

First Year of Care Parent and Patient Reported Experience Measures (PREMs) 2024

July 2023 – January 2024



Foreword

Living with diabetes can be challenging, particularly around the time of diagnosis, not just for the child but also for their parents and family. Understanding these challenges is crucial for improving care and advising support networks and funding bodies.

This Parent and Patient Reported Experience Measure (PREM) aims to capture these experiences in a comprehensive and meaningful way.

Both children and young people and their parents and carers showed overwhelming positivity about their relationship with paediatric diabetes teams, with 99% reporting positive relationships with their team. Paediatric Diabetes Units should be congratulated and highly commended for this.

However, there are areas which need addressing such as the understanding of DKA, free access to technologies and the availability of the whole paediatric diabetes multidisciplinary teams (MDT) at clinic visits. Furthermore, this PREM has uncovered the significant impact on parent/carer employment following diagnosis in a child, and a worrying influence on disrupted sleep in parents and carers.

This PREM sets the stage for a thoughtful, comprehensive assessment that respects the lived experiences of both children and young people and their parents/carers, aiming to improve their quality of life and the care they receive. It remains important that we acknowledge that excellence in care is a two-way process and it is vital that we listen and learn from the lived experience.



Professor Justin Warner
NPDA Clinical Lead

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Further information:

Further information on the background, aims, and scope of the NPDA is available at:

<https://www.rcpch.ac.uk/work-we-do/clinical-audits/npda/about>

Extended analysis:

Extended analyses of the 2023 First Year of Care PREM, acknowledgements, and a glossary of terms used in this report are available on our **PREM reports page**.

Quantitative data has been made available where there were more than 10 responses to either the Parent and Carer or Child and Young Person questionnaire. This can be downloaded on our **data files page**.

Introduction

The National Paediatric Diabetes Audit (NPDA) is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP).

HQIP is led by a consortium of the Academy of Medical Royal Colleges, and the Royal College of Nursing. Its aim is to promote quality improvement 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 dependences.

“

'Patient experience' is what the process of receiving care feels like for the patient, their family and carers. It is a key element of quality, alongside providing clinical excellence and safer care... If safe care and clinical excellence are the 'what' of healthcare, then experience is the 'how'. Starting with the patient, listening to their needs, and designing the experience to meet these needs is achievable and results in an environment where individual patients feel cared for and supported.

”

**The Patient Experience Book (2013),
NHS Institute for Innovation and
Improvement**

Parent and Patient Reported Experience Measures (PREMs)

This national report covers the experience that children and young people and parents and carers receive in their first year of care for diabetes, as they interact with the NHS through attending Paediatric Diabetes Units (PDUs).

The PREM surveys were open to children and young people who have had diabetes for between 6 and 18 months, and their parents and carers. The surveys were available online between 24th July 2023 and 23rd January 2024.

Collecting PREMs data complements the routine collection of other health checks and diabetes outcomes by:

1

Enabling children and young people with diabetes and their families to provide anonymous feedback on what they value about their care and how it could be improved

2

Assessing whether care provided is meeting standards considered important by children and young people with diabetes and their families

3

Providing local teams with insights into the experiences of the families they serve that can be used to improve engagement with outcomes

Participation

There were 2712 PREM responses received, of which 726 were from children and young people and 1986 from parents and carers.

Based on the number of parent/carer responses, this represents approximately 34% of the total number of eligible (newly diagnosed) children and young people over the data collection period.

Of the 172 PDUs included in the NDPA and eligible to participate, 170 (99%) achieved at least one response to either the child/young person or the parent/carer survey.

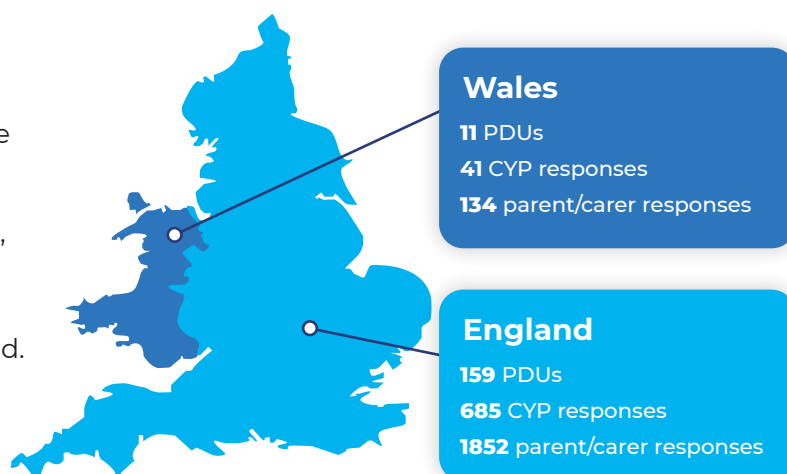
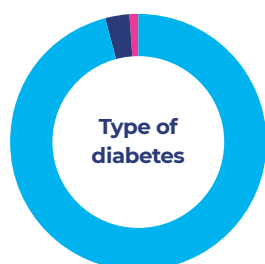


