Using Adaptive e-learning technology to provide medical education for children with cancer

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A dissertation submitted to the University of Dublin, in partial fulfilment of the requirements for the degree of Master of Science in Health Informatics 2009.

Declaration:

I declare that the work described in this report is, except where otherwise stated, entirely my own work, and has not been submitted as an exercise for a degree at any other university.

Signed: _____

Asma Hussain

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Summary:

Research has revealed that children who are more informed about their condition can have better outcomes and cope better with their disease. These children can also endure a number of psychosocial problems, which can often hinder their treatment and recover. These include isolation, anxiety, and depression to name but a few. This study looked at empowering these children through providing medical information adapted to their specific needs and thus improving their sense of control over their situation. This information was provided using an adaptive e-learning system called Adapt. The module was then integrated into a private online network for children with chronic illness called Solas. Solas was developed by the Centre for Health informatics at Trinity College Dublin and provides a secure online environment for children in hospital, supporting communication and creativity. The module was then evaluated by health professionals in order to assess the usability and effectiveness of this method of delivery of medical information to children. Initial findings suggest that this may be an appropriate and feasible solution to providing such information in a healthcare setting.

Table of Contents

List of Figures:

List of Tables:

List of Abbreviations:

TCD	**Trinity College Dublin**
CHI	**Centre for Health Informatics**
KDEG	**Knowledge and Data Engineering Group**
ADAPT	**Adaptive Plug-in-for Run Time composition of personalised E-learning and Adaptive simulations**
ACTSim	**Adapt Composition Tool**
FAQ	**Frequently Asked Questions**
HCI	**Human Computer Interface**

1 Chapter one - Introduction

1.1 Overview

Research has revealed that 10-15% of children under the age of 18 years have a chronic illness or condition ((Tak, 1995)). An admission into the hospital is a disturbing and overwhelming experience for a child that generates fear, anxiety and confusion which can cause a certain loss of identity and leave a child with many questions in relation to pain, loss of function and loss of control over their situation. Health professionals are often unsure of what, when and how information relating to their diagnosis and treatment should be provided to them. These professionals have a great responsibility for all the serious conversations about chronic illness. There is also a child's ethical right to know about their condition, diagnosis, treatment plan etc and it is also a health professionals ethical duty to provide medical information about their condition that is appropriate to the child's age and level of understanding.

This research study focuses upon a research question aimed at investigating the feasibility of using e-learning technology to provide children with information about medical education in a health care setting. It is an important aspect of the provision of paediatric care that can make medical examinations and procedures less stressful for the patient, the medical staff administering it and the child's parents. The quality of care can also be said to be directly related to the type of outcomes of treatment. Linked to this, there is evidence to suggest that

appropriate information provided to children before procedures, fosters better outcomes.

There is a wealth of current literature in the field related to this research which is explored in this thesis. In particular, literature relating to psycho- social issues that children with chronic illness endure, current information resources available to children and the different methods used to deliver this information will be reviewed. This study will explore the feasibility of providing medical information by integrating two existing systems. The first is SOLAS, an online network developed by the Centre of Health Informatics[1] at Trinity College Dublin. Specifically, this system aims to support children in hospital facing medical and psychosocial challenges on a daily basis, through providing a variety of tools for communication and creativity. Addressing these psychosocial challenges is also the motivation for this research which aims to develop an adaptive e-learning module that provides specific information about forthcoming procedures for children with cancer that will link from the SOLAS system.

The second system is ADAPT (an e-learning system) which is a set of learning tools to rapidly build and deploy interpersonal communication skills training. It uses the context of simulation so that the learner is placed in a safe environment

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[1] www.cs.tcd.ie/chi

in which to practice and master a range of communication skills. The benefits of this tool include supporting both patients learning about their own conditions and staff in becoming more adept at communication in sensitive areas of healthcare. In the context of this research ADAPT is used to design an e-learning module for children.

1.2 Research Question:

'An Investigation into the feasibility of using adaptive personalised e-learning technology to provide medical education for children in a health care environment. This statement is broken down into further sub-goals and objectives'.

1.3 Research Objectives

- ✓ Examine the need for providing medical information to children.
- ✓ Knowledge Acquisition for medical content.
- ✓ To assess the different medium used for information provision
- ✓ To examine how health Care Professionals deal with the questions that children ask in the health care environment.
- ✓ Develop an adaptive e-learning module using the ADAPT system and integrate it within the SOLAS system.
- ✓ Evaluate the usability of the design and the feasibility of using adaptive technology to provide such content.

1.4 Chapter Outlines

The rationale for the project will be presented in chapter 2 which explores the current literature related to the need for providing information. It will also provide the background information of SOLAS and ADAPT.

In Chapter 3, the Needs Analysis phase will describe the research methodologies that have been chosen for this study and the pilot of informal interviews and random survey facilitated with doctors, consultants, nurses, psychologists and paediatricians based on the questions that children might ask. The aim of the interviews was to find out about frequently-asked questions and common answers provided based on children's' ages.

Chapter 4 describes how the design phase of the project was carried out which include the configuration of ACTSim tool both functional and technical design.

In chapter 5, the implementation of the research study is described, including testing and the linkages to the SOLAS system.

Chapter 6 is devoted to the evaluation of this research study in which the health professionals will evaluate the usability of the design and feasibility of using ADAPT from their perspective.

Chapter 7 will consider the extent to which the research question has been answered and offer some thoughts on the limitations of the study. As a summative reflection, the author will also draw some conclusions and make recommendations for future research in the field.

2 Chapter two- Rationale for the Study:

2.1 Introduction:

This chapter will review the literature relating to childhood cancer and the impact it has on the lives of children and young adults. It moves on to review the literature in an effort to identify the communication process of children and health professionals and the importance of providing medical information to children with chronic illness, followed by the discussion of the state of the art. It will also aim to detail SOLAS and ADAPT projects. As Solas is currently being piloted on the Children's Cancer Unit of a major acute paediatric hospital, the information that will provided will be related to a cancer diagnosis.

2.2 Childhood Cancer

Childhood cancer is rare. 1 in 600 children under the age of 15 years develop cancer and this means approximately 1700 children are newly diagnosed in the UK every year (cancer Research UK). According to National Cancer Registry Ireland (NCRI) a total of 787 cases of childhood cancer were recorded in Ireland during the seven-year period from 1994-2003 averaging about 112 cases per year. The name cancer is given to a group of diseases and involves the uncontrolled growth and spread of abnormal cells. Childhood cancer is different from adult cancer because the type of cells, tissues and organs involved are

usually different. There are 200 types of cancer; each has its own treatment and side effects. In Ireland data extracted from the National Cancer Hospital is shown in Figure 1:
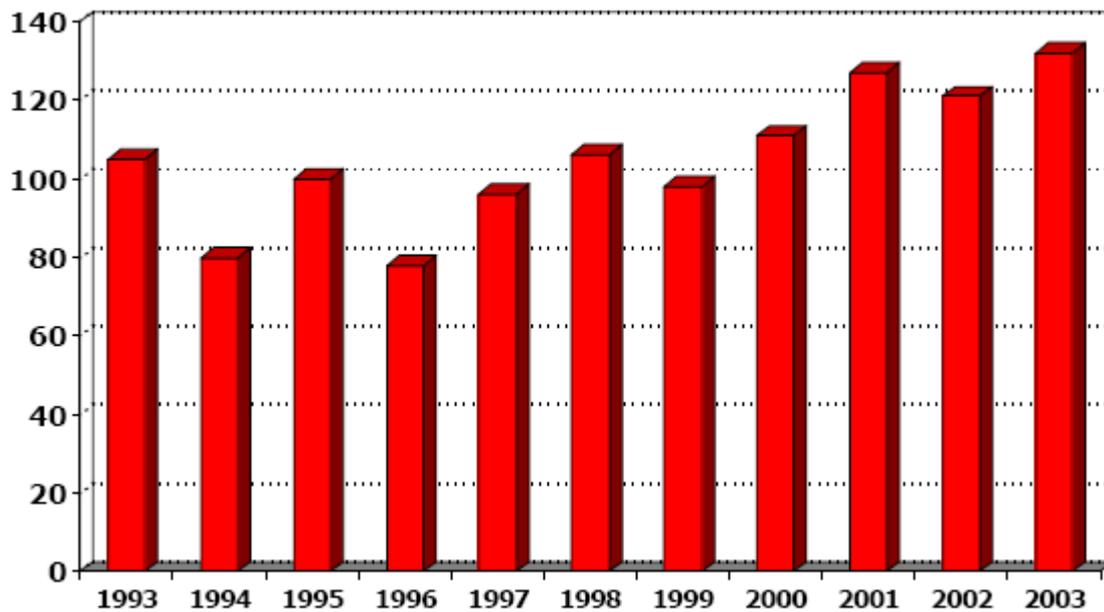
Figure A: children diagnosed in National Paediatric hospital between the years 1993-2003

2.3 Leukaemia:

Leukaemia is the most common type and the largest incidence of childhood cancer. There are four types. Acute Lymphoblastic Leukaemia (ALL), Acute Myeloid Leukaemia (AML), Chronic Myeloid Leukaemia (CML), and Chronic Lymphocytic Leukaemia (CLL).
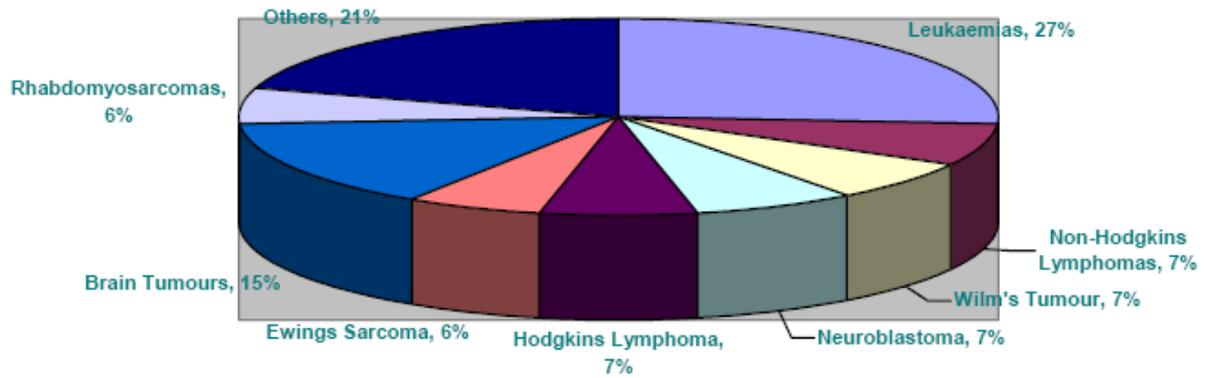
Figure B: percentage of different types of cancer diagnosed in Ireland

2.2.1 Acute Lymphoblastic Leukaemia (ALL)

ALL is predominantly a disease of childhood cancer and is responsible for up to one third of all childhood cancer. Research into cancer and its treatment is ongoing and survival rates have improved dramatically since the 1960's. The 5 year survival rate for ALL is 70 per cent of cases and in some instances a cure for 95% can be expected (Coleman *et al* 2007). A normal health body produces lymphocytes to protect the body from infection. In Leukaemia cells do not mature properly and become too numerous in the blood and bone marrow. The normal functions of the bone marrow, such as the production of red cells, white cells and platelets are reduced.

2.3.1   Signs and Symptoms:

These include that the child is usually tired and lethargic and perhaps breathless on exercise. This is because of the lack of red blood cells in the blood. Bleeding gums occur and the child gets bruises very easily because of the low number of platelets in the blood. Other symptoms are joint pains, aching bones and continuous fever.

2.3.2   Treatment:

Acute Lymphoblastic Leukaemia is treated primarily with chemotherapy and the course of treatment has different phases. An intensification phase is given in three blocks of intensive treatment. This aims to kill off any Leukaemia cells which may be left but cannot be detected.

The Induction phase involves intensive treatment which aims to destroy as many Leukaemia cells as possible. This usually lasts four to six weeks after which a bone marrow test is taken to check if the child is in remission.

Continuing maintenance therapy lasts up to two years or longer from diagnosis and involves daily tablets and monthly injections of chemotherapy. In this period, children can actively participate in routine activities.

2.3.3 Side Effects:

There are different distressing and life threatening side effects to the treatment of leukaemia. These include pain in the mouth, nausea or vomiting, skin rashes, hair loss, more chances of acquiring infections, feeling tired and fatigued(Kumar, 2002). When children are diagnosed with cancer and undergo further investigation, this is an overwhelming experience for the child and the whole family. The child may be frightened as well as having symptoms of the cancer or side effects of treatment to cope with. Usually treatment for ALL in girls is 2 years and for boys it is 3 years (Coleman *et al*, 2007). These treatments can also create difficult long-term health-related outcomes. These late effects can become visible months or years following completion of treatment. Late effects are often chronic problems such as memory and concentration problems or difficulty in learning, processing and organising information.

Childhood cancer is viewed as a life-threatening, but not necessarily terminal illness (Trask, 2009). With improved survival rates, investigators have been able to study the impact of being treated for and ultimately surviving childhood cancer. There is an awareness of the need for innovative interventions that will support surviving patients to develop self care skills and attitudes that will improve their recovery and quality of life (Butow *et al*, 2001, cited by(Bradlyn, 2003)).

Childhood cancer has long been considered a highly stressful, burdensome and even distressing experience for those children who must face it (Kazak, 2005).Children and young people need information and knowledge about their disease at different stages of their diagnosis and treatment. For example, in a first admission into an oncology department, a child might be worried about the hospital environment, frightened to see new faces around and undergo painful investigation tests. At this stage a child needs information about the tests they are going to get in the hospital and why these investigations are necessary. In addition, some information is required to address some of their psychosocial issues which include the loss of peers and school absence. At this stage the Health professional's main concern is to investigate the diagnosis, start treatment and inform children about their treatment and diagnosis at an appropriate age level. There are many types of cancer with different severities; different courses of diagnosis and treatments, and children and young people only need information about their own situation.

As new medical treatments are developed, childhood cancer is no longer equated to death and more children are survivors of cancer and continue normal lives after treatment. Interest has been increased with a focus on psychological well being and coping with the initial phase of diagnosis and treatment. (Kupst, 1994)

Children with cancer face both the physiological and the psychosocial challenges of their illness. Psychosocial issues include isolation and loss of peer interaction. These challenges impact on a child's ability to cope socially, emotionally and physically.

2.4 Motivation of the study:

T o combat some of these issues SOLAS was introduced in a paediatric oncology setting as a tool to facilitate hospitalised children with an environment of communication and creativity.   SOLAS is an online private network created by the Centre for Health Informatics Trinity College Dublin[2] which is currently being piloted on the Children's Cancer Unit of the national paediatric hospital in Dublin with over 180 users to date. SOLAS is a web-based solution offering a fun environment for children to communicate outside of their isolation ward. Through this they play games and music, as well as chat, text, and email to alleviate the boredom of long hospital stays. A comprehensive needs assessment was carried out between November 2005 and March 2006 by the Children's Research Centre Trinity College Dublin. One of the findings identified by children, parents, and health professionals was the provision of medical information for this target group.

2.5 Literature Review:

A literature review was conducted to identify the communication process of children and health professionals and the importance of providing medical

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[2] https://www.cs.tcd.ie/chi/

information to children with chronic illness, followed by the discussion of the state of the art. It will also detail SOLAS and ADAPT projects.

2.5.1   Communication with Health Professionals:

There are a huge number of studies which have focused on the importance of communication between the adult patient and health professionals, but little is known about the communication of a child patient and health professional. Effective communication is important in family-centred care which has evolved throughout the decades and a requirement of the department of health. Family-centred care means "*the professional support of the child and family through a process of involvement, participation and partnership underpinned by empowerment and negotiation*" (Smith et al 2002 p. 22). Health Professionals need to balance the communication process between a child and their family. In a recent study from (Lambert et al., 2008) who explored the communication process of a child, parent and a health professional in paediatric hospitals in Ireland, the author highlighted the issues of assessing children's individual communication needs and claimed that there are no such policies or strategies in place as how to communicate with the child within the hospital environment. In this study data was collected from children by informal conversations and through observations while given different activities in the ward with a series of open-ended questions.

