A Generic Framework for Providing Psychosocial Support to Patients
through an Online Virtual World

By

Swapnil Mahajan

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To my parents & my little sister, for their love and support.

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Abstract

Virtual worlds have been used in the medical domain for providing social, psychological, educational support to patients with chronic and serious diseases. Semantic Web features including structured type systems (i.e. ontologies) and rule-driven execution have been used effectively in the past to help patients make informed decisions about how to manage their own care. In this thesis, we present an extensible framework using an open source virtual world platform called 'OpenWonderland' and a Semantic Web reasoning engine, designed to facilitate supportive online communities for patients. We also present a prototype implementation called YouCan World for providing psychosocial support for patients. Using data from previous research data, we populated our reasoning engine with treatments, interests, and other information about a small set of personas we created. Finally, we report the results from a focus group evaluation, major recommendations were related to privacy & security concerns, addition of new features and improvements.

LIST OF ABBREVIATIONS USED

YouCan World   Youth Cancer World

SWRL   Semantic Web Rule Language

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CHAPTER 1. INTRODUCTION

A virtual world is a 3-D environment in which the individual can immerse him/herself and interact with meaningful objects for work, entertainment and education. *Online* virtual worlds allow people to connect via the virtual world from different locations. They have been predominantly used in gaming, but may provide an interesting alternative to face-to-face encounters between patients and care providers. Healthcare environments are at times perceived as 'cold', and health care encounters within these environments are perceived as 'uncomfortable' in some clinical situations. Young patients on the one hand are particularly sensitive to clinical environments and encounters. On the other hand, they are attuned to gaming environments, therefore they are prime candidates for exploring the potential of virtual healthcare for delivering psychosocial support and disease-specific programs. Indeed, some young patients may not be able to communicate their problems with health professionals in the physical world as freely as they can through a virtual world. This is because virtual worlds can be more easily manipulated or changed due to the specific needs of a young patient than the physical world can [45]. Virtual worlds may also prove more suitable than the physical world for patients with severe disabilities or illnesses that make it difficult for them to visit the hospital or clinic regularly.

A patient support environment using a virtual world has many potential advantages over other mediums for providing support to patients with chronic diseases. For example, patients can simply chat with each other through text, voice, and using mobile phones, but

a virtual world provides the feeling of sharing a 'living' space [2], providing an immersive environment for realistic experiences. A virtual world provides an opportunity to introduce new techniques and serves as a space of social interaction, participation and collaboration for delivering realistic and vivid health experiences [1]. Patients can optionally make themselves anonymous using an avatar in the virtual world. This allows them to maintain privacy and yet still interact with care providers, fellow patients and educators without feeling the pressure of stigma or embarrassment. As the virtual world is perceived as a "safe" social environment (whether anonymous or not), patients may be more comfortable discussing psychosocial issues. Patients can engage in interactive activities and seek certain types of help that may be more difficult to find in a clinical setting. This includes psychological support by accessing information in the virtual world shared by care providers or other patients, or the social support of talking with patients like them. Accessing information in the virtual world can help them form queries regarding their treatment that they may be too nervous or shy to ask in the clinical settings. Since the virtual world can be accessed from anywhere, it can facilitate connectedness even when patients cannot coordinate or are unable to travel to support centers and healthcare facilities. From a design perspective, one of the major advantages of using a virtual world is the vast amount of space one can devote to developing personalized worlds according to the needs, intents and interests of patients.

Young people are often attracted to virtual worlds, as many like to play video games. Virtual worlds have also been used in a range of healthcare contexts [9]. For these reasons, virtual worlds may be effective in providing support to patients with chronic diseases [9]. A virtual world for patients can be considered a *virtual community*. A virtual community

is defined as a social unit consisting of people who relate to each other in some way, interacting using communication technology that bridges geographical distance [26]. In health care, a virtual community refers to a group of people that use telecommunication for conducting activities related to health care and education. The activities involve discussion about health and treatment related problems, reading informative documents, consulting doctors and sustaining relationships. The participants in these communities can consist of health care professionals, patients, patient family members and other related people.

Virtual communities are one tool that can be used to make a shift from institution-centric to patient-centric information systems [29]. Virtual worlds provide a means of communication between patients, health care specialists and family members that overcomes the distance barrier. There are many applications available which are specific to a particular institution or a hospital, which are used as a virtual community for the purpose of health care [29]. YouCan World is designed to be patient-centric and provides personalization of virtual world via profiles stored in a database or otherwise accessed. Personalization refers here to populating the virtual world with informative documents, messages, and behavior based on each patient's profile.

Previous research says that seeing an avatar which resembles you doing things in the virtual world will affect your thoughts, feelings and actions. Specifically, watching yourself in the virtual world communicating with others and reading documents can enhance your confidence and improve your state of mind [41]. In YouCan World, the participant used the avatars to do things provided in the OpenWonderland framework. There was an option for configuring the avatar to change the clothes, hair and shoes. But still it was not close to make avatar to appear like real persons. In future work, it would be helpful to consider

giving option to the users to make their avatar resembles them only if they are comfortable with it.

We developed a basic application framework that allows such virtual environments to be designed, evaluated and deployed. It is based on Open Wonderland, an extensible open source virtual world platform first developed at Sun Microsystems Labs and now managed by an independent foundation. Using Open Wonderland, one can create virtual worlds easily, control access and deployment, and integrate custom features through well-defined extension points called modules. Our framework also borrows from the Twinspace infrastructure [3]. Twinspace's core feature is to support the integration of virtual environments with physical collaborative environments. While our work does not use this capability specifically, we believed that it may be beneficial for connecting physical clinical settings with online virtual worlds. TwinSpace also provides a rudimentary reasoning engine, which has been used to respond to virtual world events (including when someone logs in, or speaks) by updating how the world is presented to a group of viewers. For example, a virtual world client might pop up a screen that shows an avatar while they are speaking. In our work we adapted the functionality and intent of the TwinSpace reasoning engine to work in a medical context. For example, in our prototype virtual world (YouCan World), we reason about patient information in order to tailor the virtual world experience for patients.

Our framework permits the combination of a context-aware virtual world and an ontology-based e-health system. Context-aware computing is a research field which considers health care a relevant area of application [18]. "A system can be considered context-aware if it can acquire, interpret and use the captured information to adapt its behavior to the current

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context" [18]. For example, in our framework, we have developed 'proximity cells', which can be placed anywhere in the virtual world. These cells are capable of providing information about avatars in that region. Proximity cells plays a very important role in making our framework to provide the room-based functionalities by triggering behavior and messages based on proximity.

We have used an ontology for creating our knowledge base of patients' drugs and personal attributes. "An ontology can be defined as a formal, explicit specification of a shared conceptualization" [18]. We can capture the information in the ontology the same way as we interpret it in the real world. In the process of modelling the information in the ontology, we have to identify relevant concepts which refer to the conceptualization of the situation of the patients in the virtual world. Then we will define the concepts with the related constraints (explicitly) which will be machine readable and should have consensual knowledge. Ontologies can be used to facilitate management of complex health care systems. Ontologies have been used to define common terminology for the medical domain, which can be used unambiguously by various components of the system. Ontologies have also been used in virtual worlds. For example Pellens et al. developed an approach called VR-WISE which uses ontology to describe the virtual world [35].

Semantic web technologies have been used before to provide health support based upon the information stored in the OWL ontologies. Bouamrane et al. discussed using semantic web technology for adaptive patient information modeling in a clinical decision support system [12]. They used ontology to store domain knowledge of preoperative assessment, including classification of procedures and guidelines for various tests. Based on the information stored in the ontology, they provide personalized patients' reports consisting

of relative preoperative tests. In our system, we use semantic web technology to store background information about the patients. We use this to infer what content, activities, messages and recommendations are suitable for the patients and trigger changes in the virtual world as a result.

In this thesis we have developed a framework that aims to (a) facilitate the development of 'virtual' psychosocial support environments to deliver personalized educational and support interventions (cancer patients being a target demographic), (b) model patient information, content and activities using a formal representation scheme—in our case ontologies; (c) provide a rule-based personalization approach that selects relevant educational content and/or activities based on the patient profile, and (d) identify commonalities between patients and bring patients with common characteristics together in the virtual world for peer psychosocial support. We have also developed a prototype application using the framework, called YouCan World. For our prototype we focus on young cancer survivors (aged 10-18 years) to whom we are providing follow-up care, psychosocial support and self-management educational messages based on their therapeutic regime (in particular to their cancer drugs). Youth cancer patients undergoing intensive therapies tend to get isolated due to the effects of the therapy, yet at such a tender age they need to socialize and enjoy their youth. It is for this purpose, we believe that a virtual world for youth cancer patients provides an alternative social environment where they can meet other cancer patients of their age. It also provides a viable medium for delivering psychosocial support and educational interventions as part of social interactions.

We present our prototype a Youth Cancer Patient Support World (YouCan World) that features a virtual world that (a) allows patients to develop their own personalized avatars

and, displays personalized educational messages to patients at strategic points in the world, (b) navigates the patients through their long-term care process by delivering them appropriate educational and psychosocial resources, (c) provides them with the information relevant to their profile in the form of pdf documents in the library. We have developed an ontology-based data module that features a large set of personalization rules that take as input the patient's profile—currently, the patient drug therapy and other clinical characteristics—and in turn generates a set of drug-related messages relevant to the patient's profile. These educational messages and psychosocial support mechanisms are then presented within the patient's virtual world. Although the literature presents systems that use virtual worlds to support patients, the novelty of our work is the fine-grained personalization approach that not only delivers patient-specific messages and interactions with patients, but also at a technical level offers a scalable knowledge-base to which new personalization rules and messages can be readily added to enhance the patient experience and support relationships between patients. The personalization rules and the associated messages are derived from research data about ongoing treatments of the cancer patients. The virtual world and personalization components of the YouCan World are integrated using our framework. YouCan World can be accessed through a URL, which loads a Java-Based client on the machine.

1.1 Thesis Contribution

The thesis contributes in following areas:

1. A framework for building online virtual supportive communities for patients.

2. A prototype implementation of our framework called YouCan World for providing psychosocial support to cancer patients.

3. Feedback on design and functionalities developed in the prototype from HCI researchers and students.

1.2 Solution Overview

This section describes how this thesis addresses the above mentioned contributions.

1.2.1 Requirements Gathering

Our research objective was to build a framework based on the TwinSpace framework with an improved Context/Mapping Engine (CME) to build applications for providing psychosocial support to patients. The TwinSpace framework employs an open source virtual world engine called OpenWonderland as a virtual counterpart for mixed reality, mixed presence groupware. OpenWonderland is itself an easily scalable module-based framework. Our framework uses Open Wonderland and a number of the communication and context sensing mechanisms of TwinSpace.

We combined research data about cancer patients' ongoing treatment with demographic data of sample patients to form a database tied to an ontology and rule based reasoning engine. Our challenge was to transform this data into a form that could be used to extract recommendations and messages to the young patients in the virtual world. We developed our own patient ontology and defined SWRL rules based on the data we had. The ontology creation process is explained in detail in chapter 3 of this thesis.

1.2.2 Design and implementation of the Framework

Our framework can be used for building applications that support virtual communities of patients. These virtual communities will allow patients from all around the world to come together and share their fears, thoughts, and experiences about their ongoing treatment and disease. We also developed a prototype called YouCan World, an online virtual world, using our framework to provide psychosocial support to cancer patients. The design and architecture of the framework and the prototype 'YouCan World' is explained in detail in chapter 3.

The data used in the prototype comprises of an ontology and personalization rules. We created our own patient ontology using the prior research data and patient's demographics along with rule-based reasoning engine. We wrote personalization rules in SWRL language. The framework for providing support to patients using an online virtual world is described in section 3.2. The ontology creation process and rules are described in detail in section 3.2.2.

1.2.3 Evaluation of YouCan World

The other major contribution of this thesis is the design and evaluation of a prototype virtual community for cancer patients. To evaluate the functionalities and the design of our prototype we conducted 2 focus groups with human-computer interaction students from the Graphics and Experiential Media (GEM) lab in the Faculty of Computer Science and students from the Faculty of Engineering at Dalhousie University. The first group were able to give informed feedback on the interactive elements of YouCan World, while the second group provided the first impressions and feedback of a more novice group of users.

Chapter 2 Related Work

In this chapter we explore the related work in terms of need of psychosocial support in patients, Virtual communities in health care, History of virtual world applications in health care and ontologies in virtual world based applications. Lastly we conclude with what functionalities we found in the literature from virtual world applications and what we are providing in our framework.

2.1 Need for psychosocial support in cancer patients

Patients with long term chronic diseases experience numerous illnesses over the period of the disease [21]. During the span of their disease, they frequently seek knowledge about medical care for acute or short-term problems [21]. The diagnosis and treatment of chronic diseases such as cancer in patients has affected and changed their lives. Suddenly they have to cope with new situations like painful symptoms, uncertainty of prognosis and changes in social relationships [23]. Therefore, it is important to provide patients some degree of social and emotional support. Many interventions have been developed in the hospital setting, but a virtual world provides a home-based environment to provide psychosocial support according to the needs of patients.

A social stigma is still attached to cancer which leads to societal distancing from cancer patients [29]. Even if the patients are provided with all available advanced medical support and care, it is not sufficient for addressing their emotional and informational needs. Being

diagnosed with cancer is a dramatic change in a person's life, drastically affecting their daily routine and imposing demands on them to take decisions about treatment.

Although young patients get support from their parents, schools and peers in their day-to-day life, there is still a lot of potential in providing psychosocial support to patients using games and the internet [23]. There are many online forums which help patients to communicate with each other about their problems. For example 'PatientsLikeMe' and 'Online Support Groups - Patient Empowerment - About.com'. Virtual worlds have many potential advantages over these online forums. Online forums do not give the feeling of togetherness or sharing a space like a virtual world can, and virtual worlds provide malleable spaces that can be used for different purposes and modified as required. Patients can hold live discussions with peers or health care specialists through the virtual world, and can leave messages in the world (or receive messages left for them) for asynchronous communication. Virtual worlds may also provide advantages over face-to-face meetings, as patients may be self-conscious about their looks, or may be feeling too tired or ill to socialize in person.

Through virtual world we can not only address the social needs of the patients in a virtual world, but can also provide them with useful recommendations and messages. This displayed information will support them psychologically by helping them to talk with their health care specialist and peers in the virtual world. They will be able to meet other patients face to face in the form of avatars, without concern of their looks and can socialize with each other.

2.2 Virtual communities in health care

Virtual communities in health care can be defined as a group of people collectively conducting activities to deliver health care and education [26]. Health virtual communities can empower patients with knowledge, facilitate health information dissemination, and provide social and psychological support [56]. El Morr broadly classified virtual communities in health care into 2 categories [56]. The 2 categories are Mobile and Non-mobile virtual communities. Non-mobile virtual community is the community where members use desktops or laptops to participate from their home or office, while Mobile virtual community is the community where members used mobile devices. The main difference between both is that in Non-mobile communities, the physical location of the member is not collected and made available. El Morr proposed a collaborative community model to explain difference between mobile and Non-mobile virtual communities [56]. This models explains about their common and divergent aspects. Figure 2.1 describes the characteristics of the collaborative communities in general.
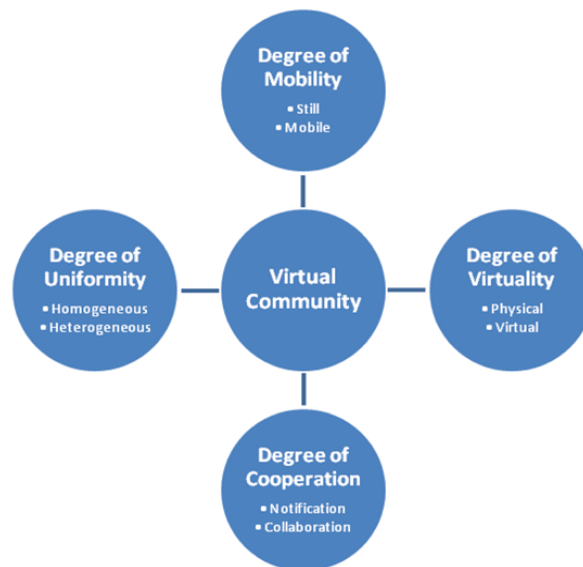
Figure 2.1 The 4 characteristics of collaborative communities [56].

The 4 characteristics of a collaborative virtual communities are

1) *Degree of Mobility*: It signifies whether the member is mobile or still.

2) *Degree of virtuality*: It signifies degree of how close the members are with each other geographically. They can be physically in same place or they can meet virtually.

3) *Degree of Cooperation*: It signifies are the members are notified about the presence of other members or they can actively collaborate for the common aim.

4) *Degree of Uniformity*: It signifies members are homogenous of same domain i.e Patients or heterogeneous where members can be patients, Nurses, Doctors etc.

Non- mobile virtual communities in health care can be classified into 3 categories (1) Patient centered, (2) General public centered and (3) Professional centered [56]. Patient centered virtual communities involves patients and health care professionals and the main aim to provide support to patients. Professional centered virtual communities includes exchange of knowledge and research teams. And General public centered virtual communities are open and public which can be educational services, discussion forums etc. Demiris researched through the medical and social science literature and came up with 4 categories of virtual communities in health care [26]. The categories are Virtual health care delivery teams, Virtual research teams, Virtual disease management and Patient & caregiver peer-to-peer applications. Virtual health care delivery teams falls under the category of General public centered virtual communities. Virtual research teams falls under Professional centered virtual communities. And Virtual disease management and Patient & caregiver peer-to-peer application comes under patient centered virtual communities.

Virtual health care delivery teams are the virtual communities which concentrates on addressing the needs of patients in their complex treatment protocols. Virtual research teams is the communities of cancer researchers. Virtual disease management is the virtual community for coordinating healthcare interventions and communications in patient self-care process. And lastly Patient & caregiver peer-to-peer applications are the communities developed for communication between peers to exchange the information.

Our framework support the combination of Virtual disease management and Patient peer-to-peer type of virtual communities. The concept of disease management refers to a set of coordinated healthcare interventions and communications in which patient self-care efforts are significant [26]. The Patient & caregiver peer-to-peer applications enables the peers to exchange information between each other without any control or authorization. Our framework not only facilitate patients to self-manage their disease by consulting with doctors and reading informative documents, but also peer-to-peer communication by displaying similarities among the patients in the virtual world. Our framework provides a way for patients with chronic diseases to login into the virtual world from anywhere to meet doctors, healthcare specialist and their peers. It intends to form virtual communities of patients to facilitate the peer psychosocial support and educational interventions. It displays tailored health related information for helping patient to get desired support from doctors and peers.

An example of Virtual disease management category is the asthma tele-monitoring system which assist patients by helping them manage their daily routine by personalized interventions and alerts [26]. Similarly there are other applications used for data collection from the patients, allows communication of patients with health care providers and decision

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support. Example of Patient & caregiver peer-to-peer applications is PeerLink which is developed for patients with disabilities to share information with each other [55]. Specifically this type of applications are developed to bring patients with similar clinical conditions or health together to ask questions, provide support and exchange experiences [26]. Sharf studied the breast cancer group and found three main dimension of communication among the patients, which are exchange of information, social support and personal empowerment [54]. We are also targeting these dimensions of communication in our framework by offering functionalities to facilitate them.

2.3 Virtual worlds

Online virtual worlds are very popular, especially among children and youths in the form of games. There are some popular online 3D virtual worlds like Second Life and World of Warcraft, which serve as an alternative medium of socializing to the physical world. There are many online virtual worlds available for playing or 'hanging out' with friends. Some of those are 'There' [52], ' chit chat city' [47], Say Say girls' [48], ' primary games for kids' [49],' Bearville' [50] and 'Weeworld' [51]. Most of these virtual worlds are intended to be used for socializing, hanging out and meeting new people. These virtual worlds are not open source, and do not provide any APIs for developing new modules for customization. Our framework was inspired from the Twinspace framework, which uses an open source virtual world platform called OpenWonderland, and we used the same platform in our work.

2.3.1 History of Virtual world applications in Health Care

A virtual world is a computer-based, simulated multi-media environment, usually running over the Web, and designed so that users can 'inhabit' and interact via their own graphical self-representations known as avatars [53]. There is a history of using video games with patients for providing support. It has been evolved to focus on tailor-made video games for disease specific patients. Second life is the most commonly used virtual world environment for developing virtual communities of patients. Some of the applications of Second Life in medical and health education are the HealthInfo Island and Virtual Neurological Education Centre (VNEC) [53]. The HealthInfo Island consist of various buildings designed for providing educational interventions to the medical community [57]. The main objective of HealthInfo Island is to provide training programs to virtual medical communities and one-to-one support to Second Life residents [57]. HealthInfo Island provides proper environment and displays information to help medical community to learn about various aspects of health care. Similarly there are other examples like "Heart murmer sim" [59], "Ohio University sim" [60] which used Second Life to build centers for educating patients about healthy diet, treatments, diseases etc. The Virtual Neurological education center (VNEC) was built for patients with neurological disabilities [58]. It provides ways for the patients to come together and share their experiences, knowledge and provide support to each other. It also consist of 3D models of the equipment used in treatments from which patients can learn about the treatments along with the information in forms of videos and webpages.

Basically VNEC was developed to educate patients with neurological disorders and bring them together so that they can exchange their knowledge and support with each other. They

created specific areas in Second Life to educate and support patients. It was assumed that the patients will access the information in the virtual world and will communicate with each other. There was no encouragement for the patients to use the resources present in the world. But in our work we wanted to encourage patients to use the resources by displaying personalized messages and recommendations.

Second Life has also been considered as a tool for providing medical-related education in a virtual environment [10]. Using virtual worlds as a classroom can allow a large number of students and teachers to participate at the same time in learning [11]. This can be applicable in case of doctors and patients. Virtual worlds have a lot of potential to be used as a tool to provide support and education to patients regarding their treatment and their diseases. Online virtual communities provide an environment in which social relationships can be readily established between patients, which helps them to cope with their disease and its treatment [29]. Nowadays young people are in constant touch with their friends through texting, mobile phones, social networking websites, and online video games. Digital connectivity may be enhanced through online virtual worlds by promoting exploration and interactions that are crucial for healthy psychosocial development in patients.

Virtual worlds have been used previously for providing social support to patients with chronic diseases. Sawyer et al. discussed about how we can use virtual world to address the social needs of older patients [2]. They discuss aspects of designing virtual world for the elderly from a user centric perspective, their needs and how to serve them. Their main focus was on how we can encourage users to communicate with each other. They proposed an architecture for addressing social needs of elderly through meetings in virtual worlds

and discussed various interaction scenarios through pictorial representation. Becker and Pentland [6] used a virtual environment to educate cancer patients about relaxation and self-imagery. In their work they used patient gestures to navigate them through the blood stream as white cells killed malignant cells, which gave a feeling of relaxation to the patients [6]. This experience gave the patient the required inspiration for going through the treatment with a more positive attitude.

Welbourne et al. discussed the use of virtual worlds as a tool for online supportive communication in infertility groups [7]. They proposed that virtual environments are suitable for discussions and sharing queries for infertile women. They also conducted the studies to find out how the sense of virtual community serves as a buffer between stress and physical health symptoms [7]. They found that the sense of virtual community (SOVC) is positively related to observing exchange of emotional support. Their observation supports that the virtual communities helps patients to come out from the isolated state of mind and discuss their queries with others. Virtual worlds are also being used for providing healthcare support for people with intellectual disabilities [8]. People with intellectual disabilities find it hard to understand information from brochures and booklets [8]. Hall et al. conducted studies to see how effective virtual worlds to provide educational support to people with disabilities. With the study population of 20 people they found that participants enjoyed the 3D virtual world. They also learned from the health care related scenario presented in the virtual world and remember it even after a week. Lack of access to healthcare information will also cause poor access to healthcare facilities. Virtual worlds provide a 3D computer generated environment which can be manipulated in any ways

which physical world cannot and can convey concepts without using any language or symbols [8].

2.4 Ontology in virtual world based applications

Defining an ontology is the most successful way of structuring medical domain knowledge [16]. The main reasons that ontologies are useful for capturing biomedical knowledge are that they capture the knowledge in formal, but in a powerful and incremental manner, and that they can be readily used in the reasoning processes part of a decision support system [16]. Ontologies have been used in many systems as a tool to store patient related data for building personalization and decision support systems. Ontologies helps to solve problems related to terminology and allow automatic processing of information [35]. For example ontology can be used to define the terms needed to describe the condition of the patients. It also supports reasoning on the data stored based to provide personalized recommendations or messages.

Kim et al. used ontology to build a healthcare context information model for ubiquitous healthcare services. Seven categories of data were defined, including medical data related to the disease of the patient and individual data (the personal attributes of patients) [17]. In our framework we concentrated on these 2 types of data and provided recommendations and messages based on this data.

Applications based on virtual worlds can use ontologies. Pellens et al. proposed an approach for describing virtual environments at the conceptual level [35]. They developed a behavior ontology which captured all the objects present in the virtual world along with all the behaviors of the objects that they can emulate in the virtual world. This allowed

enhancement of the interoperability and intuitiveness among the components of the system. By defining the terminology for describing the objects in the virtual world helps different components of the system to use and understand them. Using ontologies allows systems to be made more intelligent by reasoning about situations in the virtual world. Bille et al. intelligently modelled a virtual world by expressing the virtual world in terms of an end user's perspective [36]. This helps in developing the virtual world for people who are not expert users. They proposed a 3-step approach consisting of specification, mapping and generation. In the specification step, the user defines the virtual world without any consideration of implementation, creating a domain ontology. In the mapping step, the virtual world building blocks will be developed, mapping them with the concepts defined in the domain ontology. The final step consists of the creation of the virtual world based on the domain ontology and mappings done in the previous steps.

