

The Type 1 Kidz project. Part 1: Engaging children and young people with type 1 diabetes in their own health and wellbeing

Helen Mulhearn, Chloe Brown

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Article points

1. Type 1 Kidz is a peer support project for children and young people with type 1 diabetes.
2. The programme provides monthly sessions in which young people can meet with others who share their condition to socialise and get peer support, in addition to learning opportunities.
3. Having been patient-led since the very beginning, the agenda for the group meetings is set by the young people who attend.
4. The project's overarching aim is to encourage children and young people to manage their own diabetes and improve their emotional health and wellbeing.

Key words

- Education
- Investing in Children
- Peer support
- Type 1 Kidz

Authors

Helen Mulhearn is Operations Director and Chloe Brown is Project Worker, both at Investing in Children CiC, Chester-le-Street, Co. Durham.

Investing in Children (IiC) is a registered Community Interest Company based in the north east of England. Our vision is that children and young people (CYP) possess the same human rights as the rest of humanity. They will experience a better quality of life if society in general, and the services they access, recognise and respect these rights. IiC facilitates a project, Type 1 Kidz, which engages and brings together CYP living with type 1 diabetes. This article provides details of what we do, how we have done it, the role of healthcare professionals and the impact the project has had on all parties involved.

Investing in Children (IiC) is a registered Community Interest Company based in the north east of England. IiC believes that children and young people (CYP) possess the same human rights as the rest of humanity, and that they will experience a better quality of life if society in general, and the services they access, recognise and respect these rights. Mostly, we do this by creating spaces for CYP to work out their own ideas, and then supporting them to enter into dialogue with the adults who can make such changes.

IiC has supported CYP with type 1 diabetes to have their say in their own medical care and the services provided by the local paediatric diabetes teams, identifying what is good, what is less good and what needs to change. Over recent years, this work has expanded into the north-east region as a support group to provide a forum for in-depth discussion between peers, allowing children to share their views and experiences of living with diabetes. The success of the Type 1 Kidz (T1KZ) project is a result of a unique partnership with CYP, families and a multidisciplinary group of professionals.

The development of T1KZ

Whilst supporting CYP to have their say in their medical care and the services provided by the paediatric diabetes team in County Durham and Darlington NHS Foundation Trust, it became apparent that CYP and their parents appreciated the support they received from each other when the occasion was provided for them to come together. With this in mind, IiC developed a peer mentoring programme with the aim of supporting CYP with type 1 diabetes to “be in control of their diabetes and not let diabetes control them.” This proved successful and, with a support session built in for parents, families and other adults, the work was expanded to facilitate a support group once per month, starting in October 2012. The attending CYP named this group Type 1 Kidz.

Encouraging initial feedback was given regarding the project, and the group generated a lot of interest. Paediatric diabetes teams across the region expressed a desire to offer the same opportunities for CYP with type 1 diabetes in their area, and so funding opportunities were explored. To introduce the concept of T1KZ to

CYP in Newcastle and Gateshead, IiC worked closely with the paediatric diabetes teams to share information with those who accessed clinics in The Great North Children’s Hospital and Queen Elizabeth Hospital. This was achieved through clinic visits by an IiC Project Worker and young people who attended T1KZ in Durham. This was complemented by lead nurses beginning to share information with CYP during clinic appointments.

A “taster day” was arranged as an introduction to T1KZ in order to establish whether it was something CYP and their families would want, find useful and attend. Working with the Young People’s Steering Group already established in Durham, CYP and families were invited to the Kenton Leisure Centre for some fun activities and to meet Team T1KZ in May 2014. The young people facilitated discussions to determine what they and their families would like to gain from T1KZ and to get their opinions of how it should be established. After listening to the Young People’s Steering Group, local venues were researched, considering accessibility, child-friendliness and the activities they could offer. In addition, locations for discussion groups were researched. Following on from this, a group was established in September 2014, and monthly sessions have been running from the Teams Community Education Centre in Gateshead on a monthly basis.

During the development of the new group, good practice and learning were embedded, and IiC began to develop a protocol for the continued development of T1KZ groups. This supported the further set-up of a group in Sunderland in partnership with City Hospitals Sunderland and South Tyneside NHS Foundation Trusts. Sessions started to run monthly from January 2015.

