

Access to Psychological Support and Transition Improvement for Diabetic Teenagers; A collaboration between Tellmi and NHS Somerset

Children and young people with diabetes are at high risk of anxiety and depression, and it is important that they have early access to mental health professionals when they need it (Nice, 2016).

This pilot was designed to provide psychological support to 450 young people aged 11-25 with a diabetes diagnosis in Somerset via the Tellmi app. Tellmi is a 100% pre-moderated, anonymous, age-banded, peer support app which includes an extensive directory of National and local diabetes services and psychoeducation. Tellmi (ORCHA rating 84%) enables young people with diabetes to access support anytime, anywhere. Young people with diabetes can connect anonymously to other users experiencing similar problems, reducing feelings of isolation, share personal stories and connect to an extensive range of tailored, local support services via an NHS portal. The National Voices report 'Peer Support: What is it and Does it Work?' found peer support led to significant improvements for people with long-term physical and mental health conditions including increased knowledge, skills, confidence and motivation to manage self-care, improved physical functioning, quality of life and increased social functioning and perceived support.

Midpoint Project Review

The Team.

The team was coordinated by Mel Grenville, Commissioning Project Support Officer at NHS Somerset, and included paediatric diabetes clinicians and psychologists from Somerset Foundation Trust together with Dr Suzi Godson, CO-CEO of Tellmi and Tellmi Service Delivery Manager Billie Kerr. The team set up a working group which met every Friday morning to ensure that we made progress. Not everyone made every meeting but the fact that it was always in the calendar meant that deadlines were met and the project was kept on track.

Directory Updates

Adaptations to the Tellmi app included adding 32 diabetes specific resources and services to the Tellmi directory. From the BERTIE diabetes education programme to Diabetes UK local support groups to dealing with diabetes during Ramadan and videos about recovering from diabulimia, the Tellmi Directory is now a junction box to all sorts of amazing resources. We

even liaised with Professor Partha Kar and Mayank Patel and got permission to integrate their four part Type 1 Diabetes comic series into the app.

Survey Development

The team developed a survey to generate more granular insights into the specific issues that affect young people with diabetes. The questions on the survey were agreed on by the working group which was led by clinical psychologist Anna Disney and tested and approved by two young people with diabetes.

Engagement Strategy.

Once the survey was embedded into the app and the Directory had been updated with resources, engagement began in earnest. Posters and flyers were designed by a young person who has Type 1 diabetes and the images reflect just how complex living with diabetes can be. Printed and digital marketing materials were then distributed by clinicians and diabetes nurses in hospitals across Somerset in order to encourage young people with diabetes to download the Tellmi app and do the survey.

NHS Somerset tellmi

Are you aged 11+ and living with diabetes? Tellmi is a safe, anonymous app where you can talk about anything with people of your own age. We are doing a study to understand how we can support young people with diabetes more effectively. We'd love you to take part.

- Scan the QR code, download Tellmi and register. Don't forget to validate.
- Fill in the survey to help us to help you.
- Leave your email address.
- If we select you for an interview, we'll send you a £25 Amazon voucher :)

FREE SAFE ANONYMOUS
Are you aged 11+? Join our diabetes study and use your experience to help other young people with diabetes.

Launch

The pilot was finally launched in late October 2023 and once the engagement strategy began in earnest, there was a correspondent increase in posts about diabetes within the Tellmi app.

“I have type 1 diabetes. I also have a lot anxiety and have previously had frequent panic attacks about my bloods, specifically low blood sugar. I spent 2 years starting to overcome this myself and 1 year with a paediatric psychologist. since this has ended I've been getting worse, I'm scared that I'm never going to get better”

Data Analysis

We were aware that young people with diabetes from Somerset might use the app but might not necessarily talk about diabetes, so we conducted data analysis using a range of related search terms.

Diabetes, Diabetic, Type 1, T1, T1D, pump, Type 2, insulin, injections, pump, HBA1c, BM, blood sugar, blood count, CGM, Dexcom, Medtronic, Omnipod, Tresiba, NovoRapid, Fiasp, keytones, glucose, high, low, hypo, hyper

These terms revealed posts that would not have been identified otherwise.

“had a crap crap Christmas. collapsed at a Christmas Eve party, was held down and force fed sugar to get my blood sugar up (hello trauma reactions) then vomited nonstop into the flowerbeds, taken in an ambulance to hospital. sent back home vomiting, fever, pain, sore throat. blood count super high. whole family sick. did I mention it was crap?”

