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# A social networking website that provides educational support to children living with Type 1 diabetes

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## Abstract

Increasing access and use of social networking websites and tools by young people is enabling new opportunities for use in health care (Kamel Boulos & Wheeler, 2007). But, little is known about how these technologies can be used by hospital-based clinicians for the purposes of communicating, educating and supporting young people. Thus the research study reported in this case study investigated how to design, build and implement a hospital-based social networking website for children and adolescents to interact with clinicians and themselves. This case explains how the site was designed to support children living with Type 1 diabetes using an iterative research design process, the decisions made during this time, and the experiences of the clinicians as the website was implemented. Additionally the chapter describes the design principles and processes necessary for successful social networking websites that support young people living with diabetes.



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# A social networking website that provides educational support to children living with Type 1 diabetes

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## EXECUTIVE SUMMARY

Increasing access and use of social networking websites and tools by young people is enabling new opportunities for use in health care (Kamel Boulos & Wheeler, 2007). But, little is known about how these technologies can be used by hospital-based clinicians for the purposes of communicating, educating and supporting young people. Thus the research study reported in this case study investigated how to design, build and implement a hospital-based social networking website for children and adolescents to interact with clinicians and themselves. This case explains how the site was designed to support children living with Type 1 diabetes using an iterative research design process, the decisions made during this time, and the experiences of the clinicians as the website was implemented. Additionally the chapter describes the design principles and processes necessary for successful social networking websites that support young people living with diabetes.

Our research suggests that social networking websites can be successfully designed and implemented within hospital-based services, however these websites must be private, trustworthy and secure. Social networking websites have the capacity to enable new and sustained links between clinicians, children and their parents. We found that these links created new opportunities for clinical care, support and education including: being able to observe the lived experiences of the children through, for example, reading the children's online posts; being able to offer timely clinical interventions; providing ongoing emotional support; involving the children in real-world based, authentic self-management education and problem solving; and being able to provide sustained support and supervision to children and their parents.

Clinicians have a critical role in the provision of ongoing facilitation, providing coaching, guidance and clinical supervision. From our research, the clinician's time, confidence and facilitation skills were issues that influenced the nature of interaction between the clinician and the children. One key recommendation is that clinicians need to be supported to help them transfer and adapt their skills so that they can effectively use social networking websites.

## ORGANIZATION BACKGROUND

In Australia, Type 1 diabetes is estimated to cost between $430 and $570 million each year, with the average annual cost per person estimated at $4669 (Craig, et al., 2011). Between 2000 and 2009 the annual rate of Type 1 diabetes for children aged 0-14 was 23 cases per 100,000. Each day during this period two new cases were diagnosed (Australian Institute of Health and Welfare,

2013). Type 1 diabetes is a very serious disease that cannot be prevented or cured. Treatment involves the young people in lifelong insulin replacement, monitoring and continuing education to prevent serious short and long-term complications (Daneman, 2006).

Specialist multidisciplinary teams of clinicians that manage diabetes include endocrinologists, nurse educators, psychologists, and dieticians. They are typically based in large city based paediatric hospitals. This case was based within one such specialist diabetes unit at the Women's and Children's Hospital (WCH) in Adelaide, South Australia. This publicly owned hospital is part of the Women's and Children's Health Network that employs approximately 3,600 people and has an annual budget of approximately $360 million. The WCH is visited by 261,000 outpatients each year (Children, Youth and Women's Health Service, 2011).

As well as continuous insulin therapy, one of the fundamental tenets of diabetes care is ongoing diabetes education and support for each child and their family (Craig, et al., 2011). A diagnosis of diabetes places a considerable burden on young people and their families and the experience at WCH is typical for children around the world living with diabetes. The condition is difficult to manage and maintaining control, especially during the adolescent period is particularly challenging (Christie, et al., 2009; Court, Cameron, Berg-Kelly, & Swift, 2009). Lack of diabetes metabolic control is very serious and results in short and long-term complications.

When young people attend the WCH outpatient clinic their diabetes is monitored, support is provided and self-management education offered. Occasional hospital or community-based special education days are also available to families. Diabetes education and support tends to be spasmodic, largely hospital-based, and requires travel for families to attend.

The use of social networking websites as part of the clinical services was a new concept within the WCH. None of the diabetes team had used social networking websites for the purpose of providing diabetes education or support. The use of Internet generally for the provision of health information to patients has been common practice in health, however clinicians have concerns about the content of these websites and believe that information needs to be checked for currency and accuracy on an ongoing basis. They also believe that information is also often misunderstood by patients (Gilmour, Huntington, Broadbent, Strong, & Hawkins, 2011). Yet a meta-analysis of the literature conducted by Krebs, Prochaska and Rossi (2010) concluded that computer-based interventions have potential to improve health behaviours and recommended that future designs should address:

- the problem of decline of effect after completion of the intervention
- the need to develop innovative techniques to help maintain behavioural changes
- the need for the interventions themselves to be sustainable
- integration into usual clinical care systems
- the need to integrate assessment and feedback
- the fact that no study had examined, or mentioned graphic, visual and human factors

Hospital-based social networking interventions have the potential to address these issues, for example by providing sustained links between clinicians and families, being able to be checked and information changed as required and by providing direct communication with children. A key challenge was to adopt a research approach that would lead to outcomes that would be acceptable to both clinicians, and children and their parents, incorporate the recommended requirements, and incorporate educational and support approaches that were likely to result in behavioural changes. Prior to commencing this research the diabetes clinician's experience and

confidence with information technology in general was low. Thus this research faced a number of challenges as explained below.

