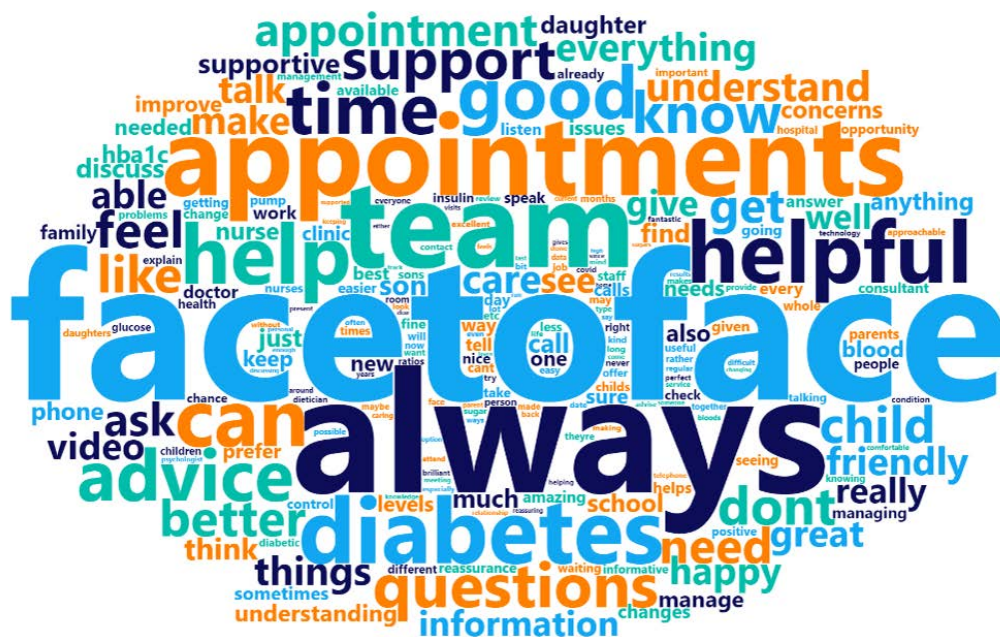


# Parent and Patient Reported Experience Measures (PREMs) 2021



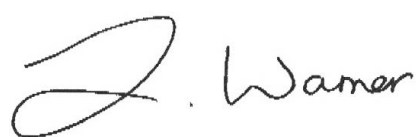
The word cloud on the cover of this report was created in the analytical software RStudio, using comments received from all respondents who completed the two open-ended questions in the survey (“What do you find helpful about your clinic visits?” and “What could your diabetes team do to make your clinic visits better?”) The size of the words indicates frequency of usage – the larger the word, the more frequently it appeared in all comments. The word cloud included words that appeared in the comments more than 5 times, excluding articles, pronouns and conjunctions. The word “nothing” was a common response to “What could your diabetes team do to make your clinic visits better?” Context is necessary to interpret this word. Therefore, “nothing” was removed from the word cloud in the cover.

# Foreword

Measuring experience of care is not without its difficulties in terms of encouraging and motivating providers and customers to complete a questionnaire but also completion of complex analyses. To achieve an experience measure in paediatric diabetes during the Sars-COV-2 pandemic, achieving feedback from 4,177 children and young people, and 6,789 parents/carers, is admirable to say the least.

This report, the second national PREM for paediatric diabetes from England and Wales, delivered by the NPDA and the RCPCH, covers many aspects of experience which can be utilised along with an individual unit level report to enhance the care provided to children and young people with diabetes and their families. Although the results in this 2021 survey are similar to those achieved in 2019, the circumstances under which the measurements were taken varied considerably. Centres have been forced into providing care in new innovative ways due to the pandemic (who would have imagined a 'drive through' HbA1c check three years ago?), yet despite this, the reported experience from children and young people with diabetes and their parents and carers remains generally very positive. Amazingly, most centres were still able to provide some face to face consultations with almost 90% receiving such experience in the six months of the survey in 2021. In the qualitative analysis, families, still very much prefer this way of communication despite the online technologies that have developed. The overall PREM score is a useful way for centres to benchmark the experience they provide against others and scrutinize their comments from their individual reports to help inform change. Experience measures can be very powerful drivers for quality improvement, and I would encourage centres to take these comments seriously.

Finally, I would like to thank all those children and young people and their parents and carers who have taken the time to complete a questionnaire, this information is invaluable. I would also like to thank all the healthcare professionals in the centres who have encouraged their families to participate.

A handwritten signature in black ink, reading "J. Warner". The signature is stylized, with a large, looped initial "J" and a cursive "Warner".

Professor Justin Warner

**NPDA Clinical Lead**  
**Paediatric Endocrinologist, University Hospital of Wales**

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# 1. Glossary of terms used in this report

**Child centred care**

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

**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 alerts 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.

**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 health care workers who are members of different disciplines (e.g. diabetes specialist nurses, psychologists, dietitians), 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.

**Quantitative data**

Data expressing a quantity, amount or range, e.g. numbers, counts or measurements.

**Qualitative data**

Descriptive information that cannot be counted, measured or easily expressed using numbers.

**Sick day rules**

Guidance for managing blood glucose levels during illness or infection.

**Standard deviation**

A statistic indicating the dispersion of data points relative to the mean.

## 2. Introduction

The RCPCH is commissioned by the Healthcare Quality Improvement Partnership (HQIP) to deliver the NPDA 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](http://www.hqip.org.uk/national-programmes).

The overarching aim of the National Paediatric Diabetes Audit (NPDA) is to improve care and outcomes for children and young people living with diabetes in England and Wales. The audit is commissioned by the Health Quality Improvement Partnership (HQIP), funded by NHS England and the Welsh Government, and is managed by the Royal College of Paediatrics and Child Health. The annual NPDA core report covers the outcomes of care measured against NICE guidelines (NG18, NICE 2015) including treatment targets, recommended health checks, patient education, psychological wellbeing, and assessment of diabetes related complications. The impact of the core audit is maximised by the delivery of additional national 'spotlight audits' looking in greater detail at aspects of care that may influence the outcomes achieved locally and nationally.

This national report covers the experience that children and young people and parents and 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 checks 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 second national PREM report published by the NPDA, with the first published in November 2020 on data collected in 2019.

### 3. PREM survey development

The questionnaires used in this 2021 PREM survey were the same as those developed and utilised in the 2019 PREM data collection (RCPCH 2020).

The 2019 survey took place when face to face care was routine, whereas the 2021 survey covered six months during the second year of the COVID-19 pandemic when children and young people with diabetes and their families had also experienced remote clinic appointments, either via video link or the phone. Some questions were therefore adapted so they were applicable to appointments attended either in person or remotely. Adaptations to the questions asked are presented in bold where responses are presented within the body of this report.

## 4. Methodology

The surveys were available online (via Survey Monkey Enterprise) between 2 August 2021 and 2 January 2022. PREM leads within each PDU were each sent an information pack including tips on maximising response rates from PDUs who had previously achieved high numbers of responses, along with template emails promoting the surveys to parents including a link to the survey. Digibete, a digital content platform for diabetes-related education, was also commissioned to promote the survey via their app.

Flyers and posters for the surveys including a QR code linking to the questionnaires were distributed to teams and promoted via the NPDA's Twitter account.

Participation was further incentivised by optional inclusion into a prize draw for a £50 Amazon voucher, which was included in the promotional materials and information.

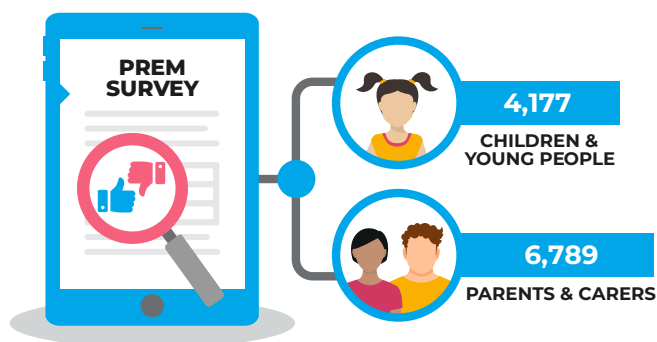
Participation rates per PDU were published fortnightly during this period to enable teams to monitor the results of efforts to encourage participation.



## 5. Key findings

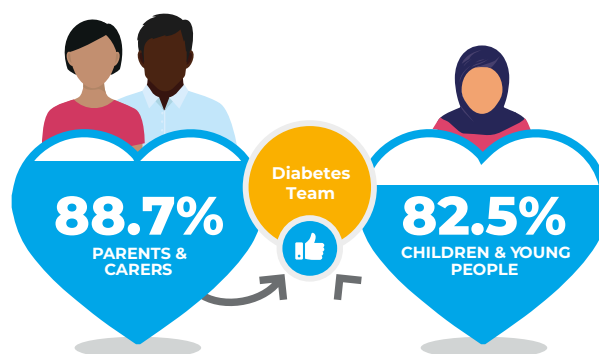
### 5.1 Key findings: Quantitative analysis

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



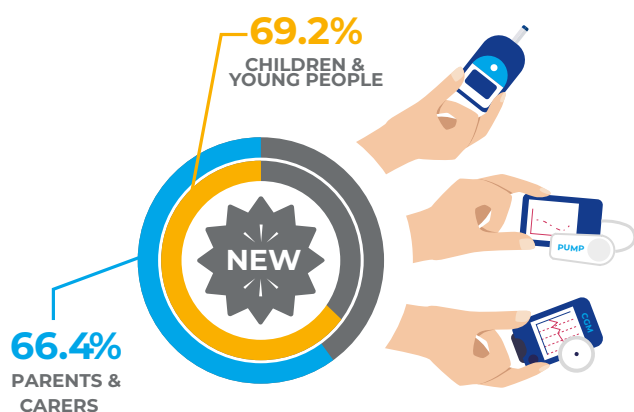
#### PREM survey completion

**4,177 children and young people** and **6,789 parents and carers** attending paediatric diabetes services in England and Wales completed a Patient Reported Experience Measure (PREM) survey in 2021, when 31,615 children and young people were receiving care from paediatric diabetes services.



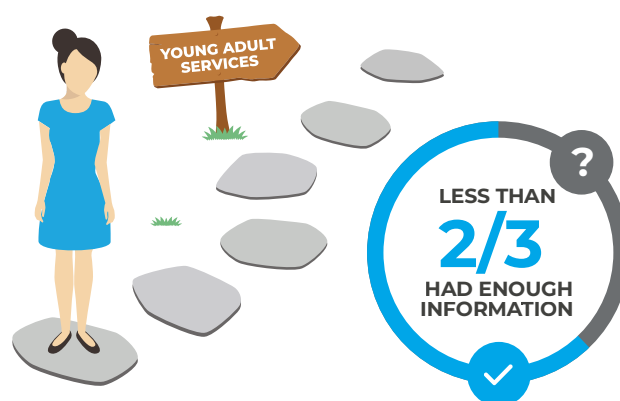
#### Relationship with diabetes teams

**82.5% of children and young people** and **88.7% of parents and carers** reported that they **always had a positive relationship** with their diabetes team. In 2019, similar percentages agreed the same: 79.9% of children and young people and 90.0% of parents and carers.



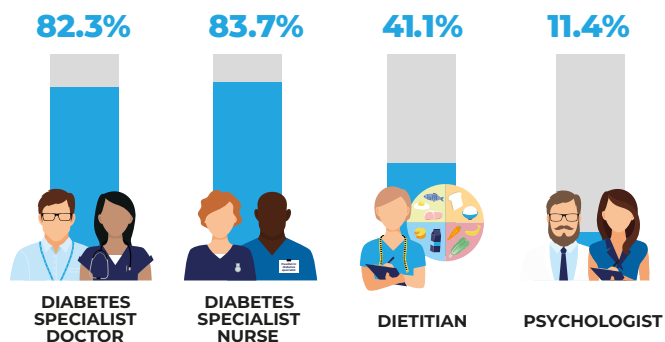
#### Diabetes-related technologies

**66.4% of parents and carers** and **69.2% of children and young people** agreed that their diabetes team **always kept them up to date with new diabetes-related technologies**. These were increases from 63.7% and 61.8%, respectively, in 2019.



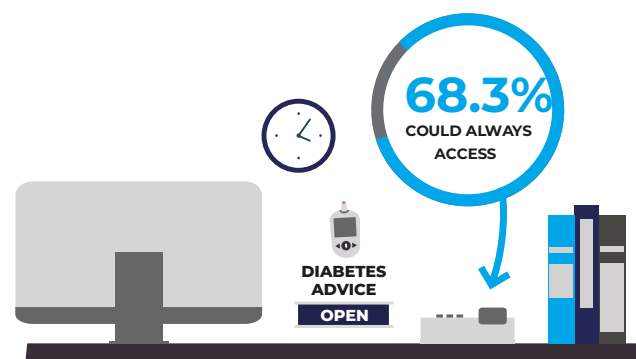
#### Transfer to adult care

Less than two thirds of parents and carers (**64.2%**) and children and young people (**62.3%**) agreed their diabetes team were providing them with the **information, resources and support needed to prepare for their transfer to adult care**. These results are similar to those reported in 2019 (64.0% of parents and carers and 58.2% of children and young people).



### Availability of specialists

82.3% of parents and carers reported that they could see a diabetes specialist doctor at each visit, 83.7% could see a paediatric diabetes specialist nurse at each visit, 41.1% could see a dietitian at each visit, and 11.4% could see a psychologist at each visit. Percentages were smaller for each staffing group compared to 2019.



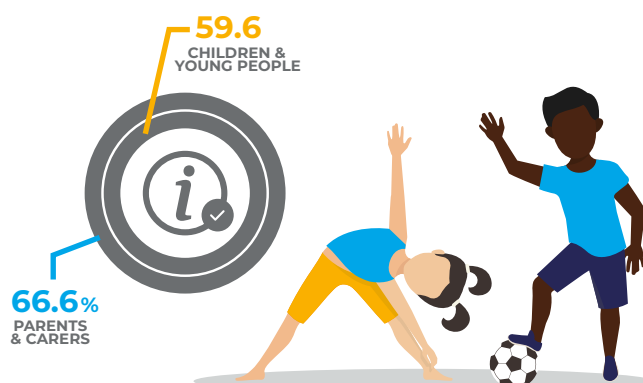
### Access to specialist diabetes advice

81.1% of parents and carers said they could always access specialist diabetes advice during core hours. This was similar to 2019 (81.3%). However, **only 68.3% said they could always receive advice 24 hours a day.** This was also similar to 2019 (68.8%).



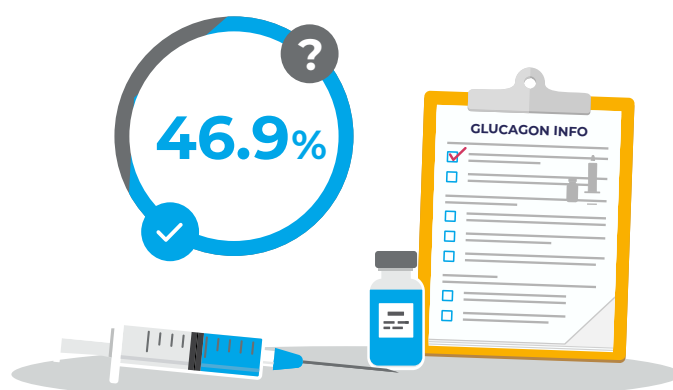
### Managing diabetes at school

**72.3% of children and young people and 71.9% of parents and carers agreed their diabetes team always gave them enough information to effectively manage their/child's diabetes at school/college,** down from 74.1% and 75.2%, respectively, in 2019.



### Information about exercise

**59.6% of children and young people and 66.6% of parents and carers agreed their diabetes team always gave them enough information to manage exercise.** These percentages were similar to 2019.



### Glucagon preparation & administration

**Only half (46.9%) of parents and carers agreed they always received enough information on the preparation and administration of glucagon,** similarly to 2019.

## 5.2 Key qualitative findings

Children and young people with diabetes and their parents and carers were asked

- 1) What do you find helpful about your appointments with the diabetes team?
- 2) What could your diabetes team do to make your appointments with the diabetes team better?

## What do children and young people find helpful about their appointments with the diabetes team?

Over a third of children and young people's responses to this question (38.4%) highlighted the **assistance** received within their appointments as being helpful, with sub themes being help, questions, advice, concerns and issues. Nearly a fifth (18.6%) highlighted the **modality of the appointment**, with the majority expressing a preference for face-to-face appointments. The third most prominent theme was the **support from the staff team**, which was highlighted in 16.6% of children and young people's responses. Sub themes within this category were the helpful nature of the appointments or team, and the support, reassurance, and understanding experienced.



## What do parents and carers find helpful about appointments with their child's diabetes team?

Similarly to the responses from children and young people, the most prominent theme amongst parent and carer responses was the **assistance** they received during their appointments, which was highlighted within two fifths (40.8%) of comments. Sub themes were advice, help, questions, concerns, information, issues, and contact with the team. A third (30.8%) of parents and carers' responses referred to **support from the staff team**, highlighting the support and reassurance received, and the helpful and understanding nature of their appointments. The third most prominent theme was the **modality of the appointment** itself, with over a quarter (28.3%) of parents and carers' comments highlighting this, and the majority of these expressing a preference for face-to-face appointments over video or phone calls.



## What could diabetes teams do to make children and young people's appointments better?

A third (31.4%) of children and young people commented **‘Nothing’, ‘Not applicable’, ‘No improvements needed’**, or similar. The most prominent theme within the remaining comments was the **modality of the appointment**, with a fifth (20.2%) highlighting a preference, and face-to-face appointments being the most common preference expressed. The next most prominent theme was a desire for more **assistance**, with more ‘help’ being the most common subtheme.



## What could diabetes teams do to make appointments better according to parents and carers?

Similarly to children and young people, almost half (46.5%) of parents and carers responding to this question expressed that **'nothing'** could make their appointments better, that the question was not applicable, that they were already happy with their appointments, or similar. A fifth of responses (19.5%) highlighted that the **modality of the appointment** attended could suit the respondent better, with the majority again expressing a preference for face-to-face appointments. The second most prominent sub theme was a desire for more **assistance** (9.3%), with sub themes being help, advice, information, support with questions, issues, concerns, and contact. Another tenth (9.1%) referred to **staff**, with sub themes being interactions with specified members of the multidisciplinary team (doctor, nurse, psychologist, dietitian).



## 6. Recommendations

### **Paediatric diabetes teams and parents and carers should:**

1. Review their NPDA PREM 2021 results, identify areas requiring improvement and work with their local patients and families, and paediatric diabetes teams to establish targeted quality improvement activities.

### **Paediatric diabetes teams should:**

2. Recognise the value of face-to-face appointments but consider how to sustain and make best use of new methods of consultation with children and young people and parents and carers established in response to the COVID-19 pandemic.
3. Equip school staff to help children and young people manage their diabetes whilst at school.
4. Discuss local PREM results and seek input from families with diabetes to improve areas with poorer scores compared to other centres.
5. Provide access to specialist diabetes advice to patients and their families 24 hours per day and 7 days per week.
6. Provide access to a Psychologist with experience in diabetes to all children and young people, ensuring they understand how to access this service.
7. Provide patients and families with up to date information and advice on how to access diabetes technologies (in line with latest NICE guidelines), including:
  - insulin pumps
  - continuous glucose monitors
  - flash glucose monitors
8. 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 findings

### 7.1 Participation

Of the 171 PDUs included in the NPDA and eligible to participate, 171 (100%) achieved at least one response to either the patient or parent/carer survey. In total, 4,177 responses from children and young people were received, and 6,789 were received by parents and carers; giving an overall total of 10,966 responses.

The NPDA 2020/21 core audit, contemporaneous to the 2021 PREMs survey time period, captured information on 31,615 children and young people up to the age of 24 years under the care of a consultant paediatrician, giving a response rate of 13.2% (4,177/31,615) for children and young people receiving care from a paediatric diabetes service, and at least 22.2% amongst parents (some respondents will have had more than one child receiving care from a PDU).

**Table 1: Overall participation in PREM 2021, compared to the NPDA 2020/21 core audit**

PREM – 2021			NPDA core audit – 2020/21	
Total Responses	Parents and carers (%)	Children and young people (%)	Total children and young people in core audit	Children and young people PREM response rate (%)
10,966	61.9%	38.1%	31,615	13.2%

### 7.2 Characteristics of respondents

The characteristics of the children and young people and the parents/carers who completed a PREM survey in 2021 had similar characteristics in terms of age, gender and ethnicity compared to the children and young people who completed a PREM survey in 2019. PREM respondents were also broadly representative of the different groups included in the NPDA 2020/21 core audit. Full details of respondent characteristics are available in the appendix to this report.

