

Understanding the experiences of young people with type 1 diabetes from communities that experience marginalisation

Themes from engagement work



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About the report design

A co-production workshop was held with young people to inform the design of this report. The icons focus on areas that young people prioritised in the session including the importance of technology to support their diabetes, peer, family and community support, the importance of hobbies for young people with diabetes and finally the importance of staying active.

Executive summary

Type 1 diabetes is a lifetime condition that is often diagnosed in late childhood or adolescence, affecting around 1 in 400 young people under 20. Coming to terms with the condition can be a scary, destabilising and anxiety-provoking experience for young people. The challenges of adapting and managing a new life-time health condition may be particularly acute for young people in communities more likely to face marginalisation, where contact with health services may require targeted support.

This project aimed to hear from groups of children, young people, and families, particularly those from Black and minority ethnic communities and those living in more deprived areas, exploring their experiences of engagement in managing their Type 1 diabetes.

We spoke to 47 children and young people from a wide age range, a range of geographical locations and a number of different communities. Their feedback highlighted ways to help engage them better in managing their Type 1 diabetes and to take agency in their health care.

These included:

- **A lack of awareness:** Young people spoke of the lack of understanding of Type 1 diabetes amongst peers, family and teachers or other professionals in their lives.
- **Love and hate relationship with technology:** Whilst all young people acknowledged how brilliant new diabetes management technology is and how it makes their lives much easier, there are still many criticisms and suggestions to make it more engaging.
- **Holistic and accessible care:** A focus on young people and parents being able to access care following advice they were given and using technology well.
- **Identity and independence:** Young people wanted to be 'normal,' with older young people stressing the need for continued specialist support as they move to independence.
- **Support for wellbeing:** Young people reported that peers, schools and cultural and community activities and places were all important for their mental health and ability to cope.



Introduction & context

Type 1 diabetes is a lifetime condition that is often diagnosed in late childhood or adolescence, affecting around 1 in 400 young people under 20. There has been an increase in incidence of Type 1 diabetes since the first year of the COVID-19 pandemic. There were 33,251 children and young people receiving care from a Paediatric Diabetes Unit in 2021/22 (Royal College of Paediatrics and Child Health (RCPCH), 2023).¹

Coming to terms with the condition can be a scary, destabilising and anxiety-provoking experience for young people. Accessing appropriate services at this time, through adolescence and into early adulthood, can be particularly important in helping young people to manage the condition and prepare for a lifetime of living with it.

A key factor in supporting young people with this condition is appropriate engagement, empowerment, and involvement of them as decision makers in their treatment. Working in this way leads to better outcomes in the long term as they are growing into independence at adulthood.

The challenges of adapting and managing a new life-time health condition may be particularly acute for young people in communities more likely to face marginalisation, where contact with health services may require targeted support. This project aimed to hear from diverse groups of children, young people, and families, exploring their experiences of engagement in managing their Type 1 diabetes. Our focus was particularly on children and young people with Type 1 diabetes from Black and minority ethnic communities and those living in more deprived areas, to fill gaps in knowledge about the needs of these specific groups. This work will give direction in efforts to improve engagement with young people and support better care and improved health outcomes.

This project was funded by the [National Pediatric Diabetes Audit \(NPDA\)](#) (managed by the Royal College of Paediatrics and Child Health (RCPCH)), and led by the [Association for Young People's Health](#), working closely with the [Race Equality Foundation \(REF\)](#) and [RCPCH &Us](#). Our partnership enabled us to reach young people and their families from groups whose voices may be missing from mainstream conversations about health and inequalities.

The project included a [scoping review](#) which demonstrated that there is little evidence on the voice of children with Type 1 diabetes from communities that experience marginalisation. This engagement project was designed to fill some of that gap.

Methodology

The organisations involved in the work collaborated to create an appropriate method for the engagement sessions and interviews which was then agreed with an oversight group including the NPDA clinical lead and management team members. Engagement workshops, clinic chats (opportunistic discussions arranged while attending appointments) and interviews were structured around agreed questions (listed in the box below), which were used by facilitators in all the sessions. However, the methodology allowed for flexibility in its delivery and how questions were asked to ensure that young people who may not usually engage with projects or focus groups were able to access the sessions.