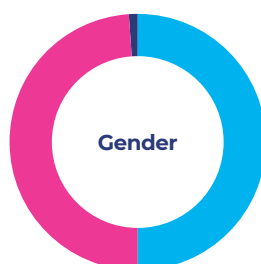
Figure 1: Participation in the 2023 First Year of Care PREM in England and Wales.

Participation Demographics:

The demographics of children and young people represented in the 2023 First Year of Care PREM is similar to those included in the 2021 PREM* apart from age, which tends to be younger.



96% Type 1
3% Type 2
1% Other



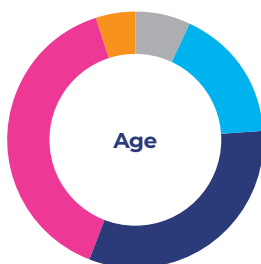
50% Male
49% Female
32% Gender not listed/
Prefer not to say



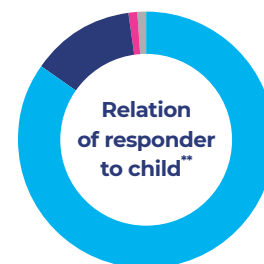
23% 6 – 8 months
28% 9 – 11 months
47% 12 – 18 months



80% White
7% Asian
4% Black
6% Mixed
1% None of the above
2% Prefer not to say



7% 3 years or younger
17% 4 – 7 years old
32% 8 – 11 years old
39% 12 – 16 years old
5% 17 years or older



84% Mother
13% Father
1% Grandmother
0% Grandfather
1% Other guardian

**parent/carer survey only

*Note: The 2023 NPDA PREM only included children and young people in their first year of care following diagnosis. The 2021 NPDA PREM included all children and young people with diabetes, regardless of the duration post diagnosis.

Key Messages and Recommendations

KEY MESSAGE 01

Diabetic Ketoacidosis (DKA) at Diagnosis

"Did you/your child have DKA at diagnosis?"



Diabetic Ketoacidosis (DKA) is a life-threatening complication of diabetes where there is a severe lack of insulin in the body.

15% are unaware of whether they or their child had DKA at diagnosis. The rate of DKA at diagnoses reported by respondents was 44%, which is higher than the rate of DKA at diagnosis in the **NPDA Report on Care and Outcomes 2022/23** (**23.3%** in 2022/23). There was regional variation (Figure 2).

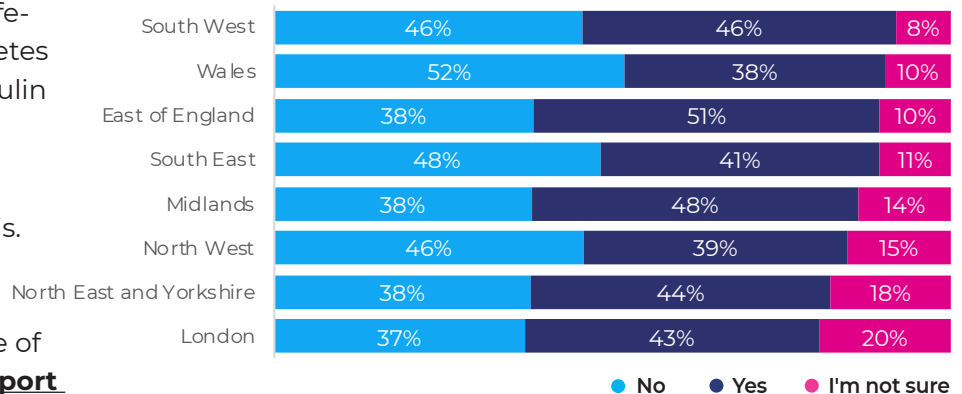


Figure 2: Parent and carer responses to the question "Did your child have diabetic ketoacidosis (DKA) at diagnosis?" by NHS region in England and Wales.

Recommendation 1

Ensure families are educated about the importance of understanding the process of DKA, as this can be a life-threatening complication. Resources should be created to support families at diagnosis in understanding DKA and these should be clearly signposted.

