

T1resources.uk – rated, reviewed, reliable: a co-created website for people with type 1 diabetes

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Abstract

People with type 1 diabetes (T1DM) spend many hours each year on self-care activities. They are often isolated and find it difficult to access trustworthy information online. T1resources.uk fills this gap: it is the first of its kind to provide a curated library of resources created for and by people with T1DM. The website is co-curated, with equal healthcare professional and peer representation and input. It signposts its users to pre-existing digital material, having first ensured their safety and usability using a robust review process. The website is low-cost, maximising on social capital. It houses a comprehensive range of resources that vary from peer blog posts to pdf files of sick-day rules. Each resource is catalogued under easy-to-navigate categories to make self-care as straightforward as possible. Since its launch in September 2016, over 7,500 users have accessed the website and feedback has been very positive both from healthcare professionals and people with T1DM.

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Introduction

People with type 1 diabetes (T1DM) spend less than two hours each year with a healthcare professional (HCP), yet perform self-management activities at least one hour every day.¹ The burden of this is often overwhelming and leads to a higher prevalence of psychological issues. The prevalence of depression is high amongst adults with T1DM, with 3.5–10% being classified as depressed, depending on diagnostic criteria.^{2,3} More than 90% of those classified as depressed, according to the eight-item Patient Health Questionnaire (PHQ8), also meet diagnostic criteria for diabetes distress.² However,

these are separate entities; the prevalence of distress is much higher, with almost half of adults with T1DM exhibiting at least moderate diabetes distress.² Diabetes distress is broadly defined, reflecting an emotional response (worry, concern and stress) associated with living with a demanding long-term condition.⁴ It is not considered psychopathological, but 'part of the spectrum of diabetes'.^{5,6} These distinct emotional states have different effects on diabetes self-care outcomes; higher HbA_{1c} is associated with diabetes distress, whilst the relationship with depression is still indeterminate in spite of its negative impact on self-care processes, particularly concordance with treatment.^{2,4,6,7} Despite recognition of the high prevalence of psychological issues and the potential to impact on diabetes self-care, it is estimated that 85% of people in the UK have no defined access to psychosocial support.⁸

Peer support may fill this gap in service provision. It allows the person with diabetes to receive encouragement and support from others. Sharing personal experiences and frustrations is hypothesised to strengthen the coping abilities necessary for behavioural change.⁹ Online peer support in T1DM has been shown to improve psychological outcomes, reducing feelings of isolation and improving perception of self-care behaviour.^{10,11} A meta-analysis of randomised controlled trials of online social networking peer support in diabetes found an improvement in HbA_{1c} of 0.5%, equivalent to that of insulin pump therapy.¹²

Barriers to accessing peer support exist, with most users being well-educated professionals, increasing inequalities in health. National Diabetes Audit data show huge variations in care, with fewer young people and fewer men receiving their eight care processes.¹³ With 80 minutes per day spent on social networking sites such as Facebook and 99% of people aged 16–24 years having an online presence, digital solutions may bridge this gap.^{14,15} Additionally, men are most likely to turn to the internet for health advice.¹⁶

Someone wanting to find out more about the day-to-day usability of different glucose meters may perform a Google search for 'good glucose meter'. This search produces over 3 million results (16 May 2017). It is not surprising that people are easily put off using the internet for their health, finding it hard to decipher what is trustworthy and what is clinically safe. Their HCPs increasingly acknowledge the power of digital information and support, but feel nervous of unmoderated forums and unsafe blog posts.

Recent research in America reports that over 80% of the adult population search online for health information. It is therefore vital that the information they find is reliable and accurate. This project

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works iteratively to create a collaborative structure to highlight safe and reliable digital resources to people affected by T1DM.

Methods

In January 2016 a team of HCPs and people with/affected by T1DM (PWDs) set out to create a library of useful quality-assured self-care resources aimed specifically at people with T1DM. The website T1resources.uk was co-created with complete equality of decision-making between HCPs and PWDs. A robust governance structure was put in place, with an editorial board made up of experts in T1DM care, digital solutions and social media.

The editorial team identified over 100 online resources which ranged from peer YouTube video clips to personal blogs about eating disorders and NHS created sick-day rules. We began to catalogue them in a shared database, agreeing on a taxonomy with which to categorise the diverse content.

A robust review process was created to ensure the safety and usability of all resources. Each resource required approval by both a HCP and PWD before being accepted. A review team with broad expertise was invited, including HCPs from multidisciplinary backgrounds and PWDs from different locations with different experiences and interests. By summer 2016 the review team and process was in place (Figure 1).

Information was specifically created for people new to social media, explaining the different channels and the advantages/disadvantages of each. A governance structure was created which considered website moderation, dealing with problematic resources or those from different healthcare economies. This included the ability for the editorial team to add notes to resources felt to be of value but needed clarification or discussed thorny issues that required highlighting to users.

