

With a little help from my friends: experiences of building a virtual community for children with cancer

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Background

Approximately 31% of children under 18 years of age have a chronic physical illness or condition. (Tak & McCubblin, 2002) This population, along with their families, has a range of medical, developmental, social, emotional and environmental needs (Grey & Sullivan-Bolyai, 1999). Spending a lifetime with a serious or chronic health condition can be traumatic and physically and emotionally painful. This is especially true when the individual enduring the condition is a child or adolescent. Children and adolescents with chronic illness are faced with a myriad of challenges that their healthy peers may never experience. They can have difficulty coping with the challenges of managing pain, adhering to treatment and sometimes undergoing invasive diagnostic and treatment procedures. In the case of more chronic conditions, children and adolescents may have frequent school absences and potential physical differences. The impact of hospitalization for treatment can add many other concerns for children and adolescents who are not just struggling with being displaced from their community but are also contending with a loss of control in almost all areas of their lives. These problems can hinder a child's treatment and recovery. (Boman & Bodegard, 2000), (Rode, Leask-Capitulo, Fishman, 1999) Enduring a chronic disease and its treatment can cause much disruption to schooling, and also to a child's family's social life and relationships. According to the Canadian Paediatric Society (2008), for adolescents, in particular, who are themselves striving for control over their lives and attempting to become increasingly independent from parents, the normal psychological and social changes are often delayed or altered due to chronic illness. (Canadian Paediatric Society, 2008) These issues are due in part to the reduction of developmentally normal activities such as school, sports and socializing which leads to a discrepancy between the physical and emotional development that can be a source of great stress for adolescents. (Blum, 1992)

Addressing the specific needs of these young people through the use of virtual communities has been at the core of some of the research work currently being carried out at the Centre for Health Informatics, Trinity College Dublin (TCD) in collaboration with The National Paediatric Haematology/Oncology and Bone Marrow Transplant Centre, Our Lady's Children's Hospital, Dublin.

Virtual communities in health

The terms 'virtual community', 'online community' and 'virtual spaces' are used interchangeably to define similar concepts. Many researchers have tried to clearly define what a 'virtual community' is. Virtual communities usually bring together people of similar interests, or indeed similar experiences, with the resultant communication facilitated through the Internet (Wellman & Gulia, 1999). Motivations for joining virtual communities are similar to motivations for traditional face-to-face groups: the need to belong and be affiliated with others or needing information or help in achieving a goal. Many friendships are forged through virtual communities via information exchange and social support. According to Demeris (2006) the use of virtual communities in healthcare implies a number of potential activities such as: delivery of healthcare services, health information for staff or patients, support tools for sharing and discussing treatment related issues and problems, consulting with experts and sustaining relationships on a number of levels, between patient-doctor and wider among patient-family and patient-peers. (Demeris, 2006) The development of such virtual communities for children and adolescents is also vulnerable to concerns regarding child safety and the dangers presented by the Internet. The necessity for security and safety of a virtual community needs to be balanced against the necessity of maintaining a formative and viable community to mitigate psychosocial vulnerability of prospective members. Virtual communities are one of the tools that can promote patient empowerment through supporting patients in managing disease and helping themselves. Demeris (2006) reports the difficulties in evaluating and measuring such initiatives, and as a result there is little evidence as to the real affects that such communities can have on empowering patients and improving health outcomes. (Demeris, 2006) Compounding these difficulties are the broad range of technologies that virtual communities can comprise of including; videoconferencing, asynchronous and synchronous communication services, chat rooms or online message boards.

Young people and their use of technology

It is generally accepted that we live in a technological age. Information and Communications technology (ICT) is pervasive to the extent that our economy and quality of life depend on it. (Fisher, Dwyer & Yocam, 1996) The use of ICT is embedded in the daily lives of children and adolescents; children and adolescents can play, socialize, create and undertake a range of activities that would not have been imaginable ten years ago. Children and adolescents with chronic illnesses are, with respect to their use of ICT, no different from their peers. The use of ICT to develop and maintain relationships is particularly attractive to children and adolescents. They are at the cutting edge of the social and technological revolution of the Internet, and are going online at a younger age, accessing a diverse range of mobile and networked media resources. Children and adolescents who are experiencing, first-hand, the social and technological revolution of the internet; they are going online at a younger age, accessing a diverse range of mobile and networked media resources.

