

STORIES OF CHANGE

TOGETHER TYPE 1

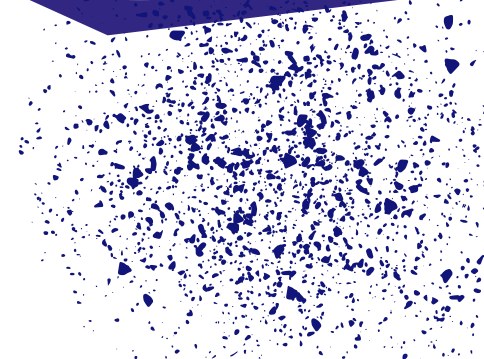
Sharing the impact
of Together Type 1 on
young people living
with type 1 diabetes



In partnership

DIABETES UK
KNOW DIABETES. FIGHT DIABETES.

Steve Morgan
FOUNDATION



I am delighted to introduce this selection of inspiring stories from the first year of **Together Type 1** – the community for young people living with type 1 diabetes.

These exciting stories show how Together Type 1 is creating dynamic change at a strategic level – engaging healthcare systems and teams, and political decision makers – and at a personal level. Young people are telling us how this community is transforming their lives and making life with type 1 diabetes better for them.

We have deliberately chosen the **Significant Stories of Change** evaluation method to capture the rich depth of impact that Together Type 1 is having. As we look forward to future years supporting this

community, we hope to see many more stories like this – changing diabetes care, social attitudes, political priorities and young people's lives.

I really appreciate you taking the time to read this report. I hope you find it encouraging and inspiring. Thank you for all your support for the Together Type 1 community and Diabetes UK.

Finally, none of this work would be possible without the incredible generosity of the **Steve Morgan Foundation**. We thank them for their commitment in funding Together Type 1 and for transforming lives.

Colette Marshall, CEO, Diabetes UK



Together Type 1 is aimed at 11 to 25 year olds who are living with Type 1 diabetes. With a strong youth empowerment approach, the programme puts young people in the driving seat for change.

Funded by the Steve Morgan Foundation and run by Diabetes UK, Together Type 1 is a flexible programme, where young people can select activities that suit their needs and preferences, with the freedom to change their activities over time.

For example, some young people will join primarily to meet and connect with other young people living with type 1 and may participate in the fun activities. Others may want to develop their leadership skills by becoming a Young Leader, which requires a level of training and a greater time commitment.



Report overview

This report illustrates the positive changes that the programme has made in the first year of delivery using the Significant Stories of Change approach.

What are Significant Stories of Change?

Stories of Change complements other evaluation methods used to explore and understand why and how change happens. The stories are like case studies but always focus on change. The stories can be about a change to an individual, a group of people, an organisation, institution, or network.

Why is Together Type 1 using Significant Stories of Change?

Together Type 1 has chosen to use Stories of Change to assess impact for its participatory and reflective nature. Stories of Change complements other evaluation methods and key performance indicators.

Using Significant Stories of Change aligns well with the Together Type 1's youth empowerment approach. Those people closest to the 'action' generate, document, and share stories of change that matter to them. By doing so, they take an active role in critically reflecting on the work.



Step 1

The programme team (UK wide) came together in a workshop that lasted one and a half days to generate and share their stories.

They documented their stories on poster sized templates so they could be displayed around the room. In the workshop they shared and discussed their stories, learning and reflecting on the difference they have made, from their perspective.

Within this workshop the programme team from each region and nation decided on one story that was significant to them. The stories of change were specific to the changes they had seen in young people participating in the programme and their influence on the health care system. They told these stories to one of the Young Leaders participating in the programme who interviewed them on film.

33 stories were generated overall and 7 were chosen to illustrate change (1 from each team working in the nations and regions).

Step 2

A few weeks later, a 'senior stakeholder group' met to look at the themes and a selection of stories. This group made recommendations on how to develop our themes and stories into a more compelling narrative, bringing our stories to life to demonstrate impact.

Step 3

The final step was to interview young people and health care professionals to gain their perspective on change and what that meant to them.

This report is the culmination of this 3-step process and an illustration of the changes we are seeing for young people and the health care sector.



PART 1:

Story 1: Empowered campaigning in Northern Ireland

Background

Young Leaders in Northern Ireland communicated an important message to politicians in Northern Ireland – that living with type 1 can negatively impact mental health and peer support is an effective way to help improve poor mental health.