### 7.3 The clinic environment

#### 7.3.1 The waiting area

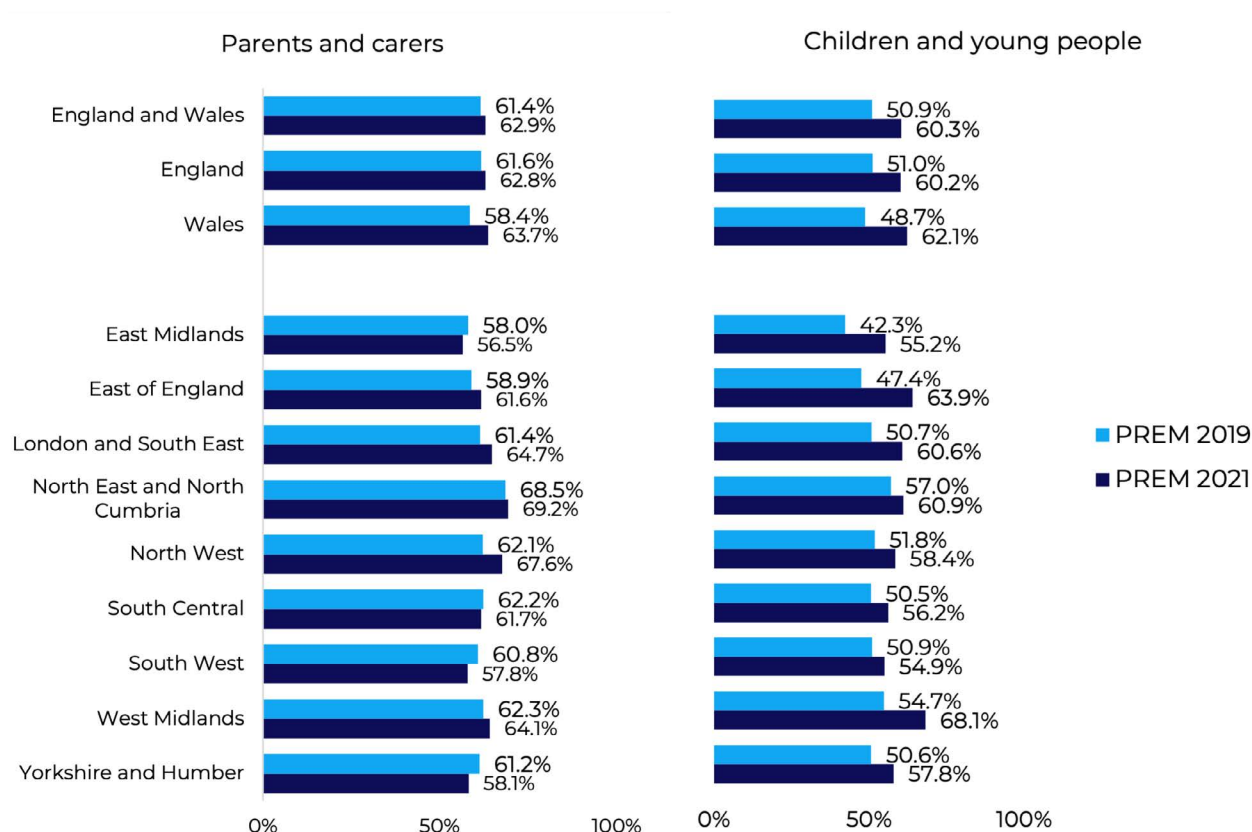
Respondents to the 2021 PREM survey were asked to think about their clinic visits over the previous six months, and then indicate their agreement with the following group of statements.

Q. Thinking about your/your child's care over the last six months...

The clinic has an area for me/my child to wait that is appropriate for their age

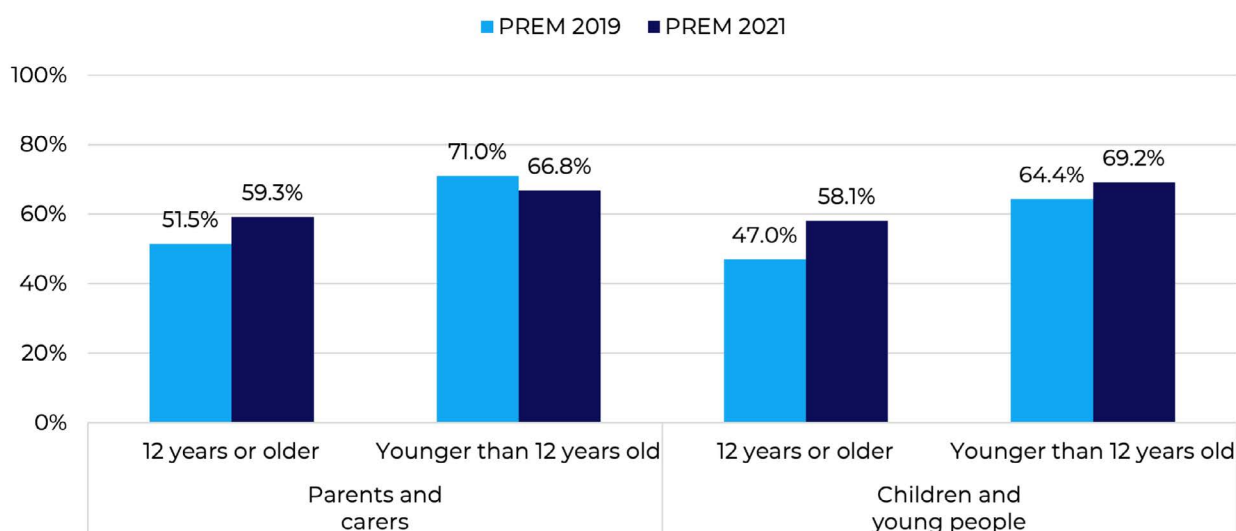
- i) Yes, definitely
- ii) Yes, to some extent
- iii) No, but I would like them to
- iv) No, but I don't mind
- v) Don't know

Figure 1 shows the percentage of children and young people and parents and carers who responded “Yes, definitely” to the statement “the clinic has an area for me/my child to wait that is appropriate for their age” in 2019 and 2021. It shows that children and young people were more likely to agree with the statement in 2021.



**Figure 1: Percentage of respondents who agreed “yes, definitely” that the clinic had a waiting area appropriate for their/child/children’s age, by country and by region in PREM 2019 and PREM 2021**

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).



**Figure 2: Percentage of respondents who responded “yes, definitely” that their clinic had a waiting area appropriate for their/their children’s age by age group in 2019 and 2021**



## 7.3.2 Structure of clinic appointments

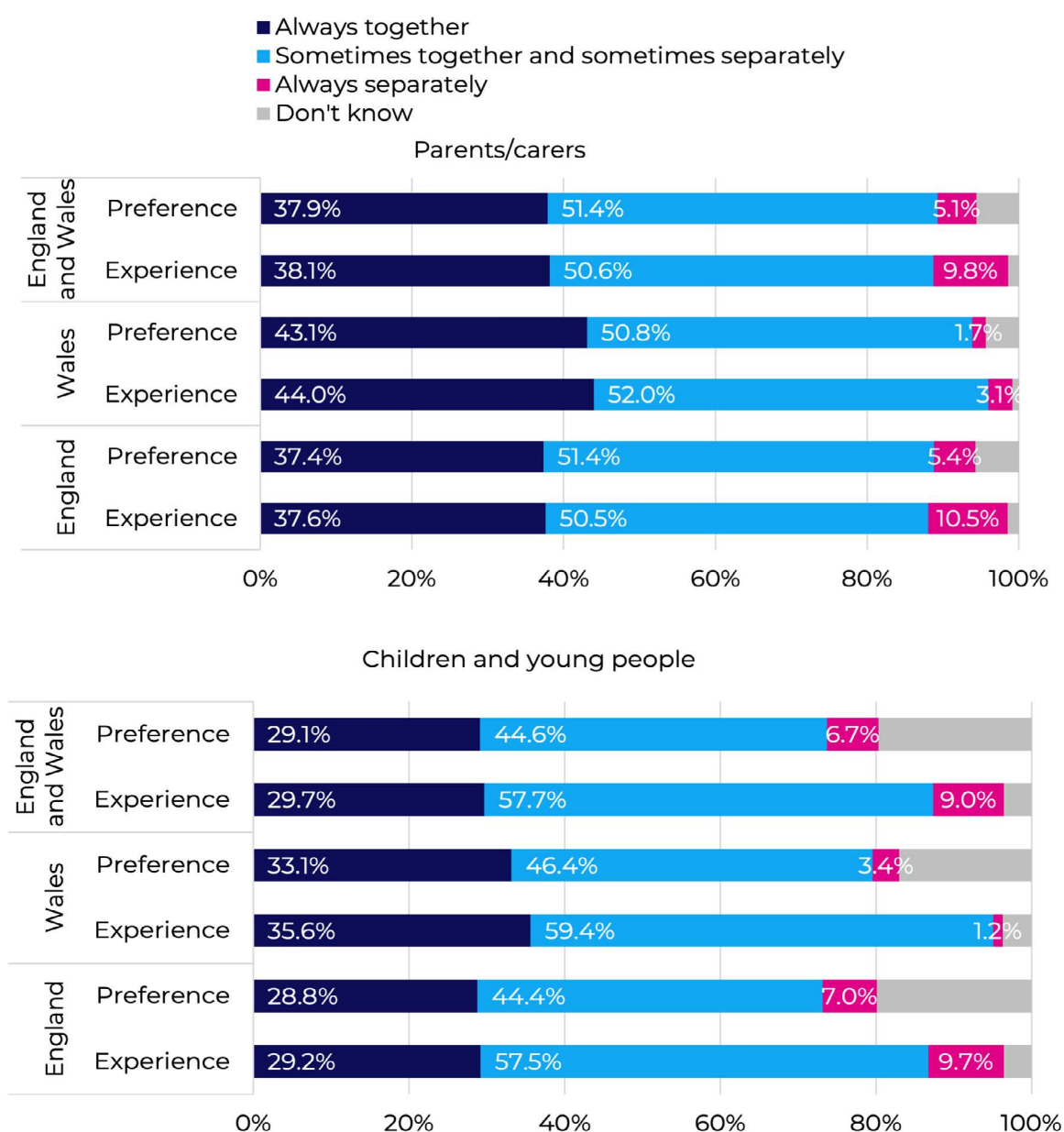
Respondents were asked what their experience was when meeting with their diabetes team, and how they would prefer to meet with the team via the two following questions:

Q. Do you see your diabetes team together **(in one room/on screen/on the same call) or separately?**

Q. How would you prefer to see your diabetes team?

The same list of responses were available to both questions:

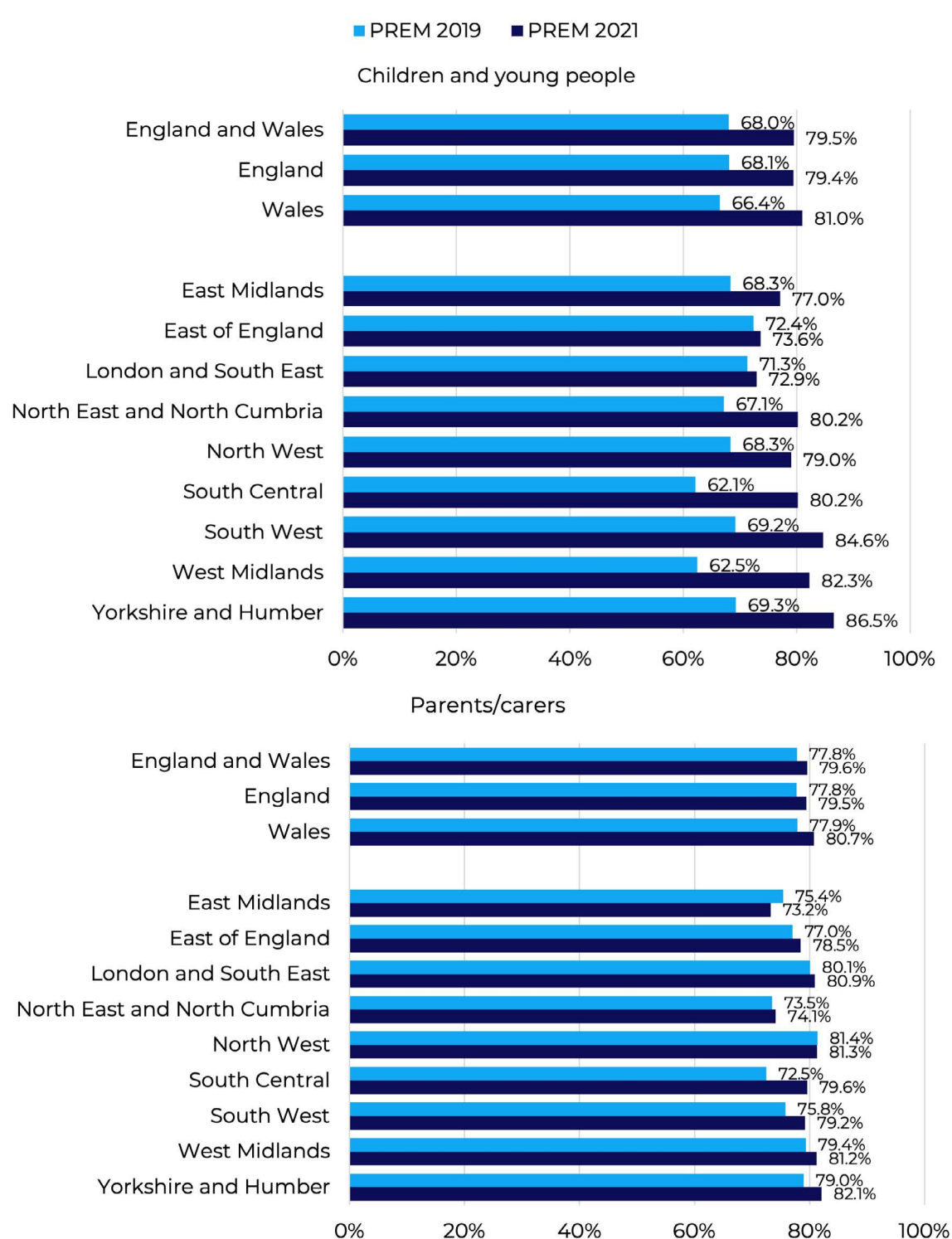
Figure 3 shows that experiences and preferences aligned closely for both parents and carers and children and young people.



**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, 2021.**



Figure 4 shows that in PREM 2021, 79.5% out of 3,236 children and young people and 79.6% out of 6,258 parents and carers reported that their experience met their preference.



“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.

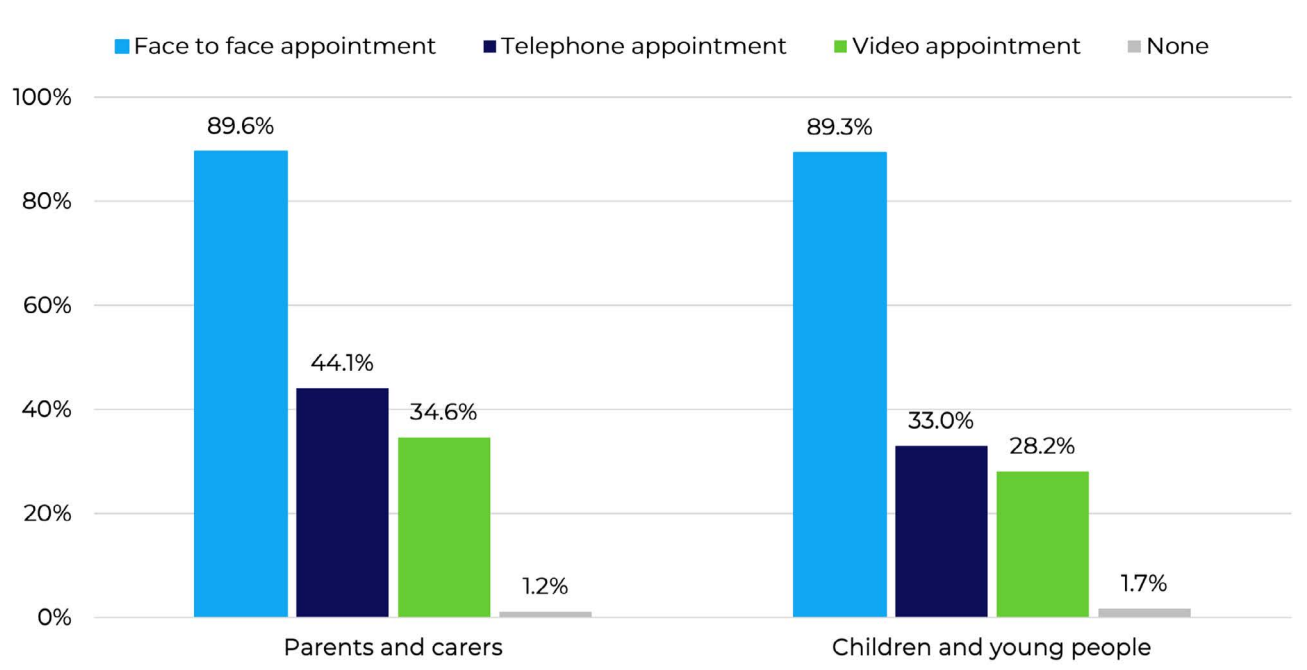
**Figure 4: Percentage of respondents whose preference for clinic visit structure met their experience by region and country, 2019 and 2021**

### 7.3.3 Modality of clinic appointment

Respondents were asked how they have received support from their diabetes team over the past six months in view of COVID-19 pandemic changes in service provision via the following question:

Q. Over the previous six months, how have you received support from your diabetes team? (Please select all that apply)

Figure 5 shows that almost all had had an appointment with their diabetes team, with the majority having a face-to-face appointment, and around a third having a telephone or video appointment.



**Figure 5: Modality of appointments with the diabetes team attended over previous six months, 2021**

## 7.4 Continuity of care

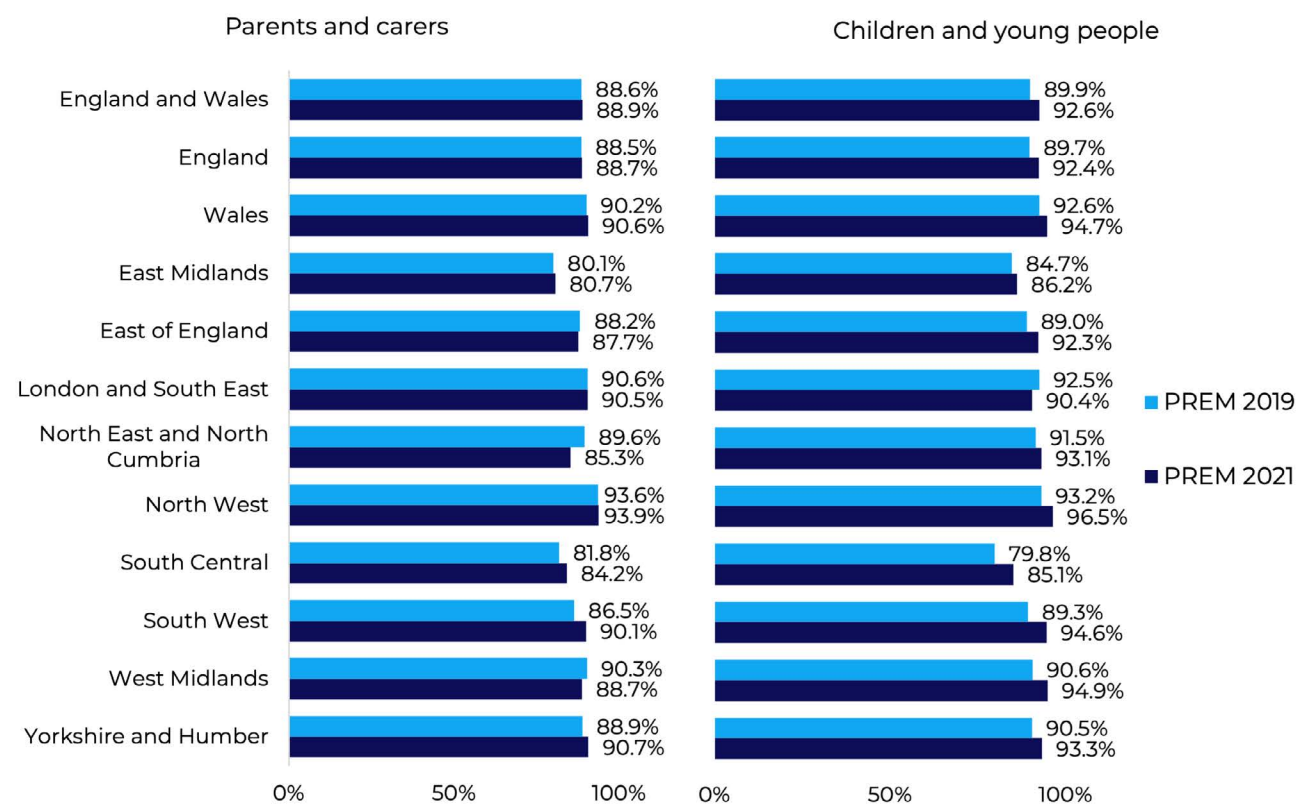
Respondents were asked to consider the following statement when thinking about their/their child's care over the previous six months:

Q. We are able to see the same doctor on most visits (**virtual or in person**)

To which the following list of responses were available:

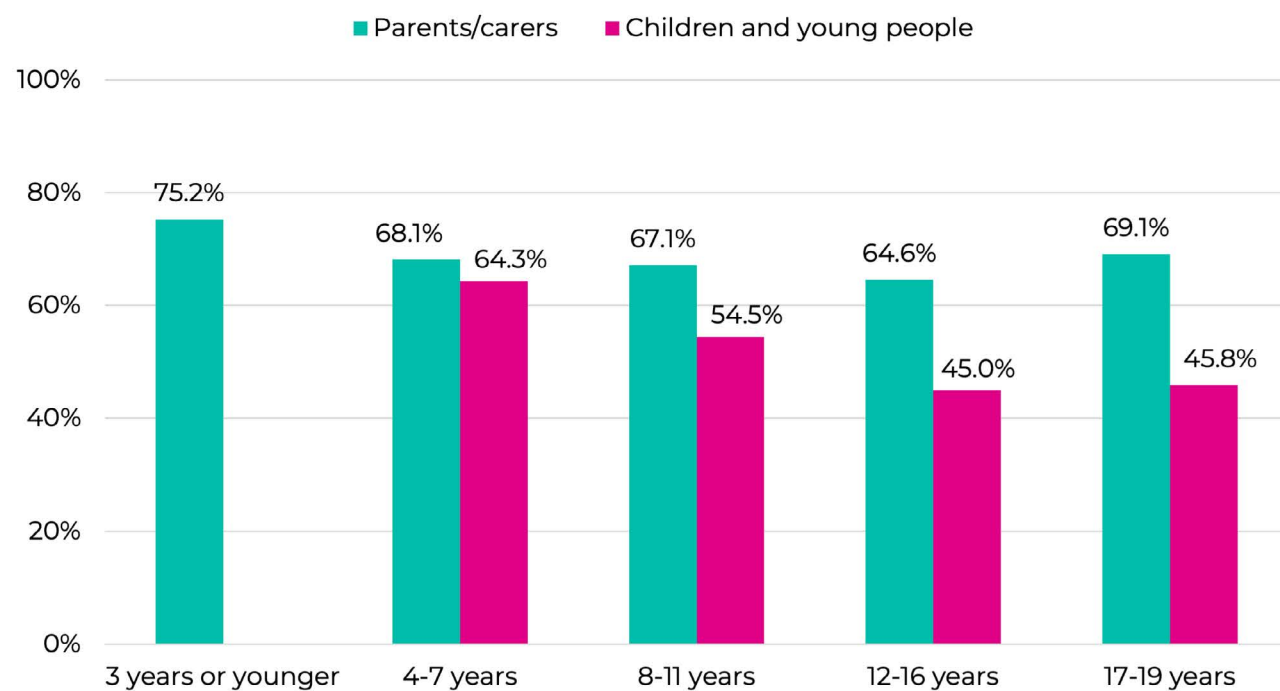
- i) Yes, and this is important to me
- ii) Yes, but I don't mind if I'm not able to
- ii) No, but I would like to be able to
- iv) No, but it is not important to me
- v) Too early to say / newly diagnosed
- vi) Don't know

Figure 6 showed that the majority were able to see the same doctor on most visits.



**Figure 6: “We are able to see the same doctor on most visits.” Percentage of respondents answering “Yes, and this is important to me” or “Yes, but I don’t mind if I’m not able to”, by country and region, 2019 and 2021**

Seeing the same doctor at each visit appeared more important to parents/carers, with older children and young people finding it less important (Figure 7).

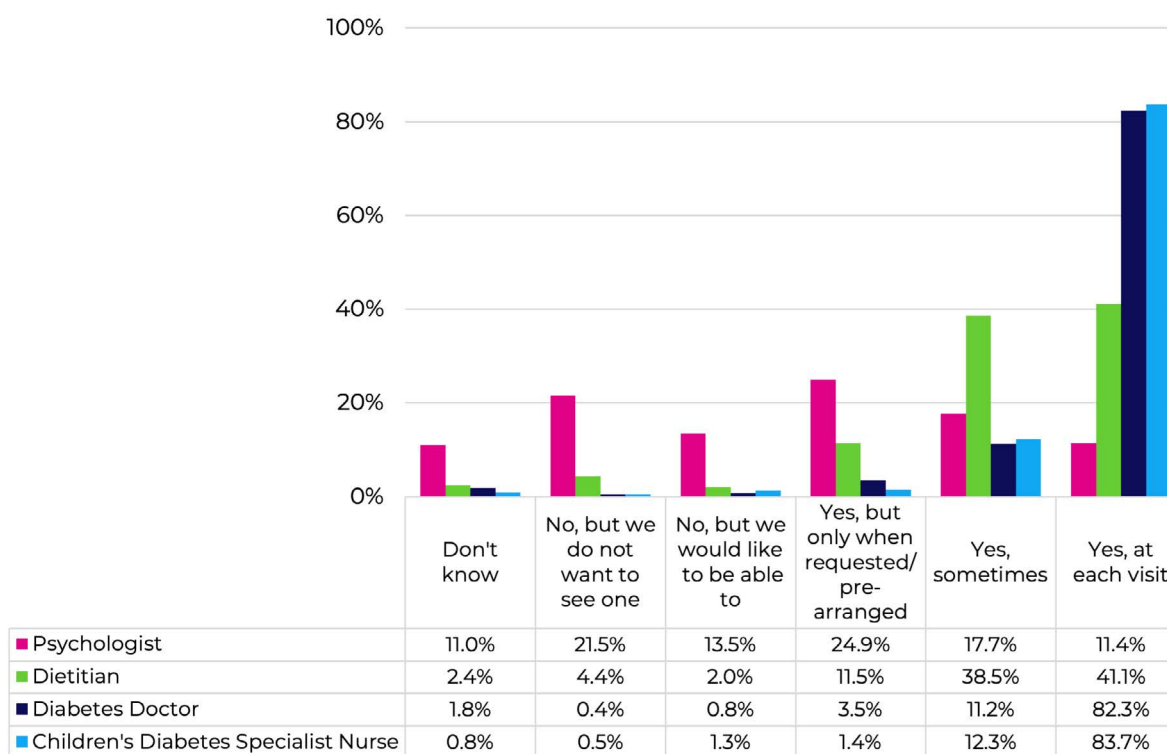


**Figure 7: “I am/ we are able to see the same doctor on most visits”. Percentage of children/ young people and parents/carers responding “Yes, and this is important to me”/“No, but I would like to”, by age group**

## 7.5 Multidisciplinary care

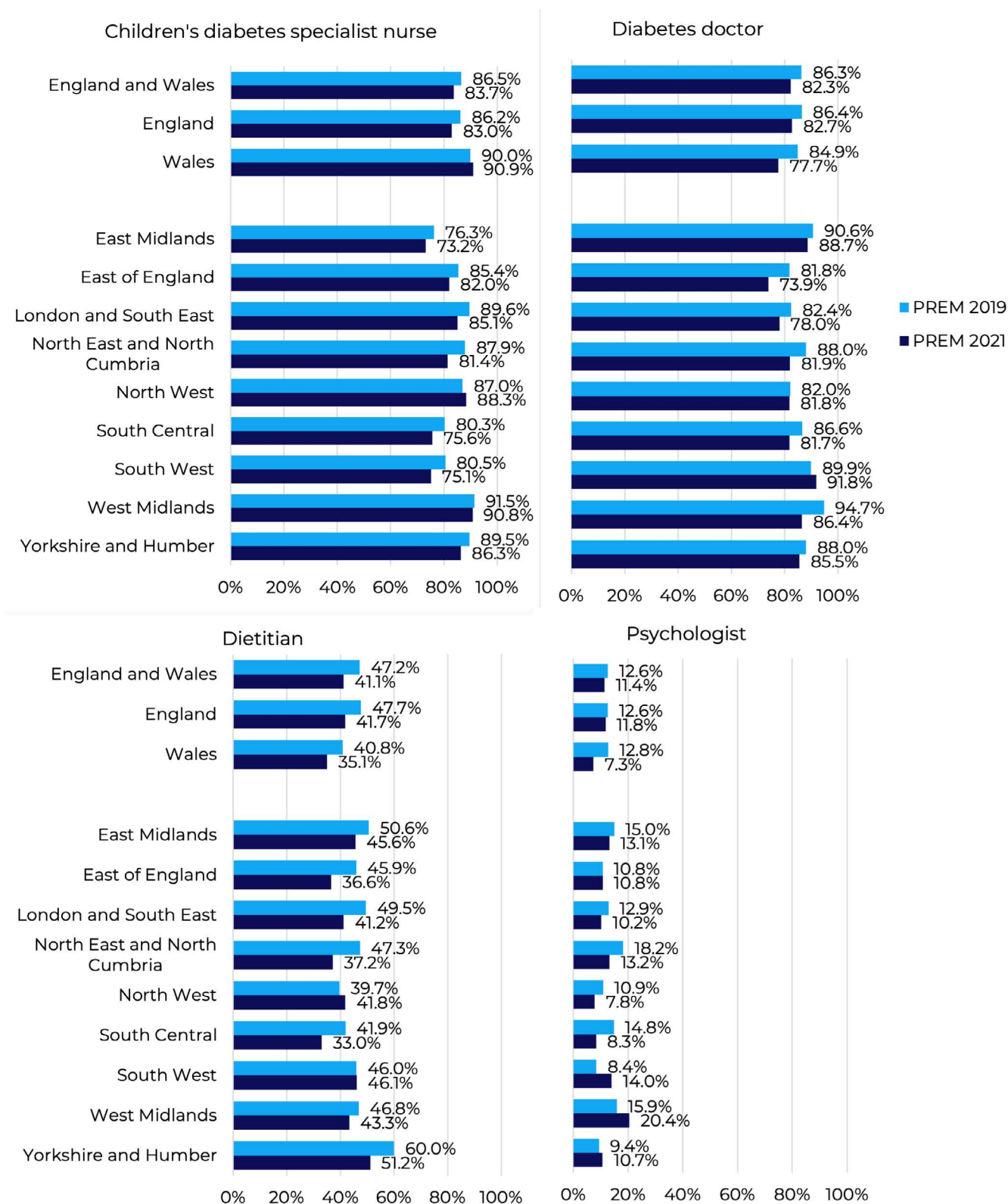
Respondents were asked to consider the following statement when thinking about their child's care over the previous six months and asked to select one answer from a list of available responses (presented within Figure 8) in relation to each of the team members listed below:

Q. We are able to see the following members of the team during our appointments with the diabetes team:



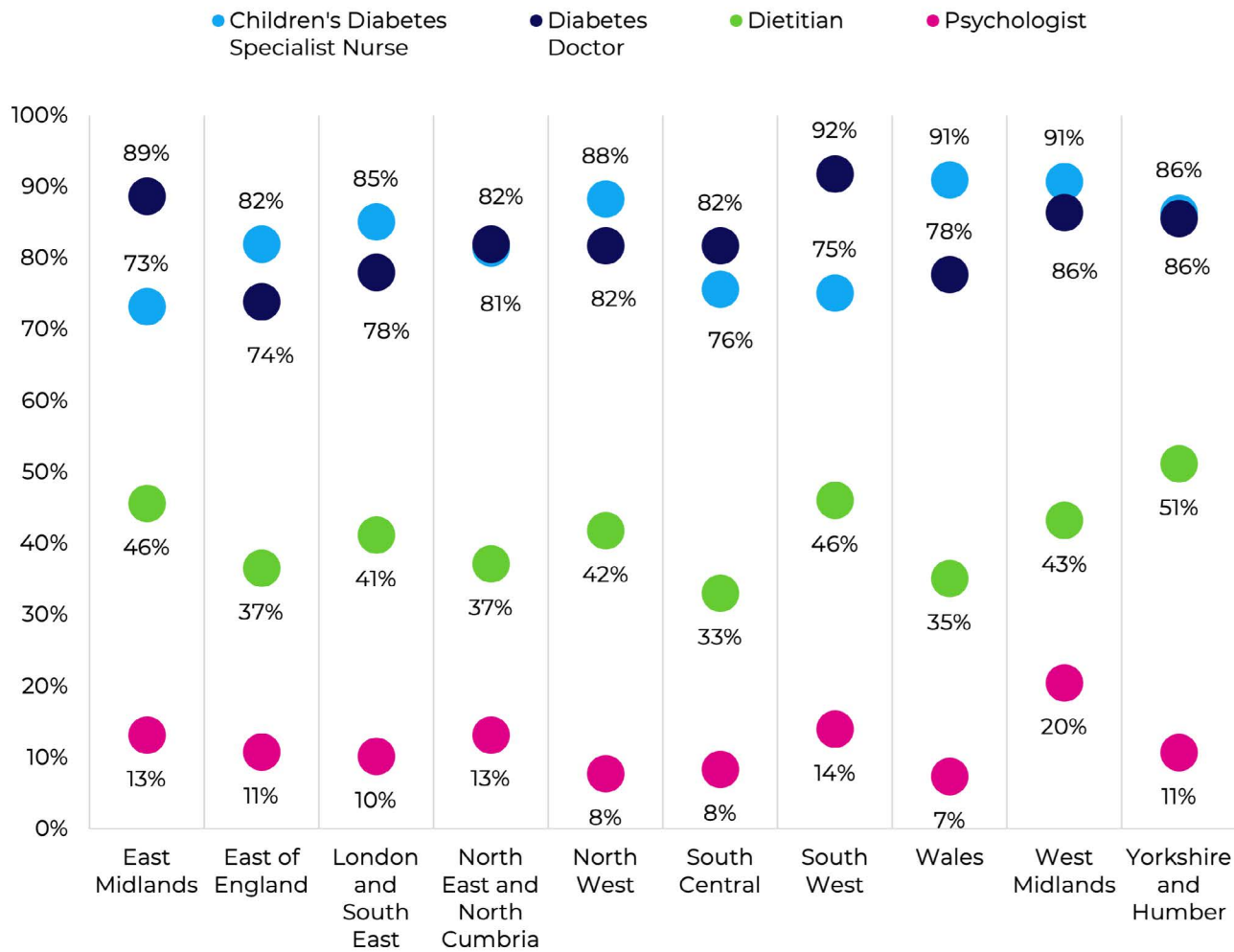
**Figure 8: “We are able to see the following members of the team when coming to clinic”. Responses from parents and carers, 2021**

Figure 9 compares the availability of specialists between PREM 2019 and PREM 2021. In general, the percentage of carers responding “Yes, at each visit” to each specialist decreased in most regions between the audit years.



**Figure 9: Percentage of parents and carers responding “Yes, at each visit” that they could see each specialist, by country and by region 2019 and 2021**

Figure 10 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. It shows that parents and carers were least likely to report seeing a psychologist at every visit.



**Figure 10: 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**

## 7.6 Access to diabetes advice

Respondents were asked to consider the following statements when thinking about their child's care over the previous six months:

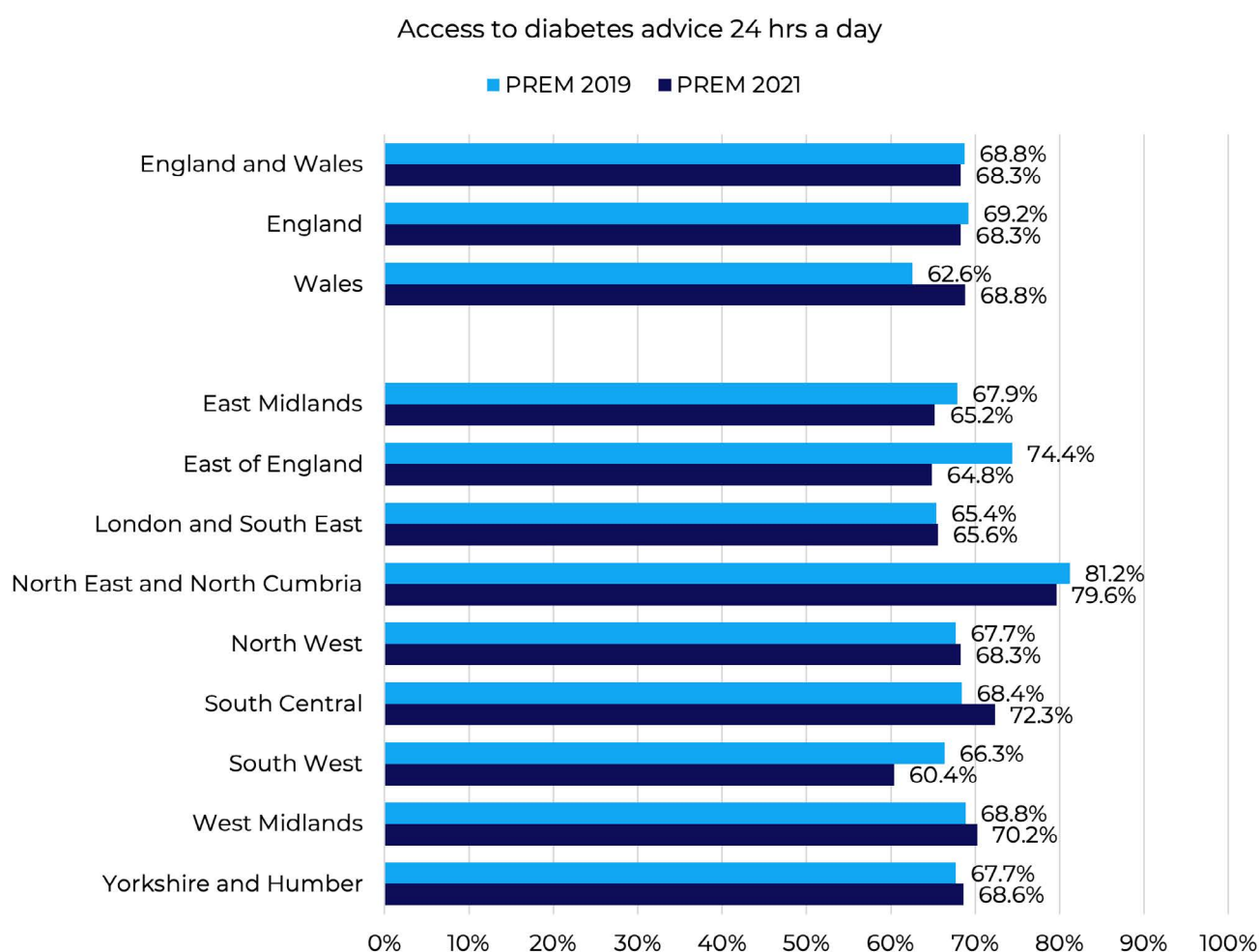
Q. I am able to get appropriate advice about my child's diabetes from the hospital 24 hours a day

Q. I am able to contact a member of the diabetes team for advice during core team hours, Monday to Friday

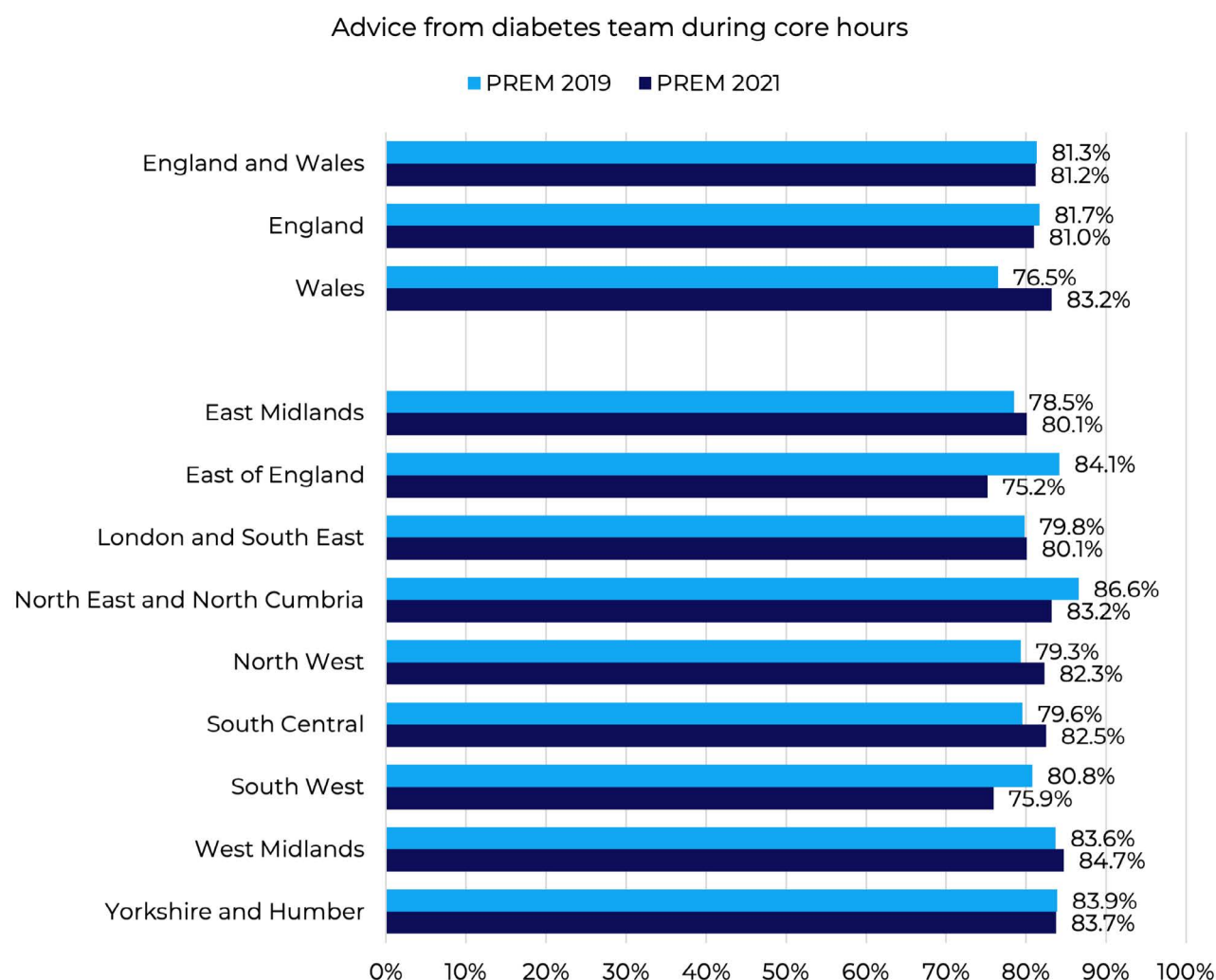
Respondents were asked to select one answer per question from the following list:

- i) Yes, always
- ii) Yes, sometimes
- iii) No, but I would like to be able to
- iv) No, but I don't mind
- v) Not had a need to contact them
- vi) Don't know

There was more regional variation in access to advice 24 hours a day (Figure 11a) than during core hours (Figure 11b), with access varying little between 2019 and 2021.