Action by: National Children and Young People's (CYP) Diabetes Network and PDUs.

KEY MESSAGE 02

Structure of Care

"Does your clinic have an area for your child to wait that is appropriate for their age?"
"How do you prefer to see your diabetes team?"



Parents/carers and children and young people are happy with the age appropriateness of the clinic waiting area (**93%** and **87%** respectively).

Most respondents prefer to sometimes see all members of their diabetes team together, while a small percentage prefer to always see the members of the diabetes team individually (Figure 3).

"Every time I have an appointment, it's with the entire diabetic team and I find it a bit scary to open up completely to my doctor about my problems."

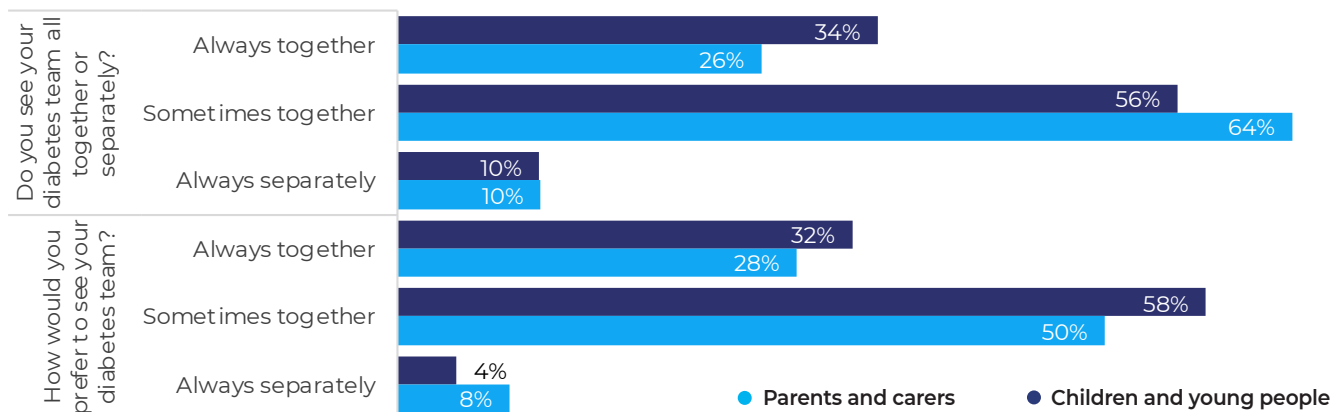


Figure 3: Preference of appointment structure by respondent, excluding those who answered "I don't know", in England and Wales.

For **81%** of parents and carers and **79%** of children and young people, preference of appointment structure matches reality.

Clinic waiting areas should be age appropriate, and diabetes multidisciplinary teams should respect how families wish to be consulted.

KEY MESSAGE 03

Availability of Specialist Advice

"Are you able to contact a member of the diabetes team for advice during core team hours and get appropriate advice about your child's diabetes 24 hours a day?"

"Since diagnosis of diabetes, how have you received support from your diabetes team members?"



82% of parents and carers are always able to contact their diabetes team during core 9am-5pm hours, and **71%** can always access advice 24 hours a day (Figure 4).

Almost all (**97%**) of the respondents received face-to-face support. **85%** of parents and carers and **60%** of children and young people received support via telephone contact. Over half of parents and carers received support via hospital ward visits, home visits, or school visits.

"I found the WhatsApp contact in the first few weeks really helpful."

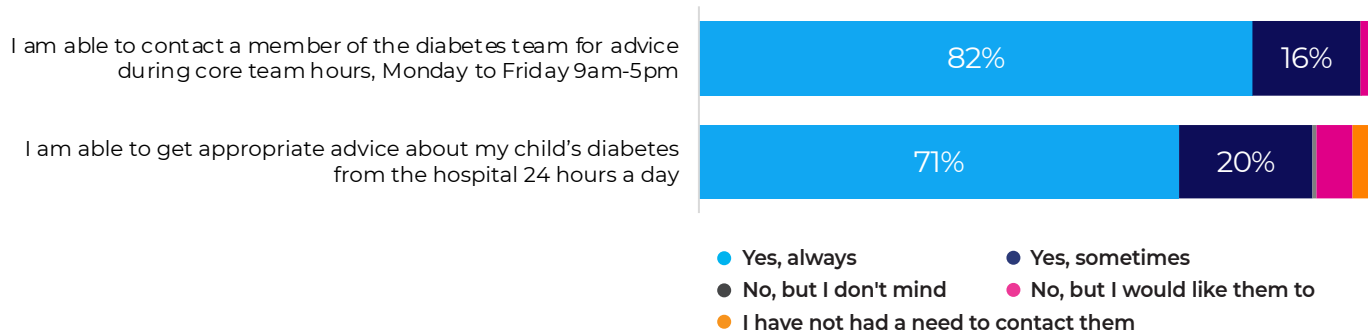


Figure 4: Availability of diabetes advice in England and Wales, excluding those who answered "I don't know". This question was only asked of parents and carers.

