

*Practice Point*

*Innovative mobile alcohol education for young people with type 1 diabetes*

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### *Abstract*

Views of young people with type 1 diabetes are vital in developing quality services and improving health-related quality of life (HRQOL), yet research on their lifestyle and use of web and mobile technology to support their condition and in non-health related areas is sparse. The aim of this research was to develop an insight into young people's current use of web and mobile technology and its potential impact on HRQOL by constructing an in-depth picture of their day-to-day experiences, exploring how they made use of technology in their lives and in relation to their condition and treatment. Then, building something to help them.

Data was collected by semi-structured, in-depth qualitative interviews ( $n=9$ ) of young people with type 1 diabetes aged 18-21. Interviews were transcribed and loaded onto NVivo for theme identification. Data analysis was also undertaken during initial interviews ( $n=4$ ) to locate potential ideas for technical development. Latter interviews ( $n=5$ ) assisted in the iterative sociotechnical design process. Three suggestions for improvement were taken forward for prototyping with one – an alcohol education guide - being developed into a clinically approved app.

This practice point documents the procedures and sociotechnical design principles involved with the creation of a patient centric app. Providing an innovative example of how education with an aim of improving HRQOL can be designed in a way which meets the needs of a particular group and values and encourages their input to assist in the creative process, whilst at the same time conforming to clinical guidelines.

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### *Keywords*

Education, Type 1 Diabetes, Alcohol, Mobile, Apps, Apple, Android

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### *Key Points*

- This article highlights an innovative, patient-centric approach to the development of a mobile app concerning diabetes education about alcohol.
- Mobile and web technology can be seen as innovative ways of improving communication between health professionals and people with diabetes – with the caveat that not everyone has access to it or might want to use it in their diabetes management - which could be used for education and helping to improve self-management in young people with type 1 diabetes
- At time of writing, there is little research relating to the demand for, design processes, development, regulation and use of type 1 diabetes related apps by individuals or groups.
- This practice point provides an example of how education can be designed in a unique way, which meets the needs of a specific group and values and encourages their input to assist in the creative process, whilst also conforming to clinical guidelines.

## **Introduction**

It is thought that access to information about diabetes could help people with the condition empower themselves to manage it more effectively<sup>1</sup>. For many young people, communication and peer support is now delivered through social networks, which are increasingly being accessed through mobile devices. However, use of mobile functionality (like phones) for clinical interventions in diabetes has to date yielded little impact and it seems that technology cannot as yet remove the largely behavioural barriers to good diabetes control at a younger age, although offering opportunities to engage young people more closely<sup>2,3</sup>. At time of writing, there is little research relating to the demand for, design processes, development, regulation and use of type 1 diabetes related apps by individuals or groups. By using qualitative methods we were able to include young people with type 1 diabetes in the process of generating ideas, which might improve their health-related quality of life (HRQOL) and ask them to use and feedback on iterations of any tools developed. Three technological suggestions were taken forward for prototyping. One – an alcohol guide - was taken forward for development, as a clinically approved app. Alcohol is a recognised risk factor for hypoglycemia in people with type 1 diabetes<sup>4</sup>, it is recommended that they should be alerted to this possibility and advised regarding appropriate preventative measures. This is an important issue for young people with diabetes<sup>5</sup>, as highlighted by it being their choice for actual development. This practice point describes the development of this guide.

## **Methods**

Qualitative research methodology has become more recognised and valued in diabetes behavioural research<sup>6</sup>, as it helps to answer questions that quantitative research might not answer - by exploring individual motivations, preceptions and expectations. This study aimed to gain a deep understanding of the perspective of young people with type 1 diabetes and connect with their views, by building a picture of their everyday experiences with the condition and how they used technology both socially and for health - influenced by approaches from qualitative research in healthcare<sup>7-8</sup>. Then, integrating this perspective in the creation of a technical tool influenced by these views, which might improve an aspect of HRQOL by utilising humanising sociotechnical principles<sup>9</sup> during the design and build. Recruitment was conducted at a district hospital located in the South West of England (SWDC) and a local university, with data collected by qualitative interviews with young people with type 1 diabetes aged 18 to 21. Although the clinic had children under 18 attending, it was decided to focus on older members as this alleviated the need for parental consent. The upper limit of 21 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* and was *Purposive*, with participants considered eligible if they had type 1 diabetes, were six months post diagnosis, were within age range at time of recruitment and were fluent in English. The design utilised in-depth, one hour, semi-structured interviews, with an interview guide prepared beforehand. The pool of participants willing to be interviewed in the target age group was deemed to be low. This group being particularly time poor with busy lifestyles, usually juggling a combination of jobs or living and studying away from the area, which made making additional visits to the clinic in addition to their biannual scheduled appointments difficult. We therefore wanted to ensure that any willing interviewee was granted a

