the specialized environment [60]. methontology methodology is application independent and it uses middle-out strategy [52].

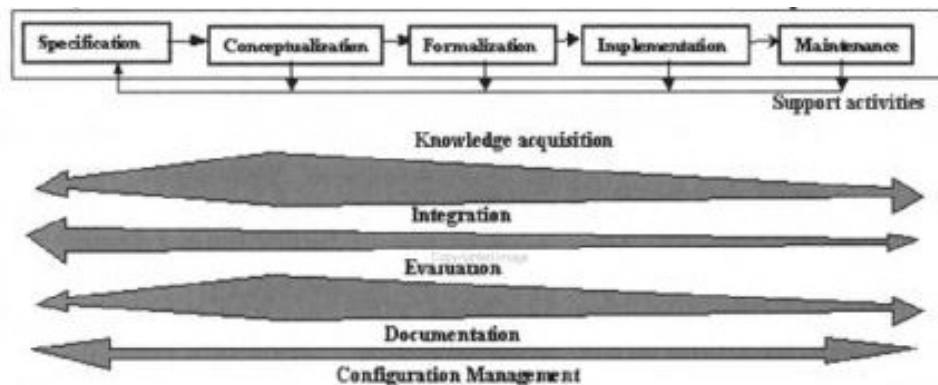


Figure 7 Lifecycle Of Ontology Development. Taken from [7]

### 3.2.1) METHONTOLOGY IN DETAIL:

The Methontology methodology constitutes a sequence of phases, where each phase may contain a number of activities, to help develop an ontology based knowledge model.

These phases are (a) **Ontology Specification**: It includes some important aspects about the ontology that covers domain, purpose of the ontology and the knowledge sources. It explains why the ontology is being built and who will be the end users of ontology [55]. (b) **Ontology Conceptualization**: This phase has strong relationship with knowledge acquisition phase [7]. After knowledge is acquired in the knowledge acquisition phase, it needs to be formulated and organized in the conceptualization phase. This phase has 11 tasks illustrated in (figure 8). According to the methontology methodology, it is not necessary to perform all these tasks, and the ontologist can return to any task if required for addition of any new term [6]. The outcome of conceptualization phase is ontology conceptual model [55]. This conceptual model represents the domain knowledge which is not formalized yet. (c) **Ontology Formalization**: It is the process to convert the conceptual model acquired from abstracted knowledge into formal model which is computable [55]. (d) **Ontology Implementation**: It is the transformation of computable model into particular Ontology language [55] for example, OWL [58], RDF schema [57], ontolingua [60]. (e) **Ontology Evaluation**: According to the methodology, evaluation is done during the whole development phase of the ontology life cycle [7, 61] mostly during the conceptualization phase to prevent any errors and to prevent its transmission to the implementation phase. It helps to validate the ontology.

### **3.3) OUR RESEARCH METHODOLOGY:**

Our research is aimed to develop a high level knowledge model for a care plan of chronic disease management as explained in chapter 2. This knowledge model will also serve as a merge point of chronic disease management and care planning. To develop such unified

platform that can unite chronic disease management and care planning, the middle out approach is appropriate for conducting our research as it helps in identifying high-level concepts that are common across multiple knowledge sources. These knowledge sources were found in the form of (1) Care Plan templates for chronic diseases and (2) literature review of chronic disease management. There was no generalised Care Plan model which begins with the healthcare encounter of a chronically ill patient and serves as a Generic Care Plan for chronic disease management. We developed our knowledge model through (a) Selection of common concepts and (b) Identification of essential concepts, in both care planning and chronic care. In search of these concepts our research passes through a series of phases which include knowledge identification, knowledge abstraction. After knowledge abstraction this knowledge was used to develop a generic care plan model that can support the longitudinal care in chronic disease management. Our research then leads towards the computerisation of the generic care plan model into Care Plan ontology for chronic disease management and then finally evaluation of the developed model by using another set of randomly selected care plans for different chronic diseases .Our research phases and its outcome are illustrated in figure 8.



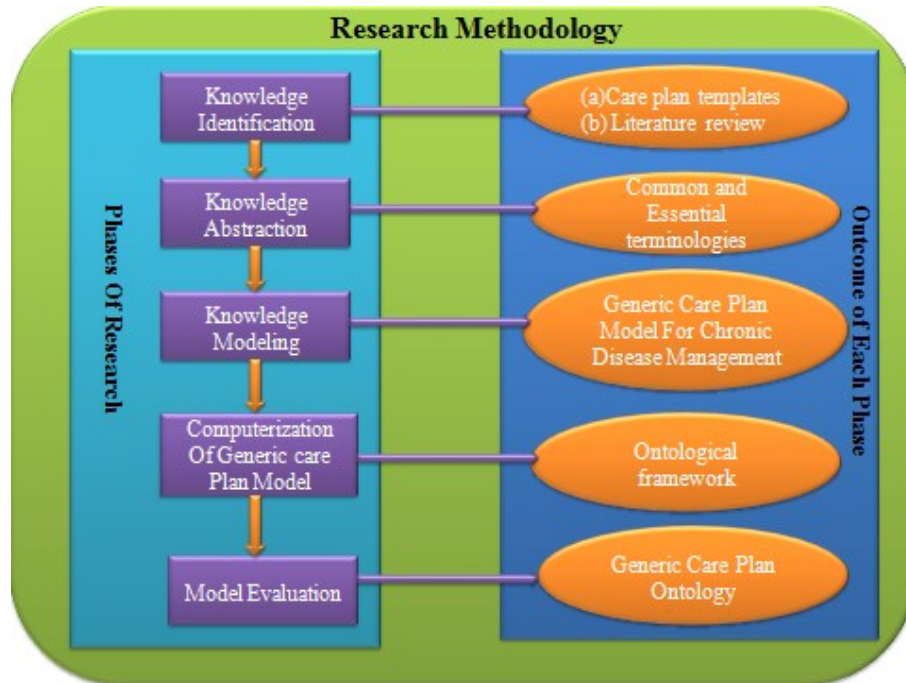


Figure 8 Research Methodology: Phases and Outcome

In the above figure we have shown the different phases of our research and their outcomes. In order to achieve the desired outcome, several different kinds of tasks and activities were performed. In the first phase of the research knowledge identification was done by virtue of performing text analysis and search of literature which results in identification of care plan templates and chronic care literature. After thorough review of these care plan templates for several different chronic disease and chronic care management, list of concepts was made that are common between care planning and chronic care and this list also contains term and concepts that are not common but essential. For example, in knowledge modeling phase the identified common and essential concepts were arranged in a systemic way in order to develop the Generic care plan model which not only provides the steps in care planning but also support the cyclic

process of chronic care management. Computerisation of this model was done using Protégé in OWL language that results in an ontological framework of the care plan model. This model is then Evaluated by instantiating several care plans in it and the end result is the Generic Care Plan Ontology.

In an effort to develop a knowledge model of Care Plan for chronic disease management in an organised and systematic manner and also to validate our research methodology there was a need to adapt a scientific research methodology. In search of an appropriate research methodology a review of existing knowledge modeling methodologies was done as mentioned in section (3.2). Based on our review of the existing knowledge modeling methodologies, we decided to use the methontology methodology as it appears to be the most mature and well used [52]. In essence, the methontology methodology (as illustrated in figure 7) helps in the development of ontology at the knowledge level, and includes a life cycle based on evolving prototypes. The methodology encompasses all the activities in the development of a formal ontological model from knowledge acquisition to the implementation of the ontology. Methontology uses middle-out approach for ontology engineering as compared to top-down or bottom- up approach which involve either too much detail or lack the detail [7]. The advantage of using a middle-out approach for developing an evolving knowledge model is that it supports the identification of general principles and high-level concepts that are common across multiple knowledge sources, whilst helping in the specializing high-level concepts to capture more specific concepts that exist across different knowledge sources. The top-down strategy involves identifying abstract concepts first and later categorizing them into more specific concepts while on

the other hand bottom-up approach uses a strategy in which more specific concepts are identified first and later generalized into more abstract concepts.

### **3.4) OUR RESEARCH ACCORDING TO METHONTOLOGY:**

After choosing Methontology as our research methodology we conducted our research in accordance with the different phases of this methodology. The detail of each step, which includes specification of goal, activities involved in achieving the goals and the expected outcomes, is explained below.

#### **3.4.1) Ontology specification:**

Ontology specification specifies the domain and purpose of the ontology in addition to the knowledge sources that are identified for the knowledge acquisition purposes. Following are our specifications for Care Plan Ontology.

a) Domain: The main domain of our care plan ontology is chronic disease management. Care Plan Ontology is intended to capture the information for the activities and phases involved in the chronic disease management.

b) Purpose: The main purpose of developing the Care Plan ontology for Chronic Diseases is to formally capture the knowledge relating to management of chronic diseases that can be understood and manipulated by a computer program in order to achieve automation in a number of healthcare related applications.

c) Knowledge sources: The knowledge sources we identified include paper based care plans, research papers, author's knowledge of chronic diseases and text books.

### **3.4.1.1) Knowledge Source Identification:**

The goal of this research is to develop a formal model to represent the form and functions of care plans for chronic diseases. We have chosen informal text analysis for our work. This is a manual exercise that requires detailed understanding of healthcare artefacts. We identified the sources of knowledge that are relevant, authentic, comprehensive, and that fit the standards based and accepted in the community. We used following knowledge sources to acquire knowledge about the domain:

- 1) Published literature on care plans, personalized care planning and its implementation in health care institutions.
- 2) Care planning proposed by different healthcare associations. For example: American Diabetes Association.
- 3) Literature published on care planning by different hospitals and medical centres, for example: North Bay General Hospital, Dartmouth Hitchcock Medical Centre.
- 4) Text books.(All in one care planning resource, Nursing home care, Care maps and Continuous quality improvement)
- 5) Domain experts
- 6) Existing care plan templates and their use in real settings.

We select knowledge from multiple sources in order to cover the entire range of concepts related to care planning. We note that text books provide more details and background material about care planning and care plans, but they do not provide standards or approved guidelines for handling different healthcare scenarios. Likewise, research papers present current research and findings but they are not approved by standards

organizations. We noted the availability of care plan templates recommended by health institutes and organizations; however, they lacked details about related issues or background material. We note that expert opinions are usually informal but provide insights related to clinical practices that may not be recorded in formal documents. This variation in the knowledge entailed within different types of knowledge sources led us to work with a range of knowledge sources as listed in table 1.

Table 1: Types of knowledge sources

Knowledge Source	Standards, Templates, Guidelines	Background material, Related Material	Insight	New Trends, Alternatives
Books		✓		✓
Research Papers and Articles		✓	✓	✓
Care Plan Templates	✓			
Experts			✓	

Our prominent knowledge sources along with respective author or developer are mentioned in table 2: The selection criteria for each source were:

- (a) Recognition of the source in research community.
- (b) Research contribution of the source in the area of chronic care management for example, chronic care model by Wagner [46, 47]
- (c) Level of standard knowledge that can be retrieved from the selected source.
- (d) Domain knowledge of the author about the sequence of clinical activities involved in the management of chronic diseases.

Selection of the two sources for care plan templates for diabetes enabled us to compare two standard templates in order to identify the common recommendations. Similarly, the reason behind the study of various books was that the knowledge in books is always in detail. This detailed knowledge is useful in proper understanding of any process. After reading the selected books [1, 7, and 8] the care planning process was studied in detail to understand the fundamental concepts of care planning. Recent publications [11, 12, 13, 14] from well known sources i.e. journals and well reputed authors [46, 47] who are active in the field of research had enabled us to align our research according to recent trends in chronic care management.

Table 2 Description of Knowledge sources

<b>Knowledge Source</b>	<b>Title</b>	<b>Developer/Author</b>	<b>Selection Criteria</b>
Care Plan Templates			A
a)Diabetes.	1)Diabetes patient care flow sheet for adults 2)Diabetes Medical Management plan	Canadian diabetes association  American diabetes association	

<p>b)Breast cancer</p> <p>c)Asthma</p> <p>d)Osteoporosis</p>	<p>1)Typical patient journey for cancer patients</p> <p>2)Breast cancer survivorship care plan</p> <p>Asthma management plan &amp; Care plan for asthma from book</p> <p>Management plan for osteoporosis Team care arrangements for osteoporosis</p>	<p>Dartmouth –Hitchcock Norris Cotton Cancer Center Retrieved from[38] <a href="http://cancer.dartmouth.edu/breast/breast_patient_journey.html">http://cancer.dartmouth.edu/breast/breast_patient_journey.html</a></p> <p>NCI Community Cancer Centers program</p> <p>Retrieved from: 1)<a href="http://www.getastmahelp.org/actionplan_components.asp">http://www.getastmahelp.org/actionplan_components.asp</a>[39] 2)All in one care planning resource by Swearingen[37]</p> <p>Retrieved from 1)<a href="http://www.health.gov.on.ca/english/public/pub/ministry_reports/osteo/osteo_0205.pdf">http://www.health.gov.on.ca/english/public/pub/ministry_reports/osteo/osteo_0205.pdf</a>[40] 2)<a href="http://www.monashdivision.com.au/resources/templates.htm">http://www.monashdivision.com.au/resources/templates.htm</a>[41]</p>	
<p>Books</p>	<p>All in one care planning resource</p> <p>Home health nursing Assessment and care planning.</p> <p>Care maps and continuous quality</p>	<p>Swearingen[37]</p> <p>Karen Monks[42]</p> <p>Canadian medical association[43]</p>	<p>c</p>

	improvement.  Methods for Ontology engineering	Fernandez and Lopez[7]	
Research papers	Adaptable personalized care planning via semantic web framework.  Process mapping the patient journey through healthcare: An introduction.  Collaborative management of chronic illness.  Improving chronic illness care: Translating evidence into action.  The role of patient care teams in chronic disease management.  Understanding patient journey: Process mapping.  Ontology engineering to model clinical pathways.	Abidi & Chen [6]  Timothy M Trebble,Navjyot Hansi,Theresa Hydes, Melissa A Smith, Marc Baker[44]  Micaheal Von Korff , Susan.J, Edward .H.Wagner,Jessie Gruman and Judith Schaefer[45]  Edward H. Wagner, Brian T. Austin, Connie Davis, Mike Hindmarsh, Judith Schaefer, and Amy Bonomi[46]  Edward H Wagner[47]  Retrieved from: <a href="http://www.scotland.gov.uk/Resource/Doc/141079/0036023.pdf">http://www.scotland.gov.uk/Resource/Doc/141079/0036023.pdf</a> [5]  Katrina F.Hurley & Syed Sibte Raza Abidi[48]	B
Dictionary	Health and social care data dictionary	NHS by Scottish government [49] Retrieved from <a href="http://www.datadictionaryadmin.scot.nhs.uk/isddd/38337.html">http://www.datadictionaryadmin.scot.nhs.uk/isddd/38337.html</a>	C



Management plan	Chronic Disease Management Plan	Northern Territory Government.[50] Retrieved from <a href="http://www.healthdwt.nt.gov.au/rhd/forms/Chronic_Disease_Management_Plan.pdf">http://www.healthdwt.nt.gov.au/rhd/forms/Chronic_Disease_Management_Plan.pdf</a>	A
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### **3.4.2) Ontology Conceptualization: Knowledge Abstraction to develop a generic Care plan model:**

This step involves the development of a generic care plan model using a middle-out approach by drawing upon different knowledge sources. The main idea of knowledge abstraction is to (a) identify key concepts across the different knowledge sources; (b) align similar concepts that maybe presented in different terminology; (c) identify sub-specializations of the key concepts; (d) identify relations between the key concepts; and (e) synthesize the key concepts in order to formulate a generic model. Knowledge abstraction is not a one-off process, rather it is an iterative process whereby in an accumulative manner the knowledge model is developed—first a straw model is developed using the best knowledge sources, and then through a number of iterations the model is refined by consulting other knowledge resources so that new concepts are added and existing concepts are modified to better account the domain knowledge. A knowledge model is deemed to be sufficiently rich to represent the domain when it reaches a saturation point—i.e. as new knowledge sources are applied to the model there are no new concepts found and no modifications needed to the existing concepts in the knowledge model. In our research, the knowledge abstraction process follows the above inductive approach for knowledge modeling.

Information collected from above mentioned sources did not present a complete care plan, rather what we found were care templates recommending a set of tasks. To develop a generic care plan, we worked with a range of chronic diseases templates, covering surgical, medical, immunological, oncological and depressive disorders, to formulate a complete care plan for a particular chronic disease. The steps in the management of each disease were taken as set of activities, and each activity may contain single or multiple tasks. We developed four complete care plans for the following conditions:

- Diabetes
- Asthma
- Breast cancer
- Osteoporosis

With the availability of the four complete care plans, then we proceeded to develop a high-level generic care plan model through a knowledge abstraction process that involved logical and constructive procedures (explained later in Chapter 4). Our strategy was as follows:

Arranged all activities having similar characteristics under one common class → associate the activities with the clinical procedures required in care planning → Develop an evolving care plan knowledge model → Improve the knowledge model by knowledge gleaned from the four chronic disease care plans

It may be noted that the selection of activities was based on published literature on care plans by different healthcare institutions and carefully analyzing those care plans which are used today in the real world setting. This was the most time consuming task as

it involves information gathering from different available sources and then connecting them with the proposed structure of general care plan.

**3.4.3) Ontology Formalization & Implementation:** The conceptual model acquired after conceptualization phase was not formalized. This means although it's a meaningful conceptual model it still needs to be converted or formalized into computer readable format. So, the first task was to convert this model into computable format. After formalization of generic care plan model, we presented our abstracted care plan model in the form of ontology using OWL language and protégé served as an ontology development tool for our ontology development. We defined the most salient concepts first using the middle out approach. And later identified higher and lower level classes for our ontology. Once class hierarchies were defined, the relationship between the classes and subclasses was created by setting the properties for each class and their relationships (value type, domain). This phase is explained in detail in chapter 5.

**3.4.4) Ontology Evaluation:** According to the methodology, evaluation is done during the whole development phase of the ontology life cycle [7]. Our ontology evaluation comprises of testing the refined model in four phases. First, evaluate the model by encoding three new randomly selected care plans and note if there is any problem in instantiating. Second, evaluate the model against the ontological design principles given by Bordeneider et al [68]. Third, by using pellet reasoner to check for consistency for ontological framework. And finally instantiate the model with a test case to represent the patient specific information.

Results of evaluation are mentioned in chapter 6.

### **3.5) CONCLUSION:**

We have chosen methontology methodology for our research, due to the fact that it has several advantages over other methodologies. Some of the salient features and advantages of this methodology are [7, 52, 55, 60] (a) Proposes life cycle for development of ontology (b) Describe in detail the techniques to carry out each phase (c) Helps in the development of the ontology at the knowledge level either from scratch or by re using existing ontologies (d) Methodology allows user to add, delete or change terms in the evolving ontology [7]. It proposes middle out strategy through which we have first identified the most relevant concepts related to the care planning and chronic disease management and then these concepts were generalized. Although it has more advantages over other methodologies but still it requires details for some techniques and activities [52]. This methodology helped us in carrying out our research in a systematic manner which resulted in a conceptual Care Plan model during the conceptualization phase and also includes verification of the model at the knowledge level. Using the conceptual model we developed an ontological framework while passing through the formalization and implementation phases of the methontology.

## **CHAPTER 4: DEVELOPMENT OF GENERIC CARE PLAN MODEL**

### **4.1) INTRODUCTION:**

In this chapter we will discuss the development of a generic Care Plan model for managing chronic diseases based on knowledge abstracted from an assortment of paper based care plans for chronic diseases and literature articles for the management of chronic illness care. The intent of the generic Care Plan is to identify the salient (a) care plan concepts, such as care steps, care tasks, role of care providers, schedule of care tasks and their outcomes; (b) the functional and medical relationships between the care tasks leading to the definition of a care plan; and (c) disease- and institution-specific constraints to care planning. The generic care plan model will subsequently be used to develop Care Plan ontology (as explained in chapter 5).