**Figure 11a: Percentage of parents/carers responding “Yes, always” that they could access appropriate advice 24 hours a day by country and region, 2019 and 2020**



**Figure 11b: Percentage of parents/carers responding “Yes, always” that they could access appropriate advice during core hours, 2019 and 2021**

## 7.7 Relationship with the diabetes team

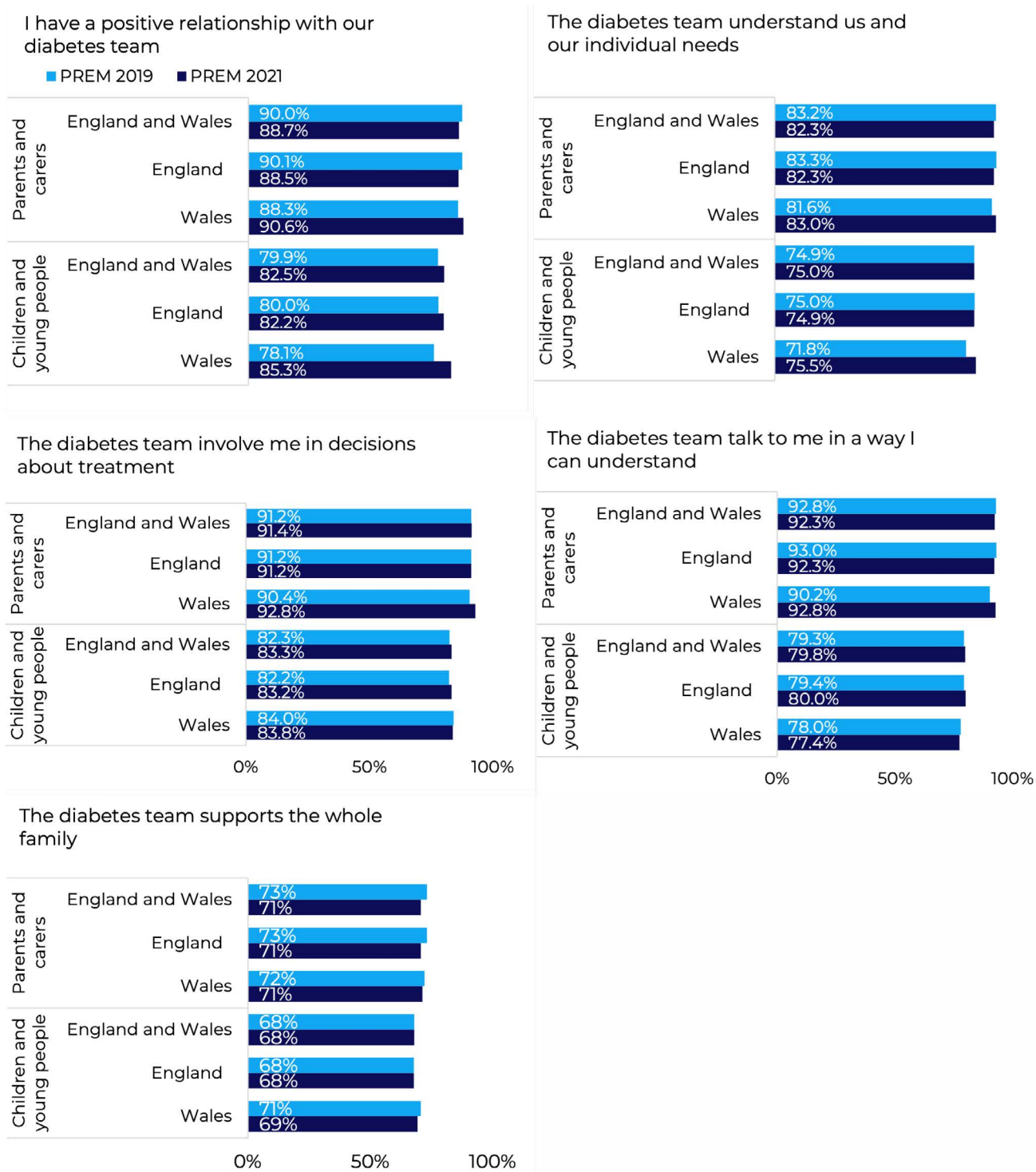
Respondents were asked to consider the following statements when thinking about their/their child's care over the previous six months:

- I have a positive relationship with my/our diabetes team
- My diabetes team understands me/us and my/our individual needs
- My diabetes team involves me/us in decisions about (my) care and treatment
- My diabetes team talks to me in a way I can understand

The following response options were available:

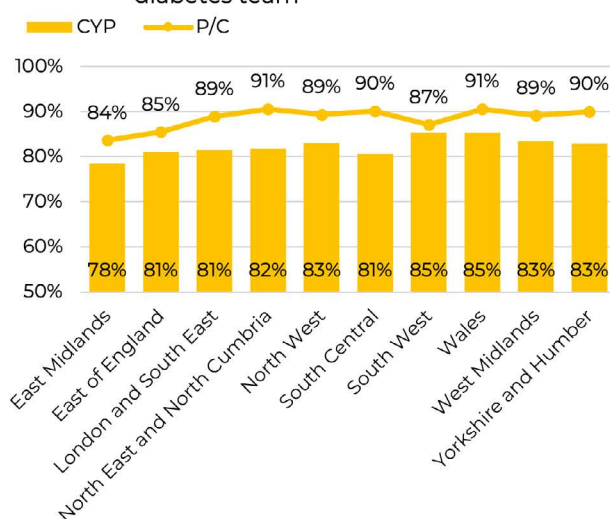
- i) Yes, always
- ii) Yes, sometimes
- iii) No, but I would like to/like them to
- iv) No, but I don't mind
- v) Don't know



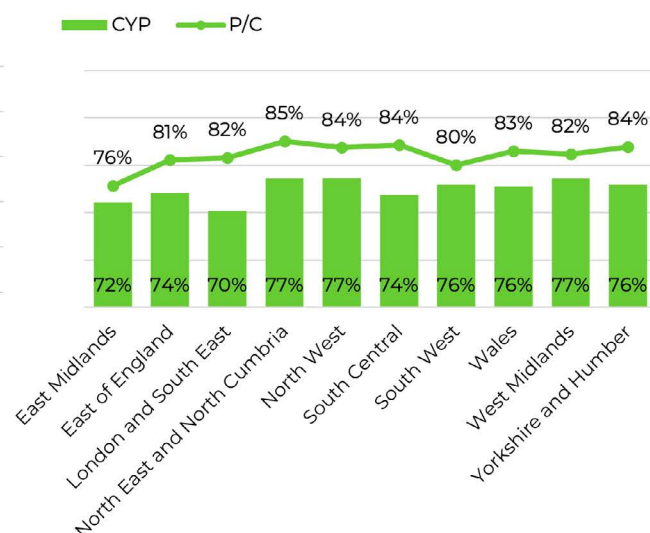


**Figure 12a: Percentage of children and young people and parents/carers responding “Yes, always”, to questions about their relationship with the staff team by country and overall, 2019 and 2021**

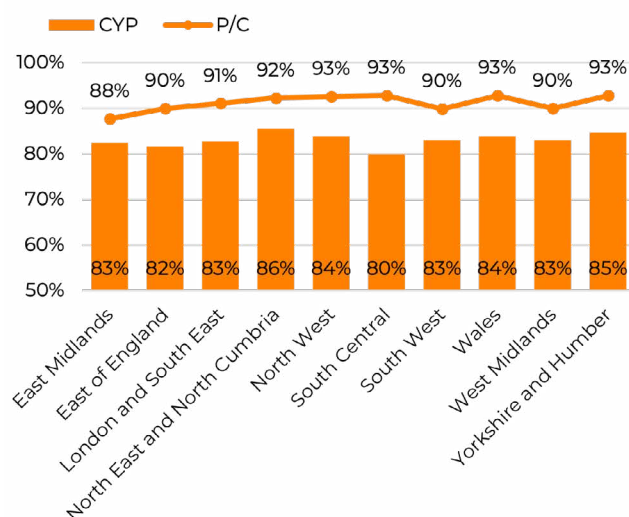
I have a positive relationship with our diabetes team



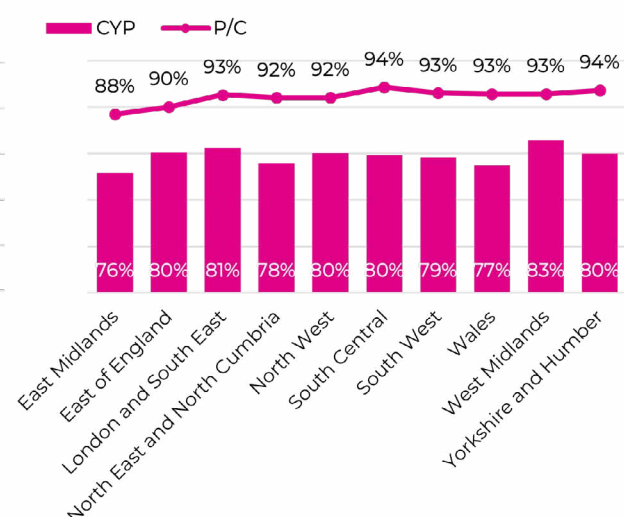
Our diabetes team understand us



Our diabetes team involve me in decisions about treatment



Our diabetes team talk to me in a way I can understand



**Figure 12b: Percentage of children and young people (CYP) and parents/carers (P/C) responding “Yes, always” to questions about their relationship with the staff team by region, 2021**

## 7.8 Culturally competent care

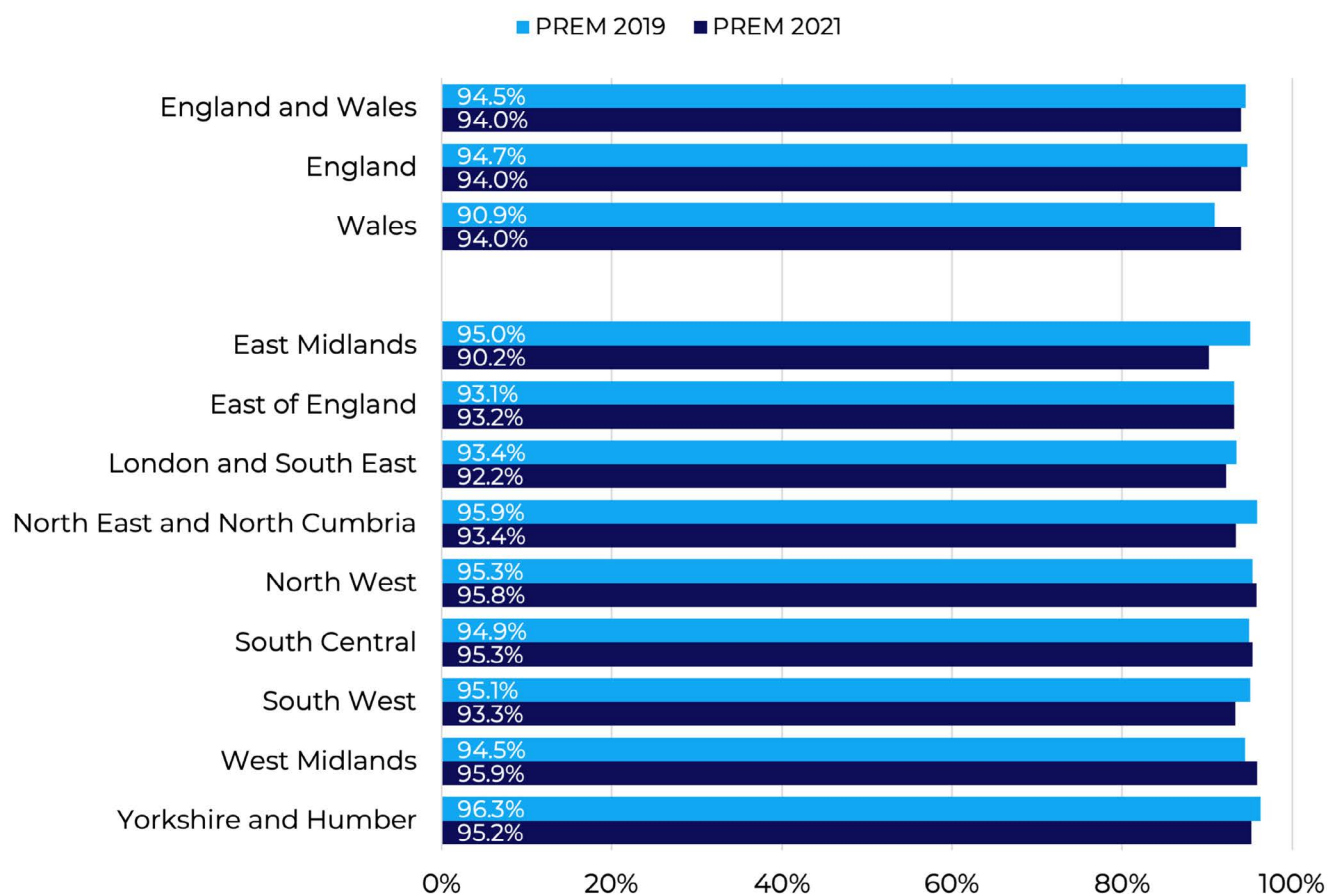
Parents were asked to consider the following statement when thinking about their child's care over the previous six months:

Q. Our diabetes team respect our religious and/or cultural beliefs

The following response options were available:

- i) Yes, always
- ii) Yes, sometimes
- iii) No, but I would like to/like them to
- iv) No, but I don't mind
- v) Not applicable

Figure 13 shows that a high percentage of parents and carers who considered this question applicable to them (n= 3,577) agreed that this was always the case in 2021, similarly to 2019.



**Figure 13: “Our diabetes team respect our religious and/or cultural beliefs”: percentage of parents and carers responding “Yes, always”, excluding “Not applicable” responses, by country and by region in PREM 2019 and PREM 2021**

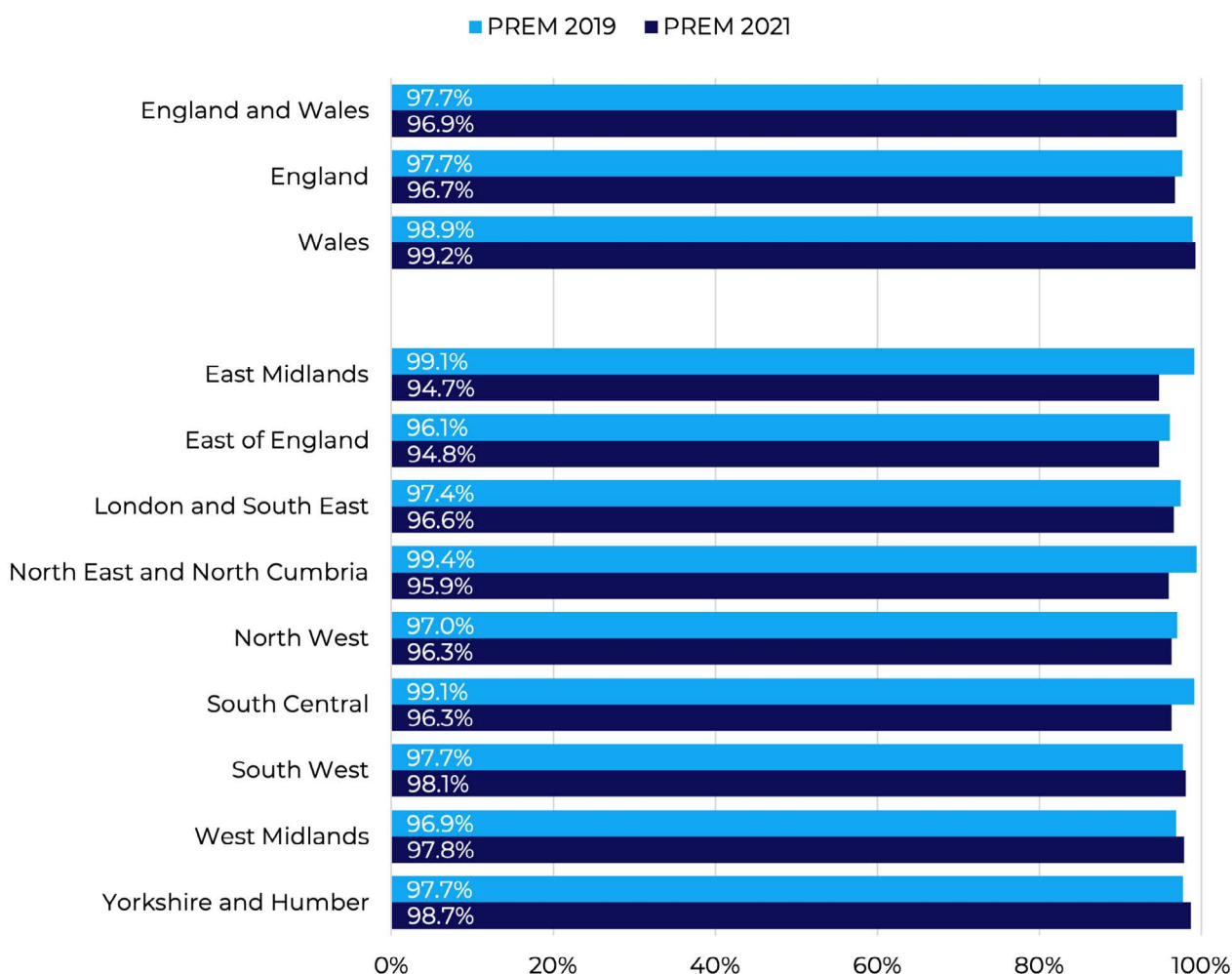
Parents were asked to consider the following statement when thinking about their child's care over the previous six months:

Q. Our diabetes team offer the opportunity to have an interpreter attend consultations

The following response options were available:

- i) Yes, and we use one
- ii) Yes, sometimes
- iii) Yes, but we have not been able to get one
- iv) No, but we would like them to
- v) No, but we do not need/want one

Figure 14 shows the percentages of parents stating “Yes, and they used one” and “Yes, but we have not needed/wanted one”, with the denominator being the sum of all possible responses excluding “No, but we do not need/want one” (n = 1473). It shows that access to interpreters was common across all areas, and that the availability of interpreters was similar between PREM 2019 and PREM 2021. However, given the small proportion of responses completed in a different language (n=22), these results may not be representative.