## SETTING THE STAGE

The overall aim of our research was to determine an appropriate design approach, develop a prototype website and test this intervention. As there were broad issues to address, for example clinical considerations, engagement and involvement of children, and pedagogical approaches, we adopted the iterative and pragmatic Design-Based Research approach where key stakeholders – the children, their parents and the clinicians (diabetes educator, dietician, psychologist and medical specialist) could be involved during all phases. Design-Based Research is a way of exploring complex issues in naturalistic settings, and designing and testing a proposed solution. Design-Based Research has been widely used to address practical education problems including the problems of designing technology-supported interventions (Cobb, Confrey, diSessa, Lehrer, & Schauble, 2003; Reeves, 2006; van den Akker, Gravemeijer, McKenney, & Nieveen, 2006). Our research was conducted in four Phases. Data obtained from each phase of the development process was used to continuously improve the design solution as highlighted in Figure 1.

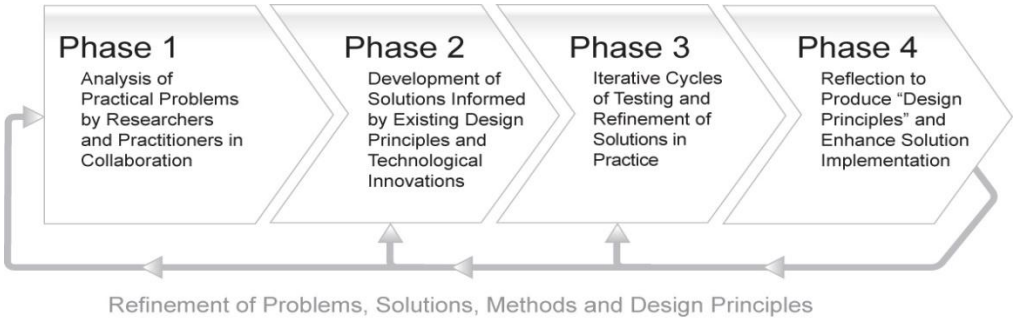


*Figure 1: The four iterative phases of Design-Based Research used in this study* (Reeves, 2006)

Our research methods were predominantly qualitative and entailed persistent observation and substantial engagement with the participants, that is, the young people, families and clinicians, for a period of approximately two years within the WCH. The research commenced by reviewing the literature and conducting a needs analysis with the key participants.

### Literature review

Although the Internet is used by young people for information seeking (Eynon & Malmberg, 2012), our review focused on the use of social networking websites by young people and the uses of social networking websites in teaching and learning. Young people are increasingly using social networking websites for communication, socialisation and keeping in touch with friends, and in many ways these websites express lived experiences (Lenhart, Madden, Macgill, & Smith, 2007). Social networking websites have created new opportunities for health care education (Kamel Boulos & Wheeler, 2007), however, literature reporting the use of these tools in informal, social-based learning contexts is limited. Adapting teaching and learning to informal, social settings is also stated to be challenging for teachers generally (Cox, 2012). Literature reporting the uses of social networking websites targeted at young people living with chronic diseases for the purposes of social connection and support was emerging when this research study commenced (Third & Richardson, 2009). These websites were however not designed for education, were not hospital-based and did not provide sustained links between children and clinicians. Recurring themes for suggested uses of social networking web sites included the need

to integrate Internet-based interventions within clinical care, the need for these programs to be sustainable, and the integration of assessment and feedback (Krebs, et al., 2010).

A broader review of Internet-based diabetes education was performed and found an important distinction between the uses of the Internet to provide information about diabetes, and the use of the Internet to facilitate learning. Prominent Australian diabetes websites were found that provided diabetes information to individuals such as children, adolescents and families. For example Australian Diabetes Council NSW (www.diabeteskidsandteens.com.au), the Juvenile Diabetes Research Foundation (http://www.jdrf.org.au/living-with-type-1-diabetes) and the Royal Children's Hospital Melbourne www.rch.org.au/diabetes. These websites typically provide indexed information, often in text form, and sometimes as animations, stories and videos about diabetes. Some also provide forums where questions can be answered by clinicians. These websites are typically public; are not socially based; are not within usual care settings; do not offer sustained, real-life learning interactions; do not offer guidance, supervision or support, and do not integrate assessment or feedback.

The educational technology literature as early as the 1990s proposed that the Internet should be used as vehicle to encourage collaborative learning. Educators were enthusiastic about the opportunities offered by Web 2.0 and social software tools (Brown, 2006; Downes, 2005; Owen, Grant, Sayers, & Facer, 2006; Richardson, 2009). Social networking websites include ways of creating and sharing content, for example text, images and videos, and collaborative in online social communities. By the mid 2000s, social networking websites were being created (boyd & Ellison, 2008) and these were becoming increasingly popular with young people (Selwyn, 2007). The creation of online learning communities were argued to be possible through application and use of these new technologies and software tools (Brown, 2006; Wenger, White, & Smith, 2009).

