Technology, telemedicine and social media are tools to improve health outcomes, education and patient engagement in a paediatric diabetes service

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On behalf of the Paediatric Diabetes Team

Abstract

Few centres in the UK within adult and paediatric diabetes units adopt digital technology, telemedicine or social media within their services. Perhaps this is due to both lack of investments and to some extent clinical leadership to champion and drive change.

The 2018 Mary MacKinnon Diabetes UK lecture is aimed at showing how health outcomes, education and patient engagement can be significantly improved using novel digital and technology strategies as effective means of driving change and delivering good quality of care within a paediatric diabetes service. Copyright © 2018 John Wiley & Sons.

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Key words

technology; telemedicine; social media; diabetes; paediatric

Introduction

It is an honour to be awarded the Diabetes UK Mary MacKinnon Award for 2018. Mary MacKinnon was one of the earliest practice nurses since the 1980s who was described as a driving force behind improvements in care for people with diabetes. She wrote that: ‘Empowering people with diabetes helps them make informed choices and patient empowerment is a key component of the National Service Framework for Diabetes.’1 In the UK, around 400 000 people are affected by type 1 diabetes mellitus. Life expectancy is reduced on average by 23 years in people with type 1 diabetes.2 Diabetes is the leading cause of blindness in people of working age, the leading cause of renal failure and second most common cause of lower limb amputation.

Despite a wide range of national initiatives and guidelines aimed at improving services and driving outcomes, the UK has the highest number of children with diagnosed diabetes in Europe but the lowest number of children and young adults attaining good diabetes control.3 There are an estimated 29 000 children and young people with type 1 diabetes, and the incidence is increasing by 5% year on year.4 In view of these facts, it is essential that children and young people with diabetes are supported to intensively self-manage their diabetes effectively in order to prevent the development of long-term complications. Ongoing patient engagement and education are vital in establishing successful self-management, long-term glycaemic control and a complication-free future for all people with diabetes.5

Today’s health care requires engaging the millennial generation where 71% of adults go online every day, and an additional 11% go online three to five times per week. One in three young people uses a form of technology in their daily lives.6 The optimal use of innovative technologies can help improve patient engagement and deliver effective education within the diabetes services.

Southport and Ormskirk Hospital NHS Trust

Southport and Ormskirk Hospital NHS Trust was established from a merger in 1999 and is the principal health care provider to 300 000 people across Southport, Formby and West Lancashire which has a diverse population. The principal commissioners are Sefton, Formby and West Lancashire clinical commissioning groups. The trust’s principles are ‘Supportive, Caring, Open and Honest, Professional and Efficient’ (SCOPE) care, with integrated pathways across acute and community care. The trust provides a combination of services, which is split between the two hospital sites, namely Southport & Formby District General Hospital and Ormskirk District General Hospital. All paediatric
Inpatient and outpatient work is mainly based at Ormskirk District General Hospital. In terms of population health, Southport and Ormskirk, like many other parts of the UK, has seen a steady rise in younger children diagnosed with type 1 diabetes.⁷

The paediatric diabetes service

In 2011/12, the National Paediatric Diabetes Audit® reported our unit’s mean HbA₁c of 74mmol/mol and admission rates were 28%, and median hospital length of stay was 2.7 days. Annual submissions to national paediatric audits were reliant on manual input into CSV files and, in 2011/12, the trust had 43% of incomplete records of care processes due to errors in manual data entry procedures. Our average HbA₁c was 74mmol/mol (8.9%) with 23% of patients achieving HbA₁c less than 58mmol/mol (7.5%) in 2011. Hospital admission rates due to diabetes were high at 28% and median hospital length of stay was 2.7 days. We were faced with some difficult challenges to improve our health outcomes.