**Figure 14: “Our diabetes team offer the opportunity to have an interpreter attend consultations”. Percentage of parents and carers responding “Yes, and we use one”, by country and by region in PREM 2019 and PREM 2021**

## 7.9 Information and advice

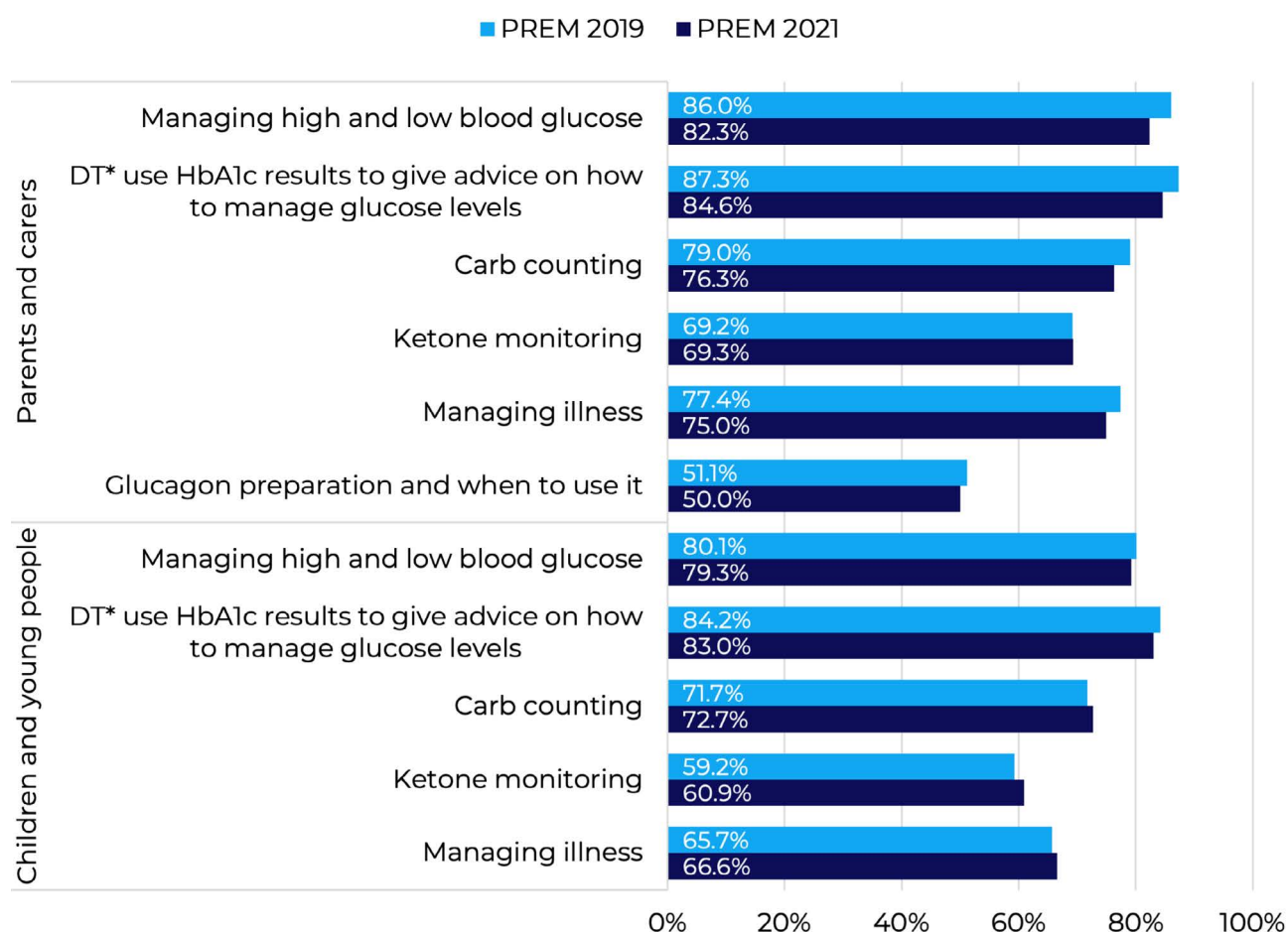
### 7.9.1 Diabetes management

Respondents were asked if they had received enough information from their diabetes team over the past six months to manage different areas of diabetes care effectively via the following question:

Q. Over the last six months, have you received enough information from your diabetes team to manage the following areas effectively? Respondents were asked to choose from one of the following responses to the question for each area of diabetes management shown in Figure 15:

- i) Yes, always
- ii) Yes, sometimes
- iii) Yes, but I would like to have
- iv) No, but I don't need this
- v) I don't know
- vi) Not applicable

Figure 15 shows the percentages of responding 'Yes, always' with reference to each aspect of diabetes management covered within this question.

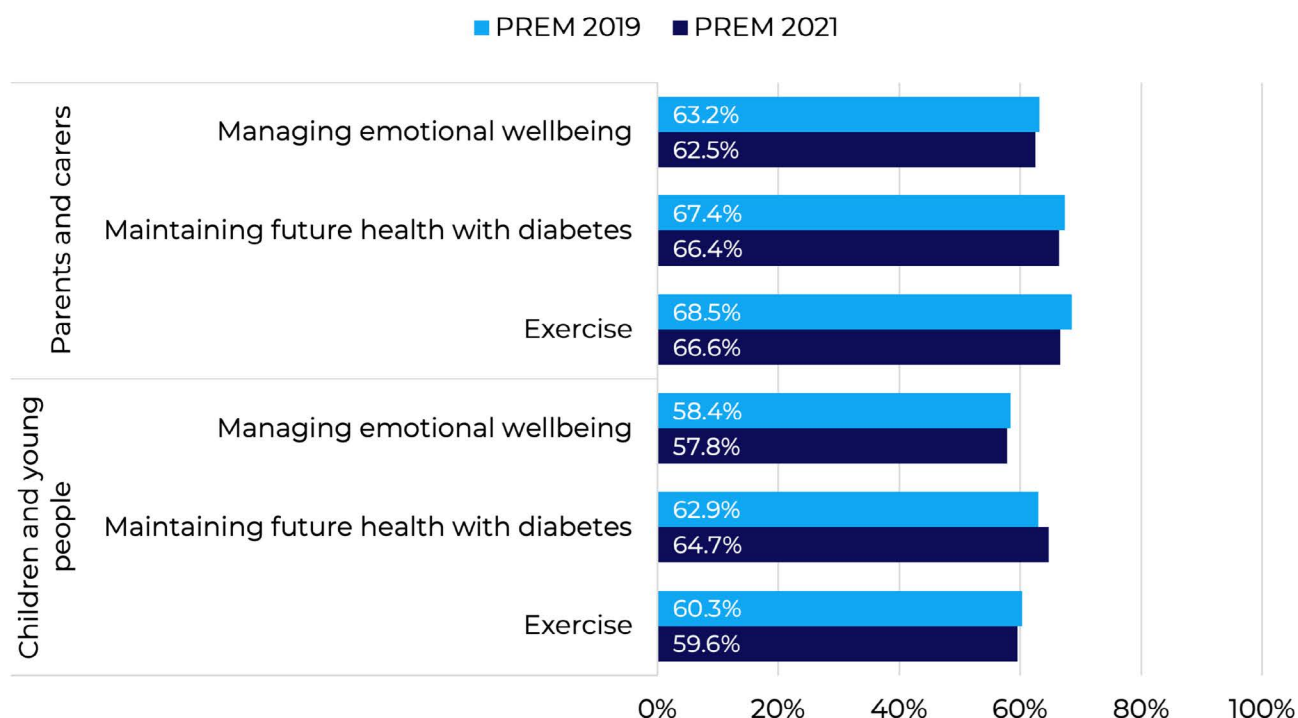


\*DT= diabetes team

**Figure 15: Information and advice on managing diabetes: Percentages of “Yes, always” responses, 2019 and 2021**

## 7.9.2 Maintaining wellbeing

Figure 16 shows the percentages answering 'yes, always' to questions about receiving advice on different aspects of maintaining wellbeing with diabetes.



**Figure 16: Information and advice on maintaining wellbeing. Percentages of “Yes, always” responses, 2019 and 2021**

## 7.9.3 Diabetes technologies

Respondents were asked to consider the following statements when thinking about their child's care/their own care over the previous six months:

Q. Our diabetes team keep me up-to-date with new technologies e.g. devices/pumps/apps, to help me manage my child's/my diabetes

The following response options were available:

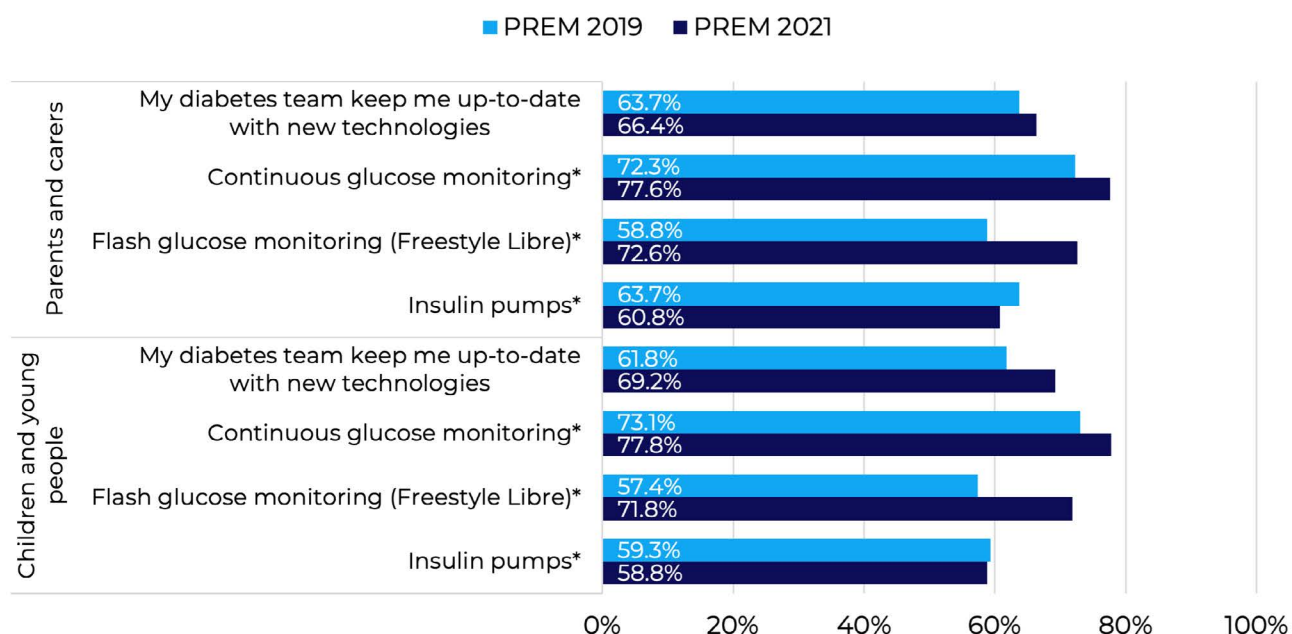
- i) Yes, always
- ii) Yes, sometimes
- iii) No, but I would like them to
- iv) No, but I don't mind/prefer to do this myself
- v) Don't know

Q. Have you received enough information from your diabetes team to manage the following areas effectively?

- Continuous glucose monitoring
- Flash glucose monitoring (Freestyle Libre)
- Insulin pumps



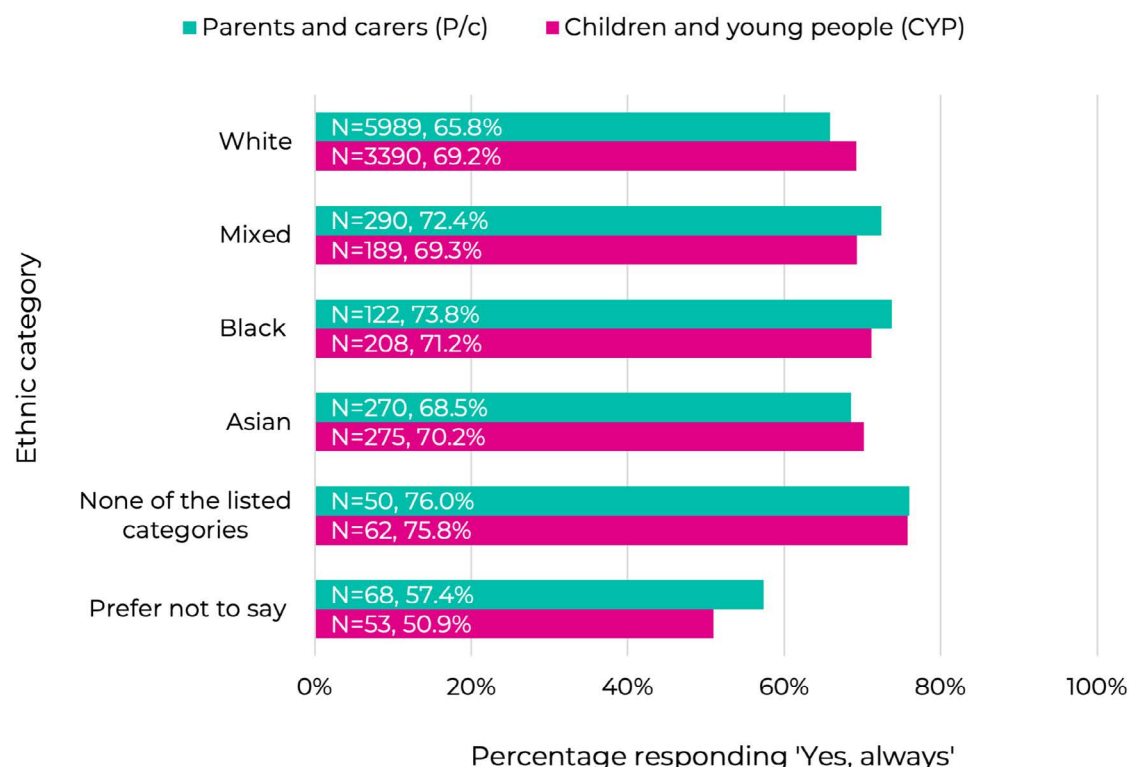
Figure 17 shows the percentages responding “Yes, always”, about each area:



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

**Figure 17: Information and advice on diabetes related technologies. Percentages of “Yes, always” responses, 2019 and 2021**

The NPDA core audit has found consistently lower use of diabetes related technologies amongst children and young people of minority ethnicity. Figure 18 presents a breakdown of ‘Yes, always’ responses by ethnic group to the statement “Our diabetes team keep me up-to-date with new technologies e.g. devices/pumps/apps, to help me manage my child’s/my diabetes”.



**Figure 18: Our diabetes team keep me up-to-date with new technologies e.g., devices/pumps/apps, to help me manage my child’s/my diabetes. Percentage of ‘Yes, always’ responses by ethnic category, 2021**

**Table 2: Information and advice: Percentage of children/young people and parents/carers responding “Yes, always”, by region in PREM 2021**

		East Midlands	East of England	London and South East	North East and North Cumbria	North West	South Central	South West	Wales	West Midlands	Yorkshire and Humber
Managing high and low blood glucose levels	CYP	74.5%	79.7%	80.2%	83.6%	81.0%	76.0%	74.8%	76.9%	78.4%	81.0%
	P/C	78.1%	79.0%	81.1%	84.4%	82.6%	83.2%	78.8%	84.3%	83.8%	86.5%
Diabetes team use my HbA1c results to give advice	CYP	79.3%	78.0%	81.5%	87.3%	83.5%	80.1%	79.9%	86.5%	86.0%	83.9%
	P/C	80.8%	78.9%	82.0%	88.4%	85.8%	86.7%	82.2%	88.1%	85.0%	87.6%
Carbohydrate counting	CYP	69.1%	72.3%	72.2%	77.4%	71.1%	70.8%	68.8%	73.4%	74.5%	73.8%
	P/C	75.4%	73.4%	76.1%	78.2%	75.1%	75.9%	73.1%	77.8%	77.6%	79.8%
Ketone monitoring	CYP	57.1%	63.3%	58.7%	60.4%	60.0%	61.4%	57.2%	59.9%	67.0%	61.9%
	P/C	67.8%	65.3%	67.7%	72.2%	68.6%	69.7%	63.6%	71.4%	74.2%	72.2%
Glucagon preparation (P/C only)	CYP	-	-	-	-	-	-	-	-	-	-
	P/C	44.6%	45.7%	50.5%	57.0%	48.5%	45.0%	40.2%	50.7%	53.0%	61.0%
Managing illness	CYP	62.7%	62.9%	66.6%	74.4%	67.2%	64.7%	60.4%	70.1%	66.8%	64.5%
	P/C	72.1%	69.1%	74.0%	80.1%	75.1%	76.2%	70.3%	78.8%	75.5%	77.7%
Exercise	CYP	53.2%	58.5%	58.8%	62.5%	59.9%	62.5%	54.8%	60.9%	61.4%	59.3%
	P/C	64.3%	63.4%	62.9%	70.4%	66.8%	67.5%	62.4%	68.9%	68.5%	71.5%
Maintaining future health with diabetes	CYP	60.7%	65.0%	61.2%	69.3%	63.7%	64.4%	62.1%	68.1%	66.1%	65.7%
	P/C	62.4%	60.3%	61.7%	73.7%	68.4%	64.5%	62.7%	70.0%	68.8%	71.8%
Managing emotional wellbeing	CYP	53.0%	58.1%	54.5%	59.2%	54.9%	59.9%	55.9%	61.4%	63.2%	57.7%
	P/C	59.0%	58.7%	59.2%	68.1%	62.5%	62.1%	61.3%	61.3%	66.2%	66.5%
My diabetes team keep me up-to date with new technologies	CYP	66.4%	61.8%	70.0%	71.5%	71.9%	69.3%	63.8%	70.0%	72.0%	69.5%
	P/C	64.5%	57.2%	67.2%	73.1%	69.4%	70.0%	59.2%	65.7%	67.5%	67.3%
Continuous glucose monitoring*	CYP	76.6%	78.8%	73.2%	80.0%	79.0%	77.8%	74.4%	77.3%	80.4%	79.6%
	P/C	77.0%	72.7%	75.7%	78.3%	79.4%	77.7%	71.6%	81.8%	79.9%	81.3%
Flash glucose monitoring*	CYP	75.2%	74.8%	71.4%	71.4%	72.7%	67.2%	66.2%	65.7%	75.7%	74.4%
	P/C	72.8%	64.0%	72.2%	73.0%	74.8%	71.6%	70.4%	70.9%	77.0%	77.1%
Insulin pumps *	CYP	61.0%	60.8%	57.6%	61.3%	61.5%	63.3%	48.9%	62.2%	52.8%	59.9%
	P/C	60.1%	58.2%	62.0%	67.3%	59.3%	62.3%	54.2%	59.6%	60.4%	64.1%

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



## 7.10 Managing diabetes at school or college

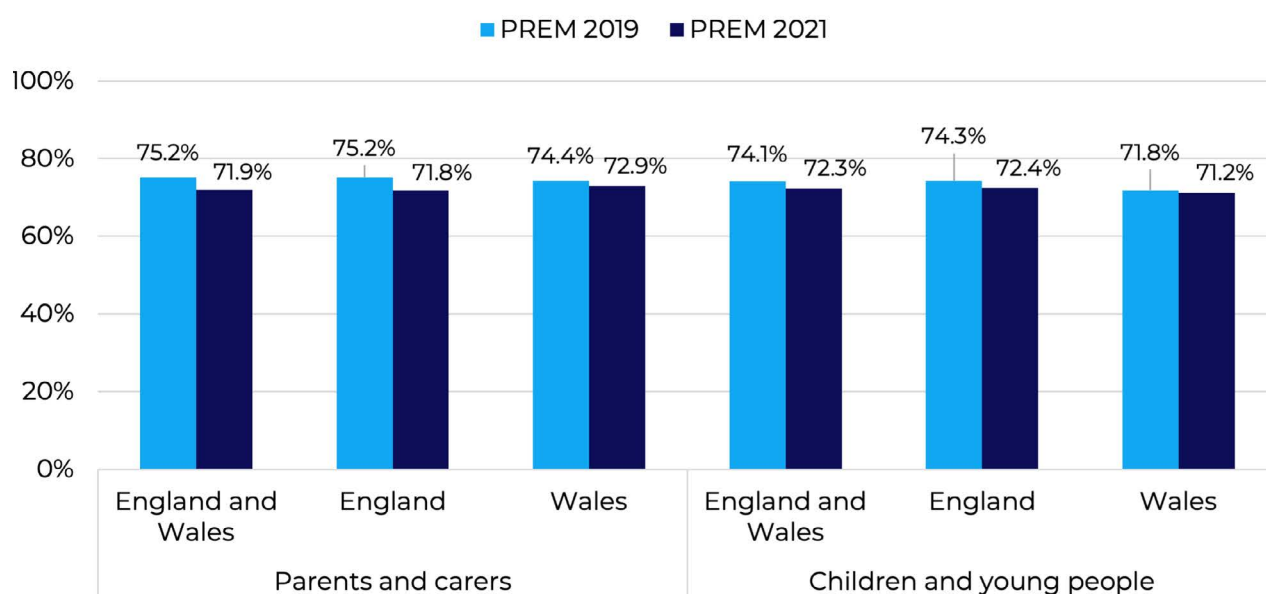
Respondents were asked to consider the following statements when thinking about their child's care/their own care over the previous six months:

