

The Type 1 Kidz project. Part Two: Introducing a simple telehealth system

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Article points

1. Two simple telehealth systems, in which text messages are sent automatically to children who sign up to them, have been developed.
2. The motivational system focuses on supporting young people who are struggling with the management of their diabetes, while the reminder system helps them to remember to test their blood glucose and take their insulin.
3. Simple telehealth systems are a useful tool that can make a big difference to some (but not all) young people with type 1 diabetes.

Key words

- Children and young people
- Florence
- Telehealth
- Text messaging
- Type 1 diabetes
- Type 1 Kidz

Authors

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In this article, the authors describe the process of developing and implementing a simple telehealth system to assist children and young people in self-managing their diabetes. Through collaboration with young people participating in the Type 1 Kidz project, two pathways were identified: one for motivation and the other for reminders. The pathways are tailored to each user, allowing them to choose the content and timing of the text messages that are automatically sent out. Feedback suggests that the pathways have been for the most part beneficial, helping users to feel supported, more confident and less anxious, and improving measures of glycaemic control. However, it also suggests that the system is not for everyone, and that consultation with the users is important.

Telehealth is the remote exchange of data between patients at home and their clinical team to assist in diagnosis and monitoring. It is typically used to support people with long-term conditions. A simple telehealth system, known as Florence (Flo), is a basic text-messaging system that allows messages to be exchanged between patients and healthcare professionals in a variety of ways. The system has no cost to the patient. Once a pathway is developed, it is processed into the Florence system and text messages are automatically sent to people who have signed up to that pathway, and clinical teams can view the patients' responses.

Through discussions with children and young people participating in the Type 1 Kidz project (Mulhearn and Brown, 2017; described on page 28 of this journal), paediatric diabetes teams in the north east of England became interested in exploring whether young people with type 1 diabetes would want to use Flo, and how they would want to use it. In this article, we describe the development of two simple telehealth pathways and their effects on outcomes.

Development

A paediatric diabetes nurse educator at The Great North Children's Hospital, Kerry Camara, met with the Type 1 Kidz Young People's Steering Group on a number of occasions to identify the times they felt that receiving Flo text messages would be most helpful to them. The group identified holidays, exams and periods of burn-out and general stress as potentially helpful occasions, and general reminder messages were also deemed to be useful. As a result, two pathways were developed: one for motivation and one to send reminders.

Pathway 1: Motivation

The Young People's Steering Group thought that stress and burn-out should be addressed first and started to develop a 6-week motivational pathway. This focused on supporting young people who were identified to be struggling with the management of their diabetes by encouraging them to look at the positives, make small goals and changes, and seek support from those around them, including the diabetes team.

The young people worked with the diabetes educator to design each text message and decided on the times and days each text message should be sent; this was generally every two or three days, at 4 pm. The clinical team were also involved in these discussions.

Each young person piloted the pathway and filled out an evaluation form and diary each time they received a text message. The general feedback suggested that Flo was helpful, with appropriate amounts of texts and timing; however, the messages were not always relevant to every young person. It was thus proposed that the messages should be interactive to make them more relevant to each person and to allow the recipients to engage with the texts and actions more.

The pathway was adapted several times, based on feedback, according to the process in *Figure 1*. Now, many of the messages are interactive; examples can be seen in *Figure 2*. The pathway has also been shared across the north east.

Pathway 2: Reminders

Young people often reported having poor glycaemic control because they forgot to test their blood glucose and take their insulin. In response to this, a reminder pathway was developed, in which young people are offered individualised reminder text messages to be sent at prespecified times of the day/week. The young people decide what they would like the text message to say and when they would like it to be sent. The reminder pathway is offered to young people in clinic who may forget to take their insulin or test their blood for a variety of reasons. Examples of young people who have benefited from the pathway are those who tend to have a chaotic lifestyle and have little routine, those who find it hard to either inject while at school or on weekends, and those who want to be reminded to test their blood and take insulin before going to bed late at weekends.

Example texts include “Remember your Glargine! [Long-acting insulin]”, sent at 4.30 pm every day, and “Have you remembered to test your blood? :-)”, sent at 10 am on weekends.

Using the motivational and reminder pathways

Both pathways are offered to young people when they attend clinics and other educational events.

A booklet was developed to inform young people about Florence and offer them the two pathways. If young people opt in to one or both pathways, they are signed up whilst at clinic.

Impact of the pathways

At the time of writing, 40 young people in Newcastle have used or are currently using the pathways, including 13 on the motivational and 27 on the reminder pathway. Preliminary findings have been evaluated by Joanne Levey (Project Manager of Telehealth at Newcastle upon Tyne Hospitals NHS Foundation Trust), although it is worth noting that the samples used for the data were relatively small.