It may be noted that the medical literature does not provide a generic Care Plan structure, rather in a clinical setting the care planning process is an ad hoc exercise that is based on the patient's conditions, the care provider's knowledge and the hospital's care practices. For our purposes we want to specify a generic, high-level care plan structure—highlighting the constituent activities, practitioners involved, intermediate results, timing and resource constraints and expected outcomes—that can be used to specify the longitudinal care process for a chronic disease.

Our model is a combination of chronic disease management and care planning, so the generic care plan model should begin with a health care encounter of a chronic disease patient. By encapsulating the essential component of chronic disease management in this model we try to achieve a systemic presentation of the knowledge which is generated

during the care process. At the same time the generic model should also provide step by step recommendations to guide the care process. The starting point of our research is investigating the commonalities like tasks, activities, roles etc that occur in chronic disease management and Care planning. After determining the commonalities these were incorporated into the generic care plan model along with the essential concepts of chronic disease management and care planning. Ultimately in the end our model will serve as a merge point of (a) chronic disease management and (b) Care Planning because it present all the essential components of these on a single platform. We claim this merging platform as our Generic Care plan Model. The generic care plan model is a result of the knowledge abstraction process and in the subsequent section of the chapter we'll illustrate some of the available care plan templates for chronic disease management and care plan followed by the details of knowledge abstraction process.

**4.2) PHASE 1: KNOWLEDGE ABSTRACTION AND MODEL DEVELOPMENT:** The objective of this phase is to abstract a generic Care Plan structure from existing paper-based care maps. Notwithstanding the individual characteristics of chronic diseases there is an underlying care process that is common across all diseases—it is this common care process that we aim to abstract and represent as a *generic Care Plan*.

Our knowledge abstraction process was based on our study of different care plan templates (pieces of information for specific chronic disease management), published by various health care institutions, and the management of four selected chronic diseases for our research. These diseases are diabetes, asthma, osteoporosis, and breast cancer. The

rationale behind choosing these four diseases to develop our care plan model was that (a) all four are chronic diseases. As our goal is to capture the clinical care processes involved in the chronic disease management (b) the first three diseases cover three different physiological systems, namely the endocrine, respiratory, and musculoskeletal systems respectively and (c) the fourth disease covers the domain of cancer care. All these care plans were in the form of templates, such as the samples shown below in template 1.

Template 1. Care plan template showing various clinical examinations. Taken from [14]

<b>CARE PLAN</b> N=NEW R=REVIEW
<b>GENERAL</b>
Routine clinical items (BP, Weight, Waist, BMI,BGL,U/A)
Feet
PEFR/Spirometry
Urine ACR
Skin
Teeth
<b>BLOODS</b>
FBE
LFT
Lipids
EUC+/- Cr Cl
BGL (fasting)
HbA1c
Renal Bloods
Other
<b>IMMUNISATIONS</b>



STEP 1: Given the diversity of care templates for the same disease, the first task was to align and synthesize these different templates to generate a disease-specific paper based care plan.

Template 2. Care plan template showing various systemic examinations. Taken from [50]

Routine Clinical Examination by DMO or GP		Date: ...../...../.....	
Eyes:	Visual acuity: R ___/___ L ___/___	Cataracts: Yes <input type="checkbox"/>	No <input type="checkbox"/> Eye Check <input type="checkbox"/>
Oral health:			
Cardiovascular:			
Respiratory:	PEFR		
Abdominal:			
Gastrointestinal			
Musculo skeletal:			
Neurological:			
Renal / urological:			
<b>Feet</b>	Pulses	Skin integrity	Sensation
Use diabetic foot check where indicated	Right foot Yes <input type="checkbox"/> No <input type="checkbox"/>	Intact <input type="checkbox"/> other <input type="checkbox"/>	Normal <input type="checkbox"/> abnormal <input type="checkbox"/>
	Left foot Yes <input type="checkbox"/> No <input type="checkbox"/>	Intact <input type="checkbox"/> other <input type="checkbox"/>	Normal <input type="checkbox"/> abnormal <input type="checkbox"/>

Template 3. Care plan template showing the concept of Referrals. Taken from [50]

Referrals made							
Physician <input type="checkbox"/>	Cardiologist <input type="checkbox"/>	Optometrist <input type="checkbox"/>	Dentist <input type="checkbox"/>	Renal <input type="checkbox"/>	Mental Health <input type="checkbox"/>	Pharmacist (Item 900) <input type="checkbox"/>	Other <input type="checkbox"/>
Dr's Name:			Dr's Signature:			Date: / /	
Please record clinical goals on page 3							

STEP 2: In the next step, we studied the different care plans to identify core concepts that were frequently present across the care plans for chronic disease management, as

practiced by different healthcare institutions [38, 39, 40, 41, 64,50]. The initial abstraction resulted in a primitive care plan model that entailed a cyclic process of care tasks pertaining to (a) assessment (b) treatment planning and (c) follow up (as shown in Figure (9a)). The concept of assessment includes the initial investigation process needed to assess the state of the patient or the stage of the chronic disease at the first health encounter. These processes include taking a patient history, recording patient complaints, conducting general physical examination, reviewing previous laboratory results, etc. Treatment planning covers the different options for the management of the patient and follow up provides a schedule of future visits for the patient to ensure the long term care process.

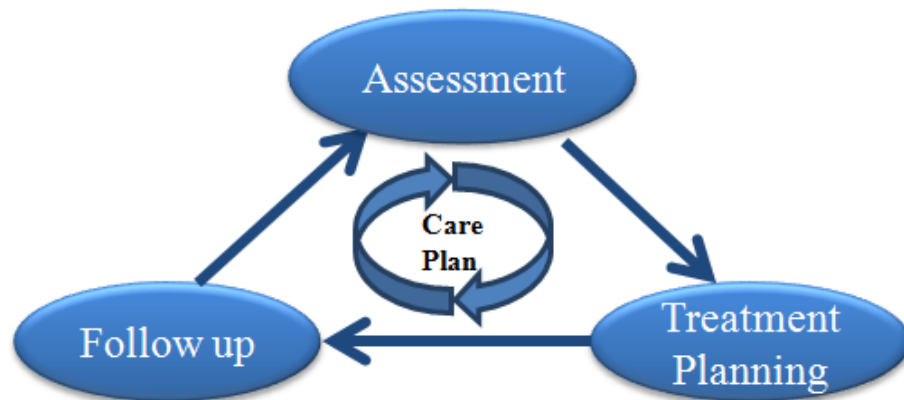


Figure 9a: Primitive Care Plan Model illustrating three (3) major stages in chronic disease management

In addition to the above basic concepts related to chronic diseases management, some concepts were also added in the primitive model based the on general understanding of author, and literature reviews of health informatics and computerization of healthcare

knowledge [61, 62, 63]. These concepts were found common in the management of all chronic diseases and also helpful later during the computerization phase of this research.

The detail of each concept is mentioned as follows:

**Decision Option:** This concept represents the options available for treatment, where the decision depends on the healthcare provider and the patient's consent.

**Role:** To perform specific tasks at certain stages of disease management there is always a responsible person. We have captured this information in our care plan model as the concept of role. For example (1) Surgery is performed by a surgeon, (2) For investigation, blood is drawn by a lab technician and (3) Vitals recorded by a registered nurse.

**Schedule:** This concept captures time and duration for any specific stage in chronic disease. Since chronic disease patients require longitudinal care planning, there must be regular follow ups and assessment periods. In case of chronic diseases, treatment periods are placed between follow up and regular assessment of chronic disease patient.

**Patient Status:** Current state of a patient's chronic condition decides patient state, whether to treat him/her as an outpatient or refer for admission. This state mainly depends on the results of assessment and investigation reports.

Incorporation of the above mentioned concept into our primitive model leads to the extension of the primitive generic care plan model as shown in Figure (9b). This explains that the assessment is being performed by a particular role, and the results of assessment determine the patient state. Once the patient state has been determined there could be a

number of decision options related to treatment planning. The treatment provided to the patient must have a particular schedule that leads to patient's follow up which also has a schedule. The follow up completes the cyclic process of care planning by entering the patient again into the above loop through assessment.

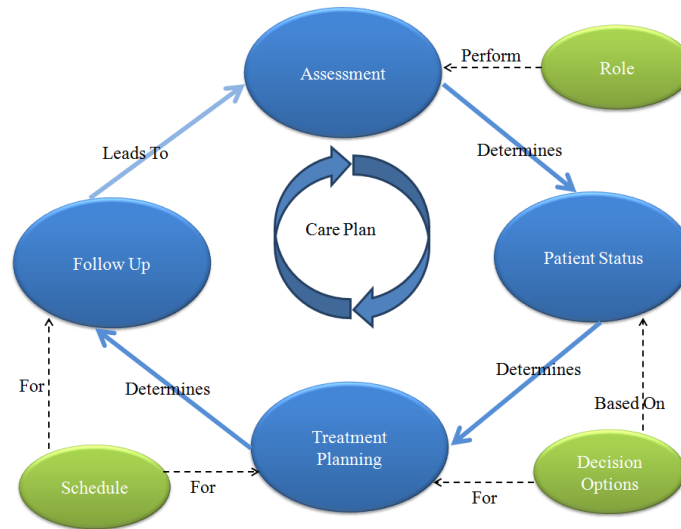


Figure 9b: Primitive Care Plan Model with new concepts.

After addition of four more concepts in our primitive model, our model is now showing basic concepts needed in chronic care. In order to further extend this primitive model with appropriate concepts to capture the complexities of different care plans we then performed four iterations (Figure 10) in this phase, each corresponding to a different chronic disease:

1. Diabetes
2. Asthma
3. Breast cancer
4. Osteoporosis

The process of iteration was performed in order to refine our primitive model into a Generic Care Plan Model. Thus iteration is a knowledge modeling exercise, i.e. the process of iteration starts with the review of two knowledge sources which are (a) care plan templates for chronic Disease X and (b) general literature about management of chronic disease X. This process leads to identification of essential concepts and particular steps in the management of disease X. This abstracted knowledge is then incorporated into the knowledge model resulting in refinement of the model. This process is repeated N times (in our case we have chosen four chronic diseases) and the final result would be a generic care plan model having all steps and concepts necessary for chronic disease management. Now we describe in detail the specifications developed during iteration and its impact on the generic care plan model.

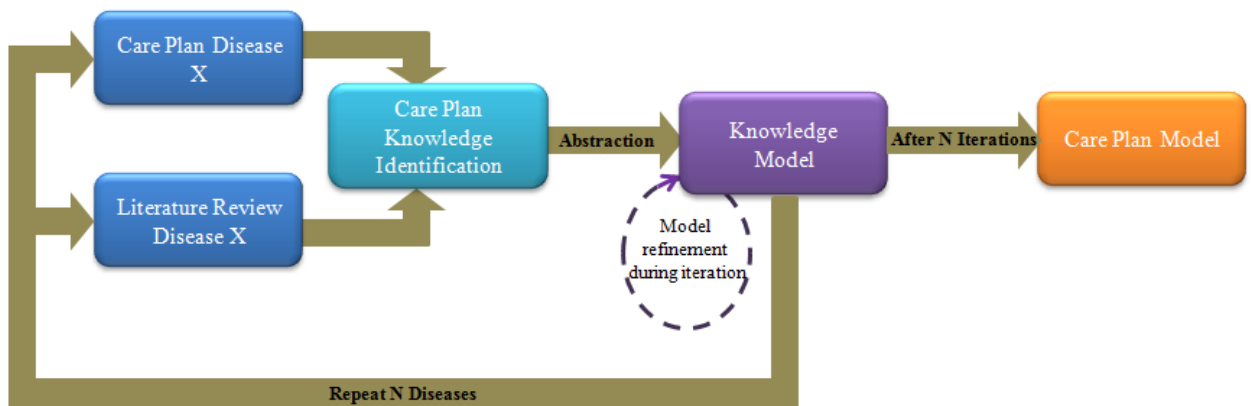


Figure 10: Knowledge Abstraction and Modeling process

#### **4.3) ITERATION 1 ABSTRACTING KNOWLEDGE FOR DIABETES CARE MANAGEMENT:**

This stage involved the development of the initial care plan model using the care plans for diabetes [42, 64]. We selected 2-3 care plan templates for diabetes developed by different healthcare associations, and also studied in detail the process of care planning for diabetes from books [37] published by experts in the field. After a thorough review of the literature on care planning for diabetes, we identified the following five steps in which the different tasks of the care plan can be categorized:

1. **Assessment:** Identification of the needs and risks on the basis of patient's current state of the disease. It begins with an individual story, covering all the problems present and all the domains which include clinical, social, and psychological lifestyle. This phase helps in identifying the current stage of the chronic disease.
2. **Investigation:** A list of the investigations is created on the basis of the patient's story (experience and issues) and the professional's story (evidence and experience). Together with the assessment, the results of the investigations help in generating a specific treatment plan.
3. **Treatment Planning:** This step includes a list of activities for the patient and the health care provider. It also includes identification of the need of equipment (supplies or medical instruments) if required for treatment. The treatment plan basically addresses how to live with chronic condition medically and socially. It should be adaptable as the patient passes through the process of care to meet the changing requirements of an individual.

4. Patient Education: Includes a list of activities primarily for patients. This phase of the care plan encompasses patient self-monitoring and home based interventions. The patient is educated about his/her condition and how to manage emergent situations.
5. Follow up: Covers the temporal aspect of the care planning process. Follow up is one of the most important aspects of chronic disease and determines visits of chronic disease patients. The time period for follow up depends on individual condition. It can be weekly, monthly or yearly.

These five steps consist of one or more tasks. For example, in assessment phase, recording of general information i.e. weight, BMI constitute task1 and performing general physical examination (GPE) constitute task2. Similarly the treatment planning phase includes multiple tasks based on the results of patient’s current stage of the disease. A further detail of each step and the tasks included in each step of a diabetes management plan is mentioned in Table 3.

Table 3: Categorization of tasks related to diabetes care management into different phases of Care Planning

Steps	Tasks
Assessment	Task1: Check weight, BMI, Blood Glucose. Task2: Do General Physical Examination (Vitals & Non Vitals) Task 3: Assess general skin condition, wound condition or

	any other lesion.
Investigation	<p>Task 1: Order blood tests</p> <p>(1) RBS</p> <p>(2) FBS</p> <p>(3) HbA1c</p> <p>(4) Lipid profile</p> <p>Task 2: Eye exam.</p>
Treatment Planning	<p>Task 1: Note patient condition</p> <p>Task 2: Order oral hypoglycemic or insulin</p> <p>Task 3: Advice moderate physical activity for atleast 150 minute /week, discourage sedentary lifestyle.</p> <p>Task 4: Consult with dietician.</p>
Patient Education	<p>Task1:Self monitoring</p> <p>Task 2:Dental care</p> <p>Task 3: Foot care</p> <p>Task 4: Look for neuropathies and nephropathies symptoms</p>
Follow up	<p>Task 1: Weekly/monthly visit</p> <p>Task 2: Annual reviews for nephropathy, neuropathy, retinopathy, CAD assessment, lipid profile, vaccination.</p>

Initially our starting model had three steps only i.e. assessment, treatment planning, and follow up figure 9. By performing the above knowledge modeling exercise we extended



our primitive knowledge model figure 9 and incorporated two new concepts into our general care plan model namely, investigation and patient education. At the end of iteration 1 our primitive model captured the different steps and the flow among these steps in relation with diabetes management plan as shown in figure 11.

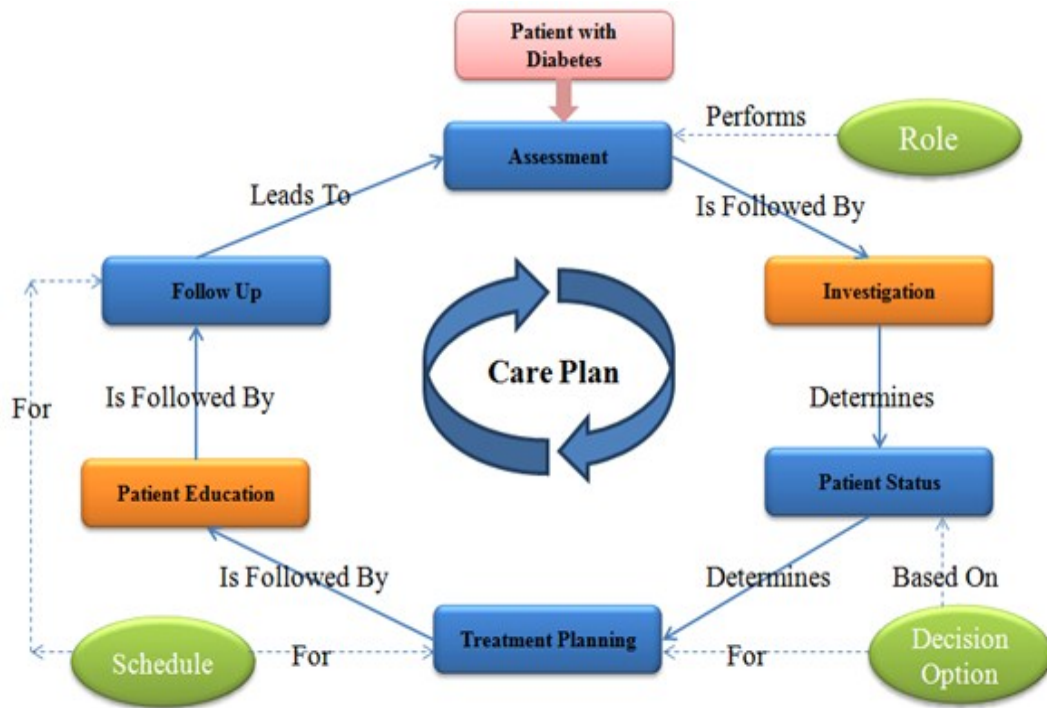


Figure 11: Model Refinement: Addition of 2 New Concepts (Investigations & Patient Education) after Iteration 1.

#### 4.4) ITERATION 2: ABSTRACTING KNOWLEDGE FOR ASTHMA CARE MANAGEMENT:

In this iteration, we extended the generic care plan model developed in iteration 1 using care plan templates for asthma. In this iteration we found that most of the steps involved

in asthma management were similar to the ones noted in the diabetes management plan, as explained in iteration 1. In the process of knowledge abstraction, by reviewing the management plans of asthma, two new steps were identified namely monitoring and re-consultation.

**Monitoring:** Once a care plan is implemented, patient condition should be monitored, in a timely manner, to make any changes in the plan. In the process, any changes made should also be documented. If the patient's condition worsens, the care plan advises for re-consultation.

**Re-consultation:** The main intent of the care plan is to address how the patient can live better in the presence of a chronic condition, medically and socially. It should be adaptable as the patient passes through the process of care to meet the changing requirements of the individual. The change in care plan may require re-consultation with the same or multiple healthcare providers.

The next version of the care plan model is shown in Figure 12.