The fact that designing effective learning environments for use on the Internet can be difficult in practice tempered this enthusiasm. For example Barrass and Fitzgerald (2008) argued that as technologies were new, usability and technical issues could be barriers to learning, and reported that even young people who were competent social software users had problems using the technologies. Further, Naismith and Corlett (2007) considered usability and accessibility important issues for successful adoption - user-friendliness, size, noise, aesthetics, obtrusiveness, interface, device operation and access to mobile networks. Demiris et al. (2008) agreed that users needed to be competent and confident with the devices and software applications.

Issues of safety and risks to young people using the Internet and online social networks were discussed (Palfrey, Sacco, boyd, Debonis, & Tatlock, 2008)), as were the possible unintended consequences such as distraction and disengagement from learning caused by social networking sites (Selwyn, 2007).

There is a significant body of literature pertaining to application of Internet-based learning environments and pedagogies. This research demonstrates that well designed Internet-based learning environments are capable of overcoming issues of peer and mentor connection, and geographic isolation (Keppell, Jong, Tsang, Bennett, & Lockyer, 2006). Researchers have argued that pedagogies need to be re-designed for use on the Internet, for example finding ways to support the learning and teaching processes (Lockyer & Bennett, 2006). The inclusion of peer-based learning and authentic activities have been proposed as effective pedagogical strategies (Herrington & Oliver, 2000).

The diabetes literature was reviewed with the aim of identifying effective approaches that might be adapted to use on social networking websites. A worldwide DAWN youth study (Aanstoot,

2009) specifically asked young people living with diabetes how to improve psychosocial support. Findings included calls for better support for parents and families; improved age-appropriate, family-based education and support; and improved peer-support. Clearly social networking websites had potential to meet these needs. However effectiveness of current diabetes self-management education was questioned with most reporting only modest effect (Swift, 2009). Factors included the child's own emotional maturity, resilience, life experience, stress, and the parents' level of diabetes knowledge and competency (Aanstoot, 2009). Individual diabetes self-management style was also reported to impact on learning and diabetes competencies (Schneider, et al., 2007).

In summary the key principles and effective strategies for the provision of diabetes education and support that emerged from the literature included:

- considering physiological and psychosocial challenges
- considering maturity and life experience of the children
- considering the parents' own levels of knowledge
- considering individual learning styles
- embedding educational interventions within usual-care settings
- facilitating positive support of peers, parents and clinicians
- providing ongoing age appropriate learning opportunities, and adaptive pedagogies
- providing extended and ongoing follow-up
- enabling flexible delivery options.

## Participants in the study

Ten children aged 11-13 years, their parents, and six specialist clinicians participated in the research. The children were patients of the WCH Diabetes Unit. The children's age range was determined as appropriate, from both the developmental and the diabetes self-management education point of view. Four of the specialist clinicians were from the WCH. They included an endocrinologist, a dietician, a psychologist and the senior diabetes nurse educator. In addition two community-based nurse educators, one community-based social worker, and four young adults who were living with Type 1 diabetes were involved. Prior to recruitment ethics approval was obtained from the WCH ethics committee. Data sources from these key stakeholders included interviews and questionnaires as summarised in Table 1.

**Table 1: Summary of participants and the sources of data for the needs analysis (Phase 1)**

| Participants | Sources of data |
|---|---|
| Children | - Face-to-face meeting to determine needs, discuss possible design approaches, perceived barriers, and introduce the social networking idea<br>- On-line questionnaire to collect reflective information about possible design approaches and needs |
| Parents | - Semi-structured meeting to determine needs, concerns, barriers and gauge interest in the use of social networking websites. |
| Young adults | - Interviews asking perceptions of key issues for young children living with Type 1 diabetes as they developed diabetes self-management competencies<br>- On-line questionnaire to list key topics and design approaches that might be adopted |
| Clinicians | - Informal interviews to determine requirements, limitations, and needs |

## The emerging design solution

From the literature review and needs analysis the following seventeen design characteristics surfaced as needing to be addressed in the social networking website:

1. Young people living with Type 1 diabetes expressed their desire to be securely connected with their peers who also have diabetes and to socialise via an online social networking website.
2. Flexible access is required for all children no matter where they might live or who they are. For example for children who are living in regional areas.
3. The online social networking website must be exclusively for those who are living with diabetes. It must be private and supportive. Some children feel uncomfortable and/or embarrassed talking about diabetes with their friends.
4. Opportunities must be provided for parents to be involved and supported.
5. Parents require their own space within the website.
6. Ways for children to obtain permission from parents for learning activities, and/or when changes are proposed to treatment regimens must be included.
7. The social networking website needs to be age appropriate, active, fun, and engaging.
8. Rich communication experiences with others were expected, for example the use of Web 2.0 tools and technologies, video and live chat.
9. Opportunities for shared activities and face-to-face contact were valued.
10. Diabetes clinicians stated that all young people living with Type 1 diabetes have a broad range of diabetes knowledge, skills and competencies, however as young people develop this knowledge, skills needs to be further developed so that high level self-management competencies emerge. Parents need to be supported during this process.
11. Pedagogies that are enabled via social networking websites should be appropriate, enjoyable and relevant to the children.
12. Children require scaffolding and support as they learn new self-management skills.
13. Support and feedback should be provided that reflects the perspectives of the child and parents.
14. The children require close links to expert clinical support and parental supervision as they learn new skills.
15. Links with hospital-based diabetes educators are essential so that relevant clinical supervision can be provided.
16. Guidelines of expected behaviours and rules are required on the website.
17. Access should be provided to diabetes role models and clinical experts.