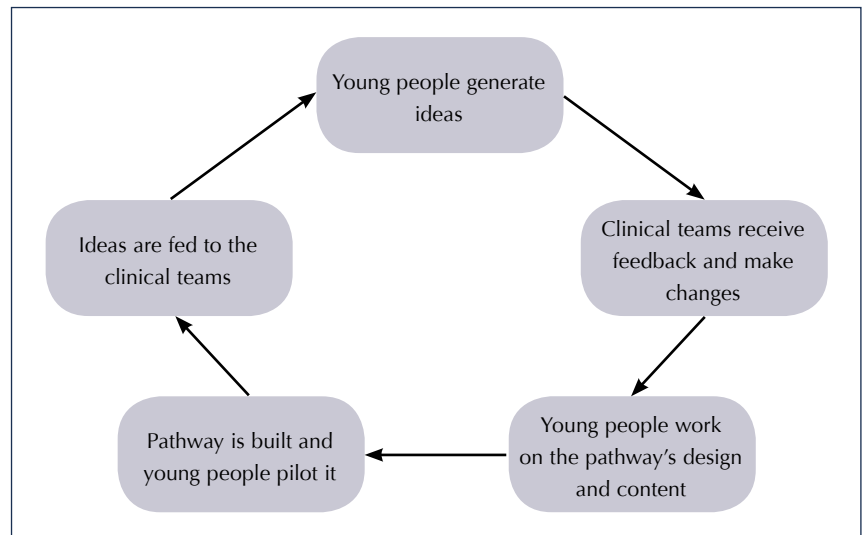


Figure 1. Process for developing the simple telehealth pathways.

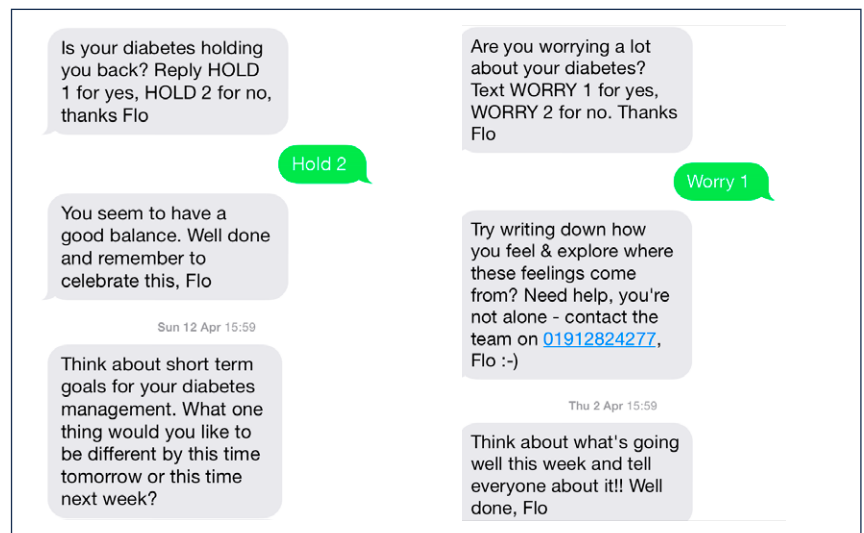


Figure 2. Examples of text messages sent from the motivational pathway.

Motivational pathway

The initial findings looking at the motivational pathway appear encouraging. Of the 10 young people evaluated, four had more blood glucose readings in the target range after using Flo, and this was associated with an improvement in HbA_{1c} levels in 45% of the sample (Figure 3). In addition, 30% increased the number of times they tested their blood per day and 30% had a reduction in average blood glucose levels.

Figure 4 demonstrates how seven young people felt about their diabetes after completing the 6-week motivational pathway, using a scoring system ranging from 0–5. The average ratings given for each statement indicated a positive

impact of the system on all aspects of how the young people were feeling, including feeling less worried/anxious, more confident, more motivated to make changes, better supported, less alone and with an improved mood. When asked whether these improvements were a result of Florence, the young people gave an average score of 3 out of 5.

Reminder pathway

One particular case study from 2015, shown in Box 1, shows how the reminder pathway influenced a 14-year-old girl to reduce her high HbA_{1c} by 34 mmol/mol (3.1%) in under 2 months, simply by reminding her to take her long-acting insulin.