Bhatt et al. propose a similar kind of approach for developing an ontology-based system for storing patients' profiles [34]. In their approach they were providing personalized profiles of patients by sub-ontology (partial view) extraction. We have developed a reasoning engine which is responsible for providing support to patients. Semantic profiling of the patients is one of the major requirements of any medical support system [34]. The sub-ontology extraction process would be effective if a very large amount of data about patients was available. But in our case, the data was well-structured along with the rules defined on the data. Due to this it was suitable to send the messages between the framework components using terms defined in the ontology. Also our framework required a reasoning component to extract the exact knowledge required at particular situation occurring in the virtual world (for example, moving documents when a patient enters the library). As our

ontology was sufficiently small and precise, we did not require partial views. The reason why our ontology was small and precise was because it consist of very few number of classes along with properties defined on the classes. As we were building just a prototype, we consider only 10 patients in our ontology. Therefore the size of our ontology was not so big as to require use partial views. The data which we have is not large enough to use the partial views.

In our framework, we developed an ontology called 'Patient' ontology and recommendation rules using the research data about each patient's disease and their ongoing treatment. Then we mapped the functionalities we wanted to deliver to the patients with the knowledge we have captured in our ontology and recommendation rules. For creating the prototype YouCan World, we developed and populated the virtual world according to the functionalities offered. The functionalities offered in our prototype are explained in detail in chapter 4.

2.5 Conclusion

There is a need for an online system which will provide a way to meet their peers and health care specialist from their home. As explained in the related work virtual world can be used for this purpose. It overcomes time, distance and space barrier and allow patients to login from anywhere around the world. Nowadays, patients go to meet their doctors with printouts of material found online about the disease or its treatment [29]. That shows patients wants to learn about treatments and to self-manage their health care. We are proposing a framework to provide such support to patients through an online virtual world. Table 2.1 provides the summary of the virtual world applications and studies discussed above along with the functionalities each of them address.

	Social support	Educational interventions for patients or specialists	Provides tailored information (for learning)	Self-imagery and relaxation	Knowledge sharing	Patient-doctor consultation
HealthInfo Island [53]	No	Yes	No	No	Yes	No
VNEC [53]	Yes	Yes	No	No	Yes	No
Welbourne et al. [7]	Yes	No	No	No	Yes	No
Becker and Pentland [6]	No	Yes	No	Yes	No	No
Heart murmur sim [53]	No	Yes	Yes	No	No	No
Ohio University sim [53]	No	Yes	Yes	No	No	No
Hall et al.	No	Yes	Yes	No	No	No
Sawyer et al. [2]	Yes	No	No	No	Yes	No

Table 2.1: Summary of virtual world applications and functionalities provided

Our framework addresses all the functionalities from table 2.1 except self-imagery and relaxation. The framework is described in next chapter. Our work is inspired from Twinspace infrastructure which was developed to connect interactive workspaces and collaborative virtual worlds [3]. It uses ontology for defining the context in both physical and real world and also perform intelligent selection of resources through reasoning of rules and ontology. Twinspace uses the EventHeap distributed message passing infrastructure [13] for communicating between various components and devices using the Twinspace framework. In our framework, we are also using EventHeap for communication between the Semantic Web and virtual world components.

Chapter 3 Design and Implementation of our Framework

Our framework supports and facilitate the development of combination of virtual disease management and Patient & caregiver peer-to-peer applications as described in the previous chapter. It was developed using the OpenWonderland open source virtual world platform and the semantic web technologies like Owl-DL and SWRL. It provides a general architecture and components for building online virtual worlds intended to promote psychosocial support to patients.

3.1 Framework for Building Patient Support Online Virtual Application

We proposed the framework for building virtual applications for virtual disease management and Patient & caregiver peer-to-peer applications. Based upon the research done in literature review and brainstorming we come up with three functionalities which facilitates psychosocial support to patients. Figure 3.1 shows the conceptual diagram of our framework. Our framework consist of 3 main functionalities based on the features described above and the literature review in chapter 2. As we can see in the figure, the functionalities are based on location of the patients in the virtual world. The reasoning engine plays a very important role of generating recommendations by using the stored patients' profiles.
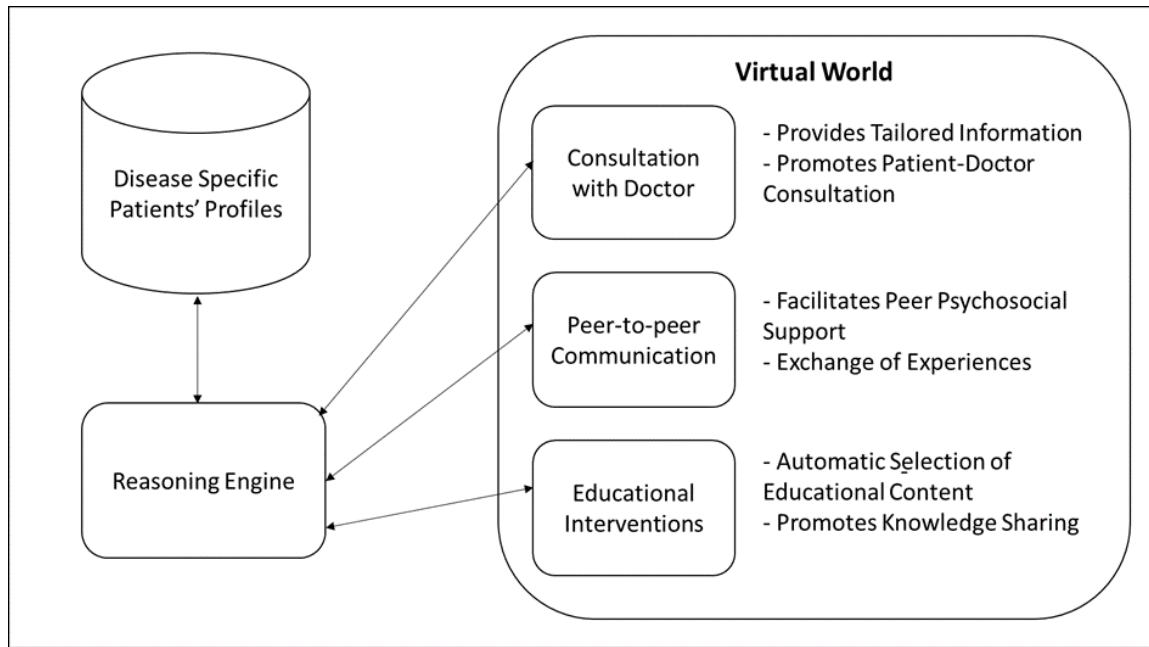
Figure 3.1: Conceptual diagram of our framework

The first functionality is to allow patients to consult with doctors. We will be displaying tailored information which will help patients to ask doctors about their ongoing treatment and disease. The second functionality offered is to promote the peer-to-peer communication by bringing patients with similar conditions and treatments together. And the third functionality was to provide educational interventions to the patients about the particular disease. In our framework we are considering PDF documents as educational content for displaying in the virtual world. How we came up with these functionalities and how these functionalities provides Virtual disease management and Patient & caregiver peer-to-peer application is explained below.

1. *Consultation with doctor*. As virtual communities of the patients involved doctors, we expected that patients would meet their doctors in the virtual world. We will be displaying tailored information in the form of recommendations which will be

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based on the data stored in our database. There was a project developed in university of Minnesota TeleHomeCare which enables patients with chronic diseases to communicate with health care providers through personalized webpages [26]. Similarly the displayed personalized recommendations would cue patients to talk with their doctors and also provide guidance about how the conversation should proceed (questions to ask, etc.). These recommendations were derived from the information stored in our data model.

2. *Peer-to-peer communication*. The communication and knowledge exchange between patients can be facilitated by online virtual worlds [28]. Leimeister et al. conducted survey among members of patient virtual communities. They found out that the relationship formed through virtual communities meets the social needs of the patients [26]. They also concluded that the emotional support and the information exchanged in virtual world may help the patients to cope with their illness. Also there are applications developed using Second Life like HealthInfo Island [57] consist of building structures providing suitable environment for the patients to communicate with each other. In our application, we wanted to encourage the communication between patients by displaying some form of commonalities that will trigger communication between them. For example, patients with the same type of cancer are likely to benefit from talking to each other. We believed that this could also overcome awkwardness between patients to some level.

3. *Educational Interventions.* Providing education to the patients is one of the main component of Virtual disease management applications. The education have been

provided by displaying tailored information in the virtual world. VNEC (Virtual neurological education center) provides information regarding various neurological disabilities in three forms, web URLS, videos and podcast [58]. We also wanted the patient's experience with our application to be informative and educational. The idea was to have pdf documents arranged in the form of a book shelf. When the patients are in the library, content (pdf documents, websites, images, etc.) relevant to them will be displayed more prominently, and if more than one patient moves into the same region, a subset of documents relevant to these patients will be displayed. We expected that patients could view these documents (possibly together), and exchange their knowledge with each other. We can also added videos regarding diseases or any topic related to it in the virtual world.

Our framework provides a general architecture for building a patient support application using an online virtual world. It provides a way to give recommendations and suggestions to the patients in the virtual world at run-time. Which is beneficial especially in the scenario where we want to display information in the virtual world when patients are using it. It will be more effective when the information is displayed according to the events happening in the virtual world. For example, displaying recommendations when the patient is in consultancy room. Our framework also provides a structured way to manage patients' profiles along with the rules to give out patient-centric information, depending upon the current location of the patient in the virtual world. Our knowledge base which consist of ontology can store the profiles of the patients in terms of demographics and their ongoing treatment. We can extend our framework by supporting other events happening in the

virtual world that can be used to provide support to patients. For example a doctor logged in the virtual world notifying patients about it.

The major tasks in developing our framework was as follows.

3.1.1 Creating a knowledge base.

Our knowledge base consist of ontology and the rules written in SWRL. Ontology captures the medical domain knowledge and patient profiles in a systematic manner. Rules defines various events and conditions in the virtual world. The process of creating the ontology and rules is explained in detail in section 3.2. We used SWRL (Semantic web rule language) to write the rules. The semantic web rule language (SWRL) is a combination of OWL-DL and OWL lite sublanguages [38]. The main reason for using SWRL is that we can use variety of rule engine to reason with them. Interoperation is the main goal of the semantic web. SWRL allows to write permanent rules in terms of OWL concepts. This served the purpose of representing knowledge about patients and their ongoing treatment in the form of rules. SWRL rules also allow reasoning about OWL individuals. In SWRL we can write rules about individuals of OWL classes in terms of its data-type properties. This property of SWRL language allows reasoning about patients as the individuals of the class Patient in terms of their properties. We can define the patient demographics as data-type properties of class Patient. This allows us to reason with patients demographics through rules. SWRL rules are written in 2 parts -antecedent and consequent. Only when all the conditions in the antecedent part are satisfied, will the consequent part be executed. Also the research data we have was in the form of decision points and the recommendations. It was suitable for using SWRL for writing rules by defining the

decision points in antecedent part and the recommendations in the consequent part. Therefore we decided use SWRL for writing the rules.

Another main advantage of using SWRL is that we can reason SWRL rules using any reasoner. We used 'Pellet reasoner' with Jena API to reason with SWRL rules whenever needed, because Pellet is leading choice for reasoning with OWL-DL ontologies. Our reasoning engine reasons on the personalization rules and the properties in the ontology to trigger actions, and provide recommendations or messages to be displayed in the virtual world.

3.1.2 Build client-side components

For providing functionalities to patients in the virtual world based on the events happening, we developed virtual world client components which will be operating to facilitate these functionalities. These components consist of 'Virtual world event listeners', 'Virtual world updater' and 'Client UI updater' Virtual world event listeners keeps track of the events happening the virtual world and notifies reasoning engine. Virtual world updater and Client UI updater are the modules which will react to the information coming from reasoning engine and perform updates in the virtual world or to the Client UI (In our case Heads-Up-Display). All of these components are explained in detail in section 3.2.

3.1.3 Develop a Reasoning Engine

We need a Reasoning engine to reason on the knowledge base which consist of medical knowledge base, patient profiles and rules. Reasoning engine will be responsible for generating personalized information needed for providing functionalities to patients. Reasoning engine will notify Virtual world updater and Client UI updater and depending

upon the information send to them, they will update consequently. It is explained in detail in section 3.2.

3.1.4 Connect the components using EventHeap

And the last task is to manage the communication between the components of our framework. The communication is carried out using EventHeap events. This is explained in next section.

3.2 Implementation of the Framework

In this section we will see the implementation of our framework. Figure 3.2 shows the functional architecture of our framework. It consist of three main parts 1) Virtual world server and clients (On right), 2) Semantic web components (On left) and 3) EventHeap. The reasoning engine plays a very important role of generating information to be displayed in the virtual world by using the stored patients' profiles. The reasoning not restricted to the patients' profiles but can also use incoming data about objects and events in the virtual world (avatar locations, for example) and data in a medical knowledge base (such as potential courses of treatment). The OpenWonderland client is used by the patient to access the virtual world. We define two kinds of client-side module for performing actions based on reasoning engine messages: Client UI updater for updating the client user interface (e.g. places content on the HUD), and Virtual world updater for updating the virtual world (e.g. moves media into the foreground). A third type of module (Virtual world event listener) receives messages from in-world virtual sensors called "Observers", processes the messages and relays some detail (or possibly an aggregation of detail from several

messages) to the reasoning engine as an event (for example, when the client's avatar enters a room where an active discussion is in progress). OpenWonderland also supports media repository which is accessed through LDAP, which can be queried by keywords. It may be used by Client-side components to tailor media delivery to patients using keywords provided by reasoning engine. The reasoning component is decoupled from the virtual world components via a template matching communication protocol called EventHeap.
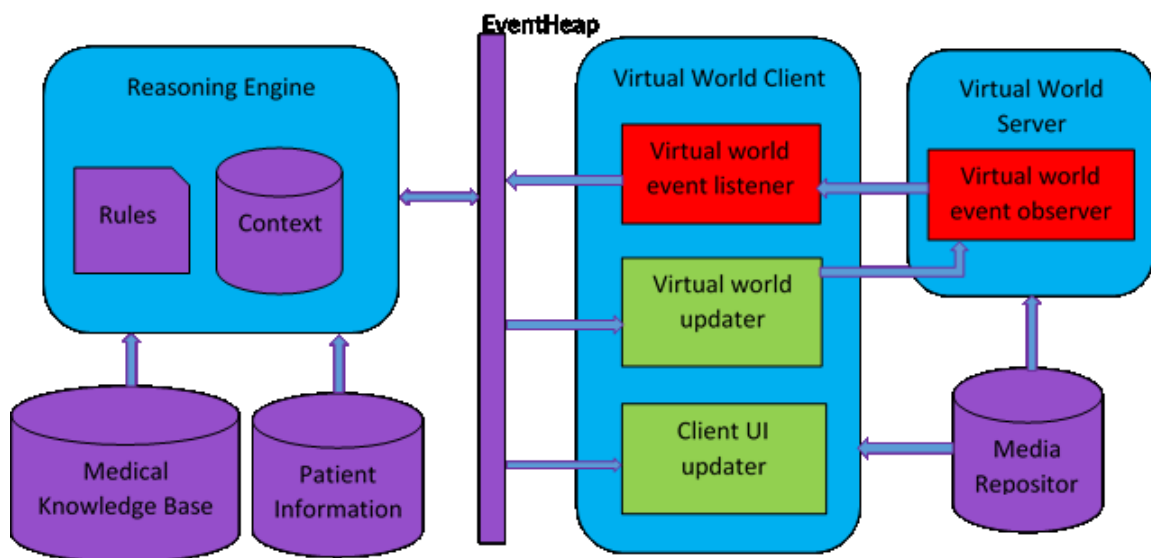
Figure 3.2: Functional architecture of our Framework

By decoupling reasoning over patient and medical data from virtual world interfaces and actions, our framework provides a general architecture for building a patient support application using an online virtual world in a manner that allows both to evolve independently. Medical and profile information resides with the reasoning engine in a format that can be readily generated by many health information systems. Developers can honor requirements for security and privacy by deciding what content appears on messages leaving the reasoning engine, and what event information is sent to the reasoning engine

by virtual world clients. It provides a way to give recommendations and suggestions to the patients in the virtual world at run-time.

The framework is highly adaptable and extensible. OpenWonderland's module support allows new kinds of event observers, event listeners and updaters to be written and easily deployed. New rules are easily added to the reasoning engine using SWRL, as are new ontology classes and attributes, while the three classes of messages (recommendation, commonality, and keyword) generated by the rules help to maintain a logical application structure. New responses to reasoning engine messages can be achieved by configuring one or more updater modules to match the message's template.

The next sections describes all the major components of the architecture of our framework along with implementation of all the components with respect to our prototype (YouCan World) is also explained as follows.

3.2.1 Communication through EventHeap

The communication between the components of our framework through EventHeap events. EventHeap is the infrastructure which allows different machines and devices to access the system generated events simultaneously [13]. Any component which will put an event on the EventHeap will create the event with the correct template and use putEvent () method. Similarly any component which wants to get this event will register for that event using its template beforehand. Template matching will be done, if the same event is on the EventHeap then that component will be notified.

Following is the syntax for defining the EventHeap template.

Event template = new Event (My Event Type);

template.addField ("AGE", new Integer(27));
template.addField ("NAME", "Tico Ballagas");

3.2.2 Medical Knowledge Base & Patients Profiles

The information about the ongoing treatments of the patients (Medical knowledge) and their personal attributes (Patients profiles) are captured in an ontology. The rules are based on the knowledge stored in the ontology. The knowledge base consists of an ontology and SWRL rules. The use of semantic web technologies allow us to perform high-level modelling of patient information. For example all the personal attributes of the patients can be made data type properties of class patient. Also, decision support is based on classification of the patients based on various factors [8]. These factors can be type of disease a patient is suffering from, ongoing treatment, nationality, age, favorite sport, etc. In our prototype, we are not providing any decision support, but will facilitate psychosocial support in the form of displayed recommendations and commonalities for the patients. We are hopeful that these recommendations and commonalities will encourage patients to talk with their peers and doctors. We are not displaying any information which help patients to take decisions instead it will help them to socialize, discuss their issues and learn from displayed educational content.

We developed the patient ontology using the research data of our currently cancer patients (target population) along with the drugs taken by patients and other personal attributes such as favorite sport, country of origin. For our prototype implementation, it was not required to use any defined ontology for health care. Because our framework required only three classes, 'Drug', 'Patient' and 'Decision', where Decisions are the recommendations which

will be given to patients depending upon the firing of the rules. We have around 142 recommendation sentences which are the individual of class Decision. Depending upon which rules get fired, these sentences are displayed on the screen of the patients. Our ontology is not final and was developed for our prototype 'YouCan World'. It can extended by adding new classes and properties to support different scenarios and different types of users. Currently we have stored information about 10 patients in our ontology for our prototype. We can add new patient profiles by creating individuals of class Patient. Figure 3.2 shows the number of patients as individuals of the class Patient and its properties on the right side. There are 20 drugs in our patient ontology, each of which has its own effects and side-effects. The rules are written in SWRL, which has decision points which are defined on the data type properties. When this conditions get satisfied, the rule gets fired and the corresponding recommendations are given out. We used Protégé 3.4.8 to develop our ontology and to write the SWRL rules.
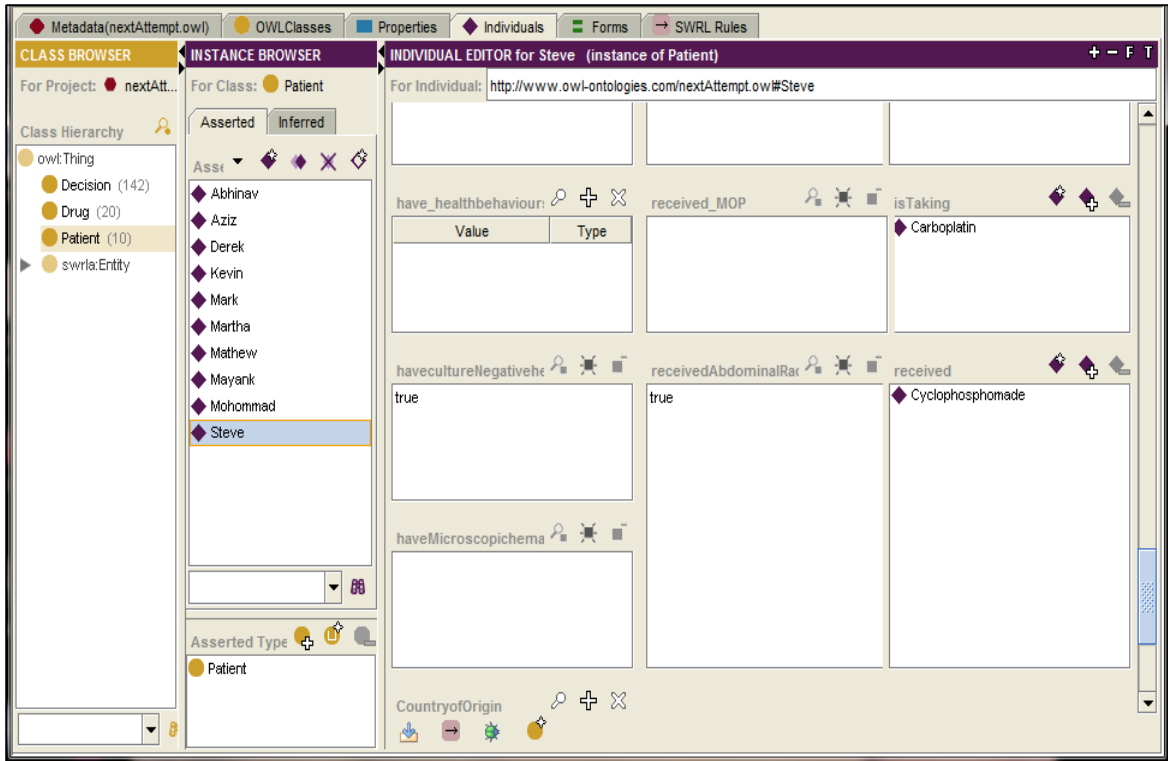
Figure 3.3: Snapshot of patient ontology showing individuals of class patient

Table 3.1 describes the part of our research data for the drug Bleomycin, which we used for building our ontology. Similarly we have more 19 drugs in our data. In the table we can see in the Decision Points column that parameters like the age of the patient and the amount of the dose are considered along with the drug. As described above, we have 3 classes Patient, Drug and Decision. We defined class Decision for the sentences in the suggestions column in table 3.1. The suggestions are the guidelines for the patient when they will meet their doctors for follow up.

Sr No	Drug Name	Decision Points	Suggestions
1	Bleomycin	IF age > 10 years at treatment AND dose <400 units/m2	Ask your doctor to check your lung symptoms (cough, wheezing, shortness of breath) and do a physical exam every year.
2	Bleomycin	IF age < 10 years at treatment	Ask your doctor to do a baseline breathing test (including peak flow, diffusion capacity and spirometry). Ask your doctor to check your lung symptoms (cough, wheeze, shortness of breath) and do a physical exam every year. Ask your doctor to repeat your breathing test every 5 years or so - or when he or she thinks there is a clinical need
3	Bleomycin	IF dose >= 400 units/m2	Same as rule 2
4	Bleomycin	IF received chest irradiation	Same as rule 2
5	Bleomycin	IF received Busulfan, BCNU or CCNU	Same as rule 2

Table 3.1: Text rules of patient's treatment

In the patient ontology the patient's attributes like 'age at time of treatment' and 'is overweight' are represented as data type properties (we have around 50 data type properties). We converted our text rules from the database into SWRL rules to be used for reasoning. Figure 3.4 shows a number of the SWRL rules written in protégé. All the SWRL rules have a consequent part as these suggestions and the antecedent as the decision points from the database. The following are some of the SWRL rules for a patient taking Bleomycin. These rules are specifically defined for displaying the recommendations in the consultancy room to follow-up with the doctor (askTheDoctor data type property). The ontology and SWRL rules can be easily extended by inserting new properties and classes in the ontology. Likewise we can write new rules based on patients conditions in their treatment.

- Patient(?x) ∧ isTaking(?x, Bleomycin) ∧ hasAge(?x, ?z) ∧ swrlb:greaterThan(?z, 10) ∧ drugDose(?x,　?w) ∧ swrlb:lessThan(?w, 400) → askTheDoctor(?x, D-1).

- Patient(?x) ∧ isTaking(?x, Bleomycin) ∧ hasAge(?x, ?y) ∧ swrlb:lessThan(?y, 10) → askTheDoctor(?x, D-2) ∧ askTheDoctor(?x, D-1) ∧ askTheDoctor(?x, D-3).

- Patient(?x) ∧ isTaking(?x, Bleomycin) ∧ drugDose(?x, ?y) ∧ swrlb:lessThan(?y, 500) → askTheDoctor(?x, D-1).