¹ Royal College of Paediatrics and Child Health (2023) [National Paediatric Diabetes Audit \(NPDA\) Report on care and outcomes 2021/22](#)
London: RCPCH

Each conversation was run by a facilitator with expertise in directly working with children, young people, and families from their communities/areas of focus. We were fortunate to have a facilitator who spoke Punjabi, which enabled better engagement when talking with families and young people who spoke this as their first language. This enabled young people and parents to feel as comfortable as possible answering the questions. The facilitators had the freedom to respond to the needs of those involved by amending or asking additional questions or designing and running activities around the questions, to make the session as engaging, sensitive and safe as possible for those involved. For example, RCPCH &Us staff adapted the materials to be more engaging for younger children.

Workshops and interviews took place in-person and remotely via video call. RCPCH &Us ran their engagement sessions via clinic chats in Type 1 diabetes clinics in a range of geographical locations. Transcriptions or notes were made of each of the clinic chats, group sessions, and interviews. These have been systematically analysed to extract the main themes, drawing on a simplified grounded theory method, allowing ideas and concepts to appear directly from the data.

Questions from the engagement approach

1. For children and young people with Type 1 diabetes **what** gets in the way of them getting good care?
2. **Where** do you think children and young people would like to get more support from to manage their Type 1 diabetes?
3. **Who** are the people who can best support children and young people's care?
4. **What** are the technologies which support children and young people with Type 1 diabetes best?
5. **What** are the methods children and young people currently use to support their health and Type 1 diabetes.
6. **What** stops children and young people with Type 1 diabetes using technology?
7. **What** do you think is the most effective way to communicate with children and young people, to support better Type 1 diabetes care?
8. **What methods/types** of communication are the best for young people? Staff, teachers, social media, and which social media?
9. **What** are children and young people's biggest concerns about managing Type 1 diabetes in the long-term?
10. Tell us one thing that you would like to change for the next generation of children and young people with Type 1 diabetes.

Who took part?

In total we engaged with 47 young people from England and Wales, with an even split of young men and young women. The majority of young people we spoke to were White British but a third identified as Black and/or from a minority ethnic community and came from Black African, Pakistani, Black British, Black Caribbean, Bangladeshi, Somali, Other White ethnicities and Mixed ethnicity. Several of the young people identified as LGBTQ+. The majority of young people we spoke to (28) were aged between 11-17. Whilst our focus was on young people, we spoke to a wide age range with the oldest being 25 and the youngest 4. Younger children were supported by their parents or carers and were generally seen during the clinic chats run by RCPCH &Us.

Our aim was to speak to as diverse a collection of young people as possible according to our criteria. Each project partner worked with their established networks and with a specific focus to do this. The Race Equality Foundation focused on reaching young people from ethnic minorities with Type 1 diabetes and RCPCH &Us focused on running clinic chats in areas with higher levels of deprivation and more significant Black and minority ethnic populations. Additionally, AYPH (Association for Young People's Health) liaised with Diabetes UK and reached out via the networks of everyone in the project to find additional young people to speak to.

It can be particularly challenging to engage with young people with a specific experience of a health condition from a community or group more likely to experience marginalisation. Significant work was undertaken by all partners to identify young people and families to work with. This range of young people and families we spoke to has ensured that we have a rich set of feedback. However, many groups of young people were not specifically represented in this work including, for example, young people who are care experienced. When considering the findings and future work it is important to keep this in mind.



What young people told us

The young people who took part shared a range of thoughts, ideas, and challenges about their Type 1 diabetes and the challenges they faced as a result. Below we have summarised some of the main themes from the engagement work.

A lack of awareness

Many young people shared a variety of ways in which a lack of awareness of, and stigma about, Type 1 diabetes affects their lives. For example, one noted:

This lack of awareness and knowledge was experienced from their peers, teachers, more generally in schools, in workplaces and from the general public.

People need to be more aware of the condition and not just think it's where you have to eat a Twix.

YOUNG PERSON

Well, I've had friends say to me, like 'Oh, but you know, it's not that hard. Inject your insulin before you eat, and you eat'there's more to it than that. You can't just inject yourself'..... we have to calculate how much.

