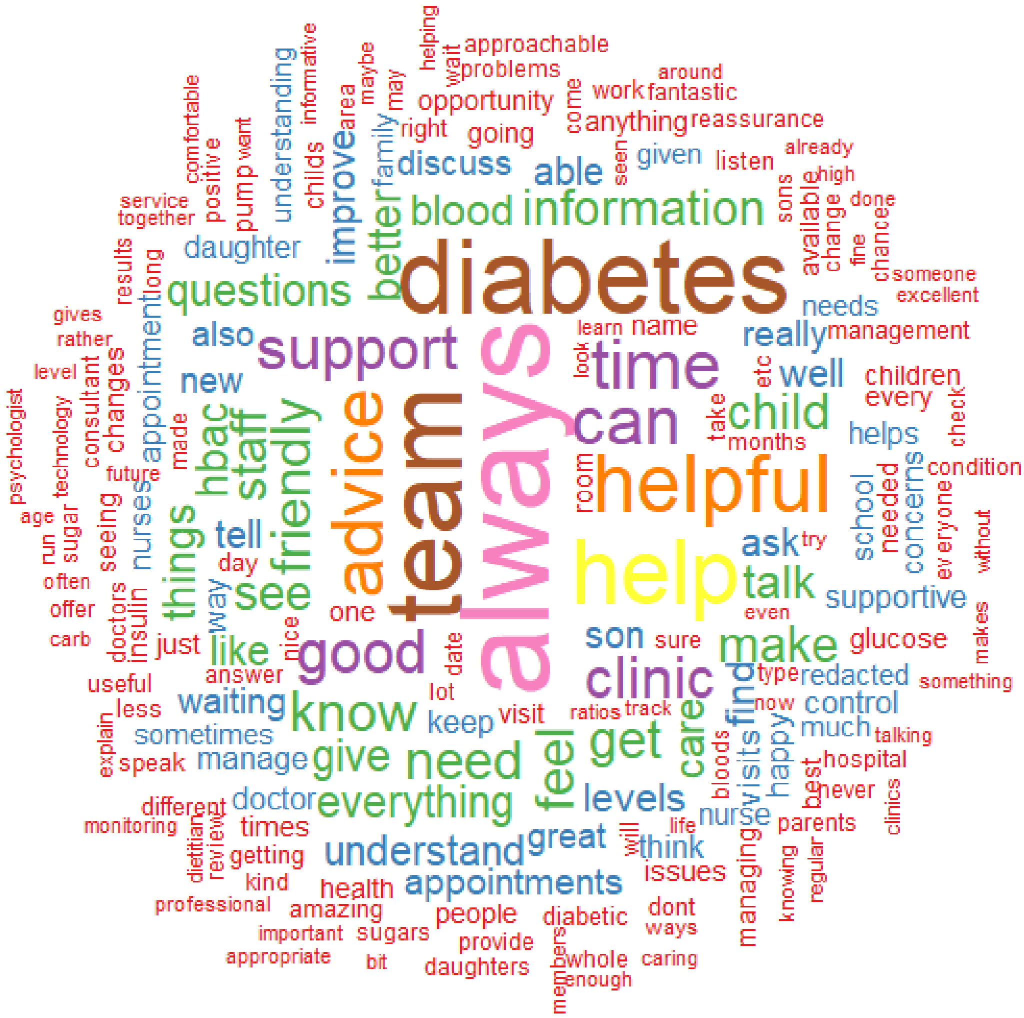
NPDA
National Paediatric
Diabetes Audit

RCPCHAudits

Parent and Patient Reported Experience Measures (PREMs)

2019



HQIP
Healthcare Quality
Improvement Partnership

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

The word cloud on the cover of this report was created in R software, using all comments received from children and young people with diabetes and their parents/carers who completed the survey in response to the questions "What do you find helpful about your clinic visits", and "What could your diabetes team do to make your clinic visits better?" The size of the words in the display indicates frequency of usage, with larger words being used more often. The word cloud was generated from 200 of the most used words, excluding conjoiners, and the word 'nothing' which was a common response to the second question, making it appear large, centrally, and incongruently before its removal.

Parent and Patient Reported Experience Measures (PREMs) 2019

This report has been prepared with support from:

1. The Royal College of Paediatrics and Child Health (RCPCH)

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It aims to:

- advance the art and science of paediatrics
- raise the standard of medical care provided to children
- educate and examine those concerned with the health of children
- advance the education of the public (and in particular medical practitioners) in child health; which means the protection of children, the prevention of illness and disease in children and safeguarding their optimal development.

2. The Healthcare Quality Improvement Partnership (HQIP)

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, the Royal College of Nursing, and National Voices. 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 dependencies www.hqip.org.uk/national-programmes.

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Forewords

Twelve years ago I didn't realise it but I was about to start what seems a lifetime of sleepless nights and perpetual worry. My son was diagnosed with Type I diabetes, he was 2. I knew nothing of the condition, nothing of 'the science', to use a current phrase; nothing of the complications, medical or social.

Like all parents caught in such a situation I was scared, confused, lost and found wanting. With the help of our regional Paediatric Diabetes service my family landed on our feet, as so many families have. We were taken under the wing of the local paediatric diabetes multidisciplinary team. Professionals supported, in part, by the information and guidance the Audit offers. I now know a little of what goes on behind the scenes, but then, nothing.

Diabetes is not just a health scare for the child, it has the potential to rip families apart and leave them floundering in a sea of despair, buoyed along by too much and yet, not enough information, and sadly the ever present popular dis-information.

Last year I was given two opportunities to give something back. The first, which I often use as a frame of reference to remind me what it was like over a decade ago, was when a friend joined the ranks of worried-exhausted parents. Her 12 year old was diagnosed Type 1 Diabetes and I found I could help her through some of the pitfalls and dark spots, having fallen in them myself. For each of us they were different, yet somehow the same. The second, I was delighted to be invited to the RCPCH Diabetes Audit project board. It was/is a genuine pleasure to see the progress in care across the board, but of even greater impact is the ubiquitous dedication from all the involved professions. It is this dedication which I believe is reflected in the results of this PREM. With over 13,000 responses this is a good reflection not only of the affected families' engagement, but also a good reflection on the centres' commitment to seeking feedback.

As you will find, time and again, the majority of responses are positive: enough information; continuity of care; respect; would recommend their clinic to my friend. This is not to say there is no room for improvement, as a few findings will illustrate, but that the over-all responses reflect the overall state of play, and that is one in the right direction.

Having a strong relationship with my son's diabetes team I can say that the Audit overall has a positive impact on the unit's approach, they are always looking to improve care for their children and young people and recognise the Audit is there to help do just that. It is in that vein, as a card carrying member of the worried-exhausted parents guild that I happily commend this report to readers from all walks of life.

Mr Simon Lewthwaite, NPDA Parent representative

The NPDA is increasingly aware of the importance of involving and encouraging the patient and parent voice to help shape services for children and young people with diabetes. Listening to what the 'customer' has to say is vitally important in any business development, so why should it be any less so in healthcare. The England and Wales NPDA has led the world in the development of patient/parent experience measures for paediatric diabetes care and it is a pleasure to introduce this National Report based on a survey of over 13,000 responses. Coping and living with diabetes on a day-to-day basis places a large burden and stress on families and any efforts that could be made to reduce this should be advantageous.

In this national Patient/Parent Reported Experience Measure (PREM) there is much to celebrate as overall, patients and parents rate their satisfaction as very high. However, there is always room for improvement and I would urge centres providing care to utilise this wealth of feedback in their aim to provide a 'Rolls-Royce' service. As Bryant McGill wrote (author and United Nations global champion); "one of the most sincere forms of respect is actually listening to what another has to say". Please heed this advice carefully and use this report along with your unit level report to help shape your service for the better. The families living with diabetes have spoken – now's the time to listen.

J. Warner

Professor Justin Warner, NPDA Clinical Lead

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Glossary of terms used in this report

Child centred care
Healthcare tailored to the needs and preferences of the child, who is treated respectfully, compassionately, listened to and involved in decisions about their care.

Clinical Commissioning Groups (CCGs)
Clinical Commissioning Groups are clinically-led NHS bodies in England responsible for the planning and commissioning of healthcare services for their local area.

Continuous glucose monitor (CGM)
A small device that you wear just under your skin. It measures your glucose levels continuously throughout the day and night, letting you see trends in your levels and alerting you to highs and lows.

Flash glucose monitor
Another small device worn just under the skin. It also measures glucose levels continuously, which can be read by scanning its sensor. It does not give alerts, unlike a CGM.

Glucose
A blood sugar which acts as a major source of energy for the body.

Glucagon injection
A treatment for severe hypoglycaemia (low blood glucose) that raises the level of glucose in the blood.

HbA1c
HbA1c is glycated haemoglobin. Your HbA1c level gives an indication of average blood glucose levels in the three months before the HbA1c blood test.

Healthcare Quality Improvement Partnership (HQIP)
An independent established organisation to promote quality in healthcare, to increase the impact that clinical audit has on healthcare quality improvement.

Insulin pump therapy
A small electronic device attached to the body, which continuously delivers insulin beneath the skin via a tiny tube called a cannula.

Ketones
A ketone is a chemical substance that the body makes when it does not have enough insulin in the blood.

Multidisciplinary team
A group of healthcare workers who are members of different disciplines (e.g. nurses, diabetes specialist nurses, psychologists), each providing specific services to the patient.

NICE
The National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care.

Sick day rules
Guidance for managing blood glucose levels during illness or infection.

1. Introduction

Diabetes is a condition where the amount of glucose in the blood is too high because the body cannot use it properly. High blood glucose levels over time are associated with an increased risk of developing complications associated with diabetes including damage to small and large blood vessels and nerves. If not managed, this can result in blindness, kidney failure, heart disease, stroke, and amputations. However, with good diabetes care and blood glucose control, the risks of complications are markedly reduced, enabling children and young people with diabetes to live a healthy, happy and longer life.

The National Paediatric Diabetes Audit (NPDA) was established to compare the care and outcomes of all children and young people with diabetes receiving care from Paediatric Diabetes Units (PDUs) in England and Wales. The audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP), funded by NHS England and the NHS in Wales, and is managed by the Royal College of Paediatrics and Child Health. The core NPDA involves annual submission of data from every child or young person receiving care from paediatric diabetes units (PDUs) in England and Wales. The overarching aim of the NPDA is to improve care and outcomes for children and young people living with diabetes in England and Wales. This national report covers the experience that patients and parents/carers receive as they interact with the NHS through attending Paediatric Diabetes Units (PDUs) providing care.

Measuring parent and patient experience

> ***"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**

Collecting Patient/Parent Reported Experience Measures (PREMs) data complements the routine collection of other health check and diabetes outcomes data for the NPDA by:

- 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
- assessing whether care provided is meeting standards considered important by children and young people with diabetes and their families
- providing local teams with insights into the experiences of the families they serve that can be used to improve engagement and outcomes

Previous PREM data collected by the NPDA in 2012/13, 2013/14 and 2015/16 were used to produce local reports for PDUs only. This is the first national PREM report published by the NPDA.

2. PREM survey development

Analysis of the 2015/16 PREM data showed that children and young people with diabetes were scoring their local clinics highly on many of the measures within the questionnaires which, although important, reduced the utility of the data for benchmarking purposes, or for highlighting areas for improvement. The RCPCH therefore commissioned the Picker Institute, an international charity specialising in measuring patient experience, to develop the 2018/19 PREM free from the 'ceiling effects' (overly positive scoring) observed in the previous surveys.

The following stages were conducted by the Picker Institute to develop and validate the PREM reported here:

1. Desk based research

A review of guidelines for delivering diabetes care (e.g. NICE Guidelines and Quality Standards), and of the existing previously used PREM questionnaires (parent and child versions).

2. Qualitative research

Focus groups were held with parents, and children and young people with diabetes in different age groups in Cardiff, Leeds, and London.

Topic guides were compiled for each of the different groups, which included:

- important aspects of diabetes care
- access to diabetes care
- information and involvement
- management of condition
- support (including support in school)
- transition to young adult clinics (where relevant)

3. Questionnaire design

The survey questions were developed from findings from the desk research, themes arising from the focus groups, reference to existing PREM questions for paediatric diabetes care and the Picker Institute's pre-existing question bank. A stakeholder group including MDT members of the NPDA Project Board were consulted throughout development.

4. Cognitive testing

Following initial question design, a process of cognitive testing was conducted, during which the layout, wording and language were tested to check that all questions were understandable and that response options were relevant. The questionnaire was refined and adapted, with each new version being tested until no further problems were identified.

5. Pilot

The initial surveys were piloted by twelve PDUs across the North of England, the Midlands, the South of England and Wales, who volunteered to do so. The pilot was launched on Monday 6 August 2018 and concluded on Monday 29 October 2018 (12 weeks). A total of 629 respondents completed the survey, 324 of which were completed by children/young people (CYP) and 305 by parents/carers.

6. Psychometric testing

Once the pilot had concluded, the responses were subjected to a validation process to assess the 'performance' of each question measuring quality of care within the survey. This included scrutiny of:

- item response rates: to identify and remove questions with high levels of missing responses
- uninformative responses: to identify and remove questions with a high number of 'don't know' responses
- differentiation: to assess whether responses were varied enough to be able to differentiate clinic performance on the measure
- correlations: to identify and remove or modify questions highly correlated with each other indicating repeated measurement of similar aspects of care

Response rates and repetition within answers to the free text questions within the surveys were also scrutinised.

Following the validation process, a minority of survey questions were removed or modified to remove any superfluous or poorly performing items before the surveys were launched nationally.

3. Methodology

Each PDU in England and Wales appointed a lead contact for the PREM from within the MDT to aid awareness.

PREM leads within each PDU were each sent an information pack including tips on maximising response rates from previously successful PDUs, and a range of promotional materials for display or distribution to patients and parents/carers including posters, bookmarks and postcards. Template emails including a link to the survey for sending to parents to promote it were emailed separately. Further to feedback from pilot sites, patient/parent/carer participation was further incentivised by optional inclusion into a prize draw for a £50 Amazon voucher, details of which were included in the promotional materials and information.

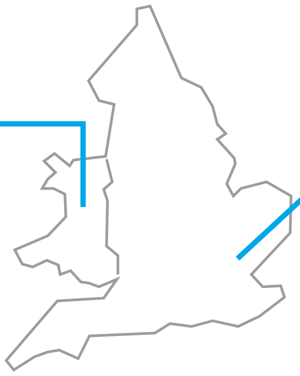
The surveys were conducted between 1 February 2019 and 31 July 2019 (six months).

4. Participation

Of the 175 PDUs included in the NPDA and eligible to participate, 174 (99.4%) achieved at least one response on either the patient or parent/carer survey. In total, 13,178 PREM responses were received, of which 6,165 were from children and young people and 7,013 from parents and carers.

The 2018/19 core NPDA contemporaneous to the 2019 PREMs survey captured information on 30,155 children and young people up to the age of 24 years under the care of a consultant paediatrician, giving a response rate of 20.4% for children and young people receiving care from a paediatric diabetes service.

The questionnaire took a mean of 16 minutes to complete. It was available on smartphones (17.0% of total responses), tablets (57.5%) and on the Web (25.6%). A total of 125 respondents completed the questionnaire in a language other than English, including Polish, Welsh, Urdu and Punjabi.



14 PDUs

316 CYP responses

457 parent/carer responses

161 PDUs

5,849 CYP responses

6,556 parent/carer responses

Table 1: Participation in PREM 2019, compared to NPDA 2018/19 report, by country and regional network

	PREM – 2019			NPDA – 2018/19	
	Total Responses	Children and young people (%)	Parents and carers (%)	Total CYP in core audit	CYP PREM response rate (%)
England and Wales	13,178	46.8%	53.2%	30,155	20.4%
England	12,405	47.2%	52.8%	28,676	20.4%
Wales	773	40.9%	59.1%	1,479	21.4%
East Midlands	923	49.9%	50.1%	2,038	22.6%
East of England	1,328	44.4%	55.6%	3,231	18.2%
London and South East	2,086	40.2%	59.8%	6,968	12.0%
North East and North Cumbria	1,186	54.6%	45.4%	1,650	39.3%
North West	1,725	48.1%	51.9%	3,756	22.1%
South Central	1,010	45.2%	54.8%	2,502	18.3%
South West	1,185	47.7%	52.3%	2,385	23.7%
West Midlands	1,378	49.9%	50.1%	3,206	21.5%
Yorkshire and Humber	1,584	48.7%	51.3%	2,940	26.3%

Table 1 shows the total numbers of respondents by country and regional network. In general, there was an equilibrium between the proportion of responses by parents/carers and children and young people, with a slightly higher percentage of parent/carer responses in the majority of regions. The response rates amongst children and young people attending a PDU varied from 12.0% in London and South East to 39.3% in North East and North Cumbria. It was not possible to calculate parent/carer response rates since it was not known how many had more than one child receiving care within a PDU or where more than one parent/carer filled in the questionnaire independently.

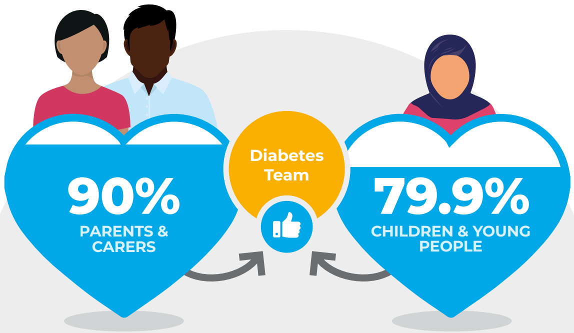
5 Key findings

5.1. Key findings: Quantitative analysis

Analysis of responses from children and young people with diabetes and their parents showed that:

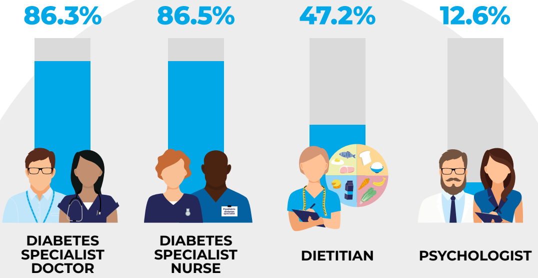
PREM survey completion

6,165 children and young people and **7,013 parents and carers** attending paediatric diabetes services in England and Wales completed a Patient Reported Experience Measure (PREM) survey. This equates to **1 in 5 children** receiving care completing a survey.



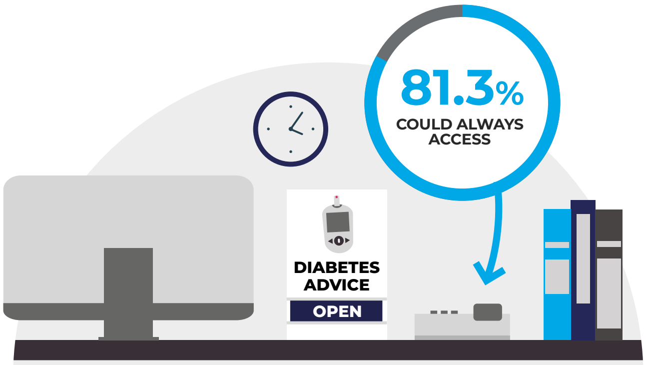
Relationship with diabetes teams

90.0% of parents and carers and **79.9%** children and young people agreed that they always had a **positive relationship** with their diabetes team.



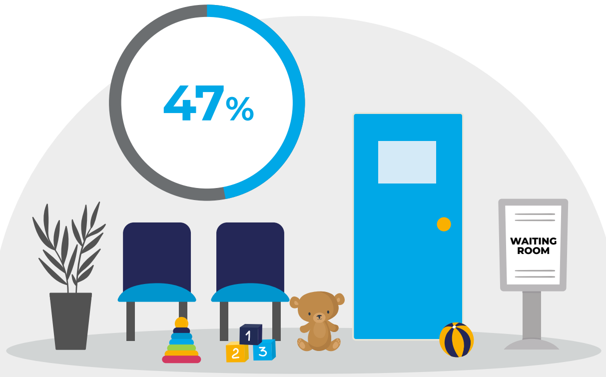
Availability of specialists

Amongst parents and carers, **86.3%** reported that they could see a diabetes specialist doctor at each visit, **86.5%** could see a paediatric diabetes specialist nurse at each visit, **47.2%** could see a dietitian at each visit, and **12.6%** could see a psychologist at each visit.



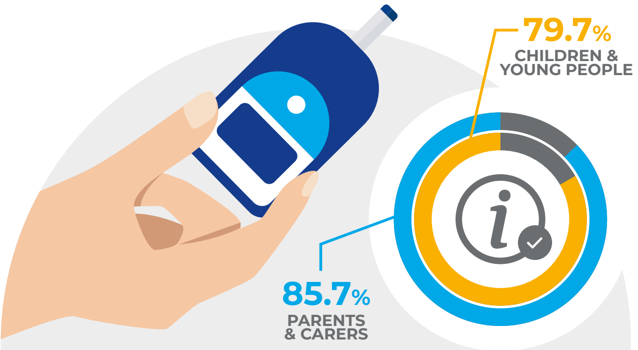
Access to specialist diabetes advice

81.3% of parents and carers said they could always access specialist diabetes advice during core hours. However, only **68.8%** said they could always receive advice 24 hours a day.



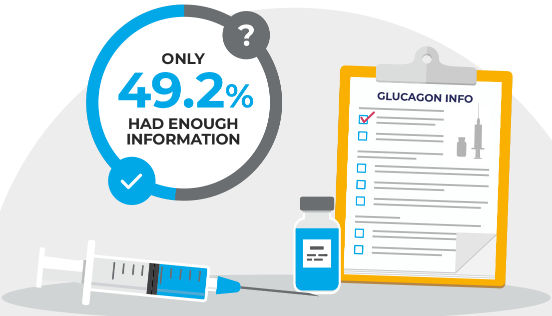
Appropriate waiting rooms

Less than half (47.0%) of all young people aged 12+ felt that the waiting area was appropriate for their age group.



Managing blood glucose

85.7% of parents and carers and **79.7%** of children and young people agreed they always received enough information to be able to manage high and low blood glucose.

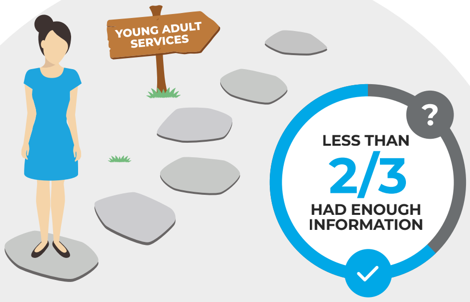


Glucagon preparation and administration

Only half (49.2%) of parents and carers felt they had received enough information on glucagon preparation and administration.

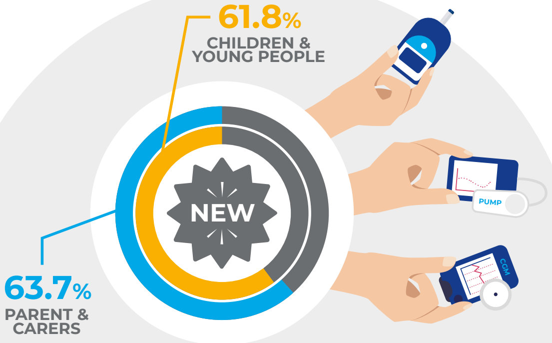
Managing diabetes at school

Three quarters of children & young people (**74.1%**) and parents & carers (**75.2%**) agreed that their diabetes team always gave them enough information to effectively manage their/child's diabetes at school/college.



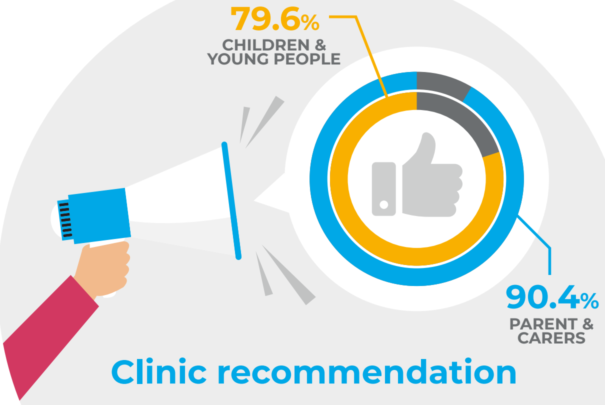
Transfer to adult care

Less than two thirds of parents and carers (**64.0%**) and children and young people (**58.2%**) agreed that their diabetes team were providing them with the information, resources and support needed to prepare for transfer to adult care.



Diabetes-related technologies

Less than **2/3** of parents and carers (**63.7%**) and CYP (**61.8%**) agreed that their diabetes team always kept them up to date with new diabetes-related technologies.



Clinic recommendation

Most (**90.4%** of parent and carers and **79.6%** of children and young people) would recommend their clinic to friends and family if they had diabetes.

Contact with other parents and carers

Less than two thirds (**59.1%**) of children and young people and parents/carers (**62.8%**) reported that their clinic made it possible to contact/spend time with other (parents and carers of) children and young people with diabetes.

Information about exercise

59.7% of children and young people and **67.4%** of parents/carers reported that they had received enough information about managing exercise.

5.2. Key findings: Qualitative analysis

Children and young people with diabetes and their parents and carers were asked two open-ended questions:

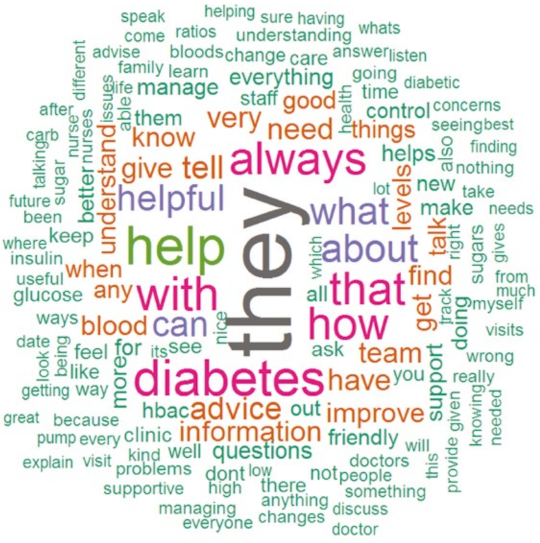
1) What do you find helpful about your clinic visits?

2) What could your diabetes team do to make your clinic visits better?

Responses were broken down into themes, coded, and quantified by the NPDA team. See page 46 onwards for a detailed breakdown of the themes emerging from all responses.