Targets

Although the Tellmi Diabetes project was theoretically available to all 450 young people aged 11-25 with diabetes living in Somerset, it was recognised that only a percentage of them would be reached by the clinical team, and of those who downloaded the app, an even smaller percentage would complete the survey.

A total of 191 new users from Somerset signed up to the Tellmi app between October and January. Of those, 7 made posts or replies that talked specifically about diabetes. The Tellmi diabetes survey was viewed 146 times by 103 unique users.

The team estimated that getting around 20 completed surveys would be a successful outcome for this project. By the end of December, we had exceeded this target; 28 young people with diabetes from Somerset commenced the survey, and 24 completed it; 19 left their email address and volunteered to be interviewed for the case studies.

Case Studies

Through the survey, we recruited volunteers to take part in interviews. These interviews provided much more granular insights into the issues that young people with diabetes struggle with. Six interviews with young people aged 13-19 were conducted between October 2023 and January 2024. Parental consent was sought for anyone under 16 and two interviews were conducted with parents present. All but one of the young people we spoke to had struggled with their mental health, and shockingly, two of the young people who took part in the interviews had tried to take their own lives. A total of ten interviews will be conducted before the end of the project and the insights will form part of a qualitative study which will be analysed and written up by the end of the project.

“The diabetes chips away at everything. Because of the way it’s affected my life, the world’s got smaller and smaller, you know, you don’t want to go out because you might need to use a toilet, might need to use it a lot, and then you don’t want to have injections when you’re out in public, so that’s my view and I think the anxiety and all that sort of stuff, I don’t know, the diabetes just like adds onto it.”

What we have learned so far.

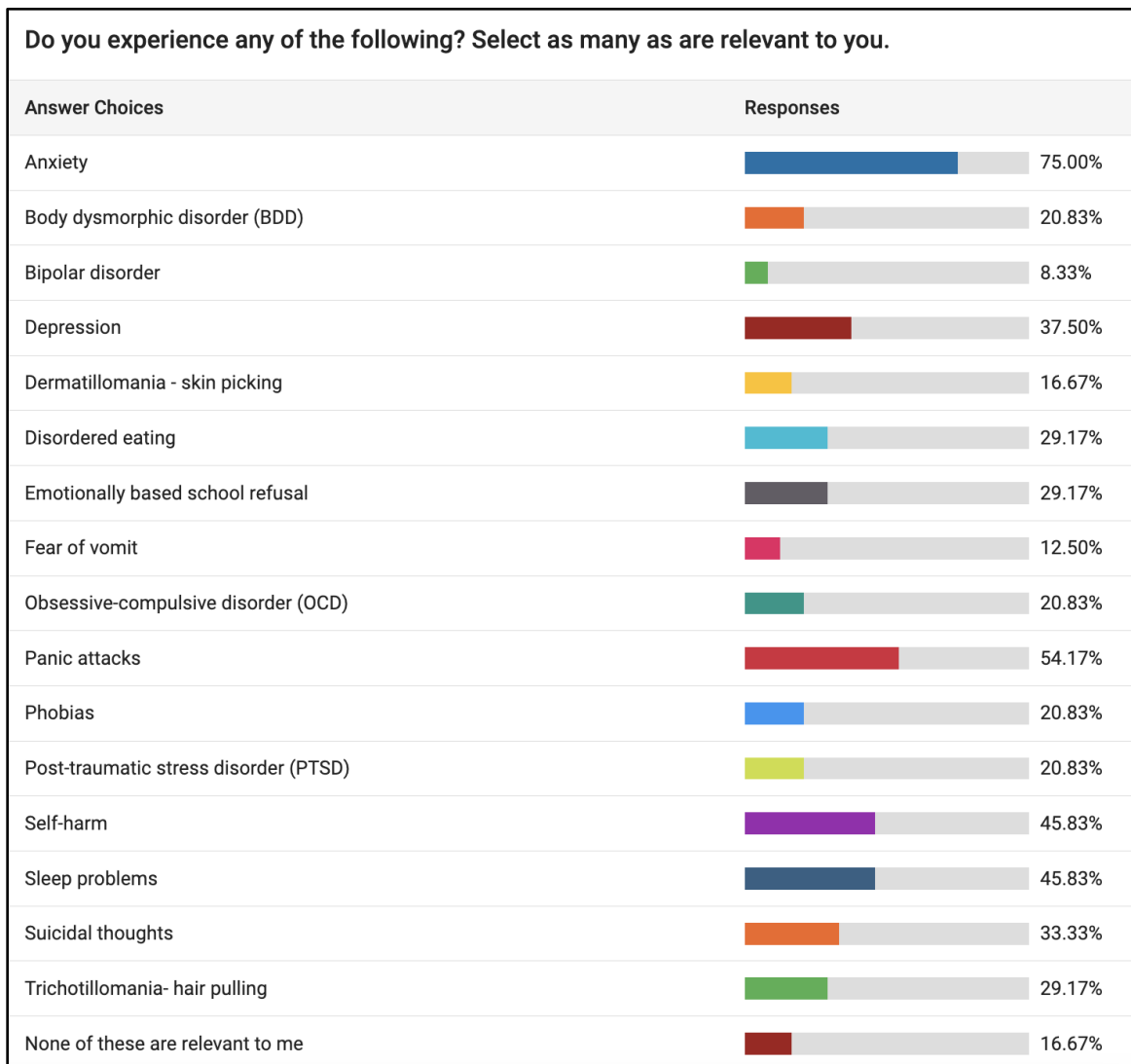
The survey sample is currently very small (N=24) so we need to be extremely careful about interpreting these results, however what we can see so far is that young people with type 1 diabetes experience significant difficulties with their mental health. Qualitative data from the survey provides detailed insights into the issues that these young people are struggling with.