A recent survey of Internet usage by Irish children between the ages of 9-16 years found that 93% regularly used the Internet at home or in school; this is somewhat above the European average of 87%. Most popular activities from an Irish context (76% in each case) include 'watching video clips', 'playing internet games,' using Internet for school work and 'visiting a social networking profile'. (O'Neill, Grehan, & Olafsson, 2011) Examples of the growing phenomenon of social networking and online environments are reported on an almost daily basis; three of the most popular of these social networking sites are Facebook, MySpace and Bebo, with Bebo claiming to have half a million Irish users. These social networks allow customisation of an individual space, as well as communication among users with the ability to share resources (e.g. pictures, videos, etc.). There is unfortunately also a downside to some of these sites; the risks include the unintentional disclosure of personal information, bullying or harassment, and, in a small number of cases, targeting of users by predators. Today's 'digital youth' have been the subject of a large scale study at UC Berkeley in the US. The study looks at what young people are doing online, how they use online resources and the impact of their use of digital media on schools, families and public life in general. The relative infancy of these new online resources means that there is little longitudinal research of the ultimate impact these technologies will have on society as a whole (Ito et al., 2008).

Technological interventions for young people with chronic illness

There is much research into the psychology of chronic illness, and a particular focus on the paediatric psychoncology. Advances in medical research have made huge impacts on the survival rate of childhood cancer and its subsequent impact on quality of life post-treatment. The resultant shift towards more open communication about the disease, treatment and prognosis have impacted many areas of research. According to Greenlee, Murray, Bolden & Wingo (2000), 75% of children diagnosed with a malignancy will survive the disease. (Greenlee, Murray, Bolden & Wingo, 2000) The consequences of the increased survival rates through improved technologies and treatments, allied with changes in attitudes regarding full disclosure of disease related information to young people within hospitals have longer term consequences for those who have survived childhood cancer. Through improved technologies and treatment protocols, there has been significant increases in survival rates of those diagnosed with cancer. A number of psychological difficulties encountered in adulthood by those who have survived childhood cancer have been termed 'late effects' these refer to psychological issues which can manifest in survivors in later life. These 'late effects' can result in significant personal, family and social difficulties (Boman & Bodegard, 2000), lower academic achievement (Hays et al., 1992), impaired or decreased social relationships (Boman & Bodegard 1995). Some studies have also looked at the prevalence of post-traumatic stress symptoms in about 5-20% of survivors. (Hobbie et al. 2000)

Kusch, Labouvie, Ladisch, Fleishhack & Bode (2000) discuss the importance of structuring psychosocial care in paediatric oncology, and the importance of translating the knowledge now available into daily practice. A number of initiatives exploring the role of technology in providing new forms of support have been documented. A small study (n=6) by Saba (1991) looked at the influence of close friends and peers on the lives of young patients following diagnosis. Those who scored higher on a measure of peer attachment tended to have higher levels of hope than those who were more isolated. (Saba, 1991) The important role of support from peers with cancer has also been documented (Dunsmore & Qune, 1995). These connections can support cancer patients with information exchange about various cancers as well as procedures and treatments (Enskar, Carlsson, Golsater & Hamrin, 1997). Some of the technical initiatives to support these young people include an array of technologies from Video, CD-ROMS, websites, online support groups and virtual reality headsets.