Politicians listened to and spoke to the Young Leaders at an All-Party Group Meeting (held online), followed by an in-person creative photography exhibition.



Story 1 continued

Thoughts from a young leader

Lea is 22 years old, lives in Belfast and was one of three Young Leaders involved. She reflected that as a young person with a passion for politics this was an opportunity for her, and her peers, to be heard and to directly influence change.



I'm a bit of a political nerd anyway so to have the opportunity to talk with politicians about something I feel passionate about was great...and to be able to set out our reality to politicians, well that really mattered to us.

Lea, Young Leader

PART 1:

The changes

From Lea's perspective, having politicians listen and engage with young people living with type 1 was significant and positive.



Our local politicians can change things and have power over changes. It felt really positive that we were able to speak to them about our reality.

Lea, Young Leader

From a politician's perspective, just listening to young people's lived experience helps shape future policy making.



I believe there needs to be better awareness of the condition and the needs of patients, but also cross departmental work alongside community and voluntary organisations...

Deborah Erskine (Member of the Legislative Assembly)

Lea has now joined the Northern Ireland Advisory Council (NIAC), representing the voice of young people. She will continue to influence future policies that benefit young people living with type 1.

PART 1:

Story 2: Changes to clinical environments in the Midlands

Background

Young Leaders in the Midlands used their knowledge and creativity to influence over 100 health care professionals at a clinical network meeting.

Delivering an artistic presentation full of engaging illustrations, they talked about what matters to young people and how clinics can remove some of the barriers to promote better participation, especially as young people transition into adult services.



The illustrations were powerful, and they have an impact in themselves. I think the empty chair one for me was brilliant, and spoke to the importance of co-designing with young people.

Heather, West Mids CYP Diabetes Network.



Illustration by Katie Lamb, Young Leader

Story 2 continued

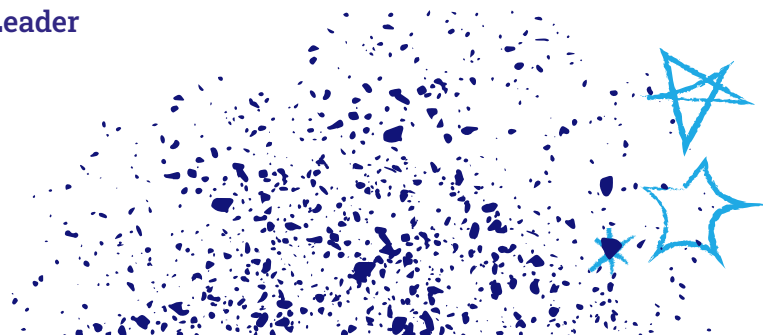
Thoughts from a young leader

Katie, 22, lives in the Midlands, and was one of three Young Leaders to present at the meeting. A great believer and specialist in using art for advocacy herself, she talked about the importance of communicating the pressures that many young people experience as they grow older, and the fear of judgement.



We might have worse outcomes as we get older where our blood sugars are more difficult to manage. And the fear of being judged, for letting things slip, for not being as good as I was as a child, all these pressures really build up. It was good to tell health care professionals this.

Katie, Young Leader



PART 1:

The changes

After hearing from the Young Leaders clinical teams are delivering a range of changes across their clinics. These include making information materials clearer so they are more appealing and engaging to young people; writing youth workers into business plans; and co-designing peer support groups and pathway transition plans with young people that use their services.



I think a lot of what we heard to an extent we knew, but being able to say this came direct from young people just has more impact, it's so valuable. We learned how we can start communicating with young people better, and some of the anxieties they may have...it's more like young people are influencing behavioural change within the NHS.

Heather, NHS Foundation Trust, Birmingham

PART 1:

Story 3: Spotlight on Service Improvement in London

Background

Barts NHS Trust support young people with diabetes to transition to adult services. The Together Type 1 Young Leaders, in partnership with Spotlight (youth centre in East London), talked to the psychology team in Barts about their experience, giving insight into what they need from a service and the main factors that negatively impact their mental health.



Story 3 continued

Thoughts from a young leader

Rayaan is 19 years old and is from London. She talked to the psychology team at Barts NHS Trust about how her life has improved since she transitioned to the insulin pump technology. She explained how using the pump gives her more freedom and how she is better able to manage her diabetes.