Q. My (our) diabetes team give me (us) enough information to effectively manage my (child's) diabetes at school/college

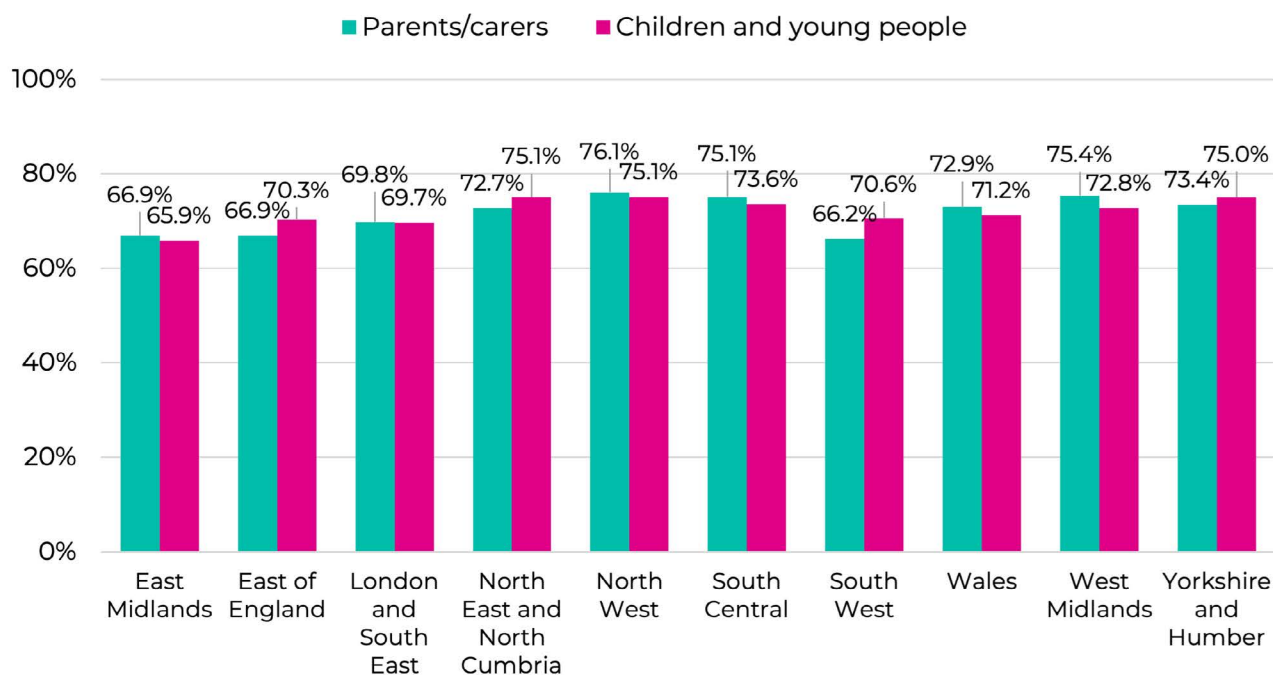
Q. My (our) diabetes team ensure that staff at my (child's) school/college have the necessary information about my/my child's diabetes in order to help me (them)

- i) Yes, always
- ii) Yes, sometimes
- iii) No, but I would like them to
- iv) No, but I don't want them to
- v) Don't know
- vi) Not applicable

Figures 19 and 20 provide comparison of percentages of 'Yes, always' responses to the former question between 2019/2021, and percentages of 'Yes, always' responses between regional networks in 2021, respectively. Figures 21 and 22 provide the same for the latter question. Overall, children and young people with diabetes were less likely to agree that their team always provided enough support for management of diabetes at school compared to parents/carers, and agreement was lower in 2021 than in 2019.

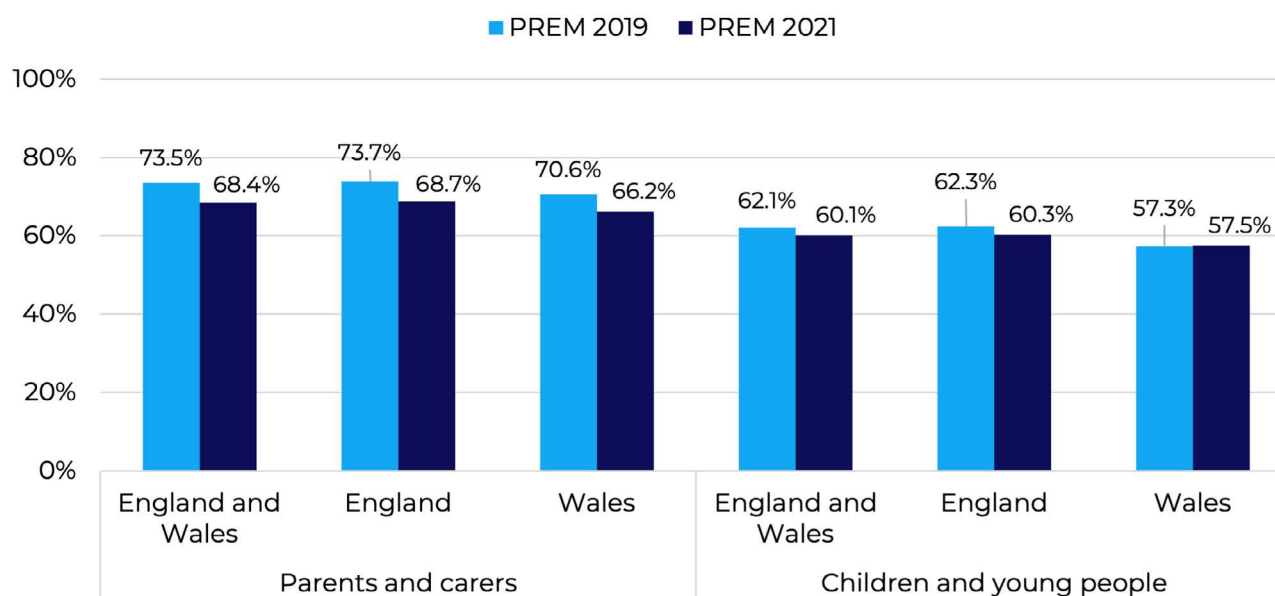


**Figure 19: Diabetes team give me (us) enough information to effectively manage my (child's) diabetes at school/college. Percentages of "Yes, always" responses by country and overall, 2019 and 2021**



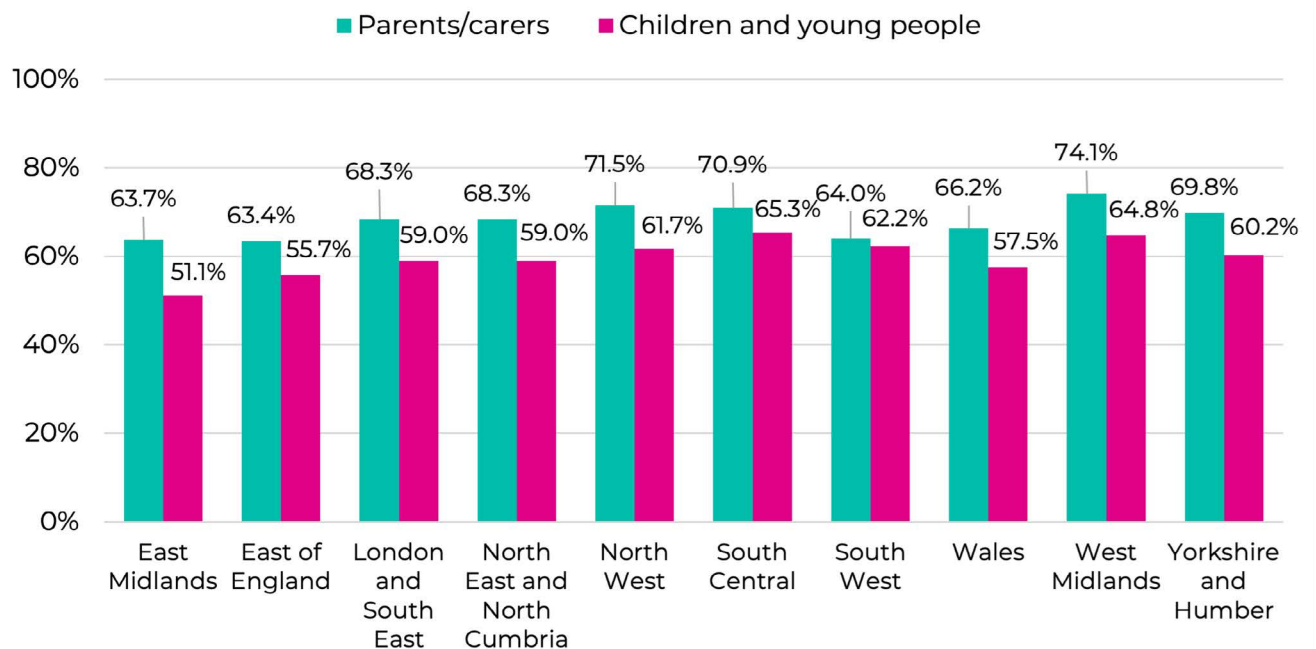
\* "Not applicable" answers were excluded from the denominator.

**Figure 20: Diabetes team gives enough information to effectively manage diabetes at school/college. Percentages of "Yes, always" responses by regional network, 2021**



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

**Figure 21: Diabetes team ensure that staff at school/college have the necessary information about my (child's) diabetes in order to help. Percentages of "Yes, always" responses by country and overall, 2019 and 2021**



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

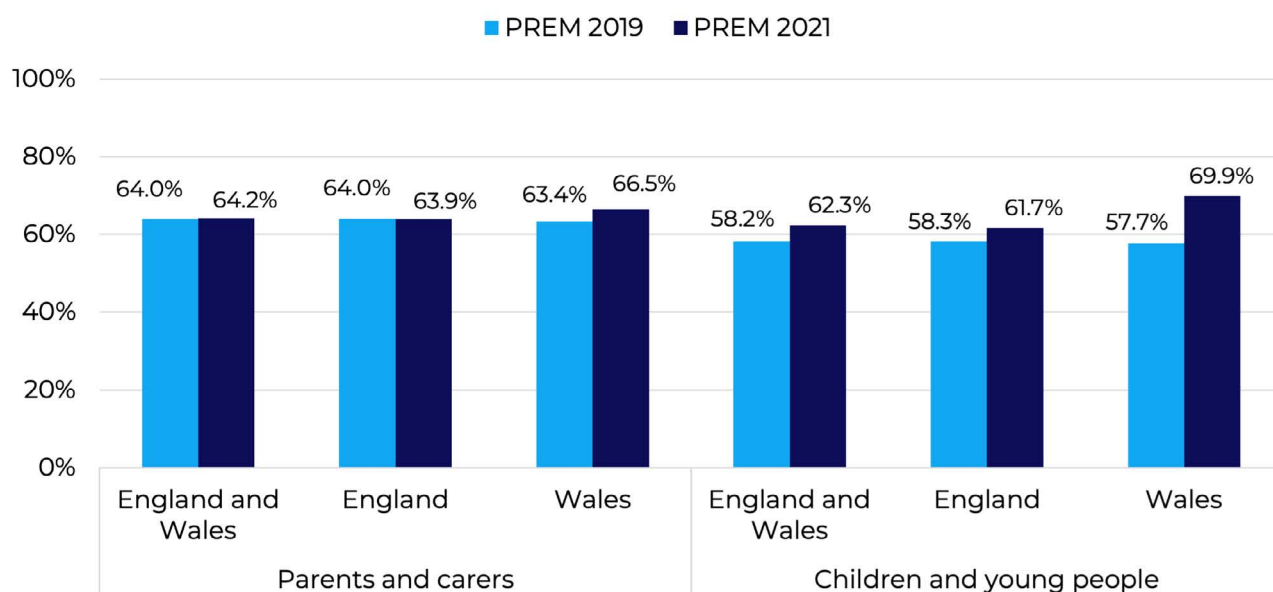
**Figure 22: Diabetes team ensure that staff at school/college have the necessary information about my diabetes in order to help. Percentages of "Yes, always" responses, by regional network, 2021**

## 7.11 Transition to adult care

Respondents were asked to consider the following statements when thinking about their child's care/their own care over the previous six months:

Q. My/Our diabetes team are providing me/us with the information, resources and support I/we need to prepare for my/my child's transfer to adult care

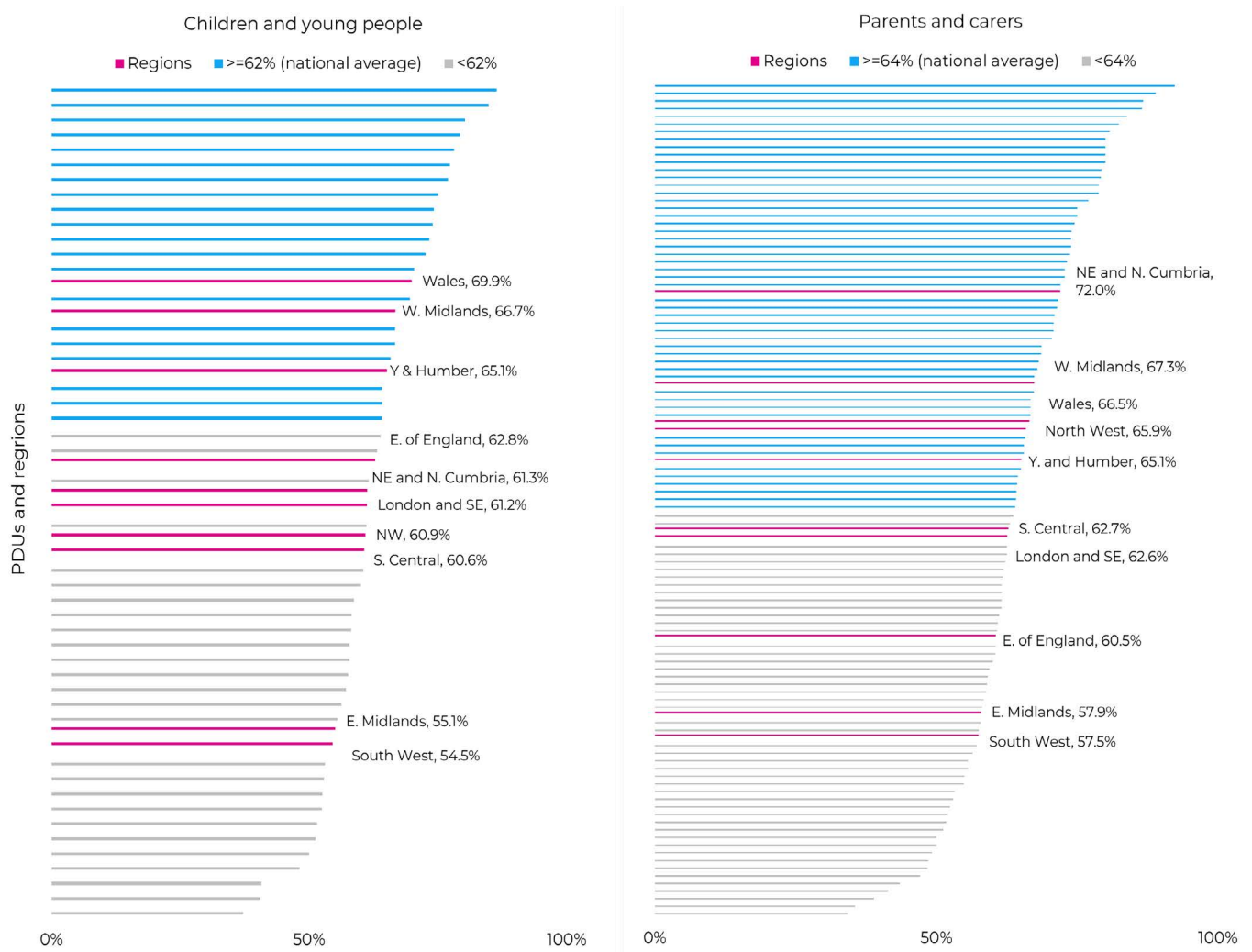
- i) Yes, definitely
- ii) Yes, to some extent
- iii) No, but I would like this
- iv) No, but I don't mind
- v) I am/My child is too young to consider this yet
- vi) Don't know



\* "I am (my child is) too young to consider this" responses were excluded from the denominators.

**Figure 23: "Diabetes team are providing the information, resources and support needed to prepare for transfer to adult care". Percentage of "Yes, always" responses by country and overall, 2019 and 2021**

Figure 24 shows the percentages of respondents stating "Yes, definitely" to the statement "Our diabetes team are providing us with the information, resources and support we need to prepare for my (child's) transfer to adult care", sorting from the highest to the lowest percentage by PDU.



\* "I am (my child is) too young to consider this" responses were excluded from the denominators.

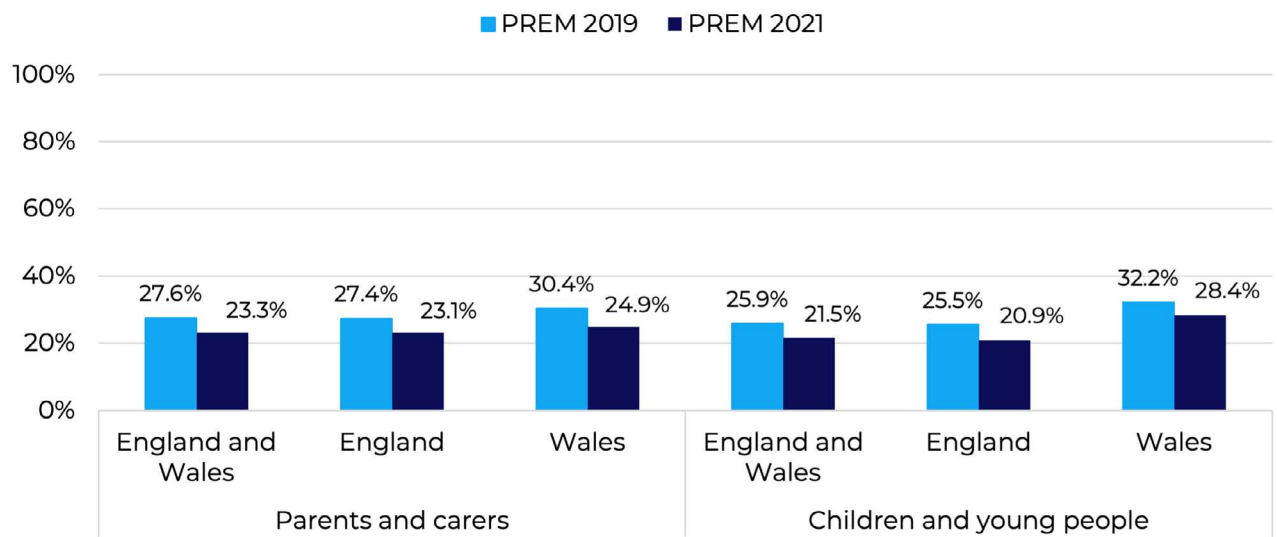
**Figure 24: "Our diabetes team are providing us with the information, resources and support we need to prepare for my (child's) transfer to adult care." Percentages of "Yes, definitely" responses by PDU and regional network, 2021**

## 7.12 Peer support

Respondents were asked to consider the following statements when thinking about their child's care/their own care over the previous six months:

Q. My (our) diabetes team make it possible for me to connect with other (parents of) young people with diabetes

- i) Yes, often
- ii) Yes, sometimes
- iii) No, but I would like to be able to
- iv) No, but I do meet people with diabetes in other ways e.g., Diabetes UK, JDRF (Junior Diabetes Research Foundation), social media, parents etc.
- v) No, but I don't want to



**Figure 25: “Our diabetes team makes it possible for me to contact/spend time with other (parents of) young people with diabetes”. Percentage of “Yes, often” responses, 2019 and 2021**

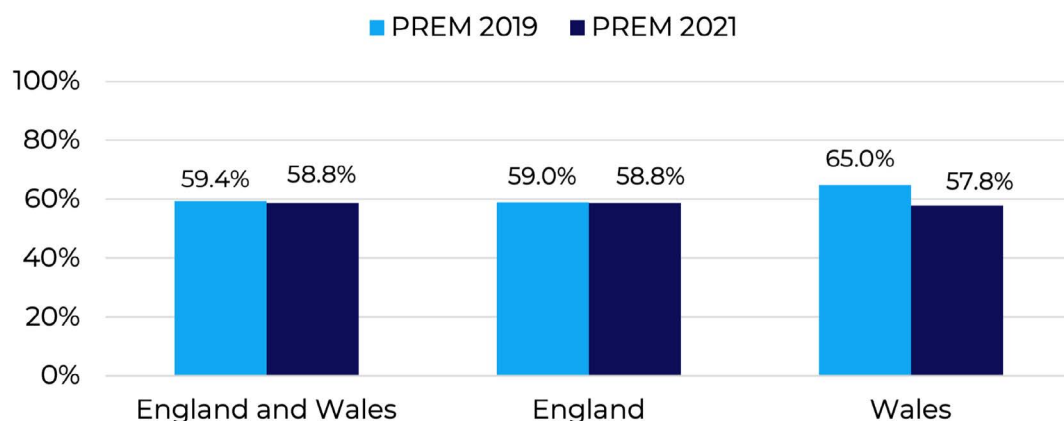
## 7.13 Access to prescriptions

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.