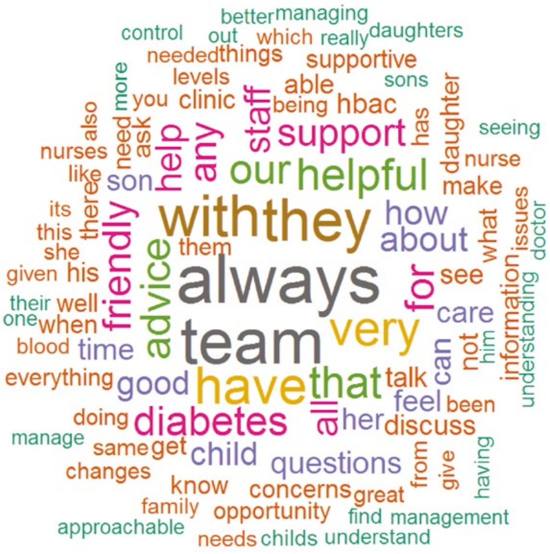
5.2.1. Summary: What do children and young people with diabetes find helpful about their clinic visits?

Analysis of the comments provided by children and young people about what they find helpful about their clinic visits suggested that:



- Children and young people with diabetes are not passive recipients of diabetes care and are interested in learning about the condition and how to self-manage to the best of their ability.
- Clinic visits provide a valued opportunity to monitor their diabetes management, keep track of trends in blood glucose management and receive reassurance, where applicable, that they are on the right track with their management.
- Diabetes team members are viewed positively by the children and young people under their care.
- Clinic visits are a valued support to children and young people with diabetes, providing an opportunity to address concerns, talk to trusted professionals about life with diabetes, and to receive encouragement to manage their diabetes effectively.
- Children and young people with diabetes value being understood as individuals, and being listened to and included in making decisions about their care.

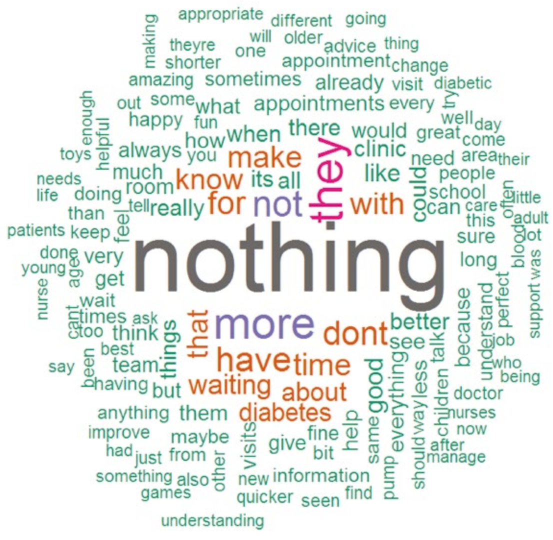
5.2.2 Summary: What do parents and carers find helpful about their clinic visits?



- Parents and carers and children and young people with diabetes, find similar aspects of diabetes clinic appointments helpful.
- Diabetes teams are viewed in similarly positive terms, with parents and carers highlighting their positive relationships with the team and consistency of staffing as helpful aspects of their diabetes clinic visits in particular.
- Clinic visits are valued as an opportunity to receive advice and information about diabetes management from a range of different professionals.
- Clinic visits also provide parents and carers with reassurance and support to help them cope with their child's diabetes, including addressing concerns and worries, and providing an opportunity to talk. Accessing support outside of clinic was also highlighted as helpful.
- Visits provide an opportunity to review blood glucose trends, to get an overview of their child's overall health, and to make changes to insulin dosage if found to be necessary.
- Parents and carers value open and honest discussions about their child's care, making collaborative decisions about care, and having care tailored to the needs of their child or family.

5.2.3 Summary: How could clinic visits be improved for children and young people with diabetes

Almost half of all children and young people who commented (49.1%) stated that they were happy with their clinic visits as they currently were, or that they couldn't think of an improvement. Analysis of comments in response to this question suggested that:



- Time spent waiting before the start of appointments could be reduced to improve the experience of some.
- Whilst waiting for their appointment, children and young people with diabetes would like access to age-appropriate activities and refreshments.
- Changes to the frequency and length of appointments would be appreciated by some children and young people, as would appointments outside school hours.

- Some children and young people would like better engagement with their staff team, with more inclusion in discussions, having their individual needs, worries and preferences taken into account, being listened to, or perceiving more empathy from the staff team about the challenges associated with managing their diabetes.
- Some children and young people with diabetes would also like access to more information about managing their diabetes, including information about diabetes-related technologies.

5.2.4 Summary: What could make clinic visits better for parents and carers?

Almost half of all parents and carers who commented (48.5%) also declined to suggest an improvement, stating instead that nothing could improve them, or that they were happy with their child's current care.

Analysis of comments in response to this question suggested that:

- Parents and carers are similarly happy with their clinic visits compared to children and young people with diabetes, and have similar suggestions for improvements.
- Parents and carers are also frustrated by delays to the start times of appointments, and would like to wait in an area that is appropriate to the age of their child, with activities and refreshments available.
- Appointments outside of school or work hours would be appreciated, with some preferring longer or shorter visits.
- Relationships with staff are important, and could be improved in some cases by better communication skills amongst certain team members, seeing the same team members at each visit, involving the child or family in discussions and decisions around care, and explicit acknowledgement of the hard work that goes into managing or supporting the management of a child or young person with diabetes.
- Many parents and carers would like additional psychological or emotional support for their child, and others would like support for the wider family.
- Additional support outside of clinic visits could also benefit some families, either through timely access to support over the phone or email, or access to peer support and group activities.

6 Recommendations

Paediatric diabetes teams and parents and carers should:

1. Ensure that future PREM survey results are representative of patient experience by:

- Participating in future surveys
- Approaching all families
- Facilitating families to complete a survey

2. Equip school staff to help children and young people manage their diabetes whilst at school.

Paediatric diabetes teams should:

3. Discuss local PREM results and seek input from families with diabetes to improve areas with poorer scores compared to other centres.

4. Provide access to specialist diabetes advice to patients and their families 24 hours per day and 7 days per week.

5. Provide access to a Psychologist with experience in diabetes to all children and young people, ensuring they understand how to access this service.

6. Review their clinic waiting area and seek feedback from patients about how it could be improved to meet the needs of older young people.

7. Enable patients and their families to confidently manage illness and sick day rules. This should:

- be revisited at regular clinic visits
- include when and how to test for ketones
- include hard copy resources and/or digital information

8. Train parents and carers to competently administer intramuscular glucagon in emergency situations to treat low blood glucose. Training must:

- be provided at diagnosis
- include how to prepare and store glucagon
- be refreshed at clinic visits

9. Encourage regular exercise and provide information about how to manage this safely.

10. Provide patients and families with up to date information and advice on how to access diabetes technologies, including:

- insulin pumps
- continuous glucose monitors
- flash glucose monitors

11. Identify and signpost families with diabetes to opportunities for peer-support. These may include:

- social media groups
- regional family and local support groups
- meet ups
- conferences
- online resources such as Digibete

12. Prepare young people and their families for transition from paediatric to adult services. Transition discussions should start in advance of the process to ensure that young people with diabetes and their families know what to expect.

7 Quantitative analysis

7.1 Characteristics of respondents

Table 2: Characteristics of respondents to the 2019 PREM and of children and young people with diabetes included in the 2018/19 NPDA core audit

Characteristic	Child and young person responses	Parent/carer responses	2018/19 core NPDA cohort
Total	6,165 (100%)	7,013 (100%)	30,155 (100%)
Sex			
Female	3,086 (50.1%)	-	14,637 (48.5%)
Male	3,004 (48.7%)	-	15,451 (51.2%)
Prefer not to say/not specified	41 (0.7%)	-	*
Missing/Unknown	34 (0.6%)	-	67 (0.2%) +
Relationship to your child with diabetes			
Mother	-	5,633 (80.3%)	-
Father	-	1,225 (17.5%)	-
Grandmother	-	59 (0.8%)	-
Grandfather	-	12 (0.2%)	-
Other guardian	-	69 (1.0%)	-
Missing	-	15 (0.2%)	-
How old are you/is your child?			
3 years or younger	-	248 (3.5%)	986 (3.3%)
4-7 years old	124 (2.0%)	1,161 (16.6%)	3,659 (12.1%)
8-11 years old	1,225 (19.9%)	2,167 (30.9%)	7,713 (25.6%)
12-16 years old	3,634 (58.9%)	2,936 (41.9%)	13,763 (45.6%)
17 years or older	1,120 (18.2%)	449 (6.4%)	4,034 (13.4%)
Missing	62 (1.0%)	52 (0.7%)	0 (0%)
How long have you/your child had diabetes?			
Less than a year	593 (9.6%)	1,053 (15.0%)	6,587 (21.9%)
1-2 years	782 (12.7%)	1,123 (16.0%)	6,621 (22.0%)
More than 2 years but less than 5 years	1,749 (28.4%)	2,344 (33.4%)	5,236 (17.4%)
More than 5 years but less than 10 years	1,946 (31.6%)	1,828 (26.1%)	8,192 (27.2%)
10 years or more	1,095 (17.8%)	665 (9.5%)	3,416 (11.3%)
Missing	0 (0%)	0 (0%)	103 (0.3%)
Which type of diabetes do you/your child have?			
Type 1	5818 (94.4%)	6,606 (94.2%)	28,597 (94.8%)
Type 2	118 (1.9%)	47 (0.7%)	790 (2.6%)
Other	58 (0.9%)	39 (0.6%)	637 (2.1%)
Unknown/Missing	171 (2.8%)	321 (4.6%)	131 (0.5%)

Characteristic	Child and young person responses	Parent/carer responses	2018/19 core NPDA cohort
How long have you been attending your current diabetes clinic?			
Less than a month	81 (1.3%)	135 (1.9%)	-
Between 1 and 6 months	479 (7.8%)	658 (9.4%)	-
More than 6 months but less than a year	299 (4.8%)	478 (6.8%)	-
1-2 years	905 (14.7%)	1,239 (17.7%)	-
More than 2 years but less than 5 years	1,776 (28.8%)	2,245 (32.0%)	-
More than 5 years but less than 10 years	1,735 (28.1%)	1,682 (24.0%)	-
10 years or more	874 (14.2%)	546 (7.8%)	-
Missing	16 (0.3%)	30 (0.4%)	-

* Indicates a number less than 5 which has been supressed
\+ Results merged to mask number <5

Table 2 shows the characteristics of the children and young people and the parents/carers who completed a PREM survey, compared to the children and young people included within the core NPDA. PREM respondents were broadly representative of the different groups included in the core audit.

A minority of 321 (4.6%) parents/carers were unable to state the type of diabetes their child was living with. Of these, 184 (57.0%) reported a duration of more than 2 years for their child's diabetes. Similarly, 113 (2.4%) of young people older than 12 years could not specify their diabetes type.

7.2 Clinic environment

Respondents to the PREM surveys were asked to think about their clinic visits over the previous six months, and then indicate their agreement with a group of statements.

Table 3 shows that just over a half (50.9%) of children and young people responding to the survey agreed that their clinic definitely had a waiting area appropriate for their age, and that the proportion of parents/carers agreeing that this was the case was slightly higher (61.4%). Figure 1 shows that responses to this question were broadly similar across regions.

Table 3: “The clinic has an area for me/ my child to wait that is appropriate for my/ their age”. Responses from children and young people and parent/carer, by country

		Total	Don’t know	No, but I would like them to	No, but I don’t mind	Yes, to some extent	Yes, definitely
Children and young people	**England and Wales**	6,157	2.1%	4.4%	14.1%	28.4%	50.9%
	England	5,841	2.1%	4.4%	14.0%	28.5%	51.0%
	Wales	316	1.6%	5.1%	16.5%	28.2%	48.7%
Parents and carers	**England and Wales**	7,004	0.6%	3.6%	8.5%	25.9%	61.4%
	England	6,547	0.6%	3.6%	8.5%	25.7%	61.6%
	Wales	457	0.4%	3.7%	9.2%	28.2%	58.4%

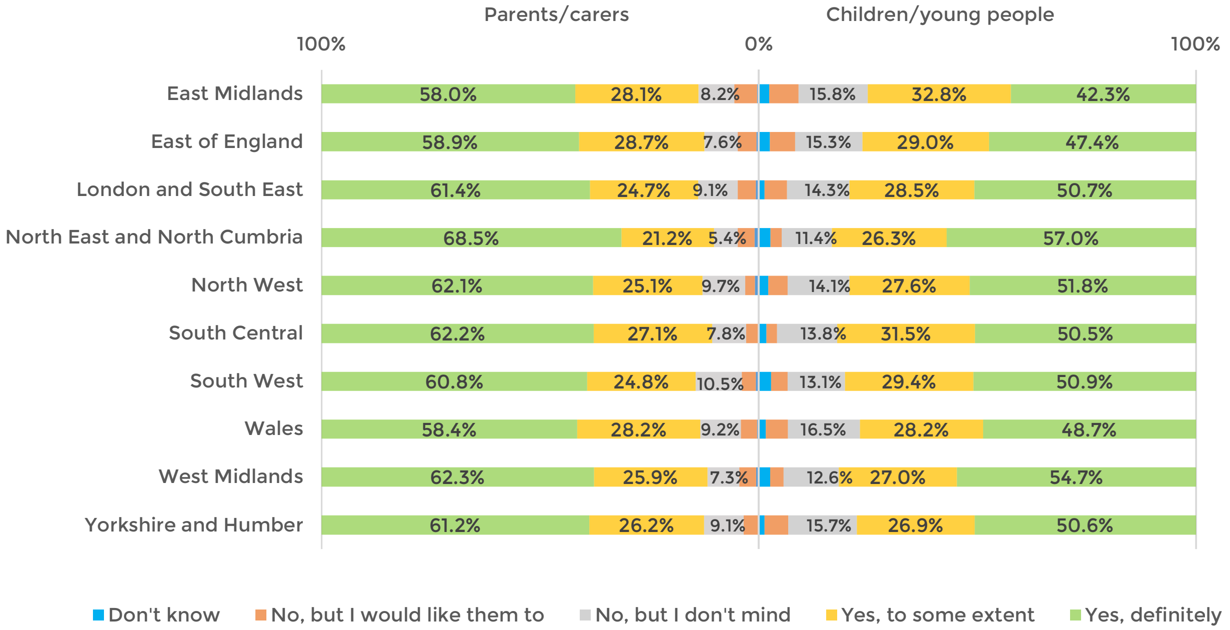


Figure 1: “The clinic has an area for me/ my child to wait that is appropriate for my/ their age”. Responses from children/young people and parent/carer, by regional network

Figure 2 shows that young people aged 12 years and older and their parents/carers were less likely to agree that the waiting area was appropriate for their age compared to younger children.

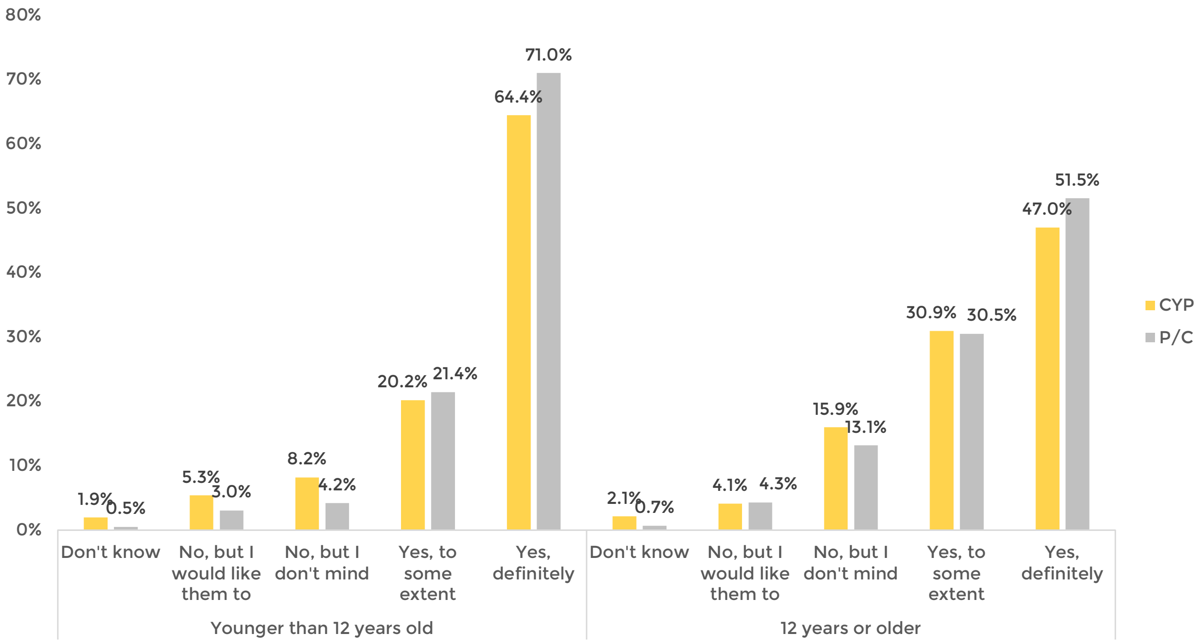


Figure 2: "The clinic has an area for me/ my child to wait that is appropriate for my/ their age". Responses from children and young people (CYP) and parents/carers (P/C), by age group

Respondents were asked how they met with their diabetes team, and how they would prefer to meet with them. Figure 3 shows that experiences and preferences were generally aligned. The most common response to the former amongst children and young people (50.4%) and parents/carers (44.3%) was 'sometimes together in one room and sometimes separately'. This was also the most common preference for children (39.6%) and carers (46.7%).

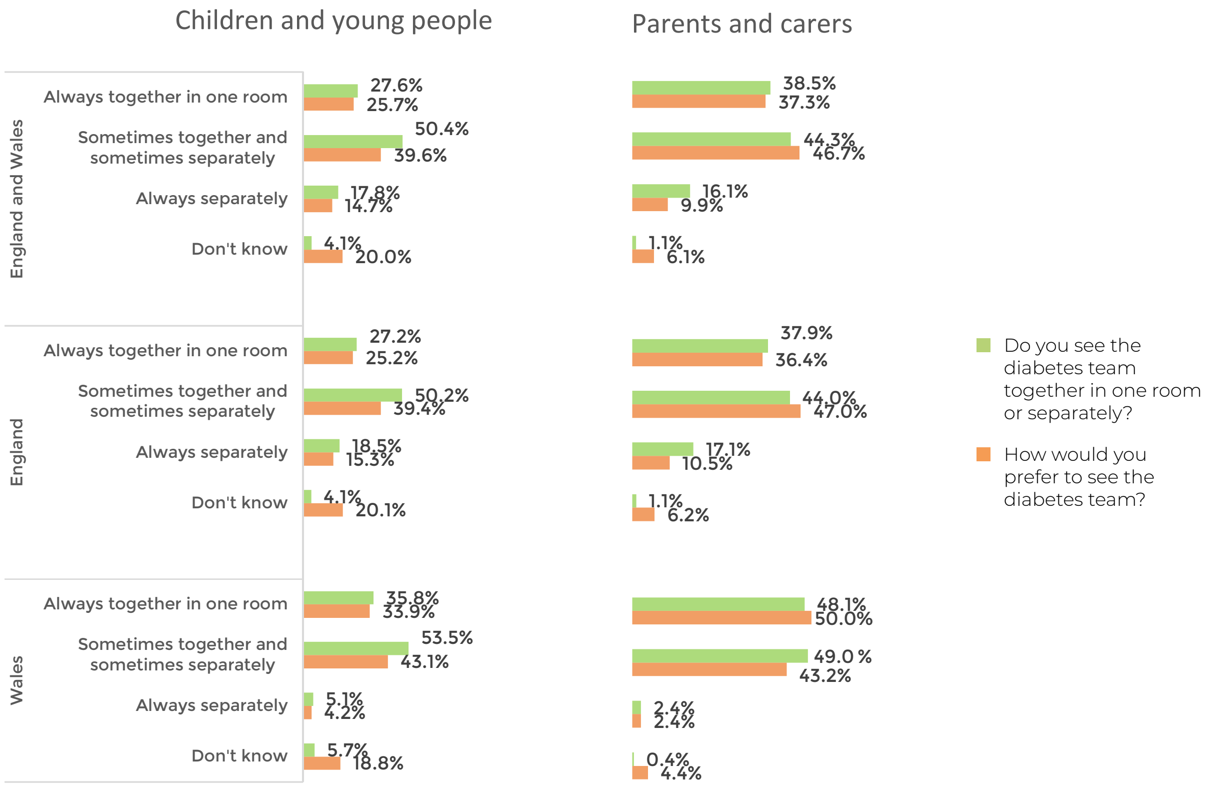


Figure 3: "Do you see the diabetes team together in one room or separately?/ How would you prefer to see the diabetes team?". Responses from children/young people and parents/carers, by country and overall

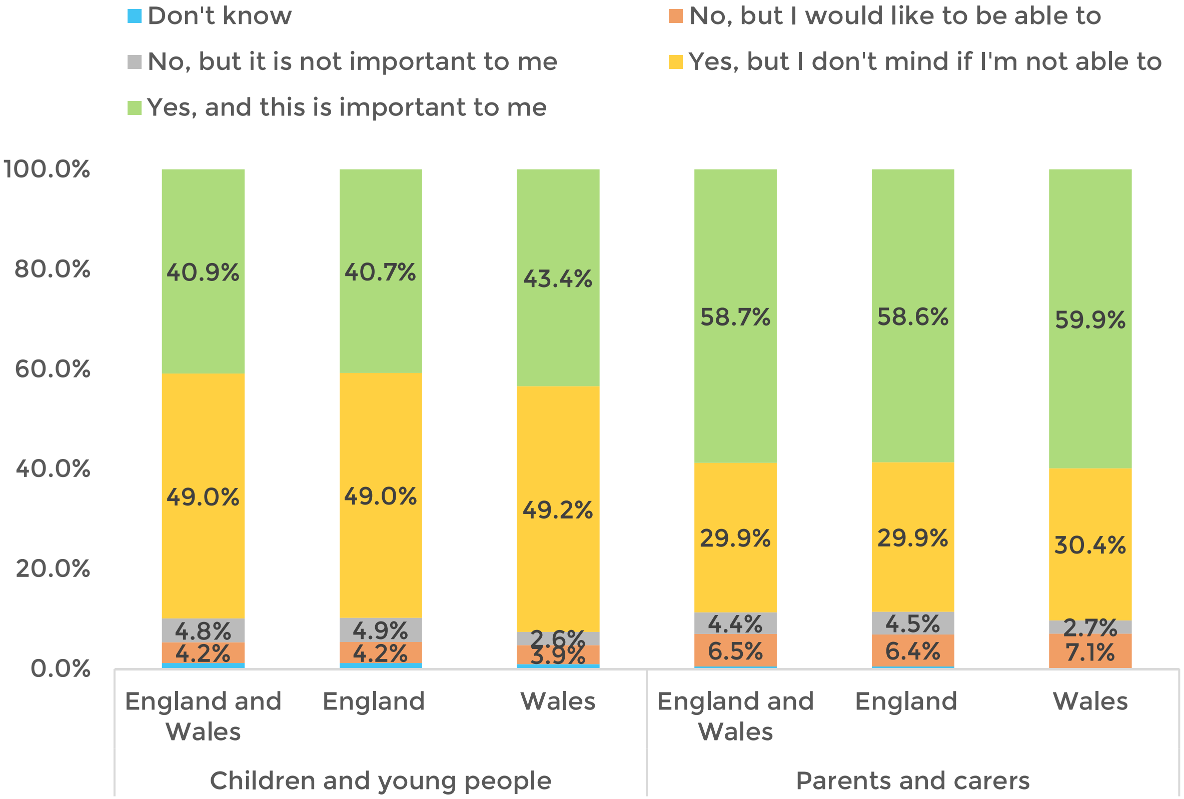
Table 4: Analysis of concordance between preferences and actual experience for clinic visit structure as reported by children and young people and parents/carers

Characteristic	(n) Total respondents*	(%) Preferences don't meet reality	(%) Preferences meet reality *	(n) Preferences meet reality *	(%) Always separately	(%) Always together	(%) Sometimes together
Children and young people							
England and Wales	5781	32.0%	68.0%	3931	17.0%	32.2%	50.9%
England	5486	31.9%	68.1%	3735	17.7%	31.7%	50.6%
Wales	295	33.6%	66.4%	196	2.6%	41.3%	56.1%
East Midlands	420	31.7%	68.3%	287	18.5%	30.7%	50.9%
East of England	557	27.6%	72.4%	403	14.9%	28.0%	57.1%
London and South East	797	28.7%	71.3%	568	3.5%	51.8%	44.7%
North East and North Cumbria	605	32.9%	67.1%	406	36.5%	7.9%	55.7%
North West	782	31.7%	68.3%	534	18.4%	37.8%	43.8%
South Central	409	37.9%	62.1%	254	39.8%	11.4%	48.8%
South West	529	30.8%	69.2%	366	15.8%	41.3%	42.9%
West Midlands	645	37.5%	62.5%	403	14.1%	19.9%	66.0%
Yorkshire and Humber	742	30.7%	69.3%	514	13.0%	37.9%	49.0%
Parents and carers							
England and Wales	6860	22.2%	77.8%	5336	11.1%	41.6%	47.3%
England	6412	22.2%	77.8%	4987	11.8%	40.8%	47.4%
Wales	448	22.1%	77.9%	349	2.0%	51.9%	46.1%
East Midlands	459	24.6%	75.4%	346	13.0%	32.9%	54.0%
East of England	727	23.0%	77.0%	560	5.2%	38.6%	56.3%
London and South East	1220	19.9%	80.1%	977	2.4%	59.8%	37.9%
North East and North Cumbria	528	26.5%	73.5%	388	35.3%	13.4%	51.3%
North West	874	18.6%	81.4%	711	13.2%	47.7%	39.1%
South Central	545	27.5%	72.5%	395	21.3%	22.3%	56.5%
South West	600	24.2%	75.8%	455	16.5%	40.0%	43.5%
West Midlands	669	20.6%	79.4%	531	11.7%	25.6%	62.7%
Yorkshire and Humber	790	21.0%	79.0%	624	6.1%	52.2%	41.7%

* "Don't know" responses to the question "Do you see your diabetes team together in one room or separately?" were not included in this analysis

7.3 Continuity of care

Figure 4 shows that 89.9% of children and young people, and 88.6% of parents and carers in England and Wales reported that they could see the same doctor on most visits to the clinic. A higher percentage of parents (65.2%) compared to children and young people (45.1%) reported that seeing the same doctor on most visits was important to them.