Recommendation 2

Families should have 24-hour access to advice by a fully trained and experienced expert in managing paediatric diabetes emergencies. Teams should ensure that families know how to access this advice.

Action by: Integrated Care Boards across England and Local Health Boards across Wales.

KEY MESSAGE 04

Multidisciplinary Input

"Were you able to see the following members of the team during your appointments with the diabetes team?"



Most parents and carers were able to see a diabetes doctor (**82%**) and a children's diabetes specialist nurse (**84%**) at every visit. This was less so for dietitians (**46%**) and for psychologists (11%) who they could see sometimes when requested and/or pre-arranged (Figure 5). Access to a psychologist at every visit was very variable across integrated care boards and local health boards, ranging from **0%** to **48%**.

"I think there should be therapy/ access to a psychologist for parents and children."

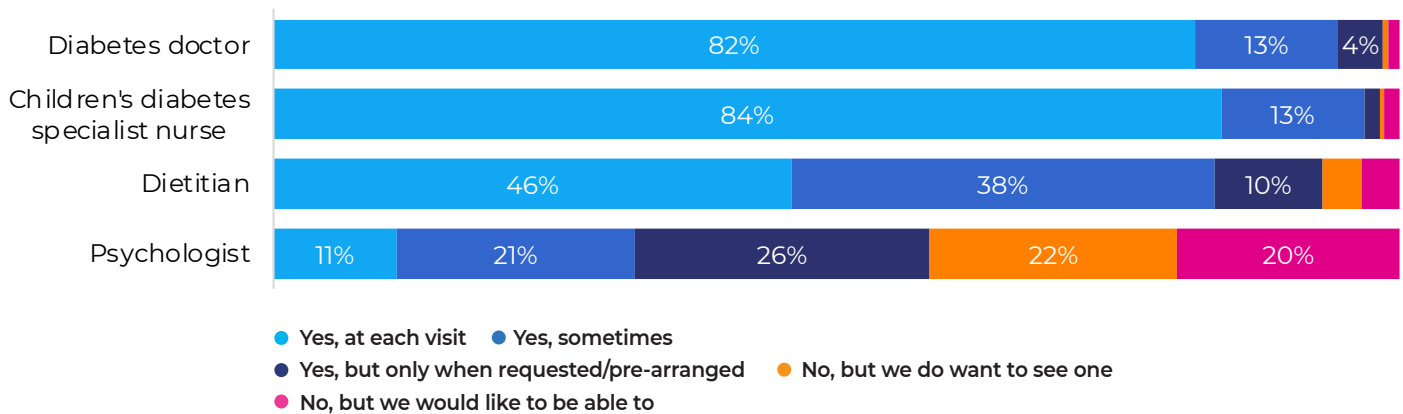


Figure 5: Responses to the statement "We are able to see the following members of the team during our appointments with the diabetes team" in England and Wales. This question was only asked of parents and carers.

Recommendation 3

All newly diagnosed children and young people and their parents and carers should be provided with full multidisciplinary team support, including a diabetes psychologist.

Action by: Integrated Care Boards across England and Local Health Boards across Wales.

KEY MESSAGE 05

Access to Technologies

“Have you/has your child been offered any of the following diabetes related technologies?”



A quarter (**23%**) of respondents were not offered an insulin pump or a hybrid closed loop system, but report that they would like to use one (Figure 6). **2.7%** of CYP were not offered either flash glucose monitors or continuous glucose monitors (CGM) and **6.6%** were not using either flash glucose monitors or CGM.

Children under the age of 12 were more likely than those 12 years or older to be offered an insulin pump, continuous glucose monitor or a hybrid closed loop system.

“I would have preferred to receive information about insulin pumps.”

