NPDA
National Paediatric Diabetes Audit

RCPCH Audits

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

Appendix 1 – Full audit analysis

Published by RCPCH June 2025

HQIP
Healthcare Quality Improvement Partnership

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

Contents

1. Extended Analysis

Note: Questions with a denominator of <10 have been masked to protect the confidentiality of respondents, in line with the RCPCH guidance on managing data disclosure risks in public reports and dashboards.

Additionally, numerators <3 in the Characteristics section have been masked.

1.1 Participation

There were a total of **2,712** responses to the First Year of Care PREM which was open from 24th July 2023 and 23rd January 2024. Of these, **1,986 (73%)** were from parents and carers, while **726 (27%)** were from children and young people (CYP) with diabetes. The number of parent/carer responses accounts for **34%** of the 5,861 eligible families of CYP newly diagnosed with diabetes over the 18 months covered by the survey (Table 1).

Table 1 provides a geographic breakdown of the number of responses and participation rates, based on the total number of CYP newly diagnosed with all types of diabetes from 24th January 2022 to 24th July 2023. Participation rates varied regionally, with the South Central regional network showing the highest rate **(44%)** and the East Midlands the lowest **(21%)**.

Table 1: Number of responses to the First Year of Care PREM and participation rates by regional network, country, and overall.

Geographic Region	Number of new diagnoses NPDA*	Total PREM responses	Children and young people (% participation)	Parents and carers (% participation)
England and Wales	5861	2712	726 (12%)	1986 (34%)
Country				
England	5527	2537	685 (12%)	1852 (34%)
Wales	325	175	41 (13%)	134 (41%)
Regional Network				
East Midlands	435	139	47 (11%)	92 (21%)
East of England	649	321	88 (14%)	233 (36%)
London and South East	1323	555	150 (11%)	405 (31%)
North East and North Cumbria	330	149	42 (13%)	107 (32%)
North West	622	363	116 (19%)	247 (40%)
South Central	308	179	44 (14%)	135 (44%)

South West	433	147	28 (6%)	119 (27%)
Thames Valley	231	58	7 (3%)	51 (22%)
West Midlands	637	349	88 (14%)	261 (41%)
Yorkshire and Humber	559	277	75 (13%)	202 (36%)

* Total number of CYP diagnosed with all types of diabetes, from 24th January 2022 to 24th July 2023

Of the 172 PDUs included in the NDPA and eligible to participate, 170 (99%) achieved at least one response to either the child/young person or the parent/carer survey, while two thirds (64%) had more than 10 participants, indicating high levels of engagement (Figure 1).

