Designing Mobile Applications to support type 1 diabetes education

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ABSTRACT

The growth in Internet usage has become increasingly important to adolescents who now use it with more frequency to search for health related information. Parallel to this growth, mobile devices have become progressively more flexible and capable of handling an increased range of functionality. They have begun to be viewed as a viable means of improving communication between health practitioners and patients, which could help to alleviate the disease burden by reducing costs through admission reduction and long-term complications in a variety of long-term conditions. This study explores what young people aged between 18 and 21 with type 1 diabetes feel about their use of mobile and web-based technology and whether it might enable them to engage in an improved way with the NHS and their own health to enhance health-related quality of life. It is intended to identify from their views and experiences how they currently make use of web and mobile technology in their day-to-day lives and in relation to their condition and treatment. To then build a small number of prototype mobile phone applications based on ideas collected during qualitative data collection. Four years into the project, this paper disseminates progress to date and provides an innovative example of how patient education can be designed in a way which meets the needs of a particular patient group and values and encourages their input to assist in the creative process - whilst also conforming to clinical guidelines.

Author Keywords

patient education, type 1 diabetes, alcohol, hypoglycaemia, illness, twitter, mobile, apps, sociotechnical design, lifeworld, humanising healthcare, patient voice, empathy, phonegap

BACKGROUND

Diabetes is a long-term condition (LTC) caused by too much glucose, a type of sugar, in the blood. In England, 2.5 million people have been diagnosed with diabetes and the number is expected to reach 4.2 million by 2025. The number of prescriptions for treating diabetes in England has increased to over 40 million - a 50% rise in six years and a 6.1% (2.3 million) rise on the number of items prescribed during 2010-11 (BBC News Online, 2012). *Type 1 diabetes* occurs when the body produces no insulin (NHS Choices, 2010). It is sometimes known as juvenile diabetes or early-onset diabetes because it usually develops before the age of 40, often during teenage years. Someone who has type 1 diabetes usually needs to take insulin injections for life and must make sure that their blood glucose levels stay balanced by eating a healthy diet and carrying out regular blood tests. Type 1 diabetes accounts for 10% of all people in the UK with diabetes and 90% of young people with diabetes (Diabetes.co.uk, 2012).

Two-thirds of the world's population – over 4 billion people – now has access to a mobile phone (Naughton, 2012). New mobile devices have become progressively more flexible and are now able to handle an increased range of functionality including the ability to access the Internet and locative technology. Adoption of mobile phone technology is being led by 16 to 24 year-olds, with 44% using a mobile phone to access the Internet (ONS, 2010). Mobile applications (Apps) harness the power of the Internet with the simplicity of multi-touch technology on a small screen and can run on computers, Smartphones or tablets like Apple's iPad. As of March 2012, 315 million worldwide users had downloaded 25 billion Apps from Apple's App Store and it now offers over 550,000 different Apps including a variety of health based ones (Apple, 2012). Health Apps offer tremendous potential as they can be specifically geared towards particular conditions and purposes or focus on providing support for specific users (e.g. practitioner, patient and carer communities). However an App requires careful design to suit the mobile platform and to ensure that it is clinically accurate and fully considers the individual needs of its users. Consideration also needs to be given to how effectively Apps might be deployed and utilised across different healthcare settings and how they are supported technically. Due to their mostly commercial nature, at this point in time there is little research related to the design process, development and

use of health-related Apps by individuals or groups, although this will certainly alter as more mobile devices and Apps are distributed and used in different healthcare settings.

As there is currently little analysis of how young people with type 1 diabetes make use of web and mobile technology and its impact on health-related quality of life (HRQOL), the research question was:

How do young adults with type 1 diabetes engage with web and mobile technology in their day-to-day life and how might this be related to their health-related quality of life?

This paper begins by discussing how the study contributes to new knowledge and then continues with the motivation behind the study and the methodological and theoretical considerations which underpin it. It then describes the methods utilised, and provides a brief overview of the four prototype Apps currently in development. It concludes by reflecting on the research journey to date, four years into the study.

CONTRIBUTION

This study contributes to new knowledge in three areas:

Contribution to Young People's Lives

Published research considering the views of young people with type 1 diabetes in their use of technology to support their condition is sparse. There is little to analyse considering how they currently use web and mobile technology and its impact on their HRQOL.