These design characteristics were used to guide the decisions made during the development of the social networking website (Phase 2). The case description that follows explains how some of these design characteristics were addressed and implemented.

## CASE DESCRIPTION

The social networking website was developed using an iterative process as illustrated in Figure 1 during the period December 2009 to December 2010. Two concurrent and dependent decision driven activities were undertaken: i) development of the infrastructure and ii) the development of the pedagogies. The pedagogies focused on developing the learning sequence, that is, the tasks, supports and resources that the children would use; designing how supervision would be incorporated; deciding on how to observe and assess learning; and ensuring that the experience would be engaging and relevant for the children. The infrastructure considerations were focused on the tools, technology, and interface design. For example, deciding which hardware technologies to use, identifying suitable Internet software and developing the visual design. This involved collaboration with people who had complimentary skills such as web developers, visual designers, and educators. Although the learning sequence and infrastructure were developed concurrently, this process and the decisions that were made during the process are described

separately to more fully understand considerations, constraints and the roles for each aspect of the development.

## Infrastructure design decisions

The Digital Media Unit within the Centre for Education and Training developed the design at the WCH in Adelaide South Australia. The unit comprised a small team of web developers, educational designers, graphic designers, photographers and video production personnel who produce educational eLearning resources for health professionals and for patient education purposes. The first task was to broadly identify the technologies and tools that might be used, that could support rich communication experiences in ways that built social connection and community. The website needed to be hospital-based, secure and private. The designers focused on infrastructure solutions that were easy for children, parents and clinicians to use, and that were appealing and adaptable. Time for development and the available budget were limitations.

Funding was obtained from grant and in-kind sources. Funding was used to build the infrastructure; to support the testing of the prototype-learning environment; and to provide computer and communication technologies to each of the children so they could participate equally. In addition to the lead researcher who worked at no cost to the project, the total available budget for hardware, software, telecommunication and salaries was AUD $32,000 as summarised in Table 2.

**Table 2: Allocation of monies for hardware, software, telecommunication and salaries**

| Item | Budget |
|---|---|
| Hardware costs e.g. provision of computers, *iPods*, & headsets for the children<br>Telecommunication costs e.g. broadband Internet connections for the children and the educator | $24,000 |
| Software e.g., social software application, graphics, tools | $1,000 |
| Salaries e.g., for web developer, server installation and reporting | $7,000 |
| **Total design and technology budget** | **$32,000** |

### *What technologies to use?*

Access to and the use of technologies by each child was required so that they could effectively participate in the social networking website. There was no shortage of potentially suitable hardware including laptop computers, smaller and cheaper 'netbook' computers, and smart phones. There was also a wide range of media acquisition technologies such as video cameras, still cameras, audio recorders, Mp3 players, microphones, and headsets. Internet connection options also included a range of home broadband and mobile broadband options.

The decisions taken by the designers were guided by the potential of these technologies to meet the required design principles. For example would the technology enable easy and flexible access? Would the technology be engaging and motivating for young people? Could the technologies support the children undertaking learning activities? Discussions and meetings between members of the design team and formative evaluation processes were used to guide the choices for the technologies. For example, the formative evaluation was used to decide which computer system to use. This commenced with searching online for suitable computers, comparing features, cost, computing power, portability, reliability, ease of use, speed and connectivity. Emerging technologies such as the *Apple iPad* (2010) and smart phones were also considered during this evaluation. Although these technologies potentially offered greater opportunities for engagement, as they were perceived by young people as being 'cool', potential limitations were identified such as functionality, stability and connectivity. These devices were therefore excluded. Suitable portable computers were identified – the 13 inch *Apple Macbook*

and the 13 inch *Toshiba T130*. Comparative testing identified possible advantages and disadvantages. The designers believed that purchasing both *Apple* and *Toshiba PC* computers would allow children to choose which type of computer and operating system they would prefer to use. In addition *Logitech* headsets were purchased for synchronous discussions.

The method by which the computers could be connected to the Internet was also evaluated. Portability was considered to be important so the young people could have access whenever they chose. Mobile broadband services were compared. The designers experienced considerable difficulties accessing broadband service providers that could offer fast connectivity in all areas. A decision was made to purchase both *Virgin* and *Telstra* pre-paid broadband modems.

***What social networking software to use?***

Core to these decisions was the choice of the software application that could support secure online interactions between young people, parents and clinicians. Existing commercially available Internet-based social network websites appeared to offer some of the required functionality as they allowed people to construct online profiles, have shared communications, and to view social connections (boyd & Ellison, 2008). These were popular and typically contained tools and applications that were designed to enable and enhance social interactions. Formative evaluation was used to make decisions on what social software might best support the hospital-based social networking website. Three broad options were available; using existing commercially available online social networking applications; using existing open source social networking application; or specifically developing a designed solution from the ground up. Commercial social networking sites were considered first.