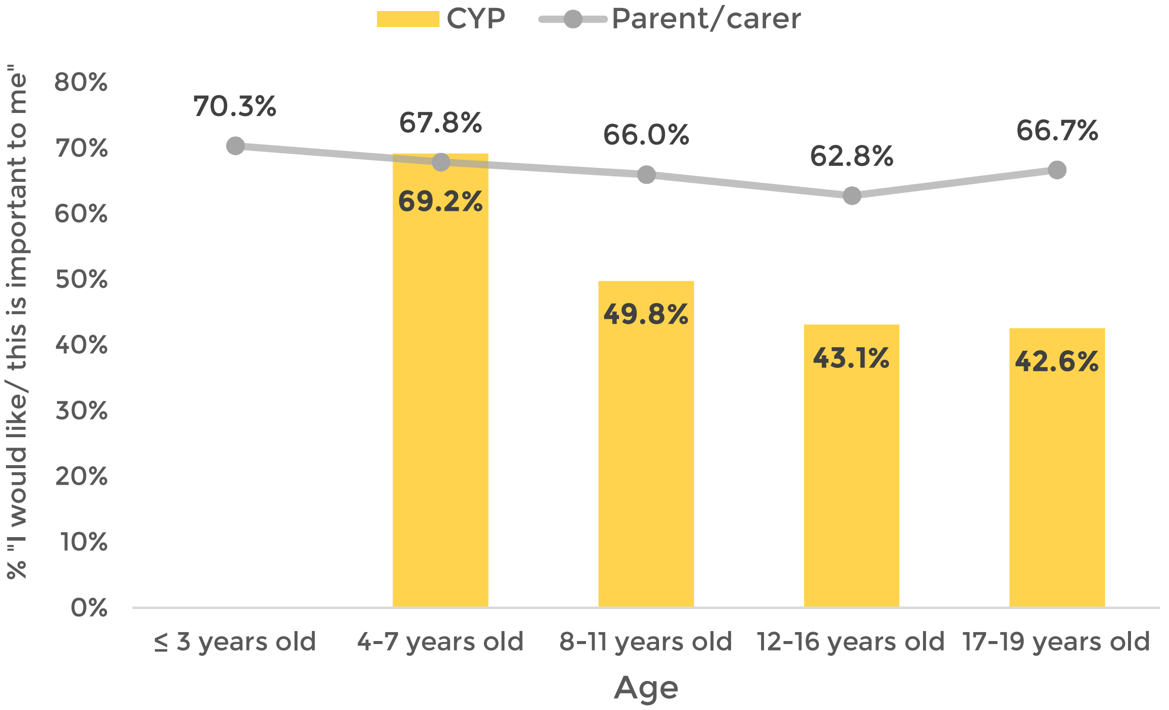


n *	6,023	5,715	308	6,846	6,395	451

* “Too early to say/newly diagnosed” answers were excluded from the denominator.

Figure 4: “I am/we are able to see the same doctor on most visits”. Responses from children/young people and parents/carers, by country and overall

Figure 5 shows how the percentage of children responding that seeing the same doctor on most visits was important to them decreases with age.



n * (CYP)	-	120	1,209	3,597	1,112
n * (P/C)	236	1,132	2,117	2,903	444

* “Too early to say/newly diagnosed” responses were excluded from the denominator.

Figure 5: “I am/ we are able to see the same doctor on most visits”. Percentage of children/young people and parents/carers responding “Yes, and this is important to me”/“No, but I would like to”, by age group

Table 5 gives a breakdown of responses to this question by region and overall for children and young people and parents and carers. It shows that, overall, parents and carers valued seeing the same doctor on most visits more than children and young people, and that most respondents in all regions could see the same doctor on most visits.

Table 5: "I am/we are able to see the same doctor on most visits". Responses from children/young people and parents/carers, by region

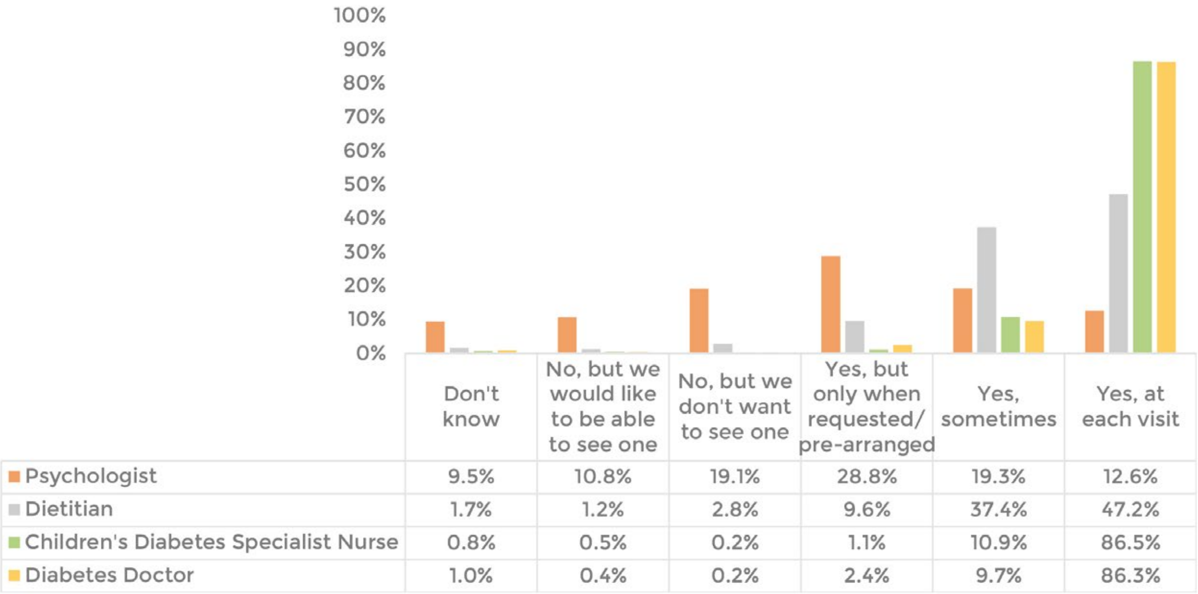
		n*	Don't know	No, but I would like to be able to	No, but it is not important to me	Yes, but I don't mind if I'm not able to	Yes, and this is important to me
Children and young people	East Midlands	457	0.7%	8.5%	6.1%	48.4%	36.3%
	East of England	580	1.2%	3.6%	6.2%	46.9%	42.1%
	London and South East	830	0.8%	4.0%	2.7%	43.4%	49.2%
	North East and North Cumbria	637	1.4%	2.7%	4.4%	53.4%	38.1%
	North West	819	1.3%	3.2%	2.3%	48.0%	45.2%
	South Central	451	2.0%	6.2%	12.0%	51.2%	28.6%
	South West	563	1.1%	4.1%	5.5%	45.1%	44.2%
	Wales	311	1.0%	3.9%	2.6%	49.2%	43.4%
	West Midlands	680	1.2%	3.8%	4.4%	51.8%	38.8%
	Yorkshire and Humber	768	1.3%	3.6%	4.6%	53.5%	37.0%
Parents and carers	East Midlands	458	0.2%	12.9%	6.8%	31.9%	48.3%
	East of England	721	0.1%	6.4%	5.3%	32.0%	56.2%
	London and South East	1,230	0.6%	6.3%	2.6%	20.3%	70.2%
	North East and North Cumbria	530	1.3%	3.2%	5.8%	40.6%	49.1%
	North West	874	0.3%	4.5%	1.6%	30.9%	62.7%
	South Central	544	0.4%	9.6%	8.3%	30.7%	51.1%
	South West	606	0.7%	6.3%	6.6%	25.6%	60.9%
	Wales	451	0.0%	7.1%	2.7%	30.4%	59.9%
	West Midlands	673	0.7%	6.2%	2.7%	31.6%	58.7%
	Yorkshire and Humber	793	0.5%	5.5%	5.0%	34.8%	54.1%

* "Too early to say/newly diagnosed" answers were excluded from the denominator.

7.4 Multidisciplinary care

Parents and carers were asked which members of the multidisciplinary diabetes team (MDT) they were able to see when they came to clinic.

Figure 6 shows that the majority of respondents (86.5%) reported that they saw a paediatric diabetes specialist nurse (PDSN) and a doctor (86.3%) at each visit. Of the MDT specialties not seen at each clinic appointment, access to a psychologist was the most commonly desired amongst respondents, with 10.8% reporting that they were not able to see a psychologist but would like to see one.



	Don't know	No, but we would like to be able to see one	No, but we don't want to see one	Yes, but only when requested/ pre-arranged	Yes, sometimes	Yes, at each visit
🟧 Psychologist	9.5%	10.8%	19.1%	28.8%	19.3%	12.6%
⬜ Dietitian	1.7%	1.2%	2.8%	9.6%	37.4%	47.2%
🟩 Children's Diabetes Specialist Nurse	0.8%	0.5%	0.2%	1.1%	10.9%	86.5%
🟨 Diabetes Doctor	1.0%	0.4%	0.2%	2.4%	9.7%	86.3%

Figure 6: "We are able to see the following members of the team when coming to clinic". Responses from parents and carers, England and Wales

Table 6: "We are able to see the following members of the team when coming to clinic". Responses from parents and carers, by country

		n	Don't know	No, but I would like to be able to see one	No, but I don't want to see one	Yes, but only when requested	Yes, some-times	Yes, at each visit
Diabetes Doctor	England	6,496	1.0%	0.5%	0.3%	2.4%	9.6%	86.4%
	Wales	451	0.7%	0.2%	0.0%	3.1%	11.1%	84.9%
Specialist Nurse	England	6,415	0.8%	0.5%	0.2%	1.1%	11.1%	86.2%
	Wales	449	0.2%	0.2%	0.0%	1.1%	8.5%	90.0%
Dietitian	England	6,291	1.7%	1.2%	2.7%	9.3%	37.4%	47.7%
	Wales	436	0.9%	1.8%	5.0%	13.1%	38.3%	40.8%
Psychologist	England	6,125	9.3%	10.6%	19.3%	29.0%	19.2%	12.6%
	Wales	430	11.4%	12.6%	17.2%	25.3%	20.7%	12.8%

Figure 7 below shows the percentages of parents and carers responding “Yes, at each visit” to the question “We are able to see the following members of the team when coming to clinic” by region.

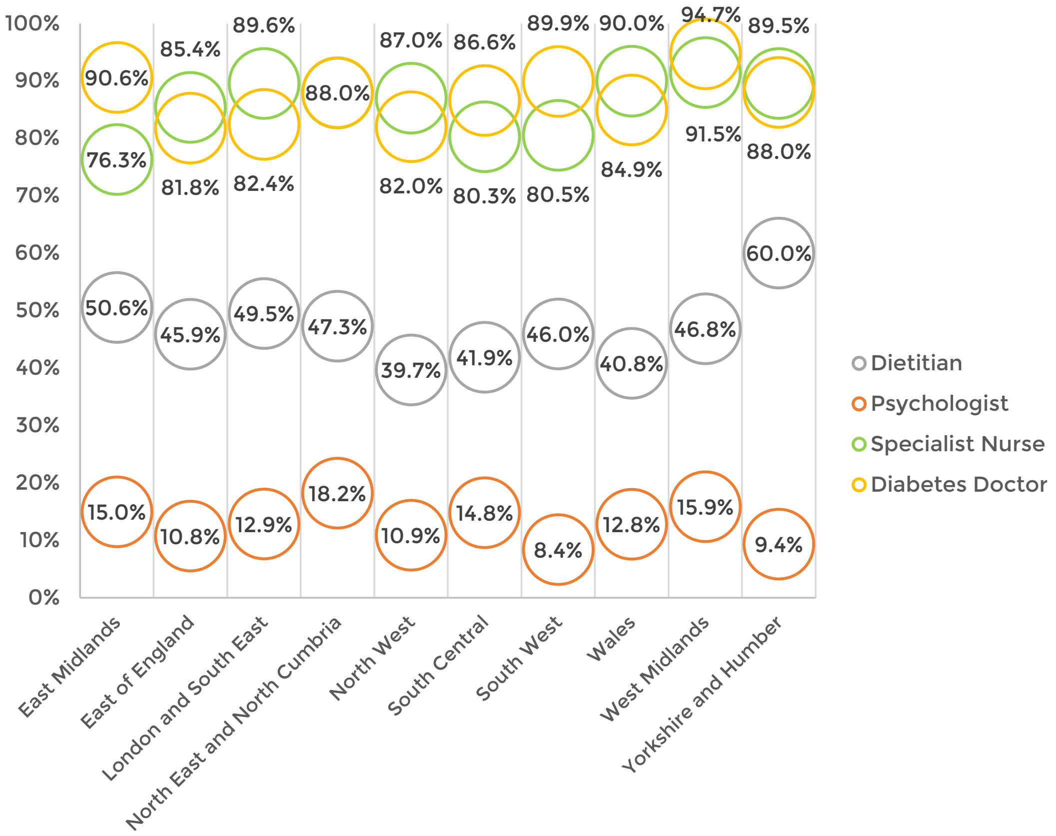


Figure 7: Percentage of parents/carers responding “Yes, at each visit” to the question “We are able to see the following members of the team when coming to clinic”, by region

Figure 7 also shows that parents and carers were least likely to report seeing a psychologist at every visit. Figure 8 (page 30) shows the regional variation in access to a psychologist, as reported by parents and carers.

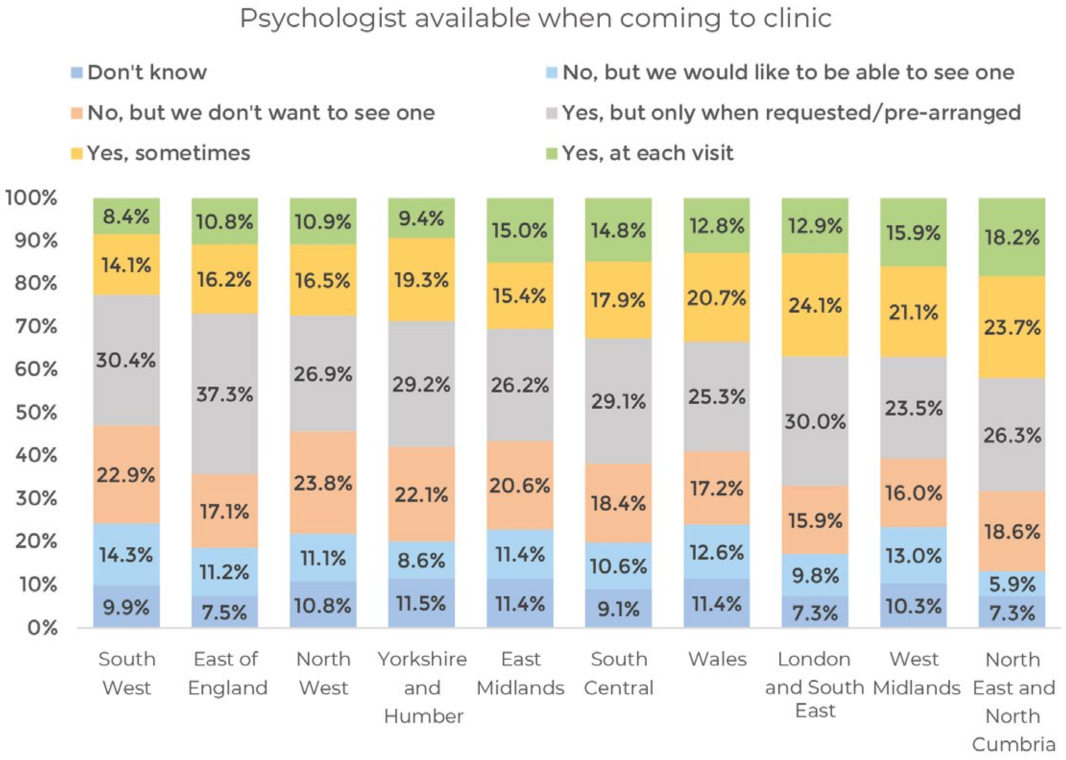


Figure 8: "We are able to see a psychologist when coming to clinic". Responses from parents and carers, by region

7.5 Access to diabetes advice

Table 7 shows the percentage of parents and carers who were able to get advice about their child's diabetes 24 hours a day, and during core hours. Overall, the majority (81.3%) reported that they were able to contact a member of the diabetes team for advice during core hours. A lower percentage (68.8%) reported that they could always receive advice, 24 hours a day. Figure 9 shows variation in access to advice during core hours and after hours by region.

Table 7: Access to specialist advice. Responses from parents and carers, by country and overall

	n	Don't know	Not had a need to contact them	No, but I would like to be able to	No, but I don't mind	Yes, sometimes	Yes, always
I am able to get appropriate advice about my child's diabetes from the hospital 24 hours a day							
England and Wales	6,832	1.8%	7.9%	5.0%	0.9%	15.7%	68.8%
England	6,386	1.8%	7.8%	4.9%	0.9%	15.4%	69.2%
Wales	446	1.8%	8.7%	6.5%	0.7%	19.7%	62.6%
I am able to contact a member of the diabetes team for advice during core team hours, Monday to Friday							
England and Wales	6,962	0.3%	1.7%	1.5%	0.2%	15.0%	81.3%
England	6,507	0.4%	1.6%	1.5%	0.2%	14.7%	81.7%
Wales	455	0.2%	2.0%	1.8%	0.0%	19.6%	76.5%

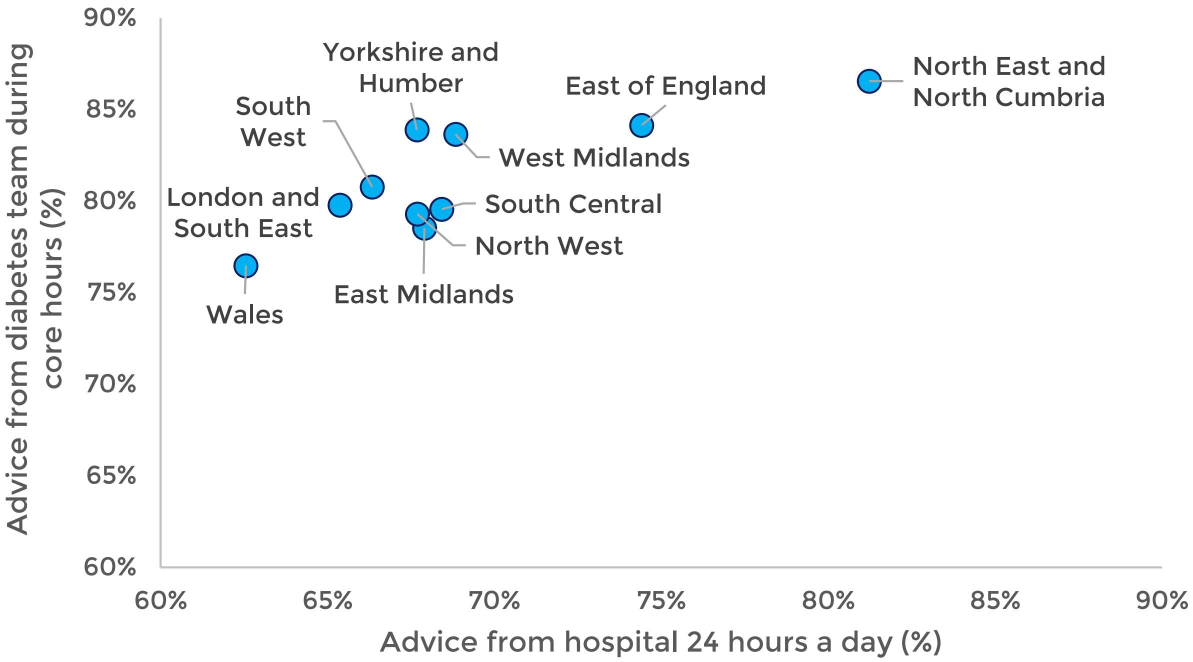


Figure 9: Percentage of parents/carers responding "Yes, at each visit" to questions about the access to specialist advice, by region

7.6 Relationship with the diabetes team

Respondents were asked to rate aspects of their relationship with their diabetes team. Overall, 90.0% of parents and carers and 79.9% of children and young people agreed that they always had a positive relationship with their team, with similar percentages agreeing that their team understood their needs, involved them in treatment decisions, and spoke to them in a way they could understand. The lowest scored statement in this section was "the diabetes team supports the whole family", with 68.0% of children and young people and 73.2% of parents and carers responding "yes, always".

Table 8 and Figures 10 – 12 show that parents and carers tended to rate measured aspects of their relationships with their diabetes team more highly than children and young people.

Table 8: "About your relationship with the diabetes team". Percentage of children and young people (CYP) and parents/carers (P/C) responding "Yes, always", by country and overall

	England and Wales		England		Wales	
	CYP	P/C	CYP	P/C	CYP	P/C
I have a positive relationship with our diabetes team	79.9%	90.0%	80.0%	90.1%	78.1%	88.3%
The diabetes team understand us and our individual needs	74.9%	83.2%	75.0%	83.3%	71.8%	81.6%
The diabetes team involve me in decisions about treatment	82.3%	91.2%	82.2%	91.2%	84.0%	90.4%
The diabetes team talk to me in a way I can understand	79.3%	92.8%	79.4%	93.0%	78.0%	90.2%
The diabetes team supports the whole family	68.0%	73.2%	67.8%	73.2%	70.6%	72.2%

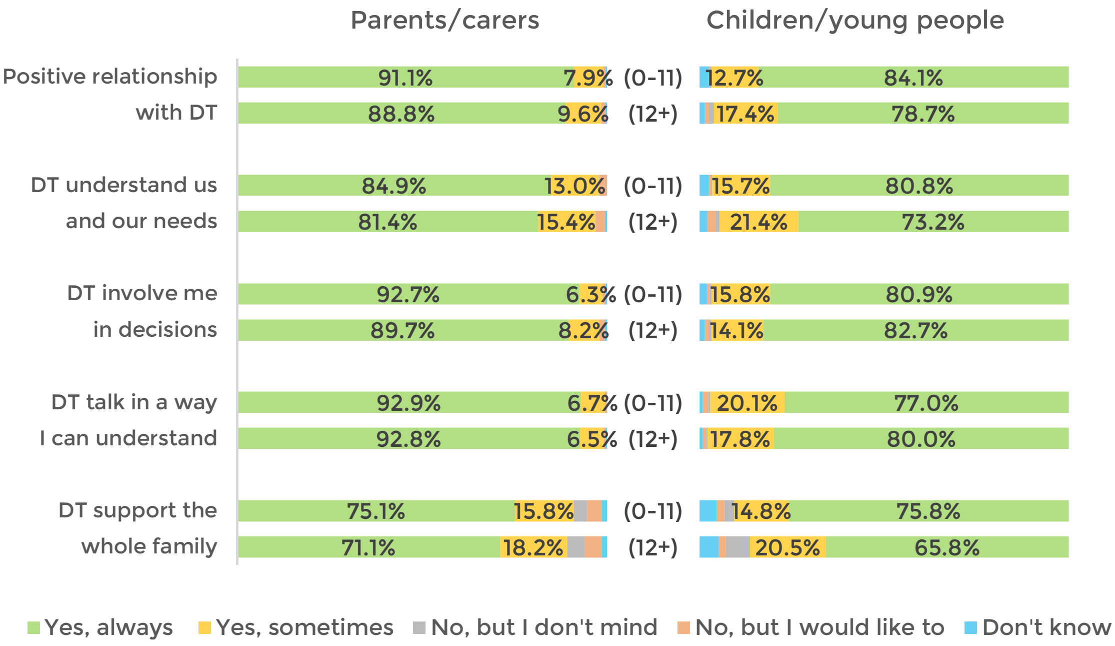


Figure 10: "About your relationship with the diabetes team (DT)". Responses from children/young people and parent/care by age group, overall figures for England and Wales

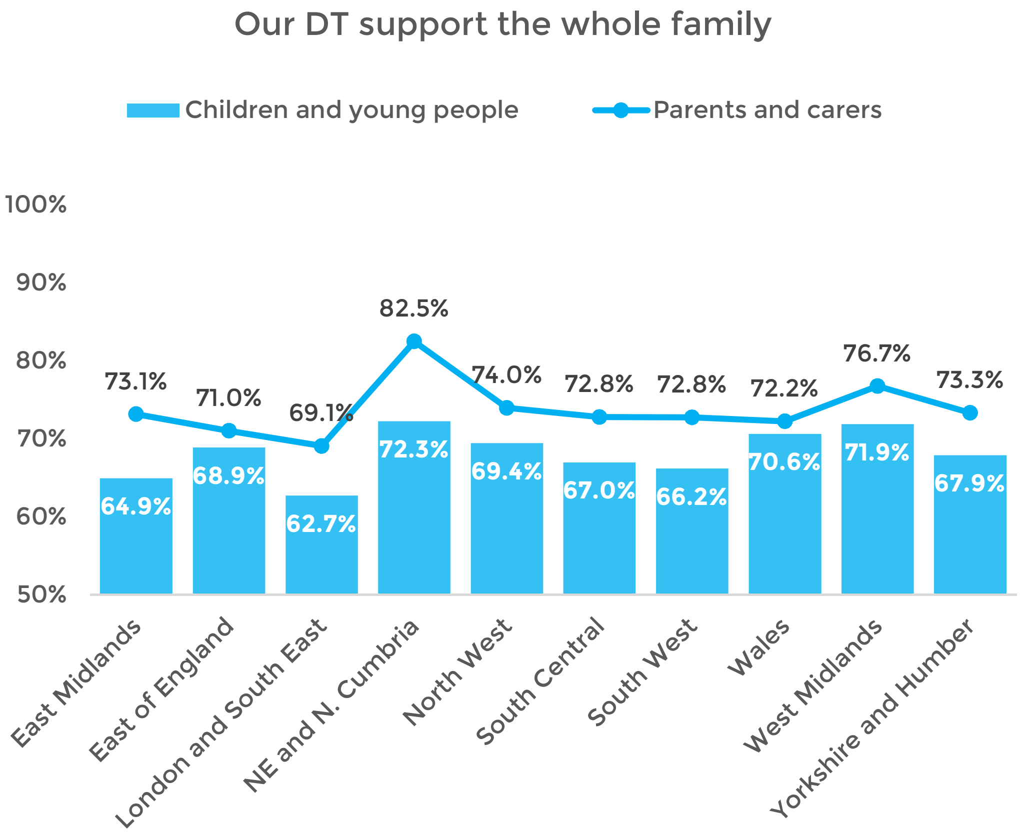


Figure 11: "Our diabetes team support the whole family". Percentage of children/ young people and parents/carers responding "Yes, always", by regional network

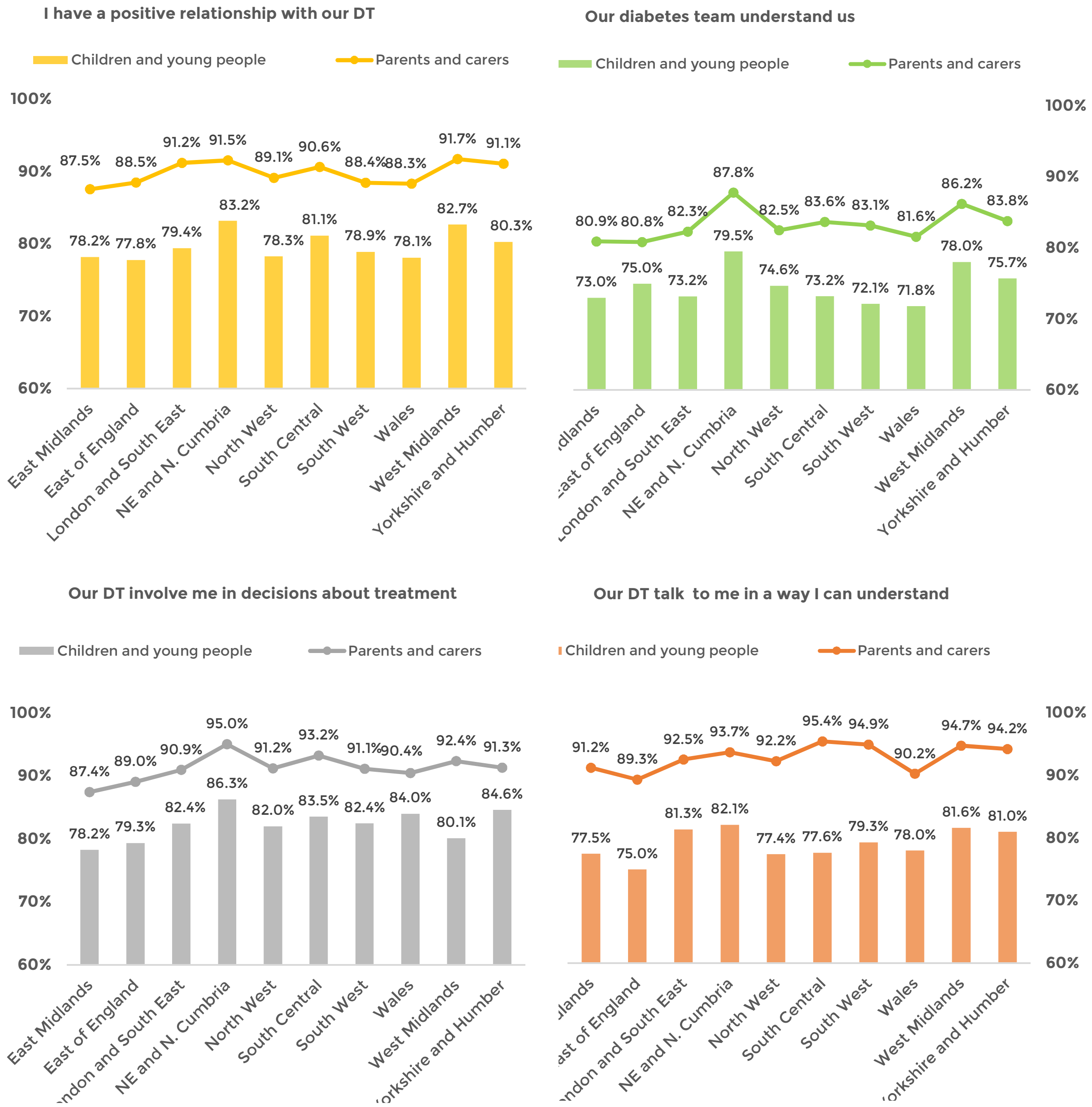


Figure 12: "About your relationship with the diabetes team". Percentage of children/young people and parents/carers responding "Yes, always", by region

7.7 Culturally competent care

Parents and carers were asked whether their diabetes teams respected their religious or cultural beliefs, and whether or not they were offered the opportunity for an interpreter to attend their appointments. Table 9 shows that the majority of parents and carers did not consider these questions to be applicable to them, however these percentages varied by region. Of parents who did consider it applicable, 94.5% reported that their team respected their religious or cultural beliefs, and 94.6% of those who needed one agreed that they always had access to an interpreter. However, given the small proportion of responses completed in a different language, this result may not be representative.