Earlier initiatives looked at the use of video games to distract from painful procedures. (Schneider & Workman, 2000) These were followed by more e-learning intervention programmes providing health-related information in an entertaining environment. Examples of these include *What are blood counts?* which was designed to teach children about blood cells and the effects of chemotherapy (Peterson, 1996) and *Kidz with Leukemia: A Space Adventure* designed to educate young people with leukemia about the disease and treatment (Dragone, Bush, Jones, Bearison & Kamani, 2002). The Internet itself has also provided a means for obtaining information and support from

the World Wide Web. The Internet offers much potential for empowering adolescents, in particular, in coping with their illnesses as independently as possible. Starbright World (SBW) is a private computer network for hospitalised children based in the USA; research studies have illustrated the positive impact of a virtual environment on hospitalised children on pain and anxiety. Children involved in the network experience significantly less pain intensity and anxiety (Holden, Bearison, Rode, Rosenberg & Fishman, 1999), (Holden et al., 2002). SBW also offers multimedia programmes on health care, and disease specific information. Based in Australia, Livewire is an online community for young people living with a serious illness or disability; a recent evaluation of the community concludes that Livewire helps empower and enhance a sense of wellbeing among its young members (Third & Richardson, 2009). This sense of empowerment, support and friendship is at the core of many online communities. A similar concept, Áit Eile (Another World), was developed by researchers in Trinity College Dublin and is currently based in hospital schools throughout Ireland. Áit Eile is a virtual community that supports children through a variety of communication and educational activities. Maintaining access to education for young people with medical needs is an important aspect to this project. Áit Eile integrates educational material, multimedia interactive learning games and activities and web resources to support children in continuing their educational objectives while out of school. Communication with other hospital schools and mainstream schools is supported through Áit Eile (Another World) in an effort to lessen the impact of hospitalisation on young users. Áit Eile is accessible through a multimedia PC in the hospital school rooms. The activities offered by Áit Eile are designed to engage the children and take their mind off their medical condition and treatment through entertainment and fun as well as fulfilling an important educational role. Activities are regularly organized for the community of users including art competitions, quizzes, and storytelling events along with guest visitors who visit one site and link up with others via a video link (Hicks, Woods, Power & Grimson, 2006).

This paper presents the Solas Project, an online community for children with chronic illness developed to support their communication needs and combat psychosocial difficulties. Harnessing this technology to address core psychosocial issues would appear to offer an innovative opportunity, but as this paper will present, using technology in this context offers many social, organisational and technical challenges.

Solas Project

The Solas system aims to provide a sense of social connectedness to isolated children and provide a learning experience through creative activities, entertainment and shared experiences. Solas is an online communications and creativity environment; a particular target group of Solas are those whose conditions necessitate them to be in protective isolation. Solas aims to empower children through facilitating communication, creative activities and entertainment that will hopefully provide a temporary distraction from their illnesses. Solas looked at providing a mobile ward-based solution without the need for supervision. The pilot site was the Children's Cancer Unit of the largest acute paediatric hospital in Ireland. Ethics approval was sought and approved at three phases throughout this project: The needs assessment phase, the pilot evaluation phase and the final evaluation phase. Led by a multidisciplinary Steering Committee the research approach looked at four key tasks these are described below;

1. Methodology - Needs Assessment

The needs assessment phase combined a variety of methods to inform the design of the Solas system. These included:

Brainstorming sessions with a Steering Group comprising key stakeholders from a variety of disciplines - this initial phase led to a concept diagram that would be used as the basis for a requirements specification. A multimedia presentation was prepared, outlining the core concepts and components. This was used as a visual aid for the second phase of the needs assessment.

A crucial element to the design of the community was a comprehensive needs assessment undertaken with members of the target population by the Children's Research Centre at Trinity College Dublin (Whelan, Daly, Hogan & Greene, 2006). A total of thirteen interviews with children and families were carried out. Two focus groups were also held with ten staff from a range of disciplines in the Children's Cancer Unit where the project is based.

Interviews with Children and Families

Parents or guardians of potential participants were initially contacted via their child's medical team once they were found to meet the criteria for inclusion in the project. The group studied was a predetermined mix of age (8 - 18 years), gender, illness type and periods spent in isolation. Once the family had expressed an interest in participating they were provided with a project pack. This provided appropriate background material and information relating to the aims of the Solas project. If the parents wished to proceed, then the consent process was explained

to them, and the importance of their child's consent was also emphasised. Following parental consent, the child was then introduced to a member of the project team by an agreed member of the medical team, in the presence of the child's parent or guardian. At any stage throughout the process it was made clear that parents and children could withdraw consent. Interviews were held in the ward while children were inpatients or attending the outpatient clinic or, where circumstances dictated, in their family home. All contributions from children and parents were treated in total confidence, with the exception of situations where a member of the project team had reason to believe that the child may be in immediate danger.