YOUNG PERSON

Some of this related to a general misunderstanding between Type 1 and Type 2 diabetes in the communities and contexts that they lived in. Young people said they had experienced public and professional assumptions that they had Type 2 diabetes. Stigma around Type 2 diabetes had impacted some young people we spoke to, which added to their sense of being blamed for their condition. This was an issue raised particularly in relation to cultural beliefs in some communities and an important issue for consideration when communicating directly with families from these communities.

It is important to note that Type 2 diabetes has genetic and lifestyle causes, and having the condition should not be considered the fault of young people living with it.

Young people wanted improved understanding and awareness generally and mentioned specific awareness in schools and colleges of diabetes technology and how it works and why young people may need to miss school due to their diabetes.


Teachers and general public need education around both Types [of diabetes]

YOUNG PERSON

School don't understand diabetes Type 1.

YOUNG PERSON

For communities that are more likely to experience marginalisation there are additional challenges including different cultural perspectives and for young people living in families affected by social deprivation access to the range of food they need. This can lead to isolation and additional stigma with young people trying to avoid certain foods or community gatherings entirely for these reasons, as this quotation shows:




[We] Pulled him out of mosque, they don't have any diabetic children, teenagers manage it themselves. I used to sit in the car when he was at mosque so now [I] have a lady that teaches him at home. He has missed out on a lot of community activities.

PARENT

A love hate relationship with technology


The young people we spoke to have a complex relationship with diabetes technology for supporting the management of their condition. 'Ugly and heavy' and a general sense of confusion were just some of the terms and stories we heard employed to describe the pump and sensors that young people used.

Despite the barriers and concerns, all attendees referenced technology in one way or another, naming a variety of brands of sensors and pumps that support them to live as 'normal' a life as possible. With this though, there were many caveats. Even though these kinds of technology make a significant difference to young people's lives, there are still many unable to engage with it at present.



The pump, it blocks and [my] blood levels go all over the place, [the] pump could be smaller and ... I wish I could change [it] after a longer time rather than every 2 weeks.

YOUNG PERSON



When on injection pens [he] was really embarrassed, children like their privacy, it's harder for kids under 10, it gets easier. When first diagnosed I didn't sleep for two years. [When] they put him on the pump.... it made my life so much easier.

PARENT

Some young people said that it would be good for technology to be more engaging for them and that even simple things as adding a bit of colour to them would be good. They also talked about times when the technology didn't work. Some young people spoke about this in relation to not having the most 'up to date' phones or tech to link the pump or sensor to, resulting in being unable to use it effectively. This would be more likely in families living with higher levels of deprivation.

...things like insulin podswe don't have them on the NHS, I think if we had that, for a little kid, that would literally probably be the best thing for them and maybe bring out like cool colours and stuff where it's like, they're notashamed of having it..... make it cool. Make it cool to have diabetes.

YOUNG PERSON

For young people and their parents from Black minority and ethnic communities, there were added layers of difficulty, due to language barriers and fear or lack of confidence about learning how to use the equipment and technology in general. This might result in, for example young people not feeling fully involved in decisions about technology, as demonstrated in this quote

A few young people also talked about how using technology could create an unhealthy obsession with counting carbs and constant tracking, which could impact their mental health.

*Not knowing about [pumps].
Not being able to be part of choosing which pump I get. Not knowing enough about them in a way that is easy to understand.*

YOUNG PERSON

It can make you too much of a perfectionist [and lead to a] reliance on machines.

YOUNG PERSON

Oh, it is ugly, and heavy. And you can't do anything with it. You can't wear clothes properly with it. It's rubbish. So, I went back on injections.

YOUNG PERSON

For one young person some of the challenges of the technology had meant they stopped using it and returned to injecting insulin.

Finally, the issue of a lack of awareness both of the technology available and more generally societal awareness of diabetes technology was raised by young people. Again, this may be exaggerated in communities that experience more marginalisation.



Holistic and accessible care


Young people shared the importance of tailored care and support that covers all the ways in which Type 1 diabetes can change their lives.

They spoke about the role of parents and carers in their care. They highlighted the importance of listening to their parents especially when English was not their first language but also highlighted that parents can sometimes make decisions for the young person that may not always be what they want.

When young people are getting older and start to want to develop independence or 'rebel', Type 1 diabetes can get harder to manage and some further support with this would be appropriate. Ways to involve young people in their care from earlier on were suggested as being helpful alongside training for medical staff on age-appropriate care and youth appropriate conversations and terminology.