Figure 3.4: SWRL rules derived from the text rules

Figure 3.5: A SWRL rule written in Protege

There is an example of the SWRL rule shown in Figure 3.5. As you see in Figure 3.4, the Antecedent part (before implication) consists of the conditions to be satisfied about the patient and the consequent part (after implication) contains the recommendations. For example, consider the rule from the Figure 3.4, the patient is taking Bleomycin, has age greater than 10 years and has a drug dose less than four hundred milligrams then the rule is fired giving out the recommendation D-1. We are maintaining a text file where we have mapped D-1 to D-142 to the actual recommendation sentences. The reason for maintaining a text file of the sentences is because we don't want the individual names of class 'Decision' (this is the name given to the class of recommendations) to be long sentences. Rather giving them long names we name them in coding range of D-1 to D-142 and correspondingly maintained a text file mapping the codes to the actual recommendation sentences. We will retrieve these sentences from the text file when needed. The reason for storing sentences in the text file is that we can easily update them or change the language. Based on the patient's treatment data and their details, rules are fired. We can also find similarities between two or more patients by reasoning with the ontology. For example, we can find the patients who are currently logged into the virtual world and taking the drug Carboplatin. Similarly we can implemented other functionalities by reasoning with the ontology and the recommendation rules. For example we can provide appointment remainders to the patients in the virtual world. We are using 'Pellet reasoner' along with Jena API to reason with the SWRL rules. The recommendations resulting from the querying of SWRL rules are added to the EventHeap server in the form of events.

3.2.3 Virtual World client Components

For implementing our prototype, we bundled a server side virtual world event observer with a client side Virtual world event listener into a single Proximity module. We also bundled a virtual world updater and a client UI updater into a single Display module in our prototype implementation (bundling like this reduces the complexity of testing and deployment). Developing a new module requires coding one or more client updaters, event listeners or server-side event observers. Each bundled client-side component will define one or more EventHeap templates for sending or receiving information to/from the reasoning engine. Server-side observers generate event messages via OpenWonderland to linked client-side event listeners.

3.2.3.4 Proximity Module

While lot of applications have been developed using an online virtual world to support patients socially, this project attempts to also provide psychosocial support in the form of recommendations and commonalities in real time. For this purpose, it needed a mechanism to track the movement of avatars in the virtual world. The system should be aware of avatar positions in order to act upon this and make changes to the world. The module responsible for doing this is the proximity module.

The proximity module is a one type of event listener developed using proximity sensors available in OpenWonderland API for our prototype. It is responsible for context-aware features of the YouCan World through which we come to know when and where the avatar is present in the virtual world. We have developed a proximity cell (invisible sphere) which we can place anywhere in the virtual world. It notifies by sending a message when an avatar

enters into the sphere helping us to know the current location of that avatar. Each object in OpenWonderland virtual world is denoted as a cell. The properties of the proximity cell can be changed depending upon the requirement of how much area it should be covering and its location in the virtual world.

Proximity cells can be placed in several locations where we want to monitor avatars entering the cell. Each proximity cell has a unique ID and name, which helps to distinguish between various cells. The proximity module not only handles all the proximity cells in world, but is also responsible for sending related EventHeap events to the reasoning engine. Whenever an avatar enters a proximity cell, the proximity module on the server side will send notification to that client about it. Then the proximity module on that client will create an event with its username and the name of the proximity cell and put it on the EventHeap.

3.2.3.2 Display Module

The display module is responsible making changes or updates in the virtual world and for displaying information on the heads-up-display (HUD) in OpenWonderland clients. Display module is the virtual world and client UI updater which was developed for our prototype. Likewise we can develop other updater depending upon the requirements. This module registers for events coming from the reasoning engine on the EventHeap server. Depending upon the type of the receiving event (Commonalities or Recommendation) it will display in the HUD. For example following is the template of recommendation event.

Event e = new Event("PatientRecos");

e.addField ("Recommendation", String.class, FieldValueTypes.FORMAL, FieldValueTypes.FORMAL);

e.addField ("Patientname", String.class, FieldValueTypes.FORMAL,
FieldValueTypes.FORMAL);

We chose a HUD for displaying recommendations and commonalities because it was easy to implement in the OpenWonderland API. We encountered many problems when we tried displaying information above avatars' heads. This is explained in detail in section 6.1 where all the architectural issues are explained. Using the HUD also has the benefit of remaining in a stable position on user's viewport even as they move around the world. This module is also responsible for moving the PDF documents in the virtual world. This module can also be extended to support different types of events to display new kinds of information.

3.2.4 Reasoning Engine

Reasoning engine performs reasoning on the knowledge stored in the ontology, context information from virtual world and SWRL rules. Its primary responsibility is to generate information which will be used to provide functionalities to the patients in the virtual world. For our prototype the reasoning engine was responsible for reasoning with the ontology and rules to generate recommendations and commonalities depending upon the location the avatar in the virtual world. It is constantly running, waiting to receive events from the proximity module on the clients. It will register for the events coming from the proximity module about the locations of the avatars using their templates.

Currently it will get registered for the 3 events i.e. 'User Enteredconsultancy', 'User Enteredcommon' and 'move pdf'. Following is the example of the template of 'User

Enteredconsultancy'. This module will register for the 'User Enteredconsultancy' event using the following template.

Event e = new Event("User Enteredconsultancy");

e.addField ("name", String.class, FieldValueTypes.FORMAL, FieldValueTypes.FORMAL);

e.addField ("typeR", String.class, FieldValueTypes.FORMAL, FieldValueTypes.FORMAL);

When the proximity module will put this event on the EventHeap, template matching will takes place and the reasoning engine will be notified. This module can be extended by supporting new event templates and generating different types of recommendations by reasoning with ontology and the rules.

Depending upon the type of the received events, it will reason with the ontology and the recommendation rules to generate personalized messages, communalities among the patients and the select the educational content. The selection of the PDF documents in the library is not done currently by reasoning engine. This might be the future work to include information about educational documents in our knowledge base and perform reasoning over it. Display takes care of selecting PDF documents and moving them in front of the users.

3.3 Steps for Implementing the Functionalities on Existing Medical Database

In this section, we will see how we can implement the functionalities on the existing medical data source using the framework. Following are the steps for implementing the functionalities. The examples used for explaining the steps are the food ontology for diabetes control [61] and EMR-EDC interface [62] for electronic medical record system.

3.3.1 Identify Decision Points and Corresponding Recommendation Sentences
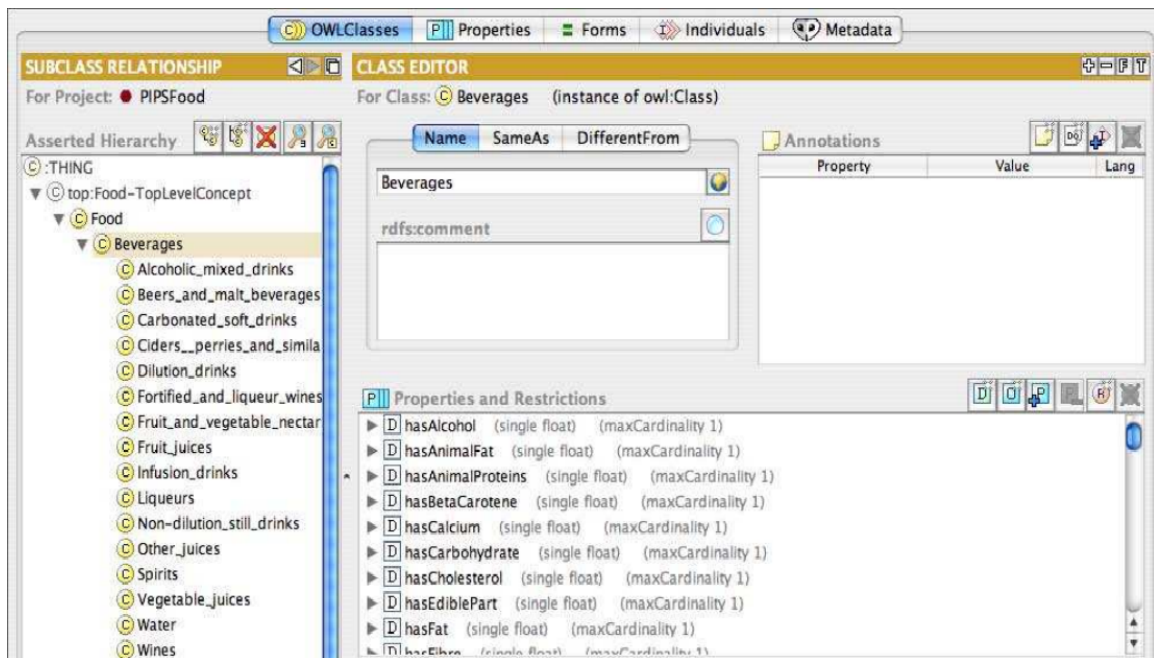
Figure 3.6 Food Ontology

The first step would be to identify the decision points from the medical data. For example hasCalcium<10mg from food ontology (refer figure 3.6). Similarly recommendation

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sentences can be defined based on the decision points. These sentences can be provided by the experts which are the doctors and healthcare providers.

3.3.2 Write New Rules Using Decision Points and Recommendation Sentences

After identifying the decision points and the recommendation sentences, the next step would be to transform the decision points and the recommendation sentences into the SWRL rules. As explained earlier the antecedent part of the rule (before implication) will be the decision points and the individuals of class Decision will be the consequent part which will be useful in accessing the recommendation sentences. These rules will be similar to the rules written in our existing knowledge base of the framework. An example of the rule written for providing recommendations using the Food ontology will be as follows.

$Food(?x) \wedge hasCalcium(?x, ?y) \wedge swrlb:lessThan(?y, 10) \rightarrow follow(?x, D\text{-}143)$.

The above rule means that, if a food contains calcium less than 10 units (or mg), then it recommendation D-143 will be displayed on the screen of the patient.

3.3.3 Reasoning over the personal & Drug related attributes of Patients
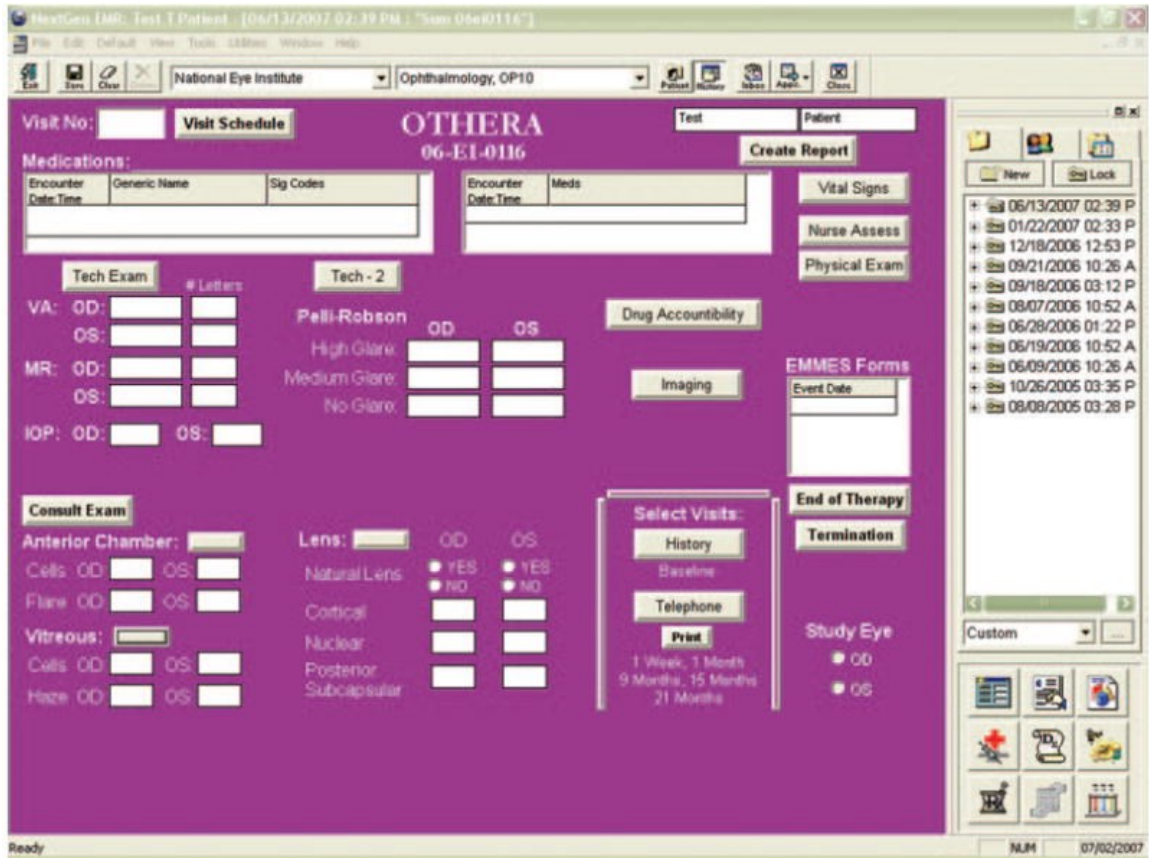
Figure 3.7 Example of an interface for entering patient's data

The third step will be to perform reasoning on the personal and drug related attributes of the patients to find similarities between them. Attributes like age, nationality and favorite sports have been used in the framework for displaying commonalities. Similarly attributes from the above example (figure 3.7) like vital signs, glare, type of therapy can be used to display commonalities which will be directed towards particular type of the patients.

3.3.4 Perform reasoning to find Keywords

Keywords from the electronic medical records and patients' information stored in the ontologies can be extracted. For example type of drug or disease name can be extracted for

the particular patient. Media files whose names will match with these keywords will be displayed in the virtual world.

3.4 Summary

In this chapter we have described the architecture of our framework. In the next chapter we will describe our prototype 'YouCan World', an online virtual world promoting psychosocial support for patients, which was built using the framework.

Chapter 4 Our Prototype 'YouCan World'

We developed a prototype 'YouCan World' using our framework described in previous section. Our prototype uses the core features of our framework and proves that our framework can be used to develop online virtual world applications for providing support to patients. It uses reasoning engine of the framework to provide psychosocial support to young cancer patient by displaying relevant and useful data in the virtual world. We are also providing the selection of the pdf documents based on the patients' profile stored in the knowledge base.

4.1 Requirements for providing psychosocial support to patients

Our prototype was developed according to the requirements for providing psychosocial support to patients mentioned before in section 1.2.1. Our prototype provides basic support for certain real-world scenarios, for example a patient consulting with the doctor, two or more patients having a conversation, and patients reading information on the web about their disease. It uses the components of our framework to provide the functionalities to meet the requirements. The functionalities offered in YouCan World are described in next section. Our framework provides all the resources needed to implement these functionalities. Our prototype shows the use of our framework to provide psychosocial support to patients.

4.2 Functionalities offered in YouCan World

YouCan World provide 3 main functionalities 1) Recommendations on what to follow-up with doctors in the consultancy room, 2) Commonalities between patients in the hangout room and 3) Selection of the relevant pdf documents among the patients in the library. Along with these functionalities OpenWonderland also provides some in-built functionalities like gestures. In this sub-topic we will describe the step-by-step working of all the components of our architecture to provide each of these functionalities. Following are the main functionalities provided in the YouCan World.

4.2.1 Recommendations on what to follow-up on with Doctors

Our application can be used by patients situated anywhere in the world to meet other patients and their doctors virtually. Thus a patient can contact a doctor who might be far away from him/her, just by logging in to YouCan World. We don't want the experience of patients with their doctor to be awkward and stressful, but instead to be easy and fruitful. The idea was to display recommendations to the patients as soon as they meet their doctors.
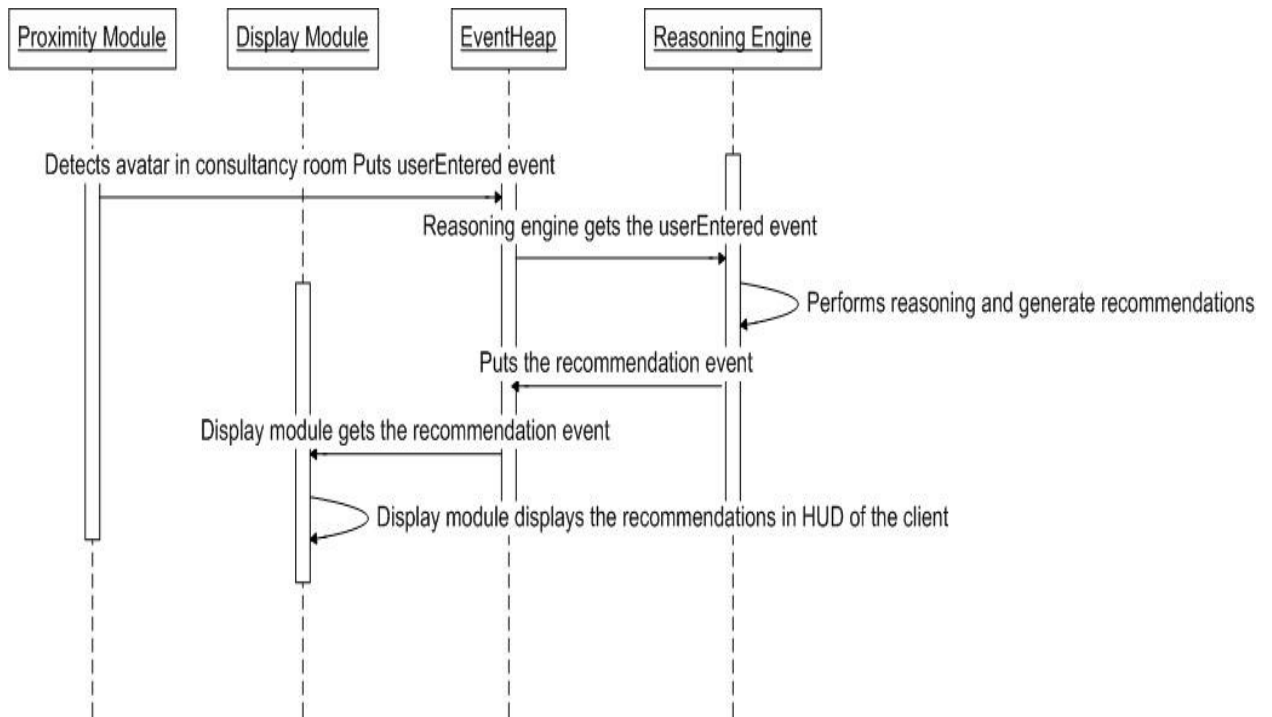
Figure 4.1 Sequence diagram for displaying recommendations

The recommendations are displayed when the avatar of a patient enters into the consultancy room. They are intended to help young cancer survivors to follow up with their healthcare specialists. These recommendations are based on the data which we have of the ongoing treatment of patients. When patients meet doctors in the consultancy room, these recommendations will remind them of what to ask or help to make their meeting valuable. The virtual world can be advantageous for meetings of patients and their doctors, as it reduces tension as compared to physical world scenario. Virtual world setup reduces the seriousness between the patients and doctors, providing the game-like (friendly) interface for the patients. Virtual worlds has been considered as the potential medium for education among patients and people with disabilities.

Currently in our prototype, doctors are not providing inputs in the recommendations displayed in virtual world. The data used in the implementation was taken from a research study conducted with cancer patients. But certainly in the future we would have to take inputs from health care providers and doctors on displaying recommendations for the patients.

Figure 4.1 shows the sequence diagram for displaying recommendations when a user avatar enters the consultancy room. One proximity cell is placed in the consultancy room. When any patient enters the proximity cell in the consultancy room, a userEntered event is generated and pushed on the EventHeap. The reasoning engine which is registered for the entered event will capture the event. Then it will take the username of the patient and give it to the reasoning engine for reasoning of the rules. Depending upon the profile of that patient, some of the rules will get fired, then the consequent part of the rules will be retrieved and made as events. These events are captured by the display module and then displayed in the HUD on the screen of the respective patient.

Figure 4.2 shows a snapshot of recommendations being displayed in HUD on the screen of the fictional user Steve. As soon as Steve enters the consultancy room, the user enter event is posted on the EventHeap. The reasoning engine captures this event, and comes up with the recommendations for Steve depending on the information stored in the ontology and SWRL rules. Now Steve can read these recommendations and will get some points to ask when he will meet his doctor. In short the recommendations are the questions that Steve needs to ask the doctor.
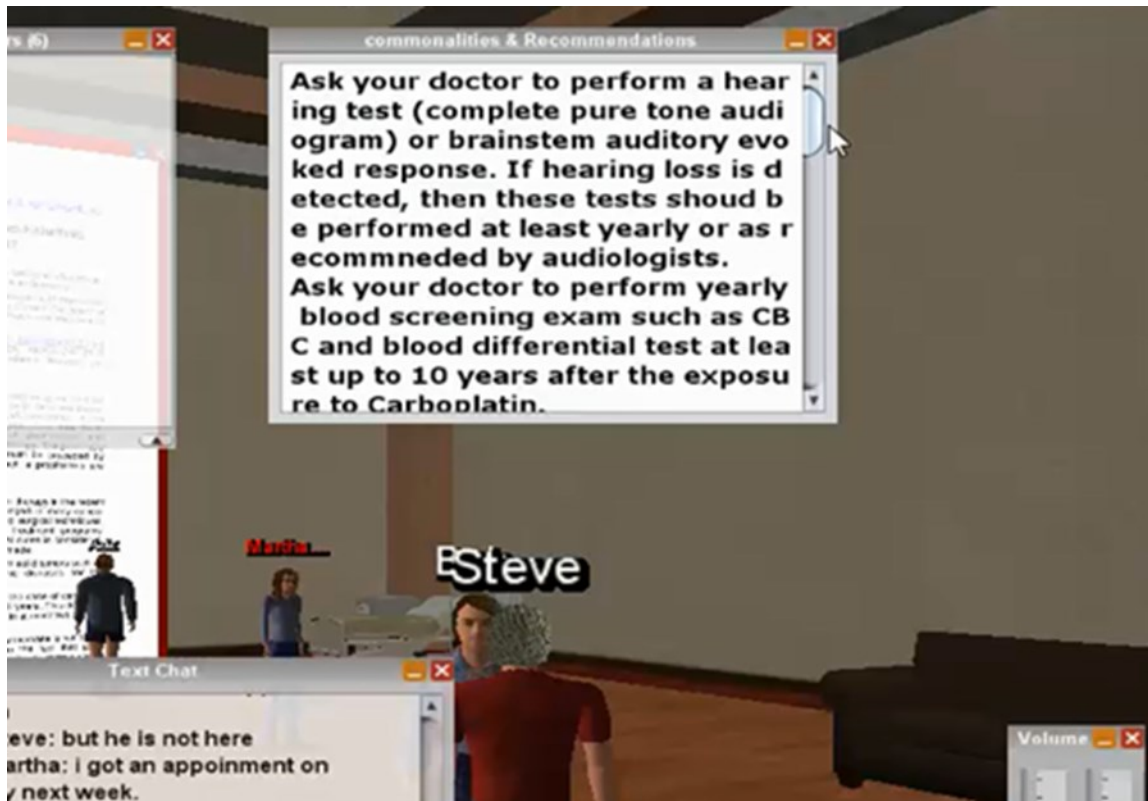
Figure 4.2: Snapshot of recommendations being displayed

4.2.2 Displaying Commonalities between Patients

YouCan World was developed primarily to provide psychosocial support to patients. We have the profiles of the patients stored in our knowledge base along with the drugs they are currently consuming. Based on the profiles of the patients, we are displaying the commonalities between the patients in the virtual world. The commonalities are displayed on the Heads-up-display (HUD) of the virtual world screen. Figure 4.3 shows the commonalities displayed on the screen of a user. We hope that this commonality will trigger conversation between the patients, which will help them to share their fears and anxiety about the ongoing treatment. Klemm et al. has done a review of the research done

in online cancer support groups [31]. They reviewed around 9 research studies focused on computer mediated or Internet cancer groups. They found that sharing of information was prevalent among all the groups who participated in this study. This research suggest evidence that this functionality will prove useful in sharing information among the patients, once they start communicating with each other.