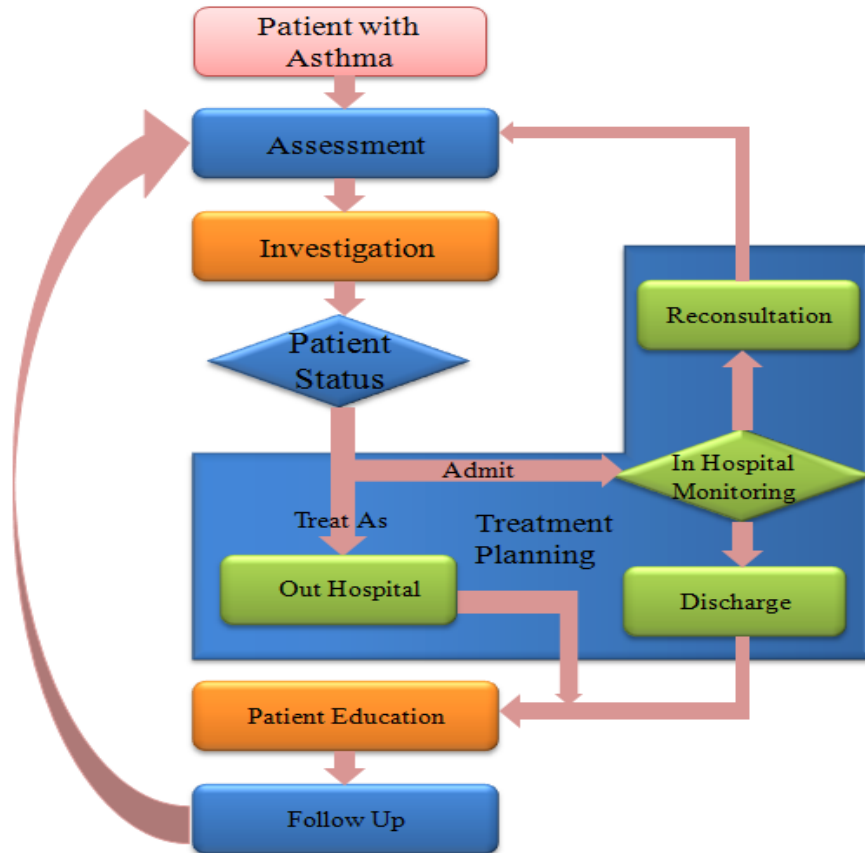


Figure 12: Model Refinement: Addition of 2 Decision option and 2 new concepts as a result of iteration 2

The above mentioned concepts are newly discovered, but implementing these concepts into our generic care plan model is not so straightforward. We already have the notion of decision options in our model. Therefore we make use of this concept and made Patient Status as a decision point. It provides us two options namely out-patient and in-hospital monitoring. The option of out-patient represents those patients who have a chronic disease (in this case asthma) but do not need hospitalization for any intervention and follow the loop by getting treatment and then patient education and so forth. The other option i.e. in-hospital monitoring represents the group of patients having chronic disease who require hospitalizations and continuous monitoring. In-hospital monitoring is again

used as a decision point in our model because while in hospital, if the condition of the patient worsens then the need of re-consultation arises. So the in-hospital monitoring provides us with two options again namely (a) re-consultation and (b) discharge. Once the patient is recovered then he/she is discharged from the hospital and follows the loop by getting patient education. In figure 12 the new concepts have been mapped on treatment planning, although this mapping shows treatment planning is a separate concept how closely it is related to and depends on patient status.

The details of the tasks related to each phase in the management of asthma are explained in table 4. Each phase corresponds to single or multiple tasks. For example, the assessment step has multiple tasks while the investigation step in asthma management has only one task. New phases introduced at this stage are shown in italics in table 4.

Table 4: Categorization of tasks related to asthma care management into different phases of Care Planning

Steps	Tasks
Assessment	Task 1: Check breathing good/ average/ difficult Task 2 : Check for cough and wheeze Task 3: Assess sleep status. Task 4: Check if exercise triggers asthma. Task 5: Assess for green, yellow or red

	zone.
Investigation	Task: Order peak flow
Treatment Planning	Task: Use chamber/spacer or quick relief medications.
<i>Monitoring</i>	<i>Task: Monitor patient, if symptoms get worsen then change medicines or advice re-consultation. Discharge if symptoms get better.</i>
<i>Reconsultation</i>	<i>Task: Advice re-consultation with same or different health care provider OR involve health care team.</i>
Patient Education	Task1:Self-monitoring Task 2: Take medicines 15 min before exercise/sports. Task 3: Advice patient to decrease cigarettes/day.
Follow up	Task: Assess patient regularly. Change treatment plan if required.

#### 4.5) ITERATION 3: ABSTRACTING KNOWLEDGE FOR BREAST CANCER MANAGEMENT:

In this iteration we extended the care plan model based on care plans for breast cancer. iteration 3 results in further extension of the generic care plan model. In this iteration, the concept of referral was identified (as shown in Figure 13). By incorporating the concept of referral into the model it covers the notion of several different healthcare providers in the process of longitudinal care. These include chemotherapists, radiotherapists, pathologists and surgeons in case for surgical treatment if needed to perform biopsy for diagnostic or therapeutic purposes. The details of each task involved in the breast cancer management are given in Table 5. The new concept added after iteration 3 is shown in italic in Table 5.

Table 5: Categorization of tasks related to Breast cancer management into different phases of Care Planning

Steps	Tasks
Assessment	Task 1: Check for weight loss Task 2: Assess irregular activities in recent month. Task 3: Check for swelling, do lymph node and thyroid exam. Task 4: Do GPE.
Investigation	Task1: Order blood test, CP, WBC,

		<p>Platelets, UCE, lipid profile &amp; serum sample.</p> <p>Task 2: Order X-ray, CT, MRI, Biopsy.</p>
	<i>Referral</i>	<i>Task: Refer to appropriate specialist</i>
Treatment Planning	Medical Treatment / Treatment options	<p>Task 1: Medically treat the patient if possible.</p> <p>Task 2: Explain treatment options to patient i.e. Surgery, Medication, Chemotherapy or Radiation.</p>
	Surgical Treatment	<p>Task 1: Surgical removal of cancer involves lumpectomy, mastectomy.</p> <p>Task 2: Send to pathologist.</p>
	Therapy	<p>Task 1: Make appointments with medical oncologist and radiation oncologist to plan treatment.</p> <p>Task 2: Begin chemotherapy, radiotherapy or hormone therapy if needed.</p>

Follow Up	<p>Task: Visit after every 3-6 months for first 3 years. Involves follow up care test:</p> <ol style="list-style-type: none"> <li>1) Medical history and physical exam</li> <li>2) Post-treatment mammography.</li> <li>3) Breast self examination.</li> <li>4) Pelvic examination.</li> <li>5) Coordinated care by primary care, Oncologist.</li> <li>6) Refer to genetic counseling</li> </ol>
Patient Education	<p>Recommendations:</p> <p>Task 1: Continue to visit physician</p> <p>Task 2: Check for symptoms of reoccurrence:</p> <ol style="list-style-type: none"> <li>1) New lumps</li> <li>2) Bone pain</li> <li>3) Chest pain</li> <li>4) Shortness of breath</li> <li>5) Difficult breathing</li> <li>6) Abdominal pain</li> <li>7) Persistent Headaches.</li> </ol>



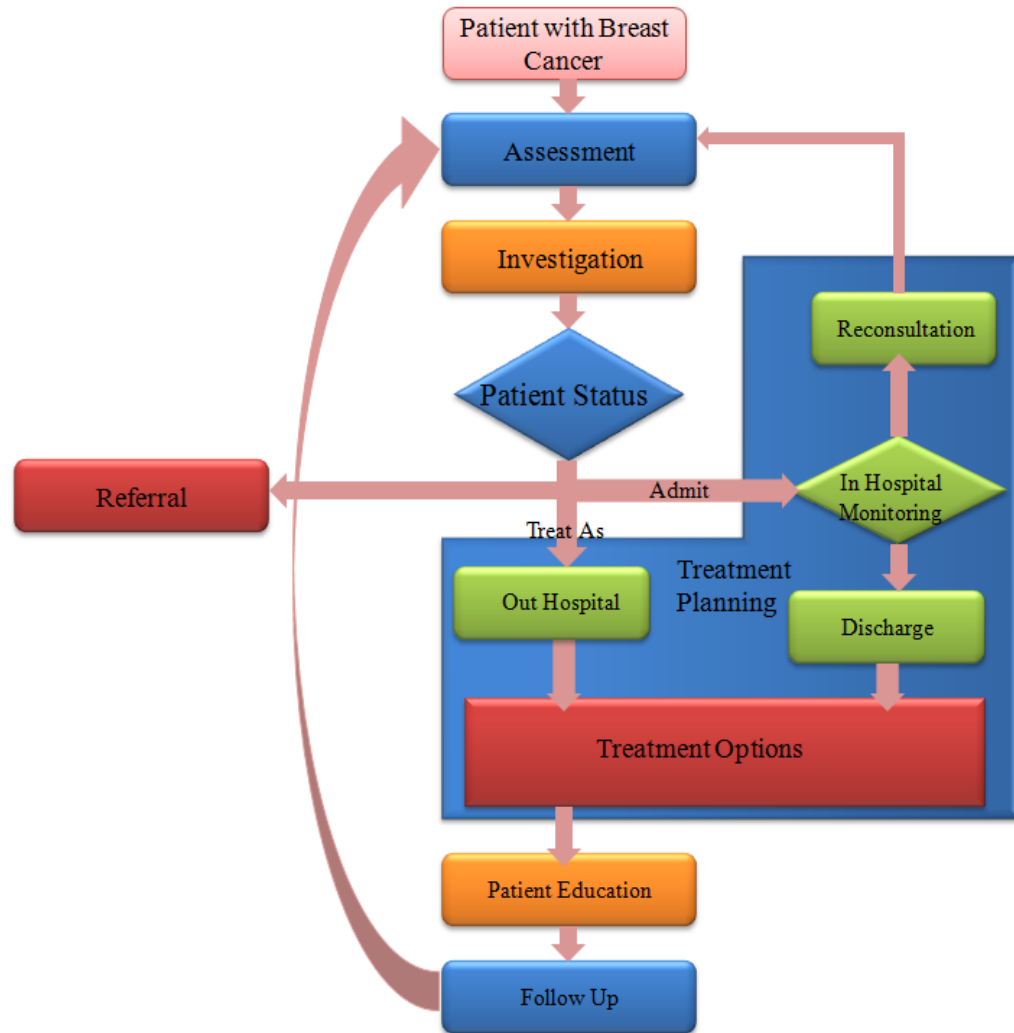


Figure 13: Model Refinement after Iteration 3

At the end of iteration 3 the generic care plan model not only has a new concept of referral but also results in further classification of the concept of Treatment Planning. Three treatment options were introduced into the generic care plan model, which are (a) medical treatment (b) surgical treatment and (c) therapies.

#### 4.6) ITERATION 4: ABSTRACTING KNOWLEDGE FOR OSTEOPOROSIS MANAGEMENT:

At this stage we encoded osteoporosis management plan into our care plan model. While performing iteration 4, the knowledge abstraction process did not reveal any new concepts. The whole management of osteoporosis was successfully mapped into the care plan model developed during iteration 3. This shows that the model developed after iteration 3 was quite mature because iteration 4 only validates the model, without adding any new concept to it. After iteration 4 we achieved figure 13 the *Generic Care Plan model for chronic diseases*. Steps required in the management of osteoporosis are listed in the Table 6.

Table 6: Categorization of tasks related to osteoporosis management into different phases of care planning

Steps	Tasks
Assessment	Task1: Check for sign and symptom. Task 2 : Do general physical examination(vitals & non vitals) Task 3: Check for joint pain, movement at joint and any restricted movement. Task 4: Check for major and minor risk factor.

Investigation	<p>Task 1:Order DEXA Scan for bone density</p> <p>Task 2:Order vitamin D blood test for vitamin D range</p>
Treatment Planning	<p>Task1:Order Calcium therapy</p> <p>Task 2:Order vitamin D therapy</p> <p>Task 3:Therapy for postmenopausal women:</p> <p>HRT</p> <p>Alendronate</p> <p>Risedronate</p> <p>Raloxifine</p> <p>Calcitonin</p>
Referral	Refer to dietician/ nutritionist
Patient Education	<p>Task1:Self monitoring/ lifestyle modification</p> <p>Task 2:Smoking cessation</p> <p>Task 3: Advice patient to avoid alcoholism</p> <p>Task 4: Depression control</p> <p>Task 5: Monitor weight, BMI</p>
Follow Up	Task 1: Annual follow up with central DEXA scan.

#### **4.7) REFINING THE GENERIC CARE PLAN MODEL:**

The general care plan model shows basic concepts and relationships involved in the management of any chronic disease. These high level concepts were further decomposed into sub-concepts based on the similarity of tasks abstracted from the care planning stages of different chronic diseases. Following is a summary of the new sub-concepts introduced in the general care plan model:

**(1) Assessment:** According to the review of phase 1 of each stage, assessment involves review of patients' present and past conditions. The sub categories for assessment were made to cover all the aspects of patients' present and past conditions. The sub categories we selected include (a) assessment of health record based on tasks of assessing patients' past medical and surgical histories (b) assessment of risk factors which will cover the assessment of major and minor risk factors for specific chronic disease and (c) assessment of presenting condition by general physical examination which include tasks such as (1) doing general physical examination (Vitals & Non Vitals), and (2) checking for joint pain, movement at joint and any restricted movement.

**(2) Investigations:** To know the current stage of chronic disease, it is important to perform various investigations. We have further categorized this concept into multiple sub-concepts to cover a variety of investigations performed during the course of chronic disease management shown in figure (14). Sub-categories we

selected include (a) laboratory tests covering the tasks, ordering vitamin D blood test for vitamin D range and ordering blood tests, CP, WBC, platelets, UCE, lipid profiles and serum sample.(b) radiology and scans will cover the task of ordering X-ray CT , MRI.

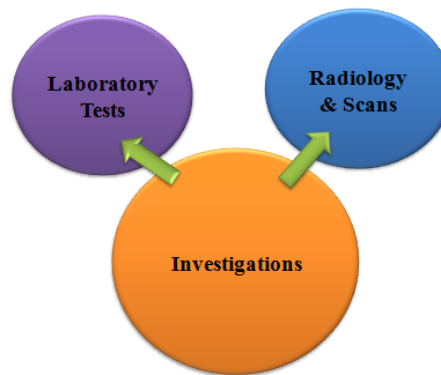


Figure 14 Concept of investigation and its sub concepts

**(3)Treatment planning:** This concept covers various treatment options available for management of chronic illnesses. Long-term of chronic illnesses result in conditions that need multifaceted care options like (a) medical treatment (b) surgical treatment and (c) lifestyle modifications, as shown in figure 15.

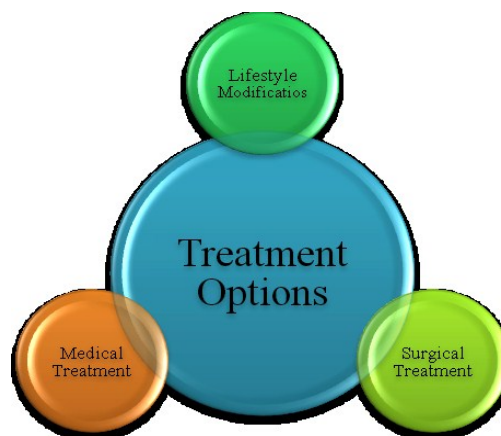


Figure 15 Multiple Treatment Options for Management of Chronic disease

In order to capture knowledge in depth these options are further decomposed into subcategories. The notion of medical treatment is divided into (a) prescription and (b) therapy. Prescription covers all medical needs as prescribed by the healthcare professionals. In these cases these needs could be in the form of drugs, either in oral form or local applicants like ointment, or medical equipment like chambers, nebulizers, and inhalers etc. On the other hand the therapy spans over various therapeutic options like, physiotherapy which is needed for rehabilitation of long term neurological deficits and also includes sports therapy, psychological therapy needed in psychological and depressive disorders, chemotherapy and radiations for cancer treatment. This different division of prescriptions and therapy is illustrated in figure 16.

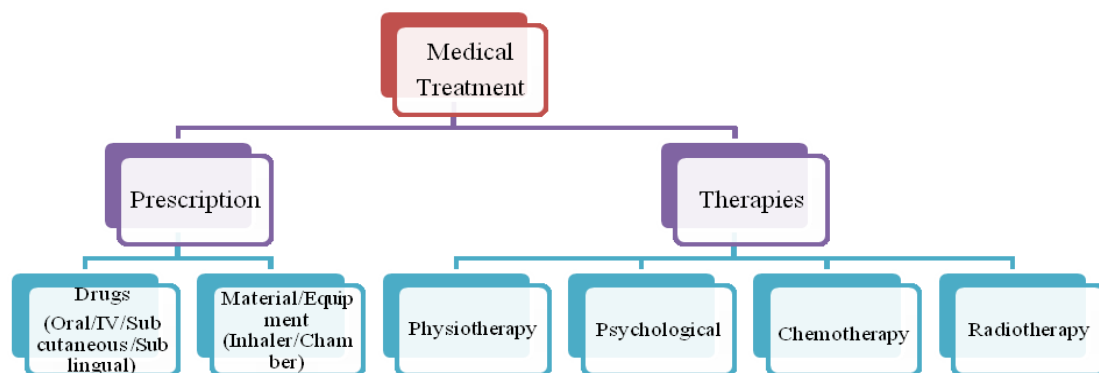


Figure 16 Classification of Medical Treatment

Surgical treatment is divided into two broad categories i.e. major surgical treatment and minor surgical treatment figure 17. This division depends upon several different conditions like severity of procedures, involvement of operation theatres, anaesthesia used during the procedure etc. The major surgical treatment involves major surgeries like,

thoracic, heart, neurosurgeries, and orthopaedic procedures. These procedures involve a complete set of surgical protocols like proper operation theatre environment, anaesthetist and surgical team involving a single or multiple surgeons with operation theatre staff and nurses. Minor surgical treatments cover minor procedures that can be performed in a doctor's office without having specialized environments like, incision and drainage, aspiration of a local abscess, etc.

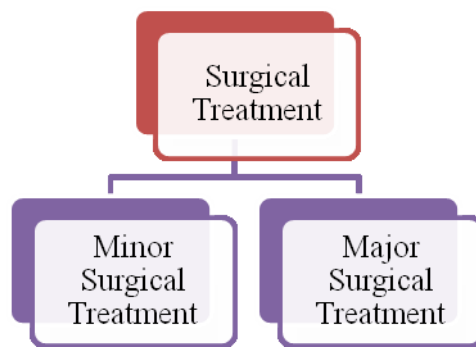


Figure 17 Classification of Surgical Treatment

The treatment option of lifestyle modifications is meant to treat chronically ill patients by altering their daily habits which helps in improving their condition without any medical intervention. This option is decomposed into three divisions namely, (a) dietary modifications (b) alteration of smoking habit and (c) physical activity as illustrated in figure 18. Dietary modification involves alteration of dietary habits that will ultimately results in improvement of chronic condition; for example, (1) consumption of low fat diet results in a lower risk of atherosclerosis and cardiovascular diseases [66] and (2) consumption of low sodium diet can help in reducing high blood pressure [66]. Though it's not impossible, it is difficult to quit smoking at once. The alteration in smoking habits provides patient a chance to reduce the consumption of cigarettes which can improve

several chronic condition outcomes like diabetes, asthma, cardiovascular disorders and hypertension. Increase physical activity and regular exercise helps to avoid sedentary lifestyle and adopt a much healthier way to live. Lifestyle modifications can also help the health care provider to keep track of patient compliance to the treatment advised by the health care provider.