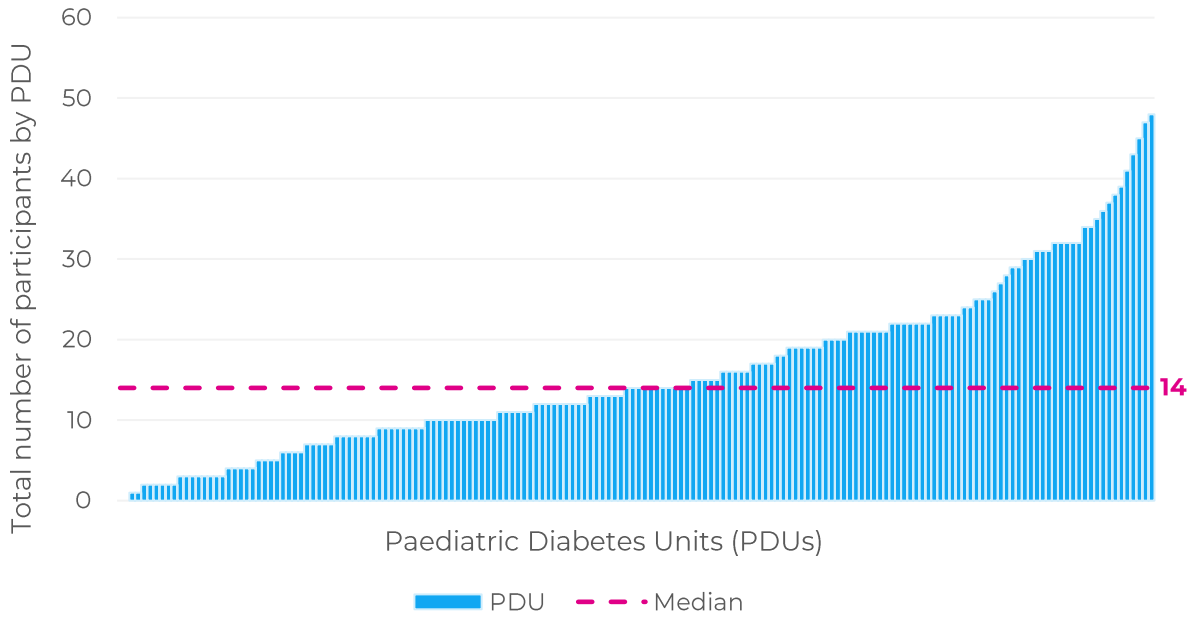


Figure 1: Number of responses (parents and carer and CYP) to the First Year of Care PREM by PDU.

1.2 Characteristics of respondents

The first year of care PREM respondents had similar characteristics in terms of gender, ethnicity, and age compared to all the CYP reported to the NPDA dataset as newly diagnosed with diabetes during the period of analysis (Table 2).

Table 2: Characteristics of respondents to the First Year of Care PREM in England and Wales.

Characteristics	Total PREM responses	Children and young people	Parents and carers	All diagnoses NPDA*
Total	2712	726	1986	5861
Relationship to your child with diabetes				
Mother	-	-	1673 (84%)	-
Father	-	-	268 (13%)	-
Grandmother	-	-	16 (1%)	-
Grandfather	-	-	5 (0%)	-
Other guardian	-	-	24 (1%)	-
Do you identify as a:				
Boy	-	360 (50%)	-	3001 (51%)
Girl	-	354 (49%)	-	2809 (48%)
Gender not listed here/Prefer not to say	-	12 (2%)	-	51 (1%)
How old are you/is your child?				
3 years or younger	187 (7%)	-	187 (9%)	760 (13%)
4 – 7 years	473 (17%)	28 (4%)	445 (22%)	1196 (20%)
8 – 11 years	874 (32%)	207 (29%)	667 (34%)	1900 (32%)
12 – 16 years	1050 (39%)	415 (57%)	635 (32%)	1895 (32%)
17 years or older	128 (5%)	76 (10%)	52 (3%)	110 (2%)
Ethnicity				
White	2167 (80%)	544 (75%)	1623 (82%)	4068 (69%)
Asian	195 (7%)	75 (10%)	120 (6%)	474 (8%)
Black	106 (4%)	37 (5%)	69 (3%)	252 (4%)
Mixed	161 (6%)	44 (6%)	117 (6%)	237 (4%)
None of the above	36 (1%)	10 (1%)	26 (1%)	131 (2%)
Prefer not to say	47 (2%)	16 (2%)	31 (2%)	699 (12%)
How long have you/ your child had diabetes?				
6 – 8 months	627 (23%)	142 (20%)	485 (24%)	-
9 – 11 months	765 (28%)	225 (31%)	540 (27%)	-
12 – 18 months	1277 (47%)	338 (47%)	939 (47%)	-

Not sure	43 (2%)	21 (3%)	22 (1%)	-
What type of diabetes do you/your child have				
Type 1	2603 (96%)	678 (93%)	1925 (97%)	5199 (89%)
Type 2	89 (3%)	41 (6%)	48 (2%)	402 (7%)
Other	20 (1%)	7 (1%)	13 (1%)	260 (4%)
At the time of diagnosis, did you/your child already have a sibling living with diabetes?				
No	2549 (94%)	659 (91%)	1890 (95%)	-
Yes	153 (6%)	64 (9%)	89 (4%)	-
Prefer not to say	10 (0%)	3 (0%)	7 (0%)	-

* Total number of CYP diagnosed with all types of diabetes, from 24th January 2022 to 24th July 2023.