“I have been diagnosed with depression, anxiety and social anxiety. I have appointments with cahms and I have a youth worker to help with this but I feel like it doesn’t help. I struggle a lot with my mental health and I have done for about 6 years now. It’s only recently I’ve been given help but it doesn’t help.”

“Diabetes used to be a big contributing factor to negative thoughts I had about myself. From the ages of 11-15 I self harmed using my injection needles, I always used to wonder why I couldn’t just be like my brothers or peers who didn’t have diabetes – no one actually led me to feel this way it was more that I never accepted the fact I had diabetes despite being diagnosed when I was 4.

Diabetes also played a big part in my trouble with eating. <-> I feel there should be more support around eating with diabetes rather than the cold hard facts of "this is how much you should eat," "this is what you should eat," and "memorise exactly how many carbs are in every food you eat."

Quantitative data from the survey shows that young people with diabetes experience high levels of anxiety (75%), panic attacks (54.17%), self-harm (45.83%), sleep problems (45.83%). One third of respondents experienced suicidal thoughts. These findings are corroborated by early insights from the qualitative interviews. Two of the first five interview participants had made an attempt on their life.



Only 41.67% of the respondents had told their clinicians about the way they were feeling but 58.33% had tried to get support for their mental health .

Have you ever told your diabetes clinician that your diabetes affects how you feel?	
Answer Choices	Responses
Yes	 41.67%
No	 58.33%

Have you ever tried to get support for your mental health?	
Answer Choices	Responses
Yes	 58.33%
No	 33.33%
I'm not sure how to	 8.33%

The impact of fluctuating blood sugar on mental health

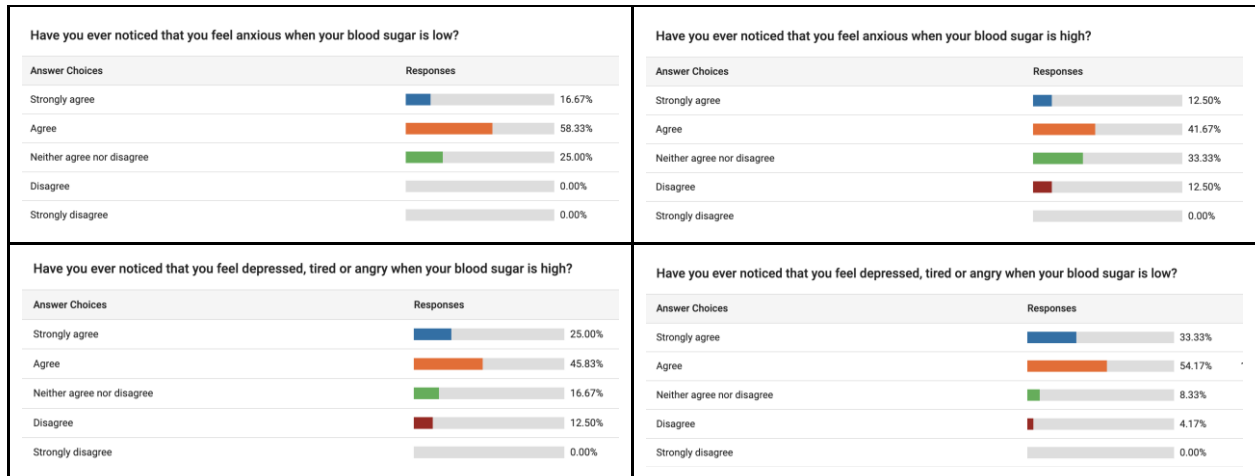
Low blood sugar and anxiety are linked, but young people with diabetes may also experience anxiety about the burden of managing the condition - ‘diabetes distress’. The results of this survey are interesting because they directly link changes in blood sugar to changes in emotional wellbeing.

