HQIP
Healthcare Quality Improvement Partnership

RCPCH
Royal College of Paediatrics and Child Health
Leading the way in Children's Health

NPDA
National Paediatric Diabetes Audit

Public and patient participation within the National Paediatric Diabetes Audit (NPDA) 2020

Introduction

The NPDA is managed by the Royal College of Paediatrics and Child Health (RCPCH) and collects data about the care received, and diabetes outcomes achieved, by all children and young people accessing the services of paediatric diabetes units (PDU) in England and Wales. The overarching aim of the audit is to support improvement to care and outcomes by providing reliable benchmarking data and communicating results so that they may be used as a basis to inform local, regional and national quality improvement activity. Patient and parent involvement in our activities is fundamental to this aim. We believe that by supporting families with diabetes to understand what good care and outcomes look like we can empower them to advocate for more support if required, and that scrutiny of local results by families with diabetes provides added incentive for teams to make year on year improvements.

The examples below detail how and why we have involved families with diabetes over the previous year, and how we have mitigated the impact of covid-19 on our original engagement plans.

Governance

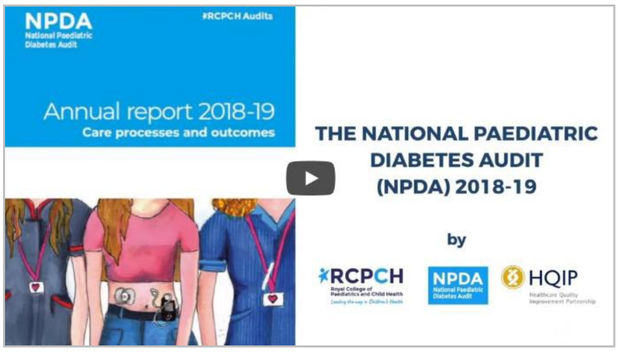
The NPDA benefits from parent representation on both the Project Board and the Dataset and Methodology Group. Both groups have two parent reps, who advise us on how best to tailor our activities and outputs to meet the needs and aspirations of families with diabetes. These parent representatives are also part of the Families with Diabetes National Network and are therefore well equipped to present the views from the wider cohort of families of children and young people with diabetes.

Pre-pandemic, these meetings took place at RCPCH HQ in London, but since March we have held them online via Microsoft Teams. Given that this was unfamiliar software for most at the beginning of the year, we held 'practice sessions' in advance of our first Microsoft Teams meetings for parent and clinical delegates to familiarise themselves with the process of logging on and participating. Despite lacking the informal opportunities for discussion and building relationships afforded by face to face meetings, these virtual sessions have ultimately proved to be a successful means of coming together to review the progress of the audit and plan and shape upcoming audit activity. Remote participation has saved our parent representatives (both with increased professional demand and parental responsibilities during the lockdown) lengthy journeys to London and time away from work and their families. The NPDA expect to offer them the option to attend remotely once we return to face to face meetings.

Core audit

The 2018/19 core NPDA report covering health checks and outcomes was published in July 2020. Due to the pandemic, many paediatric diabetes clinics were being held remotely at this time, meaning that production and mailout of our usual hardcopy lay summary of the report (aimed at parents and patients) and clinic posters for display of local results in patient waiting areas were suspended.