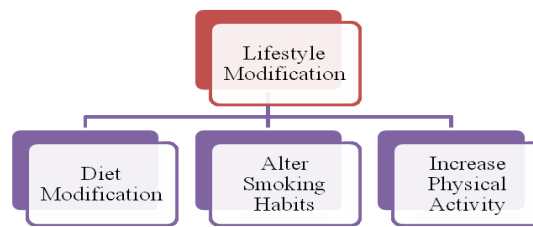


Figure 18 Classification of Lifestyle Modification

**(4)Patient Education** The concept of patient education is also refined into sub concepts, namely goal settings, self monitoring and home based procedures figure 19. Patient education helps the patient to understand their health condition and makes them more responsible about their duties towards chronic conditions. In goal setting several different ways are taught and goals are set by mutual discussion by the patient and the health care provider to improve the patient's health status, for example, to reduce weight by lowering high cholesterol diet and increasing physical activity. In this example the goal is to reduce weight and the education material provides the information on how to achieve the goal. Self monitoring includes the self examination that patients can perform themselves without any assistance e.g. self breast examination. The home based producers allow the patient to keep track of their chronic disease for example, routine monitoring of fasting



and random blood sugar testing using a glucometer and regular monitoring of blood pressure in hypertensive patients.



Figure 19 Classification of Patient Education.

At the end of the knowledge abstraction process the generic care plan model is developed which captures all aspects of chronic disease management and the care planning process: it is presented in figure 20. The generic model has 8 core concepts, 24 sub concepts and 2 decision points. The solid line in the figure 20 shows the connection between the core concepts and the dotted line shows the sub-concepts identified during the refinement of the Generic Care Plan model. The two decision points are (1) patient status and (2) in-hospital monitoring. Patient status is made a decision point because at this point a decision is made by the health care provider whether to admit, treat as an out-patient or refer to another health care facility. An admitted patient requires continuous monitoring and at this point a decision is made based on the results of this monitoring, which could be to discharge or advise re-consultation.

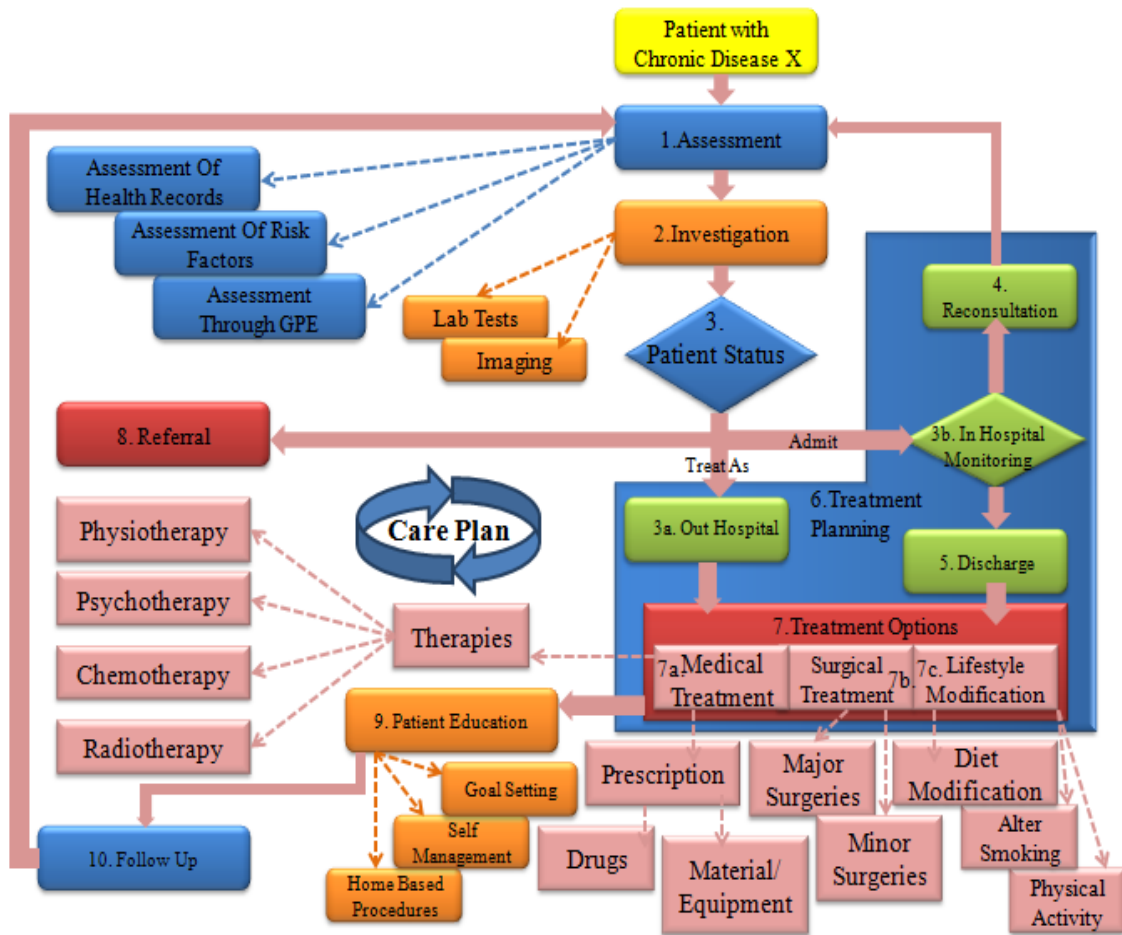


Figure 20 Generic care plan model for chronic disease management. (Presenting core concepts, sub concepts and decision points)

The core concepts represent the main concepts that were abstracted from the paper based care plan templates like assessments, investigations, and follow up. These main concepts were further broken down into sub concepts either (a) during iterations like treatment options into medical and surgical treatment or (b) during the refinement process of Generic Care Plan Model e.g. classification of assessment into three different types of assessments as explained earlier. The list of main concepts and its sub classification is shown in table 7.

Table 7: Lists of Generic Care Plan model concepts and sub concepts

Core Concept	Sub Concepts	Classification of sub-concepts	
<b>Assessment</b>	Assessment of health records.	None	
	Assessment of risk factors.		
	Assessment of present condition by General Physical Examination		
<b>Investigations</b>	Laboratory Tests	None	
	Imaging		
<b>Treatment options</b>	Medical treatment	Prescription	Drugs
		Instruments	
		Therapies	Physiotherapy
			Psychotherapy
			Chemotherapy
	Radiotherapy		
	Surgical treatment	Major surgeries	None
Minor surgeries			

	Lifestyle modification	Diet modification	None
		Alter smoking	
		Physical activity	None
<b>Re-consultations</b>	None	None	
<b>Discharge</b>	None	None	
<b>Referral</b>	None	None	
<b>Patient Education</b>	Goal setting	None	
	Self management		
	Home based procedures		
<b>Follow up</b>	None	None	

The Generic Care plan model contains all the concepts that are common and essential for, as well as the sequential flow that occurs during chronic disease management. Each concept of the model consists of a variety of activities and tasks that need to be performed in a specific environment of the healthcare system. To clarify this model, it is necessary to specify where specifically in the healthcare system each of these activities occurs. The entry point of the patient to a healthcare is usually the primary care, where

the patient is assessed and given a set of investigations. The results of the assessment and these investigations help in determining the state of the patient. If the patient needs admission, monitoring, reconsultation or provision of treatment then this will occur in tertiary care. Sometimes patients visit tertiary care for follow up or for referral but do not need admission so they receive treatment as outpatients. The provision of patient education can occur during the admitted state, after the patient is discharged or in a primary or tertiary care settings for patients treated as out-patients. Similarly, the follow up could also be either in primary or tertiary care facilities. The referral is given to obtain advice from a specialist, so the concept of referral is advised from a primary care provider but it happens in a tertiary care facility. In the figure 21 we have shown in the Generic Care Plan model where each of these events occurs in the healthcare system.

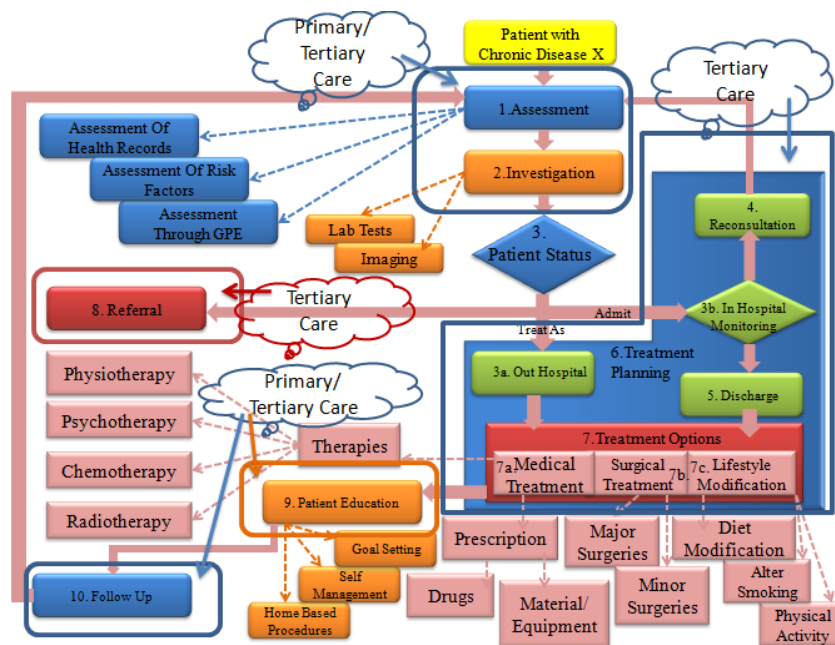


Figure 21 Generic Care Plan model for chronic disease management.

(Presenting primary and tertiary care activities)

**4.8) CONCLUSION:** Generic Care Plan Model is developed as a result of two research activities namely (a) knowledge abstraction and (b) iterations. The developmental process passes through an evolutionary phase during the iterations, while knowledge abstraction supplements the evolutionary process by addition of new concepts. Knowledge abstraction and iteration proceed in a parallel fashion and sometimes overlap each other to enrich the model with new concepts and steps of care planning and chronic disease management. In the process of model development, knowledge abstraction has served as the main technique in identification of knowledge which consists of (a) core concepts of Care Planning and chronic disease management and (b) the commonalities that occur in care planning and chronic disease management, while the iteration serves the purpose of model refinement and extension. The identified concepts were then plotted in systemic manner to achieve the sequential flow of the care process. The endeavour resulted in the formation of a Generic Care Plan knowledge model. Hence the research resulted in a Generic Care Plan model that represents (a) the essential concepts, tasks, activities related to care planning of chronic disease management and (b) a sequential flow of these task and activities which are necessary to guide the care process.

## **CHAPTER 5: ONTOLOGY MODELING**

**5.1) INTRODUCTION:** In the previous chapter an iterative process of knowledge abstraction led us to develop our knowledge model, the Generic Care Plan Model. In the Care Plan model we identified the main concepts involved in chronic care and care planning. This model provides the flow of tasks and activities that occur during chronic disease management. In this chapter, we will discuss the ontology engineering process to develop the Care Plan Ontology by using our Generic Care Plan model. We will discuss the requirements for the Care Plan ontology and present an overview of its structure and concepts. The Care Plan ontology is developed using OWL language as it provides the maximum level of expressiveness and it is possible to perform reasoning over the ontology using a range of reasoners [67].

After the process of knowledge abstraction and modeling we have successfully developed Generic Care Plan model which was presented in Chapter 4. In an effort to computerize our model in the form of ontology, it is vital to identify and discuss the key elements of Care Plan ontology.

### **5.2) KEY ELEMENTS OF A CARE PLAN ONTOLOGY:**

Based on our understanding of the form and function of Care Plans we identified a set of elements in addition to the core concepts that need to be represented in Care Plan ontology. Below is a list of functional elements:

1. **Capturing Patient State:** The concept of patient state is a vital concept in the management of chronic disease. The treatment varies according to the patient's

presenting state and the management plan is developed by considering its various parameters.

2. Capturing flow of activities in Care Plans:
  - (a) Sequential flow: Care Plans involve sequential flow among different tasks and activities. The ontology should provide a mechanism to capture this flow.
  - (b) Loops: Care Plans often required that same activities are repeated until certain state is reached or certain condition is met. This requires that the ontology facilitates definition of loops.
3. Capturing of time: In the care planning for any chronic disease, it is important to have specified date and time for each activity carried out during the management. This would help in tracking the patient's past conditions and generating treatment plan accordingly.
4. Representation of co-morbidities in Care Plan ontology: Chronic diseases are mostly accompanied with associated medical conditions called co-morbidities. The course of these medical conditions runs parallel with the course of the main disease. The impact of co-morbidities sometimes results in complications which need immediate medical attention and change the management plan of the disease.
5. Modeling of drugs in Care Plan ontology: The treatment of chronic disease involves the usage of multiple drugs at the same time. Drug interaction and contraindications are two important aspect related to drug usage. It is vital to capture drug information in order to avoid side effects caused by drug-drug interaction.



6. Description of roles involved in chronic disease management: Care Plans for chronic diseases have multiple health care providers involved during the course of treatment. It is important to capture the information about practitioners involved in specific stage of disease. The Care Plan ontology should provide the details for the responsible person at each stage.
7. Capturing list of investigations: To investigate for the current stage of a chronic disease it is important to capture the range of diagnostic interventions. Therefore, it is important that our Care Plan ontology provide the list of interventions required for the specific disease.
8. Providing patient education material: Care planning for chronic illness requires patients to actively participate in managing their condition, it is important to have patient education material which could help them in performing certain tasks and setting goals to achieve the expected outcome.

After identifying the above mentioned key elements of Care Plan ontology it is essential to match these elements with our Generic Care Plan model in order to develop a coherent ontological model. During the ontology engineering process we map the above elements with the generic model to develop our Care Plan ontology. The detail of ontology development is explained in the subsequent sections.

### **5.3) IMPLEMENTATION OF GENERIC CARE PLAN MODEL:**

The ontology engineering process began by specifying the high level classes and their sub-classes based on Generic Care Plan model. In our generic model we identified 10 core concepts and 2 decision options as explained in chapter 4. During the ontology

engineering process the main class represents a main concept for example; assessment is a main concept in our Generic Care Plan model so in the Care Plan ontology assessment represents a main class. In ontology process each main class possesses a set of unique characteristics which is modeled as properties. In our generic model, several of the main concepts have been broken down into sub concepts. These sub concepts have similar characteristics as the main concept but also possess some distinct features that separate them from the main concept. Therefore, we made these sub concepts as the subclasses in our ontology. Now we will describe some important classes with its sub classes in detail.

(a) **Care Plan:** The beginning point of our Care Plan ontology is to follow a Care Plan for specific disease which helps the chronic disease management by providing step by step recommendations. We have already abstracted these recommendations as Generic Care Plan model presented in chap 4. In order to create the starting point of our ontological model we use the class Care Plan. The instances of this class are the Care Plans for different chronic diseases as shown in figure 22.

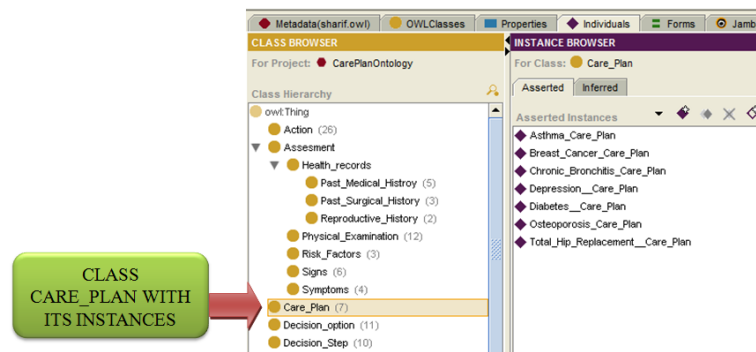


Figure 22 Care Plan Ontology showing Class Care Plan and its Instances

(b) **Assessment:** Assessment in our model provides information about the patient's current and past conditions. It is one of the main concepts and we modeled this concept as a main class. In healthcare, assessment of a chronically ill patient involves a series of steps essential to evaluate the current state of health. As mentioned in Chapter 4, the main concept of assessment is subdivided into sub concepts. We have captured the notion of assessment by making it as a class and in Care Plan Ontology we made these sub concepts as subclasses of assessment in order to capture its various aspects. Figure 23 shows the modelling of assessment in Care Plan Ontology. The main class assessment has 5 subclasses namely (1) *health\_records*, (2) *physical examination*, (3) *risk\_factors*, (4) *signs* and (5) *symptoms*. In order to capture patient information in depth these sub classes are further subdivided. The subclass *health record* has 3 subclasses which are *medical\_history*, *surgical\_history* and *reproductive\_history*. Medical history covers various medical problems, diseases and allergies. The subclass surgical history covers the information about surgical procedure, any complication during the procedure, and the time and date of the procedures. The subclass reproductive history covers the information about the reproductive health of the patients which includes breast feeding, miscarriages, abortions, number of pregnancies and any complications during delivery.

Physical examination of patient includes examination of vitals and non-vitals. Vitals include the information about temperature, blood pressure, respiratory

rate and pulse. The non-vitals are knowledge about the rest of the general physical examination which consists of examination of nails, checking anaemia, thyroid examination, lymph node examination etc. The class physical examination covers both these concepts in Care Plan Ontology

The sub class risk factor is meant to cover those factors that could be a risk for chronic conditions. In medical science, the risk factors are divided into two categories i.e. major and minor.

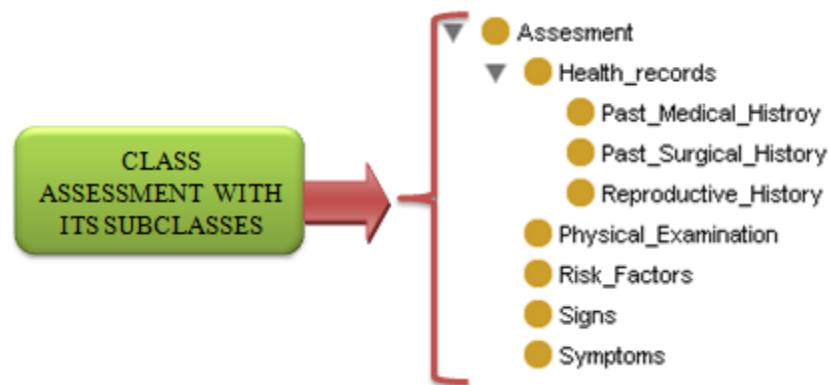


Figure 23 Class Assessment & its subclasses

(c) **Investigation.** Investigations are performed to evaluate the stage of chronic disease so that the best treatment option can be selected accordingly. In our ontology we capture this concept by making investigations as our main class. In real practice the concept of investigation involves several different types of diagnostic tests. In order to achieve granularity the concept of investigation has already been subdivided into sub concepts in chapter 4. These sub concepts helped us during ontology modeling and we had made these sub

concepts as sub classes of investigations in order to cover a range of investigations as shown in figure 24. In the ontological model the class Investigations has 2 children which are *laboratory\_test* and *radiology\_and\_scans* . The first child *laboratory\_test* includes every test that can be performed in laboratory such as blood related tests including CBC, CP, UCE , biopsy , urine, stool and sputum tests. The second child *Radiology\_And\_Scans* covers x-rays, ultrasounds, MRI, CT scans etc. The rationale behind making 2 children of class investigation is to separate laboratory data from radiological data.



Figure 24 Class Investigation with its subclasses

(d) **Decision\_Options and Decision\_Step:** In the generic Care Plan model we identified 2 decision points. Each decision point provides decision options. In order to model the concept of decision making in the ontology we made two classes namely *decision\_options* and *decision\_step*. Decision step captures the decision point and the different options of that step are modeled in the class decision option.

(e) **Route\_Step:** Having a decision step in ontology means having several decision options. To represent several options, the decision step needs to be branched. Once the branching occur it represent several further options. In order to bring these branches to a common point they need to be merged, or if a branch needs to go back to its originating point it forms a loop. The route step of our ontology covers all these concepts with its subclasses e.g. *branch\_step*, *loop\_step* and *synchornization\_step*. In our Care Plan ontology we have modelled the complete concept of route step but during instantiation of Care Plans, only the loop step was used to maintain the cyclic process of care planning.