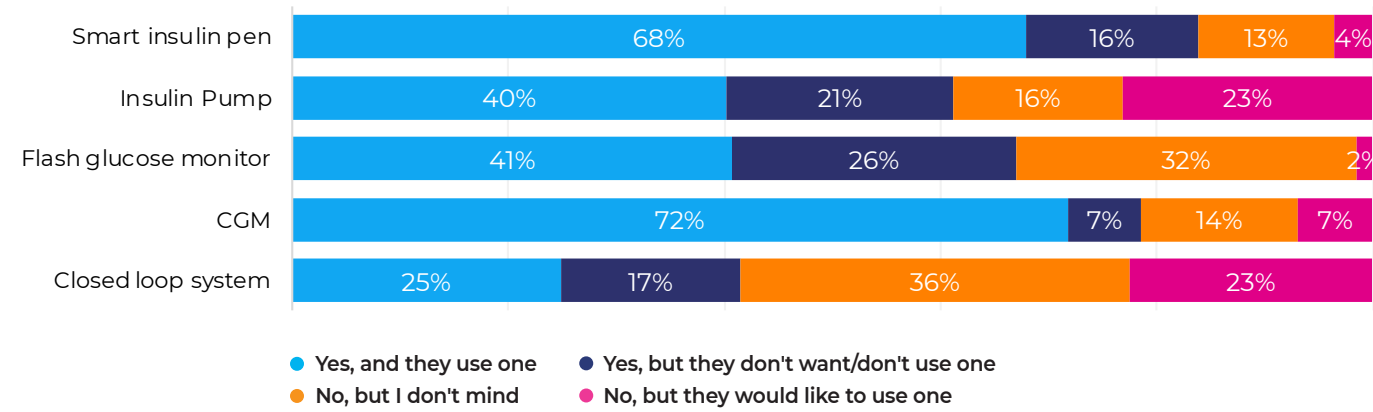


Figure 6: Responses to the question “Have you/Has your child been offered any of the following diabetes related technologies?” by technology, in England and Wales. This question was asked of both parents and carers and children and young people. PREM data collected July 2023 to January 2024. The National Institute for Health and Care Excellence (NICE) recommended Hybrid Closed Loops (HCL) for all children and young people with Type 1 Diabetes in the Technology Appraisal published December 2023. In England and Wales, a HCL 5-Year Implementation Strategy was launched in 2024.

Recommendation 4

Diabetes technologies should be offered to all children and young people with diabetes in England and Wales in line with the NICE guidelines.

The NPDA will continue to support the provision of data to inform the NHS England Hybrid Closed Loop 5-year implementation strategy.

Action by: Integrated Care Boards across England and Local Health Boards across Wales.

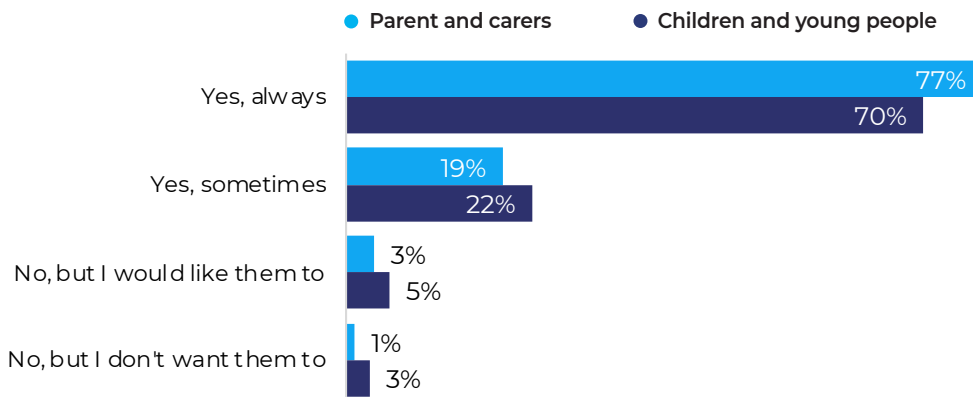
KEY MESSAGE 06

Information for Schools and Colleges

"Does your diabetes team ensure that staff at your/your child's school/college have the necessary information about their diabetes in order to help them?"



The vast majority of parents and carers and children and young people felt that schools and colleges were kept well informed with information about diabetes (Figure 7).



"They have supported with school day-to-day and special events, such as residential trips."

Figure 7: Responses to the statement "Our diabetes team ensure that staff at my/their school/college have the necessary information about my/their diabetes in order to help me/them", excluding 'I don't know' and "Not applicable" responses, by respondent in England and Wales.