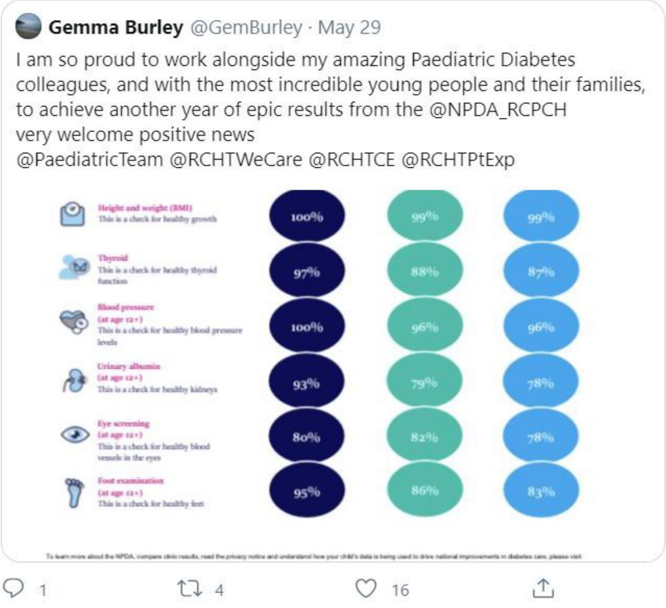
To overcome this, the NPDA commissioned an animation aimed at families with diabetes intended to be shared and viewed via social media. Digibete (a social enterprise established by parents of a child with Type 1 diabetes and specialising in creating educational digital content for families and children and young people with diabetes) were commissioned to produce this. The script was developed with the support of the parent representatives on the NPDA Board to ensure messages were clear and understandable.



Furthermore, the involvement of parents at this stage ensured that the animation covered the aspects of the audit and its findings considered most relevant to parents, and that the language and images used were pitched at the right level.

In addition to providing information on the NICE-recommended health checks and treatment targets covered by the audit, the animation explicitly encourages parents to talk to their clinic to ensure their child is receiving the appropriate care described for their age and diabetes type, and sign posts towards our online resources enabling parents to compare their child's clinic with others including NPDA Results Online.

We also produced an online clinic results poster generator to help parents and patients understand their clinic's performance at a glance. Our parent representatives were also involved at the design stage to ensure the language was appropriate and that the key information was included. The NPDA received excellent feedback from centres providing care, several of whom proudly tweeted their results:



Gemma Burley @GemBurley · May 29

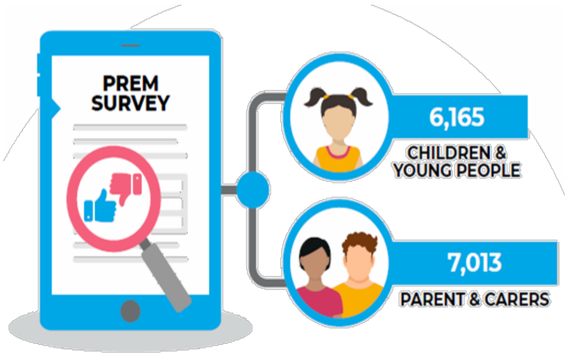
I am so proud to work alongside my amazing Paediatric Diabetes colleagues, and with the most incredible young people and their families, to achieve another year of epic results from the @NPDA_RCPCH
very welcome positive news
@PaediatricTeam @RCHTWeCare @RCHTCE @RCHTPtExp

Height and weight (BMI) This is a check for healthy growth	100%	99%	99%
Thyroid This is a check for healthy thyroid function	97%	88%	87%
Blood pressure (at age 12+) This is a check for healthy blood pressure levels	100%	96%	96%
Urinary albumin (at age 12+) This is a check for healthy kidneys	93%	79%	78%
Eye screening (at age 12+) This is a check for healthy blood vessels in the eyes	80%	82%	78%
Foot examination (at age 12+) This is a check for healthy feet	95%	86%	83%

Finally, in order to ensure a family friendly, eye catching front cover of our 2018/19 report, and to raise wider awareness of the audit, we held an art competition for children and young people with diabetes. We were delighted with the winning entry and the accompanying message from the artist, which we included in our report with her permission to underline the importance of good care to the children and young people using paediatric diabetes services:

"My name is Katie Lamb, I am 18 years old and will be marking 17 years of type 1 diabetes in a couple of weeks. As you can imagine, I have attended a fair few paediatric diabetes clinics over the years, and I have been lucky enough to have the same DSN since the very beginning. The relationship I have built with her and all members of the diabetes team is one I will cherish forever- they have become like a family to me. As I have turned 18 it is time for me to look to moving to adult care, which is one of the most difficult things I have ever had to do, because it means saying good bye to people who mean so much to me. I was thinking about the theme 'a good diabetes clinic visit' and realised that for me, it didn't matter what the numbers were, what my graph looked like or how 'good' my HbA1c is (although of course that helps), what made clinic good was being around people who were there for me, the best clinics make me feel supported by my team, confident that they are standing with me through whatever my body might throw at me. I have some truly incredible memories in the children's clinic, I really have had a lot of fun, but I know that behind it all were the incredible doctors and nurses and dietitians who never failed to be right there when I needed them the most. So I decided to draw three figures, myself with my pump and CGM in the middle, because they always put the patients first, alongside my nurse.

Patient and Parent Experience Measures (PREM)



The NPDA launched a national PREM survey in 2019 to collect information on the experiences of paediatric diabetes care in children and young people with diabetes. This was developed on behalf of the audit by the Picker Institute, a leading international healthcare charity who carry out research to understand individuals' needs and their experiences of care. The survey was based on themes identified from a series of workshops with families and children and young people with diabetes. The response to the survey was exceptional; over 13,000 responses, and a completion rate of >20% of children and young people with diabetes in England and Wales.

Analysis of the data took place during the COVID 19 lockdown period. In order to identify the 'key findings' from the results, the NPDA involved the committee of the Families with Diabetes National Network to review all the results and determine which ones they considered to be the most important to them as users of paediatric diabetes services. To lessen the burden of this task in the midst of the other challenges faced by parents during this phase of the pandemic, we extracted all the results presented within the report into a spreadsheet, so they could simply highlight their chosen key findings, with consensus coordinated by the Chair of this committee. This group were also tasked with suggesting recommendations corresponding to their chosen key findings, as it was felt more appropriate to ask this group rather than our clinician dominated Board and Dataset and Methodology groups.

The national PREM report is due to be published in November 2020. In order to publicise the findings and empower families with diabetes to use them to inform discussions about their child's care, the NPDA are commissioning another animation of the results, and uploading an online PREM clinic poster that will generate a bespoke results poster for the clinic chosen. These will both signpost parents and carers to where they can view and download their clinic's full report, which will present the quantitative analysis and comments received by parents and carers and children and young people with diabetes using the service.

We are also planning an online webinar for both paediatric diabetes professionals and parents and carers to launch the national report. This will enable us to present the key findings and answer questions on the analysis and how paediatric diabetes teams can work with their local families to improve any aspects of care identified as necessary based on their PREM reports. Our annual conference is usually co-hosted by one of our parent representatives, which helps us keep in mind the ultimate aim of the day, and the aim of the audit in general. Similarly, we are inviting a parent to present part of the webinar to amplify the quality improvement call to arms contained within the PREM report.

Now that face to face clinics are being restored, we are also sending hardcopy lay summaries incorporating the findings of both the 2018/19 core audit and the national PREM to all clinics in England and Wales for display in public areas. Both our parent representatives have been involved in the selection of content, messaging, and use of language within the document.

Clinic chats with children and young people

The pandemic has necessitated a pause in our main patient engagement activity for 2020, which is a programme of 'clinic chats' with children and young people with Type 2 diabetes aimed at finding out what this cohort understand about their condition, how they feel about living with it, and how they experience their care. Children and young people with Type 2 diabetes make up around 5% of the caseload of paediatric diabetes units and are often perceived to be 'hard to reach' via typical engagement routes. Rather than attempting to recruit participants to a workshop or similar, the NPDA in concert with Diabetes UK (one of the leading diabetes charities in the UK) commissioned the RCPCH's '&Us' patient engagement team to conduct a series of 'clinic chats' aiming to circumvent some of the typical barriers to patient engagement. The &Us team sought permission from hospitals in different regions to visit the waiting areas of their diabetes clinics on days when higher numbers of children and young people with

Type 2 diabetes would be visiting so that they could approach them to talk about their understanding and experiences of living with the condition. Several clinic chats were concluded before the lockdown, and the strategy was proving very successful in terms of engagement and information gathered. Consultation with our stakeholders resulted in a decision to pause our engagement until face to face clinics are reinstated. Subsequent clinic chats will be able to capture the impact of the pandemic on this typically vulnerable cohort's wellbeing and care.

