

Apps and online resources for young people with diabetes: The facts

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Article points

1. In this article, the authors review the use of apps and websites by young people with diabetes, following a discussion between one of the authors, LC, and her friends and followers on Facebook and Twitter.
2. The authors divide the diabetes-related apps and websites into eight groups: blood glucose recording; nutritional information; peer communication and support; sport and exercise; general information; GP websites and personal health records; psychological support; and preparation for the diabetes clinic consultation.

Key words

- Apps
- Internet

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Type 1 diabetes, perhaps more than any other chronic condition, demands self-management, upon which depend long-term outcomes. Nearly all young people turn to apps, websites and social media as the natural first solution to searches for information or to connect with others. Clinicians need to understand the Internet and all the other sources of information that patients may use in constructing their understanding of, and in self-managing, their condition. DSNs now generally work in partnership with patients, and accept that they may learn much from them. This article describes how young people with diabetes have been using apps and the Internet in an effort to help DSNs better engage with this online way of life, and to suggest ways in which they can better stay informed.

Type 1 diabetes is a common chronic condition of children and young adults. Sustained hyperglycaemia leads to microvascular and macrovascular complications in later life and reduces life expectancy (Nathan et al, 2009; Secrest et al, 2010). In contrast, good long-term control of blood glucose greatly reduces these risks (Diabetes Control and Complications Trial Research Group, 1993). Moreover, periods of both optimal and sub-optimal blood glucose levels exert long-term “legacy effects”, making the establishment of good management habits a key priority for young people with diabetes (Nathan et al, 2005).

In a recent survey, nearly all (98.1%) of 16–24 year olds had used the Internet in the last 3 months and less than 1% had never used the Internet (Office for National Statistics, 2012). While some contest Prensky’s terminology of the “digital native” (Prensky, 2001; Helsper and Eynon, 2010), many would agree that most young people turn to apps, websites and social

media as the natural first solution to searches for information or to connect with others. Dutton and Blank (2011) attribute the “next generation internet users” to the major increase in recent years of the portability and range of available devices with which to connect. Although next generation users are not just young people, there are certainly more young people using mobiles and accessing the Internet on a range of devices. Those who own multiple devices are also more likely to use the Internet “on the move” and from multiple locations; young people with diabetes are no exception.

It has long been recognised (Jones et al, 2001) that clinicians need to understand the Internet and all the other sources of information that patients may use in constructing their understanding of and in self-managing their condition. Moreover, the paternalistic ideas that doctors or nurses know best and know everything have passed. DSNs now generally work in partnership with their patients, and accept that they may learn much from patients.

The aim of this article is to describe how young people with diabetes were using apps and the Internet in 2012 to help DSNs better engage with this online way of life, and to suggest ways in which they can better stay informed. It also calls on young people with diabetes to better understand this period of transition and to play their part in this new partnership.

Understanding the terminology

The terminology of the “app” started with the iPhone. Originally, this term described any application, or small program, that is downloaded to a mobile device and runs on that device rather than on the Internet. However, as people increasingly switch from smartphone to laptop, and back, the use of this term has evolved, and the original definition of an “app” is being corrupted. Although many people are unaware, knowing whether the app routinely communicates with a website in order to work, or passes information to the Internet, are important considerations because:

- If there is no internet connection, that app may not work.
- Security issues may arise with respect to the data contained in the app.

Mobile devices can also access websites (rather than an app) as can laptops and desktop computers. When accessing a website from a mobile device, the website may appear exactly the same as on a laptop or desktop, or if the website has been developed to recognise and adapt to the accessing device, it may appear in a more device-friendly format. For example, Facebook is a website on a desktop but young people with diabetes with a smart mobile phone (one that accesses the Internet) can download an app and access Facebook in a much easier format on a mobile device.

What apps and websites are young people with diabetes using?

In order to review the use of apps and other online resources by young people with diabetes, one of the authors (LC) discussed the use of apps with her followers on Twitter and friends on Facebook, asking three questions:

1. What apps or sites do you use in relation to your diabetes?

2. What do you like about apps or sites and what don't you like?
3. If your DSN needs to know one thing about diabetes apps or sites, what is it?

At least 30 people posted responses. It is interesting that none of the respondents clearly differentiated between apps, websites and social media. Clearly, the technical issue of whether something was an app or a website accessed on their mobile device or PC was irrelevant. The only thing that mattered was what they could achieve with the technology. The types of apps and websites can be divided into eight groups (see *Table 1* for a summary of the purpose and availability of each app).