Contribution to Technical Development Process

There is little research relating to the design and use of health-related diabetes Apps. However, one of the only reviews of features of mobile diabetes applications (Chomutare et al., 2011) found that a critical feature recommended by clinical guidelines - personalised education - was not included in any current App – an area this study is interested in.

Contribution To Technology

Research and policy concerning the integration of health information and support with technology do not effectively consider the viewpoint of the patient. In terms of type 1 diabetes, young people's views are vitally important as they have a radically different view of technology than either their peers or practitioners.

MOTIVATION

It is thought that education via access to information about diabetes could help people with the condition to empower themselves to manage it more effectively, thereby reducing complications. Van Dam et al. (2005) acknowledged that better knowledge of the ways in which social support operated was vital for enhancing diabetes patient self-care, insuring adherence to advice from professionals, encouraging lifestyle changes and helping to improve outcomes of care and increase personal freedom. Öhman et al. (2003) suggested that it was important to gain a deeper understanding of how chronically ill people experienced illness and life in order to understand the illness from the perspective of the individual and their relationships with family, friends, carers and health professionals. By considering the nature of people's needs who live with chronic illness and reflecting on how they cope and adapt to their situation it enables us to obtain a better foundation for understanding systems which might have a rational basis for helping them. As an example, it has been suggested that practitioners might like to consider how best to meet the needs of young people with diabetes by seeking to understand their experiences and the social networks in which they are embedded, alongside how self-management might be supported by healthcare (Allen and Gregory, 2009). Lamb (2012, p.202) also recommended that clinicians involved in the care for young people with type 1 diabetes should explore the online forum contributions of adolescent experiences as they made sobering reading.

The use of just phone functionality for clinical interventions has to date shown little actual impact. A recent study showed traditional cognitive behaviour interventions like educational sessions through phone calls had little value in changing negative health behaviours in children with type 1 diabetes (Salamon et al., 2010). However, in the same year, Bowen et al. (2010) noted that young adults with diabetes had expressed an interest in email and mobile text messaging in previous studies to enhance disease management and that text messaging had been proven to be beneficial as a possible motivational tool (Franklin et al., 2003). In the case of type 1 diabetes, Lamb's article (2012) on integrating technology into adolescent diabetes care suggested that adolescence tended to conflict with the management of chronic conditions and that interventions utilised previously like telephones, mobile phones and text messaging might seem to empower individuals but had little to no effect on metabolic control in young adults. Williamson (2010) suggested that new technology should still be explored as a possible means of communicating with patients – an approach which could be simply applied to a new diabetes App on a mobile phone, always near to them - joining the growing number of existing Apps available (Chomutare et al., 2011; Cafazzo et al., 2012) or as a part of a mobile friendly assistive device related to their condition (Sanofi, 2011). As an example, a young person with type 1 diabetes who was just diagnosed might be given access to a mobile device or App which played an audio or visual introductory guide to the condition in a friendly non-threatening manner, directly after an initial appointment. Other examples might include an App as an

alternative approach helping to counter the high rates of non-attendance at clinics by young people after transfer to adult services - associated with poorer glycaemic control compared to those who visit clinics (Masding et al., 2010). For self-monitoring of blood glucose, it could enable patients to act on their blood glucose results, transfer and manage blood glucose data, assist with interpretation and support behavioural changes (Kerr et al., 2011).

THEORETICAL ASPECTS AND RELATED WORK

Morse (2012, p.21) defined Qualitative Health Research as:

A research approach to exploring health and illness as they are perceived by the people themselves, rather than from the researcher's perspective.