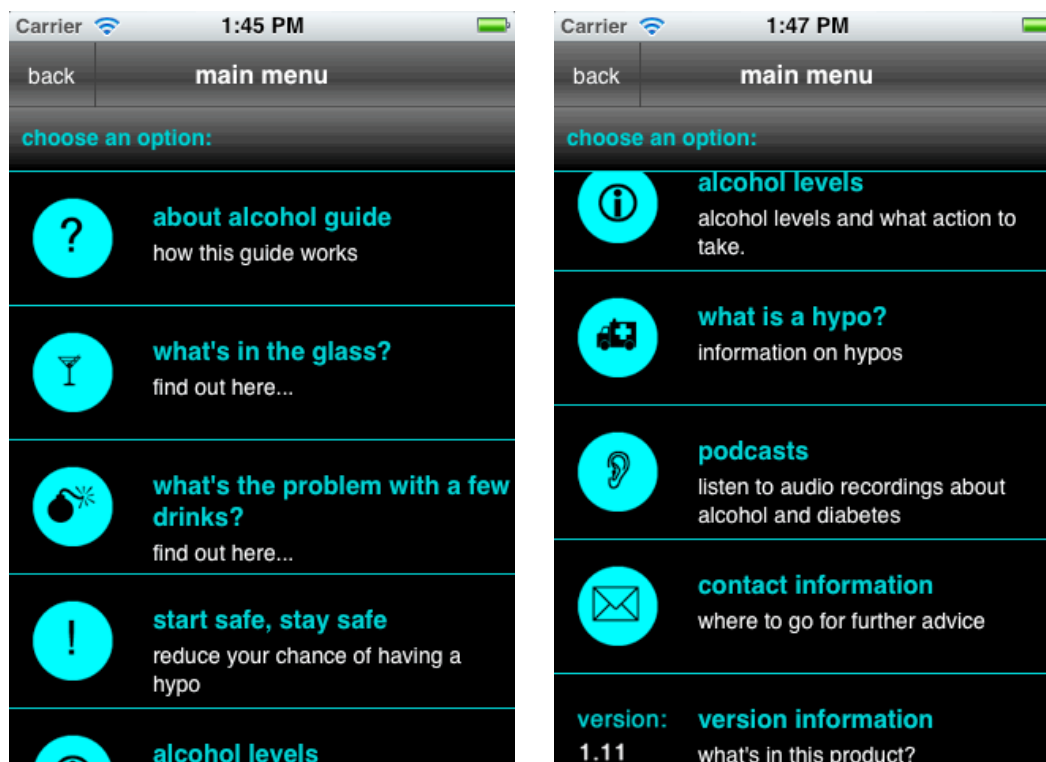
full qualitative interview rather than piloting. Each interview covered interviewee experiences and usage of mobile and computer technology; their diagnosis and how they had utilised technology (if at all) since then; different aspects of their day-to-day life with diabetes; how they coped with and used technology relating to their condition; and if they had used any social or health-related apps. When discussing problems they had experienced, we would then explore ideas or enhancements they had around improving that aspect of their lifestyle or others and whether a technical solution might help. In total, ( $n=9$ ) interviews were conducted ( $m=2$  and  $f=7$ ) and analysed using the qualitative data analysis tool NVivo to gain a deeper understanding of the perspective of the interviewees and to construct a picture of their everyday experience. Six main experiential themes were identified providing an understanding of how participants lived with and experienced their condition and how they used technology<sup>10</sup>. Data analysis was also undertaken during initial interviews ( $n=4$ ) to locate potential ideas for technical development. Suggestions needed to meet SWDC goals, reflect interviewee requirements and follow local trust guidelines. In collaboration with the SWDC, we were able to filter possible ideas for prototype development<sup>11</sup>. Three ideas were created in prototype (around alcohol, illness and hypoglycaemia education), with one (alcohol) subsequently chosen by latter interviewees ( $n=5$ ) to be taken forward for final development. Latter interviews also assisted in the iterative sociotechnical design process of prototype development. Non-prototyped ideas and suggestions are described separately<sup>9</sup>.