Young people who were using the reminder pathway were asked a series of questions to see how they felt regarding their diabetes management and the impact of Florence. As demonstrated in Figure 5, 67% agreed that without Flo they would forget to test their blood or take their insulin, 50% agreed that they felt more confident in managing their diabetes and 67% felt more supported in managing their diabetes. However, only 33% agreed that using Flo helped them to self-manage their diabetes. Overall, 50% would recommend the system to a friend.

Looking at these data raised several questions. It was clear that a majority of young people thought that Florence helped them and they felt more confident and better supported; however, only 33% felt that the reminder pathway helped them to self-manage their diabetes and only half would have

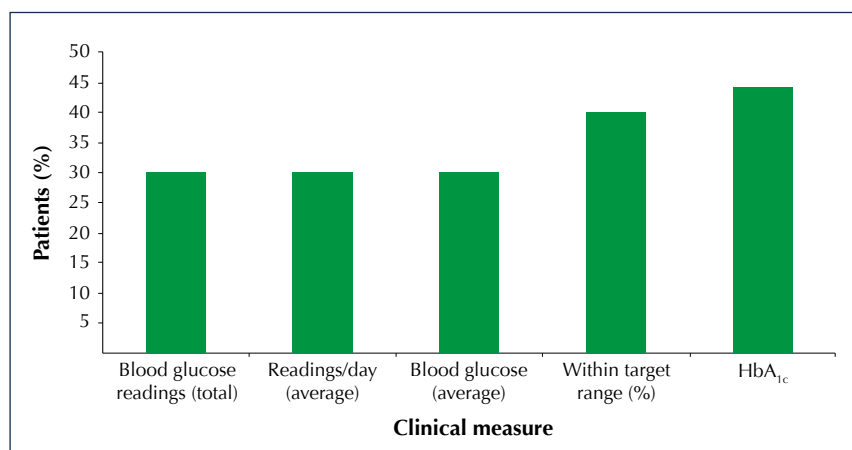


Figure 3. Percentage of young people with improved clinical measures after using the Florence motivational pathway. Ten young people were evaluated for each measure, except for HbA_{1c} for which there were nine.

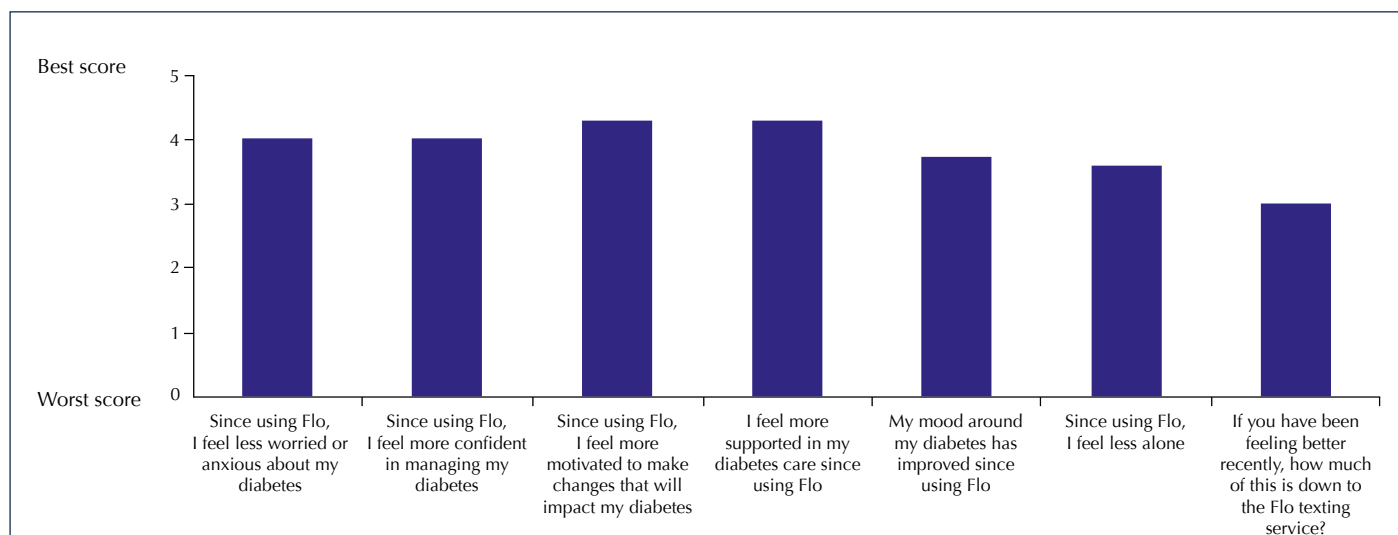


Figure 4. Mean scores on how young people (n=7) felt about their diabetes after completing the 6-week motivational pathway.

recommended it to a friend. Why were these two ratings so low? Discussing these figures with them demonstrated that, while for some young people Flo was extremely helpful and had a big impact, it was not right for everyone. Different young people also interpreted the questions in different ways. Some of the 67% who said the pathway did not help them to self-manage felt that it made them rely on something else, and thus they were not remembering on their own. Some of the 50% who would not recommend Flo to a friend felt that their friends would not need help as they would remember themselves, while others simply found getting regular text messages about their diabetes to be “annoying”.