Researchers use qualitative research methods to elicit emotions and perspectives, beliefs and values, and actions and behaviors, and to understand the participant's responses to health and illness and the meanings they construct about their experience. She believed that the most important aspect of qualitative inquiry was its moral imperative to humanise healthcare, suggesting that a humanising health care agenda included identifying methods of evaluating humanising care at all levels of application and analysis, so that the research focus included individual's experiences and conceptualisations of well-being and quality of life (QOL). Husserl (1970) was seen as the founder of the phenomenological movement and tried to make the nature of human-world intimacy more explicit. He named this the Lifeworld – the world of lived experience or the beginning place-flow from which we divide up our experiences into more abstract categories and names (Dahlberg et al., 2009). In their article on the concept of lifeworld-led healthcare, Todres et al. (2007) revisited the potential of Husserl's notion of the lifeworld and theorised how lifeworld-led care might provide important ideas and values that were central to the humanisation of healthcare practice (Dahlberg et al., 2009). Most of the time in everyday life, the lifeworld is Transparent in the sense that day-to-day life Just Happens, grounded in spatial temporal parameters which are more or less regular (Seamon, 1979). However, an integral part of lived transparency is good health which is lived as a kind of tacit attunement, normally given no direct attention, whilst illness or disability activate a resistance to the lifeworld as they transform its transparency into awkwardness, unease or discomfort. This area of research aimed to construct a vivid lifeworld of the diagnosis, post diagnosis and the day-to-day lived experience and technology use of young people aged between 18 and 21 with type 1 diabetes by using in-depth qualitative interviewing. By talking to young people with type 1 diabetes in-depth and imagining What it Was Like (Todres, 2008) to be diagnosed with the condition and to have to continually examine food labels, looking for hidden sugars in food and drink which could affect control from a young age and remembering to take insulin injections at set times every single day for the rest of your life, the philosophy of understanding offered an important opportunity to integrate understandings about the young person's experience allowing the researcher to gain a deep personal insight into the life of the person experiencing type 1 diabetes day-to-day. How they encountered human services and relationships at home, at school, at work, in clinical environments and also within social contexts. Physicians and caregivers as well as adolescents with diabetes often experience frustration and powerlessness when adolescents repeatedly return to their clinics with poor metabolic control (Frøisland et al., 2012). The Lifeworld approach might also help to provide new insight into areas such as why blood glucose control is poorest between 18 and 21 (Lamb, 2012) and how there might be new, innovative ways which might help young people to improve this, or other aspects of their life and others diagnosed with type 1 diabetes in the future. An important point from Lamb's (2012) article on integrating technology into adolescent diabetes care theorised that technology could not yet remove the largely behavioural barriers to good diabetes control, but might sometimes offer another way of engaging an individual more closely.

There is little research considering the views of young people with diabetes in their use of new technology to support their everyday life with the condition. Franklin et al.'s (2003) study was of particular importance as it was the first randomised controlled trial, which explored the impact of text message enabled behavioural support, with intensive therapy in a young age group. However, the study made no mention of engaging with the targeted audience to discuss what they would like to use on which to influence the hypothesis at the heart of the study. Similarly, in their study reporting results from YourWay - an Internet-based self-management intervention for adolescents with type 1 diabetes -Mulvaney et al. (2010) stated that to their knowledge, this was the first trial of an Internet program to improve problem solving in type 1 diabetes adolescents. However this article again makes no mention of whether young people were asked their opinions during the design of the intervention itself. Although Chomutare et al. suggested (2011) that research has consistently shown that diabetes management is one area where mobile devices could enhance QOL for people living with LTCs, actual research evidence is hard to find (Holtz and Lauckner, 2012). Mulvaney et al. noted (2010) that little is currently known about how young people currently use mobile phones for diabetes and as yet only a small proportion of Apps available have been subjected to any research. One of the only reviews of features of mobile diabetes Apps by Chomutare et al. (2011) finding surprisingly that a critical feature strongly recommended by clinical guidelines personalised education - was not included in current applications. Uniquely, this research aimed to give young people aged between 18 and 21 with type 1 diabetes a voice during qualitative interviewing which could then be used to create technological innovations which might benefit them in some way by the interpretation of their personal ideas and lifeworld experiences.