1.3 Care at diagnosis

Respondents were asked whether they/their child experienced DKA at diagnosis and the length of their hospital admission at diagnosis.

44% of respondents reported DKA at diagnosis, which is higher than in the 2022/23 NPDA Report on Care and Outcomes (23.3% in 2022/23). **15%** of respondents were not sure if they or their child had DKA at diagnosis.

The mean admission length at diagnosis was **4.3 days** in England and Wales, with a standard deviation of **2.9 days** (Table 3). Admission length was higher for young children aged 3 years or younger, with a mean length of **5.1 days**. Those reporting diabetic ketoacidosis (DKA) at diagnosis had a mean length of **4.8 days**, compared to **3.4 days** for those without DKA (Table 3).

Table 3: Length of admission and frequency of diabetic ketoacidosis (DKA) at diagnosis by country. This question was asked to both parents/carers and CYP.

	England and Wales (n = 2692)	England (n = 2518)	Wales (n = 174)
When you/your child was first diagnosed, how many nights was their hospital stay in total? Enter '0' if they did not stay overnight when they were first diagnosed.			
Mean (Standard Deviation)	4.3 (2.9)	4.2 (2.9)	5.0(2.3)
Median (Interquartile Range)	4.0(4)	4.0(3)	5.0(3)
Did you/your child have DKA at diagnosis?			
Yes	1181 (44%)	1114 (44%)	67 (39%)
No	1104 (41%)	1023 (41%)	81 (47%)
I'm not sure	408 (15%)	382 (15%)	26 (15%)

In most regions, **more than 10%** of parents and carers and **more than 20%** of children aged 12 years or older were unsure about having DKA at diagnosis, which could be interpreted as a lack of information and awareness about this life-threatening condition at diagnosis.

Figure 2 shows the breakdown of responses for DKA at diagnosis by NHS region.