### **Design Principles**

Prototype development utilised sociotechnical design principles<sup>9,12</sup>. Recent examples within diabetes research have used this approach as a means of collecting data for systems designed for staff<sup>13</sup> and people with diabetes<sup>14</sup>. A key characteristic of sociotechnical thinking lies in highlighting the importance of developing new ways of working which significantly meet the needs of clients (people with diabetes) and users (service providers). Mumford<sup>9</sup> contended that the definition of human needs should come from the people associated with, and affected by, the technology. This meant that democratic and participative communication and decision-making must always be available to give these people a voice. Therefore, the initial stage of the design process was to seek ideas generated by those who would be using the technological solutions and making use of them. We needed to ensure that anything developed was actually required by this audience and that they would be likely to use anything subsequently developed. This ensured their human needs affected by the technology would be met. The continual redesign of prototypes over several iterations with feedback from SWDC staff and interviewees aimed to create an iteratively valid product for use, whilst acknowledging the continuous process of informational and technological change likely to occur in the future.

### **First Iteration**

The U-CAIR course is run for people with type 1 diabetes at SWDC. Information on type 1 diabetes and alcohol was initially extracted from core U-CAIR materials, after they had been examined and amended for consistency and currency by a dietitian at SWDC. The information was then ported to the app development platform for individual screen design. The first iteration contained a number of different screens covering areas of educational interest to the target group (see **Figure 1**).



**Figure 1. Main Menu**

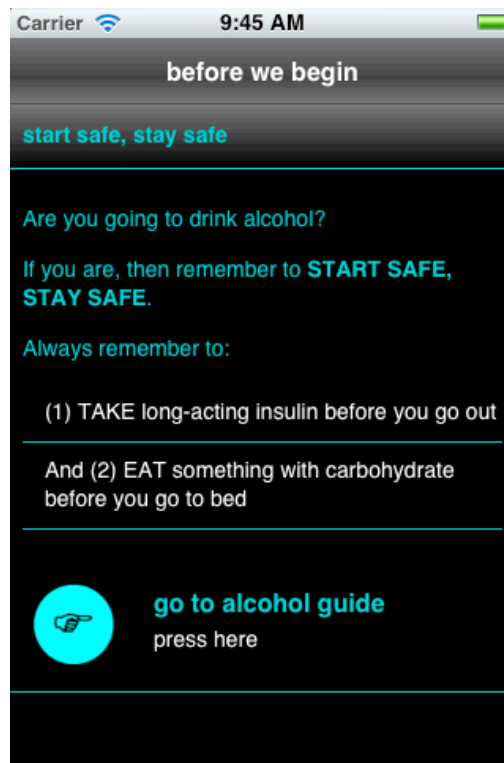
Development was initially undertaken on the iPhone platform as this was considered the most popular platform for developing and approving apps at the time of work commencing and would also have the most impact on the target group, based on discussions during interviews on which phones they owned or were anticipating upgrading to in the future. However, materials developed could also be easily transferred to other mobile systems like Android, as the prototype app was developed using the PhoneGap architecture - an open source solution allowing deployment across multiple platforms. For latter interviews ( $n=5$ ), a percentage of the time allocated concentrated on ascertaining from participants their feelings on the prototype app most closely aligned to their particular area of interest - highlighted during previous parts of each interview - to provide deep, meaningful feedback. This was important as in terms of usability engineering, unstructured interviews are able to provide a wealth of information the interviewer might not anticipate<sup>15</sup>. For these interviews, it was possible to record and segregate differing opinions on the prototypes and subsequently feed this back into the design process for the developer – look and feel and navigational purposes - and for SWDC staff – text content and the quality of the information. We were also able to observe latter interviewees ( $n=5$ ) using the prototypes for a concentrated period of time, which assisted in demonstrating how they were using them and highlighted any problems they might experience in working out how to navigate them - not apparent when listening to an audio recording or reading an interview transcription. In each latter interview, out of the three prototypes available, the alcohol guide was chosen by each interviewee as the app most closely aligned to their lifestyle requirements, the one which they wanted to explore in more depth and the one which they viewed as being the most useful to them.

### **Second Iteration**

Feedback on the first version of the prototype was encouraging, although it was considered by some interviewees that specific pieces of information could be expanded upon and occasionally the pathway of navigation through different screens needed further clarification. To ensure that from a clinical perspective anything developed met the goals of SWDC and the local hospital, a questionnaire was distributed to clinic staff ( $n=5$ ) that had first had a chance to try out the prototypes. Key feedback focused on the need for a better explanation of some of the terms listed within the app - like carbohydrate. Also requiring the clarification of some text statements and rewording others to reduce the risk of information being viewed incorrectly. It was also suggested that the information taken from U-CAIR materials needed to be more carefully adapted and displayed - in terms of the different categories used and how they were split. Like interviewees, SWDC staff also felt that the number of different drinks included could be expanded upon but overall felt the app was generally well designed. New functionality was added to the second iteration regarding a podcast about alcohol as interviewees had expressed a desire for this feature to be available to them in any developed apps<sup>9</sup>. Text was also amended as it had become apparent, once the information was displayed on a mobile screen that it needed to be reformatted to make it easier to read and understand.

