

NPDA &Us

Voices from children and young people

Living with Type 2 Diabetes: ideas from children and young people on staying healthy, happy and well.



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The Healthcare Quality Improvement Partnership (HQIP) is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote qualityimprovement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies. www.hqip.org.uk/national-programmes

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Consultation brief

The National Paediatric Diabetes Audit (NPDA) is managed by the RCPCH, commissioned by the Healthcare Quality Improvement Programme (HQIP) and funded by NHS England and Wales to provide information that leads to an improved quality of care for children and young people receiving care from a paediatric diabetes unit (PDU) in England and Wales. The audit has shown increasing numbers of children and young people being seen with Type 2 diabetes (approx. 800 in 2019/20) in PDUs. Working together, the National Children and Young People's Diabetes Network's working group on Type 2 Diabetes, Diabetes UK (DUK) and the NPDA together identified a need to develop an engagement approach to understand the needs, wishes and experience of diabetes care and management of children and young people with the condition.

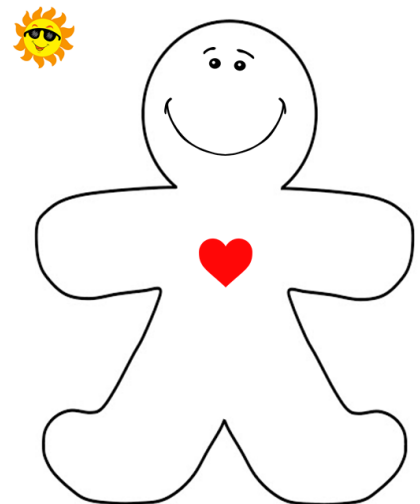
The intention of the consultation/engagement activity led by RCPCH &Us was to understand:

- What children and young people feel and understand about their condition and their long-term expectations for living with the condition.
- Why children and young people may not follow their treatment plans and what services can do to better support them.
- The barriers to completing the treatment and the motivations to do so.

Methodology

There were two approaches used in order to identify views and experiences from children, young people and their families:

1. **Desk based research** on voices from children and young people with Type 2 from existing published sources or online forums (formal/informal publications)
2. **Clinic Chats** – supporting children and young people to contribute by giving evidence on what they think are the priority areas to support those with Type 2 to stay healthier, happier and living longer. There were two clinic chats and one clinic discussion (clinician reflections) carried out between February – March 2020. A further two clinic chats were booked in but were postponed due to government advice due to the COVID-19 pandemic. In the Autumn of 2021, four clinics were approached to take part in clinic chats virtually or in person, with 1 clinic offering the chance to speak with their patients.



Our semi-structured interview questions were developed in consultation with representatives from the NPDA and DUK.

They were:

- Think about other people in your school/friends. How would you explain what Type 2 diabetes is if they have just been diagnosed?
- Who told you about Type 2 diabetes / how did you find out?
- What would you/ your peers really want to or need to know about Type 2 diabetes?

- What keeps children and young people with Type 2 healthy, happy and well? Which ones are easy/tricky to do? How could the service help?

In addition to the questions, a picture sheet was created to support with engagement through trigger materials.

Fifteen young people with 11 family members were involved through four clinics, which represented voices from the North East and London. The youngest engaged was nine years old, and there was a mix of genders and ethnicities.

Discussions were led by the RCPCH engagement team following introduction to the family by the diabetes clinical team. Conversations took a semi-structured interview approach which lasted between 10-45 minutes, depending on the family.

To find out more about the **NDPA** national audit programme go to www.rcpch.ac.uk/npda

For **information, advice or support** there are national diabetes charities working to support children, young people and families that may be able to help. Visit www.diabetes.org.uk.

For **parent support** for children/young people with a disability or condition go to www.contact.org.uk and check out the **National Network of Parent Carer Forums** for peer support and advice www.nnpf.org.uk.

If you are **not happy with the service** you are receiving, look for your hospital PALS service or your local Healthwatch on Google

Patients and families were also provided with a signposting card in case the discussion raised any questions or concerns that they wanted further support with.

NPDA
National Paediatric Diabetes Audit

DIABETES UK
KNOW DIABETES. FIGHT DIABETES.