Blood glucose recording

A range of apps, websites and packages were mentioned for recording blood glucose readings, such as DAFNE Online, Diasend and the Diabetes UK Tracker app. Two other respondents used @mysugr, one Sugar Tracker. Some of these apps allow the addition of reflective notes about possible causes of fluctuations in blood glucose levels. One person used EndoGoddess mainly owing to the rewards available for entering blood glucose data.

Nutritional information

Some six to 10 respondents used “CarbsandCals” (website available at www.carbsandcals.com, with apps for iPhone, Android and Blackberry). This includes estimates of carbohydrates, calories, protein and fat content for over 2500 food and drink photos. Some also used coffee shop websites, such as www.costanutrition.co.uk which gives the nutritional information on products (and a “make a tray” summative option), and other fast food outlets, such as Pizza Hut and McDonalds, also provide nutritional information. Two respondents would have liked to see the US app “GoMeals” (giving nutritional values, available on iPhone and iPad) developed for UK users (www.GoMeals.com). “Go Meals” links with “Calorie King” (www.calorieking.com). Another app found useful for some respondents in calculating insulin doses was “Diabetes Carb/Insulin RatioWizard” (iPhone and

Page points

1. In order to review the use of apps and other online resources by young people with diabetes, one of the authors discussed the use of apps with her followers on Twitter and friends on Facebook.
2. A number of apps are available for recording blood glucose readings, such as DAFNE Online, Diasend and the Diabetes UK Tracker app.
3. A number of respondents also noted that they use apps and websites that provide nutritional information, such as CarbsandCals which includes estimates of carbohydrates, calories, protein and fat content for over 2500 food and drink photos.

Table 1. Examples of apps and websites.

Name and location of app/website	Function/scope	Platform
Blood glucose recording		
DAFNE online (www.dafneonline.co.uk)	Blood glucose diary and forum	Free via website, iPhone and Android
Diabetes UK Tracker (http://bit.ly/Zxn1vO)	Blood glucose and other data log	Free via iOS (iPhone, iPod touch and iPad)
mySugr (https://mysugr.com)	Blood glucose data log	Free via iPhone
Sugar Tracker (http://bit.ly/ZgvmB)	Blood glucose data log	Free via Android
EndoGoddess (http://endogoddess.blogspot.co.uk)	Blood glucose and other data log	Free via iPhone and Android
OnTrack Diabetes (http://bit.ly/Lj5fFp)	Blood glucose data log; medication exercise; carb tracker log	Free via Android
Nutritional information		
Carbsandcals (www.carbsandcals.com)	Data and exercise log; food database	£3.99 via iPhone, Android and Blackberry
GoMeals (www.gomeals.com)	Data log; food database	Free via iOS (iPhone, iPod touch and iPad) and Android
CalorieKing (www.calorieking.com)	Data log; food database	Free via website, iPhone and iPad.
DF Diary (http://diabeticfriend.co.uk/diabetic-iphone-app/)	Diary; food database	£1.49 via iPhone
Peer communication and support		
Twitter (https://twitter.com/)	Online social network	Free via website & all other platforms
Facebook (www.facebook.com)	Online social network	Free via website & all other platforms
Forums on diabetes.co.uk (http://www.diabetes.co.uk/diabetes-forum/)	Online discussion community	Free via website
Forums supported by Diabetes UK (http://www.diabetessupport.co.uk/)	Online discussion community	Free via website
Sport and exercise		
Run Sweet (www.runsweet.com)	Website and forum for athletes with diabetes	Free via website
My Fitness Pal (www.myfitnesspal.com)	General fitness website but caters well for young people with diabetes	Free via website, iPhone, iPad, Android, Blackberry and Windows Phone
General information		
JDRF (www.jdrf.org.uk)	Charity for type 1 diabetes	Free via website
Diabetes UK (www.diabetes.org.uk)	Charity for type 1 and type 2 diabetes	Free via website
INPUT (www.input.me.uk)	Patient-run organisation for pump therapy	Free via website

Table 1 (continued). Examples of apps and websites.

Name and location of app/website	Function/scope	Platform
GP websites and personal health records		
My diabetes, my way (www.mydiabetesmyway.scot.nhs.uk)	Interactive website via NHS Scotland	Free via website
iPatient Medical Record viewer (www.paers.net/online-EHR-viewer.shtml)	Access to your record if GP given access	Free via website
EMIS patient access (https://www.emisaccess.co.uk/)	Access to your record if GP given access	Free via website
Patients Know Best (www.patientsknowbest.com)	Personal health record	£10/month
Health Vault (www.microsoft.com/en-gb/healthvault)	Personal health record	Free via website
Psychological support		
Living life to the full (www.llttf.com)	Coping with stress and depression	Free via website
Moodgym (www.moodgym.anu.edu.au)	Coping with stress and depression	Free via website
Preparation for the consultation		
Diabetes App Challenge (www.diabetesappchallenge.org.uk)	Various designs for young people with diabetes	Free websites, iPhone and Android apps

iPad; <http://goo.gl/7LZa9>) that calculates carbohydrate-to-insulin ratios to help in setting the pre-meal insulin dose.