The questions asked from children were to find out how health professionals communicate with them and the actual views of children and an insight into the hospital routine. The data collected from children 6-16 years was examined in two age categories 6-11 and 12-16 years to identify the differences in age groups. The author highlighted the core concept of 'Visible-ness' that children's position in the communication process which shows in Figure 4. On some occasions children were 'Being overshadowed' that is least visible, in the background between the communication of parent and doctor or 'Being at the Forefront' that is most visible, directly communicating with the health professional.
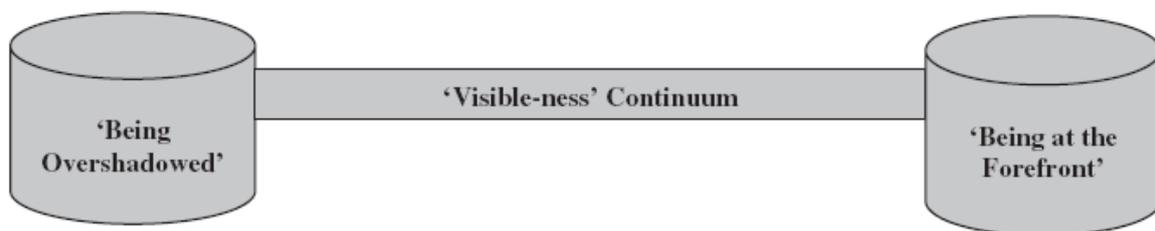
Figure C Visible-ness' Continuums source (Lambert et al., 2008)

The author describes the 2 scenarios in which one can differentiate the children's position. She also found that children's visibility is important and is contingent on four key factors and these are the Health Professional, Child, Parent and environment. The author maintains that there is a need for relevant communication assessment strategies in place to determine the ideal position of children in the whole communication process. In summary this study observed

the general communication process of a doctor and a child admitted into the hospital. Some doctors talked with the child in a very friendly manner and explained the information about a forthcoming procedure. On the other hand some doctors leave the child behind and only talk with parents about the child's forthcoming procedure. There is need to a balance the communication process.

2.5.2 Hospital assessment of Patient Journey:

A child's ability to understand and willingness to know about their medical condition is gauged during medical history-taking in the course of a consultation. The doctor will speak first with the child and then with the parents to obtain as full a medical background as possible along with any relevant surrounding information. Whilst talking with the child, the doctor will ask about the child's family, school, friends, interests, etc., which elicits the child's character and personality, level of comprehension and development. This helps to elicit the level of information the child will look for.

It is the right of the patient to be fully informed about their forthcoming procedure and prognosis which includes benefits and risks of treatment. This is recommended as a standard in Paediatric oncology (Last, 1995). If a child knows the facts it increases the ability to ask questions and express worries about the disease and the loneliness and isolation are prevented (Lansky, 1993).

2.5.3 Traditional communication methods with children:

These included an information booklet provided on admission to a hospital. Another form of communication happens when a consultant explains to the child about the procedure and treatment but at the time when the doctor is around, the child might not feel well and lack concentration because of the severity of their illness. The nature of illness of a child gives them different types of emotional and psychosocial problems. For example, a child may feel that they would like to talk and sometimes they feel very sad and these emotional problems sometime leave them with so many questions that they want to ask.

2.5.4 The need of Information Provision:

Information provision is a vital phase of preparing a child for a medical procedure. Preparing and informing these children for their forthcoming procedure is highly challenging for health professionals and parents. Health professionals and parents are often finding it difficult to know what, when and how to provide information and who should be providing this information to the child. The review from (Jaaniste et al, 2007) highlighted the potential benefits for Children and Young Adults when they are provided with accurate and age appropriate information.

2.5.5 Children and young adult's benefits:

These include fostering a child's trust, reducing uncertainty, enhancing their confidence in their ability to cope with the disease and providing accurate information about forthcoming procedures. These minimize distress and optimize treatment outcomes and recovery time.

2.5.6 Parent's benefits:

Easing the burden about what to tell their child, empowering them to support their child and reduce their anxiety levels.

2.5.7 HealthCare Professionals benefits

For providing accurate and effective information to children make the role of health professionals easier at the time of a medical procedure. To address the issues regarding when, why and how to provide the information(Jaaniste et al, 2007) described the emotional and cognitive mechanism involved in the form of an Information Provision model. This model explained how a child or Young adult responds to information when faced with a forthcoming medical procedure. The model provided the two theoretical frameworks namely Schema and Self Regulation Theory.
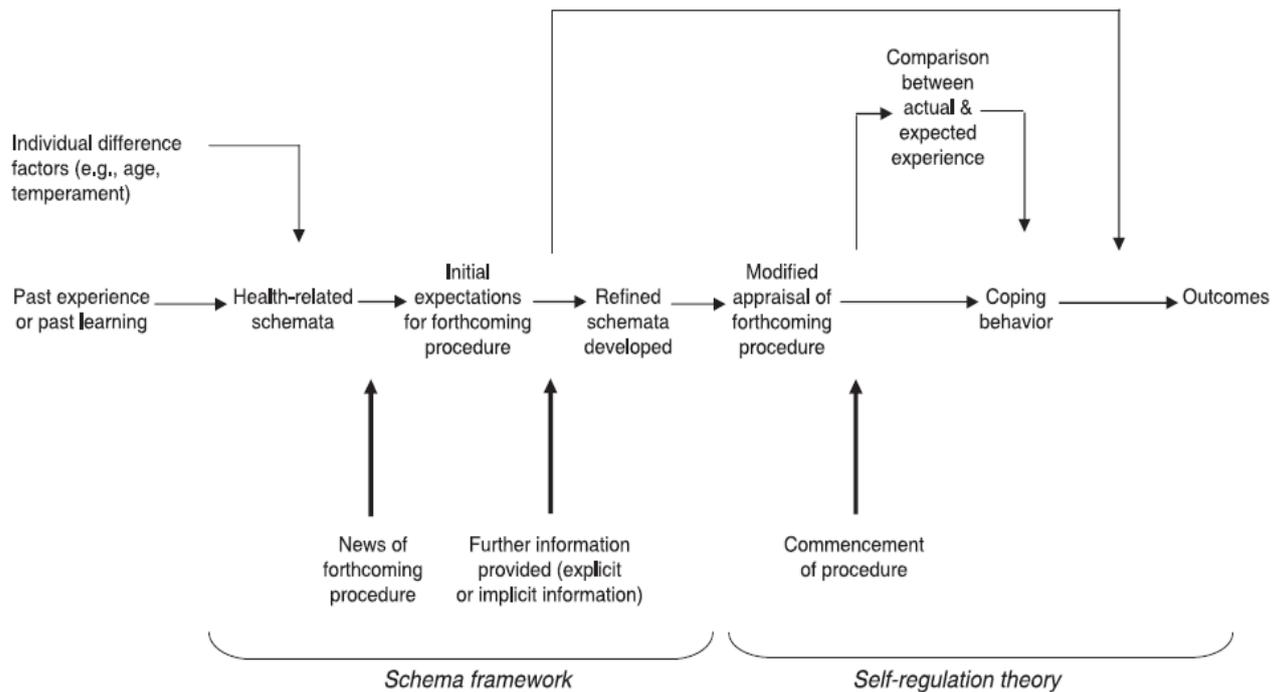
Figure D Schema Framework of children cognitive information Provision source:(Jaaniste et al, 2007)

According to this framework, self regulation relates to how individuals will make an effort to adjust their behaviour and situation based on expectations derived from past experience and from the information provided to them. (Johnson, 1999, cited by(Jaaniste et al, 2007). In the perspective of a forthcoming medical procedure, self regulation is how a child constantly adjusts his or her behaviour according to information received. Schema theory relates to mental representations of the concepts that are stored in the memory and shaped by past experiences and taking explicit information in the form of booklets or instructions and implicit information in the form of visible sign of parental distress. When a child is informed about the forthcoming procedure, these schematic memories about the past medical experience are activated. Figure 4

describes that these two approaches of Schema and self regulation are seen to be parallel and that each approach focuses on different aspects of the process by which individuals absorb and respond to the information. Past experience of a child and exposure to a variety of information influence the health related schemata which process with the further information provided to the child and is influenced by the related outcome. For example, a child's distress level depends on how the information is provided. It also reveals the importance of providing age appropriate medical information to children prior to their procedure. It is also important to examine the factors that are important when providing information such as the most appropriate contents, format, the medium of communication, timing, and also some individual factors including temperament and coping style were considered to be of high importance.

2.5.8   Psycho-Educational Intervention:

Children and young people need information about their health that is based on the context of their personality and age especially if the purpose is to illuminate the learning process.   (Bradlyn, 2003) proposed a model which described a systematic review of published research on psycho educational interventions for children with cancer. Psycho education refers to the education offered to people who live with a psychological disturbance and a goal would be for the patient to understand and be better able to deal with the presented illness. In Fig 5: (Bradlyn) explains the information provision and knowledge acquisition as an interactive loop
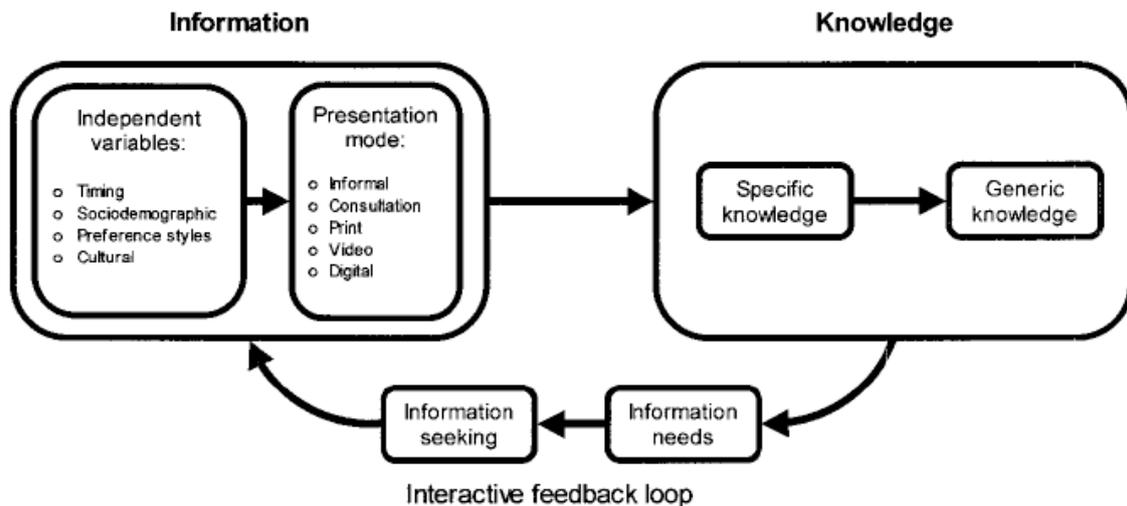
Figure E: A model for the transfer of information to facilitate health-related knowledge development in paediatric cancer patients.(Bradlyn, 2003)

The author reviewed the different studies related to providing information for children and young patients about their illness and proposed a model with an interactive loop where knowledge may be specific or general. It highly depends on individuals as to what their information needs might be, how this information may be provided to a child and also depends on different individual variables. For example, timing and preference style as well as presentation mode. An example might be the medium and whether it is in either print or video. This model found that the development of health–related knowledge in children is best accomplished by information transfer that is highly interactive and individualised. Multimedia formats such as video and games are seen as the best potential. This review clearly indicated that there is a need for a system in place which provides children with cancer information about their disease, investigation, treatment that is individualised to their own context.

2.5.9   Educating Patients about illness:

Educating patients about their illness is an important factor that affects their adjustment as well as communicating with them about the treatment program. This may need the development of unique educational resources for younger children. (koocher 1986). (Melamed et al 1975) stated that "*there is a consensus that all children need some kind of psychological preparation for the hospital experience*"p511. The aims of the preparation are twofold: 1: to provide information to a child about illness 2: to teach them coping techniques. This statement clearly highlights that even 34 years ago, the author recognized the importance of preparing children for undergoing medical treatments. It also highlighted that procedural distress is relatively common in children with chronic illness.

There is an enormous range of health information on the World Wide Web. A Google search on children with cancer gives 51,100,000 results. The variety, quantity and quality of this information are overwhelming for parents who search for their children's cancer.

2.6 Different methods used to provide information:

Various methods of communication have been designed to provide better access to the knowledge and understanding these children require. At present information provided to children about forthcoming procedures are primarily

paper-based or play doll therapies. Google search on 'childhood cancer' gives thousands of links to web pages that provide general information about cancer itself but not in a personalised manner or relevant to the child's own situation (Byrne, 1997, cited by Jaaniste et al 2007). Preparatory information is important for children to help to control their expectations and to separate from fantasy to reality.

Creating special educational materials about procedures is important for supporting child adjustment to their situation (Kooher, 1986). A study by (Strecher et al, 1994) has suggested that educational materials would have better impact when adapted to individual patient's needs. (Bental et al 2000) has developed an explicit model for the provision of computer-based information for cancer patients. This model is adapted to the individual's needs and uses patients own medical records to automatically personalize the information. However, this web-based information is only presented in text format which might not be suitable for children. Educational materials such as videotapes, specifically designed to provide information and promote active participation in treatment decisions, can be effective tools for empowering patients.(HJ, 2001).

2.6.1   Age Appropriate Medical Information

Providing age-appropriate information prior to medical procedures is recommended by different child advocacy bodies such as The Child Friendly Healthcare Initiative (Southall et al 2000, cited by Jaaniste et al, 2007).

Appropriate information provision is of key importance in the effective management of children's medical treatment. Currently, when a patient is admitted into hospital, general information in the form of books and leaflets are provided to children without much consideration as to the level of understanding of an individual child.

It is found that children need honest information from parents and health professionals about their illness. For example, a study from (Last, 1995) suggested that providing open information to children about cancer at the initial stage gives a child hope and support.

The investigators conducted a study to measure anxiety and depression levels. 56 children aged 8-16 years answered the questionnaires and their parents were interviewed about how they communicated with their child on diagnoses. It was found that children who received open information (such as, that they were told honestly that they had cancer or a tumour) at the time of diagnosis, showed less anxiety and depression than the children who received information at the later stage.

(Dragone, 2001) showed that children have increased feelings of control over their health where data was collected to make an interactive CDROM for children aged 4-11 years diagnosed with Leukaemia. In this randomized control trial children and parents were asked to either select a CDROM or a book "kids with Leukaemia". The evaluation of this study found that the CDROM is a useful and

empowering tool. However, there was no evaluation on the use of the book found in this study.

The health professionals can create an environment in which children have an opportunity to ask questions. In a survey of nine children aged between 7 and 11 years planned for surgery, as many as 61 questions were raised from the children regarding things they wanted to know about their forthcoming procedure. (Smith et al, 2005). Health professionals also have a difficulty speaking with children about a serious diagnosis as there is a lack of knowledge in children's age-appropriate cognitive skills. (B F Last, 1994).

In a British study of patients around 82% of patients undergoing surgery had articulated their need to know more about the procedure before the surgery (Bunker TD, 1983). Appropriate information provision is important in terms of providing effective management for children (Jaaniste et al, 2007).

2.7   State of the art

2.7.1   Star Bright Foundation:

In USA there is a private network (Star bright World) which aims to improve the psychosocial issues that children with chronic illness endure by providing them with entertainment, education and activities to help them cope better with pain, fear and isolation .SBW provides paediatric patients with a variety of entertaining

and educational software in the form of DVD'S, animated videos and interactive games to help them learn about the disease. Star bright has age-specific programs to cater for different age groups, information on different type of diseases, different medium of providing information from diagnosis through the entire course of medical treatment for families. This online network offers many programs to support children showing different procedures and treatment in multimedia format. One of the interesting features of star bright is 'Find a friend' which enables a child to search for other children by choosing criteria of age, location medical condition and interests etc.

2.7.2   Recent Interventions from Star Bright

One of the intervention programs from STARBRIGHT is called Hospital Pals which is designed to focus on easing fear and anxiety that children may have in connection with upcoming procedures in hospital and it focused on a specific disease and catered for specific age group preschool 2-6. This intervention uses a video to show a child a procedure, e.g. Radiation therapy, supported by preschool favourite character Barney which a child can watch during the actual treatment (Bush et al, 2002). This intervention is currently implemented in 95 cancer centres around the USA. Another intervention from this author is a series of interactive programs in the form of a CD Rom game for children with diabetes.

STARBRIGHT has illustrated the positive impact of a virtual environment on hospitalized children on pain and anxiety. Children with chronic illness who were

involved on this network have experienced significantly less pain and anxiety. It is based in USA but more recently has extended internationally to Australia, Japan and UK.