So, I remember when I used to struggle a lot mentally, I was really bad... but then when I got the pump, well it was a life changer. I'm having less hypos during the night and my blood sugars are more in range and then generally I'm just living better.

Rayaan, Young Leader

Rayaan felt it was worthwhile talking to the psychology team to influence change as they can influence other young people to move to the pump, but she also valued meeting other young people living with type 1.



PART 1:

The changes



It was nice talking to other young people. I remember thinking, I'm not the only one going through this. There were people who had almost the exact same experience as me and I was surprised... it's like...knowing that I'm not alone.

Rayaan, Young Leader



Rayaan's visit to the psychology group made me further understand the power of peer support in inspiring and motivating young adults to make positive changes...As a result, I am now even more eager to involve young adults in designing, developing and facilitating certain aspects of their care

Dr Claudia Alonso Soriano,
Clinical Psychologist for the Young Adults Diabetes Service

PART 1:

Story 4: Speaking at the Senedd in Wales

Background

Young Leaders in Wales spoke at the Senedd (Welsh Parliament) about the challenges they experience within health care. The event was well attended, and Young Leaders felt they were heard by those attending and were able to tell their personal stories about what matters to them.



Story 4 continued

Thoughts from a young leader

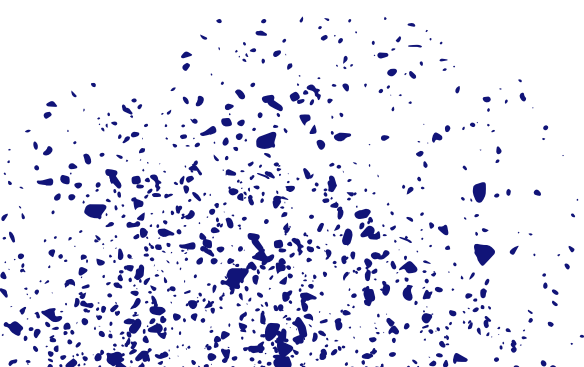
Gareth, 23 years old, lives in Wales and was one of the Young Leaders who spoke. He talked about the challenges he faced in getting hospital appointments during and after the Covid-19 pandemic.

Although he felt nervous about speaking, he overcame his nerves and delivered a powerful talk. Gareth felt his audience listened to his concerns, as some health care professionals and a politician approached him to talk about his experience after his talk.



So that boosted my confidence because it's not every day I get to speak to a politician.

Gareth, Young Leader



PART 1:

The changes

Gareth is now in more regular contact with his clinical team and has put a plan in place for a better future with diabetes. His confidence has grown because of taking part in Together Type 1, which has influenced other parts of this life.



100% this has helped my confidence. I wouldn't openly talk about my diabetes before...but nowadays I'll take the time to sit down and talk to them about it.

Gareth reflects that it is not just public speaking that has improved his confidence but also being part of a wider peer support group has played a significant role.



It's just being in a group of people who have diabetes too, going through the same things as me. It's had a massive impact in a short space of time and now I'm able to be a role model and support other younger people.

Gareth, Young Leader

PART 2:

Story 5: Connections and empowerment in the Southwest

Background

Calum is now 18 years old and lives in Cornwall. He was 17 years old when he joined Together Type 1, motivated by the opportunity to raise awareness about type 1 and address the stigma associated with diabetes.

He was diagnosed in 2020 and reflected on how isolating and stigmatising the experience can be.



I went back to school after being off for quite a few months. Quite a lot of people had no idea really what type 1 diabetes was. There's quite a lot of stigma around it, like, oh, it's just because you're not eating the right things...

Calum, Young Leader.



Story 5 continued

Thoughts from a young leader

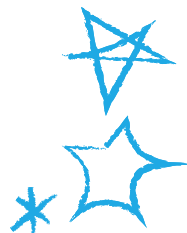
Since joining the programme Calum has valued connecting with other young people and listening to their stories.



With me, it's kind of empowered me... talking to other people and hearing their experiences and how they've got through it, especially people who have lived with it for so long and seeing where they are now, it's like, I can do that too.

Calum, Young Leader

As his confidence has grown Calum is positively influencing another young person through mentoring. He feels he is making a positive difference, through supporting his mentee to gradually open up about his diabetes to those around him.



PART 2:

The changes

Calum believes Together Type 1 has given him more confidence to share his story more widely. He has run sessions at his college to raise awareness and address stigma and truly believes in the power and impact of mentoring and peer support.