Young people sometimes found it difficult to understand what was being told to them – and to engage with services – when English was not their first language. This was sometimes in relation to language about technology or medical terms where there was often not a direct way of translating this into a different language. However, young people also spoke about a lack of understanding of cultural food – what is healthy food in my culture? We were fortunate enough to have a facilitator who spoke Punjabi, which proved vital in hearing the views of parents and young people who spoke this language.

In addition, when more than one medical team was involved in care this could make things more complex.



At the beginning, I wasn't really trusted. Because I was seen as like too much of a danger. So I wasn't allowed to do anything surrounding my diabetes ... it was kind of at the beginning of my diagnosis as well, so it probably didn't help.... But then more recently I'm involved a bit more in discussions between the two teams and things.

YOUNG PERSON



So I had an eating disorder diagnosis and then my diabetes diagnosis. Both of those teams would feed into the GP and then the GP would organise things like blood tests and treatments because like each team wouldn't deal with the other team. It was kind of like acting like a middle man.

YOUNG PERSON

Taking a holistic approach to young people's care may be particularly important for those from communities experiencing more marginalisation, as there will be additional layers of challenge and concern arising from their situations that will impact on their ability to prioritise their diabetes.

Identity and independence

Young people with Type 1 diabetes are keen to live as normal a life as possible, and to minimise the impact on their activities. They resent the restriction that diabetes engenders, commenting for example:

I really resented my life. I hated the fact that all of the things that I used to do now were more complicated so I couldn't easily go swimming I had to tell a lifeguard that I was diabetic and especially as a young teenager, it really singles you out and it makes it incredibly hard.

YOUNG PERSON

Many young people felt different because of their Type 1 diabetes and that this was challenging to manage. Young people said that handling diabetes technology, having to be taken out of school for appointments, getting 'grief from teachers' and having to explain diabetes repeatedly all added to this.

Many of the young people we spoke to referenced social, sports and other extracurricular clubs and activities, as well as being able to talk openly with friends, as being important.

Extracurricular activities and support may be particularly important to consider for young people with Type 1 diabetes living in more deprived areas or where language or cultural barriers may prevent access. It is also important to note that some young people said that they didn't want all parts of their life to be about diabetes highlighting the need for a tailored approach that works for each individual young person.

There were several methods that could support young people's ability to live life as normally as possible from quiet spaces to manage their insulin, to ensuring their parents were getting the support they needed so that they could support them. It is important that professionals understand the importance of taking a holistic view of young peoples' lives.

The honest truth is you don't want anyone to mention it at all. Because I don't want to feel different. If they understood great [it would] mean one less person [I] had to explain something to.

YOUNG PERSON


Just [have to] live your life, I have a motorbike, play video games, go to mosque, they are aware of my diabetes.

YOUNG PERSON



Support for wellbeing

For some young people their diagnosis, a lack of understanding and/or the pressures of keeping up with a busy lifestyle led to a sense of feeling isolated and unable to ask for help. Older young people particularly highlighted their concerns around these issues as they moved to being more independent and looking after themselves:




I struggled a lot with my mental health post diagnosis. I really resented my life. I hated the fact that all of the things that I used to do now were more complicated.... especially as a young teenager, it really singles you out and it makes it incredibly hard. So, I did end up having to go in an inpatient unit for a while.

YOUNG PERSON

Young people wanted to meet and talk to other young people like them. This might include a peer support group from their community or local area or a peer mentor who can support them.


Young people mentioned a range of things that would be useful from just being able to speak to other young people about their diabetes, so they don't feel alone to more formal peer support via a peer support WhatsApp group or an older young person with Type 1 acting as an ambassador.

Ensuring that there is some match to the kinds of communities that young people come from may be key to effectively build trust. Other suggestions included testimonials and top tips from other young people.



Maybe if a kid gets diabetes, during the first month or two, we could talk with other people who had diabetes, so you could understand it better because you learn more from people that are your own age.

YOUNG PERSON




If there would be like local clubs for kids where they could go and meet up and ... parents or carers can stay in the background, but the kids can play. Or ... in the summer out in the parks where you don't need to pay for anything.