We firmly believe that the success of T1KZ has been down to ensuring that all interested parties were engaged from the very beginning. The starting point for IiC is always the voice of the CYP themselves, and initially T1KZ was developed out of their desire to meet with other CYP who understood what they were going through. Perhaps one of the most important aspects of the sessions is that the CYP themselves set the agenda and look at what is important

to them. Although the clinical agenda, such as lowering HbA_{1c}, does shine through in discussions, it is not T1KZ’s main focus. In addition to this, the CYP have told us it is critical that the programme be facilitated by an organisation other than the clinical team and outside of the hospital setting, as they want to view the groups not as “education” but as social events with opportunities for learning. Through CYP-initiated discussions, we have found that the paediatric diabetes teams have been more than willing to get involved in supporting the development of the groups as well as attending the sessions to develop their own practice and relationships with the CYP, parents and carers on their caseload.

The impact of T1KZ:

On children, young people and their families

Looking at families engaging within group sessions, an average of 14.5% of the patient population attends across the six regions, with attendance rates ranging from 9% to 22%. We have been able to contact more families, either through clinic visits or attending diabetes team events, and have had contact with an average of 48% of the clinical population, with rates ranging from 20% to 86% across the regions (Table 1).

Originally it was planned that both quantitative and qualitative data would be collected to assess

Page points

1. Operating across six NHS Trusts, Type 1 Kidz is attended by an average of 14.5% of the paediatric type 1 diabetes population in the north east of England.
2. The project began in consultation with children and young people with diabetes and continues to be fully patient-led, with the agenda of each monthly session set by the young people who attend.
3. The young people stress that they consider the sessions as social events first and education opportunities second.

Table 1. Contact and attendance rates at Type 1 Kidz in each operating area.

Patient population	Contacted	Engaged
County Durham and Darlington		
292	60 (21%)	55 (19%)
Gateshead		
92	45 (49%)	20 (22%)
Newcastle		
297	200 (67%)	34 (11%)
Sunderland		
181	80 (44%)	16 (9%)
South Tyneside		
59	51 (86%)	9 (15%)
Cumbria		
150	30 (20%)	16 (11%)

Box 1. Examples of qualitative outcomes of the Type 1 Kidz (T1KZ) project.

- One young person (11 years of age) has attended T1KZ for several years now. As he gained confidence he asked to help, and he has now facilitated several sessions, including how to manage diabetes in school, for the under-11s. He has also facilitated several educational activities and games.
- One parent said her family had made sacrifices and she was learning to drive for her son, as she believed he might never be able to drive. Several older T1KZ members explained that they had diabetes and had learnt to drive. The parent said this gave her a lot of hope for her son's future.
- For two years, one boy (aged 10 years) refused to go to his hospital appointments; even getting him into the waiting room was a struggle. He attended a couple of T1KZ sessions and bonded well with one of the facilitators, S. After talking to S and seeing him in his clinic appointments, he asked S to attend his appointment with him and saw the doctors and nurses for the first time in several years. Usually, only his parents saw the clinical team. This was celebrated during the next T1KZ session, and this young boy now has the confidence to attend clinics on his own and invites his mother in at the end of the session to go over the plans.
- After attending a T1KZ session, one child (4 years old) tested his own blood glucose for the first time. This has given him a lot more confidence and independence, especially at school.
- When visiting a clinic to engage with families, one parent had a long conversation about the advantages and disadvantages of insulin pumps and continuous glucose monitoring (CGM) with T1KZ staff and other parents. This helped her to choose an insulin pump which would link up to a CGM for her daughter.
- One boy who has attended T1KZ for around 1 year was getting extremely upset and frustrated by his diabetes. He discussed this with a Project Worker from T1KZ, who passed on his concerns to his clinical team; his nurse then visited the house and referred him to Child and Adolescent Mental Health Services, and he now has access to a psychologist.
- One teenager who has come to Durham T1KZ since its launch in 2012 has had continuing difficulties in accepting diabetes, treating it effectively and getting support from her family. In one of the sessions discussing things people might do that could harm their health, she admitted that she had not tested her blood in over 4 months. In that session she remained unwilling to do so; however, by the next session, with encouragement from everyone, she tested her blood glucose for the first time in 5 months. She gave permission for this to be shared with her DSN and is now getting more support to continue testing her blood and has begun to take insulin more frequently.

the impact of T1KZ. However, it became apparent that collecting quantitative data was too difficult because of how T1KZ runs. In discussion with the teams, we originally planned to look at factors such as HbA_{1c} results, emergency admissions, clinic attendance and the average number of blood tests. However, we realised these clinical outcomes were not the true focus of the project. Furthermore, CYP and their families attend group sessions as and when they feel that they want support, and so some only attend once or twice a year, making data collection difficult.