Recruitment of children and families in the oncology ward was difficult due to the transient nature of patients on the ward. Compounding this was the level of wellness that impeded the children from taking part even if they wanted to.

The interviews took approximately one hour and were recorded by researchers who later analysed findings under four core themes: physical, psychological, intellectual and social implications of illness. Though children were given the option of being interviewed separate from their parents, most chose to have one or both of their parents present. A total of ten children were interviewed, with seven of those having a parent present. In the other three instances, the parents were interviewed separately. At the core of the interview was a 'concept' multimedia presentation containing potential components relating to improving communication and providing entertainment for users; opinions and views were elicited for these and other elements of the system along with feedback on design aspects. Qualitative open ended questions were asked and children were encouraged to discuss their current uses of the technology and provide ideas of what might be useful components for the Solas system. A total of five boys and five girls were interviewed with ages ranging from seven to eighteen. All parents were also interviewed.

Findings from interviews

Children and parents were asked a range of questions about the experiences of their illnesses and also their current entertainment and communication methods while the children are in hospital. They were also asked their opinion on the usefulness of a computer system where communication and entertainment was concerned.

Physical impacts most commonly mentioned included feelings of lethargy, listlessness following chemotherapy, hair loss and nausea. Some children spoke about the specific physical implications their illness had. For example, children described trying to manage crutches and feeling too weak to stand or take part in normal activities, such as playing pool. One interviewee spoke of how her experience of being in isolation was likened to *'being in a box'* and how the tiredness impacted her; *"you're in bed all the whole time, you can't get up and move and you just feel tired and down all the time because there's nothing else to do but sit here"*. (Child)

The psychological impact of the illness was quite unique to individual patients. Children (and their parents) spoke very poignantly about the negative psychological impact that a cancer diagnoses has had on them. Boredom from having to spend long periods of time in the hospital was another common impact mentioned by the interviewees. Two mothers described how their sons just *'switch off'* when they need to stay in hospital. Another mother describes how her young son had started asking her *'why me?'* The ward manager felt that alleviating boredom could really help to distract children from their condition: *'They're bored and the more distraction you have, the less chance you have to think of I'm going to be sick, I hate this place.'* (Ward Manager)

Intellectual and concentration implications in relation to school were also discussed. Children had missed long periods of school due to their illnesses. Some felt that their concentration was impacted through their difficult treatment regimens and that they would not be well enough to undertake any course work sent to them by their school. One child added that since her diagnosis she was unable to concentrate: *'I haven't been able to concentrate on a book or anything like that since I was diagnosed because there's too much going on, so you just can't concentrate on anything.'* (Child)

Social impact of illness raised many issues including losing friends which resulted in high levels of loneliness. Most of the children interviewed had missed out on long periods of school due to their illness and subsequent hospitalisation. Some children found it difficult to concentrate on the course work their schools had sent to them. This situation was exacerbated as chemotherapy treatment continued. Losing friends was an unfortunate impact of being ill, and was experienced by most of the children interviewed, particularly the older ones. A number of factors contributed to this such as being in hospital for long periods, missing out on school, feeling too unwell to contact friends and, for some, the risk of infection meant that they could not spend time with anyone who had the slightest ailment. Also, for those from outside Dublin there was even less of a possibility of friends being able to visit them while they were in the hospital. This lack of contact with the outside world also had an impact on parents who spoke of not being able to use their mobile phones in the ward: *'Your phone had to be off...so it was difficult...I'd have to go down the corridor to make a phone call. I wouldn't even have done that because I would have felt I needed to be there'*

and even if he fell asleep I wouldn't have been comfortable with going off....in case he woke up'. (Mother)