(f) **Treatment\_Planning:** In chronic care, creating a proper treatment plan is essential concept identified in the Generic Care Plan model. To model this concept into Care Plan ontology, treatment planning is a main class and its subclasses include (1) *treatment\_options* (2) *referral* and (3) *discharge\_planning*. Treatment options are further sub categorized into medical, surgical and lifestyle modifications as already mentioned in chapter 4. Class medical treatment holds two subclasses (1) *drug\_treatment* and (2) *therapies*. These classes capture the instances of prescription, drugs and therapies. Class *surgical\_treatment* will entail the details of major and minor surgical procedures through its subclasses major and minor surgeries. Sometimes the management of chronic illnesses do not require any medicine and can be treated by encouraging a healthier lifestyle. Class *lifestyle\_modification* includes the details for modifications required for the specific

Care Plan. In the management of chronic illness, sometimes there is a need to refer patient to another healthcare provider or to involve multiple health care providers in the management plan. In our Care Plan ontology the subclass *referral* serves this purpose. Class *discharge\_planning* includes details of discharge destination, the treatment plan to be followed in future, responsible persons discharging the patient. This class is mostly used in cases where a patient is admitted in a healthcare facility for the treatment of a chronic illness for example, minor or major surgical procedures. Figure 25 shows the subclasses of treatment planning.

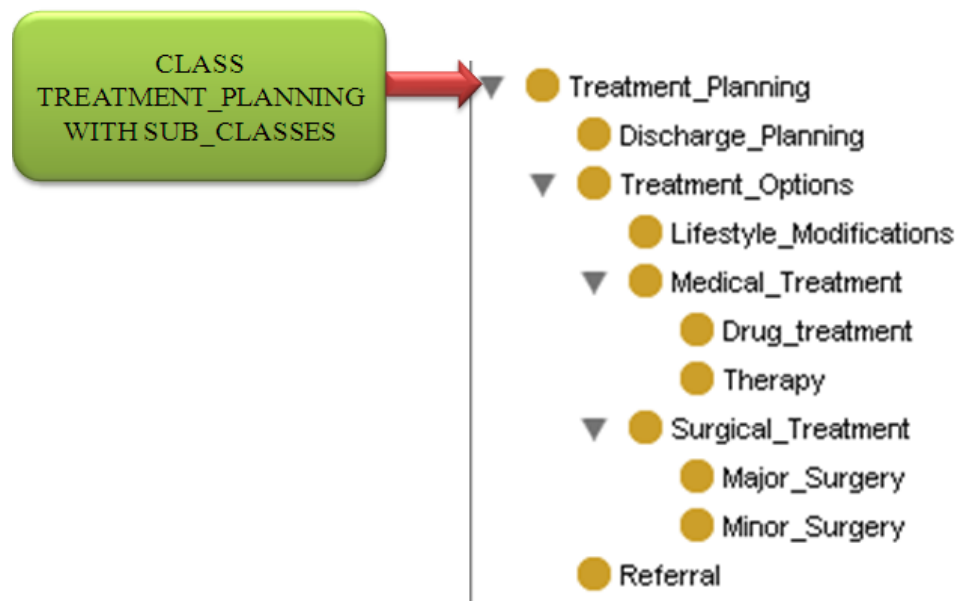


Figure 25 Class Treatment planning with its subclasses

(g) **Patient\_ Education:** An important concept of chronic care is to educate patients about the disease and the self management that could be easily performed by the patient. We modeled these concepts as a class called *patient\_education*. In our generic Care plan model the main concept was

subdivided into 3 sub concepts. While modeling this class, we use the same subdivision of this concept as in generic Care Plan model to develop the subclasses as shown in figure 26.



Figure 26 Class Patient Education with its subclasses

- (h) **Follow Up:** In chronic care management it is recommended to have regular follow up visits in order to track the patient's conditions and the treatment plans outcome. In our ontological model we developed the class *follow\_up* which comes from the Generic Care Plan model. It is important to mention that follow up could be with the same healthcare provider or with referred specialist. These follow ups have different schedules depending upon the current stage of the disease.
- (i) **Role:** Role is an important notion of the chronic disease management team. Involvement of several healthcare providers in the management of a chronically ill patient is common. To capture this wide range of healthcare providers, the concept of role gains the place of a main class in our Care Plan ontology. This range includes physician, surgeon, nurses, therapist, social



worker, radiologist etc. The class role covers these different health care providers.

- (j) **Action:** In healthcare there are several instructions and orders that occur routinely. It is vital to capture this information in ontology so class action was developed to cover this concept. For example, send investigations, perform assessment, perform general physical examination, order X-Ray etc.

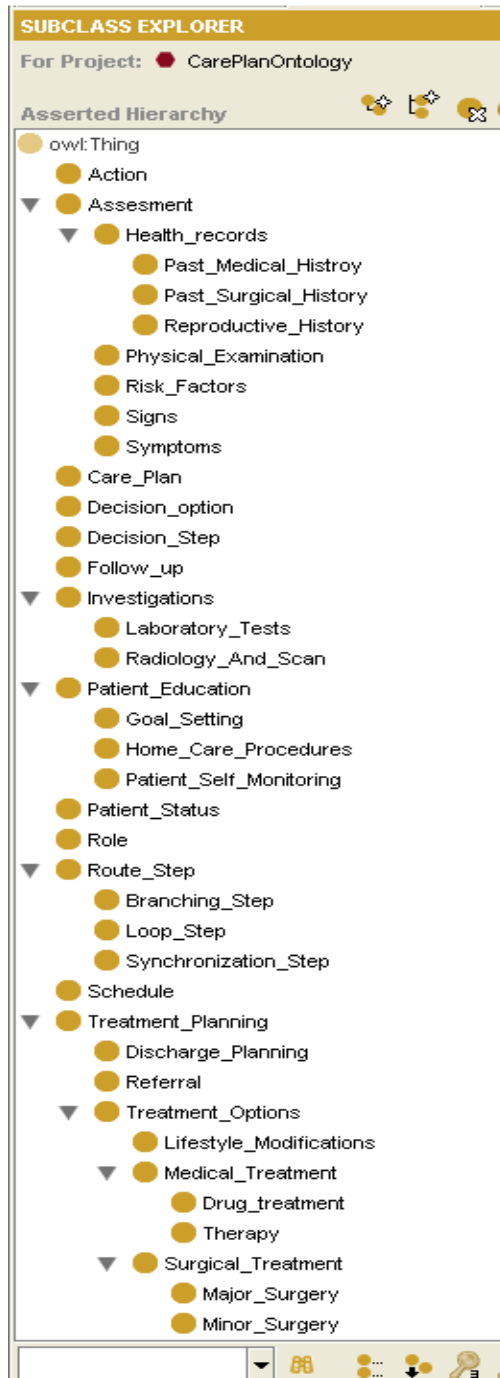


Figure 27 Care Plan ontology classes & sub-classes

The above description of the main classes and subclasses of our Care Plan ontology provides the insight of how we developed the Care Plan ontology from the Generic Care Plan model. Figure 27 shows all the classes and sub classes of our Care Plan ontology. There are 14 main classes and 26 sub classes in the Care Plan ontology. In our Care Plan ontology the connection among the classes was achieved by making properties. There are two main types of properties used in developing the Care Plan ontology (1) object properties and (2) data type properties. In the subsequent sections we will provide a description of properties with some example from the Care Plan ontology.

#### **5.4) RELATIONS AND DATA TYPE PROPERTIES IN CARE PLAN**

**ONTOLOGY:** The Care Plan ontology establishes relations between the different concepts. With the help of object properties we showed relations among different classes and sub classes. With the addition of data type properties we explained in detail individual characteristics of each concept. These properties must have a specific set of range and domain. The range and the domains are the classes and subclasses of the ontology and it is the way to create linkage among the classes of Care Plan ontology. Following tables (8and9) shows the list of object and data type properties with their domain and range. Additionally these tables also states whether the property is functional or not functional. For example, the property *patient\_status* is functional since the patient can have only one status at a time.

Table 8 Object Properties in Care Plan Ontology:

<b>Object Property</b>	<b>Domain</b>	<b>Range</b>	<b>Functional</b>
Assesed_by	Assessment	Role	No
Has_Follow_up	Patient_Status Dischrage_Plannin g	Follow_up	No
Has_Items	Action Conditions Health_records Decision_option	Conditions Risk_Factors Physical_Examin ation Assessment Patient_Education Laboratory_Proce dures Decision_options Planning	No
Has_Major_Risk_Factor	Diagnosed_Contidi on	Risk_Factors	No
Has_Tasks	Conditions Patient_Education	Patient_Education Conditions Assessment	No

		Laboratory_Procedure Planning Decision_option	
Is_Associated_With	Risk_Factors Signs Symptoms Patient_Education	Care_Plan	No
Next_Step	Care_Plan Loop_Step Synchronization_Step Decision_Option Condition	Signs Symptoms Action Risk_Factors Physical_Examination Planning Conditions Decision_option Patient_Education Laboratory_Procedures	No
Roles_Involved	Diagnosed_Condition	Role	No

	Follow_up Patient_Education Discharge_Planning		
Patient_education_material	Patient education Lifestyle modifications	Patient education	No
Performed_by	Investigations Surgical Treatment Home care procedures	Role	No
Ordered_by	Investigations	Role	No
Has_responsible_person	Action	Role	No
Condition_to_go_forward	Synchronization	Conditions	No
Has_patient_status	Treatment planning	Patient status	Yes
Has_Loop_Step	Schedule	Loop_Steep	No
Referred_To	Referral	Role	No

Table 9 Data type Properties in Care Plan Ontology:

<b>Data type properties</b>	<b>Domain</b>	<b>Range</b>	<b>Functional</b>
expected_outcome	Risk_Factors Follow_up	String	No

	Action		
Frequency	Symptoms Home_Care_Procedure	Int	No
Goals	Care-Plans Follow_up	String	No
has_complications	Diagnosed_Condition Past_Surgical_History	String	No
has_discharge_destination	Discharge_planning	String	No
has_schedule	Follow_up Patient_Education Therapy	String	No
expected_length_of_stay	Surgical treatment	String	No
invasive_to_body_cavity	Major surgery	Boolean	Yes
non_invasive_to_body_cavity	Minor surgery	Boolean	Yes
has_preconditions	Decision option	String	No
has_date	Follow up Schedule Treatment planning Action	String	Yes

	Assessment Homecare procedures		
has_indication	Drug treatment	String	No
Has_contraindication	Medical treatment Surgical treatment	String	No
plan_description	Treatment planning	String	No
number_of_pregnancies	Reproductive history	Int	No
surgical_notes	Past surgical history	String	No
Lead_to	Sign Symptoms	string	No
number_of_abortions	Reproductive history	Int	No
references	Care Plan	String	No
wait_time	Investigations	String	No
has_time	Investigations Action Home care procedures Assessment	String	No
patient_id	Health records Patient status Investigations	Int	Yes
has_range	Investigations	Int	No



After the description of classes and properties we will give few examples from our ontology to show how we have used the ontological framework to capture various components of Generic Care Plan model into our Care Plan Ontology. Description of examples with the screen shots from the Care Plan ontology are given below:

- (a) **Assessment:** In the following screen shot figure 28 we show that the starting point of our Care Plan ontology is the class Care Plan and its instances are the Care Plans of a particular disease, in this case asthma. We have started the Care Plan with the object property *first\_step* which specify the action of patient assessment by its instance assess patient. In patient assessment there are four tasks to assess patient in case of asthma. These tasks get their values from the classes signs and symptoms which are the subclasses of assessment. After assessment the Care Plan proceeds further by using object property *next\_step* towards investigations for the evaluation of current stage of chronic disease.

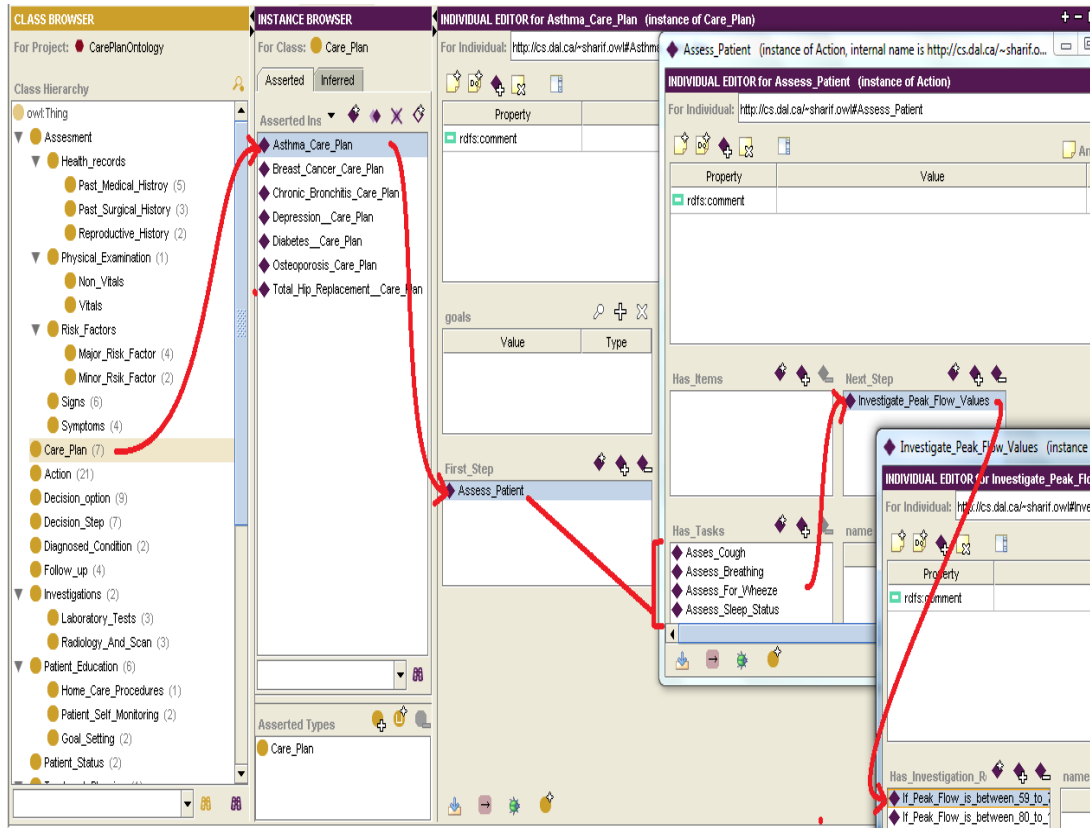


Figure 28 Care Plan for Asthma: Class Assessment and Class Investigation

(b) **Investigations:** In figure 29 we show how the Care Plan ontology captures different types of investigations and treatment options available for breast cancer management. The Care Plan of breast cancer recommends several types of investigations which includes CBC, UCE, Lipid profile, CT scan, X-Ray, MRI. The unique feature of Care Plan ontology is that it captures the class *investigations* with two children i.e. *laboratory\_test* and *radiology\_and\_scan*. The advantage of having 2 subclasses of Investigations is that it enables us to keep laboratory data separate from radiological data. This separation logically helps in gaining data or providing information to and from laboratory and radiology

information systems like PACS. Thus, Care Plan ontology captures CBC, UCE and lipid profile as instances of class *laboratory\_test* while the remaining investigations i.e. CT scan, MRI and X-Ray are modeled as the instances of class *radiology\_and\_scan*.

**(c) Treatment Options:**

Breast cancer Care Plan provides several types of treatment options like medications, mastectomy, chemotherapy and radiotherapy. In the Care Plan ontology these different types of treatment are modeled under the class *treatment\_options*. The options chemotherapy and radiotherapy are captured as instances of class *therapies* which is a child of *medical\_treatment*. The option of medication is captured under the class *drug\_treatment* which is a child of *medical\_treatment* and sister class of *therapies* as shown in figure 29. Similarly the option of modified radical mastectomy MRM is instantiated under the sub class *major\_surgery* which is a child of *surgical\_treatment*.

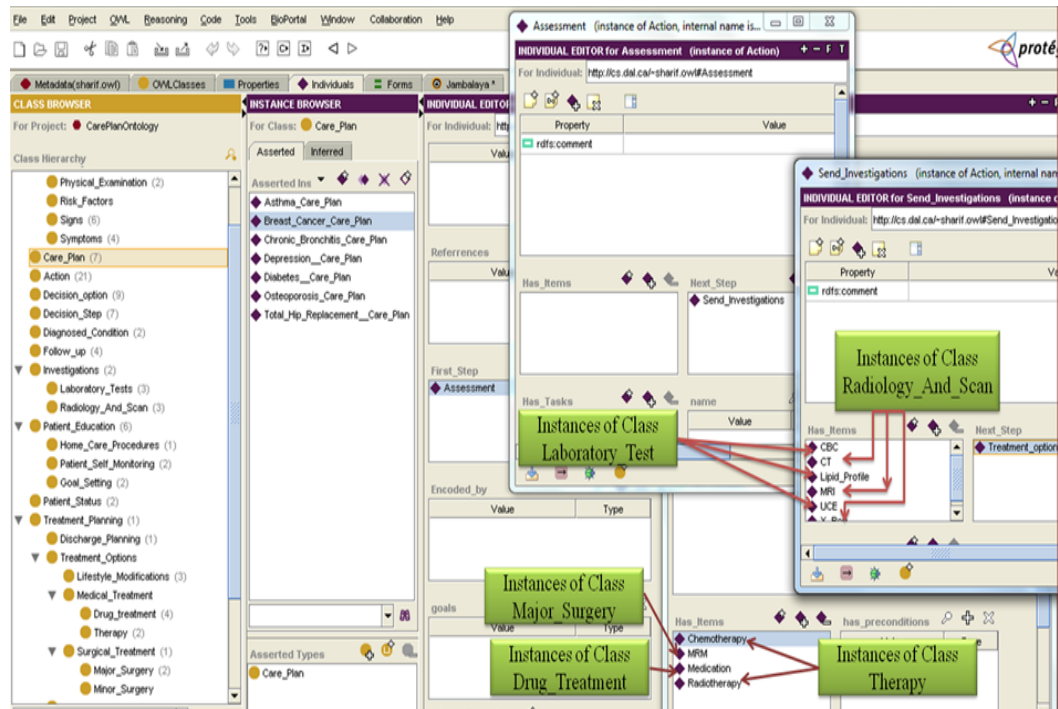


Figure 29 Care Plan for Breast Cancer: Instances of Investigation & Treatment options

The above description of the structure of Care Plan ontology in which we have described the classes, subclasses, properties and instantiation provides an understanding of the ontological framework. In section 5.2 we had mentioned the key elements of the Care Plan ontology along with challenges. In the following section we will address those challenges and present its examples from the Care Plan ontology to show how it overcame those challenges and modeled the elements using its properties.

We addressed the following challenges through the help of relations and data type properties as follows:

- **Capturing patient state:** In case of Asthma, which is a chronic disease affecting airways and breathing, patient can present in any of the three predefined states

called zones i.e. *green zone, yellow zone or red zone*. These states/ zones depend upon the severity of symptoms and the result of a lab test called peak expiratory flow. The treatment plan is different for all three zones as detailed in paper based Care Plan.

In order to capture the three state/ zones of asthma, the paper based Care Plan was instantiated into the Care Plan ontology using instance of classes, and connection are achieved by linking them together using properties. The detail of this is explained below.