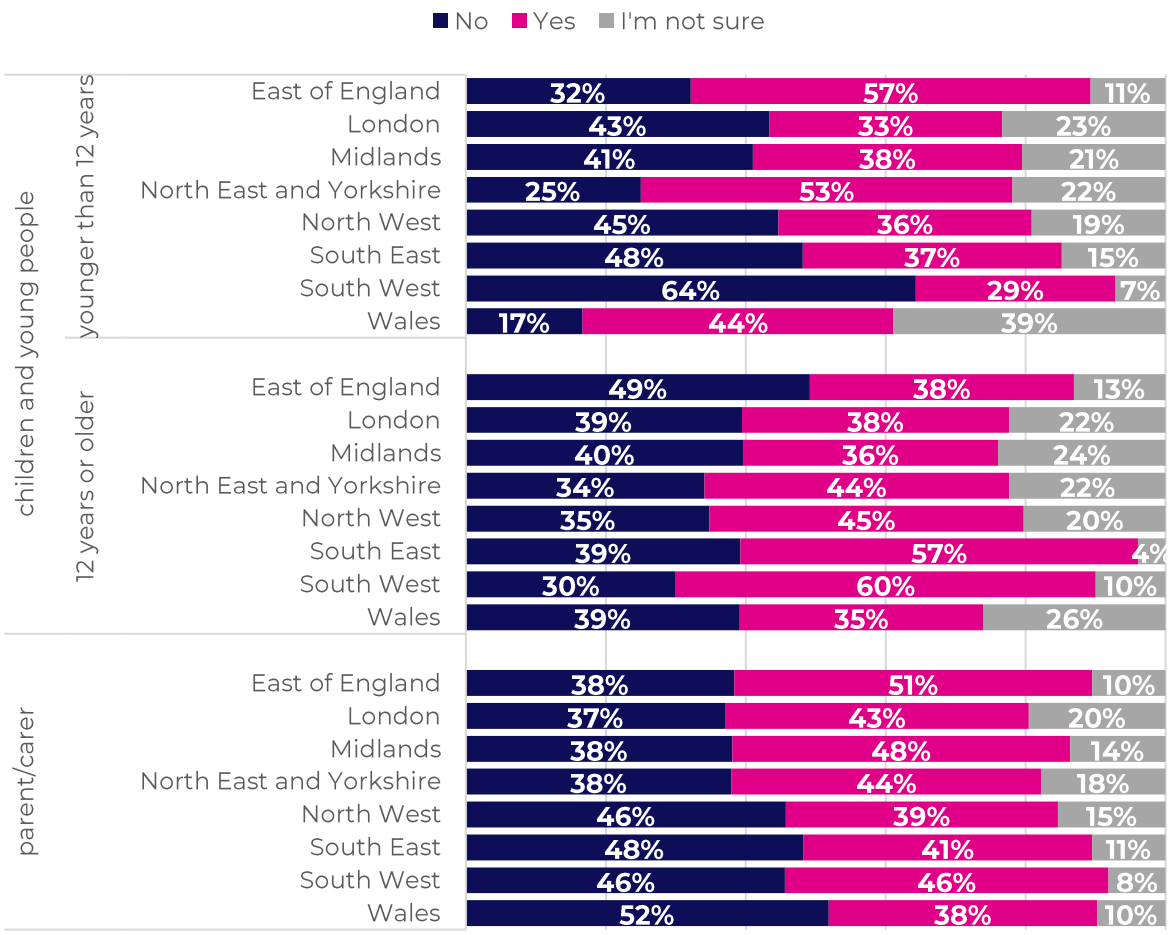


Figure 2: The percentage of parents and carers and CYP reporting DKA at diagnosis, by NHS region.

1.4 The clinic environment

Respondents were asked to rate how age-appropriate their clinic waiting area and their preferred appointment structure with the diabetes team.

93% of parents and carers and **87%** of CYP responded that their clinic 'definitely' or 'to some extent' has a waiting area that is appropriate for their/their child's age, excluding those who answered "I don't know" (Figure 3).

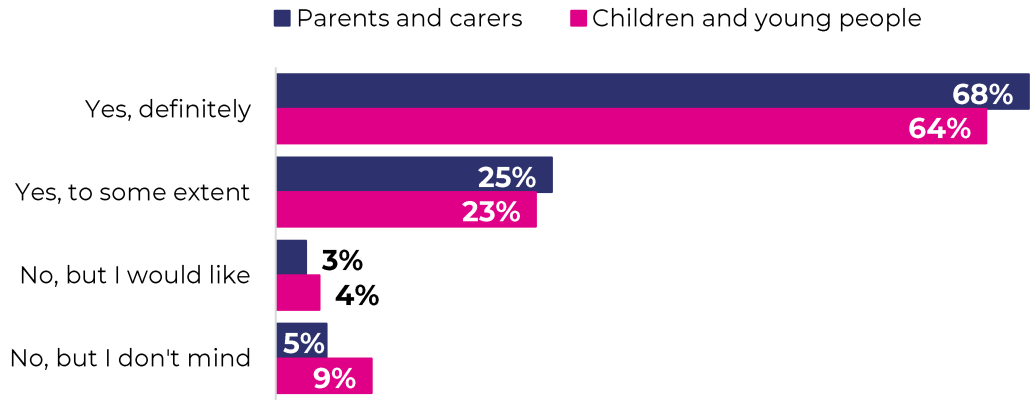


Figure 3: Responses to the statement "The clinic has an area for my child to wait that is appropriate for their age" by respondent, excluding those who answered "I don't know".