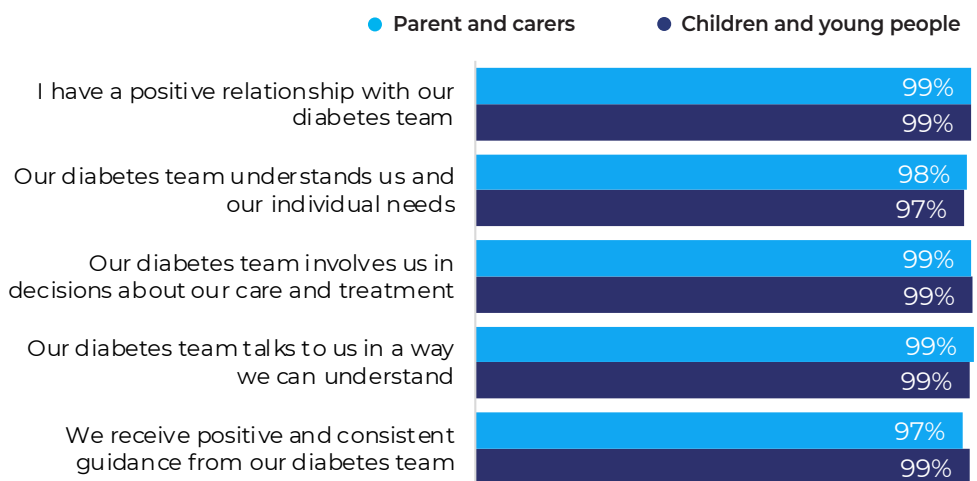
KEY MESSAGE 07

Relationship with the Diabetes Team

"Thinking about your/your child's care since you/they were diagnosed, do you have a positive relationship with your diabetes team?"



99% of respondents have positive relationships with their paediatric diabetes team and 97% receive positive and consistent guidance from their diabetes team (Figure 8). The vast majority (**95%**) report that their diabetes team always respects their religious and cultural beliefs.



"They care for me as a person rather than just a client."

Figure 8: Percentage of respondents answering "Yes, always" or "Yes, sometimes" to each statement by respondent in England and Wales, excluding "I don't know" responses.

This key message is very positive and does not require a recommendation. Suffice it to say, PDUs should be congratulated on their positive relationships with children and young people with diabetes and their parents/carers during the early months post diagnosis.

KEY MESSAGE 08

Impact on Employment

“Have the diabetes care needs of your child impacted your/your partner’s employment?”



Parents/carers’ employment may be disrupted by their child’s diabetes care needs.

30% of parents/carers reported that they or their partner reduced their working hours, and **11%** left employment (Figure 9).

Only **29%** were asked by their paediatric diabetes team about financial challenges that may impact on their child’s diabetes management (Figure 10).

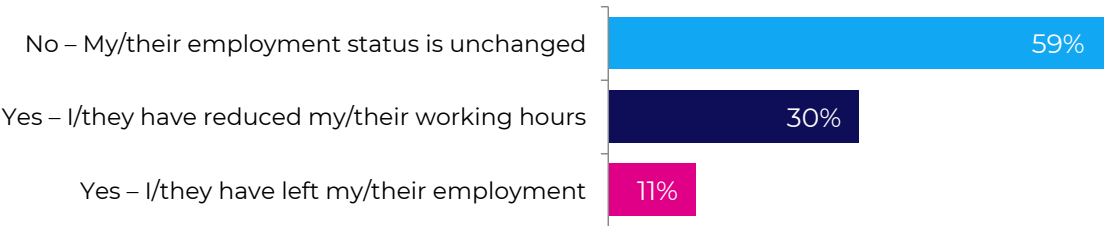


Figure 9: Responses to the question “Have the diabetes care needs of your child impacted on your/your partner’s employment?” in England and Wales, excluding “Not applicable” answers. This question was only asked of parents and carers.

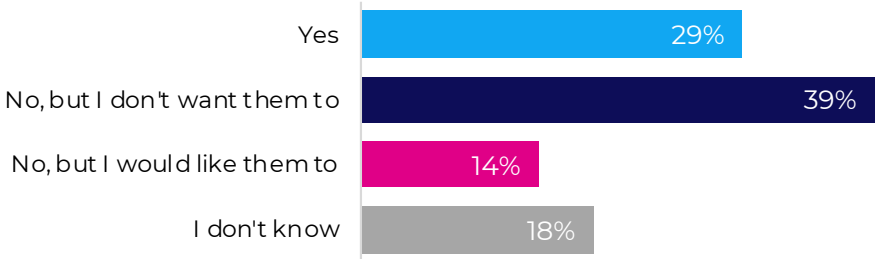


Figure 10: Responses to the question “Have your team asked you about any financial challenges faced by your family that may impact your child’s diabetes management”, excluding ‘I don’t know’ responses, in England and Wales. This question was only asked of parents and carers.