Table 9: Culturally competent care. Responses from parents and carers, by country and overall

Our diabetes team respect our religious and/or cultural beliefs							
	Total responses	**% Not applicable**	**% Applicable**	**(n) Applicable**	**% No***	**% Yes, sometimes**	**% Yes, always**
England and Wales	**6,882**	**56.4%**	**43.6%**	**2,998**	**2.9%**	**2.6%**	**94.5%**
England	6,431	56.1%	43.9%	2,823	2.8%	2.5%	94.7%
Wales	451	61.2%	38.8%	175	5.7%	3.4%	90.9%
East Midlands	461	56.2%	43.8%	202	2.0%	3.0%	95.0%
East of England	727	61.9%	38.1%	277	2.5%	4.3%	93.1%
London and South East	1222	51.3%	48.7%	595	3.9%	2.7%	93.4%
North East and North Cumbria	527	49.5%	50.5%	266	1.9%	2.3%	95.9%
North West	883	53.8%	46.2%	408	2.5%	2.2%	95.3%
South Central	537	63.5%	36.5%	196	2.0%	3.1%	94.9%
South West	609	63.2%	36.8%	224	3.1%	1.8%	95.1%
West Midlands	663	53.5%	46.5%	308	3.2%	2.3%	94.5%
Yorkshire and Humber	802	56.7%	43.3%	347	2.3%	1.4%	96.3%

Our diabetes team offer the opportunity to have an interpreter attend consultations							
	Total responses	**% Not applicable ****	**% Applicable**	**(n) Applicable**	**% No, but we would like them to**	**% Yes, but have not been able to get one**	**% Yes, and we use one**
England and Wales	**6,878**	**90.1%**	**9.9%**	**682**	**3.8%**	**1.6%**	**94.6%**
England	6,430	90.0%	10.0%	645	4.0%	1.6%	94.4%
Wales	448	91.7%	8.3%	37	0.0%	2.7%	97.3%
East Midlands	457	88.0%	12.0%	55	0.0%	1.8%	98.2%
East of England	731	90.6%	9.4%	69	5.8%	2.9%	91.3%
London and South East	1225	90.7%	9.3%	114	7.0%	0.0%	93.0%
North East and North Cumbria	521	85.8%	14.2%	74	1.4%	0.0%	98.6%
North West	879	90.0%	10.0%	88	4.5%	2.3%	93.2%
South Central	540	94.8%	5.2%	28	3.6%	0.0%	96.4%
South West	602	89.5%	10.5%	63	4.8%	0.0%	95.2%
West Midlands	676	88.8%	11.2%	76	2.6%	5.3%	92.1%
Yorkshire and Humber	799	90.2%	9.8%	78	3.8%	1.3%	94.9%

* Includes the answers “No, but I would like them to” and “No, but I don’t mind”

** Includes the answers “No, but we do not need/want one” and “Yes, but we have not needed/wanted one”

7.8 Information and advice

Respondents were asked if they had received enough information from their diabetes team over the past 6 months to manage different areas of diabetes care effectively. Figure 13 and Table 10 show that glucagon preparation, ketone monitoring and managing illness had lower rates of positive responses in comparison to information on how to manage blood glucose levels.

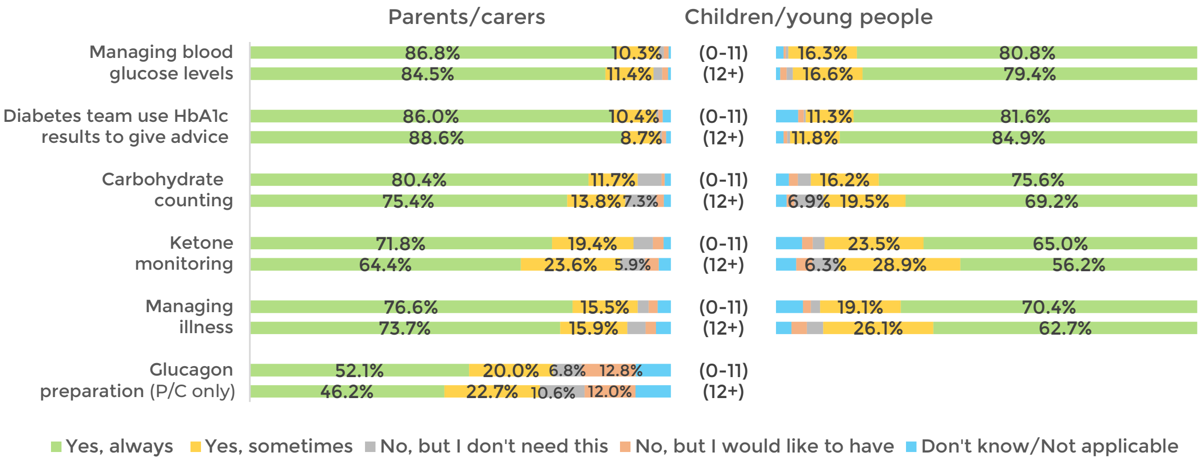


Figure 13: Information and advice on managing diabetes: Breakdown of all responses from children/young people and parents/carers, by age group

Table 10: Information and advice on managing diabetes. Percentage of children/young people (CYP) and parents/carers (P/C) responding “Yes, always”, by country and overall

Over the last 6 months have you received enough information from your diabetes team to manage the following areas effectively?	England and Wales		England		Wales	
	CYP	P/C	CYP	P/C	CYP	P/C
Managing high and low blood glucose	79.7%	85.7%	79.8%	85.7%	78.0%	85.3%
Diabetes team use HbA1c results to give advice on how to manage blood glucose levels	84.2%	87.3%	84.4%	87.3%	78.9%	86.9%
Carb counting	70.6%	78.0%	70.6%	77.9%	71.6%	78.8%
Ketone monitoring	58.1%	68.1%	58.4%	68.0%	54.3%	70.4%
Managing illness	64.4%	75.2%	64.3%	75.2%	65.5%	75.6%
Glucagon preparation (P/C only)	-	49.2%	-	49.4%	-	46.2%

Figure 14 and Table 11 show that less than 70% of respondents stated that they always received enough information on exercise, maintaining future health with diabetes and managing emotional wellbeing.

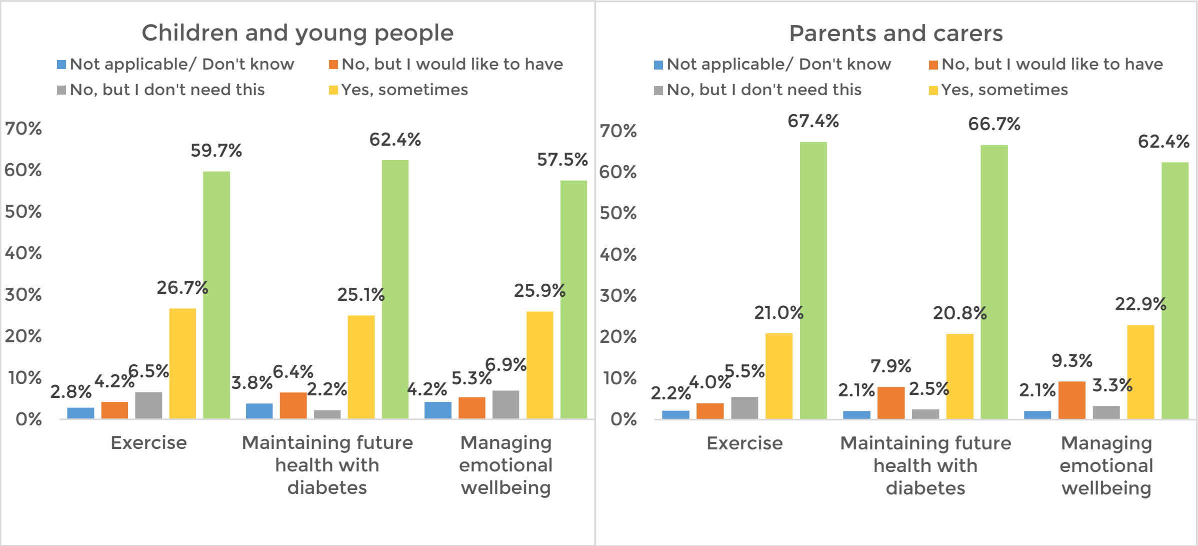
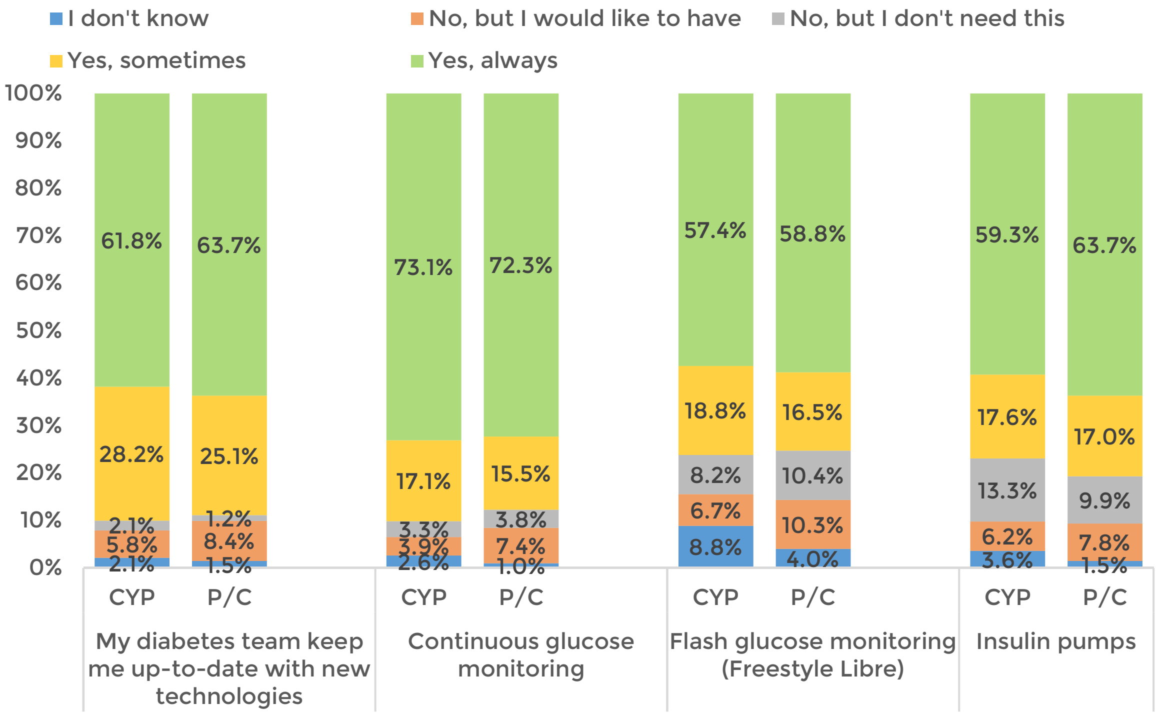


Figure 14: Information and advice on wellbeing. Responses from children/young people and parents/carers, overall figures for England and Wales

Table 11: Information and advice on wellbeing. Percentage of children/young people (CYP) and parents/carers (P/C) responding "Yes, always", by country and overall

Over the last 6 months have you received enough information from your diabetes team to manage the following areas effectively?	England and Wales		England		Wales	
	CYP	P/C	CYP	P/C	CYP	P/C
Exercise	59.7%	67.4%	59.8%	67.4%	58.5%	67.3%
Maintaining future health with diabetes	62.4%	66.7%	62.6%	66.6%	60.3%	67.6%
Managing emotional wellbeing	57.5%	62.4%	57.7%	62.4%	54.5%	62.3%

Figure 15 and Table 12 show that 61.8% of children and young people and 63.7% of parents and carers agreed that their diabetes team kept them up-to-date with new diabetes-related technologies. Of the diabetes-related technologies included, both children and young people and parents and carers were more likely to report always receiving enough information about continuous glucose monitoring compared to insulin pump use or flash glucose monitoring.



n	6,137	6,917	5,950 *	6,755 *	5,406 *	5,906 *	5,349 *	6,115 *

* "Not applicable" answers were excluded from the denominator.

Figure 15: Information and advice on diabetes related technologies: Response breakdown from children/young people (CYP) and parents/carers (P/C), England and Wales

Table 12: Information and advice on wellbeing: Percentage of children/young people and parents/carers responding "Yes, always", by country and overall

Over the last 6 months have you received enough information from your diabetes team to manage the following areas effectively?	England and Wales		England		Wales	
	CYP	P/C	CYP	P/C	CYP	P/C
My diabetes team keep me up-to-date with new technologies	61.8%	63.7%	61.6%	63.6%	65.8%	65.6%
Continuous glucose monitoring*	73.1%	72.3%	73.1%	71.8%	72.5%	79.3%
Flash glucose monitoring (Freestyle Libre)*	57.4%	58.8%	57.3%	58.4%	59.6%	64.2%
Insulin pumps*	59.3%	63.7%	59.2%	63.8%	60.7%	63.4%

* Answers of "Not applicable" were excluded from the denominator.

Table 13 shows the percentages of respondents choosing "Yes, always" by region. A scale of colours was used to highlight higher percentages (yellow) and lower percentages (blue), with darker colours representing the extreme values. Overall, higher scores were achieved for the provision of advice and information about managing blood glucose levels, whereas lower scores were associated with glucagon preparation and when to use it.

Table 13: Information and advice: Percentage of children/young people and parents/carers responding “Yes, always”, by region

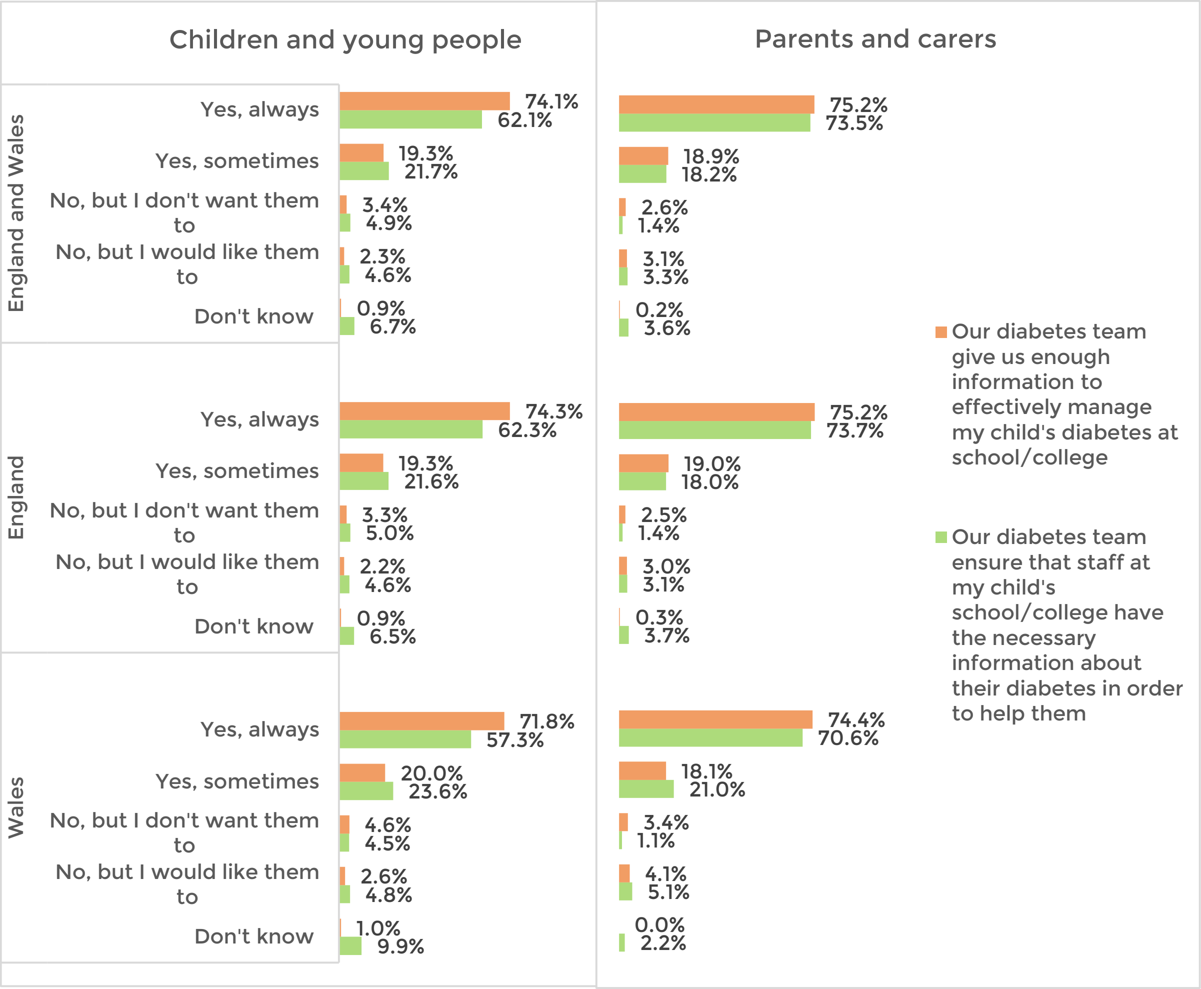
		East of England	South West	London & South East	East Mid-lands	Wales	South Central	North West	York-shire & Humber	West Mid-lands	North East & North Cumbria
Managing high and low blood glucose levels	CYP	81.2%	77.0%	80.0%	79.5%	78.0%	81.5%	80.3%	79.2%	78.9%	81.0%
	P/C	83.3%	82.6%	85.8%	83.9%	85.3%	86.4%	86.1%	87.5%	86.6%	88.5%
Diabetes team use my HbA1c results to give advice	CYP	82.4%	82.2%	83.8%	83.2%	78.9%	82.9%	84.6%	87.1%	83.5%	88.7%
	P/C	83.6%	86.9%	84.7%	89.6%	86.9%	87.3%	87.9%	88.5%	87.7%	93.9%
Carbohydrate counting	CYP	70.3%	67.6%	71.1%	69.8%	71.6%	68.8%	71.1%	70.7%	72.3%	71.8%
	P/C	76.2%	73.1%	78.2%	79.3%	78.8%	77.7%	75.9%	79.5%	80.4%	81.8%
Ketone monitoring	CYP	55.9%	53.1%	54.0%	59.5%	54.3%	60.9%	59.5%	58.9%	64.4%	59.5%
	P/C	61.5%	64.5%	64.9%	71.3%	70.4%	70.6%	67.1%	70.2%	74.5%	72.6%
Glucagon preparation (P/C only)	CYP	-	-	-	-	-	-	-	-	-	-
	P/C	40.0%	44.8%	47.6%	50.3%	46.2%	50.4%	48.8%	53.7%	54.2%	59.0%
Managing Illness	CYP	64.2%	61.8%	60.1%	62.2%	65.5%	68.1%	65.0%	65.2%	67.1%	65.8%
	P/C	72.0%	71.5%	73.3%	74.7%	75.6%	77.1%	73.6%	78.4%	76.9%	81.8%
Exercise	CYP	59.5%	60.3%	57.4%	57.7%	58.5%	60.0%	62.7%	57.3%	59.5%	63.5%
	P/C	62.6%	65.7%	66.1%	63.0%	67.3%	70.6%	68.1%	66.4%	70.1%	76.6%
Maintaining future health with diabetes	CYP	61.9%	59.7%	59.3%	63.9%	60.3%	63.1%	62.7%	62.6%	62.4%	68.5%
	P/C	60.9%	64.9%	63.4%	68.4%	67.6%	64.9%	68.0%	69.3%	69.3%	74.5%
Managing emotional wellbeing	CYP	56.3%	56.4%	54.6%	56.6%	54.5%	55.5%	58.4%	59.1%	56.3%	65.4%
	P/C	56.9%	62.5%	61.3%	61.0%	62.3%	59.2%	63.3%	64.2%	65.9%	68.8%
My diabetes team keep me up-to-date with new technologies	CYP	55.8%	57.2%	62.0%	64.1%	65.8%	61.2%	62.5%	62.7%	59.7%	68.1%
	P/C	56.1%	59.4%	61.9%	68.5%	65.6%	58.7%	67.6%	61.1%	65.7%	77.8%
Continuous glucose monitoring *	CYP	70.6%	67.6%	73.7%	72.3%	72.5%	71.9%	74.1%	72.3%	74.2%	79.1%
	P/C	65.6%	67.3%	71.6%	73.9%	79.3%	71.5%	73.7%	73.5%	70.0%	80.7%
Flash glucose monitoring (Freestyle Libre) *	CYP	55.2%	52.3%	53.7%	62.7%	59.6%	57.3%	60.4%	54.5%	58.3%	62.8%
	P/C	50.3%	55.6%	57.9%	69.0%	64.2%	59.1%	61.3%	55.4%	59.8%	62.2%
Insulin pumps *	CYP	55.6%	54.6%	55.5%	59.6%	60.7%	58.6%	60.7%	63.0%	59.0%	65.4%
	P/C	55.7%	55.7%	64.3%	70.1%	63.4%	64.8%	64.5%	66.4%	64.3%	69.8%

* “Not applicable” answers were excluded from the denominator.

7.9 Managing diabetes at school or college

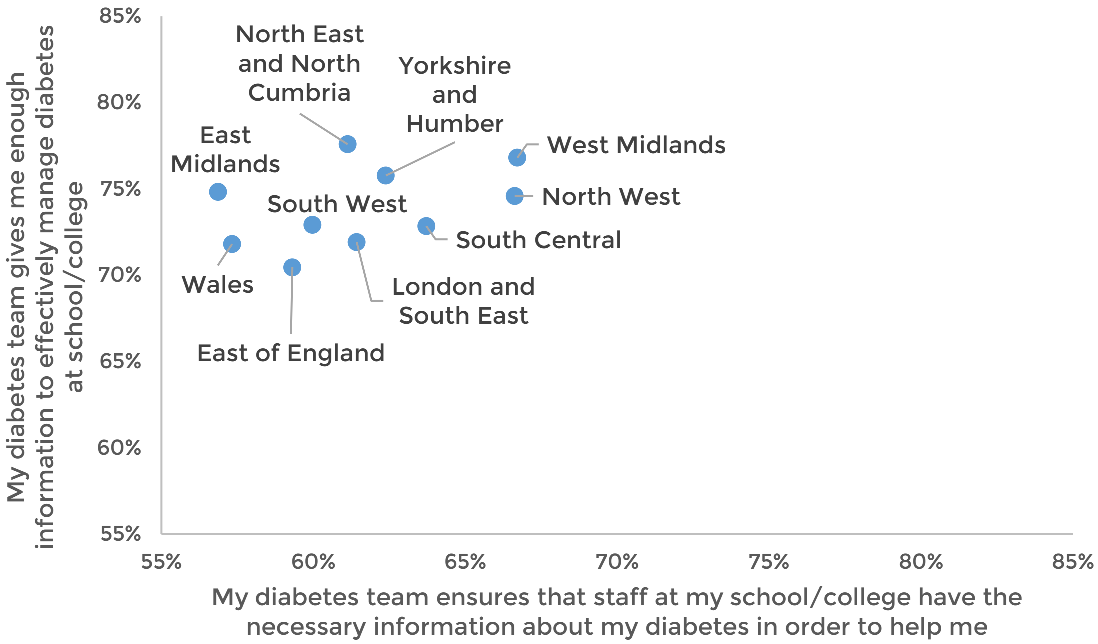
Respondents were asked how their diabetes teams facilitated support for diabetes management outside of their service. Figures 16 -18 show the responses from over 98% of respondents who considered that these questions were applicable to them.