When the CYP with diabetes were younger than 12, respondents were more likely to agree that their clinic had an age appropriate waiting room (Figure 4).

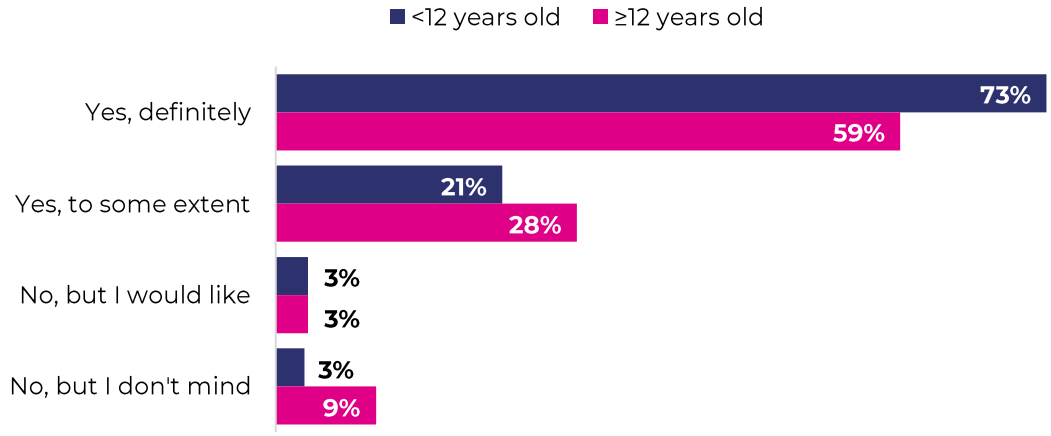


Figure 4: Responses to the statement "The clinic has an area for my child to wait that is appropriate for their age" by age group, excluding those who answered "I don't know".

34% of parents and carers and **26%** of CYP state that they always see their diabetes team together, while **10%** of both groups state that they always see the team separately. Both parents and carers and CYP were happy with the clinic appointment structure, with **81%** of parents and carers and **79%** of CYP receiving their preferred method of consultation (Figure 5).