Recommendation 5

Paediatric diabetes teams should be provided with the skills and training to be able to ask each family about any financial challenges they face. Teams should be signposting to national and local sources of information and support families with diabetes experiencing financial hardship.

Action by: Diabetes charities, such as Diabetes UK and Breakthrough T1D (formerly JDRF), and the National Children and Young People’s (CYP) Diabetes Network



KEY MESSAGE 09

Stress and sleep

“Compared with your sleep before your child’s diabetes diagnosis, has there been a disturbance to your normal sleep pattern, either quality or length of sleep?”



64% of parents/carers report that their sleep is disrupted more than once a week due to stress relating to their child’s health (Figure 11). Parents/carers with younger children with diabetes have more disrupted sleep (Figure 12).

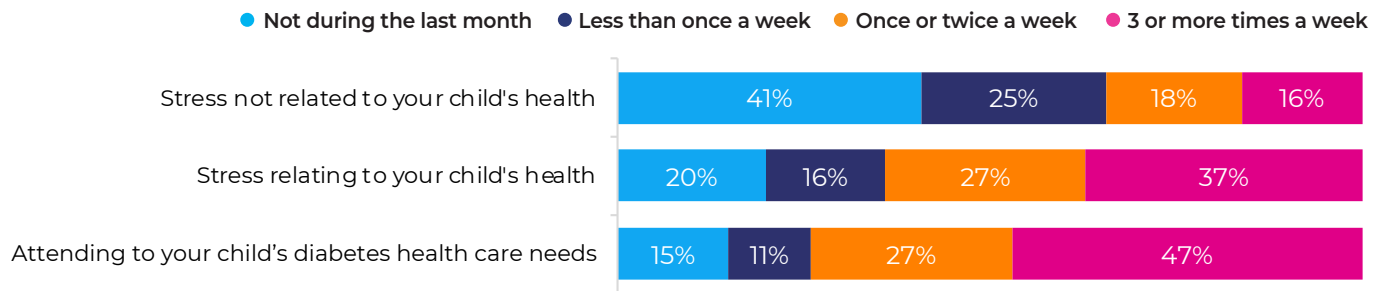
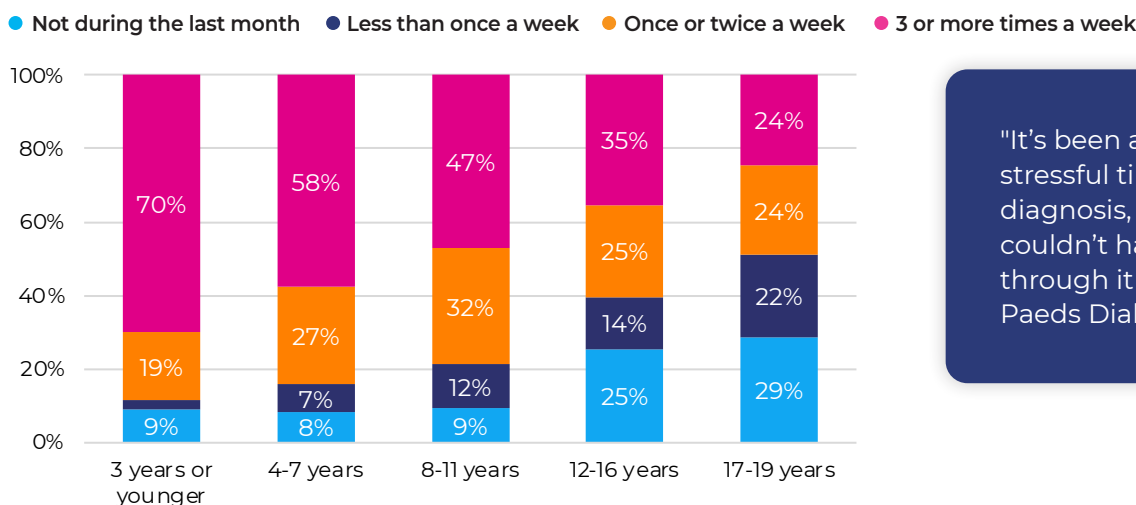


Figure 11: Responses to the question “Compared with your sleep before your child’s diabetes diagnosis, has there been a disturbance to your normal sleep pattern, either quality of sleep or length of sleep” by reason for disturbed sleep. This question was only asked of parents and carers.



“It’s been an extremely stressful time since diagnosis, but we couldn’t have got through it without the Paeds Diabetic Team.”