To evaluate the impact of these educational programs, several studies have been undertaken. Few looked particularly on child outcomes and some looked specifically at outcomes for Parents and health professionals, (Bush et al 2002). Some of these are discussed below. Children reported less pain and anxiety using the Star bright programs as they were engaged in different programs/activities. This is reported in a study from Holden 2000 who examined the impact of starbright world on pain and anxiety of hospitalized children.

www.curesearch.org is one of the health information websites for children with cancer which does provide some minimal tailoring. For example, it displays the information in different search criteria such as Age groups and different phases of cancer stages,

2.8 SOLAS:

SOLAS is an online network developed by the Centre of Health Informatics Trinity College Dublin for children suffering from childhood cancer in hospitals. The system is currently being piloted in a cancer unit for children with over 180 users to date. In particular, it is designed for those who need to stay in

protective isolation in an acute paediatric hospital in Dublin. This network is designed to link seriously ill children into an interactive online community in which they can play games as well as communicate with the outside world to combat the effects of isolation. The target audience for SOLAS users ranges from 7-14 years. This system was primarily developed to address some of the psychosocial issues including isolation that children face through hospitalisation. It allows communication with family and friends during their stay in hospital and home via email, live chat and video link. The main aim of SOLAS is to support children in hospital to face the medical and emotional challenges they experience on a daily basis. The SOLAS environment offers an intuitive interface to a variety of services, integrating a range of current Web technologies in a secure environment. (Solas Needs Assessment). The services offered for communication is shown in Table 1.

Features	Solas	Features	Solas
Communication		**Entertainment**	
Text	✓	Games	✓
Instant Messenger	✓	Art	✓
Video Conferencing	✓	Music Composition	✓
Forum	✓	Audio Books	✓
Notice Board	✓	Web Links	✓
SMS	✓		
Email	✓		

Table 1 Solas Functionality

This functionality is accessed through links from the Solas colourful homepage:

2.8.1 SOLAS Needs Assessment

A comprehensive needs assessment which was carried out between November 2005 and March 2006 by the Children's Research Centre Trinity College Dublin. The needs assessment phase of the project incorporated qualitative and quantitative data analysis, following interviews with children, their families and focus groups meeting with staff members of various disciplines. To assess physical, psychological and social impact children and parents were asked range of questions about the impact of the illness and problems with communicating with family and friends as well as their opinion about introducing a computer system to help them tackle their boredom and isolation in hospital.

The needs assessment reported on the physical and psychosocial issues children with chronic illness face during a hospital stay. Physical issues included tiredness as the most common problem mentioned by children interviewed. They frequently mentioned the feeling of illness and pain along with a desire to sleep, which resulted in feeling too tired to undertake normal activities.

The psychological issues of children reported in the needs assessment were very varied and quite negative. Interviews found that the nature of the impact of illness was individual to each child. Parents were concerned that their children were "switched off", while some were asking questions about their illness as a punishment 'why me'. For young girls a big challenge was dealing with side effects and fear of losing social contacts. Interviewees were then shown an example of what SOLAS would provide and asked to give their opinions about the interface and suggestions about what they would like to add or change.

There were many suggestions noted from the interviewees such as collaborative gaming (where by children in separate rooms could play games together). Also suggested was providing access to education and connecting to the hospital school. There was also a suggestion to add a section where information on medical procedures could be provided. This study found that such a system could have a potentially positive impact and would be welcomed by children, parents and staff. They also felt that providing information on medical procedures is an important element that would be useful for children and parents (Needs Assessment). This study also suggested that further research on providing

medical information on procedures that children undergo should be at an appropriate level for children.

2.9 E-Learning:

The arrival of e-learning has bought many changes in the educational world and the way people learn. E-learning is online learning but there different names such as Web Based Learning, Web-Based Training, Internet Based, on demand Learning, anytime, any place learning. *"E-learning can be viewed as an innovative approach for delivering well designed , learner-centred, interactive, and facilitated learning environment to anyone, anyplace, anytime by utilizing the attributes and resources of various digital technologies along with other forms of learning materials suited for open, flexible and distributed learning environment" (Khan, 2005).*There is one new approach to e-learning is 'One size fits all' which provides adaptive and individualised and personalised information to learner. An Intelligent Teaching System is commonly described in four models, architecture: the interaction model, the learners' model, the domain expert, and the pedagogical expert. The learner model represents learning style, and pedagogic approach takes the learner as an individual learner.

2.10 Using e-learning to provide medical education:

Computer technology in the form of e-learning is helping to refine health education and have a positive impact at different levels, from health care

professionals to medical students to patients. Health care professionals and medical students are using e-learning for continuing medical education. At the patient level multimedia is a valuable tool for providing information about their disease. But the e-learning concept is relatively new to this kind of information.

ADAPT is an interactive multimedia e-learning system that has being developed at Trinity College Dublin, it has been piloted to help medical professionals and students for teaching the techniques of interviewing psychiatric patients. This tool is a joint project between the Knowledge and Data Engineering Group (KDEG), Department of Computer Science and the Department of Psychiatry at the University of Dublin, Trinity College.

ADAPT is an eLearning system, which has a capability to personalise eLearning content for the user. The system is a set of eLearning tools to rapidly build and deploy interpersonal communication skills training. ADAPT uses simulation to place the learner in a realistic and safe environment where they can practice and master a range of communication skills such as interviewing, conversing, communicating information, etc.

These simulations have been successfully used for medical students for teaching communication skills for Psychiatry department in Trinity College Dublin and could be adapted for different categories, different subject matters and different target audiences. It may have a potential role in providing health information for cancer patients. However further research is required to investigate its suitability

for this type of health care environment. The benefits of adapting the simulation tool for providing information to patients would include allowing patients to interactively engage educational material appropriate to them for their particular condition and treatment in a dialogue based fashion. It would also allow staff to practice their communication skills in this sensitive area of healthcare.

Facilitating the psychosocial adjustment of the child with cancer begins at the time of diagnosis. Recent data suggests that a child's adjustment is linked to the social support available to them. Having an individualised e-learning tool to provide information on the child's own type of disease and give them appropriate information to their age is important.

2.11 Chapter Summary:

This chapter reviewed the local and international literature to assess the need of providing medical information to children and young people and the importance of efficient communication between the health professionals. The purpose of this study is to assess the feasibility of using adaptive eLearning technology to support the provision of this type of content for children, and also to evaluate if this personalised information improves the child's overall wellbeing, through understanding and empowerment.

The rationale was discussed in this chapter which explored the different types of cancer and the impact of treatments on these children which elicits that there is a high instance of psychosocial issues. The published research has been reviewed in this chapter to find out the current methods of providing information and it was found that it is important to provide medical education to children who have chronic illness. Also there is substantial literature published that children need highly individualised and interactive multimedia knowledge transfer methods in multimedia format such as video games. Research has indicated that children who are more informed and knowledgeable about their condition have improved coping and adherence to treatment.

The next chapter, describes the Needs Analysis which provides in detail the factors that influenced the design process when providing information to children and young people and the research methodology chosen for this project. It further discusses the requirements for the stud

3 Chapter Three- Needs Analysis:

This chapter will describe the research methodology that was chosen for this study. It will also detail the needs analysis phase of the project which included informal interviews and a random survey facilitated with doctors, consultants,

nurses, psychologists and paediatricians based on informing the needs that children with cancer may have in relation to information provision. The aim of the interviews was to find out about the frequently-asked questions and common answers provided to children of differing ages. This chapter will also detail the requirements gathering exercise.

3.1 Research Methodology:

A methodology is an operational framework within which the facts are placed so that their meaning may be seen more clearly (Leedy, 1989).

The primary objective of this research was to explore the feasibility of using adaptive e-learning technology to provide medical education for children with chronic illness. To achieve this goal the primary objective is divided into sub-goals.

3.1.1 Objectives:

- Examine the need for providing medical information to children.

- Knowledge Acquisition for the medical content

- To assess the different medium used for information provision

- To examine how health Care Professionals deal with the questions that children ask about their illness in a health care environment.

- Develop an adaptive e-learning module using the ADAPT system and integrate it within the Solas system

- Evaluate the usability of the design and the feasibility of using adaptive technology.

Choosing a research approach is a method of seeking out a procedure that will yield answers to the research questions posed. This enables the researcher to draw a comparison between the published and newfound research. As this research is based on investigating the feasibility of using the system in a healthcare environment, (Bowling, 2002) the process of the investigation method chosen depends upon the investigators assumption about a society. The choice of approach has a long history of debate in the philosophy of science and in the social science. There are two main philosophical approaches in research; positivism and Interpretive (Galliers, 1991).

3.1.2   Quantitative Approach Positivism:

Positivism assumes that there is a single objective reality which can be determined by the senses, and tested subject to the laws of the scientific method(Bowling, 2002).For example an investigator may start with the general ideas and develop a theory and test a hypothesis with it or first start collecting the data and building up through observation. Positivism is a dominant philosophy underlying quantitative scientific methods which defined the approach as "one that seeks to explain and predict what happens in the social world by searching for regularities and casual relationship between it's constitute elements".

3.1.3 Qualitative Approach Interpretivism:

This qualitative approach takes the view that the understanding of a researcher is fundamental to the output of the process. It also proves that the world is

constructed by its' participants. This method is also said to be a naturalistic enquiry and it's less obtrusive than quantitative research and does not manipulate a research setting.

Bowling 2002 has described a process of choosing a research methodology as depending on a researchers aims. If the aim is to find out information on any topic where little is known or it's too complex then it is called qualitative method and an example of data collection method is observation, in-depth interviews and /or focus groups. But if the research aim is to investigate cause and affect issues then the method used would be quantitative. In some cases these methods should not be seen as isolated and need to combine the both methods which are called a triangulated approach or action research where different data collection techniques can be used. Action research uses multiple research methods, most of which are qualitative, while some quantitative surveys may form an element. Hart and Bond 1995(cited by Bowling 2002) outlined seven criteria which outlines the types of action research there are:

1. is educative
2. Deals with individuals as members of social groups
3. Problem focused, context-specific and future oriented
4. Involves a change intervention
5. Aims to improve and involve
6. It involves a cyclical process in which research, action and evaluation are interlinked.
7. Founded on a research relationship in which those involved are participants in the change process.

For the purpose of seeking the best possible methodology, the researcher adopted an action research methodology which is an umbrella type research in the form of research, action and evaluation. The author chose this methodology for the purpose of this cyclic process:

3.2   Research Methods for this study

Phase 1: Exploratory method used by way of searching published and grey literature to find out the current system of providing information to children about their disease and identify the problems in this area.   Informal interviews with health professionals were also conducted to find out how they provide information to children: Findings of the literature were that there is a need for providing such information in an individualised manner.

Phase 2: This information then prioritised with the random survey of 37 participants including Consultants, Non Consultant Hospital doctors, Nurses, paramedical staff and parents. Findings of this survey prioritised that four factors influenced for the information provision for these children.

Phase 3: Designing an artefact of e-learning module with Adapt and integrated with Solas. This phase was time consuming.

Phase 4: This phase has been done by taking feedback from the health professionals:

Selection of Methodology:

It was decided to conduct informal interviews with health professionals to identify the need for providing medical education to children and find out the existing methods of delivery of such information. For this purpose, data was collected from one of the national paediatric hospitals of Ireland. Informal meetings were arranged with 5 professionals including a paediatric oncologist, a child Psychiatrist, a paediatric consultant, a clinical nurse manager and a play therapist from the two wards. This method was chosen because of its flexibility and benefits" *Informal interviews are core part of gaining an understanding of a setting and its member's way of seeing*" (Cohen). These interviews were carried as a means of informing the author about the type of information that children would need but also what type of questions children ask about their condition. Informal discussion with these 5 Health Professionals indicated that it would be difficult to meet with them again and recruit any more health professionals in this study because of their busy schedule and heavy demands of time. However, they were happy to be contacted by e-mail because e-mails are a quick and easy way to communicate and respondents can fit them easier into their own schedule. A covering letter (Appendice) in the form of an email was then created and sent in the email to these health professionals. They then agreed to send to their doctor's mailing list and whoever was happy to respond to the survey would. A random survey was then created

3.3 Pilot of Informal Interviews:

This research aims to provide medical education for children in an e-learning environment. The ADAPT system uses simulation to present information which is

based on interactive Frequently Asked Questions (FAQ) with generic dialogue between patients and doctors. As part of the needs analysis/requirements phase informal interviews were held with doctors, consultants, nurses, psychologists, paediatricians based on the questions that children might pose when faced with a diagnosis of cancer.

The aims of these interviews were to find out about:

- The frequently asked questions that children of varying ages might ask. This type of information can only be provided by a health professional working in the hospital because they are the key provider of this type of information related to disease.

- The common answers to these questions based on their age.

- The current and different techniques and medium used in providing such information e.g. Books, Puppets, dolls or diagram...

- The timing of providing information to each age group that is most effective.

- How Health Professionals provide information to patients and the difficulties in providing information to them.

The literature review and informal interviews from health professionals endure that there is a wealth of research going on about the provision of medical education to children, but that every child is different and takes information differently. There is a need, therefore, for a system to provide children with information that is suited to their own context and in a personalised manner.

These findings also suggested a number of factors that influence providing information to children. These are age, content, format, and type of disease, stage of disease and their individual behaviour such as coping style and timing of when information would be provided. The informal interviews with healthcare staff have highlighted that it is important to elicit what a child already knows and their understanding of their condition. It is also important to check the accuracy of their understanding of what they have been told to-date and what their perception of the situation is.

Due to the large scale of influencing factors suggested in the literature and discussed throughout the needs analysis phase, it was decided to determine and prioritise the four most relevant in an Irish context through a random survey conducted for this study with doctors, consultants, nurses and other hospital staff.

The online survey was sent to 50 participants (health care professionals) who were willing to take part in the study. 37 participants completed the survey, and from the 7 influencing factors identified in the literature, four were prioritised for

the purposes of this study. The survey requested participants to rate these factors in relation to the most important when providing medical information to children. The four most important factors were selected to influence the design of the module for this study; the responses are detailed below:

The first question asked of the health professionals was to describe their job in the health care sector.
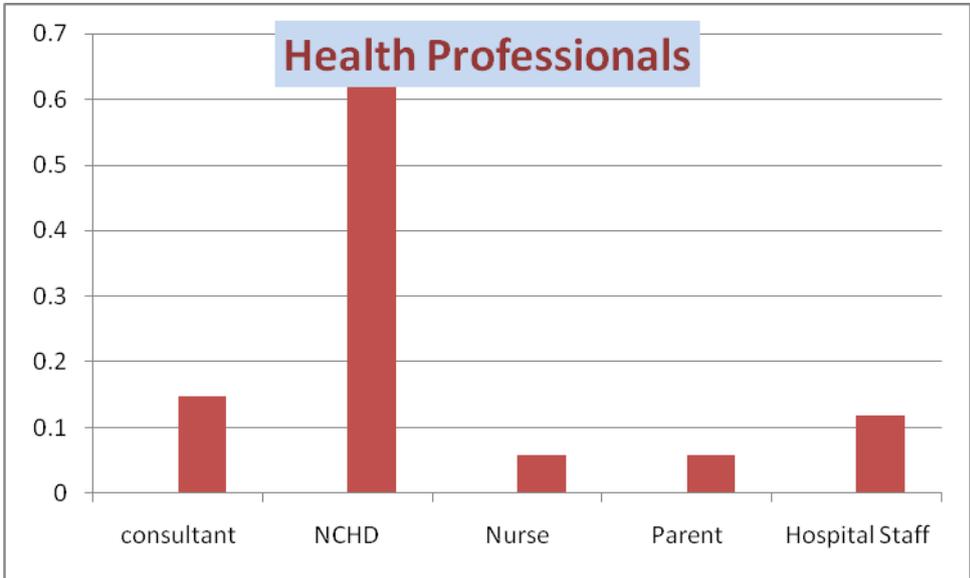
Figure G Health Professionals Survey

Total of 37 (n=37) participants took part in the survey and the above graph shows the range of participants including consultants (n=5), NCHD Non consultant's hospital doctors (n=21), nurses (n=2), parents (n=2) and other hospital staff (n=5). There are many health professionals who deal with the children at differing stages of their diagnosis and treatment, and each can provide an important insight into providing the medical information.