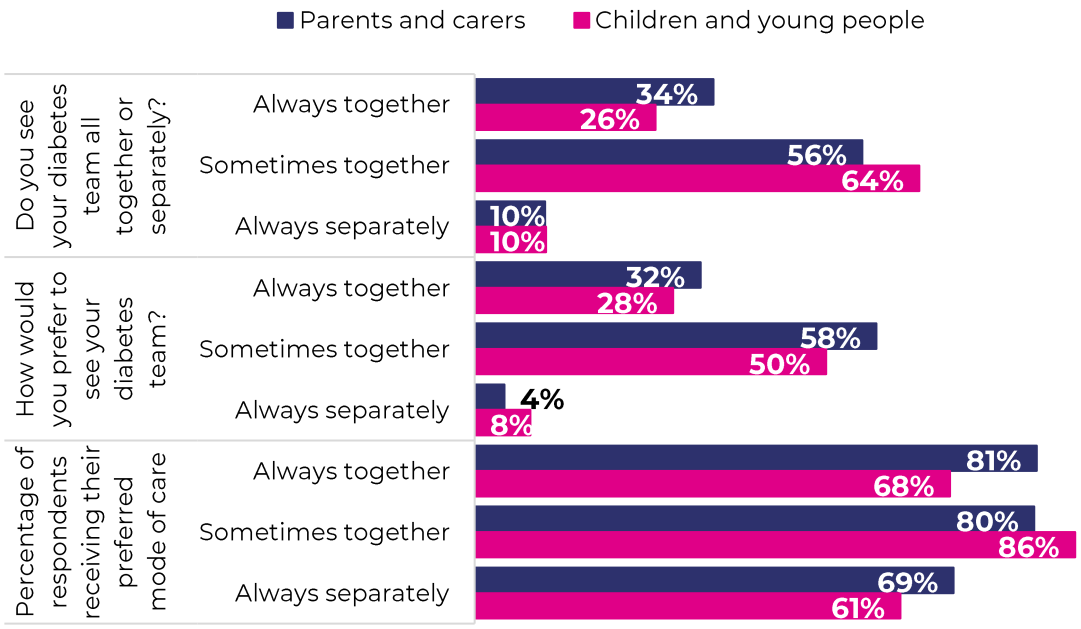


Figure 5: Preference of appointment structure by respondent, excluding those who answered "I don't know".

1.5 Continuity of care

Respondents were asked if they were able to see the same diabetes doctor at each visit.

65% of parents and carers and **54%** of CYP state that they always see the same doctor at each appointment, and this is important to them. **40%** of CYP state that they always see the same doctor, but they don't mind if they are not able to (Figure 6).

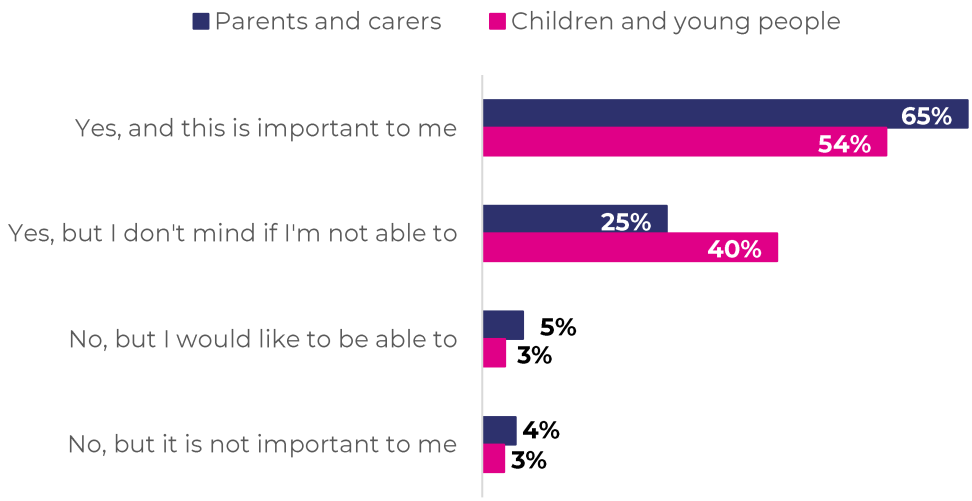


Figure 6: Responses to the statement "We are able to speak to the same doctor at most appointments (virtual or in person)", excluding "Too early to say" or "I don't know" responses, by respondent.

1.6 Multidisciplinary care

Respondents were asked to how often they were able to see each member of their diabetes team.

82% of respondents were able to see a diabetes doctor at each visit, while **84%** could see a children's diabetes specialist nurse (DSN) at each visit. **46%** were able to see a dietitian and **11%** could see a psychologist at each visit (Figure 7). This is similar to the findings of the 2021 PREM.