Figure 4.3: Snapshot of commonalities being displayed
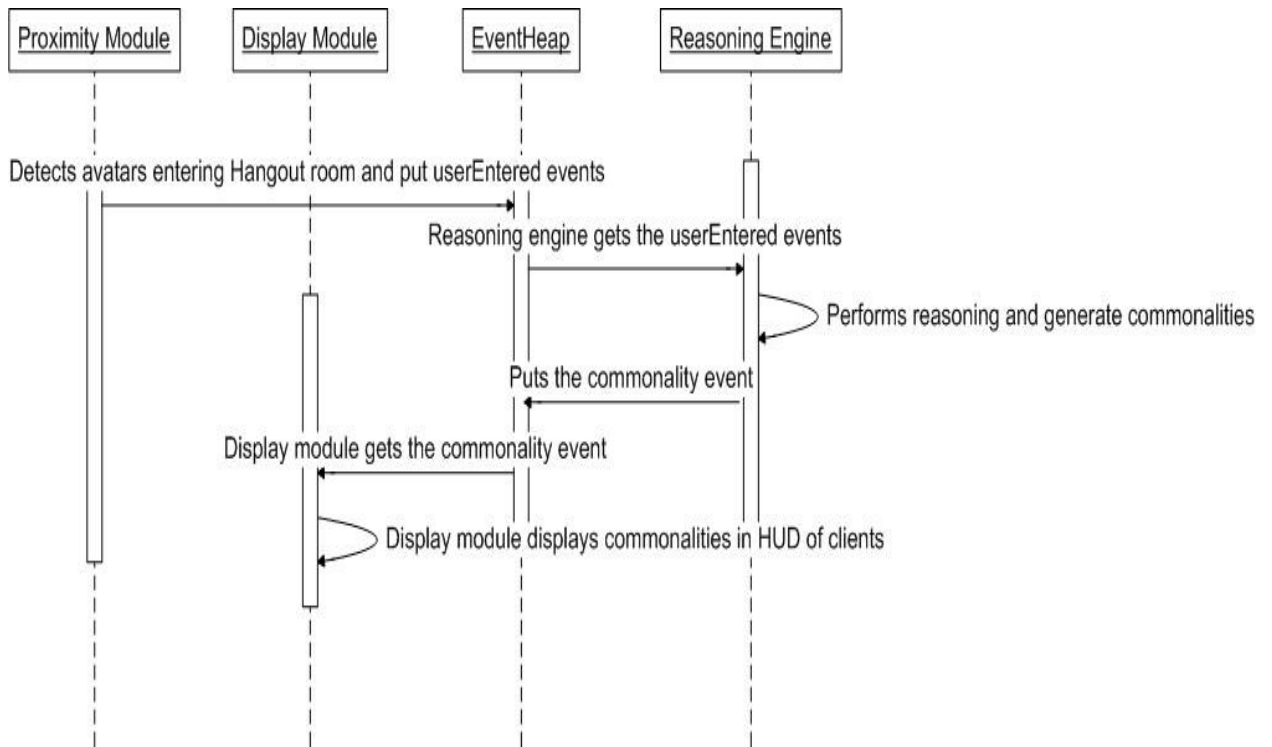
Figure 4.4 Sequence diagram for displaying commonalities

Figure 4.4 shows the sequence diagram for displaying commonalities in the hangout room. The proximity cells are placed in various places in the virtual model where we are expecting the patients will navigate their avatars. When 2 or more avatars come close to each other (Enter inside a proximity cell) their usernames are captured by the proximity module, userEntered event is generated and pushed on the EventHeap. The reasoning engine will receive the usernames of the 2 avatars. Then it will find out the commonalities between the 2 patients in terms of drugs they are taking, their country of origin and their favorite game. After retrieving the commonalities the reasoning engine will make an event named as 'commonalities' and put it on the EventHeap. The display module will capture

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this event, and depending upon the event type it will display the commonalities on the HUD on the particular patient's screen.

4.2.3 Selecting PDF Documents based on the Profiles of Patients

When we were developing YouCan World, we wanted to make it personalized depending upon the profile of the patients. We hope that this will make the virtual world more suitable for the patients and they can really benefit from it. Patients will find it hard and tedious to find the required and useful information, if we populate the virtual world with lots of resources. They might miss information which can be really useful to them and end up reading irrelevant content. This will lead to unpleasant experiences and will reduce enthusiasm regarding the application. We hope that this functionality will encourage patients to read the documents which are selected based upon their profiles.

One way of personalizing the virtual world is to select PDF documents based on patient profiles and placing it where it will be easy for the patient to find and read. The relevant PDF documents are selected based on information stored about patients. We designed a place in the virtual world where we can display these selected PDF documents.
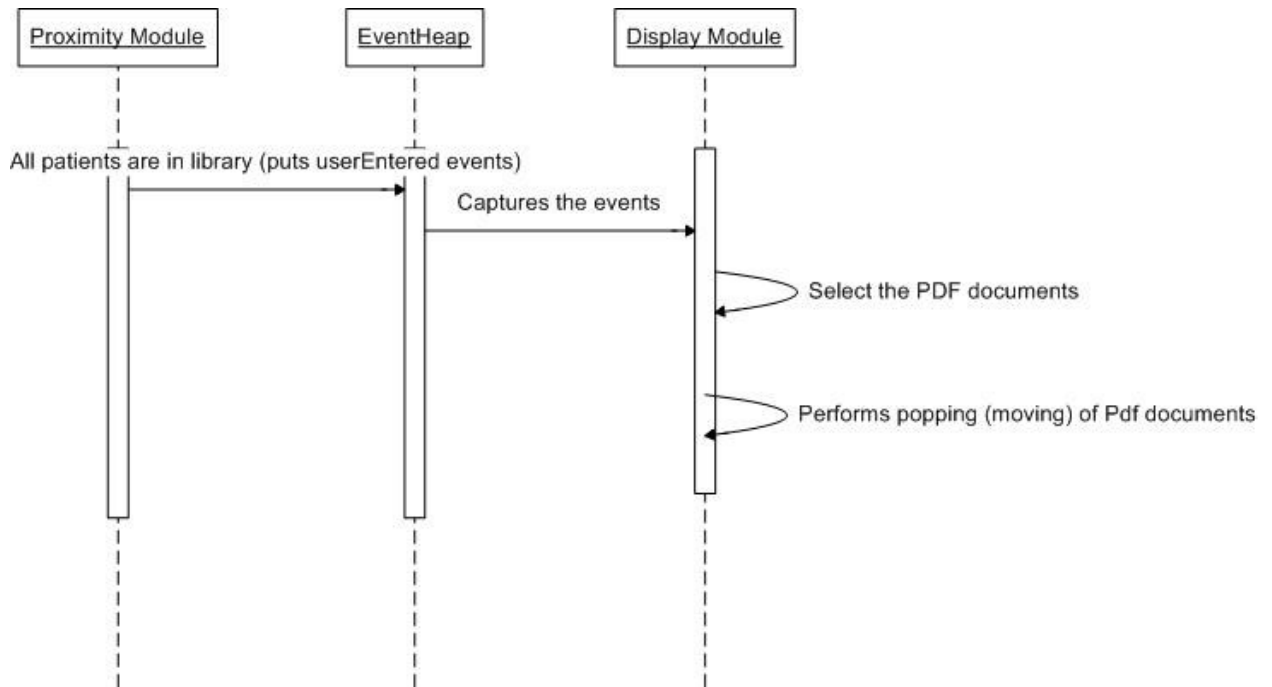
Figure 4.5 Sequence diagram for selection of pdf documents

Therefore, we created a reading room in our virtual model by inserting some 3D models, making it somewhat similar to a physical library. Figure 4.5 shows the sequence diagram for selecting and popping of relevant pdf documents in the library. When the avatars of a patients enter the reading room, the proximity cell in the reading room will detect their usernames and put the userEntered events on the EventHeap. The display module installed on the client side will receive this event from the EventHeap and then choose the PDF documents for that patient. It will make the selected PDF documents pop up from 3D book shelves in front of the patient avatar. The popping of the documents refers to the enlarging and moving the PDF documents. This gives the effect of personalization to the patient indicating that the PDF documents in front of him/her are related to his/her current treatment.

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Figure 4.5 describes the sequence diagram for the functionality of selection of relevant PDF documents in the library. As shown in the sequence diagram, when all the patients enters the library, the proximity module generates userEntered events for all of them. The display module capture these events. Then it selects documents and move them in front of the patients. Currently for our prototype the display module will be responsible for selecting pdf documents and popping in front of the users. We wanted to perform the selection of the documents through reasoning of the data stored in our knowledge base. It would be our future work and it is explained in detail in chapter7.
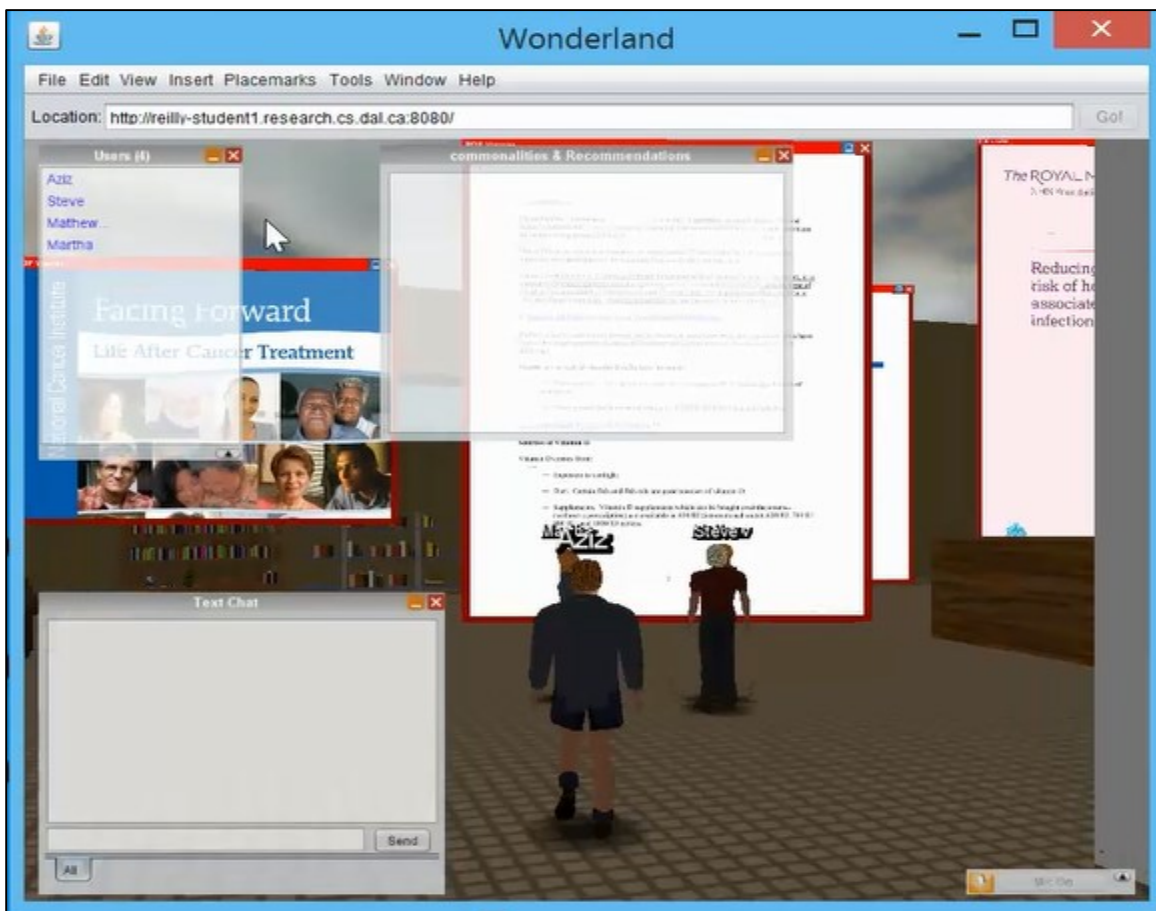
Figure 4.6: Snapshot showing participants reading and discussing the selected PDF documents in the library

4.2.4 Interactive Models and OpenWonderland Inbuilt Functions

OpenWonderland has many inbuilt resources for the users to use for more productive communication and a more pleasant experience. These resources consist of options for using gestures, text and audio modes of communication and whiteboards. We have also inserted some in our virtual model to provide a more interactive world. For example, we inserted some models of the equipment used in chemotherapy in the consulting room, which can be used by doctors to explain the therapy to the patients. These models are not interactive, but resembles the actual equipment used in chemotherapy. Figure 4.7 shows these models in the Consultancy room. Likewise, there are other 3D models in the virtual world which patients can use. We have inserted sofas and tables in some parts of the YouCan World which can be used by patients to sit and chat with each other. There are also some general purpose rooms in the world which provides extra space to socialize.
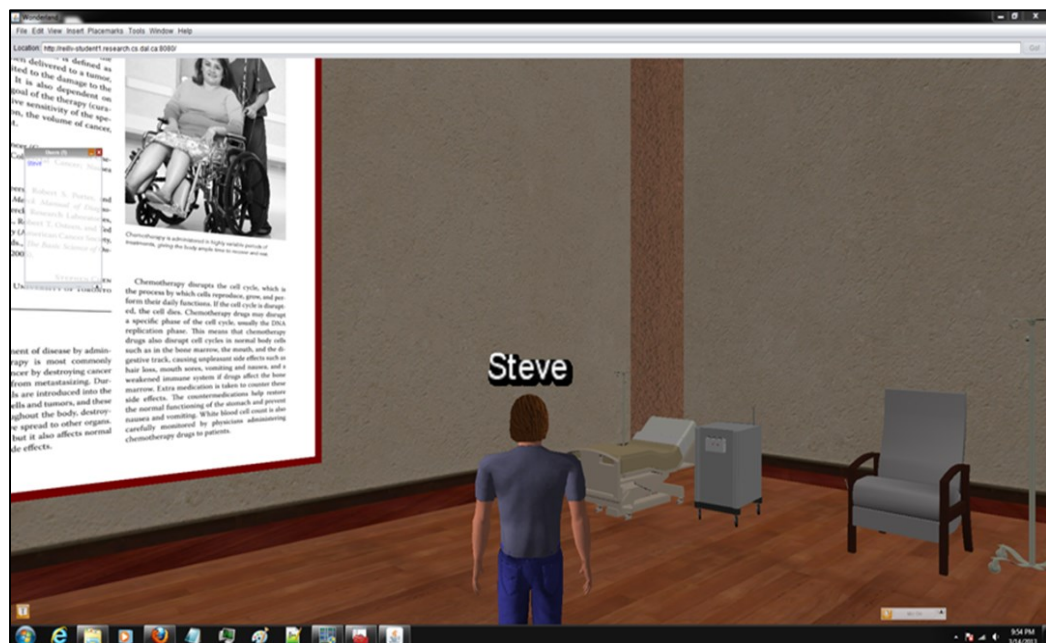
Figure 4.7: Snapshot of interactive 3D model in chemotherapy room
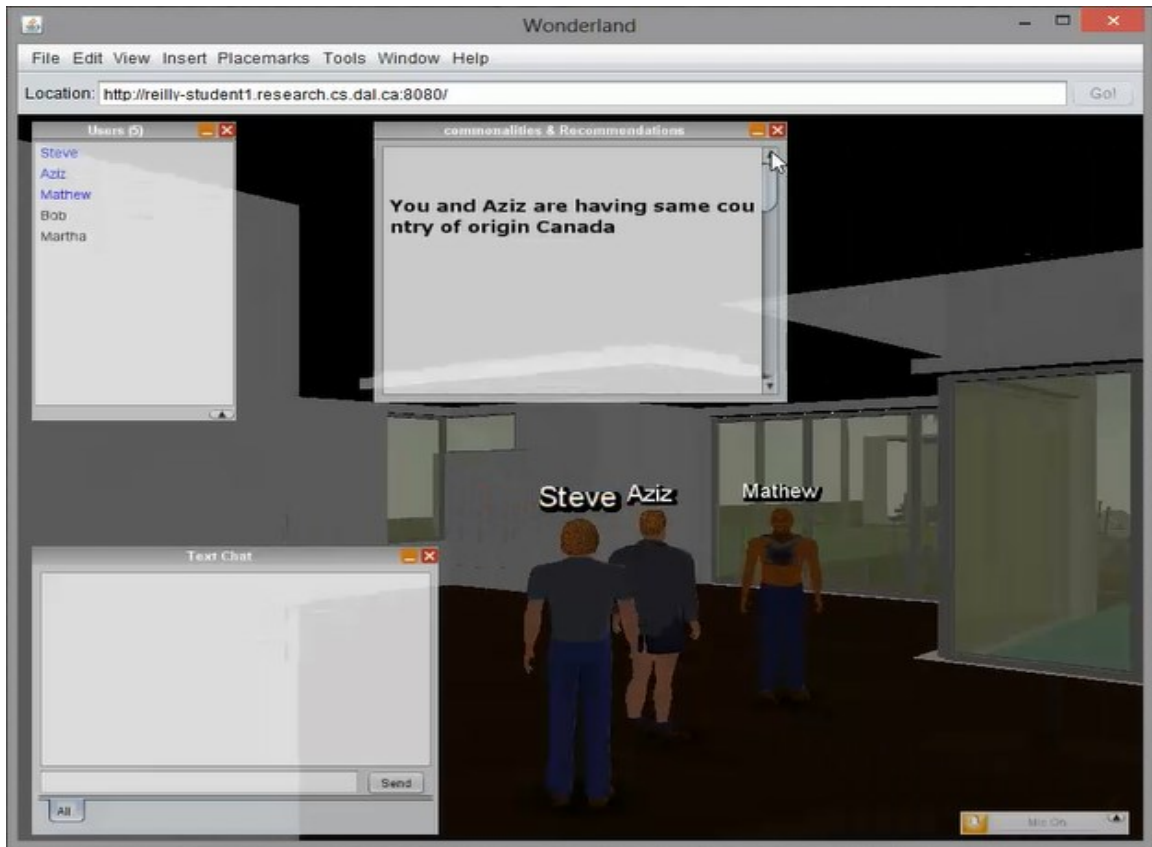
Figure 4.8: Snapshot showing patients doing conversation

Figure 4.8 shows how avatars of patients can have conversation with each other in the hangout room. We have inserted various informative PDFs in many places in the virtual world. They are easy to read and operate and also can be made full screen if required. Figure 4.9 shows a user is reading a PDF document.
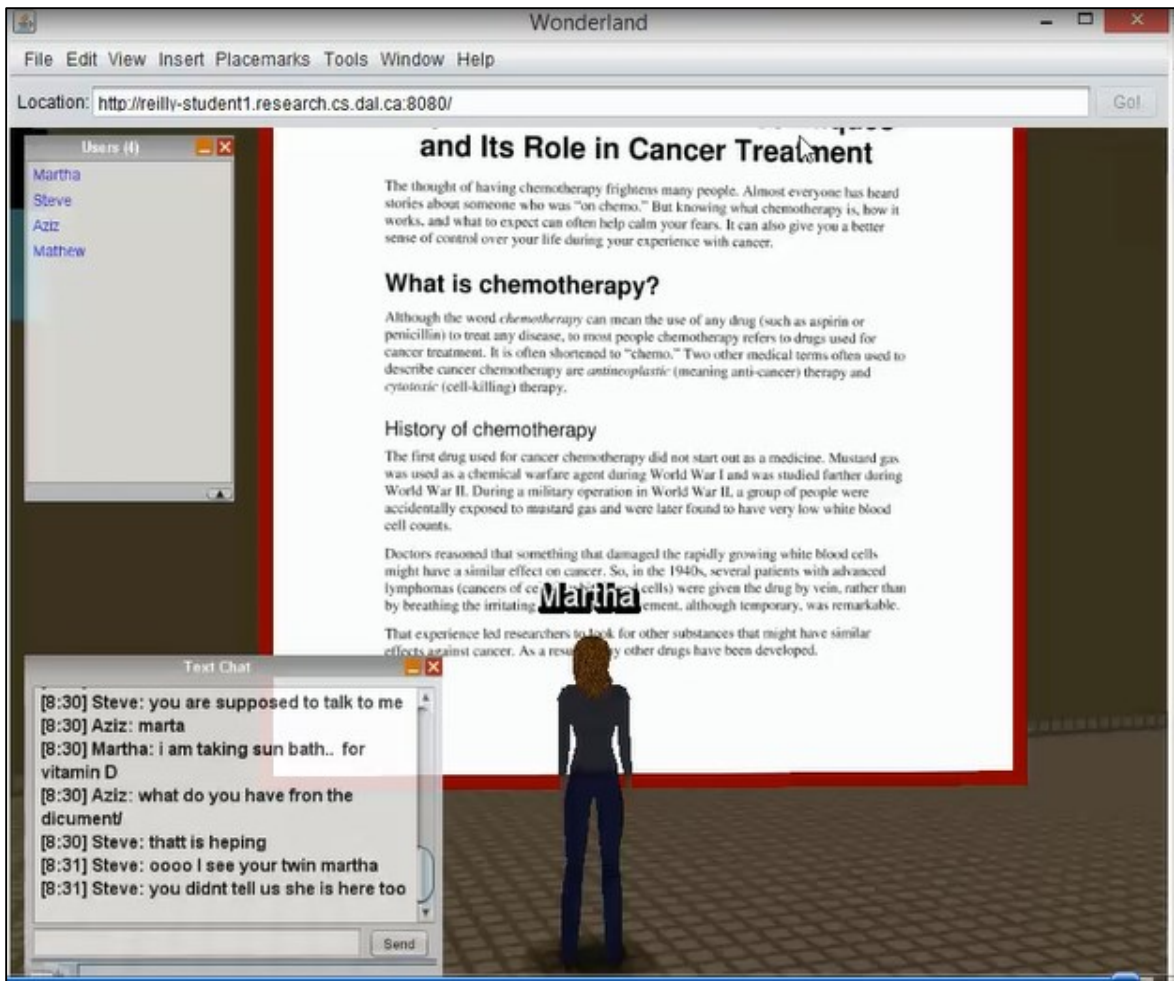
Figure 4.9: Snapshot showing patient reading a pdf document

There is a movie room in the virtual world where doctors can insert videos into, which patients can watch for various purposes. For example doctor can record message for the patients and upload it in the movie room. Likewise, patients can watch informative lectures about various treatments. Figure 4.10 shows patients watching an informative videos inserted by doctors explaining about treatment. OpenWonderland also provides a facility to access the Internet using a browser to watch any videos or documents they want to watch

or read. These models can be used by doctors to explain to patients about the therapies like chemotherapy.
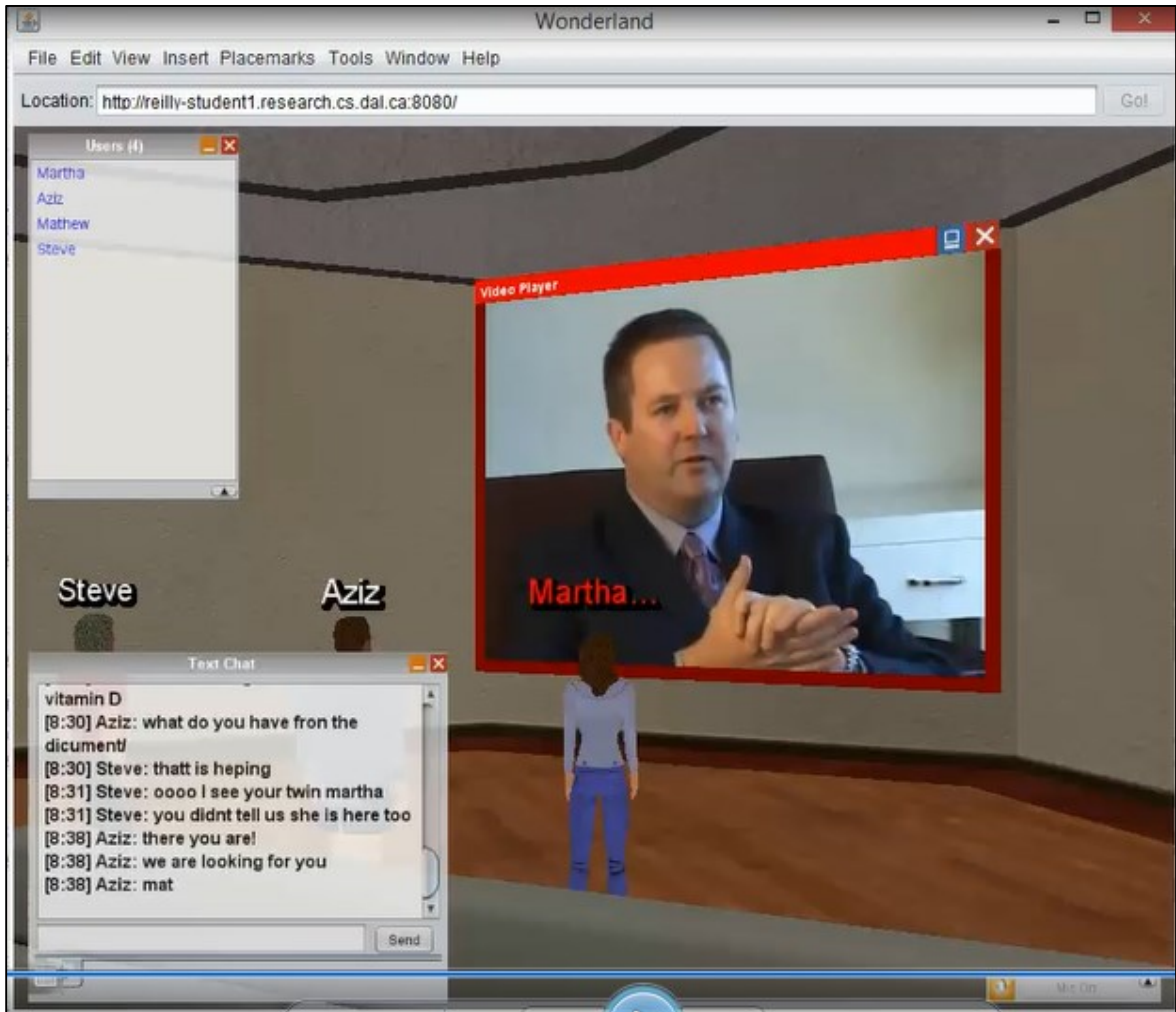
Figure 4.10: Snapshot of the video room

4.3 Summary

In this chapter, we have presented our prototype "YouCan World" which demonstrates the use of our framework. All the functionalities and features of YouCan World along with the working of the components of the framework are also described in this chapter. We

evaluated our framework by taking feedback on design and functionalities of YouCan World from HCI researchers. In addition we took feedback from students outside the Faculty of Computer Science on our application. For this we conducted focus groups, which will be described in the next chapter.

Chapter 5 Focus Group Evaluation of YouCan World

To evaluate YouCan World, we conducted two focus groups of four participants each to get feedback about the potential of the features of YouCan World to provide support to patients. Our focus group participants were HCI student researchers (first focus group) and Engineering students (second focus group) from Dalhousie University to get their feedback on the design and functionalities of YouCan World[1]. This chapter describes the design of the study (Section 5.3) and data collected (Section 5.4). The results are presented in detail in the next chapter.