Three quarters of children and young people with diabetes (74.1%) and parents and carers (75.2%) agreed that their diabetes team always gave them enough information to effectively manage their/child's diabetes at school/college. Similar percentages (62.1%) of children and young people and parents and carers (73.5%) agreed that the diabetes team always ensured that staff at their/child's school had the necessary information about their diabetes in order to help them.



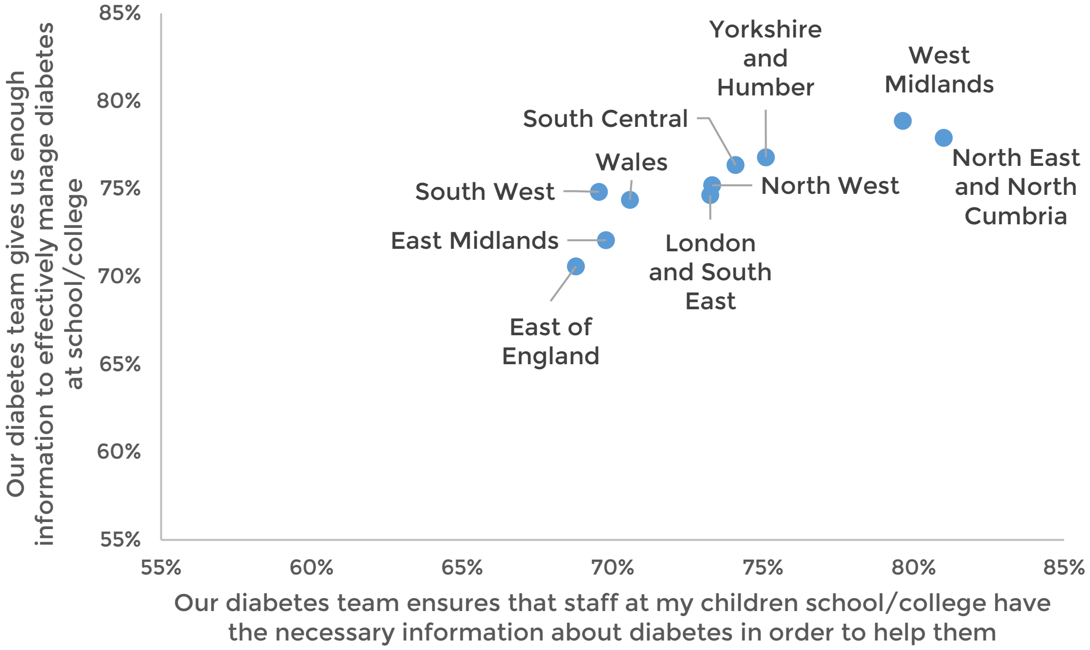
* "Not applicable" answers were excluded from the denominator

Figure 16: Managing diabetes at school/college: Responses from children/young people and parents/carers, by country and overall *



* “Not applicable” answers were excluded from the denominator.

Figure 17: Managing diabetes at school/ college: Percentage of children and young people responding “Yes, always”, by regional network *

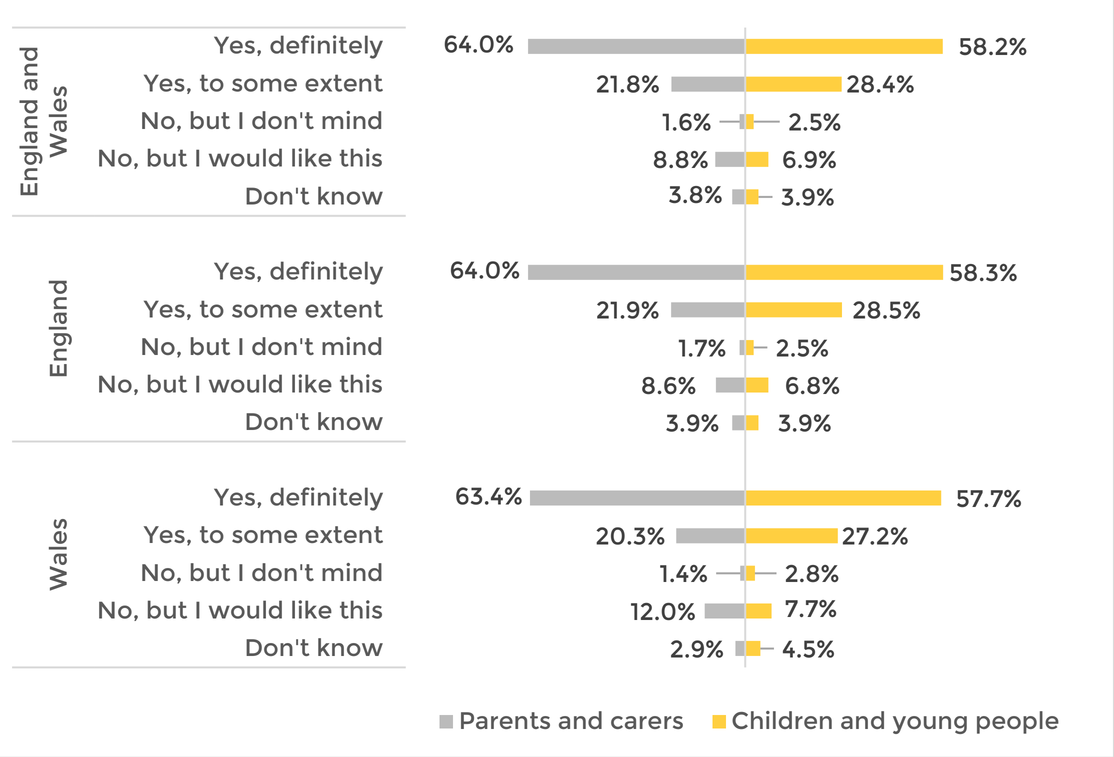


* “Not applicable” answers were excluded from the denominator.

Figure 18: Managing diabetes at school/ college: Percentage of parent/carer responding “Yes, always”, by region *

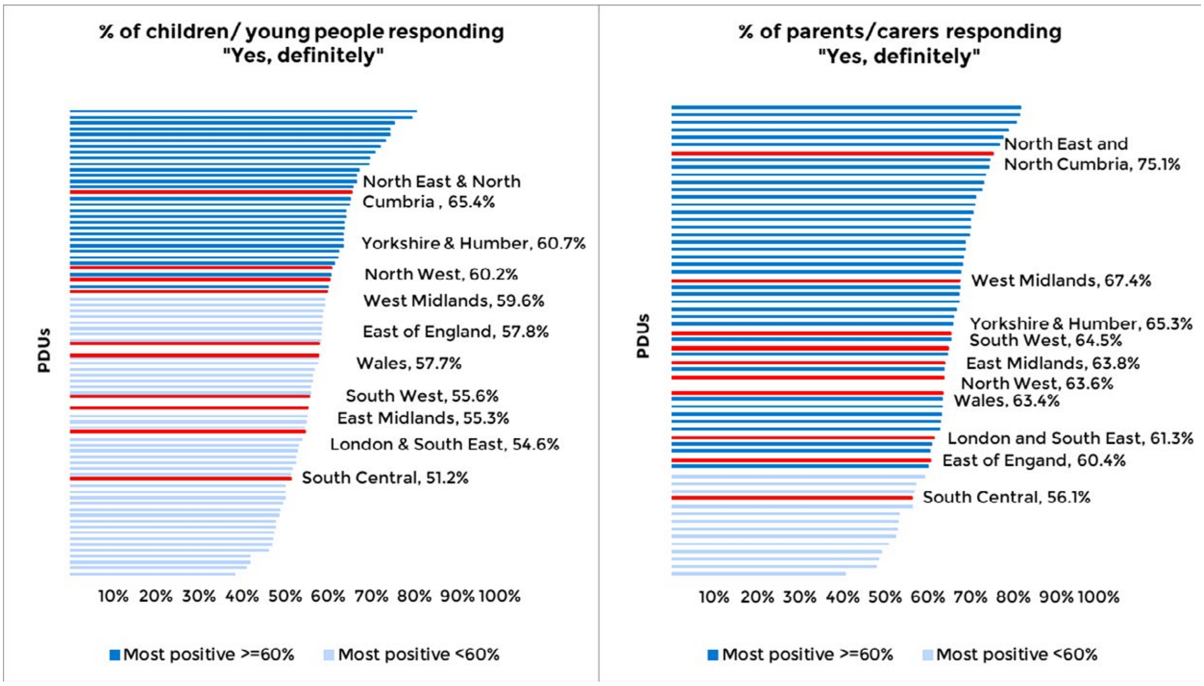
7.10 Transition to adult care

Respondents were asked whether they had received enough information and support over the last 6 months to prepare for a transition to adult care. Figure 19 shows the responses from over 83% of children and young people and 63% of parents and carers that considered this question was applicable for them.



* "I am (my child is) too young to consider this" answers were excluded from the denominator.

Figure 19: "Our diabetes team are providing us with the information, resources and support we need to prepare for my (child's) transfer to adult care". Responses from children/young people and parents/carers, by country and overall



* "I am (my child is) too young to consider this" answers were excluded from the denominator.

Figure 20: "Our diabetes team are providing us with the information, resources and support we need to prepare for my (child's) transfer to adult care" by PDU and region *

Figure 20 shows the percentages of respondents stating "Yes, definitely", sorting from the highest to the lowest percentage by PDU. There was variation at unit and regional level in children and young people's and parent and carer agreement that they were being prepared for transfer to adult care, with 51.2% and 56.1% of children and young people and parents and carers, respectively, responding 'yes, definitely' in South Central, and 65.4% and 75.1% responding the same in North East and North Cumbria. Unit percentages ranged from ~40%-80% agreement amongst both groups.

7.11 Peer support

Figure 21 (page 43) shows that more than half (59.1%) of children and young people and parents/carers (62.8%) reported that their clinic made it possible to contact/spend time with other (parents of) children and young people with diabetes.

Nearly a quarter of young people (23.3%) said their clinic did not provide these opportunities, and that they didn't want to meet with others. This percentage was lower amongst parents and carers (13.9%), with 11% of these reporting that they had not been given these opportunities but would like them compared to 8.3% of children and young people.

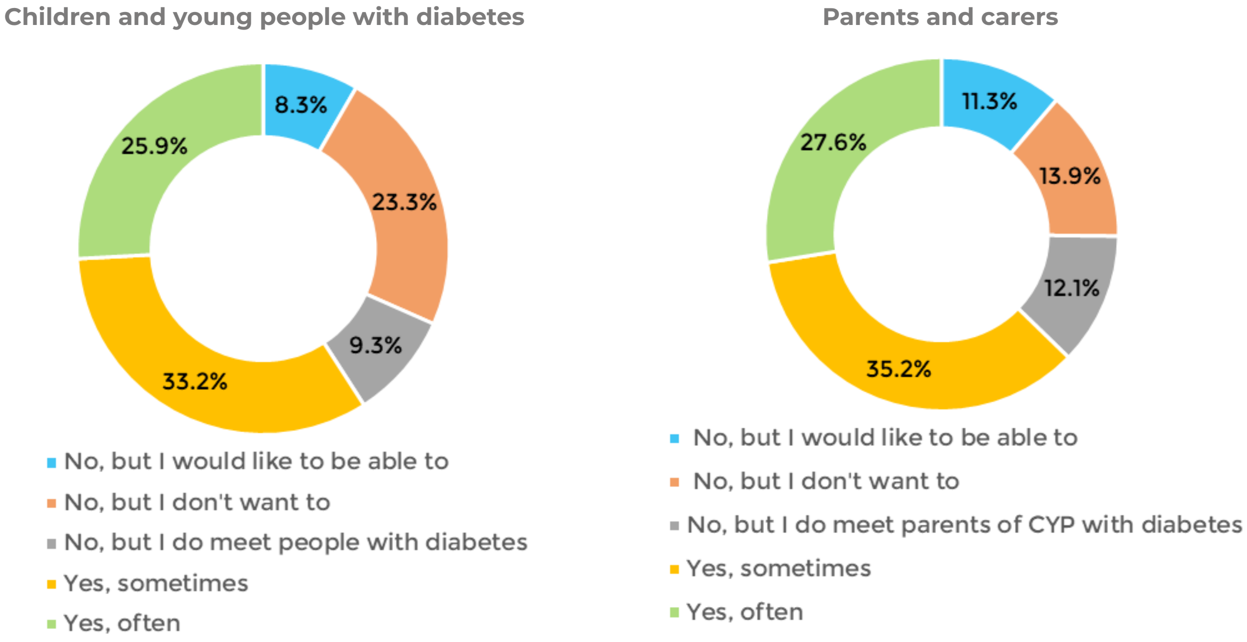


Figure 21: "Our diabetes team makes it possible for me to contact/spend time with other (parents of) young people with diabetes". Responses from children/young people and parent/carer, overall figures for England and Wales

Table 14: "Our diabetes team makes it possible for me to contact/spend time with other (parents of) young people with diabetes". Responses from children/young people (CYP) and parents/carers (P/C), by country

		n	No, but I would like to	No, but I don't want to	No, but I do meet	Yes, sometimes	Yes, often
England	CYP	5,798	8.4%	23.4%	9.4%	33.4%	25.5%
	P/C	6,508	11.2%	14.2%	12.0%	35.2%	27.4%
Wales	CYP	314	7.3%	22.0%	7.6%	30.9%	32.2%
	P/C	454	11.5%	10.6%	12.8%	34.8%	30.4%

7.12 Access to prescriptions

Access to diabetes-related prescriptions may be beyond the control of paediatric diabetes teams, however it was a strong theme emerging from the workshops with parents undertaken at the beginning of the PREMs' development. The results from this question are presented for information, rather than for action from paediatric diabetes teams.

Figure 22 shows that 59.4% of parents and carers agreed they were always able to access the prescriptions needed, without difficulty, from their GP, and that 7% disagreed that they could.

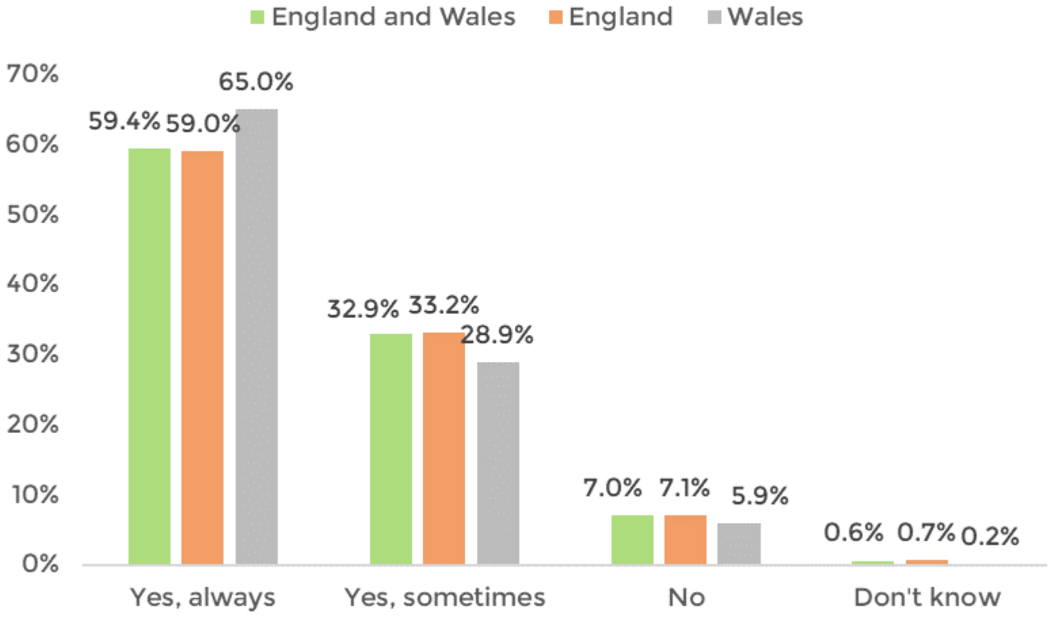


Figure 22: "We are able to access the prescriptions that we need, without difficulty, from our GP". Responses from parents and carers, by country and overall

7.13 Overall experience

Respondents were asked to choose which emoji best represented how they usually felt after leaving the clinic. Table 15 gives a breakdown of responses, and shows that overall, parents and carers typically left clinic feeling happier than children and young people, and that positive feelings were reported more frequently than neutral or negative feelings.

Table 15: "How do you usually feel when you leave the clinic?". Responses from children/young people and parents/carers, by country and overall

		n	😀	😊	😐	☹	😫
England and Wales	CYP	6,120	35.7%	42.3%	18.1%	2.0%	1.9%
	P/C	6,946	46.1%	40.3%	10.9%	1.7%	1.0%
England	CYP	5,807	35.6%	42.6%	17.9%	2.0%	1.9%
	P/C	6,495	46.0%	40.5%	10.9%	1.6%	1.0%
Wales	CYP	313	37.4%	36.4%	22.4%	1.6%	2.2%
	P/C	451	47.7%	36.8%	11.8%	2.2%	1.6%

Figure 23 shows that young people aged 12 and above tended to feel less positive than younger children, however the majority in both age groups reported leaving the clinic with a positive rather than neutral or negative feeling.

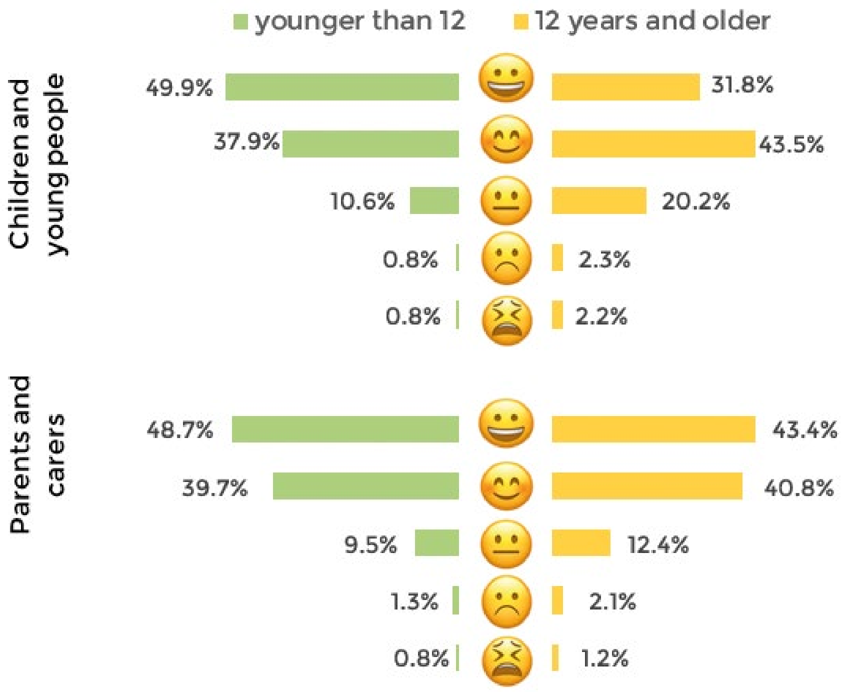


Figure 23: "How do you usually feel when you leave the clinic?". Responses from children/young people and parents/carers, by age group

Table 16 shows other questions from the PREM survey that were significantly correlated to the rating of feelings following a clinic appointment. Respondents aged 12 years and above show stronger correlations in general because their responses were more varied. For this age-group the question most strongly correlated with usual feelings following a clinic visit was "My (our) diabetes team understand me (us) and my (our) individual needs". This means that the higher the agreement with this statement, the more positive the child or parent were likely to report feeling after their appointment.

Table 16: Correlations between overall satisfaction and other questions within the PREM survey

	Correlations in Children and young people's responses *		
Questions	**< 12 years old**	**overall**	**≥ 12 years old**
My diabetes team understand me and my individual needs	0.31	0.43	0.45
My diabetes team support the whole family	0.25	0.35	0.36
I received enough information from my diabetes team to manage emotional wellbeing	0.24	0.31	0.31
	Correlations in Parent and Carers responses *		
	< 12 years old	**overall**	**≥ 12 years old**
Our diabetes team understand us and our individual needs	0.48	0.50	0.51
Our diabetes team support the whole family	0.40	0.43	0.46
Our diabetes team keep us up-to-date with new technologies	0.38	0.39	0.41
We received enough information from our diabetes team to manage emotional wellbeing	0.36	0.38	0.40

* All the correlation-coefficients presented in the table were statistically significant at 0.05

Figure 24 shows that there was variation in feelings following clinic visits between PDUs and regions.

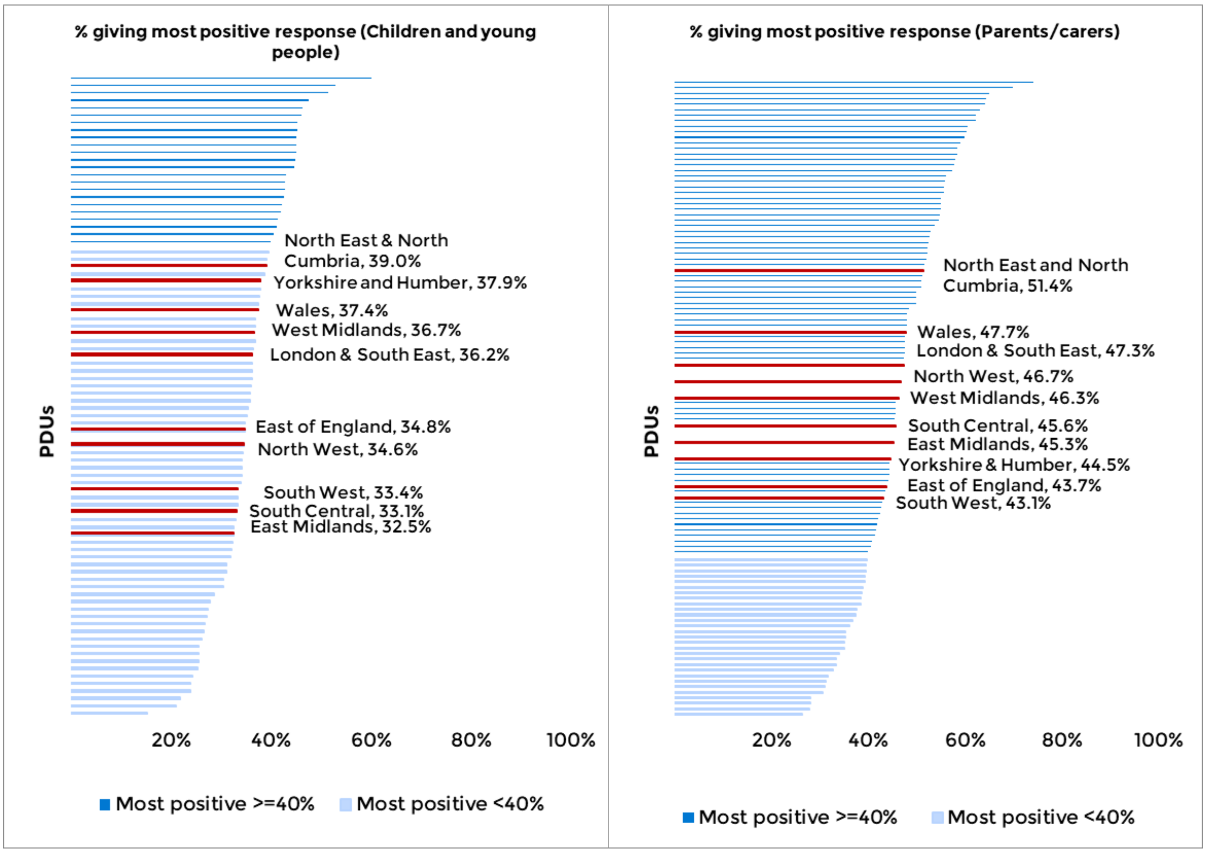


Figure 24: "How do you usually feel when you leave the clinic?". Responses from children/young people and parents/carers, by PDU and region

7.14 Friends and family test

The Friends and Family Test question was included in order to enable comparison with other local services, and as an indicator of overall satisfaction with respondents' paediatric diabetes services. Table 17 shows that over three quarters (79.6%) of children and young people and over 90.4% of parents and carers strongly agreed that they would recommend the diabetes service they were attending, indicating very high levels of satisfaction nationally.

Table 17: "I would recommend this clinic to a friend or other family with a child who has diabetes to be treated in". Responses from children/young people (CYP) and parents/carers (P/C), by country and overall

		n	I can't decide/ I don't know	I disagree a lot	I disagree a bit	I agree a bit	I agree a lot
England and Wales	CYP	6,121	4.0%	0.8%	1.3%	14.2%	79.6%
	P/C	6,978	1.0%	0.6%	1.0%	7.1%	90.4%
England	CYP	5,808	4.0%	0.8%	1.3%	14.2%	79.7%
	P/C	6,522	1.0%	0.6%	1.0%	7.0%	90.4%
Wales	CYP	313	3.5%	0.6%	1.6%	15.3%	78.9%
	P/C	456	0.4%	1.3%	0.7%	8.3%	89.3%

Figure 25 shows that overall satisfaction did not differ between different age groups or their parents and carers.

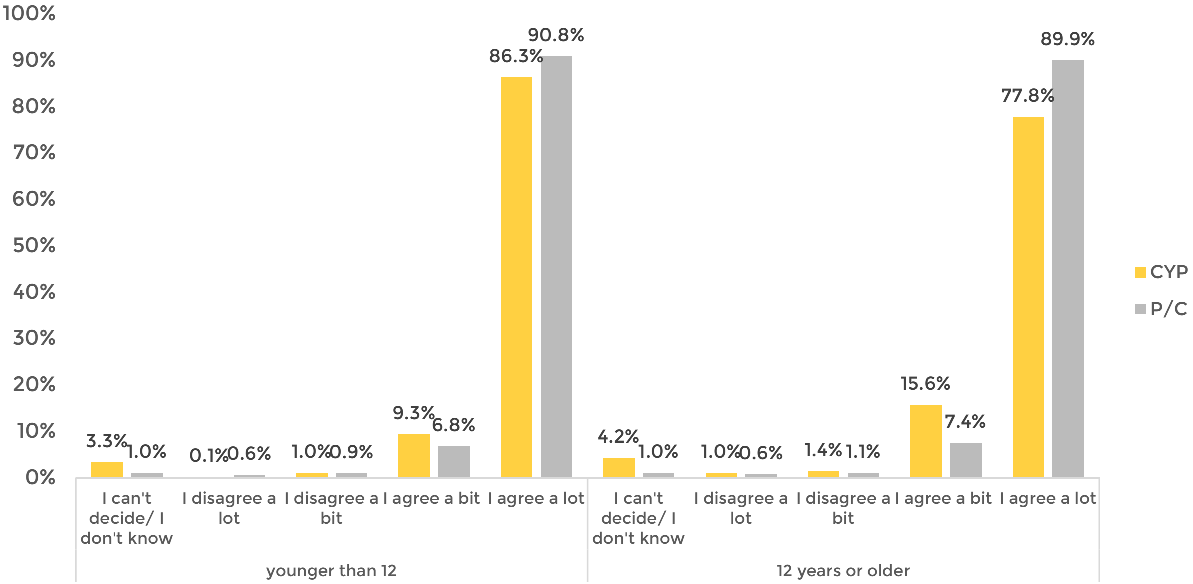


Figure 25: "I would recommend this clinic to a friend or other family with a child who has diabetes to be treated in". Responses from children/young people (CYP) and parents/carers (P/C), by age group

Figure 26 shows similar levels of satisfaction across regional networks.