Peer communication and support

Many mentioned Twitter and Facebook for communication and the importance of opportunities to talk with other young people with diabetes to help cope with their condition. One found a forum on www.diabetes.co.uk useful, although another said that she found “some of the t2s [people with type 2 diabetes] very rude” on that forum.

Sport and exercise

In regard to sport and exercise, one respondent mentioned www.runsweet.com, a website for athletes with diabetes, while another mentioned www.myfitnesspal.com, which is a general fitness website which caters well for people with diabetes.

General Information

Several websites and social media sites were considered as useful sources of general information, including the Juvenile Diabetes Research Foundation (www.jdrf.org.uk), Diabetes Support UK (www.diabetessupport.co.uk), Twitter and Facebook. It was found that they provide both general information about diabetes, as well useful tips on what to ask your doctor. In addition, one respondent mentioned www.input.me.uk, which gives information about insulin pumps.

GP websites and personal health records

At first, none of the respondents had acknowledged their GP websites, so we specifically asked about such sites. Two young people with diabetes obtained their prescriptions online and felt that such services

Page points

1. None of the respondents to the survey indicated that they use any apps or websites for psychological support, but the authors claim that many young people may receive this support through their peers via social media.
2. Last year, Diabetes UK launched the "Diabetes App Challenge 2012", a national competition in which apps were developed by young people with diabetes for the purpose of aiding preparation for diabetes clinic consultations.
3. The authors note that both healthcare professionals and people with diabetes need to be aware of how an app or website stores and uses the data that are entered, and apply caution when entering personally identifiable data.

were "really handy" and an "excellent service", but others had problems. For example, we received the following feedback from two other respondents:

"I tried to order my repeat online once and it didn't work so I stick to the old fashioned way!"

"I don't think my GP even has a website."

None of the respondents appeared to know about potential access to their own medical records, including diabetes records (e.g. in Scotland, such information is available via www.mydiabetesmyway.scot.nhs.uk).

Psychological support

Although one person mentioned the need to "de-stress more", no young people with diabetes mentioned any apps or websites for psychological support, although of course most appeared to receive their psychological support through their peers on Facebook, Twitter and discussion forums. In the words of one respondent:

"I use live chat on DiabetesDaily for psychological support. I've been there every day since April."

Preparation for the diabetes clinic consultation – Diabetes App Challenge 2012

The young people with diabetes responding to this survey did not mention using apps in preparation for their consultation but shortly after these conversations on Facebook and Twitter, a national competition, Diabetes App Challenge 2012 (www.diabetesappchallenge.org.uk) made apps, developed by young people with diabetes, available for this purpose.

The purpose of these apps and websites is to help young people with diabetes get more out of their diabetes outpatient consultations by, for example, setting an agenda or bringing reminders of what they want to talk about. Young people with diabetes are currently being invited to test these apps as part of a study funded by Diabetes UK.

What do young people with diabetes like and dislike about apps and websites?

The obvious advantages of apps and online resources, including peer support through Facebook and Twitter, the ability to better control blood glucose levels through balancing diet and insulin and the ability to access these resources in any place and at any time via mobile phones, were mentioned. The only disadvantage appears to be when an Internet connection is not available. One person noted that apps:

"... update your knowledge constantly and instantly. No stagnation. And give priceless feedback. And you make friends!"

Another respondent stated:

"Apps make for a more interactive and controlled feel for care."

There was some discussion in relation to apps not providing everything that was required. For example, one respondent said that she used Diasend to record her blood glucose readings, but she still needed to visit the clinic to attach her blood glucose meter to equipment to upload results from her blood glucose meter to Diasend. She was only then able to log on to Diasend at home and view tables and graphs of results. It was noted that ideally she would want to be able to plug her meter into her laptop and upload results from home.

In contrast, another person had a meter that allowed her to plug directly into her home computer to upload the results.

Confidentiality and data use by apps

One aspect of apps, of which both DSNs and young people with diabetes should be aware, is how an app or website stores and uses the data that are entered. If users are entering potentially identifiable data, it is important to check the privacy policy or permission section of the app and if guidance is available from the app developer regarding:

- Where the data are stored.
- How the data will be used.

