

DigiBete: Recognition and development of the video platform and social enterprise



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DigiBete.org is a video platform and social enterprise created in partnership between a patient-led initiative and the Leeds Children and Young People's (CYP) Diabetes Team. Content is designed to support CYP with diabetes and their families to self-manage their diabetes by extending the reach of clinical teams online. The site hosts a range of videos and written resources. Video content supports CYP and their families throughout their diabetes journey, providing essential information at diagnosis, age-appropriate educational videos for continued learning about diabetes and generic emergency advice for common acute complications of diabetes. Written resources produced by the CYP Diabetes Team are housed on the site and can be viewed online and downloaded to save repeated requests for additional paper copies. The site also links to pdfs of clinical and academic resources. All resources are freely available to professionals and parents alike.

DigiBete has had a fantastic 12 months building its patient-led, clinically-approved model. It has been recognised by the Health Foundation, which is supporting a process of reflection, community expansion and evaluation. During the past year, DigiBete has won:

- Leeds Teaching Hospital's Time to Shine award for Best Use of Technology and Social Media
- The 2018 Quality in Care award for Type 1 Specialist Service – Children, Young People and Emerging Adults (Thwaites, 2018)
- The National Lottery's People's Project Award, awarded by public vote (<https://bit.ly/2J0XuNk>), which provided £50,000 of funding that has enabled the team to work with CYP to create resources that will support them at home and in the community, and prepare them for adult care.

Innovation and clinical support

The DigiBete.org platform has 26,000 unique visitors and is working on a number of innovations

to support healthcare professionals (HCPs) and families to improve long- and short-term health outcomes for CYP with diabetes. The latest innovation – an ease-of-access app – will be available from the end of September 2019. This app will support DigiBete's mission to deliver continued structured education resources to patients when they need it. The app comes with a communication function that will enable hospital teams to keep in touch with patients and enable them to send out newsletters, event invites and reminders direct to patients and their families. The personal profile will provide patients and their families with a place to record and access diabetes information relevant to them and log their appointment times 24/7. The app will undergo a full real-world health economic evaluation.

The multidisciplinary clinical team supporting DigiBete consists of Dr Fiona Campbell, Consultant Paediatrician, Caroline Mullier, Children's Diabetes Nurse Specialist, and Frances Hanson, Children's Diabetes Dietitian. Its remit has been to co-create and review content, ensure clinical accuracy and adherence to national and international guidance, and provide expert opinion. Professionally, the team is using the website to:

- Provide continued structured education for all CYP, particularly those reluctant to attend group refresher sessions
- Give patients access to clinically-approved information from specialist diabetes staff outside office hours
- Bring CYP diabetes NHS care online to relieve pressure on over-stretched resources being delivered in a traditional way
- Develop a tool to help contribute to improved outcomes for CYP with type 1 diabetes
- Enhance available resources for emotional as well as physical health.

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Safety considerations

All clinical content is reviewed and critiqued by the multidisciplinary team. Generic advice follows national guidelines but no individual advice is given via the site. Patient stories are reviewed before going live to avoid issues that may affect the reputation of the site. The Goals of Diabetes Education video content was advised and reviewed by three of the document's original authors. Content meets 2018 NHS Digital safety standard SCCI0129 and a full clinical safety cycle is in operation to ensure the site is robust. All review processes are documented and archived. The app is currently undergoing a further clinical safety review and will comply fully with the EU General Data Protection Regulation.

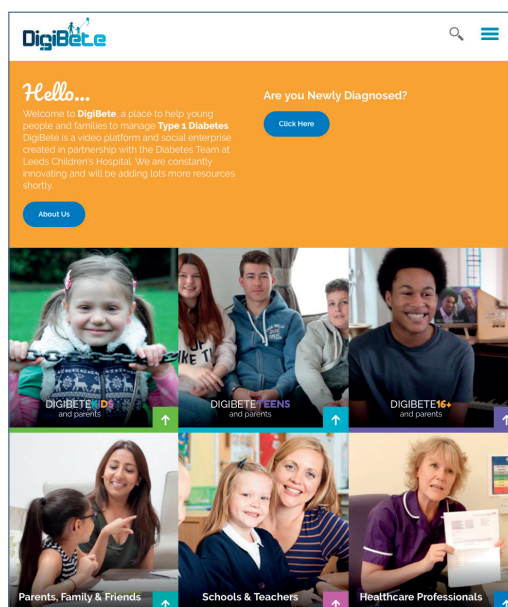
The clinical team recruits patients for participation via routine clinic appointments or publicity inviting families to be involved placed in waiting areas. Due to patient confidentiality, DigiBete does not directly market to or recruit patients. Consent forms for patient involvement have been approved by Leeds Teaching Hospitals NHS Trust Information Governance department.

During the co-design process, an active decision was made not to host a forum, as this would need moderating to prevent unsolicited advice being posted. As the site does not require users to register, no data protection of email addresses is required.

Improving patient education

Professional time has been a barrier to the speed of site development. In 2017, Frances Hanson was accepted onto the Diabetes UK Clinical Champions programme, which enabled her to commit time to DigiBete. This has led to progression of the patient education section (Goals of Diabetes Education). There are now:

- Ready-made lesson plans for HCPs providing group education using this curriculum
- Videos on which to model good diabetes management in the different age groups
- Editable recording sheets that can be downloaded and stored locally electronically
- Quizzes to check patient knowledge, which can be used as part of the assessment process.



Digibete provides targeted information for kids, teens, young adults, parents, schools, teachers, and healthcare professionals

Information for healthcare professionals

There is a designated area for HCPs that provides information to enhance professional learning, such as key clinical guidelines and conference presentations. DigiBete has been given direct access to research presentations that otherwise would only be available by attending conferences, which are featured in the resources section. Finally, tech companies have been invited to contribute to a Technology & Innovation section, where UK products can be shown.

Sustainability and spread

The DigiBete team has engaged in a huge amount of promotion at regional and events (Talking about Diabetes, JDRF, Diabetes UK) and parent groups. Professional clinical meetings have been used to showcase DigiBete and raise awareness of the evolving site content. In addition to this, recognised diabetes professionals and people with diabetes have engaged with us, endorsing the site.

This is a quality product that NHS staff working alone would be unable to produce. DigiBete has received local and national awards for external independent validation of the platforms. We are hugely proud to be part of this project, which ultimately benefits patients and families living with type 1 diabetes, and look forward to continuing to support its development now and in the future. ■

NHS Digital (2018) DCB0129: Clinical Risk Management: its Application in the Manufacture of Health IT Systems. Available at: <https://bit.ly/2mXp50q> (accessed 27 June 2019)

Thwaites S (2018) Best practice in diabetes care recognised at 8th annual prestigious UK and Ireland awards. *Diabetes Care for Children & Young People* 7: DCCYP014. Available at: www.diabetesonthenet.com/journals/issue/563/article-details/8th-annual-qic-awards (accessed 27 June 2019)