During website development, consideration was given to usability both on desktop and handheld devices as well as accessibility compliance for people with impaired vision. Careful thought was given to the distribution of content and searchability. The design was optimised for peer interaction, including the ability to rate and

review resources, with highly rated resources appearing more prominently on the website. Prior to launch, iterative changes were made based on peer review of the beta site (prototype).

T1resources.uk launched in mid-September 2016 and continues to grow and develop with resources added regularly. An events calendar went live in April 2017, drawing together content from more than 20 separate diabetes organisations across the UK. Our promotional communication strategy included mobilising support from professional bodies and third sector (charities and other organisations) as well as a social media presence with an active Twitter and Facebook page.

Results

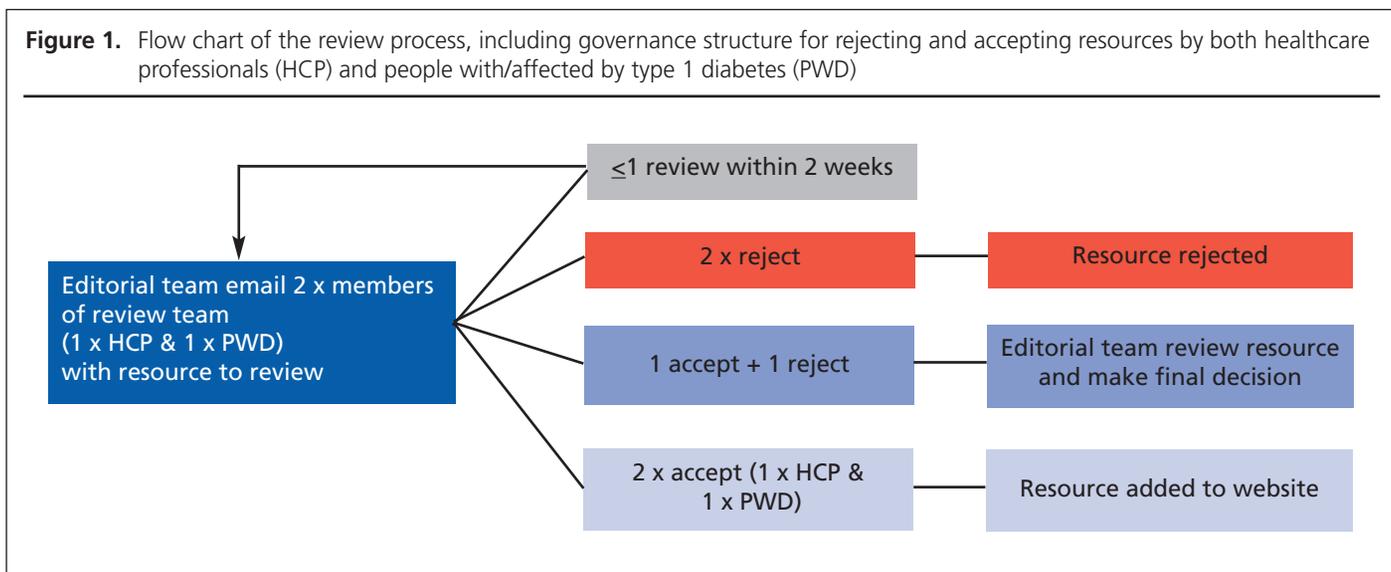
At launch of the website over 100 resources were reviewed and available; by April 2017 this had doubled to 201. Thirty-five resources were rejected for reasons such as safety concerns, mixed messages or unmoderated content.

In the first week 1,000 people visited the site, and this continued to grow with 6,500 users in the first six months. Users viewed over 38,000 pages, averaging 3.3 pages per visit and spending 2.50 minutes on the site before moving on to visit a recommended resource.

Users have created profiles to interact with the website, enabling them to submit resources and raise concerns. Thirty-five resources have been recommended. One concern has been reported; this was resolved promptly with positive feedback regarding the complaints procedure. The star-rating system (1–5 stars) allows users to identify particularly useful resources; 28 resources have received a 5-star rating. The website design allows the very highest rated resources to be shown higher up the listings, and features recently rated resources on the home page. There is functionality for user comments, which are moderated, only being published after review by the editorial team.

User opinions, including people living with T1DM, people with experience of digital health provision and HCPs, were actively sought. Feedback has been extremely positive (Box 1) and iterative

Figure 1. Flow chart of the review process, including governance structure for rejecting and accepting resources by both healthcare professionals (HCP) and people with/affected by type 1 diabetes (PWD)



Box 1 Feedback from individuals using T1resources.uk (both clinicians and people with T1DM)

As a clinician with a specialist interest in type 1 diabetes, I am really keen to have a safe, reliable resource to direct people to if they need some extra support whilst away from clinic trying to get on with their lives. The breadth of questions raised by people with type 1 diabetes is huge and can vary during someone's journey, so having a resource available to recommend that I know I can trust and that is virtually guaranteed to offer the support in a straightforward easy to navigate format and which answers the questions asked at any time of day is invaluable to me as a clinician and to my patients.