PARENT OF A YOUNG PERSON

Linked to this was the notion that professionals need to talk to young people more about their mental health, especially how lonely it can be when diagnosed.

Many young people told us how they would like schools to play a bigger part in their support. Not necessarily hands on support, but for young people, just knowing that teachers are aware, understand the condition, and that they are not going to get challenged or questioned when they need to eat a snack or check their phones, would make a real difference to their wellbeing. This was particularly noted in relation to older young people.




Secondary school[s] don't care as much because we are older. [Staff] don't let me leave lessons or sort out things because they think it's not important.

YOUNG PERSON

Other sources of support for wellbeing beyond school were also important. Several young people and parents discussed the role of support and understanding from more community-based settings, such as from spiritual leaders at their mosque or even being able to ask their local pharmacists to get help with the technology or any other questions about their Type 1 diabetes.

Other themes

Across the board, young people mentioned a variety of social media channels being effective ways to communicate with them.



The best way to accessteenagers is videos, because they use YouTube so often, I would have probably a channel on YouTube that would target the teenagers because, everything currently is more targeted for the younger children”.

YOUNG PERSON

In addition, support with food and diet more generally were also important to young people particularly in relation to snacks and better sugar free options. They also wanted support with managing and calculating carbohydrates in their food, and nutrition classes for young people were also mentioned as being useful.

Conclusion

Young people we spoke to have a range of experiences managing their Type 1 diabetes. It is important to note that we did not speak to young people from all possible communities or with experiences of all inequalities. However, overall, the issues raised by young people and families involved suggests there is a need to avoid oversimplifying the issues that can affect groups of young people more likely to experience marginalisation. Their engagement with services, technology and day to day management of their condition will not be just about life stage, family circumstances or ethnicity but a combination of all these factors that vary from individual to individual.

Overall, understanding, communication and building trust are vital to engaging young people and their families who experience marginalisation. There are some general concepts like youth friendly care² and using communication platforms that young people recognise that can help. Recognition of the language and cost barriers in relation to technology specifically also need consideration and focus.

² Eg, OHID (2023) ‘You’re Welcome’: Establishing youth-friendly health and care services

Recommendations from young people

1

Making technology more inclusive.

Ensuring that diabetes technology is accessible to families in more deprived areas and where English is not the first language is important. Stigma, language, finance and fears of technology all need to be considered when discussing options and supporting young people and families.

2

Youth led information about diabetes – by young people for young people.

Young people suggested things that could help support them as they grow older and help with some of the challenges young people face in relation to managing their condition and the technology they use. These included a top tips document created by young people, peer support groups, peer mentors or ambassadors and testimonials.

3

Increased engagement opportunities for young people and their families.

There needs to be a specific focus on increasing opportunities for young people and families to have their views heard in health settings so that care can be effectively tailored to their needs. This is both in relation to their own care and their involvement in service improvement. Times, platforms and mediums that young people use are important – such opportunities can also help young people and their families understand Type 1 diabetes and their options going forward.

4

Health services create new strategies to engage with young people and families they don't hear from.

Services need to understand who in their population is not engaging with them. Building relationships with local voluntary, community and faith organisations who can support engagement with these communities on an ongoing basis can help to ensure better understanding of the issues young people in the area are experiencing with their diabetes and the technology they use. These included a top tips document created by young people, peer support groups, peer mentors or ambassadors and testimonials.

5

Focus on increasing public awareness about Type 1 diabetes in all the spaces where young people are.

A lack of awareness of Type 1 diabetes in community health services, faith settings, schools, leisure spaces and other community spaces increases the distress that young people experience. There is a need to increase public knowledge and support children and young people and their families to have discussions about their diabetes in the places they need to. Using already developed materials to support this along with more youth led content are important.

About the organisations undertaking this work

The Association for Young People's Health

AYPH is the leading independent voice for young people's health in the UK. To find out more about our work visit ayph.org.uk.



The Race Equality Foundation

The Race Equality Foundation seeks to explore discrimination and disadvantages and use that knowledge to help overcome barriers and promote race equality in health, housing, and social care.



The Royal College of Paediatrics and Child Health/RCPCH &Us

The Royal College of Paediatrics and Child Health/RCPCH &Us is the voice of children, young people, parents and carers for the college, created to actively seek and share their views to influence and shape policy and practice.

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