To capture the concept of three zones in Asthma, Class *decision\_options* was used. There instances namely *check\_for\_green\_zone, check\_for\_yellow\_zone, check\_for\_red\_zone* were made in order to determine the current patient state. These instances are linked to the instances of class *conditions* using *next\_step* property. The instances of class *decision\_option* specify three ranges of the test peak expiratory flow and the duration of patient symptoms, these three options are

- (1)*If\_peak\_flow\_is\_between\_59\_to\_79\_percent,*
- (2)*If\_peak\_flow\_is\_between\_80\_to\_100\_percent,*
- (3)*If\_symptoms\_of\_yellow\_zone\_persists\_for\_more\_than\_6\_hours.*

Using these options, state of the patient was determined, the test ranges were captured in the class *investigations* and the symptoms were captured in class *symptoms*. Once the state was determined again using *next\_step* property it is connected with the treatment options which are specific for each zone.

- **Capturing flow of activities in the Care Plan ontology:**

1) Sequential flow: The concept of sequential flow is captured by the use of object property *next\_step*. This property helped us in making connections among different classes and to maintain the flow of treatment plan as mentioned in following figure 30.

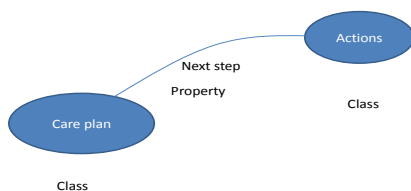


Figure 30 Linkage of two classes

2) Loop step: In order to satisfy looping in the Care Plan ontology we used object property *has\_loop\_step*. For example, to continue cyclic process of care planning as mentioned in the Generic Care Plan model, we used the above mentioned property to connect the class assessment and schedule. This connection helped us in maintaining the longitudinal care process of chronic disease management.

- **Capturing of time:** In our Care Plan ontology, the notion of time is captured through the data type property *has\_date* and *has\_time*.

For example, By setting the domain of above properties as investigations, actions and assessment, and range as string we were able to get the date

and time of each lab procedure and actions taken during the course of treatment.

- **Modeling of drugs:** To provide detail of drugs we created data type properties *has\_name*, *has\_dose*, *has\_schedule*. Furthermore, to avoid any medical emergencies caused by drug-drug interaction, we used data type properties to capture drug indications, contraindications and adverse effects. Data type properties we used are:

*has\_indication, has\_contraindication ,adverse\_effects*

- **Description of roles involved:** In our Care plan ontology, we captured the concept of responsible person by the use of class role and also by using multiple object properties such as:

*assessed\_by, performed\_by,roles\_involved, ordered\_by*

As each event in care planning has a responsible person, we have established a relationship among classes (assessment, investigation, treatment, patient education, and follow up) and role through their properties. For example,

Class assessment is linked to class role through object property *assessed\_by*

Class follow up is linked to class role through object property *roles\_involved*

Class surgical treatment is linked to class role through object property *performed\_by*

Class investigation is linked to class role through object property *ordered\_by*.

- **Capturing list of investigations:** In our Care Plan ontology, we captured the list of investigations by using the object property *has\_items* . This object property connects the class investigation and class action. By using the above mentioned

property, list of investigations required for the management of specific chronic disease can be generated.

- **Patient education material:** Our Care Plan ontology has the main class as *patient education* which is further sub- divided into three sub classes (self monitoring, goal setting and home care procedures) to capture variance of education material mentioned in the Generic Care Plan model. These sub classes will hold instances specific to the Care Plan. We established a relationship between the classes treatment planning and the patient education using the object property *has\_tasks* and *has\_goals*.

For example, treatment plan of diabetic patient include patient education for regular glucose monitoring which is captured as a task for the patient, and goals include maintain HBA1c to less than 7%, Target BMI in ranges of 18.5-24.9.

### **5.5) WORKING EXAMPLE OF DIABETIC CARE PLAN FROM OUR CARE PLAN ONTOLOGY:**

In this section we demonstrate how we captured Diabetic Care Plan in Care Plan ontology. The starting point of our ontology is the class *Care\_plan*, it has all instantiated Care Plan as its instances and *diabetes\_care\_plan* is one of its instance. The Care Plan proceeds with the object property *first\_step* leads to patient assessment. In the assessment of patient assessment of risk factors and general physical examination was done. The Care Plan proceeds further with the object property *next\_step*. In this step investigations were ordered, these investigations include lab tests. The Care Plan moves further by using the object property *next\_step* once again and specify treatment options. These



treatment options come from class *treatment\_planning*, *patient\_education* and also from *referral*. Again using the object property *next\_step* the follow up of the patient is captured. The schedule of follow up comes from the class *schedule*. The class *schedule* has the object property that captures the instance of class *loop\_step* and again starts the Care Plan from assessment. The details of instantiation are illustrated in figure 31. This figure shows how the complete Care plan was instantiated in Care Plan ontology and how different classes and properties have captured the knowledge about diabetes management. Figure 32 shows the screen shot of diabetes care plan instantiation in Care Plan ontology.

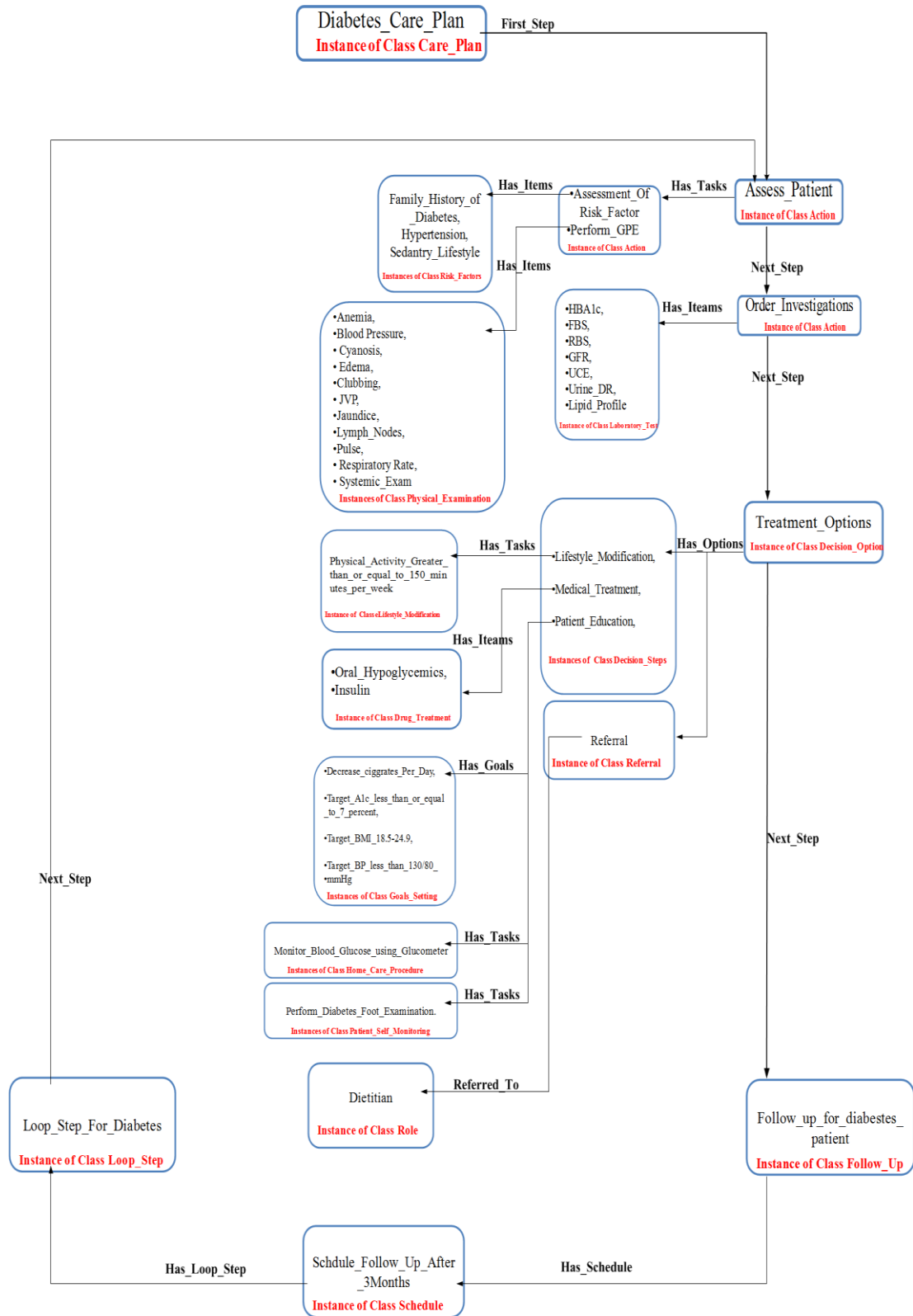


Figure 31 Working Example of Diabetes Care Plan

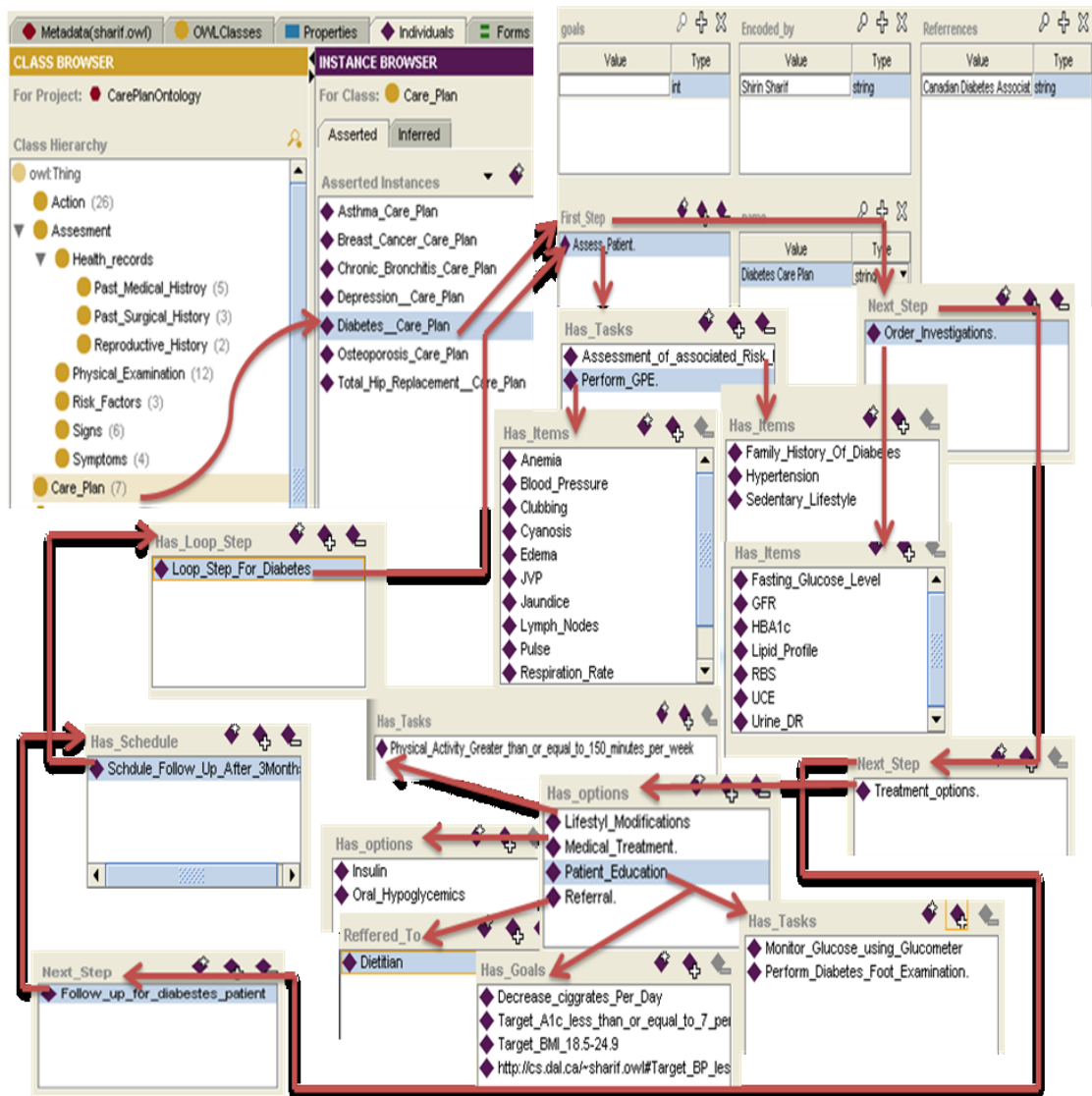


Figure 32 Screen Shot: Working Example of Diabetes Care Plan

**5.6) CONCLUSION:** Our Care Plan ontology represents important concepts and relationships of chronic disease management. Details of the domain are captured through classes, subclasses, and object and data type properties. Concepts are represented as classes and subclasses, and the relationship among classes is established through object properties.

The salient features of the Care Plan ontology include: 1) capturing of sequential flow during the management of chronic illness, 2) date and time of each activity, 3) modeling of drugs and their details, 4) description of healthcare providers involved in the chronic disease management, 5) patient's details and disease status at the time of entry into the healthcare system, 6) patient education material for home care procedures required for the chronic disease management.

Since the Care Plan ontology can capture the patient's detailed information, we can integrate it with an EMR to elaborate our research scope. Our Care Plan ontology also provides information for health records of a specific patient, which can help us in tracking the patient's past medical and surgical conditions.

The next chapter will discuss in detail the evaluation phase of our research.

## CHAPTER 6: CARE PLAN ONTOLOGY EVALUATION

**6.1) INTRODUCTION:** In this chapter we describe the evaluation of our Care Plan ontology in four phases, as noted in chapter 3. These four phases are:

- a) Encoding of three new Care Plans into our ontological model and documenting any problems with instantiation.
- b) Checking the compliance of our ontology against five ontological design principles proposed by Bordnereider [68].
- c) Consistency checking by using pellet reasoner.
- d) Instantiation of patient specific case of chronic disease to ensure that model is capable to handle personalised information and values.

We choose samples of three new paper based Care Plan templates for chronic diseases. The selection was done to cover a wide range of chronic diseases. After abstracting the concepts from the paper based Care Plan templates we generated one Care Plan for each of three chronic diseases. The chronic diseases we selected for evaluation include depression, hip replacement surgery due to chronic arthritis and chronic bronchitis. The first two were selected especially because they were from psychiatric and surgical domains which were not covered during the development phase. We selected these different domains in order to evaluate the richness of our Care Plan ontology and also to figure out the limitations of our work and possible future extensions of our research. Aside from this, our selection criteria was also based on the review of the major utilization of the healthcare services by chronic diseases in Canada as explained earlier in chapter 2.

In the following section, we will describe the concepts encoded for each Care Plan of chronic disease, with the class name of our Care Plan ontology to which these concepts were mapped. For each Care Plan we have given overview for the Care Plan objective, the specific disease for which that particular Care Plan was generated, patient state for treatment plan, Care Plan recommendations and follow-up procedures.

### **6.1) CARE PLAN FOR DEPRESSION:**

Depression is a psychiatric disorder; the reason for selection of this Care Plan [37, 70] is the difference in the management process of this disease from other chronic conditions. The diagnosis of depression mainly depends upon the symptoms and patient's history unlike other chronic diseases where investigations play vital role in diagnosis. Secondly, the treatment process of most chronic diseases involves multiple drugs and medications, while the management of depression involves fewer medications and emphasizes more on behavioural and other psychiatric therapies. The salient aspects of the paper based Care Plan for managing depression are as follows:

- a) Care Plan objective:** This particular Care Plan is intended to serve as a guide to physician and patient in managing depression.
- b) Targeted disease:** The particular disease for which Care Plan is generated is Depression which is one of the common chronic illnesses.
- c) Patient state:** Based on assessment of patient's history and symptoms, patient state is decided, which could be mild, moderate or severely depressed.
- d) Treatment plan:** Include possible treatment options depending on patient's choice availability and the severity of the disease.

- e) **Recommendations and follow-up procedures:** It includes recommendations advised for the proper management of depression which include supervised exercise, sleep and anxiety management, guided self-help psychological interventions, group psycho education, and social intervention. Follow up is recommended starting from 2 weeks to 12 weeks.
- f) **Care Plan summary:** This Care Plan helps in managing patients who have been diagnosed with the condition of depression which could be mild, moderate or severe. It starts with the outcome of patient's assessment and the treatment plan is generated in collaboration with the patients' wishes, and follow up is advised ranging from 2-12 weeks.

**6.1.1) Instantiation of Care Plan for Depression in Care Plan Ontology:** The main purpose of the instantiation of this Care Plan is to evaluate the richness of our ontological framework against this Care Plan. The instantiation also displayed how the ontology has captured the knowledge about depression in its classes using properties. The beginning of the care is through the assessment of patient for symptoms and assessment of patient history. The symptoms of the patient's include *iredness*, *aches\_and\_pains*, *poor\_sleep*, *weight\_and\_apetite\_change* and *poor\_concentration* were captured as the instances of class *symptoms*. The elements of patient's history e.g. *social\_dysfunction*, *drug\_or\_alcohol\_use*, *relationship\_failure*, *anger\_or\_aggressive\_behaviour*, *bonding\_difficulties* were encoded in the class *past\_medical\_history*. There are no particular investigations in this Care Plan.

Next we will highlight how different treatment options were instantiated in the Care Plan ontology. The treatment of depression is more inclined towards the use of different types of therapies and lifestyle modifications and patient education. We have captured this treatment plan in our ontology by using different sub\_classes of Treatment\_Planning and Patient\_Education e.g.

- *Antidepressant* is the instance of class *drug\_treatment*.
- *Couple\_focus\_therapy* is the instance of class *therapy*.
- *Focus\_brief\_psychological\_therapies* is the instance of class *therapy*.
- *Social\_therapy* is the instance of class *therapy*
- *Introduction\_of\_supervised\_exercises* is the instance of class *lifestyle\_modification*
- *Sleep\_and\_anxiety\_education\_according\_to\_NICE\_guideline\_for\_anxiety* is the instance of class *patient\_education*.

Figure 33 shows the instantiation of treatment options in the Care Plan ontology. The chosen Care Plan for depression also specifies the diagnostic process for depression. It describes three diagnostic stages of depression which are mild, moderate and severe depression. These stages of diagnosis depend on the number of symptoms in a patient. As our Care Plan ontology is for the management of chronic disease, it does capture the patient symptoms, patient history and treatment options but does not provide the details for the diagnostic process.



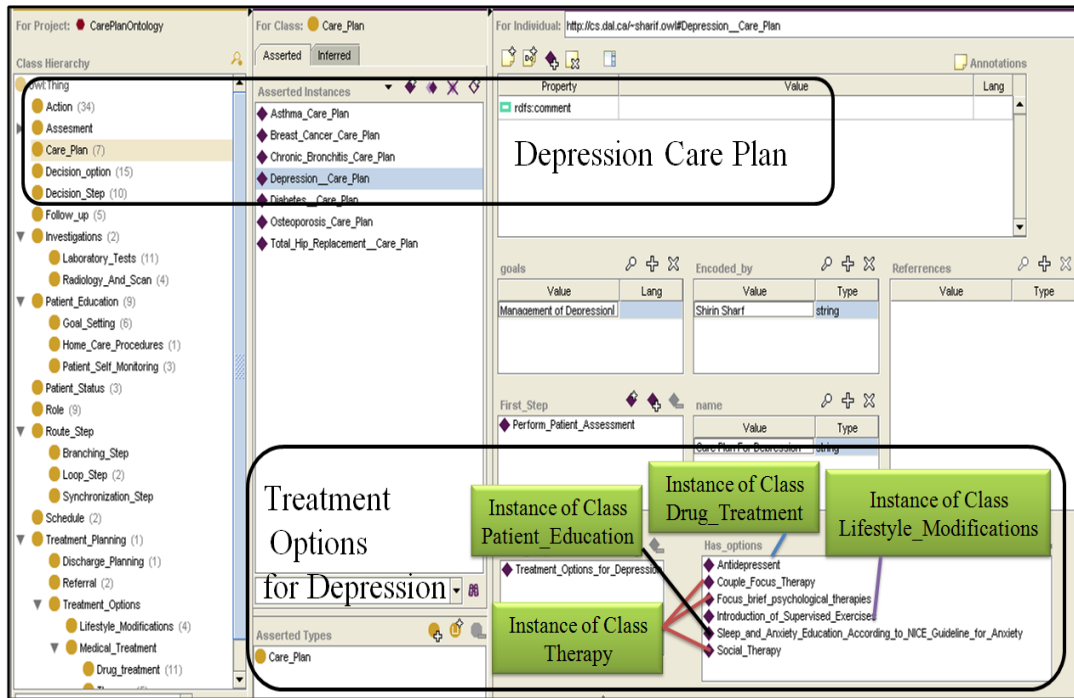


Figure 33 Instantiation of Care Plan for Depression

## 6.2) CARE PLAN FOR CHRONIC BRONCHITIS:

- a) **Care Plan objective:** This particular Care Plan is intended to serve as a guide to physicians and patients in managing chronic bronchitis.
- b) **Targeted disease:** The particular disease for which the Care Plan is generated is chronic bronchitis, which is one of the common chronic illnesses as mentioned earlier in chapter 2.
- c) **Patient state:** Usually patients get chronic bronchitis together with a lung infection like pneumonia, for which they need treatment in hospital until infection is clear.