5.1 Research objective

The main objective behind conducting the focus group studies is to get feedback on our prototype. The reason for recruiting HCI researchers for the first focus group was to get their views on the design of YouCan World and its usability for patients. We conducted the second focus group with engineering students to get feedback from users unfamiliar with online collaborative virtual environments. We were particularly interested in feedback about the room-based functionalities enabled by the framework (i.e., providing customized recommendations and suggestions to patients in the virtual world dynamically). Another important objective of the focus groups was to brainstorm additional functionalities and

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[1] We had intended to recruit doctors, nurses or cancer researchers who are often close to the patients and have thorough knowledge of patients' conditions. Due to ethics application difficulties and due to the very preliminary nature of the prototype world design we shifted to groups who could provide design feedback and novice impressions.

modifications that could make YouCan World a more effective environment for patients. Finally, we wanted to discuss possible privacy and security issues patients could face using our application. In short, the research objectives in evaluating YouCan World included:

1. Discussing with HCI researchers about the overall design of our application.

2. Determining the effectiveness of already implemented functionalities, particularly (but not exclusively) the semantic web features.

3. Identifying future directions for the system.

4. Identifying issues relating to security and privacy of patients.

5.2 Study Design

The focus group study was conducted in the GEM lab in the Mona Campbell building. For both groups, the study consisted of an introduction to the virtual world interface, followed by a group activity in which participants logged on to YouCan World and encountered its key features through a set of scripted tasks. After this questionnaires were completed individually and the group came together for an interview and a design brainstorming session. Each of these study elements is detailed in this section.

5.2.2 Study Protocol

Participants used either a provided Microsoft Surface with mouse, headset and keyboard, or their own laptops for performing tasks. The software was installed and tested on all machines prior to the focus group.

We met participants in the GEM Lab on the fourth floor of the Mona Campbell Building for the focus groups. After meeting the participants, we introduced YouCan World to them along with its functionalities and ways to use it. We explained how the application is intended to provide psychosocial support to the patients. Then we discussed the study and answered any questions of participants prior to starting the study, and got informed consent (Appendix B) from the participants. The facilitators then described to the participants use cases of YouCan World along with demos of the working scenarios. We gave the demo of YouCan World to the participants by going through each task included in the group activity. We performed a dry run of the group activity in front of the participants to give them the clear picture of what they have to do in the group activity. We explained them about the controls and resources available in YouCan World to perform these task. Lastly we answered any questions they have about YouCan World and the group activity. All this introduction, demo and background information took around 30 minutes.

Each participant was then seated in a separate working area, away from the other participants. Participants were given printed instructions with each task explained in the order they were to be completed (see Appendix D). Tasks involved using the core functionalities of YouCan World, and were designed such that participants used the functionalities as if they were patients. The functionalities were room-based and could only be accessed in particular virtual locations. Participants were asked to navigate from place to place to use the functionality and perform each task. Participants were asked to perform all tasks in the order provided; an experiment facilitator was on hand throughout to assist and answer questions. To begin, participants logged into the world as patients whose profiles were already stored in our application. Upon login, participants were located in a

virtual lobby area, with signs welcoming them to YouCan World, couches and plants. To complete the tasks, participants visited places in the world that we created for the tasks. Information about the purpose of each place and how to navigate in the world were displayed directly in the virtual world.

Completing all tasks took approximately half an hour. The tasks are as follows

1) *Consulting with a doctor in the consultancy room*. Participants were to enter the consultancy room one-by-one to meet the doctor, although no strict order was imposed (they were free to coordinate this themselves). The consultancy room was visible from the lobby and labeled. The room itself contained a PDF article on one wall, models of medical equipment and a seating area. For the sake of the activity, one of our researchers logged on and played the role of the doctor. When they entered the consultancy room, the recommended topics of discussion were displayed in the participant's Heads Up Display (HUD). Their task was to use the displayed recommendations to consult with the doctor[2]. This task was intended to give participants exposure to the automatic personalized recommendation feature, and to give them a sense of how recommendations could be used to facilitate discussions with a health care provider.

2) *Socializing in the hangout area*. The hangout area was accessed by selecting it from the "placemarks" menu on the virtual world client. The activity was included to get feedback on the functionality of displaying commonalities. When participants entered the hangout area, commonalities were displayed between them and others

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[2] Due to the knowledge base we were using, the recommendations were not related to cancer patients, but were relevant topics to speak with a physician about. This was deemed acceptable since our participants were not themselves cancer patients or care providers.

in the room in their HUD. The area consisted of an Oceanside mansion in a modern architectural style with pool and beachfront. The participants were free to explore the hangout area, although the task instructed them to use the commonalities in conversation.

3) *Reading in the library.* When finished with the open-ended hangout task, participants could again use the placemark feature to jump to the Library for the task 3. In this case, participants were placed in front of the library entrance. This task demonstrated the dynamic selection and foregrounding of documents that are deemed by the system to be most relevant to the patients that enter the library. This was included as an example of how areas of the virtual world itself could be adapted based on the profiles of patients that were at that specific virtual locale at a given moment. In the task, participants were a specific document to identify and read with another participant (identified in the task by their virtual pseudonym). Participants were then free to read any other documents in the library.

4) *Watching a movie.* This task returned participants to the lobby area of the virtual world, where they entered an adjoining room intended for viewing media as a group. We included this task at the end as a way to see how participants would reconvene with each other after the previous tasks and coordinate a simple activity in the virtual world as a group. The movie was a short clip of a physician discussing cancer treatment.

After completing the tasks the participant were asked to fill out a post activity questionnaire (Appendix C.1). The first 4 questions in the questionnaire were about the room-based functionalities, asking the participants how they felt about them and how useful they might

be for patients. The next two questions were about the virtual world layout and new 3D models that could be added to YouCan World. The last questions dealt with the modes of communication (i.e., text and audio), and asked for suggested improvements or new features. Following this, participants took part in a group affinity diagramming exercise designed to identify and classify the prototype's key strengths, weaknesses and areas for modification (Appendix C.3). This completed the study. The entire focus group studies lasted for approximately 120 minutes.

5.2.3 Data Collection

The data collected included post activity questionnaire responses (Appendix A), screen recordings of each participant using the application (using Camtasia Studio), and video recording and snapshots of the affinity diagram results (i.e. clustered sticky notes) from the brainstorming session. As participants used our application, the investigator made notes of any issues and feedback provided.

5.3 Data Collection and Analysis

We collected and analyzed the data from the questionnaires, video coded the screen recordings according to predetermined codes, and transcribed and summarized the outcomes of the participant affinity diagraming session. The predetermining codes used in video coding ware general and task oriented code such reading, speaking etc. We also defined new codes based upon observations in the screen recording for example 'going through wall'. Once this work was complete, we then combined screen recordings into

single video streams of the activities (one video per participant group). The resulting video record was separately annotated by five researchers, and the record was reviewed a second time as a group, allowing for adjustments or additions to researcher annotations. The resulting annotations were transcribed onto sticky notes and brought to a formal affinity diagramming session for qualitative analysis of data.

5.3.1 Post-activity Questionnaire

The post-activity questionnaire contained a wide variety of questions, including questions about room-based functionalities and the layout of the world. We collected the responses from all eight participants and highlighted both points made by multiple participants and points that we considered particularly relevant for the design of YouCan World.

5.3.2 Screen Recordings

The screens of the participants during the group activity was recorded along with the audio of the participants talking with others through YouCan World. These recordings helped us to review and understand the actual behavior and events happening in YouCan World. We analyzed these videos in a first pass by coding them using the Vcode software in Mac OS. We defined some ranged and not-ranged events (codes) to mark the events happening in the video for analysis. We present the results from this preliminary coding analysis in section 5.3. The results are presented in terms of number of occurrences for ranged and discrete events, and time durations for the ranged events.

5.3.3 Data collected during Brainstorming session

The data during the brainstorming session was collected in the form of video recording and the clusters of the sticky notes made by the participants. In the brainstorming session participants were asked to note down their impressions, improvements, issues etc. on the sticky notes. Then they were asked to arrange into clusters and to discuss them with the principle investigator. We captured the discussion in the video recording and preserved the sticky notes. The videos during the discussion were transcribed to get any important points made during the discussion. This allowed us to compare the comments of the participants with their actual behavior in the virtual world during the group activity. The transcribed discussion during the brainstorming session was summarized and brought to the researcher affinity diagramming session along with the post-activity questionnaire results.

5.3.4 Data Preparation for Affinity diagram session

In order to perform the qualitative analysis of the data captured during focus group studies, we combined the videos of screen captures of each focus group into a single video, using Adobe Premiere Pro software. The synchronization of combining these videos was not perfect, but sufficient for us to study the participants.

5.3.5 Affinity diagram session

The advantages of conducting open annotations and a researcher affinity diagram session in addition to the video coding of the screen captures were: a) a single researcher might miss important details in the video record, b) by not constraining the annotation process

we permitted a wider range of potentially relevant observations to emerge during annotation, and c) in the affinity diagram session, researchers could discuss and debate observations and get clarification about events that may have been confusing.

This analysis was conducted with five researchers including the author. Each researcher was asked to individually watch the combined video and note any important or interesting events, actions done by participants' avatars in the virtual world. Researchers then met to review the combined video a second time as a group, adding or changing their notes as appropriate. After noting (or copying) all observations onto sticky notes, the researchers conducted an affinity diagram session. In the session, each researcher held their own sticky notes and put them on a large, wall-sized white board, arranging them into clusters by placing similar notes close to each other. During this the researchers did not talk with each other. Each researcher was allowed to move any sticky note, if they felt that it was not correctly placed. After finishing arranging all the sticky notes on the white board (determined by a marked reduction in placement and moving activity), 9 main clusters of sticky notes emerged. The researchers then discussed and named each of the clusters. As the clusters became more defined and consensus was achieved, the researchers moved a fraction of the notes around to reflect the final understanding.

Chapter 6 Results from Focus Groups

In total eight participants participated in the two focus group studies. For our convenience, we will be referring each of our participant with a unique ID described in table 6.1.

Focus group No	Participants' YouCan World Pseudonyms	ID
Focus group1	Steve	P1
	Aziz	P2
	Martha	P3
	Matthew	P4
Focus group2	Steve	P5
	Aziz	P6
	Martha	P7
	Matthew	P8

Table 6.1: Participant IDs

We conducted the focus group study to get feedback on the design of YouCan World and the core features, rather than to explore research hypotheses. We also sought ideas for

improving or expanding both YouCan World and the underlying framework. Our analysis and results reflect these intentions.

Table 6.2 provides a summary of the group task experiences during the YouCan World activities, serving as a high-level comparison of the experiences of the two groups.

	Focus Group1	**Focus Group2**
Consultancy room	Participants consulted doctor Bob using the displayed recommendations. Participants hung around in the consultancy room after consulting while others were meeting the doctor. P2's avatar was staring at a PDF, while P1 was casually chatting with P3.	Doctor Bob was not present, as the client of the doctor crashed. Participants were instead asked to simply read the displayed recommendations and navigate inside the room. Participants entered and left the room one at a time.
Hangout area	P1, P2 and P3 were communicating with each other using displayed commonalities, while P4 was experiencing some audio problems. P4 was standing with the others, but not talking and they were commenting on each other's appearance. P2 changed his avatar's appearance after coming to hangout area. P3 was trying to figure out whose client was creating noise.	Participants communicated with each other using the displayed commonalities. P2, P3 and P4 were communicating while P1 was experiencing audio problems. All the participants explored the hangout area model inside out and seemed to enjoy their time.
Library	Participants were communicating using text chat a lot in this room. P2 and P3 performed their tasks correctly and P1 was trying to talk to them. P4 was not able to talk.	All the participants appeared to read the relevant PDF documents, but they were not discussing what they read with each other PDF.
Movie room	Participants watched the video together. Video quality was good with some audio glitches.	All the participants watched the movie together and were discussing about it after. The

			audio quality was better than that experienced by Focus group1.

Table 6.2: Summary of events in both focus groups

6.1 Results from Post-Activity Questionnaire

Tables 6.3 and 6.4 show the post-activity questionnaire responses. 6 of 11 questions are in yes/no /not decided format. We summarize the responses for the remaining 5 questions.

Sr No	Questions from Post-activity questionnaire	P1	P2	P3	P4
1)	Do you like the room based functionalities of YouCan World? (For example displaying commonalities in the hangout room, displaying recommendations in the consultancy room and selection of relevant pdf documents in reading room) If not, what changes would you like have?	No	Yes	Yes	Yes
2)	Do you think the recommendations displayed in the consultancy room will help young cancer patients to ask	Yes	Yes	Yes	Not decided

	questions to their doctors?				
3)	Do you think the commonalities displayed would help young cancer patients interact with other patients?	Yes	Yes	Yes	Yes
4)	Do you find the functionality of the library useful for young cancer patients?	Yes	Not decided	No	Yes
5)	What do you think about the layout of the rooms in YouCan World? What changes would you suggest?	Like it	Like it	Good	Good
6)	Are the PDFs in YouCan World easy to read and access?	No	Yes	Yes	No
7)	What are the potential privacy and security issues (if any) in YouCan World that would affect young cancer patients?	Private conversation with doctor	Private conversation and taking consent for displaying personal information	Provide option making public or private	Provide private space

8a)	How was your experience while communicating by audio with other avatars in YouCan World?	ok	Not good	ok	ok
8b)	Did you use text chat?	Yes	Yes	Yes	Yes
9)	Can you suggest any 3D models to improve the current YouCan World?	Unity has good option	Add models of pet, pictures	Add models with low poly count	No idea
10)	Can you suggest any modifications to improve the current functionalities of YouCan World?	Used different API other than OpenWonderland	Improve audio	Improve audio	No suggestion
11)	What additional functionalities do you think can be added to YouCan World to make it suitable for young cancer patients?	Insert games	More face expressions	More interactivity by inserting games	Functionality of saving articles.

Table 6.3 Focus group1 responses (HCI students) to post-activity questionnaire

Sr No	Questions from Post-activity questionnaire	P5	P6	P7	P8
1)	Do you like the room based functionalities of YouCan World? (For example displaying commonalities in the hangout room,	Yes	Yes	Yes	Yes

	displaying recommendations in the consultancy room and selection of relevant pdf documents in reading room) If not, what changes would you like have?				
2)	Do you think the recommendations displayed in the consultancy room will help young cancer patients to ask questions to their doctors?	Yes	Yes	Not Decided	Yes
3)	Do you think the commonalities displayed would help young cancer patients to interact with other patients?	Yes	Yes	Yes	Yes
4)	Do you find the functionality of the library useful for young cancer patients?	Yes	No	Yes	Yes
5)	What do you think about the layout of the rooms in YouCan World? What changes would you suggest?	Reasonable	Least corners	Need directions boards	Insert some more furniture
6)	Are the pdfs in the YouCan World easy to read and access?	No	Yes	No	Yes

7)	What are the potential privacy and security issues (if any) in the YouCan World that would affect young cancer patients?	Private talk with doctor	Eradicate privacy problems	Gestures should not be used	Should have private talk with doctor
8a)	How was your experience while communicating by audio with other avatars in the YouCan World?	Was noisy	Having disturbances	Noisy	Noisy
8b)	Did you use text chat?	Yes	Yes	Yes	Yes
9)	Can you suggest any 3D models to improve the current YouCan World?	No suggestions	Current are fine	Add 3D effects to PDFs and interior	Can put some art or interactive person
10)	Can you suggest any modifications to improve the current functionalities of YouCan World?	Improve the speed	Improve the Hangout room to make it more suitable for socializing	Have a reception area outside consultancy room to schedule appointments	No suggestions
11)	What additional functionalities do you think can be added to the YouCan World to make it suitable for young cancer patients?	Insert games	Add video games	Add games	Insert interactive games

Table 6.4 Focus group 2 responses (novice students P5-P8) to post-activity questionnaire

We summarize the questionnaire responses as follows:

1) Aside from some technical recommendations from the HCI students, responses were consistent between groups.

2) The functionality of displaying commonalities was liked by all the participants. 6 of 8 liked the recommendations (2 undecided), while 5 of 8 liked the library (1 undecided, 2 did not like).

3) Participants were concerned about privacy when consulting with the doctor in the consultancy room. They propose to allow private conversations with the doctor.

4) All the participants faced problems with their audio and suggested to improve it.

5) 6 of 8 participants suggested to insert small games to entertain and involve the young patients.

6.2 Results from Brainstorming session

6.2.1 Affinity Diagrams

In the brainstorming session, the participants were asked to note down any strengths, weaknesses, ideas for improvements or additions on sticky notes. Participants arranged these sticky notes on the white board and then classified them into clusters without talking to each other. After classifying they discussed and moved sticky notes over the clusters if needed. In this section we discuss the clusters of sticky notes made by the participants.

6.2.1.1 General Impressions

1) It is new kind of social platform for young patients.

2) Liked the variety of the rooms and 3D virtual models placed in YouCan world.

3) The commonalities displayed in the hangout room will help to start communication between patients and is a good way of connecting patients.

4) YouCan world can really help patients to forget about their disease and socialize with each other.

6.2.1.2 Privacy and Security

Participants made various comments about the privacy and security of the functionalities provided in YouCan world.

1) As in the questionnaire, participants stated that private conversations with the doctor should be possible. Private conversations should also be possible with each other.

2) Another suggestion was to give the users control over the displayed personal data by allowing this data to be marked as public or private.

3) Participants in the second focus group were careful to take turns visiting the doctor in the consultancy room. They suggested to have a reception area outside the consultancy room to manage appointments with the doctor.

6.2.1.3 Suggested Improvements

1) The avatars can be improved to look like real people and aesthetics of the rooms can also improve to suit the particular scenarios in the world. For example the consultancy room should look more like a real world consultancy room.

2) It can be good idea to provide natural user interfaces (e.g. touch interfaces) to the patients to use YouCan world.

3) Make the YouCan world more fun by inserting small games like shoots and ladders or music players, video players for their entertainment. This can keep them busy if they have to wait, for example for an appointment with a doctor.

4) PDF document interface needs to be more clear and easy to access.

5) The current means of displaying data to the patients (i.e. in the HUD) is interesting but kind of gets in the way.

6.2.1.4 Performance Issues

1) The audio issues must be resolved.

2) The quality of the video in the video room was really good.

3) System was slow especially when moving from one room to other.

4) There was a lag in some of the clients which created confusion when watching the movie or communicating.

6.2.1.5 Usability

1) It was easy to use the application even though the platform was advanced.

2) Good quality headsets and microphone should be provided or used for the YouCan world.

3) Prior training and manuals should be provided to teach patients how to use YouCan world.

6.2.1.6 Other/miscellaneous

1) The types of PDF content in YouCan world should be more diverse, not only related to cancer and cancer-related treatments.

2) The patients should not feel the same way when meeting the doctor in YouCan world as in the physical world (the consultancy room was very clinical in appearance).

6.2.2 General comments

Participants also discussed their experience during the brainstorming session; we briefly outline key discussion points here. All participants agreed that the idea of providing

psychosocial support to patients using online virtual world had real potential. P3 from focus group 1 said that "it can be a proven kind of social network of patients". P7 said that it allows the patients to meet the doctors irrespective of their physical location. All other participants also gave positive feedback on using online virtual world to provide psychosocial support.

The commonalities displayed helped participants to start communication with each other. Also the information displayed in library documents provided some topics for communication. All the participants were especially happy with the hangout room. P7 said that "it will help patients to connect with each other and it will lead to discussion between them".

6.3 Results from video coding of screen capture

Table 6.5 tallies the occurrences and total durations of the ranged (durational) codes used for the screen capture videos of the participants. We have screen captures of only 6 participants. We could not capture the screens of 2 participants (1 from each focus group), who were using a Microsoft Surface computer that encountered issues starting the screen recording software and intermittently freezing when it was running.

	P1	P2	P3	P5	P6	P7
Using recommendations	0; 0	1; 12 secs	2; 85 secs	2; 31 secs	1; 12 secs	2; 14 secs
Using commonalities	3; 104 secs	2; 35 secs	1; 34 secs	1; 7 secs	5; 103 secs	4; 96 secs
Sharing knowledge in Library	1; 107 secs	0; 0	0; 0	0; 0	3; 268 secs	0; 0
Speaking	28; 1032 secs	13; 291 secs	11; 297 secs	3; 46 secs	22; 1431 secs	15; 233 secs
Walking	19; 385 secs	46; 640 secs	44; 634 secs	29; 312 secs	49; 666 secs	29; 471 secs

Reading	1; 4 secs	4; 125 secs	4; 125 secs	1; 205 secs	4; 81 secs	0; 0
Watching video	2; 232 secs	4; 242 secs	3; 238 secs	1; 139 secs	2; 170 secs	3; 140 secs
Noise	3; 10 secs	10; 75 secs	9; 75 secs	9; 36 secs	0; 0	10; 58 secs
World interrupted	1; 139 secs	3; 238 secs	2; 170 secs	2; 232 secs	4; 242 secs	4; 72 secs
World loading	1; 205 secs	4; 125 secs	4; 81 secs	1; 4 secs	4; 125 secs	6; 835 secs

Table 6.5 Video coding occurrences and total durations of ranged codes

From table 6.5 we can take some significant outcomes in respect to how participants used the resources and functionalities in YouCan world. All the participants were used the commonalities displayed in Hangout room to communicate with others. All participants except one used the recommendations displayed in consultancy room. In the library only 2 participants out of six in the table did share their knowledge after reading the selected pdf documents. This might be due to the task which involves group of 2 and one participants has to share knowledge from the pdf documents to other. There was average occurrences and duration of speaking, reading pdfs, watching video during both focus groups. All participants navigated (Walking) in YouCan world especially in the rooms and their favorite place was the Hangout room.

Similarly table 6.6 gives the number of occurrences for the non-ranged (discrete) codes used.

	P1	**P2**	**P3**	**P5**	**P6**	**P7**
Text message sent	6	6	18	16	6	4

Walking through wall	4	6	7	5	5	0
Using placemark	3	6	3	2	6	5
Recommendations are displayed	0	1	1	1	1	1
Commonalities are displayed	4	4	3	2	5	2
Checking keyboard controls	9	9	8	0	10	22

Table 6.6 Video coding occurrences of non-ranged codes

Based on the number of occurrences in table 6.6, we can conclude that participants was texting quite significantly. As discussed in brainstorming session, this was due to problems faced in the audio. They were walking through the wall as the collision was disabled. All the controls required in YouCan world was used by the participants such as placemark.

6.4 Affinity diagram session

In this section we present the outcome of the affinity diagramming work conducted by five researchers (including the author) using observations derived from their open coding of the screen recordings. As previously described, the researchers watched the screen captures of both focus groups individually and then as a group, noting down any observations they felt were interesting or relevant to the research. They created 227 sticky notes in total and then clustered them into major themes through an affinity diagramming session (refer Appendix E). Each theme is summarized here.

6.4.1 Use of Documents and Text Notifications

This cluster includes comments made about accessing information from PDF documents and information displayed in the HUD. There was 16 notes in this cluster.

1) The "popping out" of relevant PDF documents needs to be more visible or clear to the users. 2 observation made was indicating this. One observation was that the process of selecting and foregrounding PDFs happened in the background and users were not aware that the foregrounded PDF documents were selected based on their profiles. The other observation was stating that the participants were overwhelmed by popping of PDF documents. Some indication of the relevance of each document may be superimposed on the document window itself, or appear in the user's HUD. The animation associated with foregrounding the PDFs should also be more visible and gradual to convey this selection process more clearly.

2) 3 observations were related to HUD (heads-up display). Most participants did not seem aware that the recommendation/commonalities HUD required scrolling to see more text. Some participants did not scroll down until they were asked to. This can be fixed either by making the scrolling automatic or using some other technique to display the information. Participants were also not aware of minimizing the HUD if they are not using it. Also they were lots of HUD on their screen which was blocking their view.

3) 5 notes in this clusters was about accessing PDF documents. Some participants were finding it difficult to access and understand the PDF document controls. Also a PDF document cannot be controlled by more than one client at a time, unless the document is brought into the user's HUD. Due to these issues, participants often

seemed to stare at the PDF document rather than paging through them, perhaps missing key details in the document. A related issue is the lack of visibility as to whether someone is actually reading a document or not. Even if a user takes control of the document, there is no indication of this on other users' screens (other than showing the document pages change if/when they do). Figure 6.2 shows a participant who was staring at the PDF document in the consultancy room for an extended period of time. It seems that the participant was not reading the PDF, but was doing something else outside the virtual world. This issue might be addressed by having a status indicator that is visible to the users. The status indicator is explained later in the design improvements section 6.4.8.

4) One of the observation was about the displayed recommendations can be improved by making the text formatted and more readable. Currently text recommendations and commonalities appear in the HUD in plain text. Once the HUD window is filled with text there is no indication when new text is added (aside from the scroll bar changing size), nor is there formatting that might suggest the kind of information that is placed there.