Information management systems are not often routinely incorporated by NHS diabetes service providers and many units including our own service at the time were still relying on paper records. Diabetes management in outpatient clinics was suboptimal with challenging interpretations of patients’ blood glucose diaries, and frequently patients were attending clinic without diaries. It was often a challenge for the team to deal with complex issues while having limited time to spend with patients and families in clinic. We were also facing workforce demands with 150 patients and a service that was reliant on a sole clinician, a 0.8 WTE (whole time equivalent) dietitian and a 2.0 WTE specialist diabetes nurse. While our staffing levels were better than many units at the time due to an increase in funding from the Diabetes Best Practice Tariff,⁹ we felt that we needed to be a lot more efficient with our time, and that the service needed to include a diabetes patient advocate to improve structured education delivery and a psychologist as mental health issues were prevalent in many of our young patients. As such, the service explored ways to drive change and progress.

Regular engagement and feedback meetings were set up with patients, families and carers from the local children and families diabetes support group – Southport, Formby & Ormskirk Children’s Diabetic Club: ‘The Lancelots’ – who reported poor patient satisfaction in the way outpatient clinics were conducted, and suggestions were discussed jointly to improve the services.

Devising a strategy and writing a business case

The team developed an integrated approach which combined submission of business cases to the organisation to fund several initiatives. This required working together as a team to get the business cases funded and we sought support from our parent representatives group. (Figure 1.)

In 2012, we achieved funding to establish the use of two systems in the outpatient paediatric diabetes clinics: Twinkle.NET, a web-based electronic paediatric diabetes information management system, and Diasend®, an electronic download system allowing the routine uploading of patients’ glucose meter and insulin pump data. Key objectives for the initiative, designed to optimise paediatric diabetes management, were to:

- Reduce HbA₁c levels.
- Decrease hospital admissions and minimise the length of hospital stays.
- Improve patient satisfaction.

Deployment of Twinkle.NET enabled a web-based electronic health record that was accessible from all web-enabled devices securely. It allowed us to capture data required for annual audit and significantly improved the unit’s audit submissions, and in 2013/14 the unit achieved 100% submission for the first time. The team used Twinkle.NET to undertake monthly audits to identify patients who had either been admitted as inpatients, had poor metabolic control, or frequently did not attend clinics. These patients were targeted for more intensive contact, education and, where appropriate, a higher frequency of follow up in outpatient clinics. The introduction of Diasend allowed patients and the team to download insulin pump and blood glucometer data at home or within outpatient clinics. This provided easy access and analysis of glucose readings and for the individualisation of treatment regimens. The visualisation of the system provides a tangible outcome for families who collect data as part of their day-to-day management.

In 2013, a business case to establish a Paediatric Diabetes Facebook page was approved by the trust information technology (IT) and
information governance (IG) departments. The Facebook page maintains frequent updates on diabetes education for patients and families and provides direct access to the team via messaging. The initiative made the unit the first within the trust to develop a Facebook presence, having satisfied the governance requirements.

In 2014, we established a team WhatsApp group to enable ease of team communications. A successful team requires that we realise we are all interconnected and that our messages and delivery of education must be consistent. It requires good teamwork and good communications to achieve any level of high performance and to build reliability to achieve our goals. The team found the WhatsApp group very reliable and useful, and we were careful that every member was aware of the ethical principles and confidentiality issues that came with its use.

In 2015, a business case to fund a full-time patient diabetes advocate in our team was successfully granted to support delivery of structured patient education to families, children and schools. In addition, regular group education was held to provide families with peer support.

In 2016/17, we were also successful in our business case to fund two days a week of a children’s diabetes psychologist as part of our team to support the high prevalence of mental health issues in children with diabetes and to improve the wellbeing of children with diabetes.

In 2017, with the support of the IT and IG departments, we started using telemedicine technology to establish Skype clinics in between face-to-face clinics to support and engage families with children with diabetes to improve their glycaemic control.

In the last five years, we have involved patient support groups by having annual face-to-face meetings with our regional Children’s Diabetic Club and parent support group; ‘The Lancelots’, affiliated to Diabetes UK. Our key performance national audit data indicators for health outcomes are now comparable with the best centres internationally and have shown sustained improvement in the last five years, winning the service multiple awards.