The next question asked was to rate the importance of the 7 factors which were identified in the literature review. Participants were asked to give their opinion on which is the most important and which are least important. Figure 7 presents the results of this question and highlights the influencing factors in order of importance.
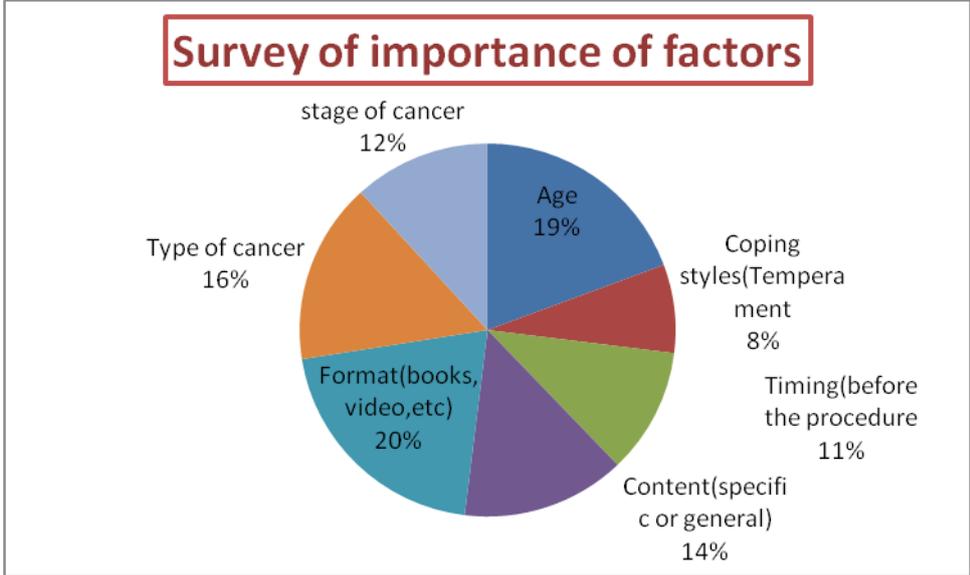
Figure H Survey representing importance of Factors

Figure 7 above shows 20% (n=17) of participant's responded that format or medium is the most the important factor when providing information to children. An example of format or medium would be books, video or any multimedia type. The survey also revealed that 19 %(n=16) of the participants agree that the age of the child is an important factor to consider when designing or presenting medical information.

A further 16% (n=13) of participants rated type of cancer as being an important factor influencing the provision of the information, with 14% (n=11) rating contents as the most important factor.

From the survey results the 4 most important factors identified by health professionals when presenting medical information to children with chronic illness are:

1. Format: the medium by which information is provided to children for example: In the form of C.D, Video, animation, in this study e-learning technology is used to fulfil this requirement.

2. Age: was also a hugely important factor which must be considered when providing medication information.

3. Type of cancer: In the context of information provision, type of disease or type of cancer is also important to consider.

4. Contents: The actual content needs to be comprehended by children according to their level of understanding and age.

3.4 Requirements Gathering

"If an information requirement is stated improperly
to begin with, then everything else that follows will be incorrect."
- Bryce's Law

In software engineering, requirements gathering encompass those tasks that go into determining the needs or conditions that need to be met for a new or altered product, taking account of the possibly conflicting requirements of the various stakeholders. Requirement gathering is critical to the success of any project. This research looked at four key tasks, needs assessment, design, implementation and evaluation as part of the process to addressing the research question.

A study of the Feasibility of using adaptive personalised e-learning technology to provide medical education to children in a healthcare environment.

- Four sub-goals were addressed in this phase of the project: What are the needs of providing medical information to children:

In order to identify the needs which should be met when providing information to children, a literature review was conducted from different searches which are described in chapter three. Providing medical information is an important aspect to the provision of paediatric care that can make medical examinations and

procedures less stressful for the patient, the medical staff administering it and the child's parents. The quality of care can also be said to be directly related to the type of outcomes of treatment. Linked to this, there is evidence to suggest that appropriate information provided to children before procedures, fosters better outcomes. The models from different literature were reviewed which were proposed by different authors to provide information to children. The first model highlighted the communication gap of children, parents and health professionals. A health professional's job is to diagnose and treat a patient's illness along with informing them about their hospital stay and their forthcoming procedures. Different health professionals have different views on providing information to a child. Research has indicated that children who are more informed and knowledgeable about their condition have improved coping and adherence to treatment.

3.4.1 Knowledge Acquisition for medical content:

To provide medical information for children about the forthcoming procedure, it was necessary to gather information about different types of cancer and its effect on children. The literature search found that every child's cognitive behaviour is different according to the individual factors that affect them in understand the information. There is a need to consider those factors when providing information to this target audience. The informal interviews which were conducted in this needs assessment phase also contributed to the knowledge acquisition phase of the project. The health professionals play a pivotal role in presenting this type of medical information to children. These recommendations fed into the design phase and were used to design a prototype e-learning module for children. Details of the types of questions are discussed below:

- What solutions are currently available to answer children questions in the health care environment?

- Answers to this question suggest the best solution to provide this type of information to children is to use a variety of different techniques, for example, in print media and the interactive media.

3.4.2 Informational Requirements:

- To provide educational material about condition, treatment and effects tailored to the context of the patient.

- Communicate the information through interactive dialogue.

3.4.3 A System Requirement:

- To provide this tailored information in a socially connected environment through SOLAS

- Develop an adaptive e-learning module using the ADAPT system and seamlessly integrate this module as an added function of the Solas system.

The newly added feature of Solas will offer medical information that is adaptive and age-appropriate.

3.5 Summary of the chapter:

The literature review and informal interviews from health professionals recognize that there is a wealth of research going on about the provision of medical education to children, but children have differing levels of comprehension so there is a need for a system to provide children information suited to their own context and in personalised manner. These findings also informed the most important factors that influence information provision and these include Age, Content, Format, and Type of disease. For the purpose of providing individual medical information to children, it was decided to make interactive frequently asked questions that take into account four influencing factors that were prioritised in a survey. These findings, along with the requirement gathering, were used to design a prototype scenario which was then evaluated by health professionals.

4 Chapter Four- Design:

4.1 Design Scope:

The core objective of the research is to implement an e-learning experience for children provided through ADAPT and integrate it seamlessly into the SOLAS system. This work will look at the feasibility of providing medical information through an adaptive medium that is tailored to the user's individual context, providing this information in an interactive and highly individualized manner through an e-learning style environment. Recommendations from the literature review and needs Analysis were used to steer the design phase. The scope of the implementation was limited to meeting the requirement that could be achieved within the project timescale.

4.2 Requirement:

- To provide educational material about condition, treatment and effects tailored to the context of the patient.
- To provide tailored information in a socially connected environment through SOLAS

- An added functionality to SOLAS is needed that provides individualised information.

There are individual differences at each age level due to variation in the acquisition of language skills. The Learning ability of a child always relies on their cognitive development. According to Piaget's Cognitive development theory there are different stages of child's development that involves cognitive process and abilities. The stages are:

1. Sensori Motor Stage 0-2 years

2. Pre-Operational Stage 2-6 years

3. Concrete Operational Stage 7-10 years

4. Formal Operational Stage 11+

Concrete Operational Stage 7-10 years: This age group have better understanding of mental operation. They begin to think logically but can't understand abstracts or hypothetical concepts.

Formal Operational Stage 11+: This age group develops the ability to think about abstract concepts and logics and can manage problem solving thinking. In table 2 below describes the differences in children's intellectual, emotional and Language development at different age groups. (ucsf.edu).

The aim of the initial prototype is to make patient and doctor dialogues for children aged between 8-12 years. The Adapt system uses a series of dialogues and scenarios to deliver the information to the user. It was necessary to gather information about the language differences for this age group to make the contents.

Age and Development Features	Communication Skills	Aspects to consider when communicate
6-7 years		
able of follow rules, take pleasure in having responsibility, uncertain about the cause/ effect	Like to tell long stories Read basic words differentiate what is truth and Lying Understand basic sequence of time Understands adverbs and 'er'	Can explain them different body parts like eyes, nose , arms , tummy etc For this age group dolls are best to explain body parts Concrete and visual examples are important
8-11 years		
Better understanding of logics and cause and effect, able to understand feelings. able to use more complex sentences	Vocabulary is better more abstract thinking concrete language and examples is important Need more detailed information	Listen to their thoughts and opinions. This age group like to have more direct, reality based explanations and facts
12-15 years		
At the age of 12, basic language and communication skills would be established	Verbal Communication would be matured at this age May express themselves with noticeable behaviour May act unemotional like don't care	Need to speak clear and honestly. They also need facts about what is going to happen like diagnosis, treatment.

Table 2: Age Groups and Language Development

This table 2 shows that children's communication level and cognitive behaviour differs with age, approach, and cognitive thinking and their skills for understanding.

When children and young people have a serious chronic illness and are isolated from the outside world, they need accurate and honest information about their own diagnosis, treatment in a personalised manner. For this purpose patient

and doctor dialogues were created to communicate the disease information with children and young people and take into account the different factors that influence these dialogues which are discussed in this chapter.

4.3 Design Approach:

The approach taken to meeting each of these requirements above is detailed below. This study is to investigate if an e-learning solution is suited to this kind of customised delivery of health information for children. The requirements of this study included.

1) Retaining all current functionality within SOLAS. After logging in a child has access to the colourful main page which has child friendly icons to choose from as mentioned in fig. These include E-mail, SMS, Video, Chat, fun, Art, drum steps, and diary. The new icon 'Doc chat' replaced the diary button to add the needed to be making to add functionality to the SOLAS system.

2) Providing generic and interactive frequently asked questions, this will be used to create the adaptive environment for users. It is decided for the initial design to provide the generic question answers but it can be adapted to child' own context and need to investigate the feasibility of this type of customised information.

3) Providing disease specific information at different phases, for example Investigations, diagnosis, treatment and psychosocial issues. A child needs information according to his/her own type of cancer and the phase which he/she is going through for example, if a child is going through the diagnosis tests then the only information needed is about the different tests which they are going to get. Similarly if a child has already been diagnosed with the type of cancer then he/she needs information relating to the treatment process.

4) Implement ADAPT design for providing simulations. The dialogues of a child and doctor conversation will be integrated into the design of ADAPT through ACTSim tool to make these dialogues adaptive

5) Implement a design of ADAPT and embedded seamlessly into SOLAS interface

6) Use the pictures and illustrations to explain the disease.

7) To make the dialogues more interactive the use a video will be included. An example of this would be when child asks a question about the disease the doctor's video appears to answer the Childs question. This video concept will give a child confidence to use the system that he/she is actually talking to real doctor.

These were the requirements identified for this study; it was decided to focus on requirements -1-6 for the initial design because of the time limitations, and to make video and illustrations at a later stage.

4.4 Functional Design:

The purpose of the functional design is to describe how SOLAS functionality would be used after integrating with ADAPT simulations. The functional design carried out as part of this research. In order to describe the functions of SOLAS after integrating with ADAPT, it was necessary to understand the current system and how it links to other pages. The main purpose of integrating ADAPT with SOLAS is to provide adaptive information to children with cancer which would give children support for their illness to help them better cope with the disease. At the moment it provides resources for a variety and diversity of users from 8 – 16 years. These are some of the tasks that need to be carried out in order to integrate ADAPT into SOLAS.

4.4.1   Identify SOLAS Users:

The child and the parents are the main users of SOLAS. Parents can make a request to be set up as a user to keep in contact with the child during a hospital stay. This design prototype will focus only on the child as a user. The Solas Facilitator has the full administrator rights and a software engineer is responsible

for development and management of the system. The SOLAS facilitator is responsible for managing the registration process.

4.4.2   Registration of Solas users

This is done through a facilitator who is present on the ward. Each user is then issued with a unique password and has access to the SOLAS community. At the moment, the registration process can only provide access through the SOLAS facilitator. Once registered the child can log on anytime and have full access to all functions. The registration process is only possible through the facilitator. The tasks carried out by a facilitator are:

- Registration –   Add New SOLAS User
- Manage Contacts –   View/Edit Email and SMS contacts for the child
- Add Contact –   Add Email/SMS contact for the child
- Manage Images –   Add/Delete accessible websites
- Manage Blogs –   Monitor content of posted blogs
- Manage Music –   Upload music files
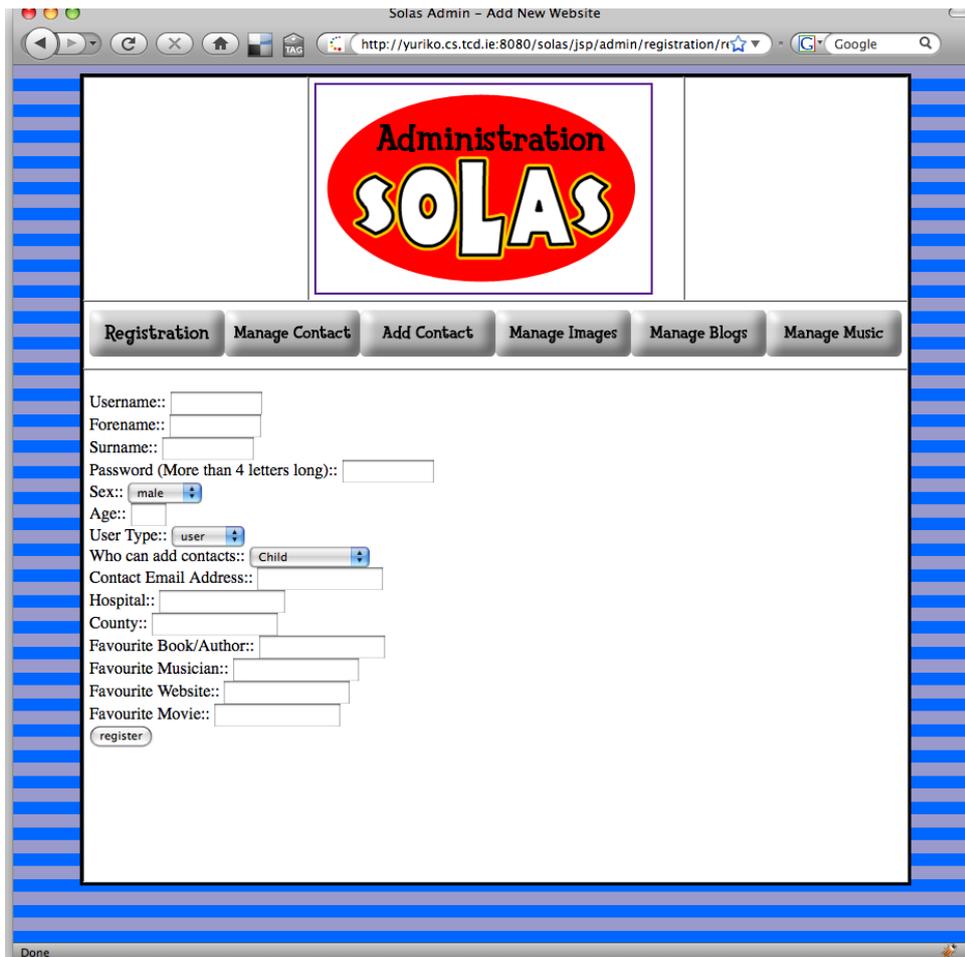
Figure I Solas Registration before

Nothing needs to be changed to manage the contents from the Solas developers, the only change would be needed was to elicit two new details from the children, which would support the adaptivity of the module.

1) Diagnosis: This will elicit the type of cancer in order to provide the disease – specific medical contents to them.

2) <u>Date of Diagnosis:</u> which will elicit the information about what type of information a child will need on admission to hospital based on their stage of cancer. For example if child is just newly admitted so he/she needs information based on diagnosis.

4.4.3   Solas and Adapt Integration

The importance of good interface design is reported by Velasco (2005); good user interface (UI) design can make the difference between acceptance of a software product and its failure in the marketplace. The purpose of designing the interface in this initial design was to satisfy end users requirements, if the end user finds the interface child friendly that makes a difference in attracting them with a colourful interface. An additional icon was then made to the solas interface and edited in Microsoft flash. The name of the icon is 'Doc Chat'.
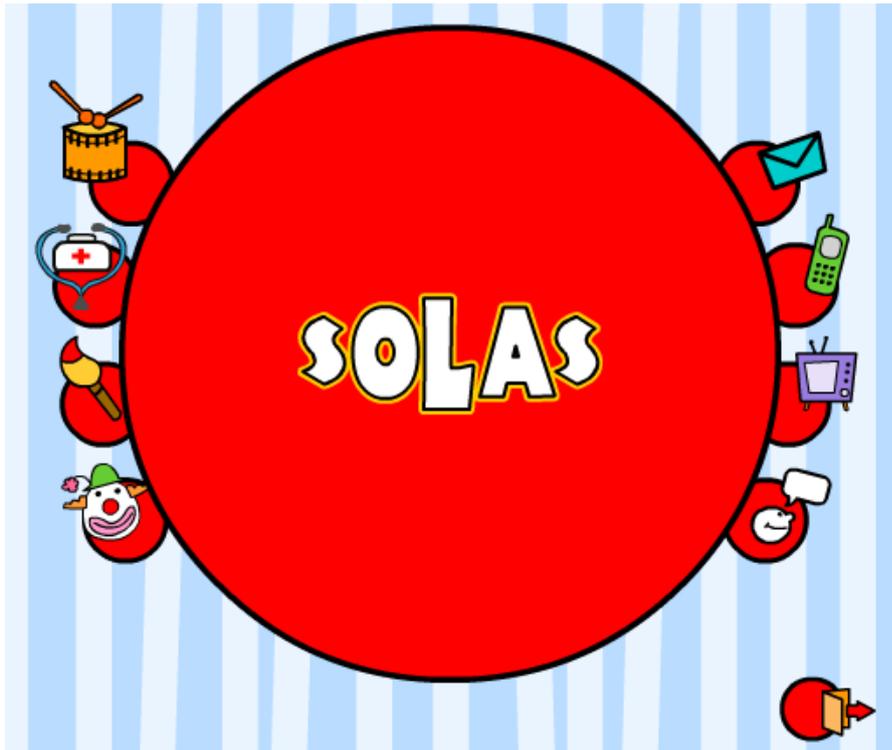
A page was designed to give an introduction to the overall purpose of this link with pictures and text. On this page an iFrame was made to embed the ADAPT module into the Solas web portal. The figure below shows the actual page

The design of the dialogues was an iterative process, including designing the scenarios and dialogues for different categories of children and making these dialogues adaptable. The influencing factors in designing the dialogues are detailed below:

Age: This study focuses on the age group of children 8-12years, to make the dialogues age appropriate this was further broken down into two age groups: 8-10years and 10-12years.