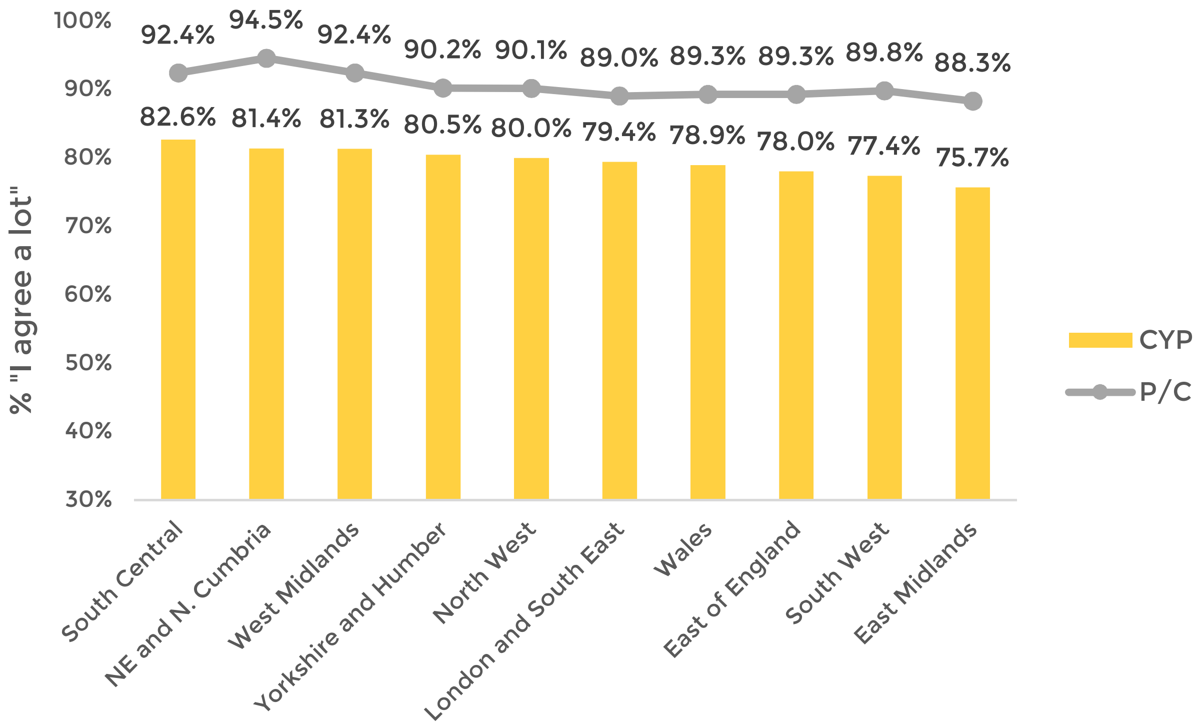


Figure 26: "I would recommend this clinic to a friend or other family with a child who has diabetes to be treated in". Percentage of children/young people (CYP) and parents/carers (P/Cs) responding "I agree a lot", by region

7.15 Overall PREM score

An overall PREM score was constructed to facilitate comparison of performance between PDUs. The scores are comprised of a selection of questions measuring performance or experience, with clear positive or negative response options, and scoring found to be reliable during psychometric analysis. The questions included are shown in Table 19.

Binary scores per respondent were calculated for each question, with the most positive response (e.g. “Yes, definitely”, “Yes, always”) given a value of ‘1’ and all other responses (e.g. Yes, sometimes”, “No, never”) given a value of ‘0’. Responses such as “Not applicable” and “Too early to say” were excluded from the analysis. A ‘perfect’ overall PREM score would therefore be 1, if all respondents responded to each question with the most positive response possible for each.

Table 18: PREM scores based on the responses of children/young people (CYP), parents/carers (P/Cs) and overall, by country

	Overall score	CYP score	P/C score
England and Wales	0.70	0.69	0.71
England	0.70	0.69	0.71
Wales	0.70	0.68	0.71

Given that children and young people tended to give less positive responses than their parents and carers, the overall score was constructed by giving the same weight (0.5) to the scores calculated from children and young people’s responses and the scores calculated from parent/carer responses. Additionally, the overall score was validated through a regression analysis, which tested the hypothesis that the proportion of responses by children and young people did not affect the overall score by unit. This hypothesis was proven. This means that if a PDU had a higher percentage of responses from children and young people compared to parents and carers, they were not more likely to have a lower overall score.

Figure 27 shows the funnel plot for overall PREM scores by PDU. PDUs with fewer than 10 responses from parents/carers or children and young people were excluded. Most units’ overall score fell within two standard deviations of the mean value.

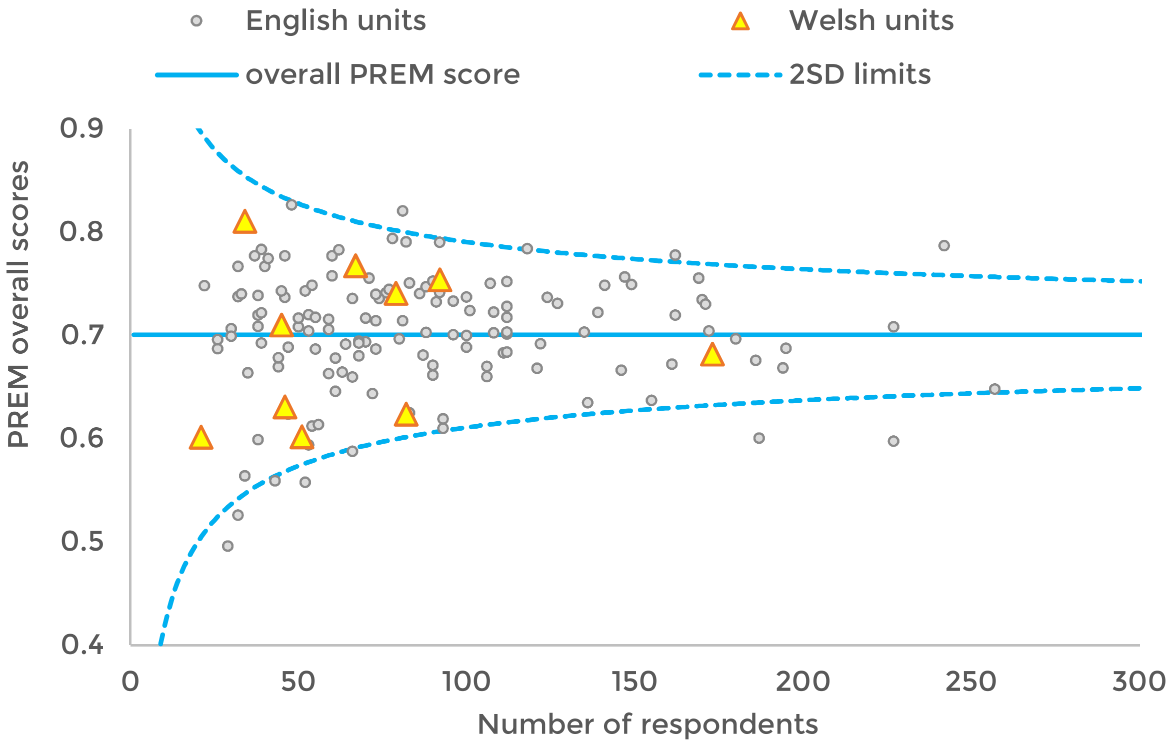


Figure 27: Funnel plot for overall PREM score, by paediatric diabetes unit

Figure 28 shows that parents and carers rated their children's care more highly than their children across all regions, and that overall scores by region ranged from 0.68 to 0.75.

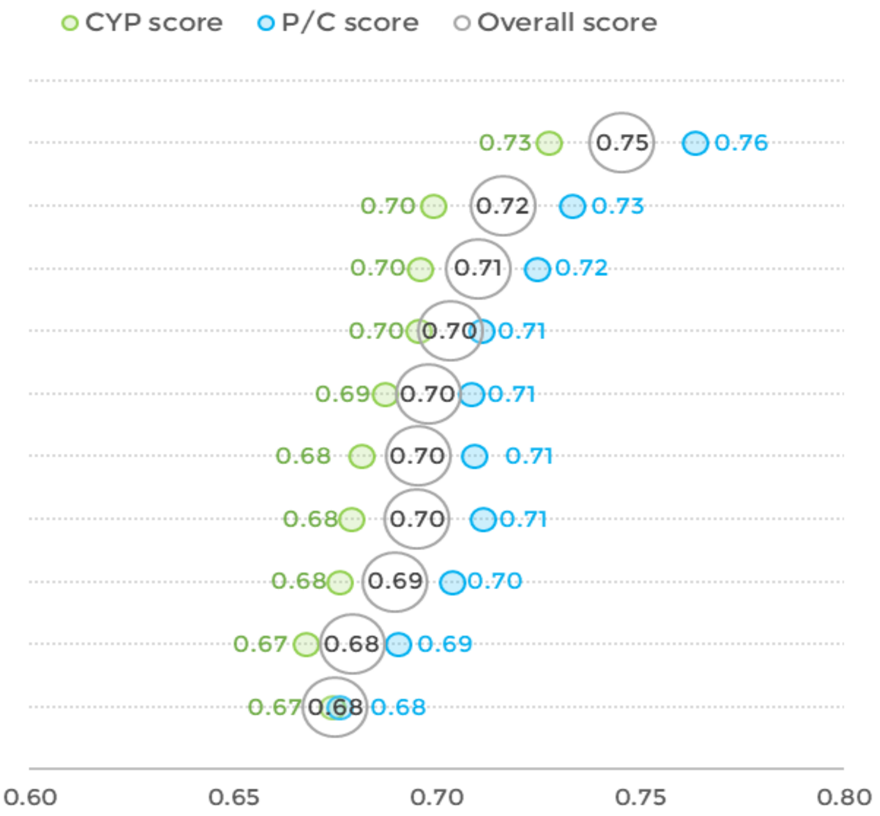


Figure 28: PREM scores based on the responses of children/young people (CYP), parents/carers (P/C) and overall, by region

Table 19 presents the questions included in the calculation of the overall PREM scores. They have being grouped into six "principles of person-centred care" as identified by The Picker Institute.

For parents and carers, the areas with lower scores were access to Psychologists (0.13) and Dietitians (0.47), followed by the provision of information and advice on glucagon preparation and when to use it (0.49), information on flash glucose monitoring (0.59) and insulin pumps (0.64), information and advice on managing emotional wellbeing (0.62), and the existence of an age-appropriate waiting area within the clinic (0.61).

For children and young people, the areas with lower scores were the provision of an age-appropriate waiting area within the clinic (0.51), information on flash glucose monitoring (0.57), ketone monitoring (0.58) and insulin pumps (0.59), and information and advice on managing emotional wellbeing (0.58).

Table 19: Questions included in the calculation of the overall PREM score

	Children and young people			**Parents and carers**		
	E&W	**England**	**Wales**	**E&W**	**England**	**Wales**
1. Fast access to reliable health care	-	-	-	**0.62**	**0.62**	**0.60**
Children and carers are able to see the following members of the team when coming to clinic:						
1.1 Children's diabetes specialist nurse	-	-	-	0.86	0.86	0.90
1.2 Dietitian	-	-	-	0.47	0.48	0.41
1.3 Psychologist	-	-	-	0.13	0.13	0.13
1.4 Diabetes doctor	-	-	-	0.86	0.86	0.85
1.5 Children and carers are able to get appropriate advice from the hospital 24 hours a day	-	-	-	0.75	0.75	0.69
2. Clear information, communication and support for self-care	**0.67**	**0.67**	**0.67**	**0.71**	**0.71**	**0.72**
The diabetes team:						
2.1 talks in a way children and carers can understand	0.79	0.79	0.78	0.93	0.93	0.90
2.2 use HbA1c results to give helpful advice on how to manage blood glucose levels	0.84	0.84	0.79	0.87	0.87	0.87
2.3 keeps children and carers up-to-date with new technologies	0.62	0.62	0.66	0.64	0.64	0.66
Children and carers receive enough information on:						
2.4 managing high and low blood glucose	0.80	0.80	0.78	0.86	0.86	0.85
2.5 managing illness	0.64	0.64	0.65	0.75	0.75	0.76
2.6 carb counting	0.71	0.71	0.72	0.78	0.78	0.79
2.7 exercise	0.60	0.60	0.59	0.67	0.67	0.67
2.8 maintaining future health with diabetes	0.62	0.63	0.60	0.67	0.67	0.68
2.9 managing emotional well being	0.58	0.58	0.54	0.62	0.62	0.62
2.10 continuous glucose monitoring (CGM)	0.73	0.73	0.73	0.72	0.72	0.79
2.11 managing diabetes at school/college	0.74	0.74	0.72	0.75	0.75	0.74
2.12 Flash glucose monitoring (Freestyle Libre)	0.57	0.57	0.60	0.59	0.58	0.64
2.13 Ketone monitoring	0.58	0.58	0.54	0.68	0.68	0.70
2.14 insulin pumps	0.59	0.59	0.61	0.64	0.64	0.63
2.15 glucagon preparation and when to use it	-	-	-	0.49	0.49	0.46

	Children and young people			Parents and carers		
	E&W	England	Wales	E&W	England	Wales
3. Involvement in decisions and respect for preferences	**0.75**	**0.75**	**0.75**	**0.84**	**0.84**	**0.84**
3.1 The clinic meets children and carers' preferences about seeing the diabetes team together in one room or separately	0.68	0.68	0.66	0.78	0.78	0.78
3.2 Diabetes team involves children and carers in decisions about care and treatment	0.82	0.82	0.84	0.91	0.91	0.90
4. Emotional support, empathy and respect	**0.74**	**0.74**	**0.74**	**0.73**	**0.73**	**0.72**
The diabetes team:						
4.1 has a positive relationship with children and carers	0.80	0.80	0.78	0.90	0.90	0.88
4.2 understands children and carers individual needs	0.75	0.75	0.72	0.83	0.83	0.82
4.3 support the whole family	0.68	0.68	0.71	0.73	0.73	0.72
4.4 How do carers feel when leaving the clinic	-	-	-	0.46	0.46	0.48
5. Attention to physical and environmental needs	**0.51**	**0.51**	**0.49**	**0.61**	**0.61**	**0.58**
5.1 The clinic has an age-appropriate waiting area	0.51	0.51	0.49	0.61	0.61	0.58
6. Overall satisfaction	**0.80**	**0.80**	**0.79**	**0.90**	**0.90**	**0.89**
6.1 Children and carers recommend this clinic to friends or other families	0.80	0.80	0.79	0.90	0.90	0.89

Linear and logistic regression models were created in order to test the relationship between PREM scores and HbA1c outcomes, while controlling for sex, age, duration of diabetes, deprivation and ethnicity. Higher overall PREM scores were not associated with lower HbA1c outcomes or a substantial reduction in the proportion of children and young people with HbA1c levels above 80 mmol/mol.

8. Qualitative analysis

Both the children and young people and parent/carer PREM surveys contained two optional free text questions:

1) **What do you find helpful about your clinic visits?**
2) **What could your diabetes team do to make your clinic visits better?**

These questions were designed to provide context to the quantitative results of the PREM surveys, and to help teams understand exactly what children and young people with diabetes and their families thought about their care, in their own words.

In total, 10,059 free text responses were received. These responses were redacted where necessary, in order to protect respondent and/or staff identities, and were subjected to an inductive thematic analysis.

Two coders on the NPDA team worked together to read through the responses and identify the main emerging themes. Once established, these were broken down into sub themes where possible. A third coder, external to the team, used the established theme and sub-theme framework to code a random selection of responses. Their coding was compared with the coding completed by the NPDA team members, to confirm the reliability and validity of the codes identified and applied.

Main and sub-themes identified are presented below for each question, in order of frequency. Some responses covered a range of subjects, and multiple theme/sub-theme codes were applied to these responses. This means that the percentages of codes applied will not add up to 100%.

8.1 What do you find helpful about your clinic visits? Children and young people's survey

The total number of children and young people completing the PREM survey was 6,165. Of these, 2,753 (44.6%) opted to provide a response to this question. One and a half percent of these responses (44) stated that the child/young person 'Didn't know', and a further 2.1% (59) stated 'Nothing' or provided a negative response. The remaining responses (2650) were broken down into themes and sub-themes as described below, in order of frequency of reference (Table 20).

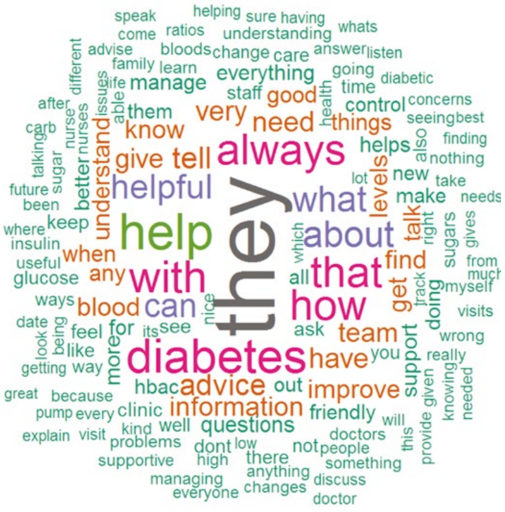


Table 20: Breakdown of themes and subthemes in children and young people's comments about helpful aspects of their clinic visits

Theme	% of total comments (n)	Subthemes	% of comments within theme (n)
Advice and information	54.2% (1,491)	General advice or information about diabetes and management	48.2% (718)
		Advice on improving management	15.8% (236)
		Advice on managing glucose	14.6% (218)
		Having questions answered	10.1% (150)
		Advice on making changes to diabetes management	6.8% (101)
		Advice on information about diabetes related technology	4.4% (65)
Staff team	19.8% (544)	Staff team qualities	92.6% (504)
		Praise for individual diabetes team members/ specific staffing groups	23.7% (129)
Monitoring diabetes management and health status	16.0% (441)	Reviewing HbA1c or other glucose trends	45.4% (200)
		General review of diabetes management and overall health	44.9% (198)
		Reassurance about management	17.0% (75)
Support	15.0% (412)	Support – unspecified	44.2% (182)
		Opportunity to talk	26.2% (108)
		Addressing worries, concerns or problems	18.7% (77)
		Encouragement and motivation	14.3% (59)
Patient centred care	9.3% (257)	Individual needs understood or met	55.3% (142)
		Ability to speak openly	20.6% (53)
		Included in decision making and discussions	17.1% (44)
		Being listened to	15.2% (39)
Organisation of visits	4.4% (120)	N/a – comments too varied to sub categorise	-
Other	14.1% (388)	Making adjustments to insulin dosing	22.4% (87)
		Everything	22.0% (85)
		Non-specific positive comments	17.3% (67)
		Availability	14.7% (57)

Please see Appendix B for more information on each theme and subtheme, and for examples of direct quotes coded under each.

8.1.1 Summary: What do children and young people with diabetes find helpful about their clinic visits?

Analysis of the comments provided by children and young people about what they find helpful about their clinic visits suggests that:

- Children and young people with diabetes are not passive recipients of diabetes care and are interested in learning about the condition and how to self-manage to the best of their ability.

- Clinic visits provide a valued opportunity to monitor their diabetes management, keep track of trends in glucose management and receive reassurance, where applicable, that they are on the right track with their management.
- Diabetes team members are viewed positively by the children and young people under their care.
- Clinic visits are a valued support to children and young people with diabetes, providing an opportunity to address concerns, talk to trusted professionals about life with diabetes, and to receive encouragement to manage their diabetes effectively.
- Children and young people with diabetes value being understood as individuals, and being listened to and included in making decisions about their care.

8.2 What do you find helpful about your clinic visits? Parent/carer survey

The total number of parents/carers completing the PREM survey was 7,013. Within this group, 3,232 (46.1%) opted to provide a response to this question. Less than 1% of these responses (16) stated that the parent/carer 'Didn't know', and 2.5% (80) stated 'Nothing' or provided a negative response. The remaining responses (3,136) were broken down into themes and sub-themes as shown in Table 21.

Table 21: Themes and subthemes in parent and carer comments on what they find helpful about their clinic visits

Theme	% of total comments (n)	Subthemes	% of comments within theme (n)
Advice and information	39.6% (1,280)	General advice or information about diabetes and management	48.6% (622)
		Having questions answered	20.2% (259)
		Advice on making changes to diabetes management	10.2% (130)
		Advice on managing glucose	5.9% (76)
		Information about diabetes- related technologies	3.9% (50)
		Dietary advice	3.8% (48)
		Advice on resolving problems or issues	3.7% (47)
		Advice on improving management	3.6% (46)
Staff team	38.5% (1,245)	Staff team qualities	88.3% (1,099)
		Good relationship with team	11.6% (145)
		Seeing the same staff members	11.4% (142)

Theme	% of total comments (n)	Subthemes	% of comments within theme (n)
Support	29.7% (960)	Unspecified support	49.5% (475)
		Addressing concerns or worries	20.4% (196)
		Help when needed	20.0% (192)
		Opportunity to talk	12.6% (121)
		Encouragement and motivation	6.8% (65)
Organisation of visits	16.3% (526)	Having input of the whole team	29.7% (156)
		Having access to specific members of the multidisciplinary team	26.8% (141)
		Timing of appointments	26.6% (140)
Monitoring diabetes management and health status	16.0% (517)	Reviewing HbA1c and other glucose trends	56.5% (292)
		General monitoring and review	53.4% (276)
Child/family centred care	12.5% (403)	Ability to speak openly	36.0% (145)
		Being included in decision making and discussions	30.0% (121)
		Having child or family needs understood or met	28.0 % (113)
		Being listened to	18.1% (73)
Reassurance	8.3% (268)	N/a	8.3% (268)
Other	9.4% (304)	Non-specific positive comments	60.9% (185)
		Making adjustments to insulin dosing	30.9% (94)

Please see Appendix C for more information on each theme and subtheme, and for examples of direct quotes coded under each.

8.2.1 Summary: What do parents and carers find helpful about their clinic visits?

- Parents and carers and children and young people with diabetes find similar aspects of their diabetes clinic appointments helpful.
- Diabetes teams are viewed in similarly positive terms, with parents and carers highlighting their positive relationships with the team and consistency of staffing as helpful aspects of their diabetes clinic visits in particular.
- Clinic visits are valued as an opportunity to receive advice and information about diabetes management from a range of different professionals.
- Clinic visits also provide parents and carers with reassurance, and support to help them cope with their child's diabetes; including addressing concerns and worries, and an opportunity to talk. Accessing support outside of clinic was also highlighted as helpful.
- Visits provide an opportunity to review blood glucose trends, to get an overview of their child's overall health, and to make changes to insulin dosing if found to be necessary.
- Parents and carers value open and honest discussions about their child's care, making collaborative decisions about care, and having care tailored to the needs of their child or family.

8.3 What could your diabetes team do to make your clinic visits better? Children and young people's survey

The total number of children and young people completing the PREM survey was 6,165. Within this group, 1,769 (28.6%) opted to provide a response to this question. Eight percent of these responses (141) stated that the child/young person 'Didn't know', and almost half of all responses received to this question (49.1%, 868 responses) stated that the child/young person was happy with their clinic visits as they currently were and could suggest no improvement. The remaining responses (760) were broken down into themes and sub-themes as shown in Table 22.

Table 22: Themes and subthemes in children and young people's comments on what their diabetes team could do to improve their clinic visits

Theme	% of total comments suggesting an improvement (n)	Subthemes	% of comments within theme (n)
Timing of appointments	29.3% (223)	Time spent waiting	45.3% (101)
		Appointment length	26.9% (60)
		Frequency of appointments	12.6% (28)
		Timing of appointments outside of school hours	9.4% (21)
Engagement with staff team members	23.7% (180)	Patient-centered care	48.3% (87)
		Communication skills	43.3% (78)
More advice and information	18.6% (142)	General information	63.4% (90)
		Information about diabetes-related technologies	31.0% (44)
Waiting area	17.5% (133)	Activities	51.1% (68)
		Teen friendly waiting area	26.3% (35)
		Refreshments	22.6% (30)
Other	21.7% (165)	Organisation of visit	34.5% (57)

Please see Appendix D for more information on each theme and subtheme, and for examples of direct quotes coded under each.

8.3.1 Summary: How could clinic visits be improved for children and young people with diabetes

Analysis of patient comments suggests that:

- Children and young people with diabetes are happy with their clinic visits in general.
- Time spent waiting before the start of appointments could be reduced to improve the experience of some.
- Changes to the frequency and length of appointments would be appreciated by some children and young people, as would appointments outside school hours.
- Whilst waiting for their appointment, children and young people with diabetes would like access to age appropriate activities, and refreshments.
- Some children and young people would like better engagement with their staff team, with more inclusion in discussions, having their individual needs, worries and preferences taken into account, being listened to, or feeling more empathy from the staff team about the challenges associated with managing their diabetes.
- Some children and young people with diabetes would also like access to more information about managing their diabetes, including information on diabetes-related technologies.

8.4 What could your diabetes team do to make your clinic visits better? Parent/carer survey

The total number of parents and carers completing the PREM survey was 7,013. Of these, 2,305 (32.8%) provided a response to this question. Of these, 1,117 respondents (48.5%) did not offer a suggested improvement, stating that that they couldn't think of one or that they were entirely satisfied with their visits as they were. The remaining 1,188 responses were broken down into themes and sub-themes as described below.