RCPCH & Us
The voice of children, young people and families
www.rcpch.ac.uk/and_us

**DO YOU HAVE TYPE 2 EXPERIENCE?
ARE YOU AGED BETWEEN 13-25?**
?

**WE WOULD LIKE YOU TO HELP US
DESIGN SERVICES FOR THE UK**
✓

IT'S EASY TO DO, JUST A 10 MIN CALL
OR WE CAN EMAIL/ WHATSAPP YOU QUESTIONS
GET INVOLVED IN FEBRUARY OR MARCH 2020

If you are interested please text Emma from RCPCH & Us
(part of the Royal College of Paediatrics and Child Health)
on 07715759795 or email and_us@rcpch.ac.uk

All answers will be kept **anonymous** in the final report that
will be shared with Diabetes UK and the
National Paediatric Diabetes Audit hosted at RCPCH.

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England and Wales (105774) and in Scotland (SC0 38299)

Clinical teams were provided with a flyer to share directly with wider cohorts of children and young people with Type 2 diabetes to give them the opportunity to get in touch and share their views.

Key findings from Clinic Chats

- Some struggled to explain what Type 2 is and were sometimes a little embarrassed:

Young person: "It's when your pancreas doesn't produce enough insulin".

Friend: "no that's Type 1 you dummy, Type 2 is when you eat too much junk food" Patient "oh ok, I don't know then, maybe it's when you eat too much junk food."

- There was often expression of guilt or shame associated with the diagnosis, or a sense that it was the young person's fault or that they weren't 'doing enough':

"At first you feel like you've got a short life and just done something wrong, so you put yourself with other people for support. Good to be reminded it's only a condition."

- Visual reminders are needed throughout the Type 2 journey to reinforce learning and key messages as information provided can be forgotten, misunderstood or challenged assertively by others who have the wrong information:

"Watched a video that was very good and helped us to understand"

"Easy to access information on a screenshot so it's on your phone. Research and information can be too long, so you just need the highlights and the links so it's easy to access"

"Leaflets are no good - they just go straight in the bin"

Parent: "they have explained it loads and loads, we just keep forgetting. It is helpful to have them repeat it a lot."

- There should be an increase in the amount of information that is available to professionals and families/patients that explains the facts, what it means long term, tips and support as some expressed having to do their own research and being given no formal information to take away:

"T1 get special things like a bear, a bag, stories but there isn't anything for T2. It would be good to get a T2 pack with a bag, video, an app, a booklet about food and suitable options."

"Doctor just told me I have to take medication, no leaflet or signposting I had to research myself."

"No real explanation, no additional information, had to find out on my own. Just told me about the medication."

- Many of the families had a history of diabetes. This sometimes meant that they expected it to happen to the children, or at least it wasn't surprising, but also that there wasn't a good understanding about the impact of the condition on different ages:

Parent: "[Spouse] has diabetes so know about it from there, also it's on the news - there's a bit of an epidemic isn't there."

Parent: "My mum has it so we knew about it already."

- There are challenges for young people which are rooted in a sense of youth identity and culture, linked to socialising, retail experiences with friends and eating with friends after school but not knowing

how to manage this well. Young people's friends were not aware of the condition making it difficult for them to check levels, take medication or make better food choices:

"It can be hard with all the fast food places after school. So, you eat with friends but don't know what to choose, then you go home and have to eat again because your family made it and it is part of our life to sit and eat with them. Both are good because you are being social."

"I have everything I need, and I'm motivated to do better but it would be good to have advice on what to do when you are out socially and food advice like when a friend comes with me."

"Friends don't know which makes it difficult to take medication and not eat sugary stuff when I'm out with them."

- There were also challenges to adherence to dietary advice for young people associated with their family background and cultural expectations:

"It's harder in the family background if you are [South Asian] like me because parents need to know more about eating sweets and being careful."

"If you got to someone's house in our (South Asian) community, to refuse the food would be considered rude and people didn't necessarily want to share [their] diagnosis in this situation."

"When the whole family helps then it works, and everyone is eating better and it's fairer for everyone and not shameful for the one who can't eat the sweet food."

- Schools and colleges were also

highlighted as needing more awareness raising, education and support to help everyone (including children and young people, families, and staff) to understand about Type 2 diabetes and how to support each other and manage it well. As well as formal all school training sessions and awareness raising weeks, it could be built into the curriculum through subjects like biology, home economics, health and social care and PE:

"Schools did help in supporting checking, but college has not been understanding at all, making me go to the back of the room to check levels. Before this my levels were always good, this has stopped me checking and my levels are now all over the place."