Figure 12: Frequency of sleep disturbance due to “Attending to your child’s diabetes health care needs” by the age of the child or young person.

Recommendation 6

PDUs should be aware of the high levels of disrupted sleep following diagnosis of diabetes. Studies should be funded to understand the impact of a diabetes diagnosis on parent and carer wellbeing, including quality of sleep, and the factors that may mitigate this impact, such as diabetes technologies. Families should be offered psychological support after a diagnosis of diabetes.

Action by: Funding bodies such as the National Institute for Health and Care Research (NIHR), Integrated Care Boards across England, Local Health Boards across Wales, and the National Children and Young People’s (CYP) Diabetes Network.

PREM Scores

An overall PREM score was constructed to facilitate comparison of performance between PDUs. This was calculated using the questions that had clear positive or negative response options and that measured performance or experience. The overall PREM score is defined as the percentage of responses to these questions that were positive. Both the parent and carer and child and young person questionnaires were included in this analysis.

A “perfect” overall PREM score would be 100%, which would be achieved if all respondents responded to each question with the most positive possible response. There was an overall average PREM score of 75%, compared to 71% in the 2021 PREM (which included all children and young people with diabetes, regardless of time since diagnosis). There was little variability in performance, ranging from 60% to 89% (Figure 13).

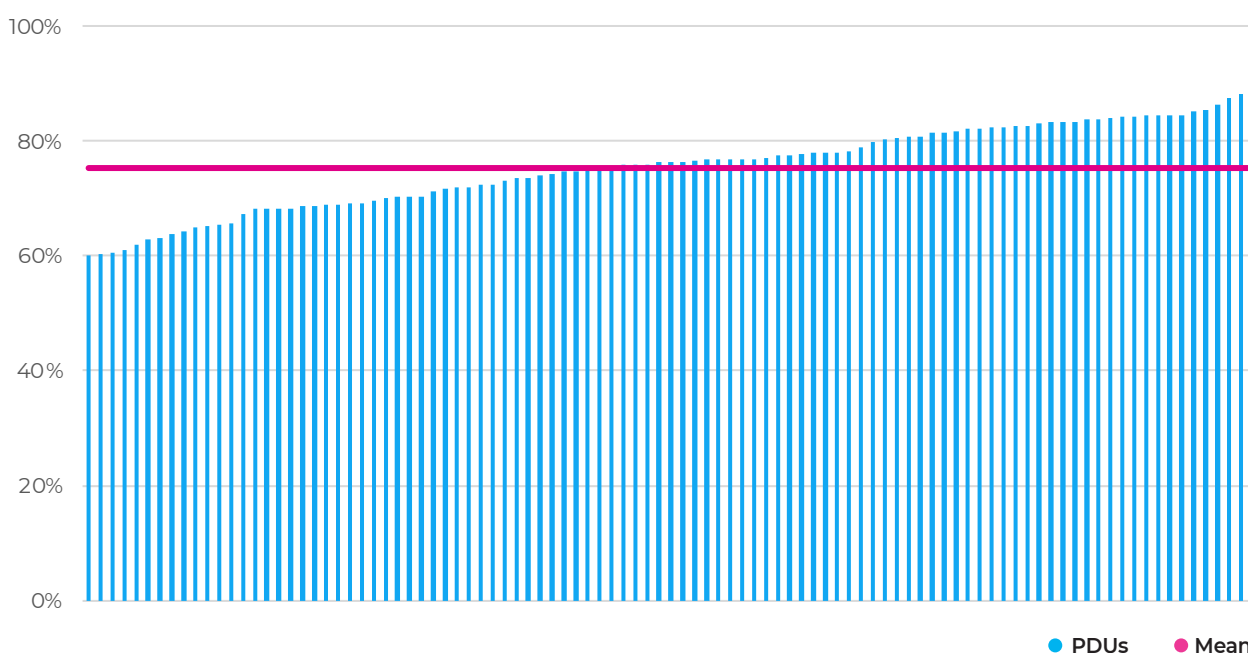


Figure 13: PREM scores by PDU in England and Wales. This only includes PDUs with at least 10 responses

Quality Improvement Resources

The [**RCPCH Diabetes Quality Improvement Website**](#) provides multidisciplinary teams with the tools to identify, design and analyse their own interventions specific to the needs of the children and young people and their families that they care for.

A slide deck is available on the [**NPDA PREM reports page**](#) for teams to customise with their own results, with prompts for team discussions around results, and links to relevant QI resources.

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