Some children mentioned that they would not like friends to visit because they felt embarrassed about how they looked, and embarrassed about being visited by peers in the hospital environment. There was often a sense of alienation from friends because of the isolating experience of being so ill. One child spoke of the alienation from friends that she experienced through being ill: *'You were sad the whole time that you couldn't do things, and you'd see people walking around town or whatever and knowing [in your] heart and soul that you just didn't have the energy to do that sort of stuff...things people my age would be doing, it was really hard to see that happening.'* (Young Person)

Though children did make friends with other patients while they were in hospital, this itself also has its complications because children often did not feel well enough to socialise, and also because children were often not encouraged to visit one another's rooms due to risk of infection at sensitive times of their treatment. Despite this, friendships were formed. Some of the children spoke of the positive benefits of meeting others with a similar condition to themselves. Four of the children interviewed had experience of being in isolation ranging from one day to a week. Two principal impacts of isolation mentioned by the children and their parents were the fact that they were not able to have visitors and were limited to their room. The experience of the vast majority of children and parents interviewed was that they were very cut off from the outside world in the hospital.

In general families spoke of their awareness that visitors were not really encouraged in the ward (due to the serious nature of the illnesses of the children). Although most of those interviewed admitted to having a mobile phone with them while in hospital, it is officially prohibited to use mobile phones in the ward. This reinforces the sense of isolation of both the child and parent and makes contact with those outside the hospital difficult. For the children, texting was more popular than making phone calls. This is because texting is a quick way to exchange information without having a conversation which would probably be difficult anyway due to the weakness caused by their illness. Staff also felt that increased communication with others would be extremely helpful: *'They're so sick as well that even just a text or a phonecall from their family probably would just make them feel so much better.'* (Clinical Nurse Manager)

Staff interviews concurred with many of the psychosocial issues addressed in literature such as the need to improve social support (Ellerton et al, 1996) and communication (Kazak et al, 1995) and were positive that facilitating these areas among this cohort could potentially address some of these issues. One other area of key concern for the staff was not just of the security of the system itself but also of the physical security of equipment in the ward.

Findings to System Design

Following the needs assessment phase, it was acknowledged by the Steering Committee that no 'one solution will fit all' due to the diversity of skills, ages and needs of the children. The needs assessment did lead to an informed system design phase and highlighted many of the issues (for example, security) which need to be continually addressed in the system design. It became increasingly evident that the key component tools of Solas could be divided into two main categories namely communications and creativity. A selection of communication components will enable users to share their experiences and keep in touch with family and friends. The creativity tools offered by Solas are designed to engage the children and distract them from their medical condition and treatment.

- Improve communication - allowing children stay in touch with peers at other hospitals, at school, and with family at home via videolink, live chat, email and SMS texting.
- Improve socialisation with peers, family and healthcare professionals, thus reducing the sense of isolation felt by children.
- Provide a means to continue their educational objectives through the provision of resources such as multimedia learning games and activities.
- Provide appropriate activities and games which will provide for support and distraction.
- Provide medical information at an appropriate level which will lead to a better understanding about their healthcare condition.

Solas from a socio-technical perspective gives as much weight to human needs as technical issues in addressing the needs requirements. This is a perspective advocated by Preece (2000) who suggests focusing on user-centred design, and attempting to gain an understanding of the user's context and its potential influence on the use of technology.

Other important areas of research included:

- *Audience and Environment Research* - The particular environment that the users would be in, required compliance with strict infection control policies, thus influencing the hardware technology choices made. It was also necessary to accommodate children with diverse levels of wellness and mobility throughout their treatment regime.
- *User Interface/Design Research* - The need to design an effective intuitive system accessible to a target audience of diverse ages and technical/motor skills was of high importance. Initial feedback on design was taken during field work with children at the needs assessment stage which fed into the design process.
- *Technical Research* - This involved investigating technical facilities and infrastructure within the pilot site, and also involved ensuring the cost-effectiveness and sustainability of the solutions chosen beyond the initial research project funding. Children are confined to separate isolation rooms during their stay. Compounding this immobility, children can feel lethargic due to their treatment regime. Hardware clients need to be mobile in order to be brought to the isolation ward. A broadband connection was installed at a base in the ward and a virtual private network was set up to run independently of the hospital network.