**d) Treatment plan:** Starts with day one of admission and continues until day four which is possibly a discharge day. Each day has specific plans for the patient including tests, physical activity, diet plan, and medication details.

**e) Recommendations and follow-up procedures:** It includes the teaching and discharge planning part of the plan. The patient will be taught about post hospital procedures for example, how to take deep breaths, self control of infections and coughing exercises. No specific time period is mentioned in follow up, it depends on patient condition. Patients are also advised to see a doctor if their condition worsens and is not under control.

**f) Care Plan Summary:** This Care Plan helps patient suffering from chronic bronchitis. It covers in-hospital and post-hospital instructions in detail. Patients are advised of their self management during the stay in hospital and also after he/she is discharged from the healthcare facility.

**6.2.1) Instantiation of Care Plan for Chronic Bronchitis in Care Plan Ontology:** The Care Plan of chronic bronchitis starts with the object property *first\_step* which specifies the action- *assessment\_of\_patient\_with\_chronic\_bronchitis*. In this action three tasks are performed which are assessment of cough, assessment for breathlessness and assessment of wheeze. The Care Plan proceeds further using the object property *next\_step* which recommend another action i.e. *send\_investigations*. The recommended investigations were captured using object property *has\_items* and these investigations are *chest X-Ray*, *WBC count* and *sputum sample*. This Care Plan suggests admitting the patient for treatment; this was captured by using class *patient\_status* and its instance *admission\_of\_patient\_with\_chronic\_bronchitis*. By using class *decision\_options*, a list of

treatment options and medical actions were given to the healthcare provider with the help of object properties *has\_options* and *has\_items*. The treatment options include antibiotic, antipyretic, analgesic and oxygen therapy while the actions include *ascultate\_chest*, *check\_oxygen\_level* and *check\_TPR*. In addition to these treatment options the next step of the Care Plan is to provide patient education. Various tasks of patient education include

*advice\_breable\_physical\_activities*, *educate\_patient\_for\_deep\_breathing\_and\_coughexercise*, *encourage\_fluid\_intake*, *self\_control\_of\_infections*. After providing treatment and patient education material it is important to monitor the condition of the patient to see if the treatment plan is working or not working. The two options were captured using the class *decision\_option*. If the patient's condition improves the discharge planning was done by using the class *discharge\_planning*. Follow up of the patient is captured through the class *follow\_up* and the schedule of the follow up comes from the class *Schedule*. In the follow up there is a need to perform the patient assessment once again, so the class *loop\_step* helps in completing the cyclic process of the Care Plan and again re-enter the patient into assessment. The other option, if the patient's condition worsens then there is an immediate need to re-assess the patient, and *loop\_step* helps in completing the cyclic process. The details of the complete instantiation of this Care Plan in Care Plan ontology is illustrated in figure 34.

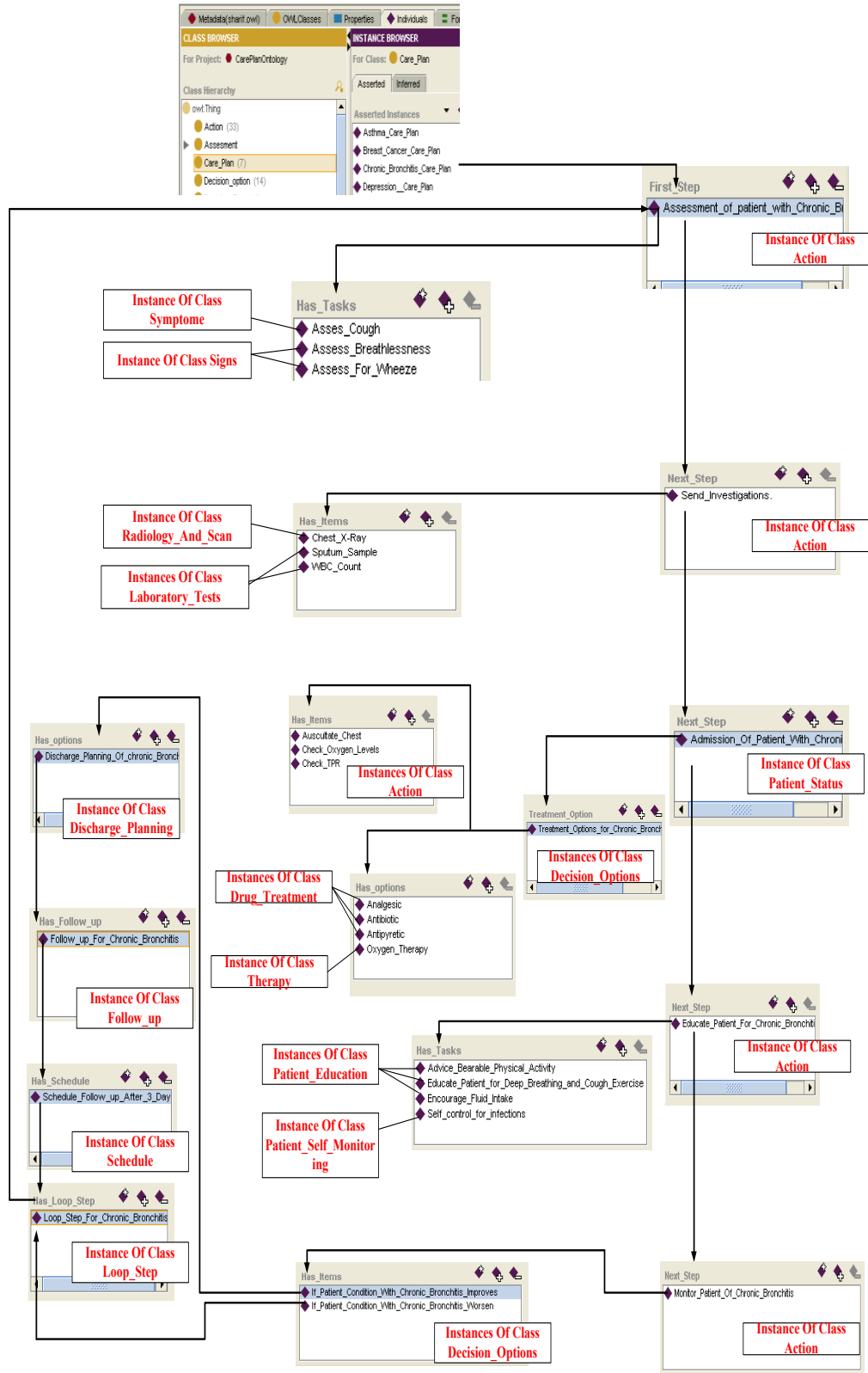


Figure 34 Instantiation of Chronic Bronchitis Care Plan into Care Plan ontology

**6.3) CARE PLAN FOR TOTAL HIP REPLACEMENT:** In an effort to capture the surgical interventions involved in the management of chronic disease, we selected the Care Plan for total hip replacement surgery [37, 69]. Patient is admitted in the hospital for surgery and our Care Plan ontology captures this as patient state *in-patient*. Some of the important and salient features of this particular Care Plan are:

- It requires patient to be admitted in the hospital for surgery rather than treating patient as an out-patient as in most chronic diseases.
- Investigations are done to see if the patient is medically fit to pass through the major surgical procedure.
- Pre-operative orders are given to prepare the patient for surgical procedure.
- Patient consent is an important aspect before taking the patient for surgery.
- It is very important to inform the patient about post-operative complications.
- Post-operative orders include continuous monitoring of the vital signs of the patient, in order to avoid any emergency situations.
- Involvement of multiple healthcare providers who perform specific actions during the surgical procedure. For example, surgeon, anaesthetists, nurse etc.

An overview of the Care Plan is mentioned as follows:

**a) Care Plan objective:** This particular Care Plan is intended to serve as a guide to the physician managing the patient having surgery for hip replacement, and also includes post op advice for patients to improve outcomes.

**b) Targeted disease:** The Care Plan was basically generated to target patients having surgery for hip replacement, where the underlying disease (cause) could be osteoarthritis, rheumatoid or traumatic arthritis.

**c) Patient state:** In-patient because they are admitted for surgery and stay in the hospital for seven days of post-op.

**d) Treatment plan:** Starting from the day of the surgery the treatment plan includes laboratory tests, mobility assessment, nutrition, medication and the expected outcome for each day. This plan is to follow until the patient is discharged, which in most cases is post op day 7.

**e) Expected discharge outcome:** Patient is discharged if vital signs are stable and there is no skin impairment, no evidence of infection and no neurovascular insults.

**e) Recommendations and follow-up procedures:** Include discharge instructions which include wound management, certain blood tests, taking pain management medications and reporting to their doctor if their condition worsens or symptoms recur. Follow up appointments may be with a surgeon, family physician, orthopaedic clinic or physiotherapist.

**g) Care Plan Summary:** This Care Plan starts from the patient's pre-admission consultation where assessment and all investigations required for surgery are

done. Then each day has a list of tasks starting from day 1 of surgery and continues until the day of discharge. Finally, the healthcare provider gives teaching and discharge planning in detail with expected patient outcome.

### **6.3.1) Instantiation of Total Hip replacement Care Plan into Care Plan ontology:**

We were able to encode this Care Plan successfully into our ontological model. An example from the Care Plan ontology is shown in figure 35. We especially found that the class action very useful as the Care Plan provides several actions involved in the surgical procedure. We were able to capture the pre-operative and post-operative notes through the class action figure 35. Admission of patient was captured through the class patient status.

However, our Care Plan ontology was not able to capture the patient's fitness before surgical procedure. Although we believed that it is an important concept in surgical plans, as patients are only taken for surgery if they are medically fit, at this point we were not able to capture patient-specific information such as patient fitness based on the results of the investigation. However, at this point we can encode such information using the attribute *plan\_description* in the class surgery.

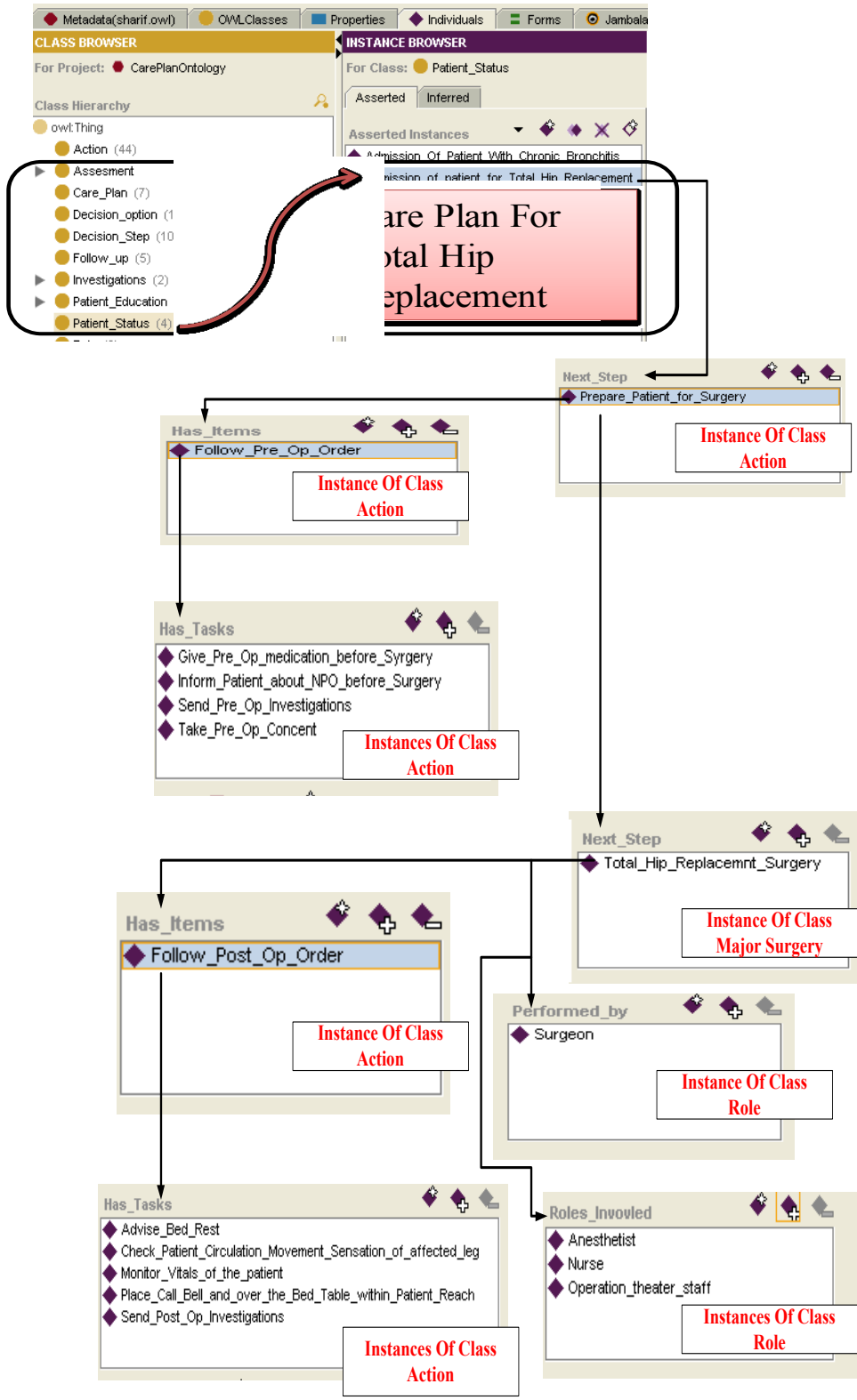


Figure 35 Instantiation of Care Plan for Total Hip Replacement Surgery



**(c) Third phase of ontology evaluation:** In the first phase of ontology evaluation we have successfully instantiated three Care Plans into the Care Plan ontology, these Care Plan were disease specific i.e. contain the knowledge about chronic disease but lack patient specific information. In an effort to evaluate CP ontology for handling patient specific information a test case of chronic disease has been instantiated. This test case is developed by using the author's medical knowledge and chronic disease related data which is mentioned below. In the subsequent section we discuss in detail the instantiation of this test case into CP Ontology

**Test Case:** Patient with diabetes for the past 2 years complains of increased fasting blood sugar levels for past 2 months. Her results of investigations are, FBS as 140mg/dl and HbA1c as 7.2. On examination by physician her GPE results are: BP 130/80mmHg, Pulse 84, Temp 98.6, R/R 16. There were no signs of anaemia, jaundice, cyanosis or palpable lymph nodes. She is currently taking oral hypoglycaemic (Metformin) with a dose of 500mg BD. The medical records show irregular control of sugar levels in the past three months. What would be the changes in the treatment plan for this specific patient?

#### **6.4) Instantiation of test case into CP Ontology**

The instantiation starts by using class *Care\_plan* and its instance *patient\_with\_diabetes*. The Care Plan begins with the first step *assessment\_of\_patient\_with\_diabetes* which is the instance of class *action*. In this case the physician should perform the general physical examination and acquire the medical history of the patient in order to capture this detail in CP ontology. *Assessment\_of\_patient\_with\_diabetes* specifies 2 tasks which are *assessment\_of\_GPE* which is the instance of class *physical\_examination* and

*assessment\_of\_medical\_history* which is the instance of class *past\_medical\_history*. The first task i.e. *assessment\_of\_GPE* has eight items. The results of four items i.e. *anemia\_assessment*, *cyanosis\_assessment*, *jaundice\_assessment* and *lymphnode\_assessment* were captured by using data type property *has\_value*. The assessment was performed by a physician so the object property *assessed\_by* is used and the value *physician* is used from the class *role*. The other four items i.e. *blood\_pressure\_assessment*, *pulse\_assessment*, *respiratory\_rate\_assessment* and *temperature\_assessment* are the assessment of vital sign. CP ontology not only captured the values and the involved role by using the attributes *has\_value* and *assessed\_by* but it also provides the normal ranges for vital signs through the data type property *has\_range*. For example, in this test case the value of pulse examination was given as 84/min this was captured by using data type property *has\_value*. Our CP Ontology also provides the normal range of pulse examination which is 60-90/min; this range is according to American Diabetic Association. The pulse examination was performed by physician so the object property *assessed\_by* is used which gets its value as *physician* from the instances of Class *role*. Figure 36 shows the instantiation of assessment in CP Ontology.