5) The remaining 5 notes were general comments on how we can add new functionalities to YouCan world. One suggestion was to add a searchable interface in the library.
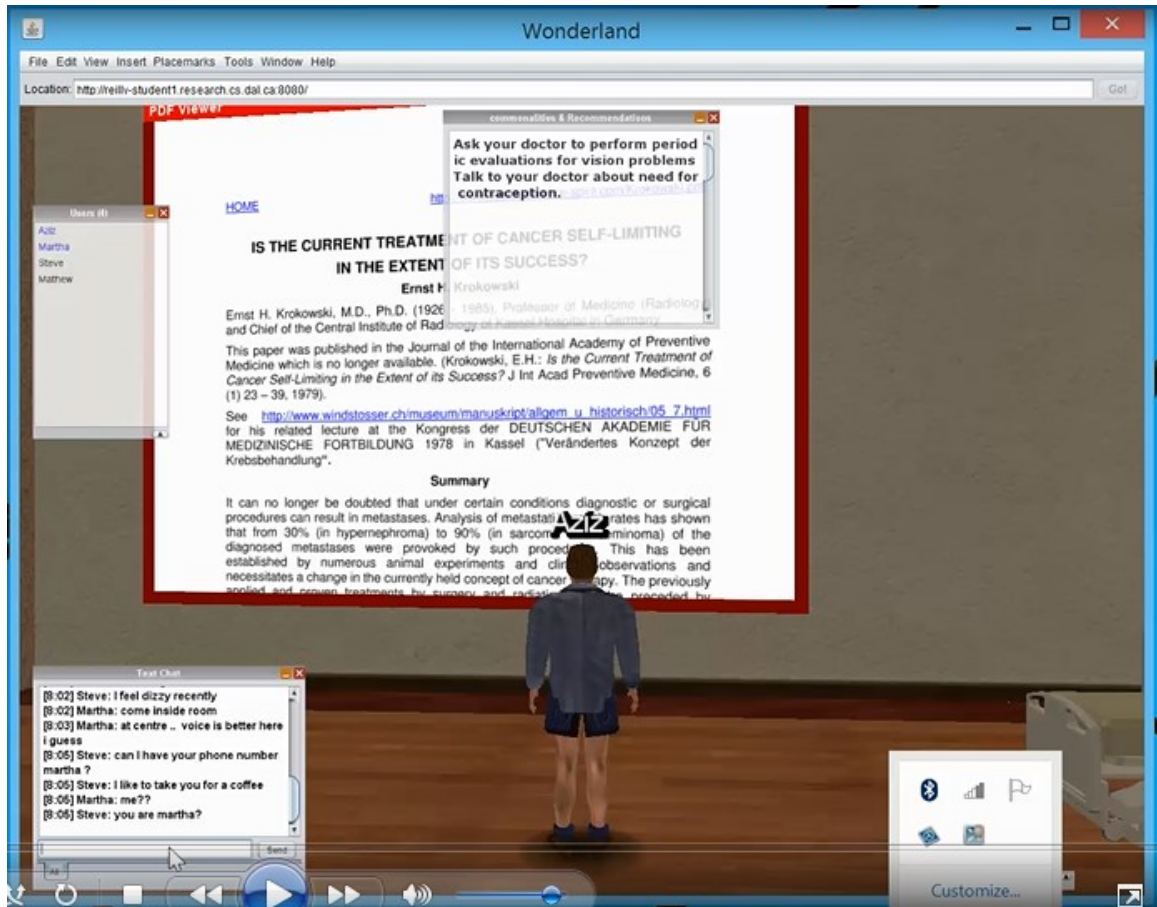
Figure 6.2 Screenshot of a participant staring at a PDF document

6.4.2 Navigation, Proxemics and Virtual Environment

The total number of notes in this cluster were 51. Navigation refers to how participants were moving in the world and were moving from one room to another. Proxemics can be defined as the interrelated observations and theories of one's use of space in relation to cultural practices and norms. By environment we mean the physical layout and design of the virtual space. Following are the major points from the notes in this cluster.

(a) Unwanted, repetitive, or unexpected avatar movement

Some of the participants were seen to be constantly moving while talking to others or watching the movie in the movie room. There can be 2 reasons for such behavior of the avatars. One is that there is a glitch in OpenWonderland which causes an avatar to appear to be walking in place in another client. The other reason is a participant's inefficient or compulsive handling of their avatar's movement. For example, some avatars were shown to be walking back and forth, or moving in circles. Finally, network latency can cause avatar movement to appear jumpy or out of sequence. For example, an avatar can be shown as moving backward if the final stop point of the avatar was not communicated to each client in a timely manner.

(b) Transition between rooms:

Participants actively coordinated the transition from one task region to another with each other. Some of quotes observed by the researchers are as follows

"Shall we teleport or shall we take a walk?" –P1, Group 1.

 People "follow the leader" out of consultancy room

As they were provided with instructions about tasks to perform in YouCan world, the participants were trying to coordinate and help each other with tasks. Group 2 also coordinated their visits to the consultancy room to meet the doctor. Most of the participants walked through walls at some point while navigating in the rooms, since collision of the 3D models in YouCan world was disabled for the activity, to facilitate navigation.

(c) Proxemics:

During the consultation task, P1 tried to find the best location in the consulting room to properly hear the doctor. This was an interesting behavior in terms of

proxemics where an avatar is trying to be in better position in a manner somewhat similar to what can happen in the physical world, but dictated in part by the audio characteristics of the virtual environment.

(d) Environment:

Consultancy room should be made private, where patients can have personal talk with doctor. This can be achieved by inserting signs at the door. The other places also need to be improved in terms of making it an even more suitable place for young patients to socialize with each other. There were suggestion to use more pleasant colors, insert models of pets and cartoons in YouCan world to make it a fun place for young patients.

6.4.3 Group Coordination

The total number of notes in this cluster was 12. Most of the notes made by researchers were explaining how participants coordinated with each whenever they needed to move from one region to another or during the consultancy visits in both focus groups. This shows how involve and in character the participants were while performing the tasks. In first focus group study, the participants did coordinate about who will go first in consultancy room, but did not bother to go inside and leave the room without coordination. On the other hand in the focus group2 participants did coordinate and went one-by-one inside the consultancy room. Such coordination is needed in these applications, which are public in nature and intended to provide support. There was always coordination among participants when they were moving to a new room. Some of the quotes observed during the affinity diagramming session was

"Can we go to Library?" –P5, Group 2.

"Who is going in first?" – P7, group 2.

"Shall I start movie otherwise" – P3, Group1

6.4.4 Communication Modalities

Total number of notes in this cluster was 35. We summarize these notes into 3 categories as follows.

(a) Interacting beyond task requirements:

One observation made during the affinity diagram session was that the participants were discussing on the topics which are not related to the task assigned. Participants discussed topics other than those displayed in commonalities in the hangout area or on PDF documents in the library. Details about how to use the virtual world was a common topic, as was the issue with poor audio. As two of our participant faced problems in audio communication (refer section 6.4.3), it was affecting the overall communication process. Participants also commenting on each other's avatar. P3 says to P1 "Are you not feeling cold, you are wearing shorts". The other participants in first group were making fun of P4 who was not able to communicate through audio. The participants made some comments on P3 such as "Mathew is doing meditation", "Are you fine". The conversation regarding who is Martha among the participants in both the focus groups were interesting and were resembling to the real world conversation and was related to the assigned tasks.

(b) Text chat:

Out of 35 notes, 19 notes was regarding participants using text chat. We summarize the reasons for the participants using text chat. Participants could choose to communicate via a text chat window with each other, or using audio. Messages on the text chat window were visible to all participants. Some participants were seen to switch from using speech to using text when the audio problems were severe. At other times, participants held side conversations using the text chat window. For example, participants were asking each other about how to use the gestures feature in YouCan World. For example P7 asked P5 "how to say hi, is there a key for waving".

(c) Gestures:

4 notes was regarding the use of gesture during the group activity. Only P1, P3 and P7 were using gestures for communication by waving at each other. There were a number of other gestures and animations available to participants. For example Figure 6.3 shows that P1 was sitting on the floor while talking to P3 and P1. We did not tell to the participants how to use gestures in YouCan world. Participants who used gestures discovered it during the group activity.
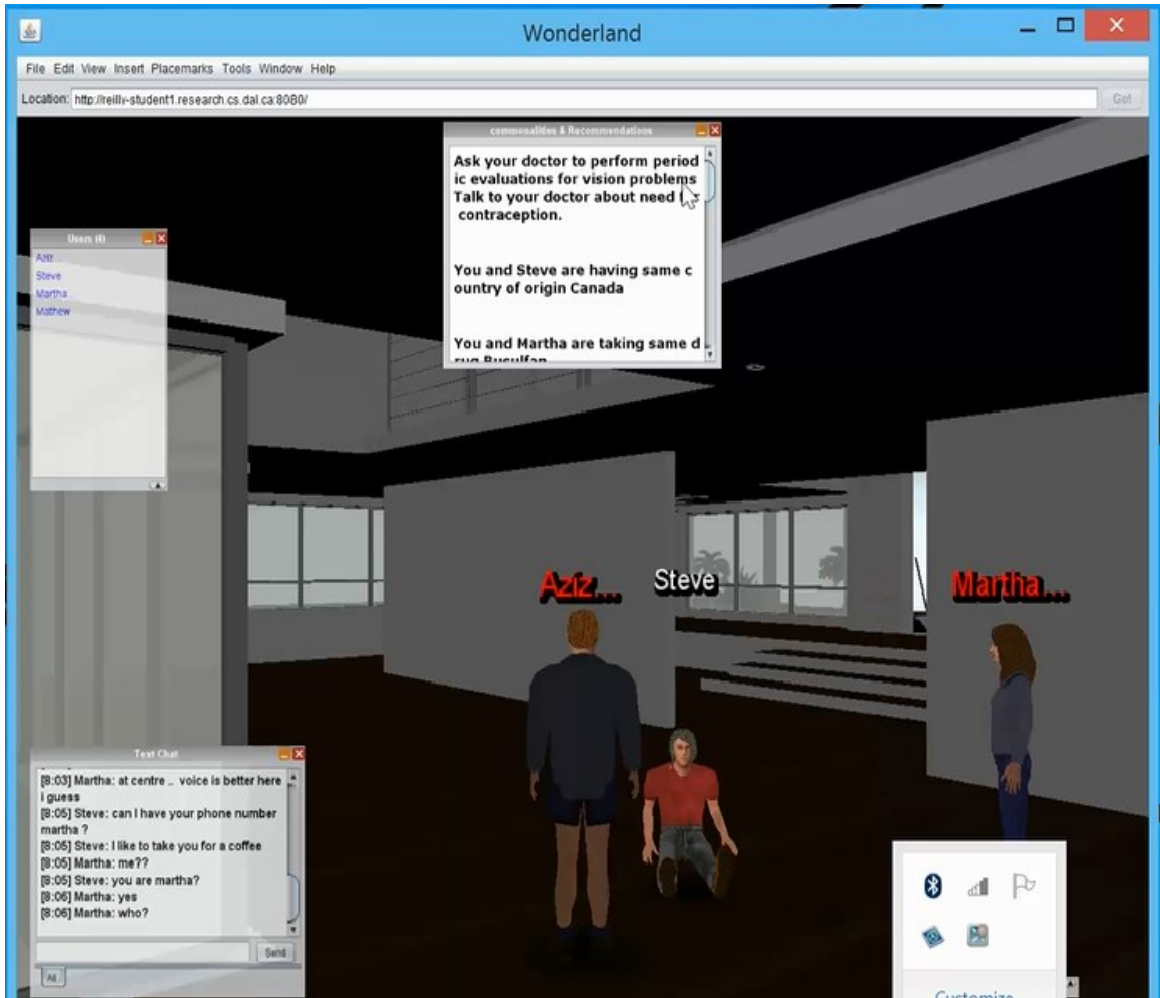
Figure 6.3 Steve(P1) sits on the floor while talking to Aziz(P2) & Martha(P3)

6.4.5 Playing and Socializing

There were 18 notes in this cluster. Out of which 6 were the quotes made by participants noted by the researchers. Participants were having fun and enjoying their time especially in the Hangout room. For example, Figure 6.4 shows P3 trying to swim on the water, but instead walking on it, as they cannot swim in the virtual world. They were also seen socializing by commenting on each other's appearance. Also it was noted in one of the note that P2 changed his avatar to be fit in the environment. He

changed to shorts and short hairs. Following are some participant texts and conversation.

"Hey Aziz you are late movie is over"

Aziz says "there you are" when he sees Matthew is already in video room

"Where did you get that hairstyle?"

"Matthew is meditating"

"Let's go to beach"
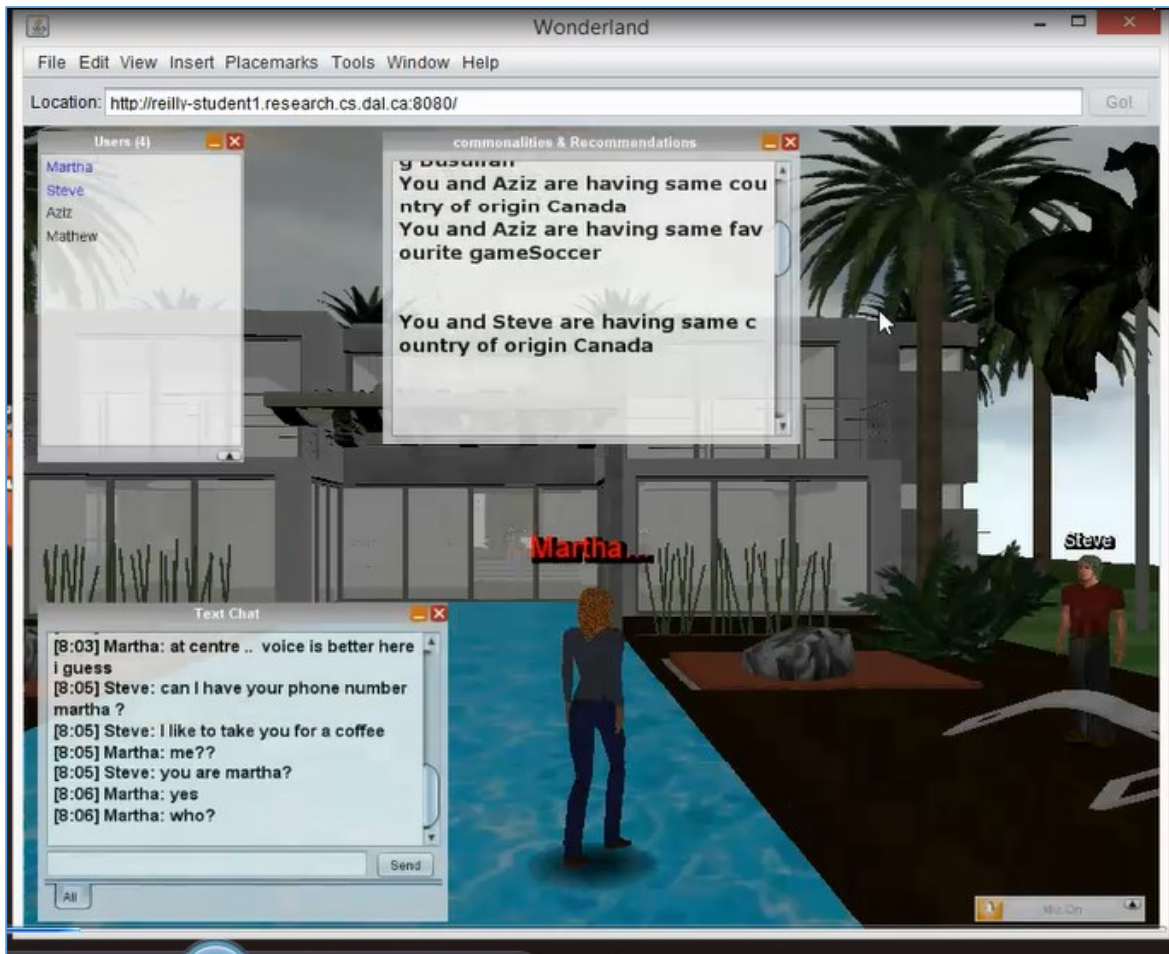
Figure 6.4 Martha is trying to swim end up walking on water

6.4.6 Gender

There were some observed patterns of behavior regarding gender among the participants. Total number of notes in this cluster was 7. Out of which 5 was about the discussion among the participants in both focus groups about who is *Martha* in the real world and other 2 was quotes made during group activity. For example during the first task of meeting the doctor in the consultancy room, P2 says to P3 who is standing at the entrance of the consultancy room "Ladies will go first". In both the focus groups, male participant was using Martha's avatar. While a female was using a male avatar in focus group 1. There was confusion among some of the participants regarding *Martha's* avatar, because they were not able to figure out whether the participant using the Martha avatar was male or female. Participant initially assumed that the female voice was associated with Martha's avatar. In focus group 1, when P1 was flirting with P3 (Martha), asking her to meet for coffee they realized that it was a male who was using Martha's avatar.

The role of gender in online virtual worlds is an active area of research. For example, Nassiri et al performed an experiment to understand the personal space anxiety level among genders in the virtual world. They found out the anxiety level among genders in the virtual world was less than the physical world [43]. They had around 50 participants in their study and the results were based on a post activity questionnaire. Facial expression, voice messaging and collision were not considered during their study. Gender will be a factor to consider while developing YouCan World in future.

6.4.7 Prior Participant Relationships

9 notes was there in this cluster. All the notes was about the factor which may impact participant behavior is whether or not participants knew each other prior to the study. Participants from the first focus group were seem to be knowing each other as compared with the participants from second group. Therefore it was observed that participants in first group was more comfortable with each other than the second one. Because there were less talk in second group as compared to first group. It was also discussed in affinity diagram session that the reason for less interaction will be due to no personal relations. The participants may study others communicating and then start talking with them. Participants from the second focus group started talking with each other only when they came to Hangout room. It was observed in both focus group that Hangout room was liked and participants felt more comfortable in it.

The behavior of the participants in the group activity was close to that of the patients as they were representing them while doing the tasks. We can say this because they were provided with the instructions sheets which was designed according the patients. The analysis of the screen recordings was not only important to find out the behavior patterns of the participants but also to see how patients will use the functionalities as they were representing them.

6.4.8 Privacy and Security Issues

This was the cluster which was made by the researchers, but the following points are taken from notes from other clusters related to privacy and security.

(a) Patient-Doctor relationship:

There are no rules or ethics defined in the medical field that apply specifically to patient-doctor consultation in a virtual world. There were times when more than one participant was present in the consultancy room. Figure 6.5 shows how other participants can easily listen to the conversation between the doctor and a participant. There should be some way of allowing only one person inside the consultancy room.
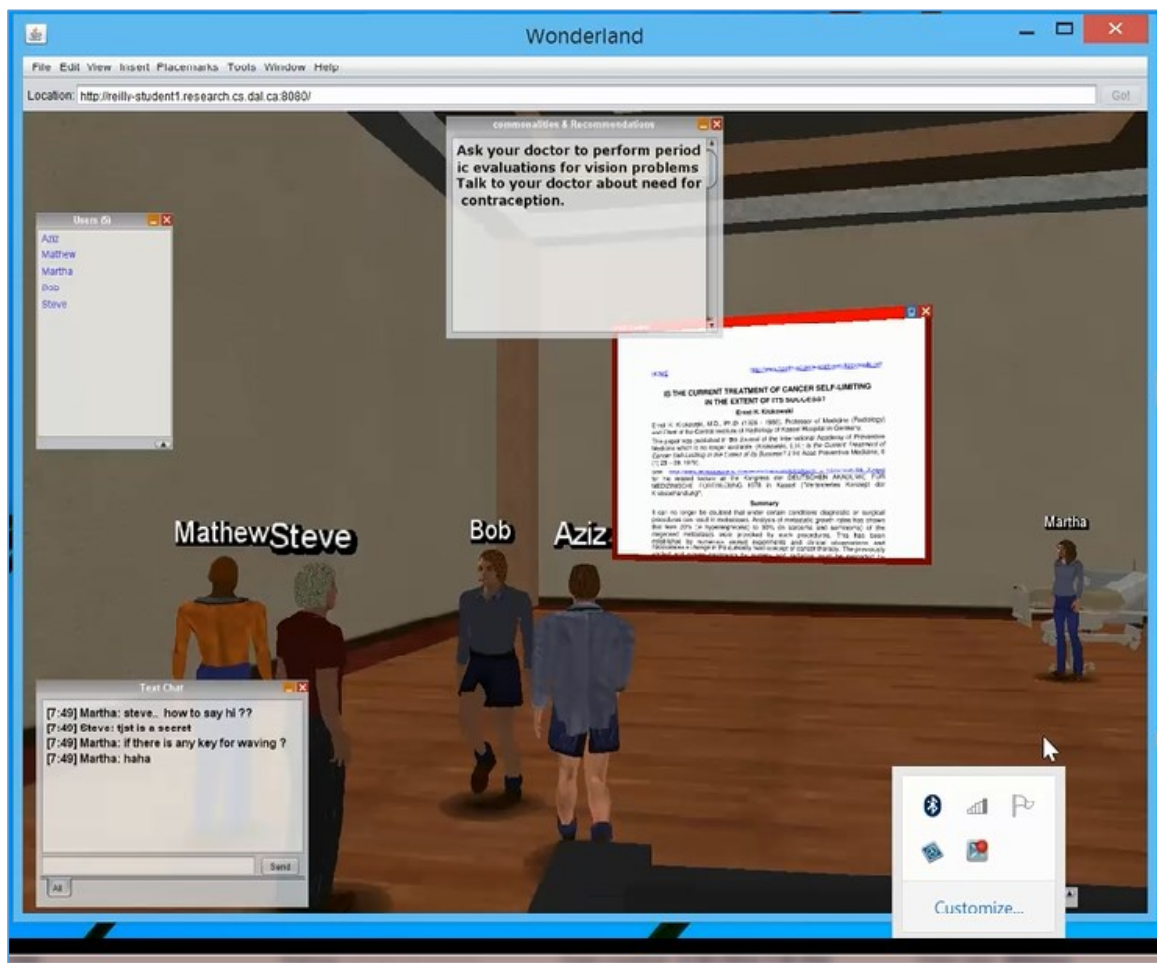
Figure 6.5 Other participants present when Steve is meeting the doctor

(b) Security and privacy in interpersonal communication:

There should be some features that give more control over communication between users. For example a user should be able to talk with someone else in private, or if he/she does not want to talk with someone they should be able to block them.

(c) Asking permission for displaying information:

Users should be asked whether they are comfortable sharing their personal data via commonalities. For example, a user may not want identifying information to be shared. There could be an interface where users can control what information they share, and with whom, in a manner similar to features found on some social networking sites.

6.4.9 Technical issues

The total number of notes in this cluster was 20. We categorize them into following points.

1) 5 notes was about the issues related to audio and noise. Audio problems were generated by one participant in each group, due to fan noise coming from the Microsoft Surface. This would be remedied by using a mic headset with the Surface. The effect was noise for any participant whose avatar came close to the avatar of the Surface participant.

2) Other 5 states that during the activity several of the participant's experienced crashes of their virtual world client, requiring a new login. Upon login, all the text in text chat window and HUD was gone. Backing up the HUD state might address this issue.

3) Remaining notes was about slowness of the systems and problems related to access of PDF documents. It was observed that the movie was not running properly on

some clients and it was too slow. Some participants was not able to access the PDFs due to their awkward angles. They were missing some of the features like scrolling the PDF documents.

6.4.10 Design Improvements

The total number of notes in this cluster was 59. Following are the interesting and major improvements from the notes.

(a) Status indicator:

Participant avatars from both groups seemed to stop and stare at something for a long time, whatever might be the reason. In extreme cases this lasted 5-7 minutes. A status indicator could be used by patients to inform others about their current status. Their status can be busy, available, away, etc.

(b) Proper tutorials and guidance:

Before patients could use YouCan world, attention must be given to the design of built-in guidance or tutorials that facilitate learning and using the system's features. During the activity we observed participants discussing and demonstrating how to use features with each other. Sharing knowledge between patients can help to build relationships, so we need to be careful that built-in guidance doesn't prevent that kind of collaborative learning and teaching from occurring. Some participants seemed to lose their way when moving from one place to another; more directional signage or a map of the world can be used to facilitate navigation.

(c) Configuration options:

There should be some form of procedure for patients that who haven't used YouCan world before to indicate initial preferences. Pre-login questions can inform how the system displays commonalities based on their personal information, for example. Are the participants are okay with displaying their personal information in virtual world.

(d) Improve layout:

YouCan World can be improved by using models and avatars that are better suited to the age group it is intended for. For example, more vibrant colors, cartoon characters and models of pets. In addition, P6 indicated that the avatar should look younger than the default in OpenWonderland, while others expressed that the avatar could be a means of maintaining privacy – which should not look like the patient him/herself.

(e) Insert small games:

Most of the participants suggested to have simple games like shuts and ladders in YouCan World, to make it a more attractive destination for younger patients. There were occasions where participants were waiting for other participants to finish meeting with the doctor; mini-games would help to pass the time in this case.

(f) Search portal:

Searching can allow patients to be more proactive and have more control over the content they access in YouCan World. Consideration needs to be given to how content selected as relevant by the system is presented to patients, and how they might provide feedback as to its actual relevance to them.

6.5 Study Limitations

We recruited HCI and engineering students for the two focus groups. These participants were not ideal for evaluating YouCan World. Patients, family members and associated care professionals would be most suitable. However, given YouCan World's current state as a prototype developed to demonstrate how to build a targeted world using the features of our framework, we were less concerned with the contextual validity of our focus groups. As previously mentioned, HCI students were able to give informed feedback on aspects such as usability and design, while the engineering students were able to give feedback as neutral users with less expertise or interest in novel interactive systems. We were also able to observe differences based on how well the groups knew each other prior to the activity.

Another limitation of the study was that the participants were given step-by-step instructions to perform the tasks. As such, it was difficult to assess how *learnable* the YouCan World prototype was. However, this was appropriate for three reasons: the time constraints of the focus group, the desire to ensure that the core features were exercised, and because there was very little in the way of built-in cues or tutorials.