2. System Design

A critical factor in the development of Solas has been the emphasis placed on innovative use of multimedia design techniques to create an exciting and entertaining community which would engage the attention of children of different ages and differing skills. The age group for the current phase is 8 - 16 years. Although this is a broad age group and poses challenges from a design perspective, it was essential that the system not prohibit specific children on the basis of age. The inclusion of these children would ensure that sufficient feedback was received for the evaluation phase.

The Solas environment offers an intuitive interface to a variety of services. It seamlessly integrates a range of current web technologies, providing a consistent and user-friendly interface via a standard web browser. Solas looked at the specific needs of children with cancer, and the need to provide a solution outside of a supervised environment while maintaining the high level of security required.

The selection of communication components include video link, SMS texting, live chat and email which enables users to share their experiences and keep in touch with family and friends. The creativity tools offered by Solas are designed to engage the children and distract them from their medical condition and treatment. In designing a software environment that works in union with varying mobile hardware clients, a number of design requirements had to be considered. These requirements included:

- Adhering to strict infection control policies which influenced the hardware technology used.
- Accommodating children with diverse levels of wellness and mobility throughout their treatment regime.
- Designing an environment suitable for children of a diversity of ages and skill levels.

Tools provided for creativity include: Drumsteps , a musical composition tool, My Blog, which allows children to create multimedia blogs, Audio Stories , which provides audio books for users to listen to online, Art, which enables children to express their creativity through art and Fun which consists of a variety of single user games and access to appropriate websites on a variety of topics. There are a number of security features which have influenced many aspects of this project. Access to Solas is password protected and each child must register. Family members, siblings and friends can also access Solas but access is limited to specific communication resources.

Figure 1: Solas Main Screen

3. Implementation

The Children's Cancer Unit consists of a 20 bed unit, which also includes a high dependency area (for isolation) where young people, who are preparing for or have received a bone marrow transplant, are isolated. A wireless virtual private network has been setup and a selection of laptops that were donated by Sony Ireland are available for use in the ward. The role of a Solas Facilitator was identified as a requirement in the ward; this person liaises with the medical team and identifies suitable users and also provides an important role of moderator. The Solas Facilitator registers new users, updates and maintains the equipment when not in use (all equipment needs to be



cleaned for the sterile environment before and after use). To date there have been over 300 registered users of Solas. The Facilitator is available to support the community development in the ward. This is a key role which enables registration of users and family and friends and enables consistent feedback to the developers. Building and promoting the community needs continual effort, with specific events or activities being organized regularly.

4. Evaluation

A fundamental aim of Solas was to reduce the sense of isolation felt by children in hospital which would in turn reduce their level of anxiety helping them to cope better with their medical condition and hospitalization. Preliminary results are very positive with a rapidly growing user population and increasing use of the system. The Children's Research Centre at Trinity College Dublin undertook an evaluation of the pilot phase of Solas. (Daly & Greene, 2007) The pilot evaluation was intended to further understanding of how Solas works and how it is used.

Pilot Phase Evaluation Methodology

Ethical approval was received to undertake a pilot evaluation with users of the Solas system. The pilot phase of the project took place over a seven month period throughout the initial implementation phase. Two methods were used to evaluate the extent of and ways in which Solas was used - observation and interview. The researcher observed the use of Solas and the process around it (set up, registering new users etc.) and these observations fed into the evaluation. Qualitative data were gleaned from interviews with and comments of the key stakeholders (parents, children who used Solas and key stakeholders from the medical team). The Play Therapist in the oncology ward was crucial in identifying potential users of the Solas system; she also fulfilled the role of identifying those who fulfilled the selection criteria for inclusion in the pilot evaluation. The criteria included the age of users (8 - 18 years), in so far as possible, an equal mix of gender, and length of time using Solas. Similar to the needs assessment phase, consent was sought from parents and children. Participants' individual circumstances and well-being was a priority and they could withdraw consent at any stage in the research process.