*Facebook* (www.facebook.com) was by far the most popular commercial social software application at the time, and although the official age for membership was 13 years, many of the young people in this study already had existing accounts and were therefore familiar with its features. This was considered to be a potential advantage. The features and tools were evaluated. *Facebook* had considerable potential to meet many of the design needs. For example, engaging the children in real-life learning contexts could potentially be well supported through the use of tools such as live chat, tagging, newsfeeds and groups. *Facebook* was also assessed as being well supported; therefore problems such as software updates, data storage and usability would be lessened. *Facebook* was however excluded from being used as the social software platform as the children stated that they wanted their online learning environment to be private and secure. Being a commercially operated site, *Facebook* could not offer the security or privacy required by the children, their parents or the hospital. The children's conversations and media such as photographs would in effect become public property. The hospital would have no control over data storage or the ways in which this was used. The fact that there were millions of other people on the network was also perceived as a problem. Although other children living with Type 1 diabetes would be on the network, it was perceived by the children, their parents and the hospital as being inappropriate. They believed that there would be no way of knowing who these people were, supervision would be difficult, and there was perceived potential for inappropriate access.

The designers considered the notion of building a customised social networking software application. This approach was immediately excluded due to the expected high costs and the time that would be required to build the software application. Potential advantages included high levels of privacy and control, and the ability to design and customise tools specifically to meet each requirement. This option should be considered for future projects.

*Elgg* an open source social software application (http://elgg.org) was identified as having potential to meet the requirements. Formative evaluation of this software commenced with

loading a copy of the software to a test server. This was tested for usability, stability, flexibility and scope of the 'plug-in' (http://community.elgg.org/pg/plugins/all/) using informal cycles of formative evaluation. An example of this formative evaluation concerned the capacity of the software to be modified, for example changing the fonts, colour of the backgrounds, adding *'Java script'* and other web scripting content to the style sheets. The test version was altered to include these changes and evaluated to check stability. The evaluation determined that *Elgg* afforded many of the design features that were required such as password protection for users and media rich social networking tools including the capability to upload images. The software appeared to be relatively easy to use. Limitations were identified including; the overall architecture not being focused on learning; the quality, extent and features of tools; and the limited range and scope of plug-in tools. *Elgg* was however chosen as the platform on which to base the online community as, despite the perceived disadvantages, the software could be made secure and private, was open source, free and afforded many of the functional features found in commercial social software. A summary of the features for each approach with the perceived advantages and disadvantages is provided in Table 3.

**Table 3: Design decisions when choosing the social software – summary of features, perceived advantages and disadvantages**

| Social software application | Perceived advantages | Perceived disadvantages |
|---|---|---|
| *Facebook*<br>http://www.facebook.com/<br><br>Biggest and most used online social network in the world (Wikipedia, 2010)<br><br>Features include – newsfeed, groups, blogs, mail, synchronous chat, push content notification, RSS feeds | No cost<br>Easy to use<br>Popular with young people<br>Well supported and maintained<br>Excellent range of tools, plug ins and applications that could support interaction and communication e.g., photograph tagging, video upload and embedding, groups, newsfeed<br>Professional support and ongoing development | Questions about privacy, information security and control<br>Age limited to 13 years and older<br>Commercially operated company<br>Not customisable<br>Data 'owned' by commercial company<br>Too many features – might be confusing<br>Not designed to support teaching and learning |
| Develop own customised social software website application | Application on own server – secure, control<br>Can be designed specifically for social based informal teaching and learning – potential to meet all of the design characteristics & principles<br>Infinitely customisable and adaptable<br>Ability to select and use tools and features | High cost<br>Future adaption and sustainability?<br>Time required to build system<br>Forward compatibility?<br>Forward adaptability?<br>Features & tools limited |
| *Elgg*<br>http://elgg.org<br><br>Features include - blogging, micro blogging (wire), file sharing, networking, groups, book marking, river (newsfeed) push content notification, RSS feeds (Wikipedia, 2010) | No cost for application<br>Easy to use<br>Open source – therefore can be adapted and modified<br>Supported by open source developer community (altruistic, large, helpful)<br>Application can be loaded to own server (security)<br>Customisable (code)<br>Data contained within own server environment<br>Adaptable to future expansion<br>Ability to re-design, add to and design own | Limitations of some tools and features (generally less developed features than commercial social networking websites)<br>Supported by open source developer community (some weakness for specific solutions and debugging)<br>Not able to support video embedding<br>Synchronous chat considered to be not well featured and functional<br>Some costs for ongoing maintenance<br>Requires some knowledge/support for installations, coding, PHP and server side support |

| | | |
|---|---|---|
| | 'plug-in' | Not designed to support teaching and learning |

*Elgg* server Version 1.7 was downloaded from http://elgg.org/download.php and loaded to the WCH server. The visual interface and tools were modified to enable the required design features and the prototype site was called 'Learning Together' is illustrated in Figure 2.


*Figure 2 the 'Learning Together' website as it appeared in Elgg*

## Pedagogical design decisions

Informed by the data obtained in the needs analysis (Phase 1), the design of the learning framework, and the planned pedagogical interactions involved examining the features of the *Elgg* software that might be used to accommodate the desired diabetes self-management education and support requirements. Decisions were made about the tasks the children would complete, how the children would be supported to complete the tasks, and what information resources would be provided by working closely with the hospital diabetes educator and reviewing the literature of face-to-face diabetes education programs to identify key topics for learning activities (e.g., Christie, et al., 2009; Funnell, Tang, & Anderson, 2007; Knowles, et al., 2006; Wadham, et al., 2005; Waller, et al., 2008). Key topics covered in the social networking site were as follows:

- Insulin administration
- Responding to symptoms
- Meal planning
- Making insulin adjustments
- Communicating with others and clinicians
- Illness behaviours