Seeking parent and patient experience of telemedicine during the pandemic

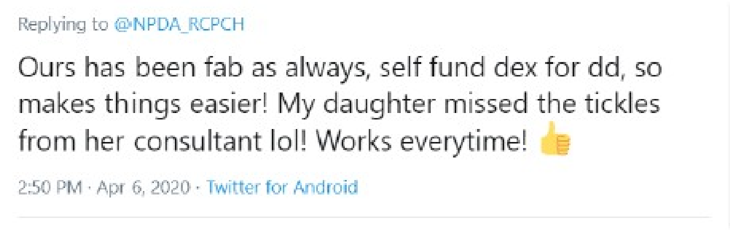
In March 2020, at the start of the COVID 19 lockdown, it was unclear how paediatric diabetes services would function. It was a time of great change and anxiety for clinicians and patients. Social distancing precluded the face to face sharing of information that had become the norm at regional and local paediatric diabetes network meetings and NPDA conferences and workshops.

The NPDA wrote to all paediatric diabetes clinics in England and Wales asking for examples of good practice they'd developed to adapt their care under new restrictions, with the aim of catalysing widespread adoption of successful new ways of working. New initiatives shared included drive through HbA1c blood testing clinics, virtual 'walk in' multidisciplinary clinics, and retaining the care of young people due to transition to adult services with the aim of reducing the pressure on overwhelmed adult colleagues and providing consistent care to this vulnerable cohort.

Replying to @NPDA_RCPCH and @CYPDN_Midlands

I'm all for keeping them out of ANY doctors offices when the visits are just routine and to talk. To many germs during flu time etc not to mention now

8:17 PM · Apr 6, 2020 · Twitter for Android



Replying to @NPDA_RCPCH

Ours has been fab as always, self fund dex for dd, so makes things easier! My daughter missed the tickles from her consultant lol! Works everytime! 👍

2:50 PM · Apr 6, 2020 · Twitter for Android

Replying to @NPDA_RCPCH

We experienced clinic a couple of weeks ago, it was what we expected, Harrys pod and dexcom downloaded and we went through everything and made a few changes, Thankyou for all your doing to keep us informed and it's great to know your still at the end of the phone when needed

10:38 AM · Apr 10, 2020 · Twitter Web App

At the same time, the NPDA also sought feedback from young people with diabetes and parents and carers on Twitter about their experiences of remote care (see above). We incorporated these comments and artworks/photos submitted in support of their teams and the NHS by children with diabetes into a document containing the submissions by teams, and disseminated this to all clinics in April.

Conclusion

All the NPDA's activities and outputs are informed by involvement with children and young people with diabetes or their parents and carers from conception, which ensures that they are aligned with the needs of these groups and appropriately communicated. We believe that quality improvement activities are most successful when clinical teams and service users work together, so our parent and patient focussed outputs are designed to empower them to recognise good care and meaningfully collaborate with clinicians to support required improvements where identified.

The COVID-19 pandemic has impeded only a fraction of our engagement with families with diabetes, and the move to meeting via Microsoft Teams has indeed facilitated our engagement with our parent representatives. Working remotely during the pandemic has forced us to develop video conferencing skills and new ways to collaborate, which we will likely maintain as life returns to normal. A move to online events will enable us to engage a much wider lay audience than has been possible at previous face to face conferences and workshops.