I used to be very cautious when my patients asked me about the use of social media and the internet. This website has made it much easier and shows how the internet can be used for the patients' benefit. Now it is very easy, I just need to tell our patients about this one website as it contains all the other places on the internet that I used to recommend one by one. I am confident that directing patients to T1resources will enable them to find trustworthy information and perhaps discuss their problems with 'real experts in diabetes' who live with it via social media.

The most powerful thing for me about managing my condition is knowing I'm not the only one and T1resources.uk not only proves that, but then signposts me to information and other sites where I can get the help, support and advice I need. I'm amazed that no-one had ever thought to put together this kind of resource before, but I'm very glad it exists now.

changes were made in response, including the addition of the events calendar. This brings together hundreds of UK-wide events from over 20 different groups, charities and organisations, encouraging face-to-face peer support as well as making people aware of regular online meetings. The review team has expanded and diversified to include those with research interests and sports enthusiasts.

T1resources.uk has global reach; however, over 85% of users come from the UK. It effectively reaches its target population, with user data showing 54% male users and 60% aged <35 years.

The website's reach has been broad, with a recommendation in the London Clinical Network Commissioning Guide and a mention in the Royal College of General Practitioners' newsletter. Being awarded a 'Piccalilly' by the NHS Academy of Fabulous Stuff has helped to raise awareness further. The Juvenile Diabetes Research Foundation (JDRF) includes a T1resources.uk flyer in their 'newly diagnosed sacks' which are sent to 10,000 people per year. T1resources.uk is signposted as a place for additional information on the websites of the three main diabetes charities. The website was presented at over 20 professional CPD events/conferences and peer meetings. Flyers and posters have been sent to over 50 hospitals in the UK.

The social media strategy has further increased awareness in the diabetes community with 56,000 Twitter impressions, averaging 308 per day, and reaching over 50,000 people in the first 10 days on joining Facebook. Creation's 'Pinpoint' HCP Social Media Study 2015–2016 found T1resources.uk was one of the five most shared diabetes campaigns/information resources by UK HCPs.

**Key messages**

- This project defines a method to co-create low cost and quality assured digital resources for people affected by T1DM
- T1resources.co.uk is more popular amongst men and those under 35 years old
- The on-going success of this website relies on healthcare professionals marketing to their patients

Discussion

T1resources.uk is unique in its co-created approach, demonstrating the ability to deliver an online diabetes resource with equal partnership between HCPs and PWDs. It has been created by a team of individuals working voluntarily across geographical and professional boundaries who are specialists in the field. It uses the expertise of the multidisciplinary team as well as expert patients and carers across the UK. The broad mix of team members provides a wealth of expertise, ensuring that the resources recommended are top quality, the best of the internet and have been extensively tried and tested by the review team prior to recommendation.

The website uses pre-existing resources, enabling it to be delivered at minimal cost, maximising on social capital. It provides access to top-quality peer-created resources that rely on user experience, such as technology reviews. This augments an HCP consultation by providing a safe place to find additional user information, access to patient stories and peer experiences. The most visited resources are those related to self-care: a YouTube video of a personal experience of DAFNE, a PDF of sick-day rules and a video explaining how to calculate correction doses.

The website is free to access, which is possible due to the low overhead costs. The editorial and review team work voluntarily and there is a reliance on the user community to help maintain the site by reporting problems and recommending good resources for review. Areas in which clinicians are involved in the website show highest uptake. This is assumed to be due to awareness of the resource and positive marketing to their patients.

The website encourages peer support, both on T1resources.uk and by signposting to recommended forums and blogs. The functionality encourages interaction and user feedback, including recommending resources and making comments.

The adaptive and reactive nature of the website means the content is ever changing, with new resources added at least monthly, ensuring top-quality and up-to-date items are available. Out-of-date resources are rapidly removed and there is a constant turnover of information. This delivers a carefully curated selection of the best digital resources. The autonomy of T1resources.uk makes this possible, as the robust review method ensures safety but, without affiliation to a specific organisation, the website has the agility to change in response to user feedback. The content is therefore peer-led and mediated by the T1resources.uk team. In addition, this governance structure means that the website can recommend

resources that candidly discuss thorny subjects such as managing glucose control whilst taking drugs at a festival.

This project is the first of its kind to provide reviewed curated resources to empower self-care in T1DM. It provides a low cost digital solution with clear governance and transparent review methods. However, it needs to be recognised that digital solutions may widen the divide between those with lower digital literacy and that alternative channels are required to provide the same access to resources and peer support.

Conclusion

This project illustrates the advantages of co-creating a library of resources. The number of users in specific geographical locations suggests that the need for this resource is there, but that further work is required to reach people with T1DM in areas where HCPs are not aware of the resource. The governance structure and review process provides a model for similar projects in other long-term conditions. HCPs should be encouraged to recommend this resource to their patients.

Flyers and posters are available on request from sophieharris1@nhs.net

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