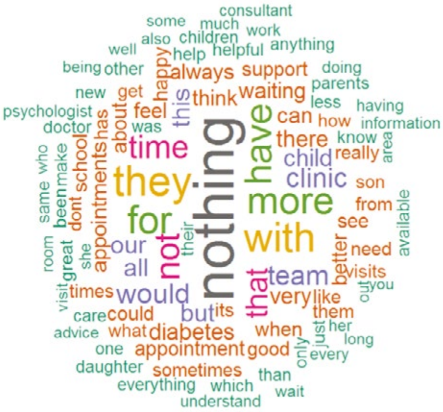


Table 23: Themes and subthemes in parent and carers' comments on what their diabetes team could do to improve their clinic visits

Theme	% of total comments suggesting an improvement (n)	Subthemes	% of comments within theme (n)
Timing of appointments	32.3% (384)	Time spent waiting	52.9% (203)
		Appointments outside of work or school hours	17.2% (66)
		Appointment length	15.4% (59)
Engagement with staff team members	20.5% (244)	Child/family centred care	37.7% (92)
		Seeing same staff	27.5% (67)
		Communication skills of staff	24.2% (59)
Organisation of appointments	13.5% (160)	Separate meetings with multidisciplinary team members	21.3% (34)
		Pre-clinic preparation	17.5% (28)
		Seeing team without child present	14.4% (23)
		Seeing team members together	12.5% (20)
More advice and information	10.9% (130)	Diabetes-related technologies	56.2% (73)
Psychological and emotional support	9.1% (108)	Psychological and emotional support for child	88.9% (96)
		Psychological and emotional support for the wider family	19.4% (21)
Waiting area	8.3% (99)	More age-appropriate	34.3% (34)
		Refreshments	27.3% (27)
		Activities	25.3% (25)
Access to support between clinic visits	6.9% (82)	Group activities and peer-support	37.8% (31)
		Timely specialist advice by phone or email	24.4% (20)
Other	24.6% (292)	Access to diabetes related technology	13.0% (38)
		General hospital environment	6.8% (20)

Please see Appendix E for more information on each theme and subtheme, and for examples of direct quotes coded under each.

8.4.1 Summary: What could make clinic visits better for parents and carers?

Analysis of comments suggests that:

- Parents and carers are similarly happy with their clinic visits compared to children and young people with diabetes, and have similar suggestions for improvements.
- Parents and carers are similarly frustrated by delays to the start times of appointments, and would like to wait in an area that is appropriate to the age of their child, with activities and refreshments available.
- Appointments outside of school or work hours would be appreciated, with some preferring longer or shorter visits.
- Relationships with staff are important, and could be improved in some cases by better communication skills amongst certain team members, seeing the same team members at each visit, involving the child or family in discussions and decisions around care, and explicit acknowledgement of the hard work that goes into managing, or supporting the management of, a child or young person with diabetes.
- Many parents and carers would like additional psychological or emotional support for their child, and others would like support for the wider family. This theme was not prominent amongst the comments from children and young people.
- Additional support outside of clinic visits could also benefit some families, either through timely access to support over the phone or email, or access to peer-support and group activities.

9. Discussion

This first NPDA national PREM report provides a detailed analysis of the care experienced by children and young people with diabetes and their families in England and Wales. With nearly 14,000 surveys returned, participating paediatric diabetes units and families with diabetes have demonstrated strong support for service improvement through user engagement.

Diabetes is a long term condition that poses unique challenges for children and young people with the condition, and their families. The high level of satisfaction with the support offered to families by paediatric diabetes teams evidenced throughout this report is very encouraging. This is testament to the hard work and dedication of the teams, regional and national diabetes networks and families who have collaborated effectively to achieve these results.

Comments from children and young people and their families about their teams serve to emphasise the importance of the relationship between the staff team and the family, and the value of advice and information they offer for successful collaborative management of diabetes.

Comments by children and young people highlight their interest and engagement in the understanding and management of their diabetes. Whilst there was general overall satisfaction with the information provided at clinic visits, areas for improvements in information provided were identified, including managing illness, exercise, future health, emotional health, use of glucagon, diabetes related technologies, and preparation for transition to adult services. Despite it being a criterion within the Best Practice Tariff in England, only two thirds of parents and carers agreed that they could always access telephone advice 24 hours a day.

The finding that higher scoring at centre level on experiences of care measured by the PREM was not associated with lower HbA1c is interesting and demonstrates that the relationship between experience and outcome is complicated. Lack of association does not imply that experience is not important in driving improvement in local or national outcomes, it remains only part of the complex 'jigsaw' required to help our children and young people and their families.

The report also shows variation in experiences between regions and centres. It is up to each centre and regional network to act upon the information to improve the care provided and ensure equal access to the same level of diabetes care and education to all children and young people across England and Wales. Overall, paediatric diabetes teams should feel very proud of the excellent care and support they are providing.

10. Conclusion

The NPDA PREM results show high levels of satisfaction amongst families with diabetes in England and Wales. Family centred care was predictive of overall positive feelings about attending clinic, and respondents valued the information and advice provided by their staff teams, who were viewed in overall positive terms. The PREM survey provides a useful source of data for comparing and improving patient and parent satisfaction with care at local, regional and national level.

Appendix A: Characteristics of respondents making comments

Table 24 provides a breakdown of the numbers of children and young people and parents and carers who answered at least one of the free text questions, against the total numbers in each group who completed a PREM questionnaire, in addition to the response rates for comments based on the number of children and young people included in the 2018/19 core NPDA, by country and overall. Nearly half of all children and young people (47.3%) and parents and carers (49.7%) completing a PREM questionnaire provided at least one response to either of the optional free text questions within the questionnaire. For children and young people, this gave a response rate of 9.7% based on the core NPDA patient cohort.

Table 24: Participation in PREM 2019, compared to NPDA 2018/19 report, by country and regional network

	PREM responses – Children and young people		PREM responses – Parents and carers		NPDA – 2018/19		
	Total	% providing a comment	Total	% providing a comment	Total CYP in core audit	CYP PREM response rate overall (%)	CYP PREM comments
England and Wales	6,165	2,917 (47.3%)	7,013	3,484 (49.7%)	30,155	20.4%	9.7%
England	5,849	2,774 (47.4%)	6,556	3,259 (49.7%)	28,676	20.4%	9.7%
Wales	316	143 (45.3%)	457	225 (49.2%)	1,479	21.4%	9.7%

Table 25 provides a breakdown of the characteristics of the children and young people and parents and carers providing at least one free text comment in comparison to the total cohort of each completing a PREM questionnaire, and against the total cohort of children and young people included in the contemporaneous national paediatric diabetes audit (2018/19). It shows that those providing comments were similar in terms of age, sex, and type of diabetes compared to the cohorts returning a PREM questionnaire or included in the core 2018/19 audit, however there was a greater proportion of comments received from children and young people with a longer duration of diabetes diagnosis and their parents and carers.

Table 25: Characteristics of respondents to the 2019 PREM, those providing at least one free text comment, and of the children and young people with diabetes included in the 2018/19 NPDA core audit

Characteristic	CYP – total	CYP with comments	2018/19 core NPDA cohort	Parent/ carer – total	Parent/ carer with comments
Total	**6,165 (100%)**	**2,917 (100%)**	**30,155 (100%)**	**7,013 (100%)**	**3,484 (100%)**
Sex					
Female	3,086 (50.1%)	1,507 (51.7%)	14,637 (48.5%)	-	-
Male	3,004 (48.7%)	1,368 (46.9%)	15,451 (51.2%)	-	-
Prefer not to say/ not specified	41 (0.7%)	23 (0.8%)	*	-	-
Missing/ Unknown	34 (0.6%)	19 (0.6%)	67 (0.2%) +	-	-
Relationship to child					
Mother	-	-	-	5,633 (80.3%)	2,841 (81.5%)
Father	-	-	-	1,225 (17.5%)	567 (16.3%)
Grandmother	-	-	-	59 (0.8%)	31 (0.9%)
Grandfather	-	-	-	12 (0.2%)	6 (0.2%)
Other guardian	-	-	-	69 (1.0%)	32 (0.9%)
Missing	-	-	-	15 (0.2%)	7 (0.2%)
Age of child or young person					
3 years or younger	-	-	986 (3.3%)	248 (3.5%)	125 (3.6%)
4-7 years old	124 (2.0%)	61 (2.1%)	3,659 (12.1%)	1,161 (16.6%)	586 (16.8%)
8-11 years old	1,225 (19.9%)	734 (25.1%)	7,713 (25.6%)	2,167 (30.9%)	1,122 (32.2%)
12-16 years old	3,634 (58.9%)	1,671 (57.3%)	13,763 (45.6%)	2,936 (41.9%)	1,408 (40.4%)
17 years or older	1,120 (18.2%)	425 (14.6%)	4,034 (13.4%)	449 (6.4%)	225 (6.5%)
Missing	62 (1.0%)	26 (0.9%)	0 (0%)	52 (0.7%)	18 (0.5%)
Duration of child's diabetes					
Less than a year	593 (9.6%)	307 (10.5%)	6,587 (21.9%)	1,053 (15.0%)	531 (15.3%)
1-2 years	782 (12.7%)	377 (12.9%)	6,621 (22.0%)	1,123 (16.0%)	582 (16.7%)
More than 2 years but less than 5 years	1,749 (28.4%)	886 (30.4%)	5,236 (17.4%)	2,344 (33.4%)	1,192 (34.2%)
More than 5 years but less than 10 years	1,946 (31.6%)	881 (30.2%)	8,192 (27.2%)	1,828 (26.1%)	858 (24.6%)
10 years or more	1,095 (17.8%)	466 (16.0%)	3,416 (11.3%)	665 (9.5%)	321 (9.2%)
Missing	0 (0%)	0 (0%)	103 (0.3%)	0 (0%)	0 (0%)
Diabetes type					
Type 1	5,818 (94.4%)	2,757 (94.5%)	28,597 (94.8%)	6,606 (94.2%)	3,286 (94.3%)
Type 2	118 (1.9%)	55 (1.9%)	790 (2.6%)	47 (0.7%)	20 (0.6%)
Other	58 (0.9%)	26 (0.9%)	637 (2.1%)	39 (0.6%)	25 (0.7%)
Unknown/Missing	171 (2.8%)	79 (2.7%)	131 (0.5%)	321 (4.6%)	153 (4.4%)

Characteristic	CYP – total	CYP with comments	2018/19 core NPDA cohort	Parent/ carer – total	Parent/ carer with comments
Length of time attending current clinic					
Less than a month	81 (1.3%)	38 (1.3%)	-	135 (1.9%)	58 (1.7%)
Between 1 and 6 months	479 (7.8%)	247 (8.5%)	-	658 (9.4%)	336 (9.6%)
More than 6 months but less than a year	299 (4.8%)	141 (4.8%)	-	478 (6.8%)	240 (6.9%)
1-2 years	905 (14.7%)	443 (15.2%)	-	1,239 (17.7%)	648 (18.6%)
More than 2 years but less than 5 years	1,776 (28.8%)	892 (30.6%)	-	2,245 (32.0%)	1,144 (32.8%)
More than 5 years but less than 10 years	1,735 (28.1%)	778 (26.7%)	-	1,682 (24.0%)	789 (22.7%)
10 years or more	874 (14.2%)	371 (12.7%)	-	546 (7.8%)	257 (7.4%)
Missing	16 (0.3%)	7 (0.2%)	-	30 (0.4%)	12 (0.3%)

* Indicates a number less than 5 which has been supressed
+ Results merged to mask number <5

Appendix B: What do you find helpful about your clinic visits? Children and young people's comments

1. Advice and information

Over half (1491, 54.2%) of all children and young people said that the advice and information they received at clinic were helpful in their responses to this question. Within this theme, the following sub-themes were identified:

1.1 Advice and information: General advice or information about diabetes and management

Seven hundred and eighteen (48.2%) of the responses coded under the 'Advice and information' theme did not specify the type of advice or information received and valued by the child or young person.

"Everything they tell me."

"Advice is regularly given and often helpful."

"It's fun and I get more information that I need."

1.2 Advice and information: Advice on improving management

Two hundred and thirty-six comments under this theme (15.8%) stated that clinic visits helped them to improve their diabetes management.

"Due to the regular meetings, I obtain information frequently on how to improve and control diabetes."

"Good guidance on what I can be doing to help improve my numbers if necessary. E.g. changing my basal rates."

"How they tell me what I can do to improve my readings."

1.3 Advice and information: Advice on managing glucose

Two hundred and eighteen comments under this theme (14.6%) specified that advice on glucose management was a helpful aspect of their clinic visits.

"Helps me to understand how to keep my blood glucose in a healthy range and how to reduce high and low blood glucose."

"I find it helpful because they help me with my diabetes and what I need to do to keep me fit and to be able to control my glucose levels."

"It's helpful because I find out how to manage my hypos and hypers easier as well as knowing when to higher my insulin for what I eat."

1.4 Advice and information: Having questions answered

One-hundred and fifty (10.1%) of the responses coded against 'Advice and information', specifically referred to the opportunity for children and young people to have questions answered about their diabetes at their clinic visits.

"That I am able to ask questions regarding my health."

"I find them very helpful, I'm still coming to terms with my diabetes and have a lot of questions, they always answer them and are invaluable [...]"

"Time to talk to the team and ask specific questions."

1.5 Advice and information: Changes to diabetes management

One-hundred and one comments on advice and information (6.8%) specified that it was helpful to receive advice about making changes to their diabetes management including insulin dosing or carbohydrate ratios when needed.

"Tell me what to do if something goes wrong or needs adjusting."

"That I can discuss how to bring my blood sugar down and the right basal."

"They always tell me if I am doing stuff wrong or doing it all right. And then definitely tell me if I need to change anything."

1.6 Advice and information: Information about technology

Sixty-five responses (4.4%) coded under the 'Advice and information' theme related to information about diabetes-related technologies.

"They keep me up to date on new technology advancements so I can keep an eye on possible options. They discuss what options would help in depth and how I would need to manage my type 1 with each/how it affects my lifestyle. [...]"

"Helps me understand my pump."

"My team keep me up to date with new technology and advice."

2. Staff team

Five-hundred and forty-four children and young people (19.8%) referred to the staff team when describing what they found helpful about their clinic visits. Within this theme, two sub-themes were identified:

2.1 Staff team: Staff team qualities

Five-hundred and four comments about the staff team (92.6%) described the staff team's perceived positive qualities. Typically, staff were described as helpful, caring, supportive or friendly.

"Everyone is always positive and can make me smile and laugh. They all understand what I'm going through which helps a lot [since] my family can't understand."

"That they will help you out and they are very nice and caring."

"The team are lovely people that are very easy to talk to and understanding. They have been there for the whole family for years and we are very grateful on how they have helped me through the years."

2.2 Staff team: Praise for individual staff/specific staff groups

In 129 responses coded against 'Staff team' (23.7%), children and young people made reference to specific staff members or staff groups being a helpful aspect of their clinic visits.

"The normal consultant I see is good at providing me with relevant information and listening to me and understanding what I say. He is then good at deciding what he should do based on both his opinions and expertise and also my opinions and personal experiences and preferences."

"My nurse, [name redacted], is very helpful and caring."

"The dietitians help me and my mother try and improve my diabetes and give me advice in a nice, clean, safe environment."

3. Monitoring of diabetes management and health status

The third most common theme arising from the answers to the 'What do you find helpful about your clinic visits?' question amongst children and young people was finding out about their diabetes management or current state of health in general. Four-hundred and forty-one children and young people's responses (16%) were coded under this theme. Within this, several sub-themes were identified:

3.1 Monitoring of diabetes management and health status: Reviewing HbA1c or other glucose trends

Two hundred (45.4%) children and young people highlighted that finding out their HbA1c or analysing other blood glucose information was helpful:

"Able to view all blood glucose readings to be able to understand which areas to improve.

"Finding out my HbA1c."

"Visits enable me to evaluate my recent blood glucose control so that we can make any necessary tweaks."

3.2 Monitoring of diabetes management and health status: General monitoring

One-hundred and ninety-eight responses (44.9%) under this theme related to general monitoring of the child or young person's diabetes or health status in general, further to checks carried out in clinic.

"Keeps me up to date on my diabetes and [allows] for more accurate and frequent health updates. It shows me the progress that I don't usually see myself."

"I like knowing about my diabetes. I like to know my height and weight."

"So I can receive an update on how I am dealing with diabetes."

3.3 Monitoring of diabetes management and health status: Reassurance about management

Seventy-five children and young people's responses (17.0%) coded under the 'Monitoring of diabetes management and health status' theme indicated that clinic visits were helpful because they increased the respondent's sense of self-efficacy in dealing with their diabetes management; through increasing their confidence or providing reassurance.

"I always feel calmer and more in control of my condition. I always feel reassured after my meetings."

"[...] it is always nice to hear that I am doing everything right to help my diabetes."

"I am always made to feel at ease and confident about how I manage my diabetes."

4. Support

Four-hundred and twelve children and young people's responses (15.0%) highlighted the support they received at clinic. Within this theme, three sub-themes were identified:

4.1 Support: Unspecified

Nearly half (182, 44.2%) of the comments coded under this theme referred to unspecified 'help' or 'support' received.

"Brilliant care and support received 24/7 for the past [>5 years]."

"[...] I enjoy my clinic visits because I feel very welcome and supported."

"It supports me in ways that my school mates can't."

4.2 Support: Opportunity to talk

One-hundred and eight responses (26.2%) coded under this theme highlighted the value of being supported through discourse, having the opportunity to talk through an issue, or to talk about diabetes with people who understand.

"Always a thorough chat with many different members of the team which I find helpful gaining perspectives and talking through things with them all."

"I enjoy talking and expressing my feelings and emotions to people who understand my mindset and condition :)"

"I like talking through my diabetes problems that I'm having."

4.3 Support: Addressing worries or concerns

Having worries, concerns and problems addressed was identified as a helpful aspect of clinic visits in 77 responses (18.7%) under the support theme.

"During my clinics staff members are always there to support me in any way possible. They are able to give me information about all issues or concerns I raise as well as knowing when something is up and helping me talk about this."

"A chance to air my thoughts, worries and frustrations about diabetes."

"I can talk to my diabetic nurses if I have concerns."

4.4 Support: Encouragement and motivation

Fifty-nine comments (14.3%) coded under the support theme highlighted that clinic visits provided encouragement or motivation to maintain good diabetes management.

"That they always involve me in conversations regarding my health, always seeing the positive in all I do to manage my health. Telling me they're proud of me."

"Seeing my specialist [name redacted], and his team encourages me to try and achieve levels that are better for me. They are always helpful and make me feel that I'm doing well."

"Motivation to carry on, to take care of myself."

5. Patient-centred care

Two-hundred and fifty-seven children and young people (9.3%) highlighted aspects of patient-centred care in their responses. These were split into four sub-themes.

5.1 Patient-centred care: Having individual needs understood and met

One-hundred and forty-two responses (55.3%) under this theme described being known or understood by the staff team, and having care tailored to the individual.

“The friendliness, open transparent discussions with difficult discussions. They know individuals and family needs and act accordingly.”

“When giving advice, they consider my thoughts and what I am able to do.”

“I find it useful that the diabetes team know about the sports and activities I do and how to manage my diabetes around them.”

5.2 Patient-centred care: Ability to speak openly

This sub-theme identified feelings of fifty-three responses (20.6%) coded under ‘Patient-centred care’ were coded to this sub-theme highlighted the value of being able to speak openly during appointments, without fear of being judged, and without worry of a question being too big or too small to discuss.

“I can always be honest with my team as they speak to me like an adult rather than someone who sometimes doesn’t have a clue where she’s going wrong. By being able to do this, this means I’m able to fix the problem rather than hide it.”

“I can say whatever I think and I’m not judged just helped.”

“The support from all of the team is invaluable I can ask any questions without feeling it’s a silly question.”

5.3 Patient-centred care: Inclusion in decision making and discussions

Forty-four (17.1%) of the responses coded under ‘Patient-centred care’ related to children and young people feeling included in the decision making and discussions taking place at their visits.

“That I am always involved with conversations involving my health and diabetes and my team are always interested in what I have to say regarding everything.”

“My nurse is very supportive and talks in a language that I am able to understand and get involved. […]”

“I am always involved in any decision-making and decisions are explained to me very well before any actions. The team are very caring and approachable and so I feel like I can talk to them very easily.”

5.4 Patient-centred care: Being listened to

Thirty-nine (15.2%) of the responses coded under ‘Patient-centred care’ highlighted the value of feeling listened to at their clinic visits.

“Always listen to my concerns and take them on board.”

“They always have time to listen even when things don’t go well.”

“My team listens to me.”

6. Organisation of visits

One hundred and twenty responses (4.4%) related to the structure or organisation of the visit itself. This included comments on the timing of appointments, the hospital location, or seeing different members of the multidisciplinary team if wanted.

“Seeing nurses and doctor separately so I have time with both.”

“Visits take place in a dedicated area where waiting is calm and relatively quiet. The team are always friendly and helpful. The appointments almost always run to time. I feel I am given sufficient time to discuss any issues or concerns. […”

“It’s helpful that they download my information before I see them.”

7. Other

Three hundred and eighty-eight comments (14.1%) did not fit under any of the key themes identified. Subthemes within this category included statements that ‘everything’ was helpful about visits (85), having changes made to insulin dosing (87), non-specific positive words such as ‘good’ or helpful (67) and availability of staff whenever the patient needed them (57).

Appendix C: What do you find helpful about your clinic visits? Parent and carer's comments

1. Advice and information

Most frequently, parents and carers providing a response to this question (1280, 39.6%) highlighted the advice and information received at clinic as being a helpful aspect of their visit.

1.1 Advice and information: General advice and information about diabetes and management

Six hundred and twenty-two responses (48.6%) coded under the 'Advice and information' theme related to the general advice given to support diabetes management outside of the clinic environment.

"Update on what we need to know."

"They listen to what I have to say and give me advice."

"They offer good advice and ensure my daughter understands everything about her diabetes."

1.2 Advice and information: Having questions answered

Two-hundred and fifty-nine (20.2%) of the responses coded against 'Advice and information', specifically referred to the opportunity for parents and carers to have questions answered about diabetes at their clinic visits.

"Getting a review of care given, and how to improve. Great at answering our stupid questions."

"I always have a list of questions and it's good to know that we are doing ok."

"That we can ask questions if anything is troubling us and get the help we need."

1.3 Advice and information: Changes to diabetes management

One-hundred and thirty comments on advice and information (10.2%) specified that it was helpful to receive advice about making changes to diabetes management including insulin dosing or carbohydrate ratios when needed.

"Changing ratio advice."

"Finding out HbA1c advice regarding changes to doses."

"Expert advice on all aspects of managing diabetes: blood glucose monitoring, adjusting ratios, administering insulin, dietary advice."

1.4 Advice and information: Managing glucose

Seventy six comments about advice and information (5.9%) specified that it was helpful to receive advice about managing blood glucose.

“They tell us what to do in case her levels are not in range.”

“It is a time to reflect on my daughter’s levels and ask for advice on how to maintain a balance”

“Helps me understand daughter’s levels etc and get ideas to help.”

1.5 Advice and information: Diabetes-related technologies

Fifty comments (3.9%) of those under this theme related to diabetes-related technologies including advice on availability and use of technologies including flash and continuous blood glucose monitors, and insulin pumps.

“It’s helpful to get information about up to date technology, such as the Freestyle Libre which my daughter has just started to use and finds extremely helpful in managing her blood glucose levels and preventing hypos.”

“An opportunity to discuss what we can do to better support my child and new equipment that can help.”

“Good advice on pump management.”

1.6 Advice and information: Dietary advice

Forty eight comments (3.8%) of those under this theme related to diet, including advice on carbohydrate counting, food options and nutrition review.

“Dietitian advice helpful, staff listen and are thorough.”

“Speaking to the dietitian is a massive help as our child struggle with exercise and food variety.”

“Reminders that the carb-counting is important.”

1.7 Advice and information: Problems or issues

Forty seven comments (3.7%) under this theme highlighted that it was helpful to receive advice about how to resolve problems encountered in the management of their child’s diabetes.

“Discussing our management in between clinics, how to rectify problems that arise.”

“Support and advice with problems and queries.”

“Always there to … offer advice and ideas to support any problems we may have now or maybe in the future.”

1.8 Advice and information: Improving management

Forty six comments (3.6%) about the advice and information received highlighted that it was helpful to received advice about how they could help improve their child's diabetes management.

"An update to how my child is managing and what I can do to support my child and improve results."

"Discussing strategies to improve management."

"They make us feel as though we're well and offer gentle guidance where we could make improvements."

2. Staff team

The second most common theme amongst parent and carer comments describing what they found helpful about their clinic visits was the paediatric diabetes team, with 1245 parents and carers (38.5%) highlighted this in their responses. Three sub-themes emerged within this theme.

2.1 Staff team: Staff team qualities

he majority (1099, 88.3%) of responses under this theme described perceived positive qualities of the staff team. Staff were often described as friendly, helpful and supportive.

"Always has been very supportive. Helpful in managing my child's diabetes. The dietitians have been very helpful and whenever help is needed I am able to receive it. The whole diabetes team is very helpful."

"Diabetes team go above and beyond. They are a brilliant team and always there if needed."

"Friendly, professional team who are knowledgeable about everything. They've been seeing my son since he was [<10], so the continuity has been fantastic. An exemplary team right across the board."

2.2 Staff team: Good relationship with team

In 145 comments about the staff team (11.6%), parents and carers made reference to having a good relationship with staff members as being a helpful aspect of their clinic visits.

"The good relationship between the team and my daughter and us."

"We work together to improve our daughter's care."

"The relationship with the team. We are not just a number."

2.3 Staff team: Consistent staffing

One hundred and forty two comments (11.4%) relating to the diabetes team highlighted that respondents valued the consistency of staffing that they had experienced.

"Always familiar faces in regard to the nurses and doctors, they are very aware of my daughter's situation so you feel you are picking up from your last visit or contact - the familiarity gives confidence that my daughters wellbeing is in really good hands."

"We have consistency within the team and this is very important to my son, familiarity makes it easier for him to be part of discussions. We also know other members of the team so if our own PDSN isn't available (perhaps if calling out of hours) we know the person we are talking to."

"We see the same dr and diabetes nurse specialist. It's so important for them to know your child and for us to know them and feel comfortable. We feel supported by our team and have from the onset."

3 Support

Nine hundred and sixty parent/carer comments (29.7%) highlighted the help or support they received at their clinic visits. Within this theme, three sub-themes were identified:

3.1 Support: Unspecified

Half the comments (475) did not specify the nature of the help and support received. These accounted for 49.5% of responses coded under the 'Support' main theme.

"It is our support."

"Always supported no matter what. I have the best diabetic team ever."

"The most outstanding support and service delivered by [a] warm and caring team."

3.2 Support: Addressing concerns or worries

One hundred and ninety six responses (20.4%) highlighted that clinic visits were helpful for addressing concerns or worries that the parents or carers had about their child's diabetes or diabetes management.

"I feel that the diabetes nurses understand my concerns and are always helpful and ready to provide advice."

"The team are so approachable, and my somewhat shy daughter feels sufficiently comfortable with them to discuss her queries, fears and concerns. I would happily contact them to discuss any issues and feel that I am treated in an understanding and practical manner."

"If I or my child have any worries they don't ever hesitate answering any questions no matter how simple they may be and that's what I really like about the diabetes team. They are very understanding and helpful with any problems or worries we have."

3.3 Support: Help when needed

One-hundred and ninety-two responses (20.0%) within the 'Support' theme related to parents and carers finding it helpful that their clinic visits provided access to support outside of clinic visits, when needed.