When asked more general questions on how they felt about diabetes after using the reminder pathway, the responses were as follows:

- 86% agreed they felt less worried or anxious about their diabetes.
- 86% agreed that Flo improved their confidence in managing their diabetes.
- 86% agreed that Flo motivated them to make changes that would impact on their diabetes management.
- 86% felt more supported in their diabetes care.
- 57% felt less alone.
- 43% said their mood about diabetes improved.

Conclusions

Offering this simple telehealth service to young people with type 1 diabetes has for the most part proved beneficial, not only by helping them to feel supported, more confident and less anxious, but also in terms of improving glycaemic control, with positive contributions towards reducing HbA_{1c}, testing more regularly and having more blood glucose levels in the target range.

What became apparent, however, was that the Florence system is not right for every young person. Although young people were involved in every step of the development of Florence, in reality, when messages were being sent on the two pathways, some young people failed to engage. When this happened, the team would continue to discuss with the individual young people to find out why they failed to respond or what went wrong for them. Young people continue to discuss the ongoing use of Florence in the Type 1 Kidz Steering Group and regular meetings, and this continuous dialogue

Box 1. Case study of the reminder pathway.

- A 14-year-old girl who has a chaotic lifestyle. Her HbA_{1c} levels had been high for several years and she would not respond to telephone calls or home visits. Most days she would return from school, eat and go out with her friends without taking short- or long-acting insulin.
- 3rd March: She attended clinic with an HbA_{1c} of 121 mmol/mol (13.2%). She agreed to sign up to the Florence reminder pathway, receiving a text message every day at 5 pm saying, “It’s time for Glargine :-)”.
- 27th March: She contacted the hospital to ask to receive the messages at 4.30 pm.
- 24th April: She attended clinic with an improved HbA_{1c} of 87 mmol/mol (10.1%).

ensures that support is offered to encourage all young people to see the full benefits of Florence.

Although not appropriate for everyone, Florence is a very useful tool that can be offered and can make a big difference to some young people. We believe that using telehealth in conjunction with other initiatives (e.g. attendance at monthly support groups, high HbA_{1c} pathways and lower HbA_{1c} targets) would have the biggest impact. ■

About Florence

Florence is a text messaging system that sends patients reminders and health tips tailored to their individual needs. The system was developed by a team at the former Stoke-on-Trent Primary Care Trust, in conjunction with telecommunications partner Mediaburst Ltd, to encourage people to stick to their treatment plans, particularly for long-term conditions such as diabetes or hypertension. More information can be found at: www.getflorence.co.uk

Mulhearn H, Brown C (2017) The Type 1 Kidz project. Part 1: Engaging children and young people with type 1 diabetes in their own health and wellbeing. *Journal of Diabetes Nursing* 21: 28–31

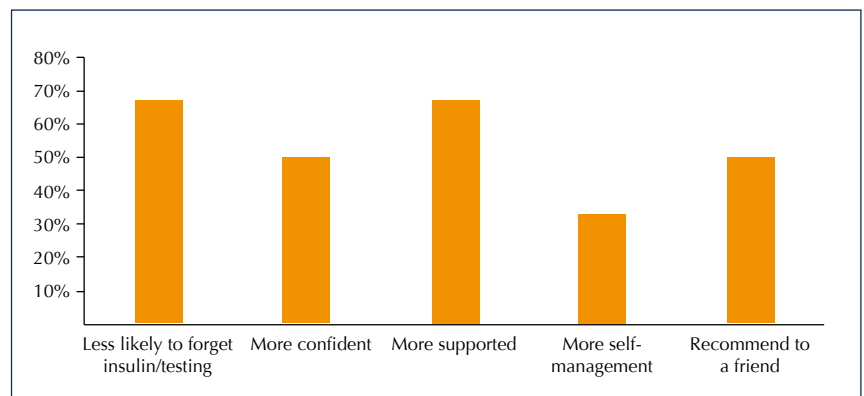


Figure 5. How young people (n=7) felt after using the reminder pathway. The graph represents the proportion who agreed with each statement.