At the heart of this project is how we encourage CYP to manage their own diabetes through peer support and education, and the impact of this on their emotional health and wellbeing, alongside the impact on the whole family. Throughout the sessions, individual impact is recorded by conversations and feedback. We feel that this is an essential ingredient to what we are trying to achieve: individual changes that support the CYP in their capacity for self-management. Some examples of these qualitative outcomes are listed in *Box 1*.

On services

Involving CYP and their families in discussions about how their care is delivered has provided many opportunities for improving services. Examples are listed in *Table 2*.

The future of T1KZ

In a short space of time we have achieved so much, and T1KZ has been incredibly successful. There are many contributing factors to this success. Firstly, T1KZ is run with dedicated Project Worker support, which provides cohesion, continuity and clarity for CYP, families and clinical teams. The IiC Project Worker, Chloe Brown, also has type 1 diabetes, and she has been involved with IiC since she was 12 years old. After completing her degree, Chloe was appointed as a Project Worker to facilitate the diabetes group. T1KZ is also well supported by volunteers and Young People Facilitators. The programme cuts across all ages and provides an environment where CYP report feeling "normal". Both newly diagnosed CYP and those who have been diagnosed for a long time attend, and separate space for parents and carers to share their stories is also provided.

Reflecting on the success of the last couple of years shows the potential this approach has to improve the health and wellbeing of CYP with type 1 diabetes and increase their life expectancy. To quote the Department of Health (2007):

"A key component of effective care management is establishing and maintaining motivation amongst young people and their families or carers, enabling them to handle the complex juggling act required to effectively manage their condition."

Table 2. Examples of how Type 1 Kidz (T1KZ) has helped to improve services.

Issue raised	Solution
Families wanted to find out more about HbA _{1c} (e.g. what is it and how does it affect the body?)	The lead nurse gave an HbA _{1c} presentation during a T1KZ session, and a psychologist is making visual resources to give families a better understanding during appointments
Children and young people wanted to know when their annual review was going to be	A board has been displayed in clinic explaining when the next review would be, and a number was given out to all families so they could call the team and find out
Families wanted continuous dialogue with the team	A Project Worker sits on the multidisciplinary team meeting to ensure that there is continuous feedback between families and the team
Families wanted better access to the OmniPod insulin pump	The team collected feedback from families to use in a letter to the Clinical Commissioning Groups. Now all families have access to the OmniPod
Children and young people wanted to be recognised when they achieved their goals	Certificates are now given out to those who have achieved their goals when they come into clinic

“We believe that Type 1 Kidz will have a long-term impact on children and young people and families, as well as NHS services, by engaging and supporting them to gain the knowledge and tools to manage their diabetes.”

Our current challenge is to ensure we develop a mechanism for a longitudinal study of the long-term benefits of this unique approach. IiC is trying to ensure that relevant information is collected and self-evaluation correctly implemented from the outset.

Currently, treating type 1 diabetes complications proves a huge cost to the local NHS across the six hospital Trusts we work with: a total of £1 563 406 per year. A breakdown of the proportioned costs across the six Trusts is shown in *Table 3*. In the long term, if CYP are supported to continue engaging in their care and keep their diabetes management optimal by attending T1KZ, the costs of treating these complications should be reduced. As an example, looking at Newcastle Hospital Trust, if there was a 10% reduction in the prevalence of long-term complications, this would represent savings of approximately £43 000 per year.

Overall, we believe that T1KZ will have a long-term impact on CYP and families, as well as NHS services, by engaging and supporting them to gain the knowledge and tools to manage their diabetes. This will hopefully result in resilient young people who continue to engage in their care throughout their lives. ■

Table 3. Breakdown of the proportioned costs of treating type 1 diabetes complications across the six* Trusts involved in the Type 1 Kidz project.

Trust	Current caseload	Proportioned cost
Gateshead	92 (8.6%)	£134 298
Durham	292 (27.3%)	£426 251
Newcastle upon Tyne Hospitals	297 (27.7%)	£433 550
Sunderland	181 (16.9%)	£264 217
South Tyneside	59 (5.5%)	£86 126
Carlisle	104 (9.7%)	£151 815
West Cumbria	46 (4.3%)	£67 149
Total	1071 (100%)	£1 563 406

*Carlisle and West Cumbria Trusts have merged; however, data are available for the two separately.

Department of Health (2007) *Making every young person with diabetes matter: Report of the Children and Young People with Diabetes Working Group*. DH, London. Available at: <http://bit.ly/2hX9vi5> (accessed 22.12.16)