Decisions on how to use the social networking features in Elgg to support learning activities were made as follows. At the core of the *Elgg* software are social connection tools such as setting up user profiles (e.g., name, email address, interests, profile images), tools for communication (e.g., email, micro blogging) and tools for sharing (e.g., images, files). Testing during the formative

evaluation identified potential problems with supporting higher levels of social connection. Many commercial social networking sites display live 'newsfeeds' or activity streams as a way of keeping people in the loop and engaged with what is going on within the site as it happens. *Elgg* is a community of developers who contribute to the ongoing improvement of the features and tools. These developments are documented on the *Elgg* website on the developer centre page (http://elgg.org/developers.php). Plug-in tools were also freely available from the Elgg website for use by the design team (http://community.elgg.org/pg/plugins/all/). The designers searched this *Elgg* plug-in tool list and identified a suitable activity stream plug-in called the '*Elgg River Dashboard'* (http://docs.elgg.org/wiki/River). This was downloaded, installed and tested for stability and functionality. The *Elgg River Dashboard* appeared to improve engagement and social connection as it displayed time and dated postings from all users, links to these postings, maintained a history, and displayed site wide announcements. A decision was made by the designers to include this feature within the design solution. The designers also considered a range of other tools, features and plug-ins that enhanced social connection in the same way. This included the addition of a 'like/dislike' tool so that users could quickly comment on others postings and a 'wire feed' so that users could send short messages.

Tools that supported synchronous discussion, for example live text chat, were considered to be important to enhance social connection. These tools were available in much of the commercial social software but were not a standard feature within *Elgg*. The *Elgg* developer community database was searched for suitable synchronous chat and discussion tools. Only one chat tool could be identified that had the potential to meet the need. This tool was downloaded and tested; however the results were disappointing. Features were very limited and the tool appeared not to be fully functional. Based on this testing, the decision was made not to include this within the design. No other synchronous chat tools for voice communications or multi-user communication, for example video chat, were available at the time within *Elgg*. Alternative synchronous software was evaluated including the commercial tool *'Skype'* (http://www.skype.com). This was shown to provide high levels of synchronous communication – text, voice, video, file and screen sharing and was chosen as an alternative option for synchronous communication. The use of *Skype* was not however considered to be ideal as it was not within the secure online environment.

Aspects within *Elgg* that could enhance privacy, comfort, and access were considered. The first consideration was where the software was to be installed. The WCH server and the governance that this provided were considered to afford sufficient levels of privacy and control. Participants were however warned that any web-enabled environment was potentially vulnerable to breaches in privacy. As 'Learning Together' was installed on the hospital server all privacy features, for example passwords, user names, email addresses and all content could be administered and edited by the hospital.

The 'groups' feature within *Elgg* was investigated to determine if it might be used to protect the privacy of young people while they participated in the learning activities. Most user information within 'Learning Together' was available to all participants, for example names, email addresses, images. Although young people wanted to be able to 'see' everyone else in the learning environment, they also wanted to be able to discuss and participate in learning activities in their own private space. The 'groups' feature provided a degree of privacy, as users could not join groups unless invited by the site administrator. Communications within groups, for example postings, images, and emails were not available to people that were not part of the group. Features within groups such as; images, group membership, discussion, group files, group videos, and bookmarks were considered to enhance privacy and comfort.

Another important issue was how to include the parents and allow them to participate without this being a barrier for the children. *Elgg* software allowed the administrator to have as many users as required and findings from formative evaluation demonstrated that 'groups' afforded ways of keeping discussions and communications separate. A decision was made to include the parents within the 'Learning Together' website as users, issuing them with their own user names and passwords. Common or shared groups for all users were set up, for example groups where help files could be found, bookmarks, fun quizzes and shared activities. A specific 'parent only' discussion group was also set up and the site administrator automatically enrolled all parents. This was private to the parents and the educator.

Many parents where unfamiliar with using social networking websites, and everyone was unfamiliar with the new 'Learning Together' website. Support resources such as help videos; links and information were therefore provided. Video demonstrations of the 'Learning Together' website were made using screen capture software to support users. For example videos were made on how to set up profiles, post comments, and upload and download images. Although embedding media such as video was easily achieved, the *Elgg* video player was not stable. Video files that were included in the 'Learning Together' website were therefore saved to an external video server site. The supervisory role of parents was supported through the parent discussion area on the website, for example, details of planned learning activities that were posted to this area. Links to several external websites that provided information about Internet safety and supervising children were also provided.

Ways of enhancing comfort through the visual design and the use of relevant graphics, colours and fonts were also considered. Although the overall structure of the *Elgg* could not be altered, for example the ways in which the menus were displayed, the content on the pages, page colours and fonts could be changed. Therefore, images and graphics with fun themes from online image libraries were included. The background colour of the website was changed from blue to pink and the names of the young people (the users) were included on the side banner of the website.

