

Helping people with diabetes make informed choices about their care: Development of a new website



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It was March 2014 and I had just left a corporate career to venture out on my own. Following many years in the pharmaceutical and healthcare technology industries, I was compelled to apply the skills and experiences I'd gained to explore opportunities in diabetes. Having been diagnosed with type 1 diabetes back in 2003, I also had over 10 years' practical experience trying to manage my condition and, albeit clichéd, was motivated to "make a difference" to the lives of people with diabetes.

The starting point was mapping all of my frustrations and challenges living with diabetes – the result being a list of 43 different themes, which I then grouped into 8 main categories. Next, I identified the categories that offered the most potential for me to develop and deliver a solution. This would be a solution that would address a genuine problem, a solution that did not already exist and a solution that someone would be willing to pay for. Unsurprisingly, this process narrowed down my options quite considerably! I was not going to find a cure, I was not single-handedly going to make advances on the artificial pancreas, nor develop a widget to tell me the carbohydrate content of my food.

One category, however, I kept coming back to was how my care was coordinated and the hassle and inconvenience of it all. In 2013, for example, I spent over 35 hours travelling to and from appointments and sat in waiting rooms, in multiple locations, at a personal cost of £50. In return, I received a total of 2 hours of "face time" from five different healthcare professionals. At first I thought this must be the norm and I should just accept it, but having come across the nine care processes recommended by NICE and the 15 Care Essentials recommended by Diabetes UK, my experience to date did not strike me as good value. I was only receiving 7 of the former and never had a care plan developed, for instance.

Around the same time, I'd read about people with diabetes getting access to Skype consultations in east London, secure text-messaging services in

Devon, multidisciplinary diabetes centres in the Midlands and personal care plans in the north west. Were these technologies/services available to me in south-west London? Combining convenience, quality and technology would demonstrably improve my engagement with, and experience of, my care (and arguably my outcomes), so I started searching online to see what was available to me locally.

Well, it was a short exercise – neither NHS Choices, individual GP practice websites nor other private websites offered much in terms of service information (hospital clinics were slightly more informative). For example, my own practice only had "diabetes clinic" listed under services and clicking on the link sent me to another link for Diabetes UK (and that link did not even work). Very little information was available on where to find foot clinics, dietary support, psychological services or eye screening, let alone any self-management support on offer. As someone who had been referred out of secondary care into primary care by a GP, only to be told by the practice nurse "I don't do type 1 diabetes", I was also looking for staff diabetes qualifications, diabetes special interests and which types of diabetes were catered for. Again, only scant information was available.

The idea for "DiabetesCareFinder" was born – a website where people with diabetes in England could search, find and review local diabetes care and support services.

To gain some perspective, I consulted widely with other people with diabetes, patient groups, GPs, nurses, clinical directors and commissioners to see if the idea had legs. Feedback was overwhelmingly positive and I decided to build a basic prototype and test it live to hear what people really thought in the safety of anonymity. As a baseline, I had mapped all GP practices and hospitals in England and linked disparate publicly available service information (for example, retinopathy screening centres, insulin pump clinics, paediatric services, structured education and psychological support) to each individual site of care.

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Rating and review functionality was added to enable service users to share their own care experiences and read others, searchable by type of diabetes.

In February this year, the DiabetesCareFinder prototype was launched as a pilot on Twitter. The result was 252 people searching for local care services across the country, with over 20% leaving a rating and review of their care experiences.

So what were people sharing? Was it, as one GP said to me, all about “creating a forum to bash the NHS?” For the record, that had never been my intention but, in short, no. Over 60% rated their experience as excellent or good, with many people offering constructive and detailed explanations as to what made their care valuable to them and/or their family. Others shared how they felt their care could be improved. *Box 1* shows some examples of feedback. Some of the recurring themes included being treated as an individual, care planning, access to specialist staff and availability of self-management support. The latter was the area where most improvement

Box 1. Shared care experiences of people with diabetes.

“They have always been available to speak to me or sort out emergency prescriptions whenever I need them. The diabetic nurses are friendly and always ask about me, not just my diabetes, which helps with understanding my care needs and what will and won’t work around my lifestyle.” **Type 1, GP practice, West Sussex**

“Very formulaic approach to type 2 care, difficult to get diabetic clinic appointments and little information given. Does not support or approve of self-testing for type 2. Failed to tell me what type of diabetes I had when diagnosed! Highlight is diabetic nurse who is excellent; supportive and well-informed.” **Type 2, GP practice, London**

“The high prevalence of diabetes in my area puts considerable strain on the surgery...no diabetes nurse now, no reminders of annual reviews, follow up if remedial actions suggested, poor self-management and educational tools never raised or offered.” **Type 2, GP practice, Hampshire**

“For children and young people, this is one of the best teams in the UK. They always know how to catch my daughter out doing the right thing and find ways to praise and encourage her so she leaves clinic feeling empowered and motivated to take care of herself.” **Parent of child with type 1, hospital clinic, London**

Box 2. Feedback on DiabetesCareFinder from people with diabetes.

“This could be a fantastically useful tool to enable people with diabetes to find the best care near them and ultimately to raise standards of care”

“Access to service information would direct me to services that are available within my area, rather than relying on my GP/specialist to pass me the information”

“Available information locally would be a real asset and remove some of the strain on my diabetes carer, as I can do this stuff myself!”

was deemed necessary with calls for more educational information, personalised advice and technology-enabled care (such as Skype consultations and apps). Help me better self-manage was a clear message!

The small pilot demonstrated the value of service transparency but to maximise the potential of the platform, it is important to ensure service information is complete and kept up-to-date. Ideally, this will be done in partnership with the NHS and, having recently secured a clinical commissioning group (CCG) pilot, early signs are positive this will happen. For providers and commissioners alike, the platform not only helps people with diabetes and healthcare professionals navigate local services, but also captures real-time patient insights to support service improvement, design and commissioning decisions. *Box 2* shows feedback from people with diabetes on DiabetesCareFinder. With more CCG pilots and strategic partnerships in the pipeline, the next iteration of the website is under development, with plans for more content (including pharmacy, community and self-help signposting) and added functionality to personalise the care-navigation process. Discussions are also underway to extend the platform to cover other long-term conditions and social care.

For many people with diabetes, but certainly not all, choice of care does exist but the information to make informed decisions does not. That’s what I am trying to do with DiabetesCareFinder and in the process, I hope to make a small but valuable contribution to raising standards of diabetes care in England. I eventually aim to roll this service out to the rest of the UK and internationally. ■

To keep updated on progress of the website, please visit diabetescarefinder.org