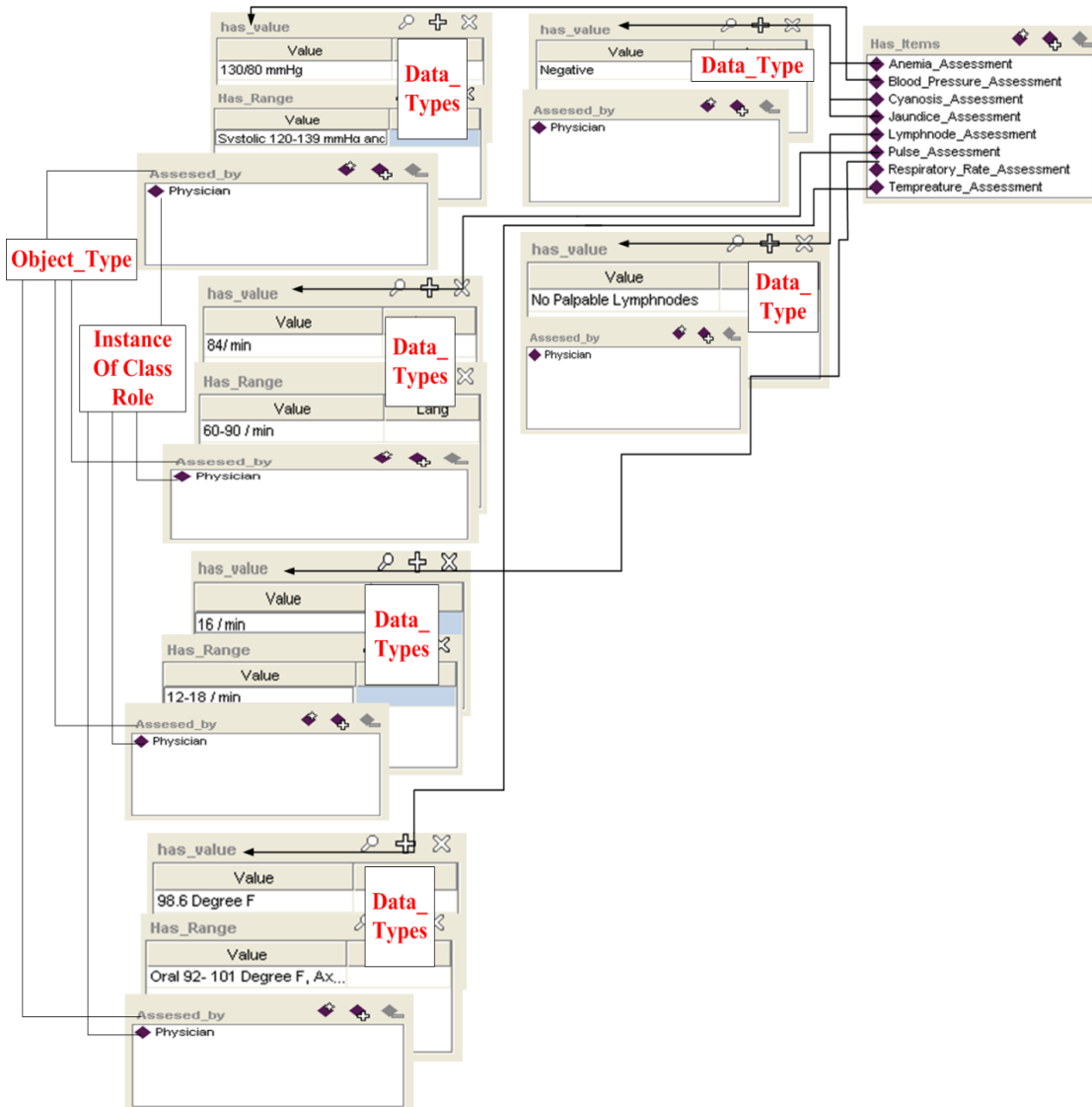


Figure 36 Instantiation of patient specific Assessment of Diabetic Patient in CP Ontology

After assessment the next phase of the test case was to capture the investigations of the diabetic patient. This is done by using the object property *next\_step* which specifies *investigation\_of\_diabetic\_Patient* which has two items which are *FBS\_of\_diabetic\_patient* and *HbA1c\_of\_diabetic\_patient*. These items are the instances of class *laboratory\_test*. The value 140mg/dl which is the result of FBS was captured by using *data\_type* property *Has\_result*. CP ontology also provides the data type property

*has\_range* to specify the normal ranges of test results. CP ontology also captures the information about the role who orders the investigation by using the object property *ordered\_by* which gets its value *aspPhysician* from the instances of class *role*. Figure 37 illustrate the instantiation of investigations.

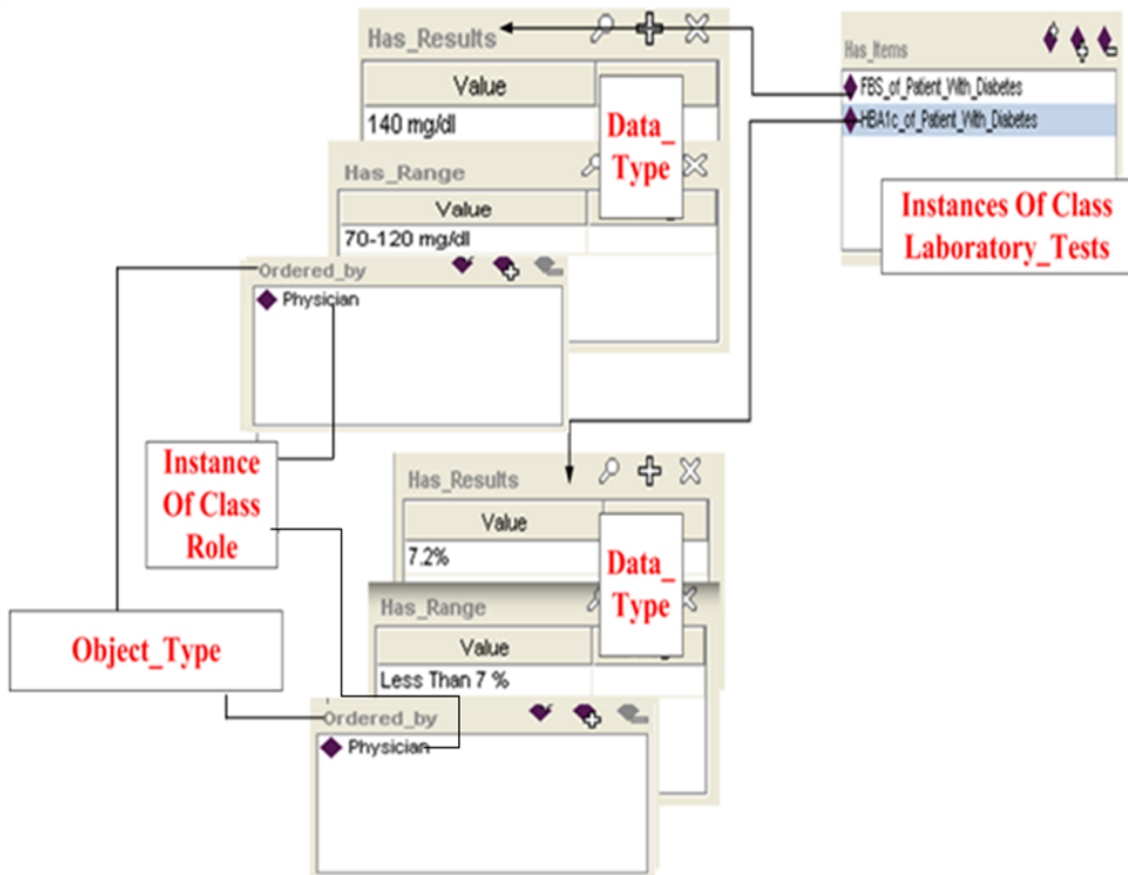


Figure 37 Instantiation of patient specific Investigations in CP Ontology

After investigations the treatment of the patient is captured by using the object property *next\_step* which specifies the treatment options as *treatment\_option\_of\_patient\_with\_diabetes*. In the test case several treatment options were prescribed. We have sorted these options into drugs, patient education material and

life style modifications. The patient was advised to use Losartan 25 mg twice daily and Metformin 500mg twice daily and these drugs were captured using class *drug\_treatment* as instances *anti\_hypertensive* and *oral\_hypoglycemics*. The detail of drug information is captured by data type properties *has\_name* specifies the drug name i.e. Losartan or Metformin. The data type property *has\_dose* capture the drug dosage like 25 mg BD or 500mg BD. Patient was advised to perform physical activity and this is captured as the instance *physical\_activity\_greater\_than\_or\_equal\_to\_150min\_per\_week* which is the instance of class *lifestyle\_modification*. After treatment options the next step is to provide patient education, which is captured using the *next\_step* which specifies the action *educate\_patient\_of\_diabetes*. The patient education material is captured using two classes *patient\_self\_monitoring* and *home\_based\_procedure*. The foot and nail examination is captured as instances of class *Patient\_Self\_Monitoring* and monitoring blood glucose level is captured as the instances of class *home\_based\_procedure*. After providing the treatment, patient is advised follow up after 1 month for reassessment. In CP ontology this information is captured by using the instances of class *follow\_up* and *schedule*. *follow\_up\_of\_patient\_with\_diabetes* is the instance of class *follow\_up* and *schedule\_of\_patient\_with\_diabetes\_after\_30\_days* is the instance of class *schedule*. The instance *loop\_step\_of\_patient\_with\_diabetes* (instance of class *loop\_Step* ) is used to perform assessment at the time of follow up. The instantiation of the test case is shown in figure 38.

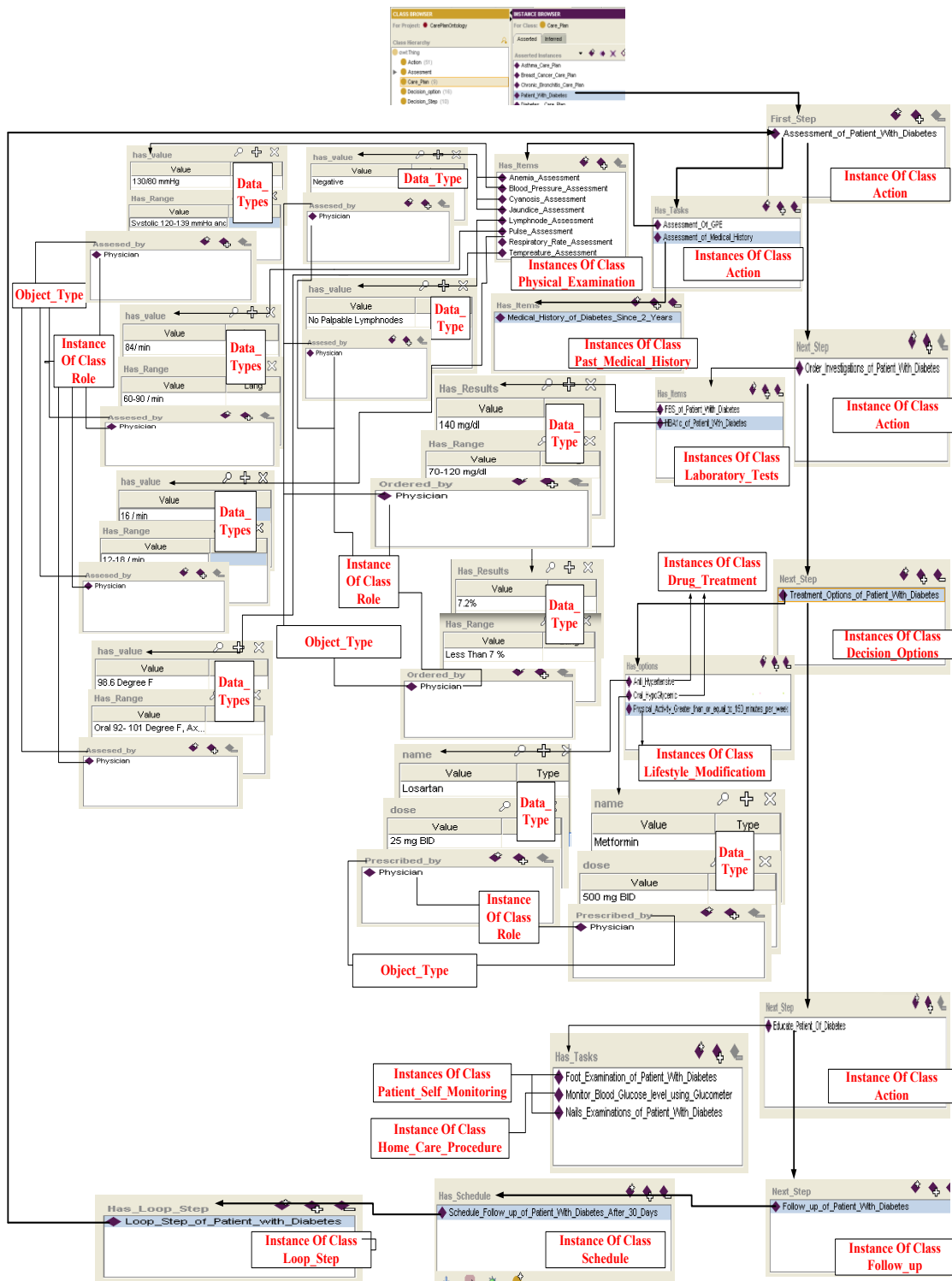


Figure 38 Instantiation of Patient Specific Test Case of Diabetes in CP Ontology

**(d) Fourth phase of ontology evaluation:** Ontology evaluation for consistency checking was through reasoner Pellet. In order to ensure that the CP ontology is consistent and coherent i.e. there is no conflict among classes and ontological framework, we have used Pellet reasoner.

**6.5) EVALUATION RESULTS:** We have evaluated our Care Plan ontology in four phases:

**(a) First phase of ontology evaluation:** Encoding the above mentioned Care Plans into ontological model was successful except for some elements that were not encoded into the ontological model as mentioned in earlier sections. We, therefore evaluate that our Care Plan ontology is the comprehensive model for the representation of general Care Planning process involved in the chronic disease management. The elements which we were not able to encode are:

- 1) Assurance of patient fitness before the surgical procedure
- 2) Capturing the process of establishing clinical diagnosis of a chronic condition using a preset criterion of condition as mentioned in the care plan template of depression

The aim was to provide a model which could represent the activities involved in the management of already diagnosed chronic condition. Therefore, we conclude that capturing the above mentioned elements were beyond the scope of our research, but we

offer possible alternatives for representing such concepts by using the data type attributes of our care plan ontology.

**(b) Second phase of ontology evaluation:** We also evaluated our ontology against the five ontological design principles given by Bordenerider *et al* [68]:

- 1) Each hierarchy must have a single root.
- 2) Children should have exactly one parent.
- 3) Non-leaf classes should have at least two children.
- 4) Each child's description must differ from its parent's description.
- 5) Children inherit the properties of their parent classes and every instance of a child also is an instance of its parent.

The second phase evaluation was done manually. We assessed the compliance of the above principles with the classes, properties and instances of our care plan ontology. We found that our care plan ontology is compliant with the proposed ontological principles. Although compliance with these ontological principles does not guarantee the full soundness of the ontology but it is believed by the authors of [68] that it guarantees the precision of reasoning. Therefore, we conclude that our ontological model is sound enough to perform efficient reasoning using suitable reasoners.

**(c) Third phase of ontology evaluation:** We had successfully instantiated the test case of diabetic patient into our care plan ontology. Therefore, we conclude that our care plan ontology can capture the patient specific data and can be adapted for personalized care planning.



**(d) Fourth phase of ontology evaluation:** The results of the consistency test by running the pellet reasoner were satisfactory as there was no inconsistency found, which showed that the ontological framework of CP Ontology is consistent.

## CHAPTER 7: CONCLUSION

In this chapter we discuss the achievements and limitations of our work as well as future directions.

### 7.1) ACHIEVEMENTS:

The main goal of our research was to develop a high level knowledge based model which can represent the form and functions of the care planning process for chronic disease management. As mentioned earlier that key stages of the care plan model involve assessment treatment plan and follow up as given by the NHS [13] these key stages are mentioned in chapter 2 (section 2.3.1).. Taking that as a primitive model we studied in depth the care planning process for different chronic diseases. The key activities of care planning given in chapter 2 were decomposed further to explain in detail each step of care planning process. It is important to note that those key stages serve as the starting point of model development. By using the main concepts i.e. assessment, treatment and follow up, we developed the primitive model. In our model we have elaborated on these concepts in detail to provide a comprehensive model that can support longitudinal care for chronic disease. The model expansion begins with the decomposition of the first concept, assessment. In the primitive model there were no guidelines for patient assessment, but after a through literature review we identified patient assessment through GPE, the assessment of health records and assessment of risk factors as very important concepts in chronic disease management. Each of these concepts was then divided into tasks and activities. Similarly, the evaluation of patient state also requires investigation, so our model decomposes the concepts of investigation into several important and essential sub concepts. The concepts of *development of care plan*, *delivery of care* and

*review* presented in crude form advise the development of a care plan but do not provide the process of care planning. On the other hand, our generic care plan model specifies each activity involved in these concepts in detail. The delivery of care is thoroughly captured in hospital, which requires patient admission; patient monitoring and depending upon patient condition specifies either discharge or reconsultation. In case of outpatient treatment the generic care plan model provides different treatment options available for outpatient treatment. In our model, the review of the patient could be done through reconsultation if the patient is admitted but in case of an outpatient, the review occurs through regular follow-up of the patient. The key stages lack the concepts of referral and patient education; we incorporated these concepts into our model. Through the concept of referral we capture the notion of health care team consisting of multiple health care providers. Patient education, besides providing the EBM recommendations and self management, enables the patient to become more aware of their disease condition and develop a sense of responsibility. This helps in taking control of their illnesses so it captures the notion of patient centeredness. Thus, from only three essential concepts, we formulated a comprehensive care plan model that covers almost every essential aspect of chronic disease management. By decomposing existing concepts and incorporating new ones this generic Care plan model will provide the sequential flow of activities and recommendations for the specific action involved in care planning process. In previous chapters we have discussed in detail the development of such a generic Care Plan model, representation of our generic Care Plan model in the form of Care Plan ontology and evaluation results of the model. This ontological framework provides a platform for computerization of Care Plan templates for various chronic diseases.

We anticipate that our Care plan ontology will be used for developing personalized care plans, based on the patient information stored in the EMR. Our Care plan ontology will help in identifying the key elements and activities required in the management of chronic disease. Therefore, our care plan ontology can act as a vital part in generating personalized care plans required for improved clinical outcomes and in maintaining the longitudinal care process in chronic disease management

We believe that we have successfully achieved the intended goals of this thesis as mentioned in chapter one. These goals are:

1. **Generic Care plan Knowledge Model:** Our generic care plan model provides sequential flow of activities involved in the management of chronic disease. It provides specification of tasks and their associated roles involved in the clinical process. Care planning is a cyclic process which starts from assessment and follows the set of activities involved in the process of chronic care. This formal model can be used in future for developing decision support systems since it provide a standardized care planning template. Although the knowledge represented in the care plan model is not new for the healthcare professional, the list of tasks involved in each step would help in providing decision support.
2. **Care Plan Ontology:** The main purpose of our generic care plan model is to use it for computerization of paper based care plans. Care plan ontology provides general recommendations for each step of chronic disease management. An integrated decision support system connecting EMR, Care plan ontology and CPG ontology can provide patient specific information at the time of healthcare

encounter. We anticipate that our generic Care plan ontological model will serve as a knowledge model and can be adapted in future for personalized care planning.

3. **Computerization of paper based care plans:** We have encoded a set of care plans for seven chronic diseases. These chronic diseases were selected to cover different domains for example: medical, surgical, oncological, psychiatric & musculoskeletal disorders. Our Care plan ontology provides step wise recommendations abstracted from these paper based care plans. These recommendations provide multiple options for each specific task, and based on these, the healthcare provider will choose the best treatment option for a particular patient based on assessment and investigation results.

**7.2) LIMITATIONS:** During the research work, we encountered some situations which limit to some extent, the use of our care plan ontology.

**1) Representation of co-morbidities:** Co-morbid conditions are particularly important because many patient's present with multiple chronic conditions. Our Care plan ontology has no mechanism to capture the concept of co-morbidities. This limits the use of our care plan ontology for patients presenting with multiple chronic diseases.

**2) Personalized care plans:** Our care plan ontology represents the process of general care planning for chronic diseases and at the same time it captures the notion of personalized care planning to a limited extent through the data type properties. We are not able to generate patient specific plans at this point because personalized care plans require information from two sources which are (1) patient specific information stored in

the electronic medical records and (2) disease specific knowledge from care plans. Our model currently consists of only the second of these sources.

### **7.3) FUTURE DIRECTIONS**

**1) Integration with EMR, CP and CPG ontologies:** The purpose of our care plan ontology is to integrate it with other healthcare ontologies like CP, CPG and EMR. This ensures the availability of evidence based knowledge along with healthcare data to the healthcare provider at the point of care. This could result in better management of chronic illnesses and improved patient satisfaction.

**2) Generation of personalized care plans:** Integration with EMR can help us in generating patient specific plans which can be available at the point of care. This integration can provide easy access decision support for healthcare providers and also a copy of a personalized plan can be issued to the patient so that they can take better care of their long term conditions on their own This in turn will decrease the number of costly unscheduled visits to the hospital.

**2) Model refinement:** Although we were able to instantiate our test care plans into our ontological model with some limitations, it is possible that the set of care plans which we have used does not cover all aspects of care planning for long-term care used in real life practice. Model refinement could be achieved with continuous evaluation and maintenance as also mentioned by methontology authors [1].One possible solution is to have further instantiation of care plans covering different domains of healthcare.

**3) Execution engine:** Our care plan ontology can be tested for its true potential, once an execution engine is developed. The execution engine will help in interpreting all the evidence based information stored for a specific chronic disease.

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