The software tools that were included within *Elgg* were essential to support learning and for engagement. The sequence of events and the user interactions could be observed in real time. Supportive feedback could be provided by other group members and by the diabetes educator. The group discussion tool could display current members of the user groups; display who was online at the time; had the capacity for everyone to post comments, edit, and upload images; and the sequence of these events could be identified through date and time stamping. The problem of how to assess learning was also considered. Unlike formal online learning, for example university students participating in online courses, this learning environment was informal. Children were not being examined on their diabetes self-management skill or knowledge development. The challenge was to develop ways of assessing competency development without learning assessment being a barrier to participation or learning. There was a need to design tools that would be relevant and effectively used within the informal online learning environment. Guided by the principles and methods outlined by Bandura (2006), perceived self-efficacy was chosen as a method by which current levels of knowledge and skills, and also learning need. Ten pointed efficacy rating scales were created using the online survey tool – *Survey Monkey* (www.surveymonkey.com) and embedded into the discussion area of the 'Learning Together' website. Questions were functionally focused on the children's diabetes self-management skills at a particular point in time.

### Early testing and redesign

Concurrent with decisions about hardware and software, the challenge was to plan a series of learning activities that anticipated how participants would engage and interact within the learning

environment over a period of time. One diabetes self-management learning activity – carbohydrate identification (the 'carbs' activity) was designed and run within an initial four-week period of testing (Phase 3). This involved five children and their parents and focused on formative evaluation and usability testing of the new social networking website. As a result of testing a number of refinements were made to the tools and features, as well as to the pedagogical design. Key findings from initial testing included:

1. Allowing more time for immersion and orientation
2. Providing written instructions to the parents (in addition to the online instructions)
3. Providing stronger supports and scaffolding to all participants including the diabetes educator
4. Encouraging children to talk to each other online, and to talk to the educator
5. Enabling access to role models and other diabetes clinicians
6. Offering more face-to-face contact and synchronous discussions
7. Encouraging children to choose their own authentic activities
8. Supporting reflection, questions and discussion and allowing children to demonstrate and share their own self-management skills and knowledge
9. Providing additional support to children who might be disengaged
10. Incorporating incentives such as awards
11. Reducing the number of ways participants could communicate online
12. Supporting the diabetes educator to develop expertise in online facilitation.

Changes were made to the learning framework design to accommodate these findings. Although most of the children were engaged by the learning activity and participated in positive ways, using the diabetes self-management topic 'carbs' was perceived as boring and irrelevant. More time was allowed for immersion and social connection. Ideas for real life diabetes self-management issues were sourced from the hospital educator and from the Australian Diabetes Council (http://www.diabetesnsw.com.au/). The educator reviewed draft versions of the learning sequence and approval was given prior to implementation. In addition, software tools that might enhance engagement and motivation including awards, simple fun quizzes and embedded polls were included. *Elgg* provided a plug-in tool called 'badges' (Version 1.0.3 by Billy Gunn) that awarded badges based on user activity. Points were automatically awarded for activities such as posting a comment or participating in discussion and badges were awarded for a number of points gained.

The number of communication tools available confused some participants, particularly the parents who were unsure about which tools to use and their purpose. In total there were five asynchronous communication tools - the wire, blogs, email, profiles, and the 'reply' function in the activity areas of the website. The 'blog' tool was identified as being very similar to the 'reply' function within the activities areas and was therefore deleted.

### Second period of testing

The second period of testing (Phase 3) of the social networking website was conducted in September 2010 for nine weeks. This number of weeks was limited by the availability of the educator. The senior hospital diabetes educator volunteered her time, despite this being in addition to her daily hospital work. Ten children and their parents participated and they were asked to go online at least two hours per week. The testing commenced with a face-to-face meeting at the hospital where children could meet each other and be introduced to the 'Learning Together' website. Online activities during the first few weeks included the children talking about themselves, their interests and activities at school and home. As the weeks progressed it was up to the children to decide on the diabetes self-management issues that they wanted to

discuss and investigate. The children thus had some autonomy over what issues to focus on. The educator and their parents helped guide this activity. Regular synchronous *Skype* sessions helped the children to discuss these issues (see Figure 3). During the later weeks the children participated in active diabetes self-management learning activities. For example the children recorded interviews with the hospital dietician (see Figure 4), investigated their own blood glucose levels before, during and after sport lessons at school and posted their results to the website, asked questions of each other about how to manage pumps during sport, and investigated external websites that contained information about diabetes.

*Figure 3 – The diabetes educator talking to the children about their diabetes management issues using the 'Learning Together' social networking website*

*Figure 4 – A child participating in an authentic learning activity – asking the hospital dietician how to manage fast foods.*

## RESULTS, SOLUTIONS AND RECOMMENDATIONS

Data from the nine week period of testing demonstrated that nine of the ten children participated actively in the online social networking website. The diabetes educator believed that there were positive learning outcomes for the children involved in the intervention. She stated that many children think they know how to manage their diabetes but they often don't. The learning environment challenged assumptions and provided opportunities for revision and learning. She believed that learning was likely to occur as the online social networking website facilitated the children's engagement in active self-management tasks. This was in contrast to more traditional approaches that are currently being used in the hospital, such as attending clinics and providing written handouts. The social networking website enabled the educator and the parents to provide sustained guidance, encouragement and supervision to the children. This not only maintained currency and relevance but also helped the children to undertake and complete their learning tasks. The educator was very positive about the use of the tool in diabetes self-management education. Provided it was guided, the educator felt that the tool was very appropriate for children as it was motivating and enabled sustained social connection when compared with traditional 'classroom' approaches. In addition she stated that the social networking website enabled expanded learning opportunities. For example the children were able to choose their own issues and topics based on their current life experience, discuss these issues together at their own pace, practice alternative solutions, and be guided by their parents, their peers and the educator in constructive and supportive ways. They were also able to reflect on their own diabetes self-management competencies.