Parents and carers were asked to consider the following statement when thinking about their child's care over the previous six months:

Q. We are able to access the prescriptions that we need, without difficulty, from our GP.

- ii) Yes, always
- iii) Yes, sometimes
- iv) No
- v) Don't know



**Figure 26: “We are able to access the prescriptions that we need, without difficulty, from our GP”, percentage of “Yes, always” responses, by country and overall, in 2019 and 2021**

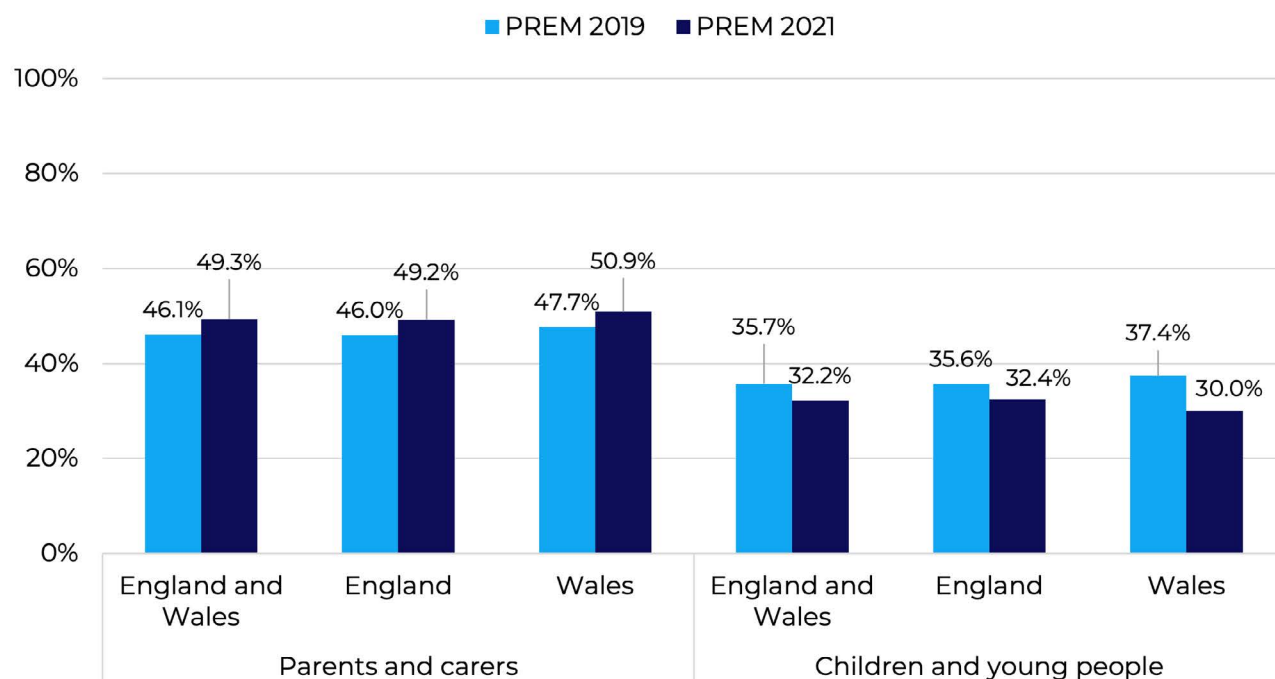
## 7.14 Overall experience

Respondents were asked to consider the following question when thinking about their child's care/their own care over the previous six months:

Q. How do you usually feel after your appointments with the diabetes team?

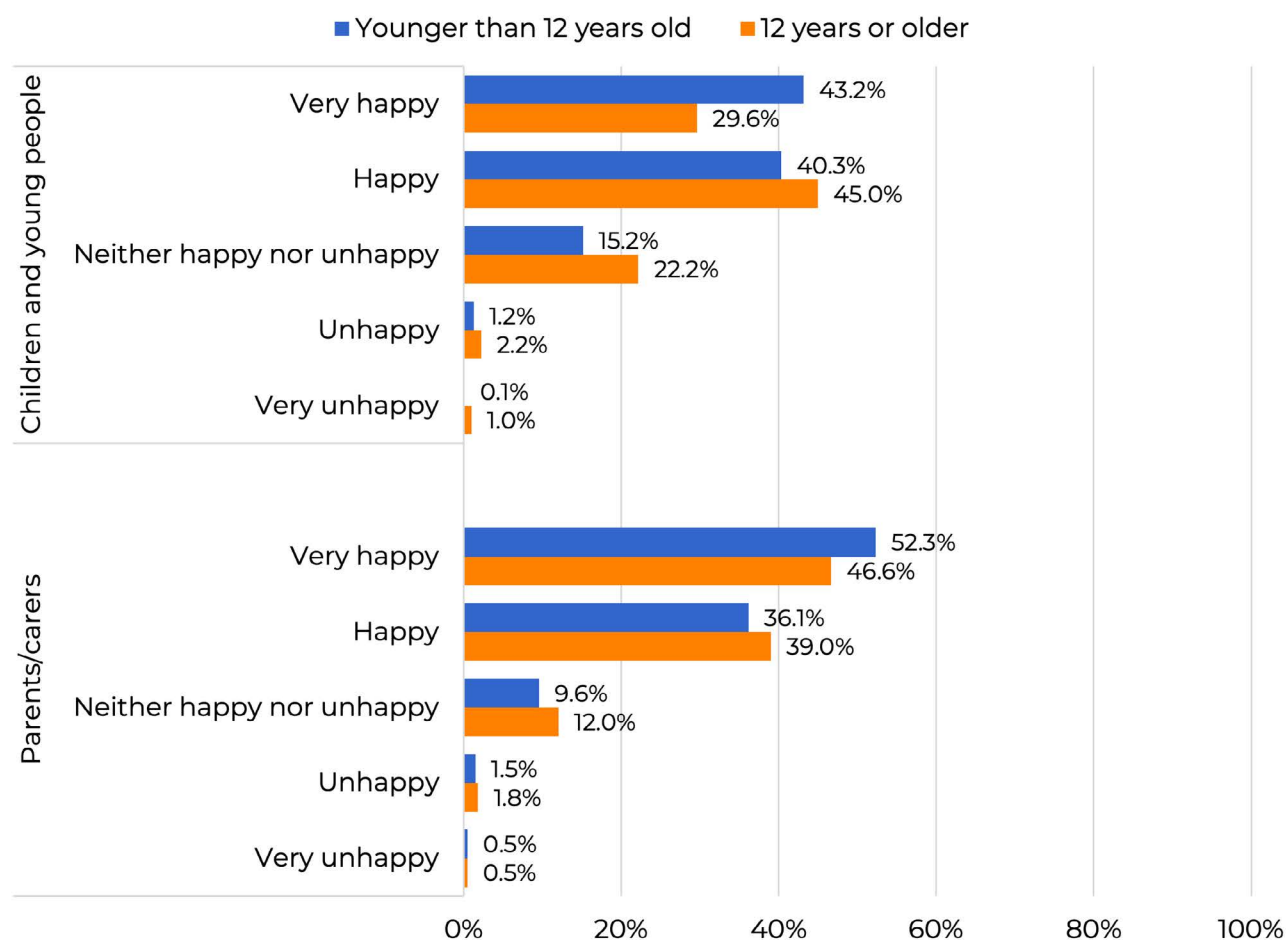
- i) Very happy
- ii) Happy
- iii) Neither happy nor unhappy
- iv) Unhappy
- v) Very unhappy

This scale corresponded to the emojis used for the response options to the same question in the 2019 PREM:



**Figure 27: “How do you usually feel when you leave the clinic”. Percentage of “Very happy” responses, by country and overall, in 2019 and 2021**

Figure 28 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 positive rather than neutral or negative feelings.



**Figure 28: “How do you usually feel when you leave the clinic?”. Responses from children/young people and parents/carers by age group, 2021**

An ordinal regression analysis (a type of analysis used for predicting a variable on a scale) was performed to explore the associations between the most positive responses ('Yes, always' and 'Yes, definitely') to the questions included in the overall PREM score and responses to the question assessing feelings when leaving the clinic (very happy, happy, neither happy nor unhappy, unhappy, very unhappy).

Age, duration of care at the clinic and duration of diabetes were positively associated with more positive feelings, with children younger than 12 and their parents more likely to be happier after the appointments than children older than 12, and longer duration of care at the clinic (for parents and carers only) and longer duration of diabetes being less likely to have happier after an appointment.

After adjusting for age, duration of care (for parent and carer responses) and duration of diabetes, the analysis identified 13 aspects of clinic appointments associated with more positive feelings following clinic visits for children and young people, and 16 aspects for parents and carers (see the appendix to the report for details).

Tables 3a and 3b show the top five aspects of care after adjustments where the most positive agreements with the statements were significantly associated ( $p$ -value < 0.05) with more positive feelings following clinic appointments, ranked by cumulative odds ratio (COR) for children and



young people, and parents and carers, respectively. The complete table of aspects of care with significant associations with more positive feelings is available in the appendix to this report. A COR larger than 1 means respondents who answered positively to the question (“Yes, always” and “Yes, definitely”) were more likely to report more positive feelings after their appointments.

Both children and young people with diabetes and their parents and carers were more likely to feel very happy after a clinic visit if they agreed that they always had a positive relationship with the diabetes team, and that their individual needs were definitely understood by the clinical team.

**Table 3a: Top five aspects of care positively associated with positive feelings following clinic appointments. Ordinal regression analysis output from children and young people’s responses, 2021**

	Cumulative Odds Ratio*	95% Confidence Interval**	p-value**
<b>Characteristics</b>			
Younger than 12 years old	1.65	1.40 - 1.94	<0.001
Duration of diabetes - 10 years or more	0.78	0.63 - 0.97	0.027
<b>Aspects of clinic appointments</b>			
Positive relationship with the diabetes team	2.68	2.21 - 3.25	<0.001
The diabetes team understands my individual needs	2.17	1.82 - 2.57	<0.001
The clinic has an age-appropriate waiting area	1.73	1.51 - 1.99	<0.001
The diabetes team talks in a way I can understand	1.69	1.42 - 2.01	<0.001
The diabetes team supports the whole family	1.63	1.41 - 1.90	<0.001

**Table 3b: Top five aspects of care positively associated with positive feelings following clinic appointments. Ordinal regression analysis output from parent and carer responses, 2021**

	Cumulative Odds Ratio*	95% Confidence Interval**	p-value***
<b>Characteristics</b>			
Younger than 12 years old	1.16	1.04 - 1.29	0.006
Duration of care at the clinic - 10 years or more	0.63	0.51 - 0.79	<0.001
Duration of care at the clinic - More than 5 years but less than 10 years	0.61	0.52 - 0.71	<0.001
Duration of care at the clinic - More than 2 years but less than 5 years	0.74	0.64 - 0.87	<0.001
<b>Aspects of clinic appointments</b>			
The diabetes team understands us and our individual needs	2.76	2.29 - 3.33	<0.001
I have a positive relationship with our diabetes team	2.49	2.00 - 3.09	<0.001
The diabetes team keeps us up-to-date with new technologies	1.73	1.53 - 1.96	<0.001
The diabetes team supports the whole family	1.65	1.45 - 1.89	<0.001
I am able to get appropriate advice from the hospital 24 hours a day	1.64	1.46 - 1.85	<0.001

\*An odds ratio is a measure of the strength of association with an exposure and an outcome.

\*\*There is a 95% probability that the 95% confidence interval calculated from a given future sample will cover the true value of the population parameter.

\*\*\* p-values < 0.05 were considered statistically significant.

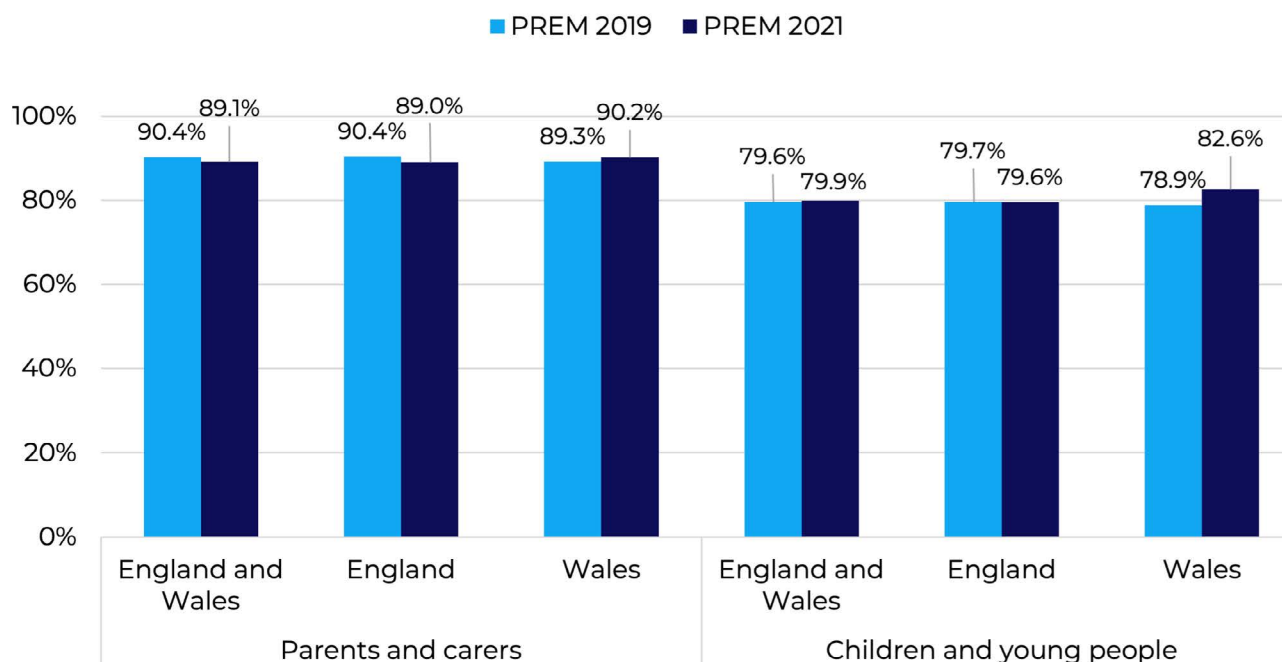
## 7.15 Friends and family test

Respondents were asked to consider the following statement when thinking about their child's care/their own care over the previous six months:

Q. I would recommend my/our diabetes team to a friend or other family with a child who has diabetes

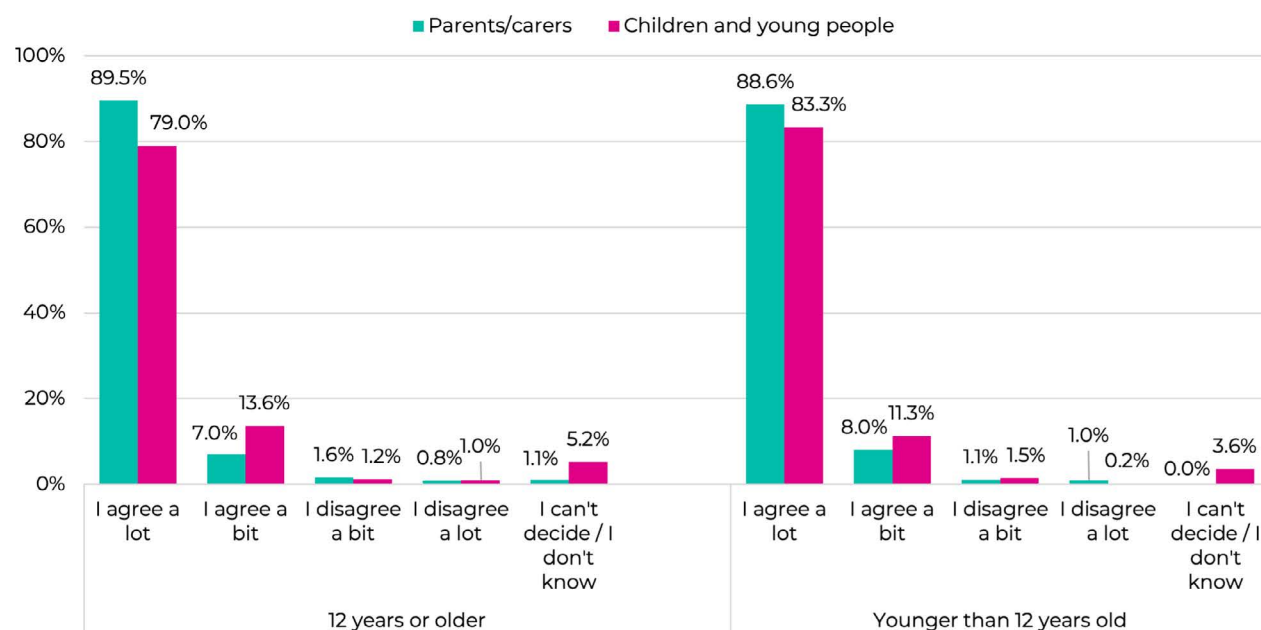
- i) I agree a lot
- ii) I agree a bit
- iii) I disagree a bit
- iv) I disagree a lot
- v) I can't decide/ I don't know

Figure 29 shows that over three quarters of children and young people and a higher proportion of parents and carers agreed 'a lot' that they would recommend their team in 2021, similarly to respondents in 2019.



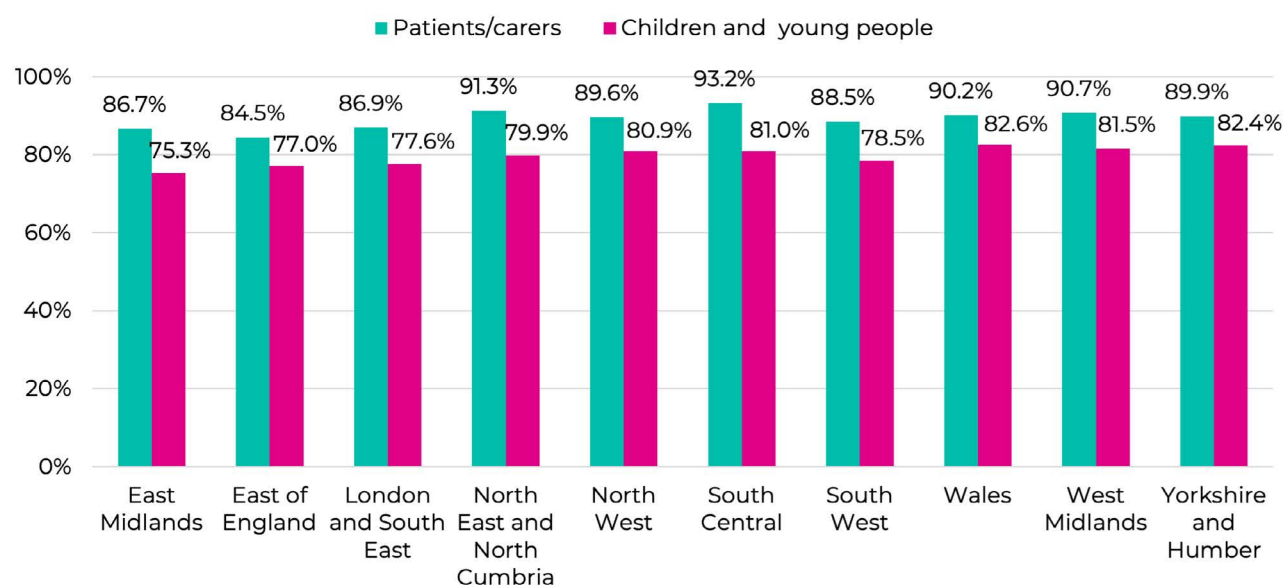
**Figure 29: “I would recommend my/our diabetes team to a friend or other family with a child who has diabetes”. Percentages of ‘I agree a lot’ responses by country and overall, 2019 and 2021**

Figure 30 shows similar levels of satisfaction amongst children or parents of children younger than 12 years old, or 12 years and older.



**Figure 30: “I would recommend my/our diabetes team to a friend or other family with a child who has diabetes”. Responses from children/young people (CYP) and parents/carers (P/C), by age group, 2021**

Figure 31 shows similar levels of satisfaction across regional networks.



**Figure 31: “I would recommend my/our diabetes team to a friend or other family with a child who has diabetes”. Percentage of children/young people (CYP) and parents/carers (P/Cs) responding “I agree a lot”, by regional network**

## 7.16 Overall PREM score

An overall PREM score was constructed to facilitate comparison of performance between PDUs. The scores were calculated from a selection of questions measuring performance or experience, with clear positive or negative response options, and where scoring was found to be reliable during psychometric analysis. The questions included are shown in Table 4.

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 be 100%, which would be achieved if all respondents responded to each question with the most positive response possible for each.