A questionnaire, constructed at the beginning of the evaluation process, was designed to ascertain whether Solas made a substantial change to the hospital experience. It was a quantitative questionnaire which determined the perceptions of children and parents regarding the means of communication and entertainment available in the ward. The challenges of this pilot evaluation included the high turnover of patients in the ward, which meant that not all children had long periods of time using the system. This limited the time available within which to conduct this research. A total of 14 Solas users participated in the pilot evaluation research.

Following the initial pilot evaluation it was evident that Solas had been enjoyed and appreciated by many of the users. The report from the Play Therapist on the level of interest amongst young people was very positive: "*The teenagers that have been in, most of them have had a shot of it.*" Half of the users involved in the pilot evaluation use Solas "*a lot*". Some parents report their children '*perking up*' when using Solas, indicating that it is helping these children to feel better, at least at the time that they are using it.

Solas users reported that Solas helped them to maintain communication with existing friends and family.

"It's a great way of keeping in touch and to keep your mind off the treatment or whatever you're going through." (child)

Solas was an invaluable source of entertainment and distraction that was much needed, not otherwise provided elsewhere, and had a positive effect on the emotional wellbeing of the child.

'..when it was there it was fun and really good to use. When it wasn't there, I was bored like hell!' (child)

A more comprehensive evaluation, that is currently underway, aims to examine if Solas is able to meet its goals and objectives, identify the potential outcome for its users and the resources required to promote sustainability. It will also explore the experience of the users to ensure that best practice is being developed and maintained.

Discussion

Human implications

With all the developments in technology and the important role that it can play in the lives of these children, it is still hugely important to look at the human factors of virtual communities. The role that an organisation can play in such developments can have a huge impact on the potential benefits and impact of the system on the end users. This is especially relevant for vulnerable young children. At the outset it was suggested that the Play Therapist would take on the role of Solas Facilitator; this would involve registering users and basic 'housekeeping' of equipment (cleaning and storage of equipment). This role has proved to be pivotal in ensuring usage of the system. The 'human' face of Solas continues to be as important as the system itself.

Acceptance among staff was initially a challenge as this invasion of technology was seen in a negative light by some. 'Hands On' workshops and information sessions for staff combated some of these initially negative views.

Challenges for virtual communities

Some of the challenges that impact the development of such systems include ethical, organisational and environmental issues. The lack of policies and guidelines within hospitals towards Internet access and usage can have a negative impact on the developments of technology interventions similar to Solas. Establishing access policies will help developments like Solas by providing reasonable boundaries within which to work while not limiting the potential for the resultant users. Focussing on either dangers or opportunities, without recognising the consequences of particular policies or provision for the other, is likely to be problematic, undermining either children's rights or their safety. Using existing technical infrastructures within hospital would provide a more cost effective longer term solution along with more possibility for further roll out. These costs while easily absorbed at the initial research phase do have to be considered for the more longer term sustainability of the project.

Environmental challenges of providing a solution in a high infection risk area is one that can be achieved but can necessitate a compromise on services provided. Restrictions and limitations on hardware selections that can be used in the ward are guided by rigid Infection Control standards. These children are extremely immuno-suppressed throughout their treatment regime, and any potential source of infection risk needs to be eliminated. For example in terms of hardware choices, the original choice would be to have a touch screen and not keyboard based input, as keyboards harbor dust particles; a potential source of infection risk. But these touch screen machines did not have a built in webcam for video conferencing. The solution for Solas was to have custom made covers for the laptops which could be easily cleaned. Each child is given their own laptop for the period of their stay and the laptop is cleaned thoroughly when the child leaves the hospital. This situation is changing with newer hardware such as ipads, tablets and smart phones potentially offering easier solutions.

In the Solas community, our endeavours have focused on the social and individual needs of the specific target audience within an ethically appropriate context. With the approach being 'helping people to help themselves', peers communities can enhance this ideal of peer to peer support through enabling a wider context for support. The scalability of Solas is something that can be explored further building a broader community across Europe and beyond.

Policies

It was necessary to extensively research current legislative guidelines, policies, and international best practise regarding children's access to the World Wide Web both in hospitals, homes and schools.