The educator was unable to clearly determine what the children had learnt through their participation in the learning environment. She believed that she would have to assess this independently through direct observation and through discussions with the child and parents and this can be considered as an area of further research. The online self-efficacy tool used was, however, perceived as a useful tool as it is easy to use and offered a way for children and their parents to self-report their perceived self-management competencies. Flexibility of access to clinicians, other families and the learning opportunities were also identified as positives. The website created new links between children, parents and clinicians. These links were child-centred, sustained, flexible and appropriate.

The educator also provided insights into the impact of the intervention generally within the WCH diabetes unit. From the outset the educator expressed anxiety about her lack of understanding and confidence in using the technologies, the 'Learning Together' website and the associated tools. The researcher helped the educator throughout the two testing periods by demonstrating and helping her with the technologies, tools and the 'Learning Together' website. Time was also an issue. As well as accessing the learning environment during working hours, the educator also did this in her own time at home. Although she stated that the impact on her time was less than expected, the educator was concerned that there would be an expectation that the online discussions with the families and children would be after school and in the evenings. This issue would need to be addressed by the organisation so that the impact on time and expectations on diabetes educators could be managed appropriately.

Secondly there were impacts on the children. The intervention enabled closer links and rapport with the children and this appeared to facilitate appropriate and timely clinical interventions. The educator monitored the online conversations between the children but did not dominate. She did not believe any of the conversations that the children or the parents had during the research were

factually wrong or required moderation. She did however intervene clinically on several occasions. For example, when one child posted a comment about his high blood glucose levels, this child was contacted by phone and an appointment made for clinical management. The educator believed that the children were better supported in this way, and better connected with each other than they would have been otherwise. Children and parents from regional areas were connected and this was seen as being advantageous. The educator believed that the intervention challenged the children's self-management knowledge in helpful ways. Parents were better informed about their child's needs and were therefore more able to support their child's learning.

Recommendations for the implementation and further development of hospital-based social networking websites include modifications to the design in the following areas. The synchronous discussion tool used (*Skype*) was the only software issue identified by the educator that required re-design. The tool proved to be unreliable and difficult for the educator to use as discussions were interrupted by connections dropping out. A combination of available bandwidth and usability issues appeared to be barriers. The educator considered synchronous text chat to be more helpful as this would perhaps enable discussion, as the children would not have to speak. These interventions should offer more opportunities for the children meet through face-to-face and compliment existing education events such as diabetes camps.

The educator offered suggestions on how the intervention might be implemented in the future. Online social networking sites for young people living with Type 1 diabetes should be operated by paediatric diabetes hospitals and clinics (such as the unit that she works in), as these clinics have all of the clinical and social information about the children and families. They have the clinical teams to support the families when required and are responsible for the family's ongoing medical care.

The educator believed that children should be introduced to the learning environment early, when they are first diagnosed with diabetes. In the cases where children are too young, their parents should be involved and supported until their child is old enough to engage with the online social networking site. The learning environment should be used in conjunction with normal medical care as a way of developing rapport with all of the clinicians, as a way of meeting other children and families, and as a way of providing sustained educational support that is developmentally appropriate.

It was recognised that the learning activities and the ways in which people were introduced and supported would be different from those that were adopted in this case, and that this would be the subject of ongoing work. It was recommended that one person should manage and coordinate the social networking website so that it remained active, vibrant, appropriate and sustained. In summary the diabetes educator was looking forward to developing the intervention further, and was convinced that specially designed social networking websites offered powerful solutions to providing diabetes education to children.

## SUMMARY

This case study demonstrates the possibilities of online social networking websites being used to address the considerable problems of providing effective hospital and community based education to young people living with diabetes. Children and adolescents expect to use the Internet and social networking websites to connect with their peers and this research has demonstrated that this medium can be motivating and engaging for children living with diabetes. This case study created a new and sustained way of linking hospital clinicians with children and their families in the WCH, and provided evidence of the potential benefits of these connections within health services. These benefits include appropriate psychosocial support, timely and

ongoing clinical supervision, the involvement and participation of parents, and the participation of children in shared and supported self-management learning opportunities. Participation in authentic, shared learning activities based on real-life issues is likely to result in new knowledge, skills and increased diabetes self-management competency. Further research is recommended to refine the pedagogies, determine behavioural and clinical effectiveness, and to address the issues of implementation. Practical implementation considerations that emerged as a result of this study will provide a sound foundation for this future research.

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## Key Terms & Definitions

**Type 1 diabetes** – Type 1 diabetes is an autoimmune disorder of the pancreas causing the destruction of insulin producing beta cells. This leads to excessive glucose (sugar) in the blood, and without treatment, life threatening complications result.

**Diabetes self-management** – diabetes requires constant management. This involves insulin injections, blood glucose monitoring, monitoring of food, exercise, general health, and being able to identify and manage symptoms. Children and parents are taught how to do this themselves. This is termed self-care and/or self-management.

**Learning sequence** – the week-by-week planned tasks and activities, resources (such as external information diabetes websites) and supports (for example how parents and/or others might help with the tasks) that the children were involved with. Intended learning outcomes would be stated.

**'Plug-in' tools** – functionally orientated features that can be added (or deleted) to the *Elgg* social networking website that change the ways in which the user interacts with the website. Many of these tools are not included within the standard downloaded edition and can be added as required.