### **Third Iteration**

Due to the current lack of NHS regulation, to ensure that the app met clinical validation standards we formally approached the local Patient Advice and Liaison Service (PALS). Future iterations of the app were submitted to PALS for approval, as a part of the five-step process for standardised patient information. Prior to submission, a new launch screen with revised content was added to focus on the ‘*Start Safe, Stay Safe*’ message; which SWDC staff wished to convey each time a user opened the app (see **Figure 2**). Links to NHS Choices Internet resources on alcohol were also added to provide additional information if a user had access to the Internet.



**Figure 2. Launch Screen**

### **Fourth Iteration**

At the first review, PALS suggested that using block capitals removed the shape of a word, which could affect legibility - relevant when people have low health literacy or are in an emergency situation. For the menu screen, it was decided to use upper case with two key words and one key phrase with everything else in lower case. Other suggestions included certain terminology changes and rewording sentences to improve legibility; expanding some text to make it more understandable; standardising bullet points; ensuring text was the right colour (for consistency); and adding in additional screens - for differing locale contact information and information on the term *Hypo*.

### **Fifth Iteration**

After further review, the third submission required only minor cosmetic changes before approval was granted. Developers submitting apps to Apple must ensure that they comply with their development guidelines. Post PALS approval, the alcohol app successfully passed Apple's authentication process and was offered as a free download in December 2012 <sup>16</sup>. A duplicate version was then ported to the Google Play Store and approved as an Android app in February 2013 <sup>16</sup>. Like Apple, Google's developer guidelines contain no specific information on designing health and medical apps and the Google approval process is quite basic with hardly any technical checks being made on either the clinical quality or purpose of the app being offered for download. This has ramifications on wrongful information being made available and subsequently used by someone within a health context <sup>17</sup>. As of May 2013, the app has been downloaded 669 times worldwide (with 603 apple and 66 android

downloads). This means that the potential user base is now large enough to warrant further research on its use. Future research might concern any HRQOL impact that can be seen to be associated with the app locally, nationally and internationally - and also investigate any benefits or problems, which have come from downloading and use of the app in a mobile environment. It is hoped that further work will then be undertaken to evaluate the usability and any potential impacts on HRQOL as a result of the use of the alcohol guide.

## **Conclusion**

Mobile and web technology can be seen as innovative ways of improving communication between health professionals and people with diabetes, which could be used for education and helping to improve self-management in young people with type 1 diabetes. Although this carries the caveat that not everyone has access to it or might want to use it in their own diabetes management. However, just as each person had their own unique perspective and a completely different personal experience of living with type 1 diabetes, so they also require different approaches and suggestions based on their own personal preferences toward technology. Current research and policy concerning the integration of health information and support with technology do not effectively consider this viewpoint<sup>18</sup>. This is all the more important as today's young adults have a radically different view of technology and how they make use of it than either parents or practitioners. The global rise in usage of mobile technology offer exciting opportunities for developing a variety of different diabetes resources aimed at practitioners and clients. However, care must be taken to ensure that any information provided through such devices is accurate, and that adapted forms of delivery - like apps - take fully into consideration the specific needs of the individual. An app also requires careful design to suit the mobile platform and consideration also needs to be given to how effectively they might be regulated, deployed and used across different healthcare settings and how they could be supported technically<sup>2, 10-11</sup>. Aspects of technology use which might be diversive, use the wrong medium to spread a health message, try to manipulate something entertaining into something educational without clear explanation and support, or exclude through cost or software system used could negatively impact on any technological enhancement implemented. For example, by excluding people in low socioeconomic groups without access to smartphone technology. They need to be given clear and careful consideration therefore, before any solution is developed. It is hoped that dissemination of this research will assist in highlighting a more patient-centric approach to the development and production of high quality, health-based mobile apps which can be applied within diabetes and other LTC. Providing an innovative example of how patient education with an aim of improving HRQOL can be designed in a way which meets the needs of a particular group and values and encourages their input to assist in the creative process, whilst at the same time conforming to clinical guidelines.



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### *Declaration of Interests*

No conflicts of interest declared.

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