Format: Here format is using an e-learning module to provide medical information to children in the form of frequently asked questions.

Contents: This required building the dialogue language at an appropriate age level and appropriate level of understanding.

Type of cancer: Cancer is used to describe a group of different diseases as mentioned in chapter 2. It was decided to make this module for the specific disease Acute Lymphoblastic Leukaemia.

Figure 12 below shows the different routes of admission to hospital for children, including transfer from different hospitals and referrals from G.Ps. The reason behind collecting this type of information was to give child adaptive information depending on their circumstances, and set the scene for the dialogues. The way doctors communicate within the hospital setting is to start talking with a child and build a rapport to gain their confidence before providing the actual disease – specific information.

Figure: Patient Journey:

Patient Journey To Ward

Parents \ Symptoms → G.P. → Blood Test → Consulting → Admission

Parents \ Symptoms → G.P. → Blood Test → Suspected Leukaemia → Admission

Child Field Fracture → A & E → Suspected → Blood Test → Admission

Parents → Child → Outpatient / G.P. / A & E
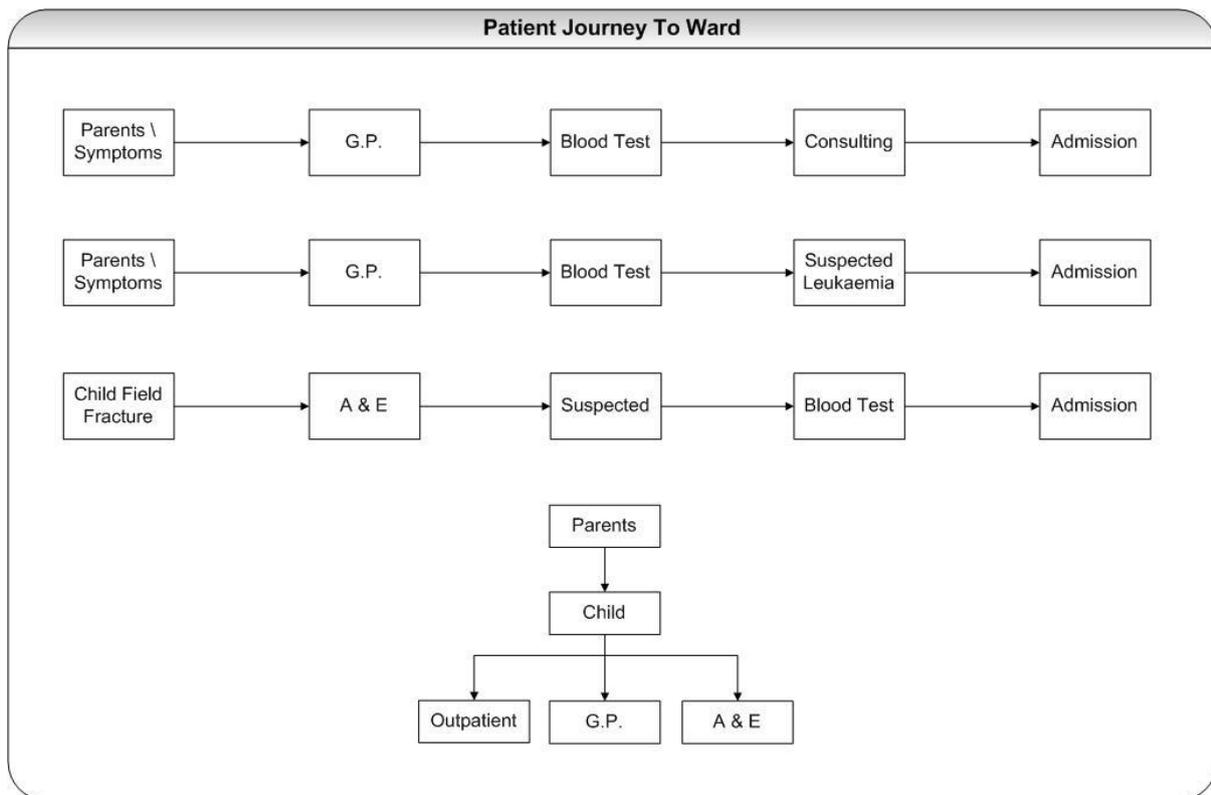
Figure L: Patient journey to the Hospital ward

The aim of these dialogues is to communicate with the children in an informative and social environment (of Solas). Choices of words can reflect age, education and development level. The characteristics of these dialogues are simple, brief, clear, relevant and adapted.

- Specific age group: 8-9 and 10-12
- Format/ medium: Adaptive Simulations
- Contents: Appropriate language to cater for the different age group.
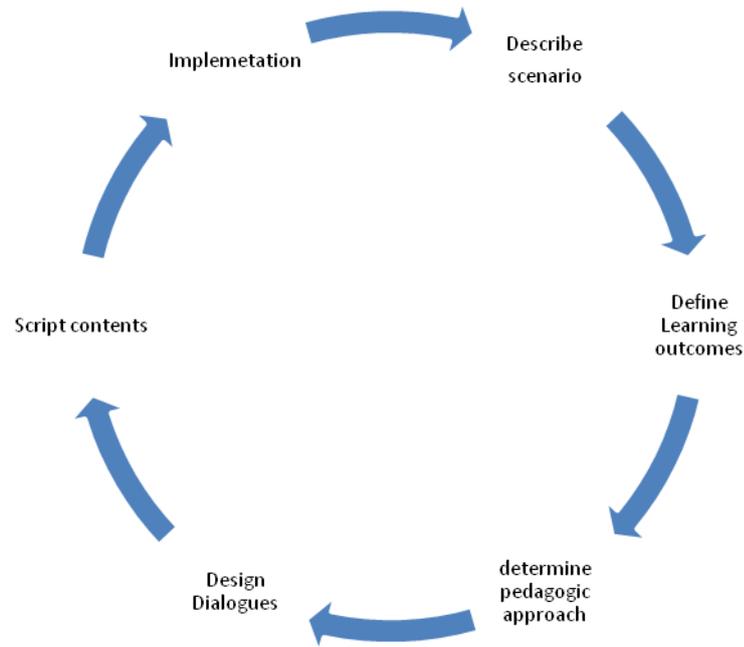
Figure M shows an iterative process of a design of ADAPT

The next phase was to make contents for the frequently asked questions. This phase was further sub-divided.

4.4.4   Build the dialogues.

The important phase of the dialogues was to find out the medical information about Leukaemia to gather the contents at an appropriate age level. For this reason the information gathered from the informal interviews from the health professionals and the medical information gathered from different medical resources was used to build the dialogues.

72

4.4.5   Structure around the Dialogues

Once the medical information was gathered the next process was to build the actual contents of the dialogues. For this purpose the author has to assemble the information in different groups and in different stages when the child may need the information.

4.4.6   Design the dialogues at an appropriate age level.

The next process was to design dialogues that meet the requirement of the end user. These dialogues are for children within specific age groups. The information collected was than edited by the author for further accuracy of the contents and to make it understandable for children at different ages. Once the process of creating the dialogues finished the next phase was to outline the learning outcomes of the dialogues.

4.5 Adaptivity Based on learning outcomes:

Every learning process should have a learning outcome to specify what the learner has achieved after this learning process. Here the learning process involves the paediatric patients' learning. The goal is to satisfy their needs in relation to medical information. This type of learning process involves them to give knowledge about their disease as well as give them a child friendly

environment in which to use this tool. These were some of the outcomes identified for the learning module:

- A patient should have better understanding of the type of cancer.
- A patient will be able to differentiate the different types of blood cells.
- A patient would be able to know his/her forthcoming procedures.
- A patient should know what chemotherapy is.

4.6 Adaptivity Based on subject or Category:

It was necessary to breakdown the information in a logical way, and the dialogues were divided into different categories and subjects. First of all the dialogues were separated by the different stages of child hospital stay. For example, a child being admitted to hospital with symptoms of suspected Leukaemia means that this the child needs only information relating to their symptoms because too much information about the disease can increase a child's stress levels. These dialogues were then created within different categories.

Symptoms: Provide general information about the hospital and the questions that may arise on admission into the hospital for example "Why I am here" or "when will I go home".

Investigations: This category provided information about the different investigations and tests that a child may need information about. The conversation includes "Why are doctors taking blood". What is an X-RAY, 'What is Bone Marrow' Will it hurt"?

Diagnosis: At this stage when a child is diagnosed with Leukaemia he or she needs the information relating to the disease, for example; what is Leukaemia? How does the doctor find out I have Leukaemia?

Treatment: At this stage the child needs different information according to their own treatment plan. For example, "what is Chemotherapy?".

Side Effects: At this stage a child is worrying about the side effects they are getting because of the treatment and need the information according to their own body's effects of the treatment. For example, "why is my hair falling out?"

Psychosocial Issues: The psychosocial issues that children can endure include fear, anxiety and feeling depressed. They are also thinking about their future and their social life, about leaving their peers and friends. These issues can raise so many questions for cancer patients. The purpose of this conversation was to give them hope and support to overcome their burden they face with the help of supporting language at this hard time for them. For example, "When will I play with my friends?"

Categories of the Disease

Symptoms • Investigations • Diagnosis • Treatment • Acute Lymphoblastic Leukaemia • Psycho-Social Issues • Side Effects • Hospital People
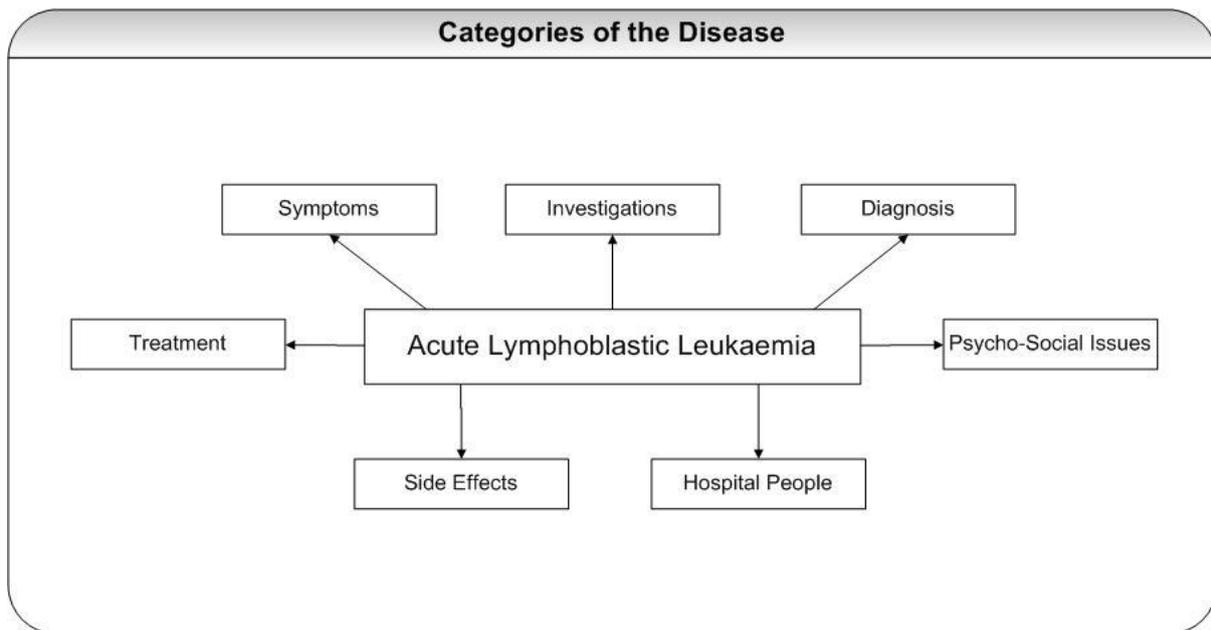
Figure N Different categories of dialogues

4.7 Adaptivity based on Scenarios:

These are the scenarios that the researcher has made to identify the childs needs and to test the system ensuring that the dialogues do satisfy the child's need. These scenarios were used in designing the dialogues

Scenarios: 1: A patient 8 years old girl was seen by a G.P with symptoms of suspected Leukaemia. She is referred to the hospital for further investigation and management. This patient is depressed in the hospital environment and needs to know about the people around the ward. She may have questions like, "what is going to happen", "who are these people around", "when I am going to get better". This patient also needs to understand the tests she will be undergoing.

At this stage the patient only needs general information about the hospital and the necessary tests and should be related to the investigation process according to their age.

Scenario: 2: A patient who is a 10 year old with diagnosed with Acute Lymphoblastic Leukaemia and requires treatment for Leukaemia and needs to understand the different kind of treatments. The patient is going to proceed to the treatment topic and can look up chemotherapy; what it is and how they receive this treatment,

Scenario: 3: A patient 9 years old quite upset and worried about the side effects of chemotherapy and needs to know the side effects. At this stage patient's only worry is hair loss and nausea and needs to know the appropriate information about the side effects.

Scenario 4: A 12 year old patient has been diagnosed with Leukaemia 3 years ago and is finished the treatment process and worrying about future and effects of this illness and impact on education and social life.

4.8 Chapter Summary:

This chapter described in detail the design process used to make generic interactive dialogues between a doctor and a child. The next chapter will give details of the implementation process.

5 Chapter Five-Implementation:

5.1 Chapter Overview

In the previous chapter the functional and technical design of the integration of SOLAS and ADAPT were described. In this chapter consideration will be given to the implementation of the design. This chapter will also describe in detail the ADAPT tool which was used to configure the dialogues and layout of simulations. The implementation of the design was carried out in three stages.

1. Input all the contents in ACTSim tool to create dialogue simulations
2. Changing SOLAS user interface to reflect the added functionality
3. Modify the SOLAS registration page.

5.2 ADAPT:

ADAPT is an e-learning tool developed by Knowledge and data engineering group at Trinity College Dublin. This tool has a capability to provide 'one fits all' for use with any kind of delivery of information or teaching skills. It has been successfully implemented to teach for medical students communication skills and interviewing techniques   Because of the 'one fits all' nature of this tool it has a capability that a developer can mould this in any kind of teaching or delivery of information. This research is based on looking at the feasibility of providing medical information to children that is individualised and adaptive to their own

context. The study investigates the use of the ADAPT tool to fulfil the requirements of children admitted into hospital, by providing them with information according to their own needs and in their own time. The benefits of providing this type of customised health information on SOLAS and ADAPT platform is discussed below.

SOLAS is a virtual environment for children in hospital who are chronically ill and isolated from their family and friends. On this platform a child can communicate through a variety of communication tools (email, SMS texting, video link and live chat) with their peers, Solas also facilitates creativity (e.g. art tools, audio books, games etc.)   The objective of Solas is to combat some of the psycho social issues that children with chronic illness can endure through facilitating communication and providing a distraction from their illness.   SOLAS can be accessed by children who are in hospital and at home.

A second incentive to using the ADAPT tool is its ability to provide a child with adaptive and individualised information about disease, their treatment, their psychosocial issues in a dialogue based fashion. This platform also gives health professionals and parents less worry about what and how to give their child information about disease.

In summary this integration of ADAPT and SOLAS will benefit the children, parents and healthcare professionals, and it will be available for them 24/7. For

this reason a prototype has been created using the ADAPT system. The architecture of this tool decomposes into three different component services.

<u>ACTSim Tool:</u> is an intuitive composition platform which can be used for any subject to design, develop and deploy high-end eLearning simulations. It uses an iterative process built on proven pedagogic theory and instructional design to guide training providers through the cyclical processes of designing, developing, deploying and maintaining e-learning simulations.