The formula for calculating the PREM score is as below:

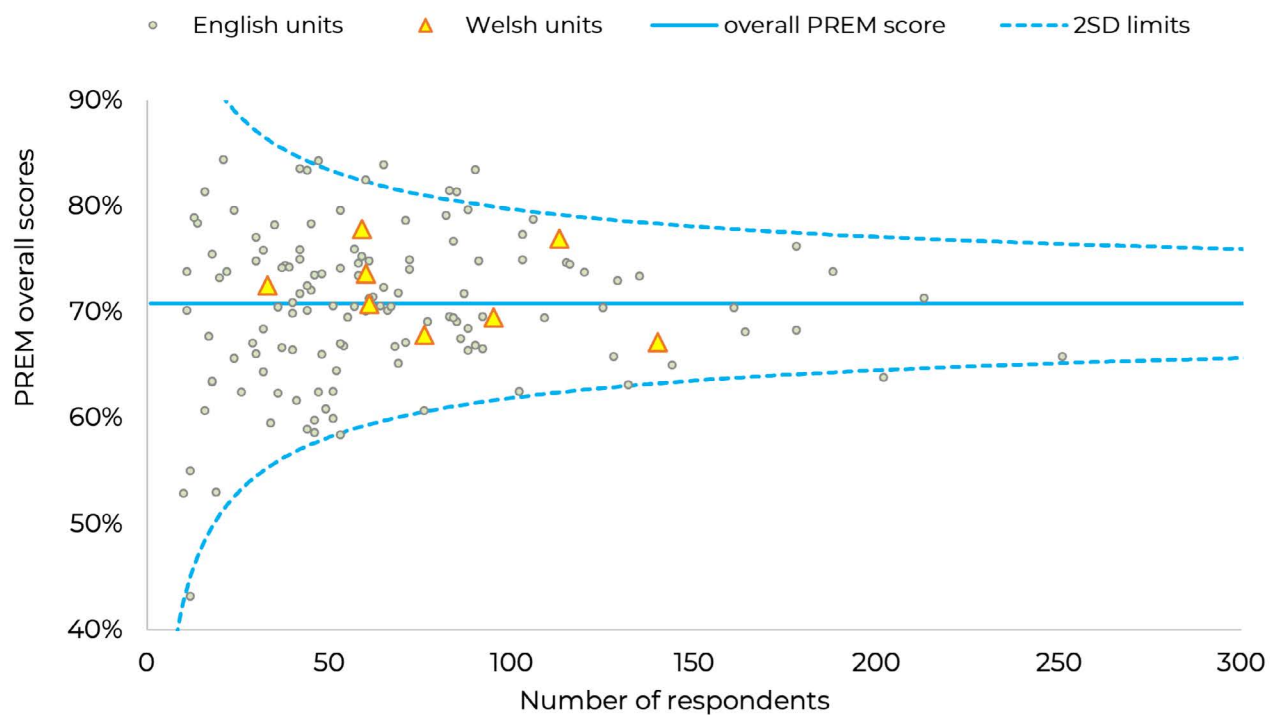
PREM score = No. of most positive responses / No. of total responses (excluding “Not applicable”) \* 100%

**Table 4: PREM scores based on the responses of children/young people (CYP), parents/carers (P/Cs) and overall, by country**

	Overall PREM score		Children and young people score		Parents and carers score	
	2019	2021	2019	2021	2019	2021
England and Wales	70.1%	70.8%	69.0%	71.3%	71.2%	70.3%
England	69.5%	70.7%	69.0%	71.2%	70.9%	70.2%
Wales	70.1%	71.6%	68.1%	72.2%	71.2%	71.1%

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.

Figure 32 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.

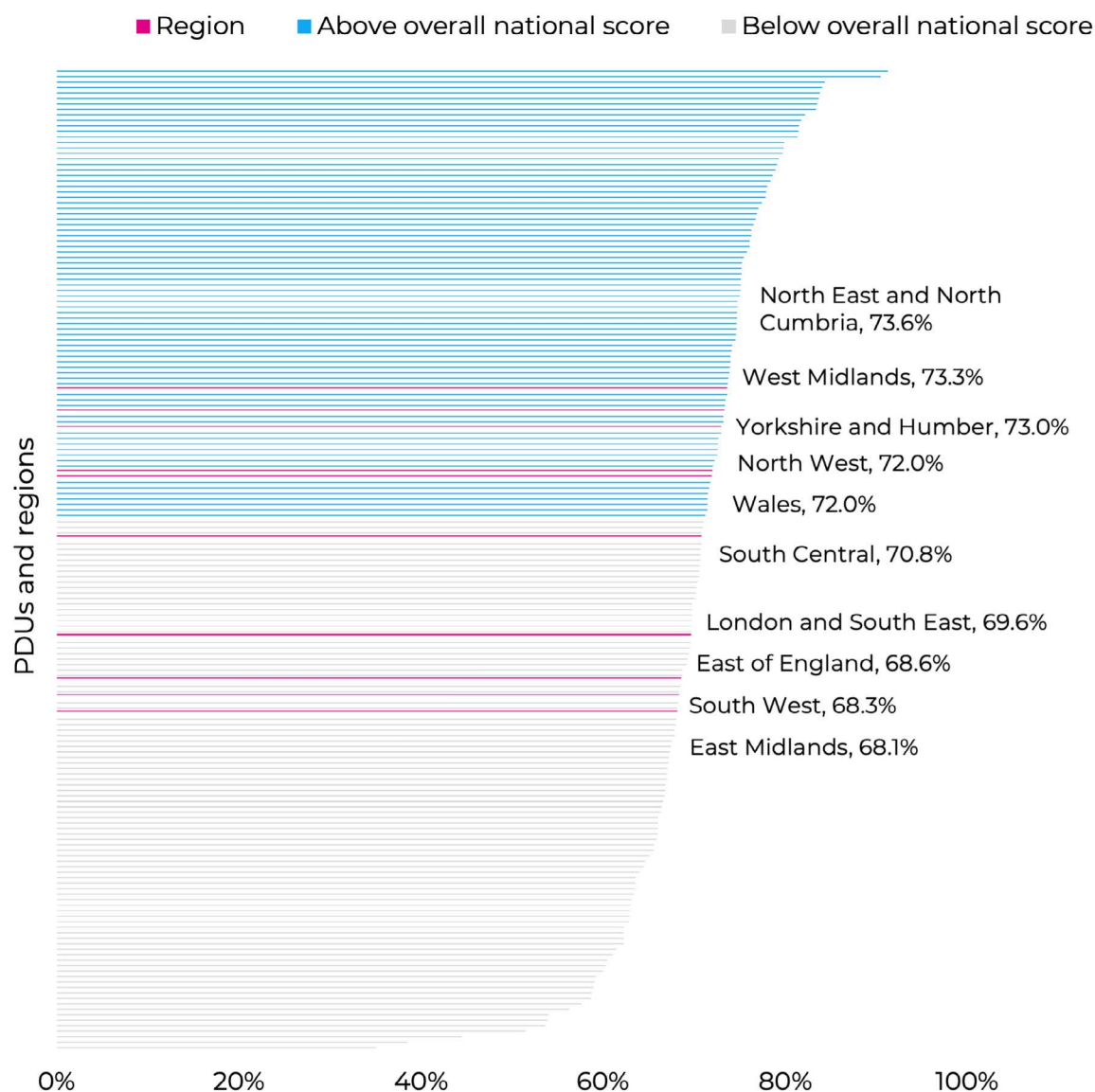


**Figure 32: Funnel plot of overall PREM score per paediatric diabetes unit and overall, 2021**

Figure 33 shows that unlike PDU scores, there was little variation at regional network level, with overall scores by region ranging from 68.1% to 73.6%.



**Figure 33: Overall PREM scores by children and young people, parents and carers, and overall, by regional network, 2021**



**Figure 34: Overall PREM scores by PDU and regional network, 2021**

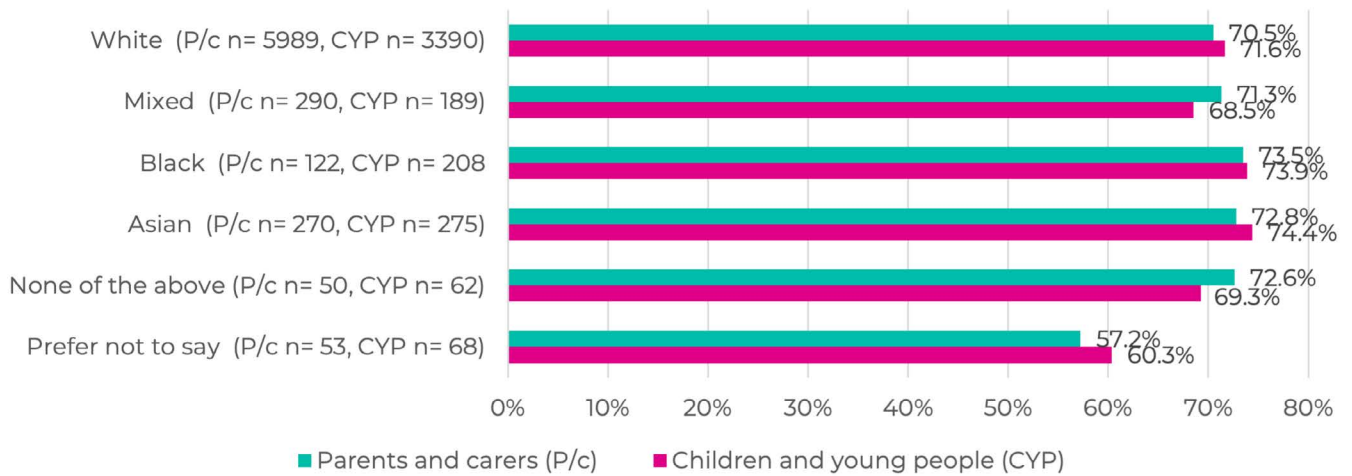
Table 2 in the appendix to this report shows the questions included in the calculation of the overall PREM scores, and the overall responses received against each one. They have been grouped into six “principles of person-centred care” as defined by The Picker Institute when developing the PREMs.

For parents and carers, the areas with lowest scores were access to a psychologist (11.4%) or a dietitian (41.1%), followed by the provision of information and advice on glucagon preparation and when to use it (46.9%), information on insulin pumps (60.8%), information and advice on managing emotional wellbeing (61.5%), and the existence of an age-appropriate waiting area within the clinic (60.2%).

For children and young people, the areas with lowest scores were information on managing emotional wellbeing (56.7%), insulin pumps (58.8%), exercise (58.6%) and ketone monitoring (59.4%).

## 7.16.1 PREM scores by ethnic group

Figure 35 provides a breakdown of overall PREM scores by ethnic group. It shows similar scores across all ethnic groups with the exception of children and young people and parents and carers who did not disclose this information, who had overall lower scores than those who did.



**Figure 35: Children and young people's and parents and carers' overall PREM scores, by ethnic group, 2021**



## 8. Qualitative analysis

The 2021 PREM contained two optional open ended questions asked of both parents and carers and children and young people. These were also asked in 2019, however the 2021 clarified that the questions applied to face-to-face, video call or phone call appointments since the latter two had been introduced to routine paediatric diabetes care since the start of the pandemic:

**1) What do you find helpful about your appointments with the diabetes team? (appointments being either face to face or via a video/phone call)**

**2) What could your diabetes team do to make your appointments with the diabetes team better? (appointments being either face to face or via a video/phone call).**

### 8.1 Analysis methodology

Unlike PREM 2019, when a quantitative thematic analysis was performed on the data by analysts within the NPDA team, the 2021 qualitative data was subjected to a machine learning analysis. This involved feeding the comments received through a programme developed to identify the overall sentiment of each comment, detecting common categories within the data, and fragmenting each comment into different categories where applicable. The themes and sub themes generated from the data by the machine learning programme were reviewed by the NPDA team, and a second iteration of the analysis was performed to refine the themes and sub themes according to the context in which they were made. The themes and sub themes were then refined further, manually, to ensure they were applicable to the questions, or to combine sub themes which overlapped semantically (e.g., “Doctor” and “Consultant”).

The output produced by the programme enabled quantification of comments within each theme and sub theme identified. Sub themes were included if a minimum of 20 comments applied to them.

### 8.2 Qualitative results

#### 8.2.1 What do you find helpful about your clinic visits?

##### **Children and young people’s responses**

Of the 4,177 children and young people attending paediatric diabetes services completing a survey, 2477 (59.3%) provided a response to this question.

##### **Assistance (n=952/38.4%)**

Over a third of children and young people’s responses referenced the assistance given to them during their appointment, with six subthemes present within these responses.

Subtheme	n	% of comments within theme
Help	406	42.6%
Questions	183	19.2%
Advice	158	16.6%
Information	116	12.2%
Concerns	50	5.3%
Issues	29	3.0%

"I always learn something new that can help me at my appointments." (*Help*)

"Good to be able to talk through any questions which arise as I learn to cope with diabetes." (*Questions*)

"Give you the opportunity to ask for advice and guidance." (*Advice*)

"They are very kind and thorough with the information they are telling me and help a lot with learning about my diabetes." (*Information*)

"They always take my questions and concerns seriously!" (*Concerns*)

"They always know how to help if I have an issue." (*Issues*)

### Modality of appointment (455, 18.6%)

Nearly a fifth of children and young people's responses to this question highlighted the nature of the appointments, with the majority expressing a preference for face-to-face appointments.

Subtheme	n	% of comments within theme
Face-to-face	387	85.1%
Video call	35	7.7%
Phone call	33	7.3%

"I feel like I have a much better understanding when at a face to face meeting since there is more conversation and better connection". (*Face-to-face*)

"It's good to review my pump settings face to face and discuss any concerns I may have." (*Face-to-face*)

"Video-phone call because I don't have to wait an hour to see them before only talking for about 10 minutes." (*Video call*)

"Phone call so I don't have to come out of school." (*Phone call*)

### Support from staff team (n=407, 16.6%)

The third most prominent theme amongst responses to this question from children and young people was the support received from the staff team at their appointments.

Subtheme	n	% of comments within theme
Helpful	201	49.4%
Support/reassurance	144	35.4%
Understanding	57	14.0%

"Being helpful and answering all my questions and very friendly." (*Helpful*)

"It is like seeing family. They know me well and collaborate well to answer questions/ plan next steps etc. They are very supportive and pro active." (*Support/reassurance*)

"There are nice and understanding." (*Understanding*)

## 8.2.2 What do you find helpful about your appointments with the diabetes team? Parent and carer responses

Of the 6,789 parents and carers completing a survey, 4234 (62.4%) provided a response to this question.

### Assistance (n= 1728, 40.8%)

Similarly to the responses from children and young people, the most prominent theme amongst parent and carer responses was the assistance they received during their appointments, with seven sub themes identified within this theme.

Subtheme	n	% of comments within theme
Advice	443	25.6%
Help	436	25.2%
Questions	367	21.2%
Concerns	169	9.8%
Information	139	8.0%
Issues	128	7.4%
Contact	46	2.7%

"It can be really lonely and scary being the parent of Type 1 child, and it makes me feel less alone, encourages me that things are going ok, and offers advice on how to better control his diabetes" *(Advice)*

"Always there to help no matter what time of day" *(Help)*

"Good opportunity to ask questions and discuss latest downloads." *(Questions)*

"That they are open for us to raise any concerns and they provide us with helpful guidance." *(Concerns)*

"It gives us more information and confidence." *(Information)*

"It gives an opportunity to discuss present/future issues." *(Issues)*

"That there is always someone available to be contacted should they need occur and they are always able and willing to help." *(Contact)*

### Support from the staff team (n=1305, 30.8%)

Almost a third of parents and carers responding to this question highlighted the support received from the staff team as being a helpful aspect of their appointments.

Subtheme	n	% of comments within theme
Support/reassurance	635	48.7%
Helpful	495	37.9%
Understanding	121	9.3%
Care	36	2.8%

The team are always supportive and never make us feel bad when things don't go to plan. *(Support)*

They are always so helpful and understanding, like an addition to the family. *(Helpful)*

Just the friendly and understanding approach to how hard it is to gain 'perfect' control. *(Understanding)*

Friendly team that ask questions and show they care about my child. *(Care)*

### Modality of appointment (n= 1198, 28.3%)

The third most prominent theme amongst parent and carer responses was the modality of the appointment itself, with face-to-face appointments being highlighted as being helpful in most of these comments.

Subtheme	n	% of comments within theme
Face-to-face	918	76.6%
Video call	140	11.7%
Phone call	140	11.7%

Face to face appointments are much easier to engage all involved, however video calls were a reasonable substitute during the height of the pandemic. (*Face to face*)

Transport (and time off work) is an issue for us so perhaps more video appointments would suit our requirements better. (*Video call*)

My son would probably prefer a phone call, he doesn't like having to go to the hospital.

(*Phone call*)

## 8.2.3 What could your diabetes team do to make your appointments with the diabetes team better? Children and young people's responses

Of the 1886 children and young people who provided a response to this question, 643 (34.1%) commented 'Nothing', 'Not applicable', 'No improvements needed', or similar.

The remaining comments (n= 1243) were too few and disparate to generate more than two main themes.

### Modality of appointment (n=253, 20.2%)

The most prominent theme within the remaining comments was the nature of the appointment, with a fifth of respondents highlighting a preference for a particular style of appointment. Face-to-face appointments were the most common preference expressed.

Subtheme	n	% of comments within theme
Face-to-face	175	76.6%
Video call	41	11.7%
Phone call	37	11.7%

"I understand that the current pandemic is to blame but I much prefer face to face appointments as I find it easier to discuss issues and solve them in person rather than over a video call with internet issues." (*Face-to-face*)

"Definitely video calling because it's hard to concentrate when they're all looking at you asking you things you don't know and how parents always pitch in and embarrass you. Plus, I'm not really one for socialising because I hate attention and at the clinic [their] eyes are all on me." (*Video call*)

"Offer [a] phone call for people who work full time/Have a busy schedule as an option." (*Phone call*)

### Assistance (n=84, 6.7%)

A third (36.9%) of responses within this theme highlighted additional help that could improve the children and young people's appointments.

"Tell me more of what I do right and help me through my wrongs". (*Help*)

"They could maybe talk about other types of technology to help with my diabetes". (*Help*)

Other subtopics identified within the assistance theme were based on fewer than 20 comments.

## 8.2.4 What could your diabetes team do to make your appointments with the diabetes team better?

### Parent and carer's responses

Similarly to children and young people, of the 3554 parents and carers providing a response to this question, 1651 (46.5%) expressed that 'nothing' could make their appointments better, that the question was not applicable, that they were already happy with their appointments, or similar.

### Modality of appointment (n= 700, 19.5%)

A fifth of responses highlighted that the nature of the appointment attended could suit them better, with the majority expressing a preference for face-to-face appointments.

Subtheme	n	% of comments within theme
Face-to-face	441	63.0%
Video call	157	22.4%
Phone call	102	14.6%

"We would like to go back to face to face clinics as [it's] easier to have height, weight blood monitoring taken in one go. (*Face-to-face*)

"I prefer video call appointments it works better around life and especially when having young children you are more able to talk to the team without having to keep the kids occupied at the hospital. This means any worries can be talked over and full focus can be given to the appointment." (*Video call*)

"I like phone appointments a lot because I'm ill myself." (*Phone call*)

### Assistance (n=332, 9.3%)

The second most common theme was 'assistance', with the improvements suggested coming under seven sub themes.

Subtheme	n	% of comments within theme
Help	70	21.1%
Advice	55	16.6%
Information	54	16.3%
Questions	49	14.8%
Issues	48	14.5%
Contact	29	8.7%
Concerns	27	8.1%

"Maybe additional video phone calls, we have a lovely relationship with our nurse and appreciate any extra help." (*Help*)

"Would appreciate if they could look at the Dexcom graphs and offer specific advice." (*Advice*)

"At points we get slightly conflicting information/alternate suggestions dependent on who it is we speak to e.g. changing ratios, keeping his levels higher before bed etc." (*Information*)

"After leaving the consultation I'm leaving with unanswered questions because it feels rushed at times". (*Questions*)

"To be able to discuss more general health issues that are affecting the child outside of their diabetes." (*Issues*)

"More contact in between appointments." (*Contact*)

"Time as a parent to be able to discuss concerns with consultant without child in attendance for fear of upsetting child." (*Concerns*)

### **Staff (n=323, 9.1%)**

Almost a tenth of the comments received referred to a member of the multidisciplinary diabetes team within their suggested improvements.

Subtheme	n	% of comments within theme
Doctor/consultant	132	40.9%
Nurse	98	30.3%
Psychologist	53	16.4%
Dietitian	40	12.4%

"Continuity of clinician we see. Tends to be a different doctor each time, out of three."

(*Doctor/consultant*)

"I would like my child to spend more time with her nurse to gain more confidence and to also be able to speak about her worries and ask her questions". (*Nurse*)

"Offer drop in clinic for dietitian and psychologist. Separate session without child to ask questions that we don't want to ask in front of them". (*Dietitian, Psychologist*)

"To have occasional appointments with a psychologist session attached (for both child and parents separately)." (*Psychologist*)

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# 11. Acknowledgements

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