- Who has access to data.
- How secure data are from unauthorised access.

For mobile apps, data are often stored on the user's device and Apple screens apps for such data before they are published in the app store. Google Play requires developers to state device permissions to which the app has access. For websites, data are usually stored on the developer's server, but this is worth checking and caution is required when entering personally identifiable data.

What do DSNs need to do?

We asked this group of young people with diabetes on Twitter how their DSN should respond to the availability of online resources.

Two respondents claimed that they simply wished for DSNs to acknowledge that apps and websites do exist, that they provide useful support for young people with diabetes, and that young people with diabetes do not become obsessed with diabetes through the use of these apps. Another said that different people will find different apps and technology useful (i.e. "whatever floats your boat").

Others wanted DSNs to be more knowledgeable and proactive, and to be able to recommend specific apps to patients. Some respondents noted that they want DSNs to get on Twitter and "find out what patients and carers really go through." One respondent had said:

"I've never found a nurse yet that actually acknowledges the internet or apps. They've all been highly suspicious."

Another thought it would be useful if DSNs followed the Diabetes Online Community hashtag #gbdoc on Twitter to understand their concerns. A number of suggestions were made by young people with diabetes about how DSNs could become more familiar with social media including:

"Dive straight in, I say. Twitter is daunting for all new users. Tweet and they will come!"

"They need to see the benefits of it and have other healthcare professionals' opinions of it. Conferences might also be good places to show the benefits."

"Participating in (or observing) some sort of organised lively #diabetes-related Twitter chat would be an excellent start."

A good place for DSNs to start using social media is Twitter where they can follow experienced social media users such as Anne Cooper (@anniecoops) who is a lead nurse with type 1 diabetes or the co-author of this article, LC (@Ninjabetic1), and join in a variety of DSN-related discussions led by @wenurses.

Conclusion

The use of apps and websites has become a routine part of the day-to-day lives for a significant number of young people with diabetes.

A variety of apps and websites have rapidly become the predominant sources of information and support upon which young people with diabetes depend. As a result of this revolution, a diverse range of resources have already been developed, and these tools offer powerful new ways to reach and engage people directly, enhancing the self-management skills that are pivotal to achieving good long-term control of diabetes. These resources offer a potential means to engage a high proportion of young people with diabetes, including individuals who have been difficult to reach with conventional approaches to healthcare. Therefore, DSNs and other healthcare professionals working with young people would benefit from a better understanding of the resources now available to young people with diabetes through apps and the Internet, and how these resources can be used most effectively.

Although it may seem daunting at first for DSNs who have yet to get involved in social media, most online communities are welcoming and conducted in a spirit of collaboration where young people with diabetes and DSNs can learn together and benefit from the shared experiences. ■

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Diabetes Control and Complications Trial Research Group (1993) The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. The Diabetes Control and Complications Trial Research Group. *N Engl J Med* **329**: 977–86

Dutton WH, Blank G (2011) *Next generation users: The Internet in Britain. Oxford Internet Survey, 2001*. Oxford Internet Institute, University of Oxford. Available at: <http://bit.ly/pej7FZ> (accessed 07.01.13)

Helsper EJ, Eynon R (2010) Digital natives: where is the evidence? *British Educational Research Journal* **36**: 503–20

Jones RB, Hampshire AJ, Tweddle S et al (2001) The clinician's role in meeting patient information needs: Suggested learning outcomes. *Med Educ* **35**: 565–71

Nathan DM, Cleary PA, Backlund JY (2005) Intensive diabetes treatment and cardiovascular disease in patients with type 1 diabetes. *N Engl J Med* **353**: 2643–53

Nathan DM, Zinman B, Cleary PA et al (2009) Modern-day clinical course of type 1 diabetes mellitus after 30 years' duration: the Diabetes Control and Complications Trial/ Epidemiology of Diabetes Interventions and Complications and Pittsburgh Epidemiology of Diabetes Complications experience (1983-2005). *Arch Intern Med* **169**: 1307–16

Office for National Statistics. (2012) *Internet Access Quarterly Update, 2012 Q2*. Available at: <http://bit.ly/RftzvN> (accessed 07.01.13)

Prensky M (2001) Digital natives, digital immigrants. *On the Horizon* **9**: 1–6

Secret AM, Becker DJ, Kelsey SF et al (2010). All-cause mortality trends in a large population-based cohort with long-standing childhood-onset type 1 diabetes: the Allegheny County type 1 diabetes registry. *Diabetes Care* **33**: 2573–9