Existing definitions attempting to integrate technology with health are primarily concerned with using concepts and technology from the healthcare or medical perspective. Consequently, the thought of refining and using new technology alongside a new or pre-existing model of healthcare overshadows and does not effectively consider how this might work from the perspective of the patient at the centre. There is therefore a need to design a framework encompassing the use of web and mobile technology for patients with LTC. A framework originating from the patient's perspective which encapsulates the use of web and mobile technology for the benefit of those who might want to support, mitigate or improve their own QOL (Pulman, 2010). Hindmarsh thought (Vodafone Group, 2006, p.40) that we needed to think hard about what methods of communication a young adult in our rapidly advancing technological environment would be most likely to use in their day-to-day life and incorporate self management into the daily routine so that it became a normal activity rather than an inconvenience. This could be achieved by exploring what the preferred methods of communication were and then designing tools which enabled young adults to engage with the health service and their own health in their preferred manner, putting the individual in charge. Communication is important because management of the disease does not just require motivating the individual, getting them to change their behaviour, but also sustaining and monitoring that behaviour over many years. The last 20 years of diabetes education have reflected an increased emphasis on integrated educational strategies and collaboration with the patient (Frøisland et al., 2012). The aim of a design is to create something that fits, but creating something that fits comfortably and naturally is not always easy. Sociotechnical design is a response to the desire to create systems which are useful and apt (Faulkner, 2000, pp.78). In 2009, delegates participated in a sociotechnical Think-Tank which included the creation of a manifesto as a meeting action. In the manifesto, Clegg et al. (2010) argue that various sociotechnical principles are of direct relevance to current NHS information technology (IT) management, design, implementation and use. They discussed how their manifesto was based on the premise that through learning from past successes and problems in the health and social care sector and by applying sociotechnical principles to future projects, better health and care and value for money could be delivered. They also suggested that a key characteristic of sociotechnical thinking lay in its ability to highlight the importance of developing new ways of working which significantly met the needs of both clients (patients) and users (service providers). Sociotechnical approaches have started to appear in literature concerning diabetes research as a means of collecting data for designing systems to be used by clinical staff (Adaji et al., 2011) and patients (Ma et al., 2009).

This area of study hopes to address this in the creation of a new framework constructed on lifeworld understanding which humanises healthcare by creating technology using sociotechnical design principles. By using a lifeworld approach to help to understand more deeply their day-to-day life and the challenges they came across and including young people with type 1 diabetes in the process of generating technical ideas which might improve their HRQOL and then asking them to use and feedback on early iterations of anything developed, the intention was to provide a humanised approach to their healthcare which also gave them an active voice (at the same time as involving clinical staff, so that their feedback could also be considered and actioned). In summary, the researcher wished to:

- Gain a deep understanding of the perspective of young people with type 1 diabetes and connect with their perspective by building a picture of their lifeworld.
- Utilise this picture and perspective in creating a technological mobile aid partially created and influenced by their own opinions (and those of clinical staff) which would help to possibly humanise an aspect of their healthcare in relation to their condition and which might then improve an aspect of their HRQOL.

METHOD

Recruitment was conducted at a local district hospital in the South West (and a local University) with data collected by semi-structured, in-depth qualitative interviews. Nine one hour interviews were conducted and transcribed with patients aged between 18 and 21 with type 1 diabetes. Although the clinic had children under 18 attending, it was decided to focus on older members as this alleviated the need to obtain parental consent for participation. The upper limit of 21 for initial recruitment was set, as this was the age at which participants no longer attended the clinic on a regular basis. The sampling strategy utilised a non-random, convenience sample as selection would be from participants who had type 1 diabetes within the population definition. The sampling strategy would be purposive (non randomised) - the selection of participants who had knowledge or experience of the area being investigated - as selection would be from young people who had type 1 diabetes within the population definition. Besides providing an understanding of their lifeworld, the initial qualitative interviewing (n=4) enabled the identification of possible ideas for development of prototype Apps. After these interviews had been undertaken, baseline data analysis was undertaken to locate potential ideas for App development. A number of innovative ideas not currently available to participants were suggested during the interviews, of which four seemed strong contenders for developing into Apps after discussions with the clinical team at the local hospital. Prototype App development began in February 2012, which enabled demonstrations of the draft versions as a part of the interview process to take place from the fifth qualitative interview onwards. Working prototype versions of the Apps being developed were installed onto two iPod Touches which could be used by participants to evaluate the features and quality of the prototype Apps. Using an Apple Developer account, the iPod Touches could be configured so that a prototype App could be installed and piloted without the need to be published on the iTunes Store first. Development of prototype Apps on the iPhone platform can be easily transferred to other operating systems (e.g. Android, Windows and