"Always great support on offer, I can ring anytime and there is always someone to talk to."

"That if I have any worries and need some support the team are always quick to ring back."

"... opportunity to contact by text/email/ phone call. Extremely approachable staff who provide support 24/7. Provide excellent support to schools and training."

3.4 Support: Opportunity to talk

One hundred and twenty one comments (12.6%) relating to support received highlighted the value of clinic appointments as an opportunity to talk to the team about their child's management, how they or the family have been doing since the last visit, or catching up and chatting with the team.

"[Being] able to speak to someone."

"It's great for our family to discuss how things are going"

"Mainly the opportunity to reflect on aspects of care and management and to discuss issues with an expert independent party."

3.5 Support: Encouragement and motivation

Sixty-five responses (6.8%) coded under the support theme highlighted the value of the encouragement and motivation parents and carers associated with their clinic visits.

"I always feel better once he's been as they re-programme his pump when necessary and always encourage us by telling us what a great job we're doing even though sometimes I think we're getting it wrong."

"Every time we go to the clinic and we feel stressed, as soon as we see the team we feel very happy. We leave the clinic full of energy and they give us a big push for life."

"They motivate my son and it brings his diabetes into focus."

4 Monitoring of child’s diabetes management and health status

Five hundred and seventeen parents and carers (16.0%) commented that they found clinic visits helpful because they were able to get an update on their child’s diabetes management or other aspects of their health. Within this theme, three sub-themes were identified:

4.1 Monitoring of child’s diabetes management and health status: HbA1c and other glucose information

Checking HbA1c or and reviewing trends in glucose levels was highlighted in 292 comments (56.5%) about monitoring the child’s diabetes management or health.

“It’s good to see the HbA1c result to see how we’re managing his diabetes, and to keep in touch with the team.”

“I find it reassuring to see his HbA1c as an indicator of how we are doing overall.“

“It’s nice to know the bloods and her long-term health is being monitored closely.”

4.2 Monitoring of diabetes management and health status: Monitoring of child’s overall health

Two hundred and seventy six comments (53.4%) within this theme highlighted the value of clinic appointments for keeping on top of overall diabetes management and wider health of the child.

“Every clinic visit has always been helpful to assess how things are going and to make sure that we are on track.”

“Checking weight, wellbeing and management of my child’s diabetes.”

“It is good for us to measure his growth as I have always worried that his diabetes/my control of his blood sugars might be limiting it.”

5 Organisation of visits

Five hundred and twenty six (16.3%) of all parent and carer comments about what they considered helpful about their child's clinic visits related to the organisation of the visit itself. Three main subthemes were identified within these comments.

5.1 Organisation of visits: Access to the whole multidisciplinary team

Nearly a third (156, 29.7%) of the comments highlighted the value of having access to the whole multidisciplinary team at once, with parents and carers describing this arrangement as being convenient, reassuring, and valuable to have professionals with differing expertise available to provide holistic care to their child:

"It's great to be able to troubleshoot with the whole team at once in one place."

"Seeing everyone in one day and not doing so many trips."

"It's extremely beneficial having a full multi-disciplinary approach to clinic appointments. All aspects of my son's care are taken into consideration. The clinic [runs] efficiently and professionally."

5.2 Organisation of visits: Access to multidisciplinary team members

Access to particular members of the diabetes multidisciplinary team was described as helpful by a further 141 parents and carers, comprising 26.8% of the comments about the organisation of visits. Time with consultants, paediatric specialist nurses, dietitians, psychologists and youth workers, or a combination of these, were highlighted as useful, with many noting that they could request access to a particular specialty when needed, including chiropody.

"We can always see a psychologist if we request and we have had extra sessions with the psychologist that have been useful. The dietitian can recommend things to us based on what we tell her - things that she wouldn't know if we weren't talking in such detail about our lives and the food that we eat, which we probably [wouldn't] tell her unless we are in the clinic."

"We always have the opportunity to see our diabetes nurse specialist at clinic visits and she is always available via phone in between clinic appointments if we need her."

"We can see as many or as few of the team as we need to."

5.3 Organisation of visits: Timing of appointments

The timing of appointments in terms of length, frequency or flexibility was described as helpful in 140 comments about the organisation of visits (26.6%). Parents and carers frequently made reference to having ample time in clinic and not feeling rushed, and others described flexibility of appointments around work, exams, or the school day. Quarterly, regular appointments were valued for the reassurance afforded by the regular monitoring of the child's health or diabetes management, or for maintaining a relationship with the team.

"We never feel rushed. We're allowed to ask lots of questions."

"As a single parent it is sometimes difficult to make appointments within working hours but they will always try to make an appointment when I can get time off work."

"Regular checks help maintain a good relationship between medical professionals and the family."

6 Child/family-centred care

Four-hundred and three comments (12.5%) described elements of child/family-centred care considered to be helpful about clinic visits. Three sub themes emerged out of these subthemes.

6.1 Child/family-centred care: Ability to speak openly

One-hundred and forty-five comments within this category (36.0%) were coded to this sub-theme. They described being able to speak openly about whatever the parent, carer or child wanted to discuss, without fear of being judged, or without worry that any question could not be raised.

"They make you feel at ease and my child feels able to talk openly."

"We always feel comfortable talking to the team about any needs. Without any judgements."

"Very open and honest sessions, lots of support and friendly staff."

6.2 Child/family-centred care: Inclusion in decision making and discussions

In 121 responses coded under 'child/family-centred care' (30.0%), parents and carers highlighted that it was helpful that they or their children were included in decision making and discussion of their diabetes management.

"The amazing relationship between our diabetic doctor and child, he includes my son in the decision making. The team talk directly to my child rather than about him and his care."

"Getting my child to take the lead. Introductory sheet filled by my child before seeing the team"

“That we have a team around our son who look after [child’s] body and mind. The team is the NHS at its best, helping our son to manage his diabetes, have a healthy diet and somebody to talk to when he is not doing well emotionally. It is a holistic service. The team treat our son with respect and involve him in all aspects of his diabetes.”

6.3 Child/family-centred care: Understanding and meeting individual needs

One-hundred and thirteen comments (28.0%) within this theme highlighted the personalised care provided by the paediatric diabetes to the respondent’s child or the family as a whole. Comments in this subtheme included age-appropriate communication and advice, knowledge of the child’s sporting activities, diet and challenges.

“Non-judgemental approach, understanding needs of the diabetic teenager, health promotion, alcohol, driving and diabetic burn out.“

“The entire service is personalised and accessible. We feel empowered by our team and appreciate them greatly.”

“They are very understanding of my child’s needs and those of the whole family and take a whole family approach to the care and advice offered.”

6.4 Child/family-centred care: Being listened to

Seventy-three responses (18.1%) about ‘Child/family-centred care’ described being listened to as a helpful aspect of clinic visits.

“Communication is good, they listen to the parents and give advice.”

“Staff are always friendly and helpful. We never feel judged by the team, they are always very positive and feel that they work with us as a family and listen to our questions/fears/anxieties.”

“They listen to our son and the DSN understands what he’s going through. Always listens to our concerns and suggest things to us and our son, do not dictate or demand us to do things.”

7 Reassurance

Two-hundred and sixty eight responses (8.3%) highlighted the value of the peace of mind or reassurance that their child’s diabetes was being well managed afforded by clinic visits as being a helpful aspect.

“To get reassured about diabetes control and management.”

“Reassurance and peace of mind.”

“Just to know we’re on the right track.”

8. Other

Three hundred and four (9.4%) of all responses received were not coded under the main themes.

8.1 Other: Non-specific positive comments

The majority of responses coded as ‘Other’, related to children and young people finding everything about their clinic visits helpful. One-hundred and eighty-five (60.9%) of responses coded as ‘Other’ were allocated to this sub-theme.

“Everything - just [love] it.”

“All fantastic.”

Good.”

8.2 Other: Making adjustments to insulin dosing

Ninety- four comments (30.9%) of those coded under ‘Other’) specified that clinic visits were helpful for making adjustments to insulin dosing.

“Any changes to be made to ratio’s/basal whilst I am gaining confidence.”

“Changes to ratios [as] I worry I am not doing it correctly.”

“Changing carb ratio and insulin levels.”

Appendix D: What could your diabetes team do to make your clinic visits better? Children and young people's comments

1. Timing of appointments

The most frequently highlighted aspect of clinic visits that children and young people suggested could improve their clinic visits was their timing. Two-hundred and twenty-three responses (12.6% of the total, 29.3% of comments describing an aspect of care that could be improved) related to this theme. Inside this theme, the following sub-themes were identified:

1.1 Timing of appointments: Time spent waiting

One-hundred and one comments (45.3%) within this theme suggested that spending less time waiting before being seen at their clinic visits would improve their clinic experience.

"Shorter waiting times."

"Lot less waiting time and maybe to have talks with the dietitian whilst you wait rather than having an extra 'ad lib' after the appointment. This also means I would be back at school at a nicer time to learn more as I am now in secondary school."

"Be on time."

1.2 Timing of appointments: Appointment length

Sixty responses within this theme (26.9%) referenced the length of the clinic appointment. Opinions were mixed, with some children and young people wanting to be seen for longer, while others suggesting that the time spent at clinic could be reduced.

"Make them longer and more detailed."

"Quicker appointments."

"Perhaps have an option for an extra or longer session when there is something you wish to discuss in more depth."

1.3 Timing of appointments: Frequency of appointments

Twenty-eight responses (12.6%) about the timing of appointments suggested that the frequency of appointments would be preferred. Some children and young people suggested that fewer appointments would be beneficial, whereas others wanted more.

“Maybe have it a bit more often as when I go home I try my best to keep my levels under control but always lose the mentality after a month.”

“There are too many clinic visits, a lot of the information/education could be done via the telephone.”

“More regular clinic appointments.”

1.4 Timing of appointments: Timing appointments outside of school hours

Twenty-one responses (9.4%) within this theme stated that clinic visits could be improved if they were held outside of school hours.

“Have them in the afternoon because sometimes it affects my school times because I get to school and then I pretty much have to come out.”

“Less appointments during school days.”

“I do not like missing school to attend clinic and would rather have after school appointments.”

2. Engagement with diabetes team members

One-hundred and eighty comments (10.2% of the total, 23.7% of the comments suggesting an improvement) by children and young people about how their clinic visits could be improved related to their interactions with clinic staff members. Three subthemes within these were identified.

2.3 Engagement with staff members: Patient centred care

Eighty-seven comments within this theme (48.3%) related to aspects of patient centred care, with children and young people stating that they wanted to be more included in their clinic visits, have their individual needs, worries and preferences taken into account, be listened to, or feel more empathy from the staff team about the challenges associated with managing their diabetes.

“Involve me more in understanding the graphs and tables so I can start managing my own diabetes, not just my parents.”

“My diabetes team need to consider my emotional health and how that would affect my decisions in caring for my illness, I feel as though they do not understand how I feel regarding my illness and they just see it as me not doing it. They do not see the bigger picture.”

“Talk to me more and understand how hard it is for me with being a teenager.”

2.4 Engagement with staff members: Communication skills

Seventy-eight children and young people's comments within this theme (43.3%) indicated that the communication skills or 'bedside manner' of team members seen in clinic could improve their experience of attending. They included suggestions for more positive interactions such as reinforcing positive aspects of the child's diabetes management rather than focussing on the negatives, avoiding 'nagging', or taking a rude or patronising tone.

"Sometimes it feels like I am told off slightly if I have not done something I should have done, which makes me sometimes unable to speak truthfully about things I am struggling with."

"Make it not so stressful to come visit and help me feel more comfortable when I am here."

"Be less patronising in their way that they tell patients things."

3. More advice and information

One-hundred and forty two responses (8.0% of the total, 18.6% of those making a suggestion) received to the question of 'What could your diabetes team do to make your clinic visits better?' from children and young people stated a wish for more advice and information about their diabetes management.

3.1 More advice and information: Diabetes management

Ninety comments under this theme (63.4%) requested further information on various aspects of managing diabetes including exercise, ketone monitoring, diet, managing stress, and help using downloaded information from diabetes technologies to improve their control.

"Having more information."

"I would prefer if they gave me advice that is specific. For example, they might tell me to test more, but I'd prefer if they gave me advice on how I can remember to test more and how I can fit it in my routine."

"Involve me more in understanding the graphs and tables so I can start managing my own diabetes, not just my parents."

3.2 More advice and technologies: Diabetes-related technologies

Forty-four comments under this theme (31.0%) stated they would like more advice about accessing and using diabetes related technologies.

"Helping me understand about the pump and to help me prepare for a pump."

"Help me with meters."

"If they would mention things like continuous glucose monitoring because we wouldn't talk about it if I didn't mention it. It would make me feel better about it if they open up the conversation rather than me."

4. Waiting area

One-hundred and thirty-three responses (7.5% of the total, 17.5% of those suggesting an improvement) suggested that improving the waiting area would make the children and young people's visits better. Three sub themes emerged from these comments.

4.1 Waiting area: Activities

Sixty-eight comments about the waiting area (51.1%) suggested that providing more activities and entertainment for children and young people would make their clinic visits better. Suggestions included toys, games, games consoles, colouring, and books and magazines.

"Bring some: consoles toys and video games."

"Add a bookshelf."

"Provide more things for me to do whilst waiting."

4.2 Waiting area: Teen-friendly waiting area

Thirty-five comments about the waiting area (26.3%) called for a more age-appropriate waiting area for teens. These included suggestions for a separate teen waiting area, or the provision of more games or toys for older children.

"To have more things for teenage girls to do whilst they wait. Somewhere we can do our homework from school."

"For older teens/young adults maybe have a section to wait in which isn't invaded with children's toys as it feels slightly patronising."

"I don't like the adult waiting room. Think there should be a teen space."

4.3 Waiting area: Refreshments

Thirty comments about the waiting area (22.6%) suggested the provision of snacks and drinks.

"Food, because my appointments are normally straight from school and I'm starving."

"In the waiting room...A SNACK BAR! Cherries, Mini Rice Cakes and stuff I could have free of insulin!"

"Provide and have available access to drinks if needed."

5. Other

One hundred and sixty five comments (9.3% of the total, 21.7% of those making a suggestion) did not fall under the main themes identified. Of these, 57 (34.5%) related to the organisation of the visits themselves, including comments about being able to choose which staff members to see, location, and timing of appointments. Other suggestions included access to peer-support and more emotional support amongst others.

Appendix E: What could your diabetes team do to make your clinic visits better? Parent and carer's comments

1. Timing of appointments

Three-hundred and eighty-four responses (16.7% of all responses, 32.3% of all responses making a suggestion) suggested that the timing of their appointments could be better. Inside this theme, the following sub-themes were identified:

1.1 Timing of appointments: Time spent waiting

Two-hundred and three comments about timing (52.9%) expressed a wish to spend less time waiting at the hospital before the start of their child's appointment due to delays in being seen.

"Improve waiting times."

"Better management of time, as we have on a number of occasions been in the hospital for over an hour waiting for the appointment to begin."

"If clinic is running behind it would be helpful to know, taking time off school is still classed as an absence and if they miss registration going back it's another time marked off. Plus, it's frustrating having to wait for longer than 15 mins for your appointment."

1.2 Timing of appointments: Timing appointments outside of school/work hours

Sixty-six parent and carer comments (17.2%) suggested that clinic visits could be more conveniently timed outside of school or work commitments.

"Morning clinics would suit us better than afternoons. As a single parent I have to take all my children out of school early and take them with me for an afternoon appointment where as a morning appointment I could just take my diabetic child."

"Offer more early appointments. It's difficult to take my child out of school for 11.00am appointment and coordinate this with my work schedule."

"Visits at different time of the day to minimise disruption from school."

1.3 Timing of appointments: Appointment length

Fifty-nine responses (15.4%) about the timing of appointments made reference to the length of the clinic appointment. These were split between parents and carers wanting their clinic visits to last longer, and those suggesting that the time spent at a clinic visit could be reduced.

"Try and make them a little shorter."

"Longer appointments would be more helpful. Spending more time discussing not only the child in question, but the family as a whole, in relation to how diabetes affects the family unit would be very helpful."

"Sometimes if clinic is running behind visits can be a little bit rushed."

2. Engagement with staff members

Two-hundred and forty-four responses (10.6% of the total, or 20.5% of all those suggesting an improvement) indicated that the engagement between staff members and families at clinic visits could be better. Four sub themes emerged from these comments.

2.1 Engagement with staff members: Patient or family centred care

Ninety-two responses (37.7%) within this theme suggested that visits could be improved if teams offered more patient or family centred care. Comments related to feeling judged rather than supported when blood results indicated suboptimal diabetes management, wanting more recognition of the challenges they faced supporting their child with diabetes, better inclusion of their child, to be listened to, and to be more actively involved in the visit discussions and decision-making.

"Spend more time talking to my son, even though he is young, he is still the patient. Sometimes I feel that he is ignored and it's just the parents who are spoken to."

"[...] We have found that some doctors are not so good at listening. We did grumble several years ago after some experiences with more junior doctors who hadn't grasped that the patient (and/or the patient's parents) will know more about their own diabetes than a doctor who has only just met them will (unless newly diagnosed).... My son and I came out of one clinic more recently agreeing that it had been pointless trying to explain something to the doctor as they hadn't been listening, so it was best to give up and sit there until we could get out, but this is not usually the case now."

"I have felt at times that we are just a number and I do understand there are a lot of patients. Also, as a parent I have felt judged just on the numbers on the screen when they have no idea how much we have put in to trying to control T1. I and many other parents eat breathe and sleep diabetes at no point in the day do we give up we just keep trying yet sometimes you leave clinic thinking I'm clearly doing a bad job of this and feel really down."

2.2 Engagement with staff members: Seeing the same staff members

Sixty-seven comments within the engagement theme (27.5%) suggested clinic visits would be better if the family saw the same staff members when coming to clinic in order to make the child feel more comfortable, or to help establish a relationship and knowledge of the child or family and their specific needs.

"Have a nurse and doctor who are dedicated to the individual child. I do not like going through the random process of phoning the office and having whoever is available return the call. I also prefer to see a consistent Dr who knows my child each visit."

"More consistency with nursing staff to build a relationship."

"Should we consistently be able to see Dr [name redacted] where possible then it would allow us a more regular even understanding, our son also gets on with [this doctor] which makes it more productive."

2.3 Engagement with staff members: Communication skills

Fifty-nine responses (24.2%) within the engagement theme showed that improved communication skills amongst team members would make clinic visits better. Suggestions included more age-appropriate engagement, and more positive interactions or praise.

"Be kinder and use appropriate language i.e. don't treat people harshly if their HbA1c is too high - work with them instead."

"Be more understanding and help with fluctuating glucose levels going into puberty not assume it is something we have done wrong. Some praise and a "you are doing a good job under the circumstances" wouldn't go amiss. Focus on the positives not always the negative."

" [...]. Also, a more positive bedside manner would be nice, talking to my child and actually asking how he feels or how he is and praising for being brave would give him a positive impression of clinic. [...]"

3. Organisation of appointments

One-hundred and sixty responses (7% of the total, 13.5% of those suggesting an improvement) suggested improvements to how the clinic appointments were organised. Five sub-themes emerged from these comments.

3.1 Organisation of appointments: Seeing the multidisciplinary diabetes team separately

Thirty-four responses within the organisation theme (21.3%) suggested that visits could be improved if parents and carers could see the diabetes team separately rather than all together when visiting. Reasons included the child or family feeling intimidated or overwhelmed, or wanting to speak in more detail with staff from a particular professional group in more detail.

“We have previously discussed seeing the doctor separately and have done so on occasions as it is often quite daunting for a child to be faced with a lot of faces.”

“I would rather not always have so many clinicians in the room.”

“Maybe once a year do a consultation with the team each separately… or have the option for this so that I can discuss different areas in more detail.”

3.2 Organisation of appointments: Seeing the multidisciplinary diabetes team together

Conversely, 20 responses (12.5%) expressed a preference for seeing the multidisciplinary diabetes team together in one room. Reasons included convenience for the family, and supporting the whole team to know about all aspects of their child’s care and individual needs.

“Waiting time, going in and out of rooms, can all this not be done at one time in one room instead of going back to the waiting [room] all the time.”

“[… It can be frustrating to see the consultant, diabetes nurse and dietitian, and answer the same questions with each person when it could all be answered in one room or even just as necessary.”

“I would prefer all team members in the same room, as complex issues are discussed for transparency and quality of outcomes.”

3.3 Organisation of appointments: Pre-clinic preparation

Twenty-eight comments about the organisation of appointments (17.5%) suggested they could be improved by more pre-clinic preparation on behalf of the diabetes team, or if the family could provide information in advance including downloaded glucose information or suggested topics for particular focus in the meeting.

“Would be helpful if Dr read the notes from last clinic session before the start of each appointment. That way I wouldn’t be repeating myself at every visit.”

“Perhaps send an email prior to the visit asking in advance if there is anything specific that needs to be discussed thereby allowing everyone to have the knowledge required/ pre-thinking opportunities to make time at clinics even more valuable.”

“Have some of the information already written - e.g. insulin levels/ carb ratios, etc. This can take up some time in the meeting. Also, have access to download information already at start of meeting.”

3.4 Organisation of appointments: Time alone

Twenty-three comments about the organisation of clinic visits (14.4%) expressed a preference for time alone with the diabetes teams to discuss aspects of their child's care without the child present. Reasons given included wanting to discuss sensitive issues more comfortably, and wanting to discuss their own worries or concerns without worrying their child.

"I find it tricky if I need to say or ask something without [child's name] being there. Sometimes worry that I'll get upset in front of him."

"Because of my daughter's age, it would be great to be able to speak to the doctor/consultant without her in the room as some of the things I'd like to ask are not age appropriate."

"Very difficult to have the conversations that we want to have as parents when our [teenager] is in the same room. He is not always honest with what he does and what he finds difficult. He just wants to get out of the appointment as quickly as possible so dismisses concerns and new information."

4 Access to more advice and information

One-hundred and thirty responses (5.6% of the total number, 10.9% of those making a suggestion) to the question 'What could your diabetes team do to make your clinic visits better?' from parents and carers indicated a desire for more advice and information. Some did not specify the additional advice or information wanted, whereas others specified topics that the parents and carers wanted to know more about, including dietetic advice, to be kept up to date with new diabetes research and diabetes-related technologies, or advice for managing their child's emotional health.

4.1 Access to more advice and information: Diabetes-related technologies

Seventy three responses (56.2%) under this theme requested further information on accessing or using diabetes-related technologies.

"The only thing I would say is to try and have a visual board or some sort of information about the different types of machines and options as I researched the Dexcom to know that was the CGM that would be most useful for my son and us as a family. I am now looking at what other options there are for insulin via pumps or Omnipods, etc. I have never seen what the different machines, types and what they all feature."

"Be up to speed with new technologies. Be able to interpret Nightscout and Loop results to advise how to change settings and make better decisions for good control... Be more supportive of helping us get access to the pump we want. If it is not on the CCG's list it seems there is no interest in helping us get access to it."

5 Psychological and emotional support

One-hundred and eight (5% of the total, 9.1% of those making suggestions) comments from parents and carers about how their clinic visits could be improved indicated a wish for more psychological and emotional support.

5.1 Psychological and emotional support for the child

The majority (96, 88.9%) of requests for psychological or emotional support were for the child.

“Access to a psychologist - son has emotional problems related to the diabetes and I feel that having access to the psychologist could help him overcome some of these.”

“I think a psychologist is really needed as it’s completely overwhelming at diagnosis. [My child] was [a young age] and accepted his diagnosis with strength and courage but went through a difficult period. He was referred to CAMHS, but their lack of understanding was uncomfortable, and they really had no experience so didn’t help at all. Luckily for us as I’ve already mentioned our DSN’s are incredible and got him through this very low point. It would be reassuring to know that another family would have the right person who understood the mental effects of Type 1 on a child would be available.”

5.2 Psychological and emotional support for the wider family

Twenty one comments (19.4%) suggested that having support available to the wider family would also be beneficial.

“Offer us as parents and my daughter’s sibling’s emotional support - for example tailored psychological advice.”

“I think diabetes diagnosis and the care has a huge impact on families and the child especially the first couple of years. I think counselling would benefit the child and the parents. I think it should be part of the treatment, as most people feel too embarrassed to ask.”

“It would be nice to voice concerns without my child beside me, also offering parents support who are struggling.”

6. Waiting area

Ninety-nine (8.3%) of those making a suggestion suggested improvements to the waiting area at clinic.

6.1 Waiting area: Age appropriate

Thirty-four comments about the waiting area (34.3%) suggested that the waiting area could be more age appropriate for their child.

"Add things for higher ages 8-11 instead of 4-7 and in the clinic things to pass time for the child."

"Have a better waiting area for my son who is 14 as at the moment, it is only geared up for toddlers and young children."

"Have a better waiting area for 7-16 age, there is a separate area, but the computer never works and there's nothing to do in there."

6.2 Waiting area: Refreshments

Twenty-seven (27.3%) comments about the waiting area suggested that it could be improved by the provision of refreshments.

"Hot drinks."

"Offer refreshments - at least a water cooler for T1 children."

"Offer tea/coffee on long visits. Especially where parent/guardian is also type 1 diabetic."

6.3 Waiting area: Activities

Twenty-five (25.3%) of these comments suggested the addition of activities to keep them, their child, or the siblings of their child with diabetes occupied while they were waiting, or while the child was being seen.

"A better waiting area would be nice with more for young adults -books and different things to keep them occupied while they wait."

"An XBox and PlayStation."

"Have appropriate age-related toys and games."

7. Access to support between clinic visits

Eighty-two comments (6.9% of those making a suggestion) suggested that it would be useful to have access to better support in between clinic visits.

7.1 Access to support between clinic visits: Group activities and peer-support

Thirty one comments (37.8%) under this theme suggested it would be beneficial to have contact with other children and young people or families with diabetes outside of the clinic waiting room.

"Present peers who have been there and what they did to turn themselves around. Wish we had a T1 Camp that the USA has."

"Better links with other families and in particular children with diabetes as daughter not met another child with diabetes since diagnosis last summer."

"I would like more info on T1 children's groups for my son to talk to more diabetic children and me to speak to parents."

7.2 Access to support between clinic visits: Timely specialist advice

Twenty comments (24.4%) under this theme requested timely access to the team when they needed advice outside of clinic visits.

"It would be helpful if non-urgent queries and questions sent via technology such as email/text were answered promptly, ideally within a day."

"Just be able to contact them at all times."

"Not so much clinic but on the occasions when we have called the ward or A&E out of hours they have never really understood the situation or how to deal with insulin pumps."

8. Other

Two hundred and ninety two (12.7% of the total, 24.6% of those making a suggestion) were categorised as ‘Other’ as the suggestions made within them were too varied to categorise into sub themes. Suggestions in this category covered improvements to the general hospital environment (20), access to diabetes-related technology (38), more online resources, and easier parking, amongst other areas.

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