Putting basic policies in place helps members know how to behave, what to expect from each other and provides a framework for social growth. (Preece, 2005) Achieving a balance between discouraging inappropriate behavior while facilitating the community's evolution requires skill, sensitivity and acknowledgement that the community's purpose and needs may change over time. Childnet International is a charity established in 1996 to support both children and parents in staying safe and getting the most out of online technology; the program also helps parents and children to work in partnership with others around the world to help make the Internet a great and safe place for children. Childnet has consistently argued that setting effective child protection policies online must involve Government, Law enforcement, industry regulators and hotlines, NGOs, parents and carers, schools, teachers and children themselves. (Childnet International, 2011) The policies of Solas bring together guidelines and best practices provided by a range of stakeholders for safe Internet use. These stakeholders include Government (Departments of Health and Education), Non Governmental Organisations, along with the recently established Office of Internet Safety (OIS); Policies are also influenced and guided by similar initiatives such as in the USA. Starbright World, which is open to children between the ages of 13 and 20, is based on regulations set down by the children's online protection policy (www.coppa.org). The Australian arm of the Starlight Charity also has an online community called livewire; this community has 3 levels of access 13-15, 15-17, 17 and older. The security within the Solas systems means that

access is restricted for the communication components to family and peers; each family is given their own private video room and password. Other measures involve each user having their own contact list for SMS and email which ensures that only those on the list can send or receive communications. It is possible for younger children to have a parent or guardian supervise this list. Most guidelines have policies related to specific ages groups: children aged under 9, 10 - 14 and 15 - 18 years. Within these levels of access, restrictions will apply and predefined content will be accessed and filtered according to the age. A balanced approach to regulation is vital if society is to steer a course between the twin risks of exposing children to danger or harm and of undermining children's opportunities to participate, enjoy and express themselves fully. Even though 93% of children use the Internet on a daily basis, there seems to be slow progress in using ICT to support children in hospital, from communication to education and empowerment. Security and safety concerns are not insurmountable. Involving the hospital organization as a stakeholder in setting policies will help alleviate some of these concerns.

At the core of social support is sharing experiences among people who may never meet. Whether we agree or not, computer mediated virtual communities are a part of modern communities that are started and maintained by people who want to share their interests. This has shown to have positive benefits from our Solas users.

Virtual communities offer a framework to provide an efficient and effective means of supporting these children. Any web-based development for children and young people is also vulnerable to concerns regarding child safety and the dangers presented by the Internet. Providing these communities within a hospital setting offers many new challenges, from facilitation and ethical issues to environmental considerations, but these are not insurmountable. Establishing such online communities for children and young people needs rigorous security and child protection policies.

Conclusions

Empirical research from the needs assessment phase means that we have a clearer understanding of the specific needs of this group of children and young people. It is clear that there is a need for improved psychosocial services for children in hospitals and indeed for this particular group of children in the Cancer Unit. There are also other groups of children whose conditions necessitate long stays in hospitals and long absences from school who would also benefit from initiatives to combat psychosocial issues. The high levels of boredom and loneliness endured by these children throughout their long treatment regimens have echoed throughout this work. Additional requirements from the needs assessment phase beyond the initial prototype leave scope for some further development of Solas. Some of these include multiplayer games, medical related information and a multilingual version of Solas. This research will contribute to furthering the knowledge we have in developing a model based on best practices in the area of online environments for children in hospital. Communities like Solas are dynamic and as such are continually evolving. Increasing demands and pressure from patients and parents alike to provide 'Internet' services in hospitals raise many difficulties for hospitals. Compounding these demands are the lack of existing infrastructure and procedures and guidelines for Internet access by children. The existing 'Duty of Care' and responsibility towards patients in paediatric hospitals make it necessary for a more customized and targeted approach. Solas bridges this gap and offers a solution which ensures that young people can access appropriate resources and communicate in a secure and safe environment. With safe and secure policies and guidelines for use, Solas offers a unique and innovative means to provide the variety of Internet services in a hospital environment.

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