**Clinical outcomes**

The results of our initiatives showed improvement in all aspects of patient outcomes and national clinical indicators. In the 2015/16 National Paediatric Diabetes Audit report, our unit’s HbA1c was further reduced to a median HbA1c of 63mmol/mol (7.9%) having continuously fallen from 77mmol/mol (9.2%) since 2009. (Figure 2.) Over 35% of all children achieved an HbA1c less than 58mmol/mol (7.5%) in 2015/16, which was significantly better than the national average and compared to 25% in 2010/11 (Figure 3).

A patient satisfaction survey conducted within the outpatient clinics in 2013/14 showed that use of technology, information management systems and electronic downloads had been very positive; over 81% of families felt they had benefited from the download technology for glucose meters and insulin pumps, and 87% believed that the technology had enhanced patient management decisions in clinic. There was unanimous
consensus from the diabetes multidisciplinary team that the use of integrated technologies has helped the unit identify trends and tailor individual responses, and has improved education and supported efforts to manage patients’ diabetes together in partnership.

**Social media and use of Facebook and Whatsapp groups in health care**

Facebook is the most popular social media networking platform worldwide with over 2 billion monthly active users. Social media has brought about a major change in communication and it offers huge potential as a versatile platform to deliver health interventions, recruitment to trials, collection of data and improve patient engagement within health care. However, key issues regarding ethical concerns – such as privacy, anonymity, informed consent and confidentiality – remain an obstacle for health care professionals to engage in social media as a platform. It is vital for health care professionals to be aware of the ethical guidelines on the use of social media and to work within the ethical principles within their regulatory bodies.10 Doctors now face a generation with internet technology readily available and online health care will soon become part of our clinical practice. Our advice would be to embrace technology today and do not shy away from it.

**Our achievements**

It is important to note that technology has not been the single driver of improvement at Southport and Ormskirk – it is just one piece of a complex jigsaw of multiple initiatives. The success of our paediatric diabetes service in the past years has been dependent on the foundations of dedication, hard work and the commitment of all members of the paediatric diabetes team. All of the initiatives have helped restructure the paediatric diabetes service and have played a major part in improving patient outcomes. We have developed a dynamic multidisciplinary diabetes team which provides leadership through innovative approaches by incorporating digital strategies – such as telemedicine, information management systems, electronic downloads and social media to improve team communications, patient education, patient engagement and health outcomes.

Our initiatives have led us to win several national awards such as: Commended Finalist Diabetes Team of the Year award in the Diabetes Quality in Care 2017; Winner of the Diabetes Quality in Care in 2015 for Best Dietary Management; Highly Commended Runner-Up Diabetes Team of the Year national British Medical Journal Awards 2015; Best Diabetes Service Performer for North West Paediatric Diabetes Peer Review Quality Assessment 2014; and the 2015 Pride Award Team of the Year at the Trust.

**Conclusions**

On its own, technology is not the answer; there are many barriers in its way and it is too easy to fall at the first hurdle. Successful organisations will be those that show the clinical leadership and determination to drive change, and develop compelling business cases that prove how digital technology can improve patient care.

The achievements of our service act as a reminder that digital strategies can be tools to drive efficiencies and these can play a central role in improving outcomes in diabetes services. These digital initiatives require a buy-in and investments from organisations and it has to be clinically led and championed.

Our team had implemented over the past years a systematic integrated approach, combining information management systems, telemedicine, patient monitoring and social media using Facebook and Whatsapp to help restructure our paediatric diabetes service, and we believe this approach has played a major part in improving patient health outcomes, delivery of education and patient engagement.

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Our patients are always at the core of our service and I am humbled on a daily basis by the experience of working with children and young people and their families living with diabetes. I thank them for their support and the continued collaboration to work together via the ‘The Lancelots’ Southport, Formby & Ormskirk Children’s Diabetic Club and parent support group, which is affiliated to Diabetes UK.

**Declaration of interests**

There are no conflicts of interest declared.

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