<u>ASPIRE Tool</u> is a white label interactive and personalised simulation platform which uses simulations to place the learner in a realistic and safe environment where they can practice and master a range of communication skills, such as interviewing techniques, conversing, communicating information etc.

<u>FUMES Tool</u> is a standards-based integration platform which supports the exchange of information and functionality between eLearning services which minimises technical requirements and allows feasible delivery of educationally effective learning experiences.

5.3 ACTSim Composition Tool:

For the purposes of implementation of the design of the dialogues ACTSim was used to make simulations and provide actual adaptivity. To identify the design

concerns of creating the dialogues in a composition tool, ACTSim tool was examined to see how to add a dialogue and simulate through ADAPT. ACTSim is a Composition Tool for Authoring Adaptive Soft Skill Simulations it is an innovative authoring tool used to compose adaptive soft skill simulations. An adaptive simulation combines content and adaptivity. Simulations provide the means to "learn by doing" in practical and safe environments. (Declan, 2007). Adaptivity means the ability to dynamically change the appearance and performance of a system based on the users own context, different roles, user's requirements, their educational preferences, etc.

Stage 1: Input Dialogues in ACTSim

The first stage of the implementation was to input the dialogues which were described in the design chapter using the ACT-Sim tool. As described in Fig 1 this application enables the content developer to input a question and an answer couplet which will eventually be linked to the video if using any. For this initial design the 50 questions and answers were input into the Act-Sim tool and simulated through ADAPT. This innovative tool gives a content developer the ability to compose and generate adaptive eLearning simulations easily. The next step after adding these dialogues in the actual composition tool was to create adaptivity. First of all a main stem was created by adding the dialogues. It was then used to separate the different features of adaptivity in the model.
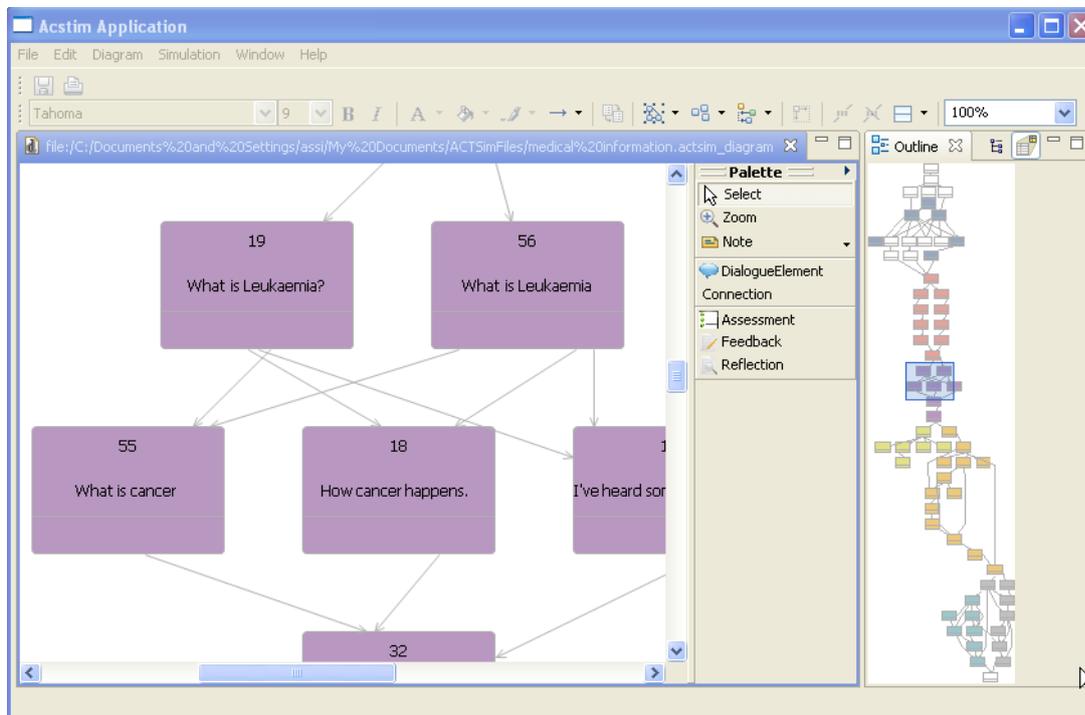
Figure O ACTSim Authoring Application

These are the steps taken to input the dialogues to make the adaptive simulations

Define the learning verbs and nouns: this was done to input the learning outcomes.

Different Roles: while inputting dialogues it was also possible to tag every dialogue with different roles, for example when inputting the question and

answer it was an option to tag which role this dialogue was made for (e.g. age group 8-10 or 11-12)

Different categories. As mentioned in chapter 4 the dialogues relating to Leukaemia were categorized into symptoms, investigations etc. Each dialogue contains a tag into which category the dialogue belongs.

After the input of dialogues the next step was to make possible connections between the dialogue elements in the ACTSim tool. These connections were made to find out the possible ways to adapt the information in the child's own context. Making these dialogues adaptive the author had to go through the iterative process with the Solas and ADAPT facilitators to create the best possible layout of the design. The examples of the connections are described in Figure below.
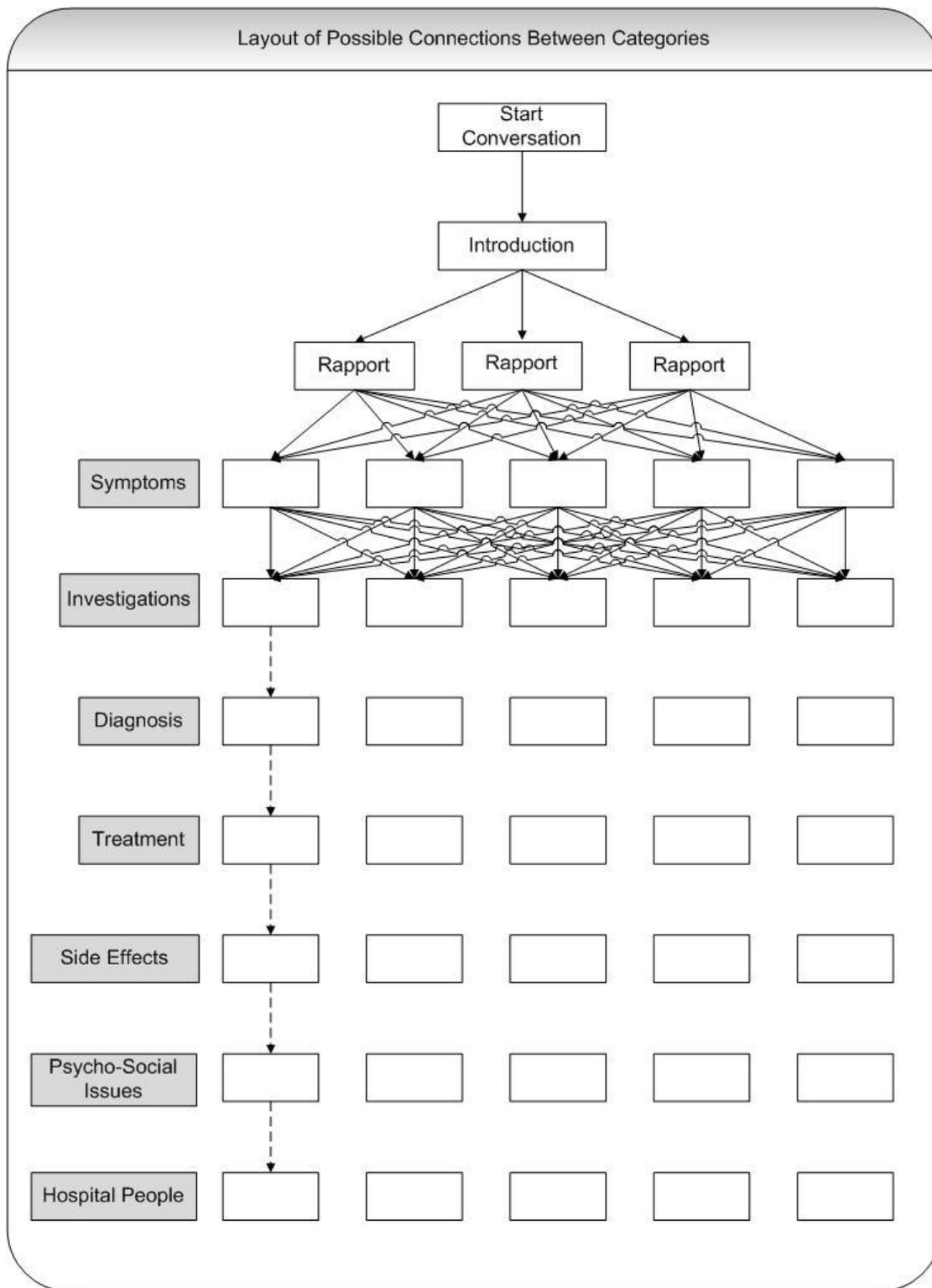
Figure P Possible Connections of Dialogues

Stage 3: Changing the Interface of the SOLAS system.

Changes to the Registration Page: In order to facilitate the adaptivity and personalisation of the information it was necessary to gather additional details about the user at the registration process.

Two changes were made to provide access to the ADAPT simulation through the SOLAS platform, Date of Diagnosis and Diagnosis. Diagnosis information is

needed to allow customised information for a child based on the stage of their treatment or diagnosis. Date of Diagnosis will inform the system when this child was diagnosed. These two additional pieces of information will be elicited at the registration phase of Solas. When a child logs in system will provide adaptive information as the need of a child. For example if child is newly diagnosed with Leukaemia then this child would provide information about the disease and the treatment of it.

The first phase of feedback was carried out with 4 HCP including Child Psychiatrist, oncologist, to find out that the contents of the dialogues are appropriate for the targeted age groups. Further editing was carried out with the dialogue.
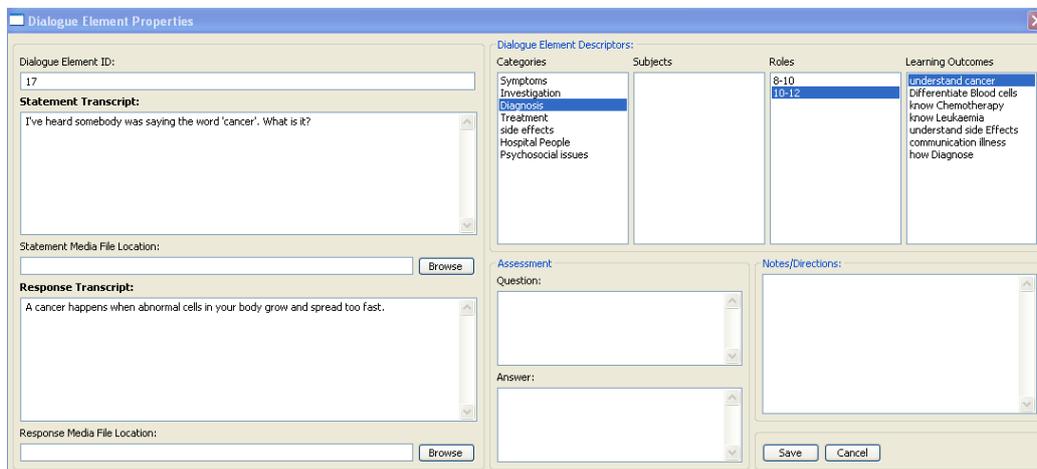
Figure R creating the dialogue in ACTSim Tool

Testing: The testing phase was done as an iterative process, and looked at both content and the look and feel of the system. Figure17: below shows the final layout in an ACTSim tool.
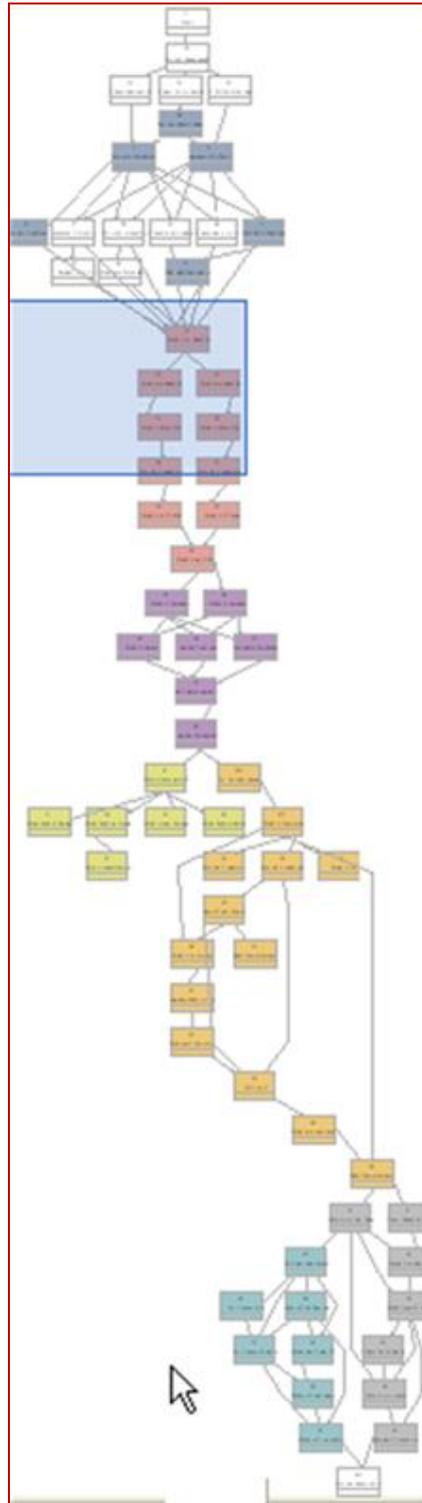
Figure S Possible Layout of the dialogues