Blackberry) as the Apps are being developed using the PhoneGap architecture. PhoneGap (2012) is an open source solution which allows users to author native Apps using web technologies like HTML, CSS and JavaScript and then deploy them across multiple platforms on different App stores. PhoneGap is an open source implementation of open standards and free to use, which means developers can use it in the production of mobile applications which are free, commercial or open source in design. A percentage of the time allocated in latter interviews (n=5), concentrated on ascertaining from the participants their feelings on the prototype App most closely aligned to their particular area of interest - highlighted by other sections of the interview process - to provide deep, meaningful feedback on the prototype. This was important as unstructured interviews - in terms of usability engineering - are able to provide a wealth of information that the interviewer might not anticipate (Faulkner, 2000). For latter interviews it was possible to utilise NVivo 9 to highlight, record and segregate the differing positive and negative comments on the prototype Apps described by interviewees and to subsequently feed this back into the design process (both for the developer - look and feel and navigation - and for clinical staff - textual content and the quality of information provided). NVivo is a software analysis package which helps to ensure that the analytical process is systematic, sequential and verifiable. Alongside the section of the qualitative interview which focused on garnering prototype App feedback, the researcher was also able to observe the interviewees (n=4) using the prototype Apps for a short, concentrated period of time. This assisted in demonstrating how they were using them and any problems that they might experience in selecting screens and working out how to use the Apps and navigate them, which would not come across from either listening to an audio recording or reading a transcription of an interview. So that the researcher could ensure from a clinical perspective that anything developed met the goals of the clinic, a questionnaire was also distributed to clinic staff that had first had a chance to try out one of the prototype Apps on one of the iPod Touches available for testing purposes. This provided another useful feedback loop on what was being developed.

INITIAL FINDINGS

Four prototype Apps were chosen for development based on the many ideas collected during the qualitative interview process. The suggestions chosen needed to meet clinical goals, reflect interviewee requirements and comments and follow hospital technological guidelines (as an example, patient data is currently not allowed to be recorded).

Diabetes and Illness Guide

If they feel unwell, people with diabetes need to take special care as any illness, even if not related to their diabetes (such as the flu), can cause their blood sugar (glucose) level to rise. The body's natural response to illness is to raise the circulating blood sugar level, but often this means that people with diabetes need to take a higher dose of insulin than usual, rather than cutting the dose or not taking any insulin. Reducing an insulin dose or stopping it altogether can lead to serious problems and often causes Diabetic Ketoacidosis, which requires hospital admission. Interviewees suggested that illness information provided on a mobile format would be positively received and utilised:

P: ...So that when I feel ill, what to do. Cos like the guidance has changed like I was ill not long ago and I was told when I'm ill and I'm not in don't take one of my injections now I've been told that I've got to take it. The guidance like that was changed somewhere and basically it's been like that for all the time but we were told something completely different. **[T1-QOL-01]**

P: Er the sort of things I guess people could do with knowing is when you're ill, like if you get athlete's foot or something someone's like oh you know that's 'cos of your diabetes. Well I've never been told that so I wouldn't of known that, you know, and it doesn't just come up on Google like oh you know what you can expect from being diabetic or why that headache is because you've got diabetes. Like everything is always... "oh that's because of your diabetes" and you think well I wouldn't have known that until this happened and so... **[T1-QOL-03]**

Diabetes and Hypoglycaemia Guide

Hypoglycaemia means an abnormally low level of sugar (glucose) in the blood and is most commonly associated with diabetes. It can occur if someone with diabetes takes too much insulin, misses a meal, or exercises too hard. An App which provided information on what to do for patients, and providing advice on what to do for friends, family, work colleagues, school staff and other possible people who might come into contact with the participant were amongst the suggestions received around the areas of diabetes and hypoglycaemia:

P: ... I think that, I think something that could just like, just something that basically, basically covers like basic um, common diabetic problems and er, like what to do in this situation so whilst you've if you've got like a friend and you're not really in a state, a friend who would, even if they know what to do but they've kind of gone out of what they need to do like not having any juice on hand. **[T1-QOL-02]**

P:...I think it could probably be quite helpful to have the App, um, I don't know, I'm, I'm a big talker so I can, I'm quite happy to talk but if there was something on an App that made it clearer. I think it would be quite useful to, to show them, or tell them that they can read it themselves if they get it or... **[T1-QOL-06]**

Diabetes and Alcohol Guide

Drinking alcohol increases the risk of hypoglycaemia (low blood glucose levels) in patients with type 1 diabetes. It is

estimated that as many as one fifth of episodes of severe hypoglycemia are attributable to alcohol (Nilsson et al., 1988). Interviewees suggested that they would find a guide about alcohol limits particularly useful on a night out which could then be accessed via a mobile device:

P:...it's quite difficult when you've been diagnosed, especially if you've been drinking before, like what what...what each one will do, you know cider, beer, there's loads, and it would be nice to know what has, what has sugar in, what doesn't and something like that... **[T1-QOL-06]**

I: ...have they actually said at the clinic what you're, what they give, give you some ideas about what you should and shouldn't be drinking if you are drinking, in terms of different types of drinks or ... *P*: Erm (thinking), they probably have, perhaps I didn't listen...(Laughs) [T1-QOL-07]

Diabetes Centre Twitter News Feed

Social Networking Sites like Twitter and Facebook are increasingly being used for health-related purposes and recent work has highlighted their value in the field of health. Twitter is a microblogging application providing users with the ability to communicate through the exchange of answers to the question: What are you doing? It has evolved beyond this basic functionality to provide other alternate uses some of which could be health related (Pulman, 2009). Twitter was suggested as a tool which might have many benefits to a young person with type 1 diabetes either used directly or through integration with other Apps. Functionality suggested during interviews included a way to meet other people of a similar age with a similar lifestyle, as an emergency link for contacting people in the health service who might be able to assist at a particular point in time, receiving direct messages from clinic staff advising on reminders about taking insulin, coming to appointments and taking blood sugar readings which would help to personalise diabetes care and also as a real time news feed for information on developments in diabetes such as new blood sugar meters, stem cell research and the development of an artificial pancreas:

P: ... Yeah. I guess a Twitter feed I suppose a general Twitter feed could also have stuff like, um I don't know like say, links to I guess if, I don't know if anyone, I'm not sure what, if anyone if like, I guess you keep an eye on stuff like technological stuff if there was like an article that you didn't have to pay for about something or like or just mention that there's been like a new type of meter like this come out... [T1-QOL-02]

P: But you could, I would also probably...er...(thinks) in the event of an emergency I mean if someone could just tweet on there help what do I do so and so's got a nose bleed and she's diabetic or something like that you know... [T1-QOL-03]

Feedback from both interviews and questionnaires concerning the prototype Apps is currently being analysed and collated. Once developed to the satisfaction of practitioners and interviewees, it is intended that the Apps will be handed over for pilot use within a clinical setting, with the users playing the key role in deciding whether any of them have the potential to be taken forward for use on a wider scale. Further work will then be able to be undertaken to evaluate the usability and any potential impacts on HRQOL as a result of the use of the prototype Apps developed.

CONCLUSION

The current and potential use of Web 2.0 applications and the emergence of new portable devices offer an exciting future for developing a wide variety of diabetes related resources aimed at practitioners and clients. Writing about concussion support. Ahmed and Pulman (2012) suggested that the increasing capability of mobile technology allied with the global population's desire to access health information and communal support groups online, showed mobile technology had a growing significance in disseminating best-practice information for a variety of conditions. However, care must be taken to ensure that any information provided through such devices was accurate, and that adapted forms of delivery (particularly Apps) took into consideration the specific needs of the individual. It also key that proactive practitioners start looking at the technology around them and seeing if they can apply it to their own practice rather than waiting for technologists to suggest what they could or should do with it. It is vitally important that theoretical concepts such as empathetic understanding, reflection of the lifeworld experiences of patients, thinking about ways of humanising healthcare and considering the patient voice are considered by clinicians and technological developers as innovative ways of finding out what patients would like to see developed for their own use and thinking about how they feel before and during the development process. Then utilising a cogent design approach – such as sociotechnical design - which is the most suitable method for providing a solution which is satisfactory to all parties. As an example, the implementation and use of touchscreen technology in GP surgeries to speed up the appointment booking process does not seem to have taken into account how some older patients might get confused and worried when using the system, an important area, which by asking them to have contributed to the design and testing of the system in its earliest phases, might have been uncovered by the developers pre-implementation. It is hoped that the current dissemination of this research project's progress will assist in highlighting a more patient-centric approach to the production of quality health based mobile applications which can be applied not only to diabetes but to other LTC as well. Additionally, providing an example of how patient education can be designed in an inventive new way which

meets the needs of a particular patient group and values and encourages their input to assist in the creative process whilst at the same time conforming to clinical guidelines.

ACKNOWLEDGEMENTS

The authors would like to acknowledge and thank staff at the local hospital in the South West for their valued help and support in relation to this study to date.

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