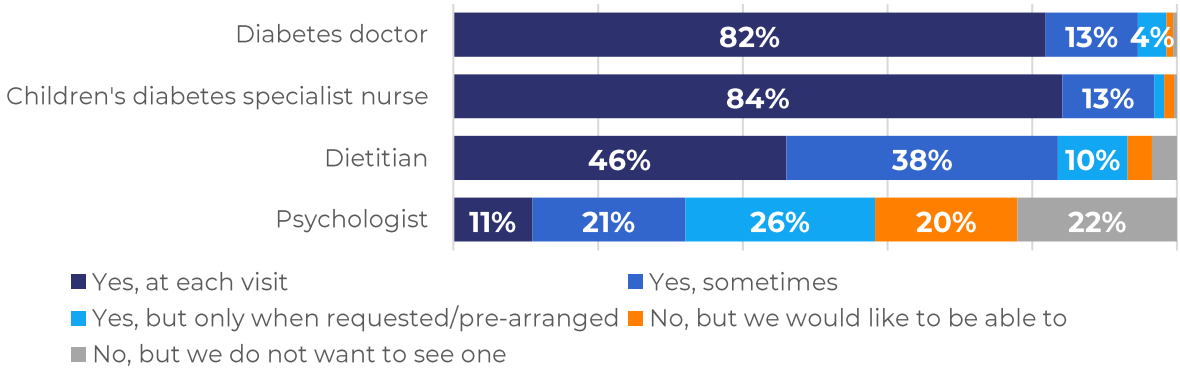


Figure 7: Responses to the question "We are able to see the following members of the team during our appointments with the diabetes team". *This question was only asked to parents and carers.*

Compared to CYP with Type 1 diabetes, CYP with Type 2 diabetes were less likely to be able to see diabetes doctors and specialist nurses at each visit, but more likely to see dietitians and psychologists at each visit (Figure 8).

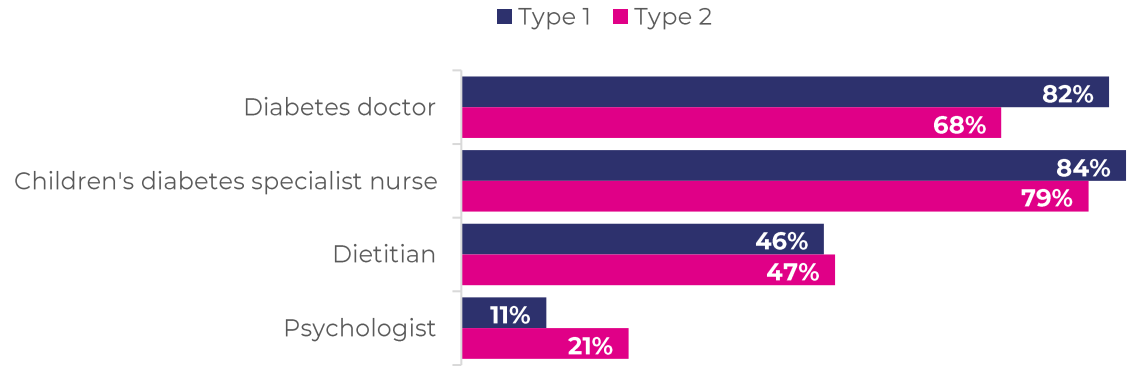


Figure 8: Percentage of respondents answering "*Yes, at each visit*" to seeing each diabetes team member, excluding "*I don't know*" responses, by diabetes type.

Access to a psychologist at every visit ranged from **0%** to **48%** at ICB (England) and LHB (Wales) level. Table 4 shows results by country, while Table 5 shows a heatmap of the percentage of respondents who could see each team member at every visit by ICB and LHB.

Table 4: Responses to the question "*We are able to see the following members of the team during our appointments with the diabetes team*" by multidisciplinary team (MDT) member. This question was only asked to parents and carers.