"They've not done a diabetes talk at school that would be good".

- The messaging around the possible trajectories of a diagnosis of Type 2 diabetes could be clearer and more positive:

Parent: "is it reversible or permanent? I was told the weight gain caused it, if they lost weight would it go?"

"It affects people's lives; your foot can fall off"

- Money was perceived as a barrier to exercise and eating healthier as fast food was cheap and easy to access:

"I would like to do martial arts but it's too expensive"

Parent: "Weight loss groups are expensive. It would be good if there was a group for young people".

"It's hard at college. You are surrounded by fast food places, like McDonalds and Burger King and they

are the cheapest place to eat.”

- There was also some confusion around what constituted a healthy diet for those with Type 2 diabetes:

“You can’t really have sugar, can you? Or can you?? I am not sure.”

“Maybe a cooking class where you could learn to make good packed lunches or what options in Tesco were good for you would be good.”

Parent: *“[I] would like a clearer dietary plan, [we] met dietitians, but they provide guidance rather than helping [us] come up with a plan of what to eat when.”*

- A range of methods are needed into order to provide family or young person focused support, increase awareness and understanding, and build a Type 2 community for children, young people and their parents, either online or in person. Parents were keen on having support or management groups for their children, but young people’s opinions were mixed, with some seeing them as embarrassing and preferring one to one support:

“It would be nice to go on trips and activities and be in a group with other children and young people with Type 2”.

“I wouldn’t really want to go to a group and talk about it with other people. I prefer to speak with an expert one to one. If it was group exercise, I would prefer to do it with mates.”

“It would be good to have a club at the hospital to meet other people with diabetes my age.”

Parent: *“In between clinics you are pretty much on your own. It would be good to*

have more support in between.”

- There were a range of ideas that linked to online tools that could be supportive such as videos on meal planning, workouts, checking your sugar levels and explaining the difference between Type 1 and Type 2 diabetes as well as making better use of social media to share relevant and real life inspirational examples and information directly to young people in a way that is reflect their experiences and friends:

“We use social media not websites, so have real life stories on insta, Tiktok, snapchat. You can put links to apps and things on there.”

“Have a list of foods you can eat. Like maybe on an app or something. Phones are better for young people.”

“There could be videos on YouTube that explain Type 1 and Type 2. So you are watching different diabetes videos that tell you how to look after your insulin, healthy eating, what to do if it is high sugar or low sugar, like if it is high, drink more water, if it is low eat a sweet. Also showing you how to tell other people you are diabetic as they won’t know.”

Key findings from desk based research

Preliminary online searches (March 2020) around Type 2 diabetes in children and young people found that there were lots of online forums, chats and community focused activity on Type 2 diabetes, however there was very focus or discussion about the condition amongst children and young people. Information about Type 2 diabetes amongst under 18-year olds seemed to fall into two categories:

- Basic factual information from health websites or diabetes organisations. This focused on the definition, symptoms, treatment and healthy lifestyle tips.
- Academic articles or medical guidelines targeted at a professional audience.

Peer to peer support or online communities for either young people with a Type 2 diagnosis or their parents were hard to find. The discussion boards, chat rooms and Facebook pages for people living with Type 2 diabetes were focused on adults living with the condition, with discussions about management, cooking and healthy eating tips.

Whilst there was very little interactive discussion from a young person's or parental perspective, there were posts by adolescents about their Type 2 diagnosis. These had at least one or two responses on the thread that questioned their diagnosis and whether they had Type 1, suggesting that information and knowledge about the increasing rates of Type 2 diabetes in children and young people is not widely known or understood.

One train of discussion was found where young people with a diagnosis of Type 2 diabetes were reaching out to find other young people in a similar situation, but this was three years ago. The Mix website (providing general advice and support for young people) did have several threads where young people were talking about their diabetes (not specifying Type 1 or 2) and its impact or relation to their mental health.

Overall, there seemed to be a lack of informal or peer / community information about Type 2 diabetes in children and young people. Information was either a factual, medical overview or was Type 1 or adult focused.