The end result of the integration of both systems using an iframe which embedded into solas html page to have access to Adapt. The figure shows the integration page of both systems.
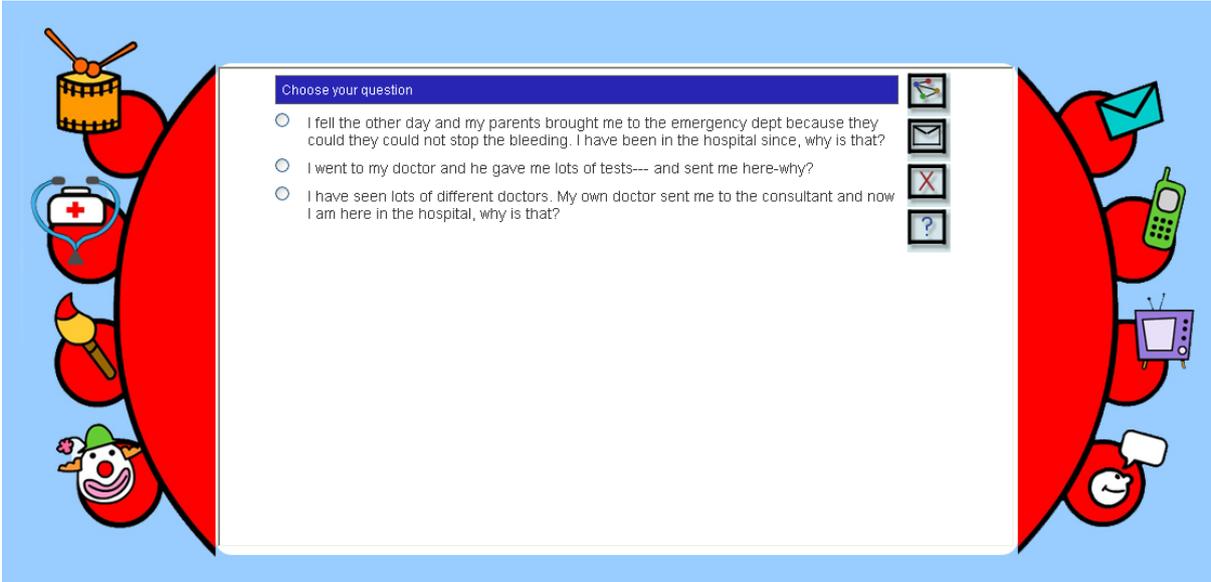
Figure T screen shot of e-learning module.
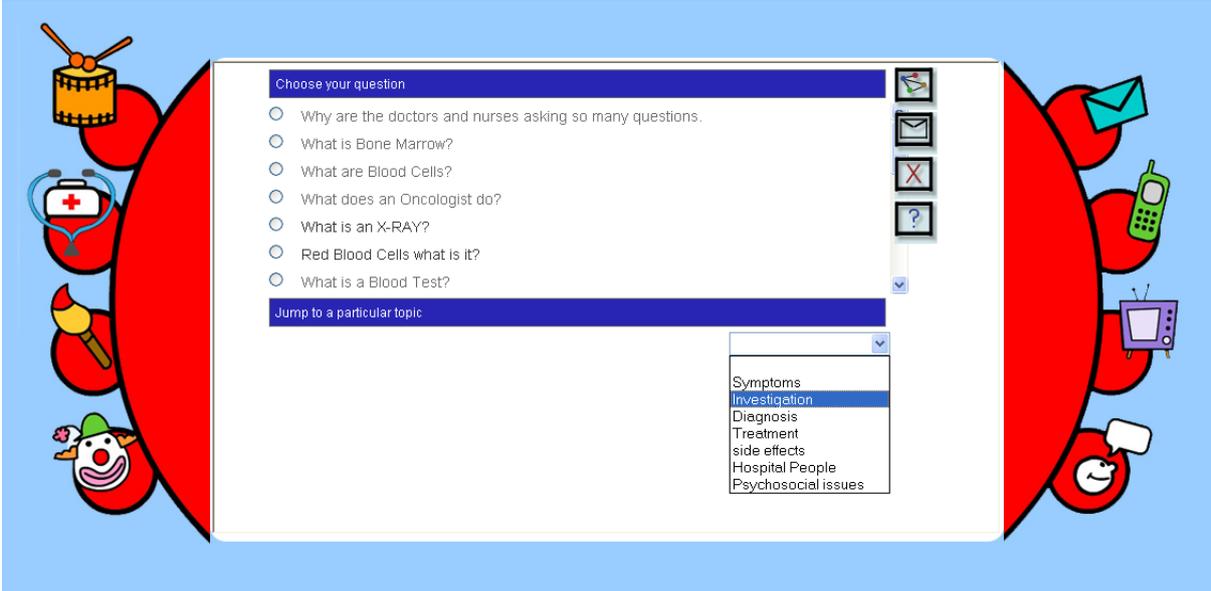
The figure 21 showing the user can jump to different categories.
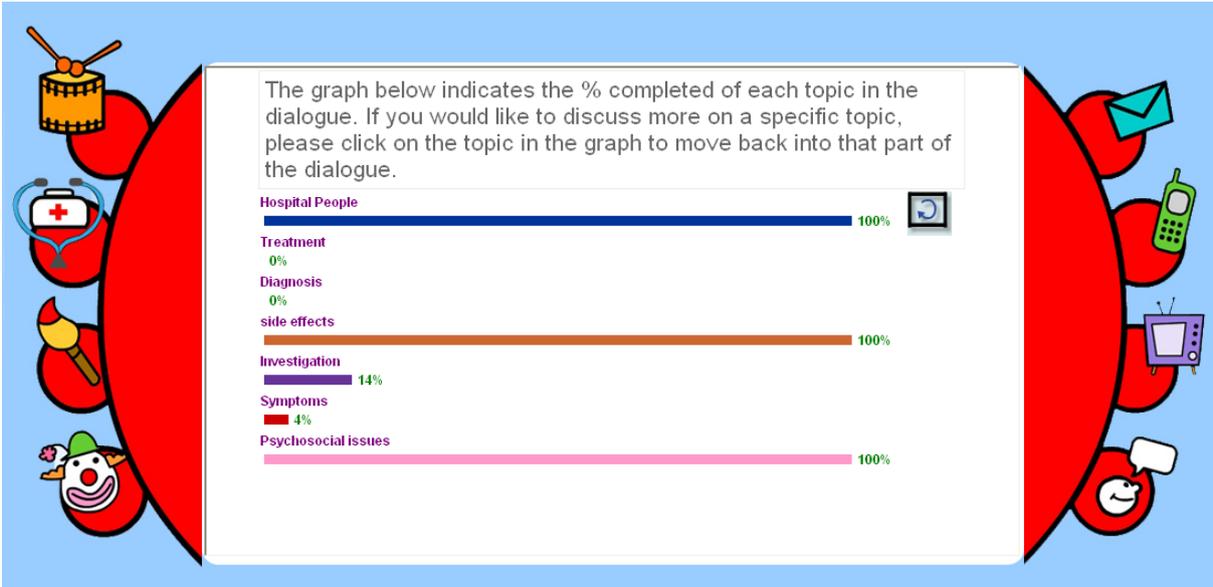
Figure V shows the % completed.

This figure 22 will show an actual graph what % the child finished and on which topic. This feature also allows clicking on categories to go back on to specific topic.

6 **Chapter Six-Evaluation:**

This report endeavoured to look at the feasibility of providing medical information to children in an e-learning environment. A prototype module was developed using the ADAPT system and then integrated within the SOLAS environment. While the implementation process has been described in chapter 6, this chapter addresses the basic goal of this research which is set out in chapter 1. It goes on to detail of usability measures taken to test the prototype:

This project aims to look at the feasibility of providing medical education to children with chronic illness who are admitted into hospital for treatment. The literature review was conducted to find out the needs of information provision. The informal interviews were conducted with health professionals to find out the different medium currently used to provide information to these children. Once the data was gathered, there were different factors identified which were then prioritized by the survey with health professionals.

The data from the survey and requirements gathering exercise steered the design and implementation of the prototype. In the evaluation phase ideally the prototype was to be evaluated with the actual user /child/ patient to find out the feasibility of the piece of work. Because of the time constraints and the limitations of requiring ethical approval, it was not possible to evaluate with the children admitted into the hospital.

It was then decided to evaluate with the health professionals to look at the efficiency, effectiveness and satisfaction of the system and also to find out whether Adapt or e-learning technology is suitable for this kind of health information delivery from their perspective.

6.1 Evaluation:

There are two types of evaluation that one can distinguish depending on the object being evaluated and the purpose of the evaluation. These are formative and summative evaluation. Formative evaluations build up or improve the object being evaluated -- they help form it by examining the delivery of the program or technology, the quality of its implementation, and the assessment of the procedures and inputs. Summative evaluations, in contrast, examine the effects or outcomes of some object.

Formative includes several evaluation types:

- **needs assessment** determines the user of the program, how vast the need is, and what might work to meet the need
- **evaluability assessment** determines whether an evaluation is feasible and how stakeholders can help shape its effectiveness

Formative evaluation can be described as prototype evaluation or learner confirmation (Smith & Wedman, 1988). This type of evaluation is often used as a process of collecting data and information in order to design and improve the

effectiveness of an instructional product. Formative evaluation is an essential part in developing multimedia software (Dick et al, 1994).

"The program may be a set of instructional materials distributed nationally, the instructional activities of a single school, or the educational experiences of a single pupil…Course improvement: deciding what instructional materials and methods are satisfactory and where change is needed…" *(Cronbach, 1963, p. 672-673)*

For this project Needs Analysis was carried out and the survey was conducted with the health professionals to find out the needs of the user. Evaluating the information is important for any project. This will help elicit the need of the user of how it should be represented and how it will look at the different aspects of the usability.

6.2   Human Computer Interaction: HCI

Evaluation is a fundamental part of the HCI and interface design. The focus on almost all evaluation in HCI has been on how someone can complete the specified task; observe error rates using the technology being evaluated.

Usability, a key concept of human-computer interface, is concerned with making computer systems easy to learn and easy to use through a user-centred design process (Preece et al., 1994)

6.3 User-Centred Design

A key methodology for carrying out usability is called User-centred design, as the process of integrating user requirements, user interface validation, and testing into standard software design methods. This is an approach which views knowledge about users and their involvement in the design process as a central concern (Preece et al., 1994). This means that the principle of user-centred design is to involve users in the design process of a particular product, and to understand the user's needs and to address them in very specific ways. Therefore, designers must understand who the users will be and what task they will do (Shackel, 1991).

Usability can be defined as "*a measure of the ease with which a system can be learned or used, its safety, effectiveness and efficiency, and attitude of its users towards it*" (Preece et al., 1994, p. 722).

6.3.1   Usability Testing

Two aspects of the Evaluation were carried out for this study - Usability of the Design and feasibility (effectiveness of using the ADAPT system). In this chapter two main types of usability testing were considered. (Nielson, 1994) has developed heuristic evaluation methods to measure the usability of the system and identify the problems in the interface design.

The ten Heuristic rules outlined by Nielsen

1. Visibility of system analysis
2. Match between system and the real world
3. User Control and freedom

4. Consistency and standards

5. Error Prevention

6. Helping users recognise, diagnose and recover from errors

7. Recognition rather than recall

8. Flexibility and efficiency of use

9. Aesthetic and minimalist design

10. Help and Documentation

Nielsen has recommendations for the usability of a system for children and young people.

- Age appropriate contents are useful for them
- Kids are keenly aware of the technology

Measures of usability (ISO 9241-11-1998) define the usability in 3 different measures. Usability refers to effectiveness, efficiency and user satisfaction.

Effectiveness:
- Percentage of goals achieved
- Percentage of tasks completed
- Accuracy of tasks completed

Efficiency:
- Time to complete a task
- Cost of performing the tasks

User Satisfaction:
- Rating scale for satisfaction
- Frequency of use
- Ease of use

6.3.2 Website Usability for children:

Children are more frequently using the internet nowadays. They are using technology for education and entertainment. Nielsen has conducted usability studies with 55 children who vary in age of 6 to 12 and are of differing nationalities. The study identified the usability problems that affect children when using the information online. The Study found that poor usability combined with their lack of patience in the face of complexity may result in them simply leaving the websites.

Nielsen has identified several types of web usability problems that caused difficulties in children

- Unclear Navigational confirmation: This problem sometimes confused the user about where to go within the site and when leaving.
- Inconsistent Navigation: provide different options for the same page which caused repeating the pages and insisting on them leaving the site.
- Non-standard Interaction Techniques: Give a user a predictive problem like selecting a preferred game.
- Lack of perceived click-ability: overly flat graphics caused people to miss features.
- Fancy Wording: Interface that has fancy words confuses the user.

6.3.3 Differences between Children and Adult Users:

Most of the differences are related to differences in online activities. Multimedia effects tend to attract children more than adults.

Nielsen has undertaken an extensive range of studies on usability for adults and children and some key points include:

Animation and Sound Effects: These are the first good impressions that encourage a user to stay on the page.

Scrubbing the screen with the mouse is a favourite part of the child user who simply likes to click more or enjoy the sound effect.

Child often likes to read instructions and in contrast adult users hate to read instructions.

6.4 Purpose of the Evaluation in this study:

In response to the question "An Investigation into the feasibility of using adaptive personalised e-learning technology to provide medical education for children in a health care environment," it was necessary to evaluate the system with the health professionals to measure the efficiency and the usability of the system. A selection of 20 health professionals agreed to give their feedback on this research via an online survey, because health professionals currently working with children are the key figures related to providing medical information for the target audience.

Recruitment of Participant: The selection was based on inclusion and exclusion criteria.

Inclusion Criteria: This selection was based on the health professionals who had a direct contact with the children to provide information which were Consultants, Non Consultant Hospital Doctors including Paediatricians, Oncologists, Child Psychiatrists and nurses were all included in this 2nd round of survey.

Exclusion Criteria: This selection was based on the other health care staff and parents who were excluded from this survey.

A selection of 28 health professionals were selected and the questionnaire was sent out to these health professionals, , responses were received from 20 of this cohort .

Procedure: A prototype of the design was sent to the 28 HCP with instructions to review the system along with a summary of the research. Data was collected with the feedback questionnaires looking at the look and feel and usability and efficiency of the system. Data collection used was a simple usability scale (SUS) which is a simple ten-item scale giving a global view of assessments of usability. Usability refers to efficiency, effectiveness and user satisfaction. This scale is the most popular scaling method used by sociologists and psychologists in their final scales. The benefit for using this scale is it is relatively quick to analyse the result. This Likert-type scale contains a series of opinions about an issue and uses a 5 point scale to measure the usability. This scale works after the system has been evaluated.

SUS yields a single number representing a combination measure from each item. Each item score contribution ranges from 0-4 in a five scale rating. Analysis: the data was collected from the health professionals to get their feedback for the prototype module. There were 18 questions related to usability and effectiveness of the module and participants were asked to rate their opinion on a rating scale of 1-5 where 1=strongly disagreed, 2 = disagreed, 3 =not sure, 4 =agreed and 5 = strongly agreed. Participants were sent via email a link to access the e-learning module prototype online along with a link to the online survey which they were requested to complete. The responses were then analysed and below are some the results.

Please give your feedback using the system

Item	Score
3.I thought there was too much inconsistency…	1.95
4.I found the system unnecessarily complex.	2.05
10.I found the content and language is not clear…	2.2
9.I found that initial introduction clearly…	3.9
13.I felt that the design is simple…	4
1.I would imagine that most children would easily…	4.05
2.I think children would find it easy to navigate…	4.15
6.I felt that children would be very confident…	4.15
15.I think this method of providing medical…	4.15
11.I felt that information is relevant to the…	4.2
Other	4.32

The results of the survey questionnaires, which are shown in appendices, show that 55% (n=11) participants were agreed and 40% (n=8) were strongly agreed that this type of information would engage children in a purposeful interaction.

50% (n=10) participants were strongly agreed and 40% (n=8) were agreed that this medium of providing medical education is effective for children. But on the other hand 20% (n=4) participants were disagree that the contents and language are easy for children and 15% (n=3) were not sure about this.

Please answer the following questions
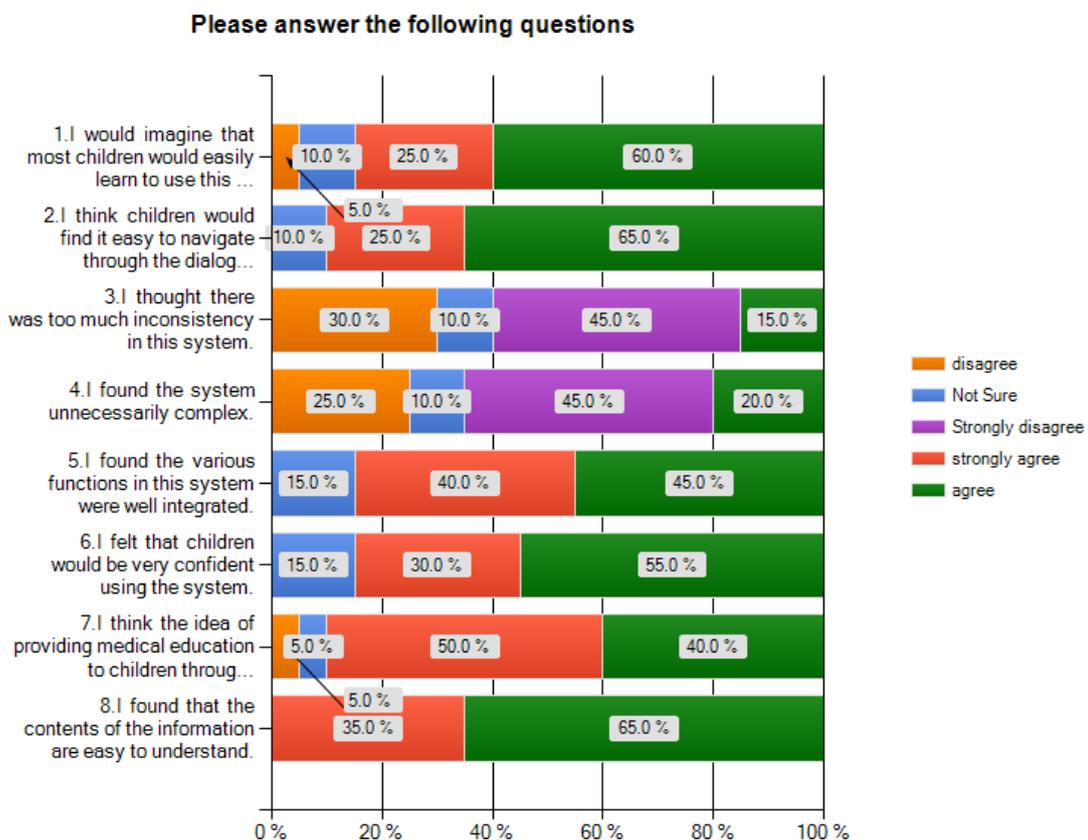
Figure X The chart showing results

The findings of this survey were both positive and negative. The health professionals were positive about the feasibility of using this system for children. The negative comments from this survey which also included a comment box for participants suggested using colourful screens and pictures to improve the interaction and understanding of them.

To answer the question of this research and the results of the survey, the author found that results suggest that this is a right approach but in its current state this is not child friendly. This research is worth further exploration of the needs of the user.

6.5 Chapter Summary:

This chapter described the type of usability testing and the results of feedback from the health professionals to look at the feasibility of providing medical information to children in an e-learning environment through ADAPT on the SOLAS platform.