There was some evidence of confusion about the meaning of questions in the post-activity questionnaire, specifically where we ask participants about their views on the key room-based functionalities provided in YouCan world. Some participants expressed confusion explicitly, while others provided mixed responses that seemed to indicate misunderstanding.

6.6 Summary

As a result of the focus group study we have a number of valuable suggestions for improvements to YouCan World. We also uncovered some technical issues that can be solved in future. The verdict on each of the core functionalities of the framework is mixed: they were working fine, but could be modified to make them more effective. For example, commonalities were useful but the HUD presentation of those commonalities could be improved, and patient control over what details to share could be provided. Conducting the open coding and affinity diagram analysis uncovered insights about privacy, gender, participant relationships, etc. that were not evident in the questionnaire data alone.

In the next chapter we will discuss the results in detail. We will also revisit our research questions and how they were (or weren't) addressed in our results. At the systems level, we will also describe the architectural issues we solved, and discuss some that remained unsolved. At last we will propose improvements for both YouCan World and the framework.

Chapter 7 Discussion

In this chapter, we will go through the system challenges solved and remaining during development of YouCan world, summarize the results from the focus group study according to major functionalities offered, discuss new research questions derived from the study, and propose more uses of the reasoning engine. This will be followed by a summary of the contributions made by this thesis.

7.1 Implementation Issues Overcome

In this section we explained the implementation issues faced and how we overcome them and what was the result of them. We faced problems in communication between the server and clients of OpenWonderland framework for building the proximity module. In proximity module it needed to send a message from server to clients about the events. These events are the avatar entering the rooms in virtual world. We overcome this issue by using an unstable module "Proximitytest" which was checking location of the avatars sending messages to the clients. We modified that module to our proximity module to track the avatars in YouCan world.

Previously we thought of displaying the commonalities close to the avatar for each user. But we realize that it needs lots of work and it will become very complicated for programming. Therefore we switched to Heads-up-display (HUD) where information displayed is private to each user and easy to implement. But these change in the

implementation results into very interesting question of which is more beneficial between displaying information on HUD and displaying information inside virtual world.

7.2 Functionalities Revisited

In this section we map the findings from the researcher affinity diagram work to responses given by participants in the focus groups in the post-activity questionnaire and outcomes from the brainstorming session, broken down by core YouCan world functionality.

7.2.1 Consultancy Room

The consultancy room was created for the patients to meet their doctors in a virtual setup. To help the patients, we provided recommendations based on the data stored about them in our data model. One of the major findings regarding consultancy room was the displayed recommendation were not enough to help patients meet their doctor. During the focus group study we debated on 2 add-ons to this functionality which will make it more helpful for patients. The first thing which needs to be added is some mechanism for conducting patients' consultancy visits (discusses in section 6.4.8). The mechanism can be sign board outside consultancy room or a reception counter where a receptionist can regulate the visits similar to real world scenario.

We noted some of the quotes made by the participants during brainstorming session and post-activity questionnaire. P1 said that "Yes [the recommendations] helped me when I was confused, useful for shy people". P4 said that it help him to understand what should be done in the consultancy room. The displayed recommendations will serve as guidelines

for the patients to talk with the doctors. P8 said that these recommendations will help the patients to interact with the doctor. P6 said due to the displayed recommendations will encourage patients to know about their treatment, is exactly the kind of support we want to provide to young cancer patient through virtual world.

7.2.2 Hangout Room

All the participants liked the hangout area model, and they were really enjoying their time by navigating outside hangout building on the beach. It has been observed in both the focus groups, after moving to hangout room for their second task the participants' appearing to adjust themselves to the virtual world and others. They seem to be more comfortable and were communicating with others. This was also seen in the video coding of the video captures of the participants. The reason for this change in behavior was the commonalities displayed among the participants. It was observed in screen captures, that they were aware of them used them to communicate with each other. The time for using displayed commonalities by the participants were more than the time used by the participants using the displayed recommendations and sharing knowledge with others from the PDF documents (refer table 6.5 and 6.6). Also it was observed in the screen captures, that participants spend more time in hangout room as compared to other rooms. All these observation proves the effectiveness of hangout room functionality instead of comparing it with other functionalities.

Figure 7.1 show how all the participants were having conversation in the hangout room. It is seen in the screenshot that all the 4 participants were having conversation together

instead of one-to- one. This was interesting, because participants was not hesitant to talk in groups. Initially the conversation was about the commonalities, but later on when participants spend more tie navigating in/out of hangout room more conversation was happening which was not related to task. There were some conversation which was the discussions about difficulties faced by the participants. Which is good in the sense of getting psychosocial support. This behavior was seen particularly in Hangout room and 2 times in other locations in both the focus group. It was also observed that participants were having personal talks especially near the swimming pool outside hangout model. There was evidence observed during affinity diagram session (refer section 6.4.4) of participants talking about topics which are not related to tasks. Also participants was observed playing and socializing near pool-side (refer section 6.4.5) of which some of the quotes was noted during affinity diagram session.
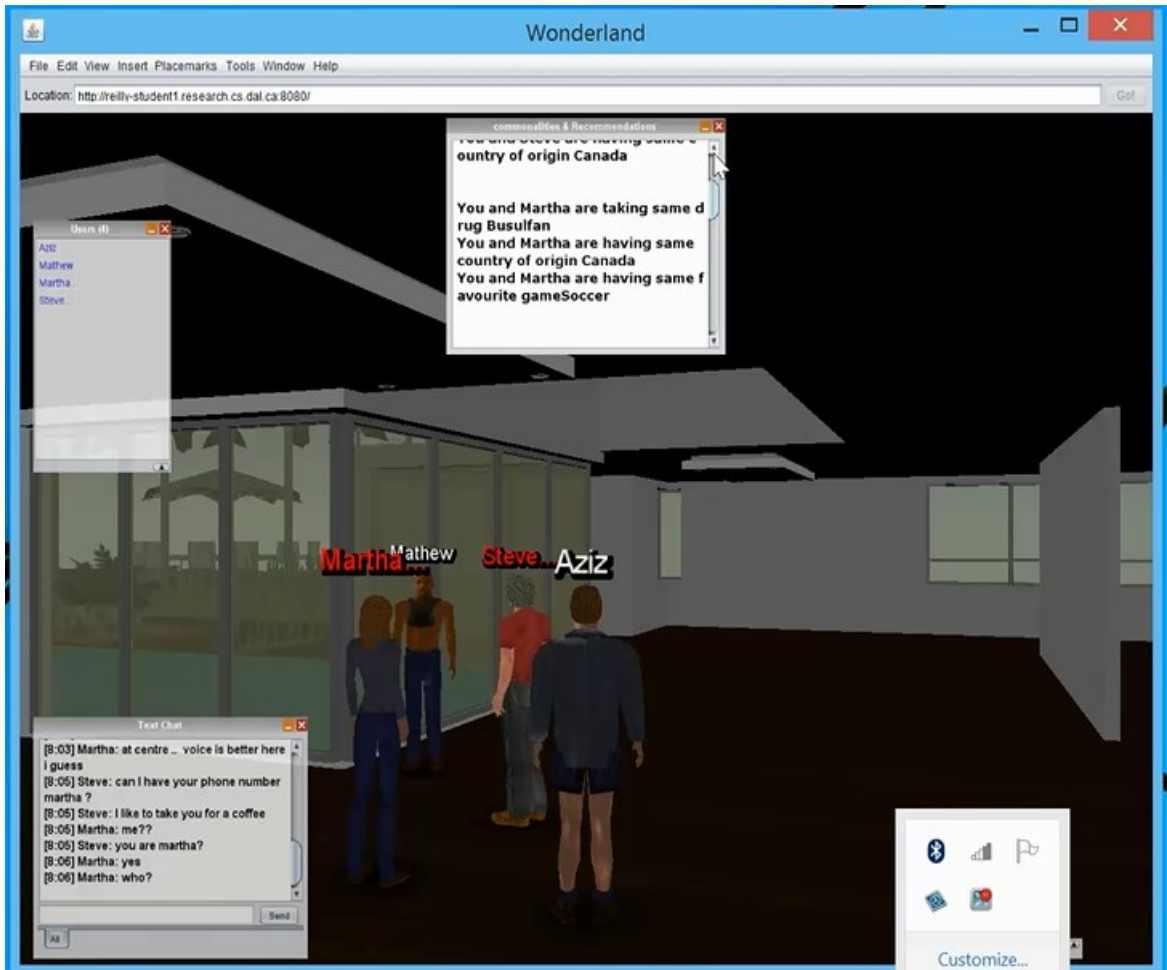
Figure 7.1 Screenshot of participants having conversation in Hangout Room

7.2.3 Library

The third main functionality offered was the selection of relevant pdf documents. For this purpose, we had a library room which was supposed to give the feeling of a library, where relevant documents popped up in front of their avatar. Again, it was seen in the screen captures analysis, that the popping up of the documents happened in the background and the participants were not impressed or not seen the PDF documents selected in front of them. They weren't aware of the documents was selected for them. Instead they stood their staring at the pdf documents and reading them. This was observed from the data analysis

of the screen captures. As given in the table 6.5, that 5 out 6 participants appeared to read the pdf documents and only 2 participants was talking about it significantly. From this result, we learned that there should be an indication to the patients about the relevant documents and one way to do this is the text message in HUD. This message may provide the required explanation to the patients that the documents are relevant to them.

Another major outcome or suggestion made in the focus group was too provide an option for searching for content in the web. In addition to the documents popping up, there should be an interface or separate window, where they can search for any topic on the web. This opens an opportunity for them to learn about various cancers, cancer related treatments and to find answers to their anxiety and doubts.

There was another suggestion made by the P4 that instead of having pdf documents arranged like a museum, the documents should be listed in a window. From that user can select whichever article he/she wants to read. Moreover, they should be able to save and re-obtains that article whenever needed. This will be useful especially when patient re-login after some days and wants to remember what they have read last time.

7.3 More Uses of Reasoning Engine

All the functionalities offered in the YouCan World are based on the reasoning done by the reasoning engine on the data stored about the patients. There were new functionalities suggested by participants and discussed in affinity diagram session. Following are the 2 uses.

1) Summary of last visits: This is one of the new functionality discussed during affinity diagramming session. It will be very helpful for the young patients to know what they did in their last session in the YouCan World. It is possible to give a report like structure displayed at the starting of new session. One way of achieving this by keeping record of whom did the patients had conversation with (for example with whom commonalities was displayed) and read which PDF documents (which documents popped up in library). Reasoning engine can store this information and display it in HUD in next visit by that patient.

2) Giving patients details to doctor: Similar to the recommendations provided to the patients, it might be useful to the doctors, if we also provide them with some information about patients before meeting them. This can easily achievable using our framework by creating a summary of the patient's important attributes and presenting it to the doctor into the form of a report.

7.4 Research Questions Revisited

In this section, we will revisit each of research questions and see how it has been answered through the focus group studies.

1) Discussing with HCI researchers about the overall design of our application: As YouCan World was just a prototype, we wanted to discuss its design with HCI researchers, who have experience in evaluating computer-based applications. We got valuable feedback from them in terms of improvements, performance, usability and privacy and security issues as described in chapter 6.

2) Determining the effectiveness of already implemented functionalities, particularly (but not exclusively) the semantic web features:- Participants from both the focus group studies gave interesting suggestions to improve the functionalities along with some issues they experienced during the group activity. All the participants responded that they liked the varieties of room-based functionalities offered in YouCan world. Commonalities is a great way to help patients to start communicating with each other. Text chat was used by all the participants whenever there was problems in audio. YouCan can prove to be a suitable environment for the patients to socialize with each other, as participants was observed playing and socializing during the group activity. Participants pointed out areas for improvements in YouCan world to make it more suitable for patients. The first area for improvement is the audio. There is also needed a mechanism to synchronize the consultancy visits of the patients as it was observed that there was more than one participants in consultancy room during the focus group studies. Another area of improvement are the recommendations and the commonalities displayed. They is potential in improving the text in more convincing tone instead of plainly displaying it. Also the HUD should scroll automatically whenever more data has to be displayed.

3) Identifying future directions for the system: Certainly we got lot of future improvements and changes to be made to our prototype to make it more suitable for patients in the previous chapter. The major key future directions are a) Status indicator to show whether user is using the application or away from the desk, b) Tutorials and training should be provided to patients before using YouCan world,

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c) Insert small games patients entertainment, d) Search option in library to search online about any topic and lastly e) improve the overall layout of YouCan world by using more pleasant colors and 3D interactive models. Along with that, we seen that there is lot potential in our rule-based framework to provide more functionalities. So there is potential to improve YouCan World.

4) Identifying issues relating to security and privacy of patients: As we stated in chapter 6, there were many privacy and security issues pointed out and suggested solutions to overcome them. a) Main concerns about the Patient-doctor consultation in the consultancy room. As we seen more than one participant in consultancy room. b) Another concern made during the study was about inter-patient communication. The patients (users) should be provided with an option to block any person they don't want to talk with. c) One more major concern made regarding security and privacy of the patients is that there consent should be taken before displaying their personal information in the commonalities.

7.5 New Research Questions

As a result of the focus group studies, some new research questions have been emerged. The following are the research questions which we found while analyzing the data.

7.5.1 Consulting doctors in the virtual world

Consulting doctors is not practiced till now, so we don't know what are the rules and ethics to be followed to allow patients to consult the doctor. As YouCan World was a just a prototype, we did not gave importance to how it will perceived by both, the doctors and

the patients. But in the real world scenario, there are many things to be taken care of such as timing of appointments, security and privacy issues regarding exchange of personal information between patients and doctor, rules to be followed accessing information in YouCan world etc. to make it work successfully. Research and work needed in this direction with the help of doctors and researchers to decide how to control factors responsible for proper functioning of such virtual world application. More studies with people related to the patients and also with patients themselves will prove very useful to find out points to be improved.

7.5.2 Displaying the information in HUD vs displaying it inside the virtual world

We displayed the recommendations and the commonalities on the heads-up-displays of the screen of the clients. There were lot of talking done about displaying text in the HUD during the focus groups. HUDs have the advantage of being a part of the screen, but not mixing with the virtual world. But it is an interesting topic for research to see whether displaying the information in the HUD is better or displaying it within the virtual world.

7.6 Extending the current framework using Twinspace Infrastructure

We intend to build on the capabilities of the TwinSpace infrastructure to facilitate a broader range of usage scenarios. For example, we can combine the physical bricks-and-mortar treatment centers with the virtual world support systems. This will enable patients who are

far away from the actual health care center to connect through the virtual world. In prior work TwinSpace was used to "fuse" an office working environment with a virtual workspace to allow remote and local people to collaborate together without needing to stay focused on a video-conference screen [11]. We believe this offers interesting possibilities for allowing bedridden or remote patients remain connected with a support group, for example.

Consider the scenario where 5 to 6 patients are having a conversation in a physical support group. Combining the physical world with the virtual world will allow remote patients to enter the conversation through the virtual world. In this scenario mapping of physical and virtual spaces can be done by using the reasoning of mapping rules. A seating area in the virtual world can be mapped to a seating area in the physical center to facilitate conversation – in this case a display in the physical room would show the virtual seating area, and a video feed of the physical room would be set up in the virtual space. If the group later moves to a chemotherapy room to discuss a treatment, participants in the virtual world could move to the virtual chemotherapy room. Through mapping rules, interactions with physical chemotherapy equipment can be manifested in the 3-D models. An audio link will keep the physical and remote groups connected in the chemotherapy room.

As previously mentioned, TwinSpace also provides support for a range of input and output technologies. This can support alternative immersive approaches to treatment-based education as explored by Becker Pentland [3], but can also provide alternative input modalities to support bedridden patients, or patients undergoing aggressive treatments.

This creates a "level playing field" for accessing the virtual world and may extend the benefits of psychosocial support into more difficult phases of treatment and care.

7.7 Conducting Studies with more Suitable Participants

After making the improvements in the YouCan World, it would be very interesting and useful to conduct study with the patients to see how they perceive it. We can also consider conducting studies with the people who are in direct contact with patients or who works for them. These people can be Nurses, cancer researchers, guardians etc. The feedback from them would be valuable, as they know how patients face problems both socially and psychologically.

7.8 Contributions

Our work was an attempt towards providing psychosocial support to patients. Our contributions are in the form of a framework, which can be used to build online virtual world applications for providing support to patients. In the related work, we have seen many applications which were either online forums of patients or virtual worlds made for socializing. But our application provides the personal virtual space which is different from the physical world, where young patients can perform tasks which they would not do in the physical world.

We implemented an initial prototype called as YouCan World using Twinspace infrastructure to provide psychosocial support to cancer patients in the age group ten to eighteen years old. We explained in chapter 2 that we will be extending the reasoning component of Twinspace infrastructure to be used for reasoning about the patients. The

reasoning engine is the component which is responsible for performing reasoning the patient's profile. Our evaluation of the prototype through focus group studies with HCI researchers and students provide thoughtful insights regarding functionalities and design improvements. Also our findings will help others who want to developed and evaluate similar kind of applications.

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Appendix A - Social Sciences & Humanities Research Ethics Board Letter of Approval

November 22, 2013

Mr Swapnil Mahajan
Computer Science

Dear Swapnil,

REB #:   2013-3112
Project Title: Providing Psychosocial Support to Young Cancer Patients Using an Online Virtual World

Effective Date: November 22, 2013
Expiry Date: November 22, 2014

The Social Sciences & Humanities Research Ethics Board has reviewed your application for research involving humans and found the proposed research to be in accordance with the Tri-Council Policy Statement on *Ethical Conduct for Research Involving Humans.* This approval will be in effect for 12 months as indicated above. This approval is subject to the conditions listed below which constitute your on-going responsibilities with respect to the ethical conduct of this research.

Sincerely,

Dr. Sophie Jacques, Chair

Post REB Approval: On-going Responsibilities of Researchers

After receiving ethical approval for the conduct of research involving humans, there are several ongoing responsibilities that researchers must meet to remain in compliance with University and Tri-Council policies.

1. Additional Research Ethics approval
Prior to conducting any research, researchers must ensure that all required research ethics approvals are secured (in addition to this one). This includes, but is not limited to, securing appropriate research ethics approvals from: other institutions with whom the PI is affiliated; the research institutions of research team members; the institution at which participants may be recruited or from which data may be collected; organizations or groups (e.g. school boards, Aboriginal communities, correctional services, long-term care facilities, service agencies and community groups) and from any other responsible review body or bodies at the research site

2. Reporting adverse events
Any significant adverse events experienced by research participants must be reported **in writing** to Research Ethics **within 24 hours** of their occurrence. Examples of what might be considered "significant" include: an emotional breakdown of a participant during an interview, a negative physical reaction by a participant (e.g. fainting, nausea, unexpected pain, allergic reaction), report by a participant of some sort of negative repercussion from their participation (e.g. reaction of spouse or employer) or complaint by a participant with respect to their participation. The above list is indicative but not all-inclusive. The written report must include details of the adverse event and actions taken by the researcher in response to the incident.

3. Seeking approval for protocol / consent form changes
Prior to implementing any changes to your research plan, whether to the protocol or consent form, researchers must submit them to the Research Ethics Board for review and approval. This is done by completing a Request for Ethics Approval of Amendment to an Approved Project form (available on the website) and submitting three copies of the form and any documents related to the change. Please note that no reviews are conducted in August.

4. Submitting annual reports
Ethics approvals are valid for up to 12 months. Prior to the end of the project's approval deadline, the researcher must complete an Annual Report (available on the website) and return it to Research Ethics for review and approval before the approval end date in order to prevent a lapse of ethics approval for the research. Researchers should note that no research involving humans may be conducted in the absence of a valid ethical approval and that allowing REB approval to lapse is a

violation of University policy, inconsistent with the TCPS (article 6.14) and may result in suspension of research and research funding, as required by the funding agency.

5. Submitting final reports
When the researcher is confident that no further data collection or analysis will be required, a Final Report (available on the website) must be submitted to Research Ethics. This often happens at the time when a manuscript is submitted for publication or a thesis is submitted for defence. After review and approval of the Final Report, the Research Ethics file will be closed.

6. Retaining records in a secure manner
Researchers must ensure that both during and after the research project, data is securely retained and/or disposed of in such a manner as to comply with confidentiality provisions specified in the protocol and consent forms. This may involve destruction of the data, or continued arrangements for secure storage. Casual storage of old data is not acceptable.

It is the Principal Investigator's responsibility to keep a copy of the REB approval letters. This can be important to demonstrate that research was undertaken with Board approval, which can be a requirement to publish (and is required by the Faculty of Graduate Studies if you are using this research for your thesis).

Please note that the University will securely store your REB project file for 5 years after the study closure date at which point the file records may be permanently destroyed.

7. Current contact information and university affiliation
The Principal Investigator must inform the Research Ethics office of any changes to contact information for the PI (and supervisor, if appropriate), especially the electronic mail address, for the duration of the REB approval. The PI must inform Research Ethics if there is a termination or interruption of his or her affiliation with Dalhousie University.

8. Legal Counsel
The Principal Investigator agrees to comply with all legislative and regulatory requirements that apply to the project. The Principal Investigator agrees to notify the University Legal Counsel office in the event that he or she receives a notice of non-compliance, complaint or other proceeding relating to such requirements.

9. Supervision of students
Faculty must ensure that students conducting research under their supervision are aware of their responsibilities as described above, and have adequate support to conduct their research in a safe and ethical manner.

Appendix B - Social Sciences & Humanities Research Ethics Board

Amendment Approval

Social Sciences & Humanities Research Ethics Board
Amendment Approval

March 07, 2014

Mr Swapnil Mahajan
Computer Science\Computer Science

Dear Swapnil,

REB #:   2013-3112
Project Title: Providing Psychosocial Support to Young Cancer Patients Using an Online Virtual World

The Social Sciences & Humanities Research Ethics Board has reviewed your amendment request dated February 28,2014 and has approved this amendment request effective today, March 07, 2014.

Sincerely,

Dr. Sophie Jacques, Chair

Appendix C - Social Sciences & Humanities Research Ethics Board

Amendment Approval

May 01, 2014

Mr Swapnil Mahajan
Computer Science\Computer Science

Dear Swapnil,

REB #:   2013-3112
Project Title: Providing Psychosocial Support to Young Cancer Patients Using an Online
Virtual World

The Social Sciences & Humanities Research Ethics Board has reviewed your amendment
request dated April 25,2014 and has approved this amendment request effective today,
May 01, 2014.

Sincerely,

Dr. Sophie Jacques, Chair

Appendix D - Post activity questionnaire For HCI Researchers

1) Do you like the room based functionalities of YouCan World? (For example displaying commonalities in the hangout room, displaying recommendations in the consultancy room and selection of relevant pdf documents in reading room) If not, what changes would you like have?

_____

_____

2) Do you think the recommendation displayed in the consultancy room will help young cancer patients to ask questions to their doctors?

  If yes, why?

_____

_____

  If no, why not?

_____

_____

3) Do you think the commonalities displayed would help young cancer patients to interact with other patients?

 If yes, Why?

_____

_____

 If no, why not?

_____

_____

4) Do you find the functionality of the library useful for young cancer patients?

If yes, why?

_____

_____

If no, why not?

_____

_____

5) What do you think about the layout of the rooms in YouCan World? What changes would you suggest?

_____

_____

_____

_____

6) Are the pdfs in the YouCan World easy to read and access?

If yes, why?

_____

_____

If no, why not?

_____

_____

7) What are the potential privacy and security issues (if any) in the YouCan World that would affect young cancer patients?

_____

_____

8.a) How was your experience while communicating by audio with other avatars in the YouCan World?

_____

_____

8.b) Did you use text chat?

If yes, when?

_____

_____

 If no, why not?

_____

_____

9) Can you suggest any 3D models to improve the current YouCan World?

_____

_____

10) Can you suggest any modifications to improve the current functionalities of YouCan World?

_____

_____

_____

11) What additional functionalities do you think can be added to the YouCan World to make it suitable for young cancer patients?

Appendix E - Focus group brainstorming activity outline

Now that you have had a chance to use and reflect on our prototype, we want you to work as a group to identify and classify strengths & weaknesses, ideas for improvement, and ideas for additional features.

We will be using an affinity diagram process to arrive at core classifications, as follows:
1. (10 minutes) **On your own**, identify strengths, weaknesses, improvements and additions. Write each item down on the cards provided. Do not think about classifying these at this stage, that will come later.

Stuck? The following set of questions may help you to think of items to add to the cards:

- What were your overall impressions of the YouCan-world?
- What security and privacy issues may arise when YouCan-world is used in various scenarios?
- What do you think of the information displayed in the virtual world?
- Are the commonalities displayed in the world is helping the patient.
- What practical design solutions can address security and privacy issues?
- How did you find the overall usability of this system?
- In what ways do you think the interfaces of this system can be improved?
- Do you have any other comments or concerns about this system?
- What more functionalities must be added to the virtual world making it more useful for the patients.
- What do you think, are the additional features require in order to consider participants from remote locations?

2. (15 minutes) Start placing and organizing the cards on the whiteboard. **Do not talk to one another during this phase.**
- If you see a card that you feel is related to a card you are placing, then place your card next to it on the whiteboard. If no other cards on the whiteboard are closely related, place your card on its own.
- If you see a card in a cluster of cards on the whiteboard that you think doesn't belong there, then take the card and move it to a more appropriate cluster or in a spot on its own if no cluster fits. Don't worry if this is someone else's card.
- If someone moves one of your cards to a cluster and you don't agree with the change, you can add more detail to the card and place it where you think it belongs (others are still able to move it later on)
- if a cluster gets very large, try splitting it into two or more subtopics.