I mentor one person, but that person could then go on to help someone else...over time maybe we can create bigger changes to society as a whole.

Calum, Young Leader

PART 2:

Story 6: Enjoying school again in The North of England

Background

Zach is 11 years old, lives in the North of England (Manchester) and lives with type 1 diabetes. He is sociable and loves playing football.

Zach was out of school for some time as his mom, Bernadette, felt he was not getting the understanding he needed from his teacher, particularly when the alarms on his blood glucose monitor went off unpredictably.



It got to a point that was quite dangerous. So he had his breakfast at the childminders, and he'd actually given himself extra insulin and not told anybody because he didn't want to be beeping high in the mornings. And then he just crashed low.

Bernadette, Zach's mother



Story 6 continued

Thoughts from a family on change

Bernadette contacted Diabetes UK for support. When Zach returned to school he had the support of Together Type 1's regional Youth Worker, Josh, who also lives with type 1.

Josh visited Zach in school, and they spent the morning getting to know each other. They generally chatted and did some activities together, like playing Lego.

Zach and his mom said that having Josh with him on the first day back at school meant he did not feel so alone. Zach said,



It was really, really good! because Josh was there and we played some games.

Zach is now much happier at school and takes every opportunity to play football with his friends. Bernadette reflects that having support from Together Type 1 has had a positive impact on Zach's outlook.



PART 2:



Zach didn't really have any friends with diabetes, so meeting with Josh was really good. It showed that he's not alone. There're other people out there, and they lead a normal life. He's also made a friend with type 1, who lives nearby.

Bernadette reflected that although Zach has support from clinical professionals, having someone he feels understands what it is like to live with type 1 has been important to Zach.



It feels nice to have support outside of the nurses as well, you know, because the nurses are there for medical support, really. But it's nice to have someone like Josh to lean on, to contact. So yeah, it's been really good for Zach.

PART 2:

Story 7: Journey to being a Young Leader

Background

Eleanor, is 21 years old and lives in Scotland. She joined Together Type 1 when she was 19 years old because she was finding life with diabetes hard.



I was going through that teenage stage of struggling with diabetes. Having no friends that understood what it's like, it was all a bit isolating.

Eleanor, Young Leader

Eleanor was signposted to Diabetes UK by her clinic and joined Together Type 1. When she first joined she was buddied with another young person for support.

Eleanor and her buddy developed a good relationship and became friends. Eleanor felt that having someone she could trust and talk to helped her open up about her diabetes and view it in a more positive way.



I think that was the turning point in my life, and I now speak about diabetes more openly. I used to hide my sensors, but now I'm like, why am I doing that? My buddy showed me that because I'd see she didn't hide hers. And I thought, it's not an issue, it's not that something is wrong with me and it's actually kind of like a superpower I have.

Eleanor, Young Leader

Story 7 continued

PART 2:

Thoughts from a young leader on change

Eleanor is now a Young Leader herself and enjoys seeing the difference in young people's openness and confidence as they progress through the programme. She reflects that being a Young Leader means that she gets a good overview of how young people are benefitting.

For the future, Eleanor hopes to continue to support other young people with type 1 and have the same positive impact on others as her buddy had on her.



Over time the young participants become more confident. In the beginning they are often quite quiet, and they don't really want to speak about it. But then as soon as we get speaking about it, I'll say 'Yes, I'm the same. I've got a sensor too and I have hypos too.' Then they become much more open, and realise they can discuss it, it's totally fine.

Eleanor, Young Leader

CONCLUSION

Our stories of change illustrate the incremental, positive changes Together Type 1 is having on children, young people and their families. The stories also demonstrate how young people themselves are influencing change in the health sector.

Our stories show that peer support helps young people feel less isolated and more open to speaking about their diabetes and how it affects their lives. A common theme is how connecting with other young people who are living with type 1 can positively affect their confidence.

Health care professionals and politicians said they found listening to young people a meaningful way to understand the challenges they face and their perspectives on what needs to change. Through engaging with young people, health care professionals can centre their needs and preferences at the heart of health services – making them more effective.

These stories of change come after only 1 year of full delivery of a 5-year programme. We are excited to develop more stories of change over the coming years to show how incremental changes lead to positive lasting change for children, young people, their families and the health care sector.



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TOGETHER TYPE 1

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