7 Chapter Seven- Conclusion and Future Recommendations:

7.1 Chapter Introduction:

This chapter will consider the extent to which the research question has been answered and offer some thoughts on the limitations of the study. As a summative reflection, the author will also draw some conclusions and make recommendations for future research in the field.

The aim of the research is to investigate the feasibility of using e-learning technology to provide medical education to children with chronic illness. These steps were taken to answer the research question.

A literature review was undertaken to examine the need for information provision for children with chronic illness, and the communication process of patient and doctor was identified. The literature found that the existing systems of providing information to children are in different forms such as cds, dvds, books or video. However, the information provided to children is general and does not take into consideration the child's own nature or their own individual behaviour. This study has identified a strong need for a system in place to solve this problem.

These findings were further developed through informal interviews with health professionals to find out how they provide information in the hospitals. The conclusions were made that children need more personalised information and solutions for providing this information should be influenced by seven important factors (Age, Type of cancer, stage of cancer, format, contents, timing and coping styles).

These factors were then prioritised with the help of health professionals. Based on interactive dialogues between a child and health professionals a prototype module was developed using the Adapt system. A link to this module was then embedded into the virtual community SOLAS. The most time – consuming part of the design phase was to design age-appropriate dialogues. 50 dialogues between doctor and patient were created. For this purpose the author had to look at the age-appropriate children's science books and the medical books. Once the author had created the dialogue, it has then emailed to health professionals to look at the language used and it was then fed into the design process. The usability and effectiveness of the prototype was then evaluated among a random group of the health professionals.

The feedback from the health professionals is worth further exploration to the feasibility of using such a system for children.

7.2 Limitations and Future Recommendations:

The biggest obstacle at the start of the project was the limitations of ethical approval in the health care environment. The time constraints of this project was limited and ideally this system would have been evaluated by the target end users (children with chronic illness), but this was not possible.

This system was evaluated with health professionals as they are the main provider of this type of information to children. The future recommendation would be to evaluate the module with the children themselves. Augmenting the dialogue with a video of a doctor answering the questions in the dialogue would be a recommendation for future work. The scope of this project meant that it was not possible to incorporate the video or multimedia elements for the current prototype, but these would enhance the user's experience. This was also a recommendation from the health professionals to take into account in the future.

For the integration of two systems the intuitive interface of Solas was easily updated for the purpose of integrating a link to the module. The Adapt system includes the Act-Sim authoring tool which is easy to use for the purposes of designing the dialogues. However, there were limitations with amendments to the front end of the module, changes to the look and feel (for example text and colour) that could not be easily done. A future recommendation would be to consider more control and access for the designer to fulfil this requirement.

Overall the author concludes that using e-learning solutions is a feasible means by which to provide medical information to this target group. However, more work is required to refine these using children as the end receivers of the information.

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Electronic Resources	
Ait Eile website	http://www.ait-eile.ie
Solas	http://www.solas.ie
Office for National Statistics	http://www.statistics.gov.uk
Crumlin Hospital Ireland	http://www.olhsc.ie
Childrens Cancer and Leukaemia Group	http://www.cclg.org.uk
National Childhood Cancer Foundation	http://www.curesearch.org
Children First For Health	http://www.childrenfirst.nhs.uk
Star Bright Foundation	http://www.starbright.org
Patient Information UK	http://www.patient.co.uk
Child Development	http://www.childdevelopmentinfo.com

Dialogue between doctor and child suffering from leukaemia admitted in hospital.

Age: 8-12

Doctor: Hello X: How are you today?

Child: not good…tired.

Doctor: What is making you feel tired?

Child: Mammy took me to the doctor and he put the needle in my arm and took lots of blood for testing…it makes me feel tired.

Doctor: Did you ever have blood tests before?

Child: Yes.

Doctor: Did you feel better after a while?

Child: Yeah I did.

Doctor: I am sure you will better in a couple of hours, yeah.

Child: Okay.

Doctor: Do you like soccer?

Child: Yeah.

Doctor: What's your favourite club?

Child: Man U.

My name is ----- I am one of the doctors working in this hospital and part of my job is to talk to young children like you who are admitted here to help them understand their illness.

I am here to answer any of the questions you have regarding your illness. If you have any worries we can discuss them also and will try to sort them out together.

Child: Why have I been brought to the hospital?

Doctor: You have been brought here so doctors can figure out what is making you feel unwell so that they can treat you or give you some medicine to make you feel better.

Child: Why are the doctors and nurses asking so many questions?

Doctor: That is the way they would be able to find out what's making you sick. They would need to know how have you been feeling lately, have you been on any medication and is there anyone else in your family who has similar difficulties. They will also be looking at the results of your blood tests that your G.P. took; they might need to do some more blood tests. They might also want to do some x-rays or scans. Did you ever have an x-ray before?

Child: No.

Doctor: I will explain that to you in a minute. So when the doctors and nurses will have all that information they will know more about your illness and then they will be able to help you get better.

Child: Why am I getting these marks all over my body?

Doctor: We call them bruises. One of the reasons you are in the hospital is that the doctors will try to find out why you have these bruises and once they know what's causing them they will be able to get them better.

Child: Why do I feel tired all the time?

Doctor: You may be feeling tired because of the anaemia and we are trying to find the cause of it.

Child: What is Anaemia?

Doctor: In our blood, we have small, little particles floating around that we call cells that are only visible under a microscope. One type of such cells are called Red Blood Cells. People who have anaemia have fewer red blood cells than normal, which sometimes can make them feel tired.

Child: How long will I stay in the hospital?

Doctor: You have been wonderful in letting doctors do the different test. We hopefully will get the results soon and then we will be in a position to say when you can go home. I hope it wouldn't be long and we will send you home as soon as possible.

Child: What is a Blood Test?

Doctor: Remember when the nurse took some blood off you; she then sent it to the laboratory where these specialist doctors look at the blood under a microscope and they will be able to look at the all the cells and they will be able to find out how many good and bad cells are in your body.

Child: What is Bone Marrow?

Doctor: If we try and feel our bones you know that they are very hard, but inside our bones are kind of filled with a soft thing called Bone Marrow. This is a very important part of our bodies because that's where all those blood cells, remember, we were talking about earlier are

made. So, the bone marrow's job is to make blood cells and send them to the body where it's needed.

Child: What is X-RAY?

Doctor: X-rays are special pictures of the inside of the body. It is not painful; it's just like taking pictures with a big camera. When the picture comes out, it wouldn't be like the ones in your photo album though, it would be kind of like funny, black and grey but doctors have learned how to look at these pictures and figure out where the problem is.

Child: Why do I need a bone Marrow Test?

Doctor: Doctors take bone marrow tests to see the actual number of blood cells that are affected by the disease. This test is also done at different stages of the treatment to find out how many bad cells are still left and to see how long more the treatment needs to continue.

Child: What are Blood Cells?

Doctor: Blood cells are tiny, little particles in our blood that are only visible under a microscope. There are three main types of cells and each has different jobs.

Red Blood cells carry oxygen to all parts of our bodies.

White Blood cells fight infections and protect our bodies from germs.

The third type is called platelets that help stop bleeding and if we get any injuries or cuts they fix them.

Child: What is Chemotherapy?

Doctor: Chemotherapy (also called "chemo") is the treatment with some very powerful medicines that are used to kill bad cells in the body. It's usually given as a liquid medicine that's put into the blood with the help of a special equipment.

Child: What is a CT Scan?

Doctor: A CT is a short for Computerised Tomography. Remember earlier we talked about an x-ray; A CT is a kind of an x-ray except it helps doctors see much better inside the body. It is done with a big machine that takes pictures of the inside of the body. It can take pictures of our internal body parts like stomach, heart and also bones. You will be required to lie still on

a couch to get this done. The machine makes all sorts of funny noises but don't worry this won't hurt.

Child: Does Chemotherapy kill all the bad cells?

Doctor: Chemo therapy or Chemo is given every week for a few months and every time when one gets Chemo, doctors will check with the help of different tests that how well it is working. But unfortunately Chemo is unable to differentiate between the good cells and the bad cell so it might kill a few of the good cells along with the bad cells. This would mean that one may get some unpleasant effects from the medication.

Child: Did I catch cancer from someone else?

Doctor: No, you cannot catch cancer from someone else; this isn't caused by any germs like flu or cold.

Child: What is Leukaemia?

Doctor: Leukaemia is a type of cancer which happens when cells in the blood become naughty and aren't behaving as they should inside the bone Marrow

When someone gets Leukaemia their white blood cells grow very quickly and do not die and make room for the new ones. The bone marrow gets filled up with these bad cells and this does not leave any space for good cells to grow.

Child: I've heard somebody was saying the word 'cancer'. What is it?

Doctor: A cancer is caused when abnormal cells in one's body grow and spread too fast.

Child: How do the doctors know I have Leukaemia?

Doctor: We have done different blood tests and bone marrow tests to see the number of those naughty cells in your body and the results of those tests and also the way you have been feeling lately tells us that it's Leukaemia.

Child: Why is my hair falling out?

Doctor: The medication used for Chemotherapy is a powerful medicine. It is used to kill cancer cells in the body but unfortunately it also kills some of the good cell such as those cells that make hair grow. But your hair will grow back once your treatment is finished.

Child: I am feeling so sick how will i get better?

Doctor: You are probably feeling sick because of the chemotherapy that you are taking. But don't worry we'll give you a special medicine to get rid of this feeling of sickness.

Child: What is a side effect?

Doctor: Remember, I was telling you about your Chemo that it helps your body get rid of the cancer cells which is the good effect of Chemo; but you know what this medication can't tell the good cells from the bad cells so it also kills some of the good cells; so when it does that it may give you some unpleasant effects such as you were mentioning about your hair falling; doctors call those unpleasant effects of medication, side effects. But try not to worry too much as the doctors will give you medicines that will reduce these side effects.

Child: Will I look bad without hair?

Doctor: Not necessarily; but I can understand your concern. I know you will look a bit different for a while but that is a little price we sometimes have to make to get better. I am sure your friends will understand it and the good thing is that your hair will grow back once your treatment is finished. In the meantime if you felt that you were concerned about the way you look you can use a nice hat of your choice to look better.

Child: When will I go back again to swimming?

Doctor: I would say hopefully soon, but please give it a little more time so that you are strong enough again to go back swimming.

Child: Am I going to die?

Doctor: I know you have probably heard all sorts of different things about cancer and leukaemia but with the modern treatment there is every possibility that we will be able to control your illness.

Child: Why do I need a Hickman Line?

Doctor: You need a Hickman Line because the type of treatment you are getting can only be given through a Hickman Line. This is good for you because nurses can give you more medicines or injections through this Hickman line so there would be no more pain.

Child: What is IV?

Doctor: IV is short for intravenous meaning 'in the vein'. It is a small tube that is placed in a vein in the arm. It quickly puts medicines and other fluids in the blood. An IV does use a needle at first to put the IV in the right spot in a vein, but it only feels like a small mosquito bite.

Child: How long does my Hickman line stays in?

 Doctor: Your Hickman line will stay in until your treatment is finished.

Child: What is a Hickman Line?

Doctor: A Hickman line is a tube that is inserted by a small operation into a vein near your heart. All your liquid chemotherapy will go through this and you can have blood tests through it as well, that means after inserting this tube you don't need any more needles.

Child: Who puts the Hickman line?

Doctor: A specially trained doctor will insert the Hickman line.

Child: Will it hurt?

Doctor: Before the Hickman line, the special anaesthetic doctor will give you an injection to help you sleep so you won't feel any pain.

Child: What are veins and Arteries?

Doctor: Veins and arteries send blood around your body. You may have seen pictures of inside of human body arteries are usually shown in red colour and they carry oxygen in the blood from the heart to all parts of our bodies. Veins are usually shown blue in pictures and they carry blood back to the lungs and heart for cleaning and pumping back to all parts of our body.

Child: Why do I need chemotherapy?

Doctor: The doctors have done different tests to find out the problem that is making you sick. Your body is making too many white blood cells that it doesn't need, so doctors have suggested a special medicine like chemotherapy. It travels inside your body and kills all the bad cells to make you feel better.

Child: How will I get Chemotherapy?

Doctor: You'll get your Chemo through a special plastic tube called central line or Hickman line. That way you'll get your medicine straight into a vein to pass around the body quickly. This kills all the bad cells.

Child: Who is Anaesthetic doctor?

Doctor: An Anaesthetic doctor is a person to give you medicine to sleep while your Hickman line will put in so you wouldn't notice any discomfort or pain.

Child: What does a dietician do?

Doctor: Dieticians are specially trained professionals who give advice on which foods are good for you. They also make a special food plan to help you get better.

Child: What does an Oncologist do?

Doctor: Oncologists are special doctors who work with patients who suffer from cancer. Oncologists who treat kids that have cancer are called paediatric oncologists.

Child: What will play therapists do to make me better?

Doctor: You know the way it can be boring being in the hospital for so many days, the play therapists that work in hospital, their job is to help young people like yourself to have fun as well as help them learn more about their illness and treatment through dolls or other toys. It can also help you emotionally overcome the difficulties you have been bravely facing lately.

Child: Who will take care of me in the hospital?

Doctor: Here in the hospital, doctors, nurses, psychologists and play therapists will all be working together to help you to get better.

Child: When can I play football again?

Doctor: Hopefully as soon as your treatment is completed, but please give it a little more time so that you are strong enough to play football again.

Child: When will I get back to school?

Doctor: I can understand your concern and I am sure as soon as you are reasonably better after completing your treatment you will be able to start going to school again. In the meantime though we will be talking to your school and other people to arrange for a teacher to come and teach you at home so that by the time you are well enough to go to school you haven't missed much of your studies and you will be able to easily catch up with you class mates in school.

Child: I don't like to eat after the chemo?

Doctor: There can be a number of reasons why you may not be eating properly. It may be because of your sickness or because of your recent chemo treatment; remember we talked about the side effects; so this could be a side effect of your medication; it could even be because at the moment you are naturally worried about your health. But hopefully after our chat you would know more about your illness and treatment and that will help to relieve some of your worries; but you know what, whatever the reason, you need nutritious food to get yourself better quicker.

Child: Am I going to get better or not?

Doctor: With the treatment you are getting there is every possibility that you will get better

Child: When will I run and play sports?

Doctor: As I said hopefully as soon as you complete your treatment and have reasonably recovered; I know it is not easy but try not to worry too much as your doctors are trying their best to get you better.

Child: How can I make my sore mouth feel better?

 Doctor: Sometimes ice pops and ice lollies can help when your mouth is sore.

Child: Why is my mouth sore?

Doctor: Chemotherapy can make your mouth sore. As I said, Chemo is used to kill the bad cells in the body but it can also kill the good cells as well; so it is another side effect of your medication but we will give you some medication that will take care of It is important to clean your mouth properly to help you with this problem.

Child: What type of side effects might I get?

Doctor: The side effects you might have after the Chemo are nausea and hair loss but don't worry this is only for the short term. Once your treatment has finished your hair grows back and the nausea stops.

Appendix   MSc Research Study:

My name is Asma Hussain and I am undertaking an MSc in Health Informatics in Trinity College Dublin. My thesis is a feasibility study to look at the best medium to provide medical information to children.This study is based on children with cancer who admits in isolated ward. Research suggests that 7 different factors including:

1. Timing: Children require shorter notice for minor than major procedures.
2. Content: Use specific rather than general and also children should have opportunity to ask questions
3. Age: A 6 year old has different interests than 14 year so age groups are an important factor.
4. Format: The medium that the information be conveyed
5. Coping styles, psychosocial background and past experience of each child should be taken into consideration.
6. Type of Cancer : Leukaemia or Hodgkin

7. Stage of Cancer: Is stage of cancer influence when provide this information to children

I am conducting the survey and would like your opinion who's working with children to prioritise this information. Please contact me on ahussai@cs.tcd.ie to participate in this research.

All the email addresses will be used solely for the purpose of my thesis.Thanks for your support:

Asma Hussain/ ahussai@cs.tcd.ie

Appendix   MSc Research Study: 2ndPhase

My name is Asma Hussain and I am undertaking an MSc in Health Informatics in Trinity College Dublin. My thesis is a feasibility study to look at the best medium to provide medical information to children.

I would like to thanks all the participants who took the survey as 1st phase of my research process. I need further help to evaluate the piece of work that I have been designed to facilitate the children. I would like health professionals to look at the web page that I have created and give their opinion on the usability and feasibility of the design. If you would like to be contacted please reply my e-mail and I will send the questionnaire and a web address.

All the email addresses will be used solely for the purpose of my thesis. Thanks for your support:

Asma Hussain/ ahussai@cs.tcd.ie