Key messages that a lay person would deduce from an initial online search into Type 2 are:

1. Type 2 is rare but increasing in children and young people and it is worth getting the diagnosis 'checked out'. Factual pages and community boards minimised the likelihood of seeing this is in children and young people.
2. It is caused by obesity and poor life choices.
3. Where young people do participate in online forums, their posts seem to be more focused on social or emotional wellbeing rather than on recipes or self-management advice, which are prevalent topics within adult community boards.

Risks and limitations

There are challenges with engaging with this group that have been experienced by other organisations, including the numbers of young people with Type 2 diabetes being small, having a lack of formal well known and well used engagement opportunities (e.g. Type 2 diabetes youth forums), and challenges experienced of bringing children and young people with Type 2 diabetes together to workshops/forums or events. The clinic chat roadshow approach was identified as being one way to mitigate low attendance compared to organised events/workshops. There are still low numbers with Type 2 diabetes being managed within most PDUs due to its relative rarity amongst children and young people, and since most children and young people with diabetes have Type 1. Non-attendance at clinics is also a barrier to engagement, so the report needs to be viewed in the context of it being a very small sample.

There is also a limitation of carrying out discussions on patient experience and understanding on a long-term condition which can be associated with 'life choices'. It was important to be mindful of framing the discussion so as not to compound familial guilt or create a sense of blame, to create an open and safe space for sharing, in an environment where it was the first time the patient/family had met with the RCPCH worker and at times in an environment where the conversation could be listened to by others. We mitigated these risks by ensuring that questions were framed in terms of thinking about others, your friends/family/school so that experiences could be shared through the third person, by having skilled engagement workers with mental health first aid experience, using separate and private spaces for discussions and by creating signposting cards to support aftercare, as well as being able to access immediate information and support from the clinical team.

One final limitation was the impact of the COVID-19 pandemic. Two February 2020 clinic chats were rescheduled by units to Mid-March. Following a risk / benefit assessment considering the physical and emotional impact on patients, families, clinical staff and engagement workers, these were postponed.

Having completed an engagement and wellbeing assessment on the potential to conduct phone interviews during March/April/May 2020, it was agreed that this was not the best option. This was in part due to the impact on clinical teams in identifying patients, speaking with them individually about the consultation opportunity, and getting written consent to share their contact details to then share with the RCPCH Team.

Secondary issues were also identified including the potential to cause harm through the questions to patients and families, where there wasn't already a relationship/rapport between the family and the engagement worker, a lack of opportunity to pick up on non-verbal cues through a remote conversation, or signpost them immediately to clinical staff support as we would in a clinical environment. To mitigate both the impact on clinicians and families during lockdown, it was agreed to halt the data capture.

Access to clinics was reduced throughout the rest of 2020 and into 2021 while the NHS focused on supporting the COVID-19 effort and their patients. In September 2021 we re-engaged with the original clinics plus extended an invite to additional units to see if they would be able to support in person clinic chats or virtual clinic chats. By doing this we were able to speak with an extra three young people and two family members.

Recommendations and next steps

All paediatric diabetes teams caring for children and young people with Type 2 diabetes should:

- Review the information provided to children and young people with the condition and their families at diagnosis and at subsequent clinic visits with reference to the key findings presented within this summary.
- Check for gaps in understanding of the condition amongst all those with Type 2 diabetes and their parents and carers.
- Identify barriers to adherence to dietary and lifestyle advice where present and work with the family and multidisciplinary team members to identify strategies to mitigate them.
- Involve their patients in their services to support thinking around unit next steps.

The key findings for this interim report can be used by the NPDA to inform a future quality improvement project with children, young people, families and clinicians to provide good quality information and develop a community for Type 2 paediatric support.

Diabetes UK can use the findings from this exercise to inform developments to the information and community resources they provide for young people with Type 2 diabetes,

These efforts need to be led by children and young people using youth social action methodology with experts in engagement, to ensure that the outputs are developed by the community for the community, with the support of diabetes experts to fact check their content.

This report should be shared with wider strategic forums internally and externally to support planning and development.

Thank you

Huge thanks to all the patients, families and clinics that supported this piece of work.

Contact details

RCPCH &Us

and_us@rcpch.ac.uk

Want to get involved/ get in touch?

If you are interested to learn more about our NPDA T2 project or our Children and Young People's Engagement Team:

Visit our website for information and free resources:

www.rcpch.ac.uk/and_us or Email: and_us@rcpch.ac.uk

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