3. (15 minutes) **As a group**, label and organize the clusters.
   - Put the name of a cluster directly on the whiteboard
   - Draw lines between related clusters, annotate the line with the kind of relationship if this makes it more clear
   - Break larger clusters into subtopics and make this relationship clear by noting it on the whiteboard

   1. (20 minutes) Present and discuss the classifications with the focus group moderators.

Appendix F - Instruction of Participants

Instructions for Steve to login in YouCan World

1) Please login with username 'Steve' in YouCan World(Virtual world application), after that you can configure you avatar by selecting on 'configure avatar' option in edit menu at the top.

2) To enable the functionalities of the YouCan World, you have to check the 'proximity enabled' and 'Recommendation & Commonalities' checkboxes in the tool menu at the top of your screen.

3) Having enabled the functionalities, your first task will be to navigate to the consultancy room using the arrow keys and enter it (**Every room must be entered through the door and you should enter one by one not when somebody else is entering**). After after 30 sec, you will see the recommendations displayed on the heads-up-display on your screen. You can ask questions to the doctor(Dummy) based on the recommendations displayed.

4) Your second task in YouCan world will be to go the 'hangout room'. You can reach the hangout room by selecting the 'hangout' placemark in the placemark menu. I recommend that you to use this placemark option instead of navigating because the hangout room is a long distance from the consultancy room.

5) Wait for other participants to come in the hangout room, When their avatar come close to your avatar, commonalities will be displayed on the heads-up-display, which will give you points to discuss with each other. We want you to talk with other participants.

6) After completing this task the third task is to go the library again using the placemark menu, once you enter it, the relevant pdf documents will pop up in front of you. You should quickly scan these pdf's while waiting for mathew to arrive when Mathew enters the library, the relevant pdf documents for both of you will be enlarged.

7) Your task is to read the pdf document titled "*Vitamin D*" deficiency information for cancer patients' and find out the sources and types of vitamin D and discuss this with Mathew.

8) Your last task is to come back to the starting location(using the placemark menu), and then go to the movie room and watch a movie about cancer treatment. The movie is set up and ready to be played. Wait until all participants arrive before playing movie.

Instructions for Mathew to login in YouCan World

1) Please login with username 'Mathew' in YouCan World(Virtual world application), after that you can configure you avatar by selecting on 'configure avatar' option in edit menu at the top.

2) To enable the functionalities of the YouCan World, you have to check the 'proximity enabled' and 'Recommendation & Commonalities' checkboxes in the tool menu at the top of your screen.

3) Having enabled the functionalities, your first task will be to navigate to the consultancy room using the arrow keys and enter it (**Every room must be entered through the door and you should enter one by one not when somebody else is entering**). After after 30 sec, you will see the recommendations displayed on the heads-up-display on your screen. You can ask questions to the doctor(Dummy) based on the recommendations displayed.

4) Your second task in YouCan world will be to go the 'hangout room'. You can reach the hangout room by selecting the 'hangout' placemark in the placemark menu. I recommend that you to use this placemark option instead of navigating because the hangout room is a long distance from the consultancy room.

5) Wait for other participants to come in the hangout room, When their avatar come close to your avatar, commonalities will be displayed on the heads-up-display,

which will give you points to discuss with each other. We want you to talk with other participants.

6) After completing this task the third task is to go the library again using the placemark menu, once you enter it, the relevant pdf documents will pop up in front of you. You will meet Steve, who will be waiting for you.

7) Your task is to read the pdf document with title "*Vitamin D*" and find out the functions of Vitamin D and discuss with Steve.

8) Your last task is to come back to the starting location, and then go to the movie room and watch a movie about cancer treatment which is already deployed there with other participants.

Instructions for Martha to login in YouCan World

1) Please login with username 'Martha' in YouCan World(Virtual world application), after that you can configure you avatar by selecting on 'configure avatar' option in edit menu at the top.

2) To enable the functionalities of the YouCan World, you have to check the 'proximity enabled' and 'Recommendation & Commonalities' checkboxes in the tool menu at the top of your screen.

3) Having enabled the functionalities, your first task will be to navigate to the consultancy room using the arrow keys and enter it (**Every room must be entered through the door and you should enter one by one not when somebody else is entering**). After after 30 sec, you will see the recommendations displayed on the heads-up-display on your screen. You can ask questions to the doctor(Dummy) based on the recommendations displayed.

4) Your second task in YouCan world will be to go the 'hangout room'. You can reach the hangout room by selecting the 'hangout' placemark in the placemark menu. I recommend that you to use this placemark option instead of navigating because the hangout room is a long distance from the consultancy room.

5) Wait for other participants to come in the hangout room, When their avatar come close to your avatar, commonalities will be displayed on the heads-up-display, which will give you points to discuss with each other. We want you to talk with other participants.

6) After completing this task the third task is to go to the library again using the placemark menu and find the pdf document with title "*chemotherapy*". You have to read information about chemotherapy given on page 3 and have to make some points to discuss with Aziz.

7) Your last task is to come back to the starting location, and then go to the movie room and watch a movie about cancer treatment which is already deployed there with other participants.

Instructions for Aziz to login in YouCan World

1) Please login with username 'Aziz' in YouCan World(Virtual world application), after that you can configure you avatar by selecting on 'configure avatar' option in edit menu at the top.

2) To enable the functionalities of the YouCan World, you have to check the 'proximity enabled' and 'Recommendation & Commonalities' checkboxes in the tool menu at the top of your screen.

3) Having enabled the functionalities, your first task will be to navigate to the consultancy room using the arrow keys and enter it (**Every room must be**

entered through the door and you should enter one by one not when somebody else is entering). After after 30 sec, you will see the recommendations displayed on the heads-up-display on your screen. You can ask questions to the doctor(Dummy) based on the recommendations displayed.

4) Your second task in YouCan world will be to go the 'hangout room'. You can reach the hangout room by selecting the 'hangout' placemark in the placemark menu. I recommend that you to use this placemark option instead of navigating because the hangout room is a long distance from the consultancy room.

5) Wait for other participants to come in the hangout room, When their avatar come close to your avatar, commonalities will be displayed on the heads-up-display, which will give you points to discuss with each other. We want you to talk with other participants.

6) After completing this task the third task is to go the libaray again using the placemark menu, where you have to meet Martha, who is another patient in the YouCan World. Your task is to listen to Martha about what she had read from the relavant pdf documents.

7) Your last task is to come back to the starting location, and then go to the movie room and watch a movie about cancer treatment which is already deployed there with other participants

.

Appendix G - Clusters from affinity diagram session

1) **Using Documents**

1. Library- Pop-up Documents, not obviously noticed by the participants. "Invisible" smart Action. Don't we need visibility?
2. Need to scroll down past consultancy recommendations to get to commonalities
3. They all stand in front of a document, did they read it?
4. Users can share knowledge and talk about pdf that they all have access to
5. After around 15 minutes, they started to relate and talk more
6. One participant faced problem of not able to access pdf, when other are accessing it. It was also seen in video room
7. Participants are not reading
8. Users were not liking the HUDS, but they were not aware of minimizing them
9. Lots of HUDs but you can minimize them if you want
10. Can you change "paper" to read? Why not relate this to their 'cancer' treatment searchable interface
11. Can you privately look at a library reference literature?
12. Recommendations are not written in easy to understand terms
13. Going back to texting in library
14. Hard to read recommendations- text is not formatted
15. In the library, what are all the different Medias? E.g. video, books etc.? not clear
16. Overwhelming in library is lots of popup documents.

2) **Technical issues**

1. Movie is slow
2. Did they use the library feature
3. Would it be better to start from a social room
4. Microphone settings are not the same
5. When movie was playing , users names were flashing but did not hear then talking
6. Users are able to watch a video or movie together
7. White shadow vs dark shadow- some avatar have white shadow others are black
8. When logged out, all text gone? is there back up?
9. Some participants were having problems due to awkward angles and positions of pdf in the library

10. This groups did not notice some of the features like scroll down pdf files
11. Experimentation to determine audio issues
12. Steve and matt are not having their conversation in library Martha ask s where's Aziz? (crash) in library
13. Nobody sounds to notice scroll down feature In the guide window
14. Is participants login when they crash or you have to login for them?
15. Nobody noticed body movement buttons (Wave etc.)
16. Sounds are not working properly in the beginning
17. 5:40 ish Steve is talking but impossible to make out
18. Pdf not scrolled!!
19. Why do some participants not have proper headphones? Should be a precondition to logging in
20. Ambient noise is an issue

3) Navigation, proxemics and environment

1. Martha computer crashed a lot
2. Are they using guide?
3. Martha tends to find a place to stand, then rotates avatar to get bearings
4. Inactivity indicator
5. Really not grouping of avatar trying to talk to Martha
6. Everyone is grouped around each other and 1 doc in the library
7. "shall we teleport or shall we take a walk"
8. Some participants were constantly moving sometime, even when they are talking or watching video
9. Martha & Aziz are just hanging around in consultancy room
10. Avatar indicates activity, but sometimes not (inactive)
11. Mathew walks up to Martha as Martha waves to him
12. Martha walking around library Steve standing still
13. Scoping out complex environment hangout room
14. Explore place before setting into task
15. Seem to be a lot movement in the more complex/interesting hangout room
16. There was suggestion that put less no of models, because many models will make it slow
17. Mathew circles around in place
18. Articles must be displayed in window instead of displaying in library. Whichever user want to read clicks it and open it.
19. 3 way commonalities conversation in close proximity
20. Mathew walks out of video room, but Martha text "Hey Mathew"

21. Consultancy room: Avatars don't approach others, stands apart, looking in different direction, not talking in this instance
22. Steve got lost going to movie room.
23. Walking right up to video room
24. Consultancy room: big huddle all at once around doctor seems only 1 avatar is talking though(Martha)
25. Why is Mathew standing by himself in the main hall?
26. Sometime users were finding it hard to control the avatar. They were going backward
27. Lots of people in consultancy room during private consultation with doctor
28. Aziz seems confused, looks around but then keeps staring at document everyone waves
29. Martha offers suggestion for Steve to improve audio. Does this via text
30. Avatar standing far apart in start
31. Steve tries to walk to a better location to hear Doctor
32. Some find gestures good, some find it annoying
33. Mathew walks in after 7 minutes
34. Tried to swim- but walked on water
35. May be if an avatar isn't active for a while , may be can have a visual to run this e.g.- Martha + Aziz –group- maybe not if reader
36. C.R- Martha reposition avatar in ran. Not clear why
37. Sounds like they are trying to discover the place, Aziz would walk back and forth
38. Steve sitting on floor in movie room
39. Environments: consultancy room- private + some association , social room: music, couches etc., reading room: library Dr does not like dr
40. Areas that invite exploration are most difficult to structure?
41. Aziz walks directly into Mathew, Martha is there also, "Mathew can you talk"
42. Aziz moves around checking out spaces , others don't move
43. In the video, avatar walking through the walls and flowers many times
44. Avatar walking on the pot- confusing
45. Conversation about who is Martha looked like a real world conversation in terms of proxemics
46. Steve seems to say "hello is there anyone there "standing beside Mathew but not facing him
47. Steve sits down to talk with doctor
48. People "follow the leader" out of c.r
49. Making sense of environment- seems to be consultancy eg- where to go what to do
50. Steve follows into c.r just as Martha ans aziz talk about coffee proposition. He figures out who is Martha & who is Aziz

51. Why do they something in hangout room, seems to know next task is library

4) Prior participant relation

1. Did the both groups do same order of tasks? Wonder if starts with room of more interactivity or second task so they more comfortable
2. Did participants knows each other? Seem familiar
3. First group is more comfortable with each other than second group
4. Less talk than other video focus group1
5. Is previous knowledge important? Or some discussion about the application
6. No personal relationship among them which affect the interaction
7. Possible differences in motivation to use WL between groups
8. Trying to figure out real identities of participants
9. Other users could study participants also interact with others

5) Group coordination

1. Should examine based on tasks, avatars helping other understanding process telling others about appointments, Martha directs Aziz back
2. "shall I start movie otherwise"(Martha)
3. "can you type it for me, I can't hear you"
4. "Who is going in first ?" trying to coordinate consultancy visits
5. Aziz Martha talk! Martha is still muted, Aziz seems nervously lonely, am I alone here?
6. 2nd video participant were less motivated
7. Aziz sees Steve leaving c.r room , I think he says" yeah I will go next" But Martha walks towards c.r
8. "who is going first", trying to coordinate consultancy visits
9. Steve is running from here to there(Martha)
10. Coordination to jump to next region
11. Aziz reading scientific paper waiting In c.r
12. Martha carryon talk? 4.00(Aziz) walks around to try to face Mathews avatar

6) Communication modalities – when use what?

1. Is it better to inform the user about scrolling down or about knowledge management
2. It took participants some time to discover features, Martha texting Aziz
3. Using text chat to ask for help using the interface/controlling the avatar "how to say hi" "is there is a key for waving"
4. Text chat- matt, Aziz & Martha to bet Mathew know that he is not forgotten
5. Steve types " hey matt" (matt doesn't talk)
6. Using text chat for "out of character" discussions
7. Matt using text to indicate that his mic doesn't work
8. Used text chat when audio is bad
9. Gestures as social capital
10. Issues hearing Dr bob
11. C.R Steve says Dr bob is not there but he has an appointment(text chat)
12. Steve joins Aziz & Martha group until he gets text confirmation from matt
13. 2:30 Martha wrote text message(1st one)
14. In hall, Steve uses hand wave-trying to contact Dr Bob
15. Martha& Aziz gives out gestures in the end
16. Video was so clear with one client
17. Group2 did not use text feature as group1
18. Using text chat to get current status of everyone "are you waiting for Dr Bob"
19. Steve is still talking voice with text chat even though Martha & Aziz talking using voice
20. User update other members of the group about what they were doing (reading)
21. Someone needed to ask the others to talk
22. Is it common in virtual worlds to talk about voices and technical issues?
23. Does ask for text chat when can't hear each other but user respond with voice
24. Text chat vs talking, why texting and not talking?, does this have a disjoint?
25. Limited usage of text feature
26. Martha wave others (without gesture window open) immediately ask how to do it
27. 4:24 and still not use of text
28. 2:40 Feedback: seems to be Martha who moves avatar to try to reduce it. Then mutes, uses waving gesture
29. Use texting to get better quality communication
30. Audio issue caused group to work together- gave them a topic an unexpected commonality

31. In some room uses texting, scoping out new environment
32. Mathews audio not working but he still doesn't text chat or seem to more?
33. A lot of texting at the beginning but in some room, hanging out together+ just talking .. more natural
34. Mathew finally text chatting- but not until 1 just before last task, but others wait for him in the library
35. Interacting "Beyond common points" – how to use feature making fun of Mathew, exploring environment together

7) Gender

1. Steve flirts with Martha over text chat
2. They are playing around with the gender confusion
3. Running joke about going for coffee
4. After first task, avatar working together coordinating eg. "see you there"
5. "Ladies first "- some research into gender & online communities would be relevant
6. Martha walks towards c.r holds back at entrance , Aziz joins then "ladies will go first"
7. Avatars make assumptions about environment e.g. Assumes female avatar is female , can't associate voices to avatars- more own assumption

8) Play, socializing

1. "hey Aziz you are late movie is over" (Martha)
2. Ability to change locations fast
3. Changing avatar to fit environment (Shorts)
4. Steve mentions that he feels dizzy to all via text chat
5. Joking about server glitches (twin Martha)
6. They all noticed that Mathew is not interacting "he is meditating " can't hear him
7. If some user in another location can't hear users in other location
8. "Mathew is meditating"
9. Where did you get that hairstyle?
10. Trying to swim
11. Participants noticed the change to the avatar – shorts their cuts
12. User trying to figure out some of the features (wave 1 changing clothes)

13. Really playing parts e.g. Making upside effect of drugs
14. Aziz says "there you are " when he sees matt is already in video room
15. Distraction might apply = work on computer not the game
16. Aziz changed into shorts during hangout room – its summer time
17. Reading about topic (vitamin D)
18. "let's go to beach"

9) Design improvements –avatars, environments, tool , activities

1. Status indication –busy, available etc.
2. May HUD windows block the virtual world
3. Dr avatar should look like Dr
4. List of predefined and common question, (to express young users to express them)
5. Observation mode to encourage shy young users
6. Why do the participants have different gender avatar?
7. One- to- one session, privacy
8. Steve uses cut and paste communicate recommendations on text chat window
9. Mood status or face expression to indicate patients mood
10. Reward system based on time spent in virtual world (or completed session)
11. Why is Mathew avatar different?
12. Mute options(mute specific user)
13. Colors and decorations to match young ones
14. Is the logout automatically
15. Activity indicator
16. Leadership could be used to motivate users
17. Should the avatars be cartoon avatar
18. Is it good idea to have video tutorial the review features
19. Cues in room to establish correct actions
20. Interface for searching for content
21. Priority indicator (Assist healthcare providers to determine critical cases)
22. Welcome to YouCan world sticky note pretty Spartan
23. Is it helpful to have a coordinator that is different from the other avatar
24. Why do they have to set appointments in public
25. Is this children environment colors/design
26. May be idea for future work. Search in library
27. The guide does not have text
28. Nobody used text feature
29. Should be a private conversation one to one
30. Privacy issues, one to one talking
31. Not cancer related recommendations
32. Not sure why there is scientific paper in c.r
33. How to better schedule/notify for consultations with doctors?

34. System requirement to login
35. Reading preference at login page
36. Are the names of avatar flashing when texting and talking
37. On screen instruction to show different features such as gesture window
38. " emotionally patients are always have doubts about whether they are given right treatment it will help them communication"
39. At first do they just walk around get to know the place
40. Where is the doctor
41. Changing avatar in middle of session may confuse young patients. This may threaten privacy
42. Steve lost, insert map to guide users ….
43. Option to block background audio
44. Need skew morphism
45. C.r even though Steve says that dr bob is not there, bob avatar is right front of his. Perhaps dr was not at his client
46. 13:00 log silence in hanging area
47. Arrange tutorials to make sure that they are familiar
48. The environment does not look like children environment
49. Avatar is connected to patient emr, gender, age, case
50. Is there influence if people know each other in real world
51. Steve got lost sometimes
52. The ability to change avatar to fit in environment
53. Users sometimes move in same spot
54. Race and gender options
55. For generally young kids- would recommend a reading room in the library, where a book is read to them(whether library)
56. Fun world
57. Avatars status and appearance define behavior
58. Is this for young children? Avatar- young depending on age –cartoon chars, for example penguins
59. Choose fun avatar not realistic

Appendix H - Video Coding for Participant Martha of Focus group1

Offset: 0, Movie: MoviePathHere, DataFile: (null)
Tracks: world loading, user walking, user speaking, recommendation are displayed, commonalities are displayed, reading pdf, user checking button, user using placemark, user going through wall, noise, world interrupted, user using recommendation, user using commonalities, texting, general, watching video, user sharing knowledge from pdf
Time, Duration, TrackName, comment

1007103, 0, general, clicking on avatar
1022497, 0, texting, (null)
1042864, 0, texting, talking about audio
1065613, 38000, user walking, went out of consultancy room
1125850, 1282, user walking, (null)
1134084, 598, user walking, (null)
1135951, 908, user walking, (null)
1137517, 84503, user walking, walking backwards and also walk through the plant
1165674, 0, general, enters consultancy
1174862, 881, reading pdf, (null)
1184598, 0, general, go near pdf
120439, 748, user walking, (null)
1221320, 18620, user speaking, speaking with Aziz general
1242194, 0, texting, (null)
1267895, 38712, user speaking, talking with Steve
1303471, 2562, user walking, (null)
1313053, 0, user using placemark, use the placemark to go hangout room
1324549, 0, general, reached hangout room
1344078, 754, user walking, (null)
1383643, 13865, user walking, (null)
1386798, 0, commonalities are displayed, (null)
1390275, 0, commonalities are displayed, (null)
1404618, 0, commonalities are displayed, (null)
1413537, 10236, user walking, goes inside of hangout room
1437511, 34806, user speaking, talking with Steve about commonalities
1440172, 29302, user using commonalities, (null)
1477627, 94886, user speaking, talking with Aziz about commonalities and general
1493567, 16647, user using commonalities, (null)
1500730, 0, general, 3 users are talking to each other at the same time
1512832, 24499, user walking, going to beach side
152473, 1197, user walking, (null)
154739, 1383, user walking, (null)

1567749, 25611, user walking, (null)
1576800, 45177, user speaking, (null)
1582966, 37344, user using commonalities, with Steve and Aziz
1607838, 17040, user walking, goes inside hangout room
1609838, 0, user going through wall, (null)
1635946, 12518, user speaking, trying to talk with Mathew
1650600, 185953, user speaking, talking with Aziz and then Steve and also with Mathew
1690881, 40257, user using commonalities, (null)
1739513, 16416, user using commonalities, (null)
1776102, 0, texting, (null)
1837354, 57634, user speaking, (null)
1838106, 9264, user walking, (null)
1888256, 3915, user walking, (null)
1898524, 225276, user speaking, talking with Aziz
1902273, 0, texting, (null)
1935626, 3980, user walking, (null)
1946855, 0, user going through wall, (null)
1948531, 0, general, going again to sea side in hangout
1951889, 21611, user walking, (null)
1965771, 0, texting, (null)
1980556, 14613, user walking, (null)
1984463, 0, user going through wall, (null)
1989063, 0, general, came inside
2005245, 0, user going through wall, (null)
2006659, 6498, user walking, (null)
2020010, 44065, user walking, (null)
2022126, 0, user going through wall, (null)
2058435, 0, texting, (null)
2067628, 6109, user walking, (null)
2070659, 0, user going through wall, (null)
2107958, 0, user using placemark, (null)
2125647, 0, general, reached the library
2143727, 0, texting, (null)
214770, 0, texting, texting to Steve about how to make gestures
2156113, 0, texting, talking to Mathew about liking his haircut
2169811, 0, texting, (null)
2186045, 28889, user speaking, (null)
2195644, 0, general, inside the library
2201418, 46639, user walking, walking inside the library
2249180, 15530, user walking, (null)
2267909, 101453, world interrupted, server disconnected Wi-Fi problem
2317729, 0, general, restarting the client
2368129, 139000, world loading, (null)
239687, 0, texting, (null)
2434697, 0, user checking button, (null)
2439617, 0, user checking button, (null)
2441545, 0, user checking button, (null)
2509585, 3992, world interrupted, (null)

2514615, 201295, world loading, restarting application
251550, 0, texting, (null)
2561154, 0, texting, (null)
2588802, 0, texting, (null)
2627, 52611, world loading, (null)
2631074, 0, texting, talking general
2688134, 0, user checking button, (null)
2689860, 0, user checking button, (null)
2695173, 0, user using placemark, (null)
2699645, 0, general, reached library
2722095, 4964, world loading, (null)
2729834, 61724, reading pdf, (null)
2768732, 19571, user walking, (null)
2772893, 219757, user speaking, talking with Aziz about what she read in pdf
2780694, 0, user sharing knowledge from pdf, (null)
2783991, 185912, user sharing knowledge from pdf, sharing with Aziz
2816669, 15930, reading pdf, (null)
2993818, 139784, user speaking, talking with Steve and Aziz
3026358, 82973, user sharing knowledge from pdf, telling about history of chemotherapy
3119447, 3296, user walking, (null)
3159413, 0, user using placemark, gone to staring location to go movie room
3182467, 31852, user walking, going to movie room
3207270, 16780, watching video, (null)
3224050, 0, general, movie stopped
3226264, 12428, user speaking, talking to Aziz
3240479, 23654, user speaking, (null)
3268206, 0, general, walks outside movie room
3268206, 0, user going through wall, (null)
3268206, 4992, user walking, (null)
3278043, 165549, user speaking, talking with Aziz about the movie
334487, 1792, user walking, (null)
3357422, 2452, user walking, (null)
338020, 1882, user walking, (null)
3403481, 0, general, movie started again
3404293, 153616, watching video, (null)
3446173, 0, general, going near the screen
3449486, 2882, user walking, (null)
3464802, 13367, user speaking, (null)
3471320, 3703, user walking, (null)
3479487, 6831, user walking, (null)
3492494, 21092, user walking, walking in movie room
3530213, 0, general, opened gestures and doing them
3556458, 4730, user walking, (null)
3560714, 67726, user speaking, talking with Aziz
3570015, 0, general, doing gestures
366754, 1664, user walking, (null)
369354, 965, user walking, (null)
393605, 1881, user speaking, (null)

450806, 1449, user walking, (null)
466757, 12523, user walking, going inside the consultancy room
477062, 0, general, stuck with plant in the way to consultancy room
481949, 10334, user walking, (null)
486605, 0, general, inside the consultancy room
493568, 35514, user speaking, talking to the doctor
526284, 0, general, goes inside consultancy without activating functionalities
527949, 16912, user walking, walking out
536381, 0, user checking button, (null)
548316, 0, user checking button, (null)
559016, 5771, user walking, going in consultancy second time
562184, 0, recommendation are displayed, (null)
567109, 49268, user speaking, now speaking with doctor about recommendations
576577, 35816, user using recommendation, (null)
617246, 3880, user walking, (null)
628880, 0, general, waiting for other participants to get finish with the doctor
632873, 7999, user walking, walking around consultancy
691670, 2928, user speaking, general
843639, 4920, user walking, (null)
864291, 8688, user walking, (null)
866510, 3286, reading pdf, (null)
88024, 0, texting, (null)
89214, 6324, user speaking, general stuff
939055, 0, texting, telling about what he had talk with doctor
961509, 0, texting, (null)