Low Blood Sugar

- 75.03% agree (58.33%) or strongly agree (16.7%) that they feel anxious when their blood sugar is low.
- 87.5% agree (54.17%) or strongly agree (33.33%) that they feel angry, tired or depressed when their blood sugar is low.

High Blood Sugar

- 54.17% agree (41.67%) or strongly agree (12.5%) that they feel anxious when their blood sugar is high.
- 70.83% agree (45.83%) or strongly agree (25%) that they feel angry, tired or depressed when their blood sugar is high.



Thoughts on Tellmi

The number of young people we have reached is small, however the response so far is largely positive.

"I think the fact that its anonymous really helps because its not about who people are its about being able to get support from other people who know what your going through and knowing that your not the only one who struggles with things like diabetes"

"It made me feel less alone and finally understood"

"Good, I could see everyones posts about their own unique experiences with it."

Some young people don't think that they will engage with the app but they have downloaded Tellmi and they know that it is there for them if they ever need support.

"I haven't started to talk about that and im not sure if i will."

Problems we have encountered

Because the number of young people with diabetes in Somerset is so small, the team agreed that the best way to recruit young people to the app and to the survey was to get clinicians, nurses and youth workers to share the information directly with young people. One positive that has emerged from this strategy is that young people found it beneficial to have someone show them how the app works and demonstrate how to use the directory and find the survey. The downside of this strategy is that NHS workers are all time poor and this project was probably not a priority for them so the numbers we have reached seem very small. We have

also failed to make the same level of connection with young people being seen in adult clinics. Only one person between the age of 21 and 25 filled in the survey.

What could others learn from your experience of working with a range of stakeholders?

This project is a really good example of how collaboration between clinicians and health tech can quickly and effectively gather new insights into complex problems. Because Tellmi is an anonymous app we have been able to gather information that might not necessarily be disclosed in face to face meetings with clinicians.

This project also shows the need for better collaboration between mental and physical health support for young people. Currently, psychologists working within paediatric diabetes clinics are only able to support young people with distress that relates directly to their diabetes. Young people who present with more serious problems such as self-harm are referred to CAMHS where they may have to wait to get support.

“I got referred to CAMHS by my diabetes clinician but I got declined about three times. I was waiting to be seen for just over a year because apparently I wasn't high risk enough.”

What are the next steps for your project over the coming months?

Although there is a lot of information on diabetes on websites such as Diabetes UK, most of it is addressed to adults or parents. When it comes to areas like education there is virtually nothing that speaks directly to young people.

Over the next few months we plan to develop a diabetes module which addresses knowledge gaps for young people with diabetes. The module will include information on mental health, sexual health and eating disorders. The articles will be written with young people with diabetes and approved by NHS clinicians.

The project has also confirmed the importance of school support for young people with diabetes. As a result of the findings from this project we are now planning a National campaign to support the rights of young people with diabetes in school.

How can the community get involved in your project?

The number of young people with diabetes in Somerset is relatively small and we feel that the data we are gathering through the survey would have more value if the sample size was bigger.

We would like some support from other clinics to get the survey out to more young people with type 1 diabetes around the country. This would enable us to compare findings by region and would give us more granular insight into the relationship between mental health issues and fluctuating blood sugars. We can share our engagement materials digitally or send printed posters and flyers to anyone who is willing to help.

Contact: mel.grenville@nhs.net or suzi@telmi.help