	England and Wales (n = 1891)	England (n = 1761)	Wales (n = 130)
Children's diabetes specialist nurse			
Yes, at each visit	1585 (84%)	1467 (83%)	118 (91%)
Yes, sometimes	239 (13%)	228 (13%)	11 (8%)
Yes, but only when requested/pre-arranged	26 (1%)	25 (1%)	1 (1%)
No, but we would like to be able to	26 (1%)	26 (2%)	0 (0%)
No, but we do not want to see one	7 (0%)	7 (0%)	0 (0%)
I don't know	8 (0%)	8 (1%)	0 (0%)
Dietitian			
Yes, at each visit	854 (45%)	791 (45%)	63 (48%)
Yes, sometimes	696 (37%)	642 (36%)	54 (42%)
Yes, but only when requested/pre-arranged	179 (9%)	170 (10%)	9 (7%)
No, but we would like to be able to	62 (3%)	59 (3%)	3 (2%)
No, but we do not want to see one	64 (3%)	63 (4%)	1 (1%)
I don't know	36 (2%)	36 (2%)	0 (0%)
Psychologist			
Yes, at each visit	191 (10%)	178 (10%)	13 (10%)
Yes, sometimes	370 (20%)	344 (20%)	26 (20%)
Yes, but only when requested/pre-arranged	457 (24%)	428 (24%)	29 (22%)
No, but we would like to be able to	344 (18%)	316 (18%)	28 (22%)
No, but we do not want to see one	385 (20%)	362 (21%)	23 (18%)
I don't know	144 (8%)	133 (8%)	11 (8%)
Diabetes Doctor			
Yes, at each visit	1530 (81%)	1433 (81%)	97 (75%)
Yes, sometimes	238 (13%)	212 (12%)	26 (20%)
Yes, but only when requested/pre-arranged	74 (4%)	70 (4%)	4 (3%)
No, but we would like to be able to	17 (1%)	15 (1%)	2 (1%)
No, but we do not want to see one	10 (1%)	10 (1%)	0 (0%)
I don't know	22 (1%)	21 (1%)	1 (1%)

Table 5: Heatmap of the percentage of respondents who were able to see each member of the MDT at each visit, by Health Board and ICB.

* An asterisk (*) indicates fewer than 10 responses, which have been suppressed to protect confidentiality.

0% to 25% | 25% to <50% | 50% to <75% | 75% to 100%

NHS region	ICB/LHB	Diabetes doctor	Diabetes nurse	Dietitian	Psychologist
East of England	Bedfordshire, Luton and Milton Keynes	74%	74%	35%	6%
	Cambridgeshire and Peterborough	67%	92%	31%	0%
	Hertfordshire and West Essex	92%	77%	46%	4%
	Mid and South Essex	90%	87%	60%	7%
	Norfolk and Waveney	85%	85%	35%	6%
	Suffolk and North East Essex	65%	88%	46%	4%
London	North Central London	69%	78%	51%	20%
	North East London	90%	76%	21%	3%
	North West London	60%	84%	37%	22%
	South East London	86%	81%	58%	20%
	South West London	100%	98%	60%	15%
Midlands	Birmingham and Solihull	89%	85%	51%	14%
	Black Country	63%	86%	46%	6%
	Coventry and Warwickshire	77%	96%	60%	19%
	Derby and Derbyshire	83%	83%	49%	12%
	Herefordshire and Worcestershire	78%	96%	63%	8%
	Leicester, Leicestershire and Rutland	100%	67%	60%	0%
	Lincolnshire	*	*	*	*
	Northamptonshire	100%	70%	50%	11%
	Nottingham and Nottinghamshire	73%	89%	26%	15%
	Shropshire, Telford and Wrekin	93%	63%	50%	14%
	Staffordshire and Stoke-On-Trent	95%	100%	25%	25%
North East and Yorkshire	Humber and North Yorkshire	81%	81%	51%	4%
	North East and North Cumbria	81%	86%	42%	25%
	South Yorkshire	85%	82%	30%	5%
	West Yorkshire	90%	91%	59%	8%
North West	Cheshire and Merseyside	87%	84%	48%	14%
	Greater Manchester	79%	86%	43%	2%
	Lancashire and South Cumbria	90%	96%	54%	11%
South East	Buckinghamshire, Oxfordshire and Berkshire West	88%	73%	34%	21%
	Frimley	70%	65%	39%	3%
	Hampshire and Isle Of Wight	82%	73%	51%	4%
	Kent and Medway	55%	84%	43%	2%
	Surrey Heartlands	92%	88%	56%	28%
	Sussex	94%	89%	65%	15%
South West	Bath and North East Somerset, Swindon and Wiltshire	88%	97%	29%	0%
	Bristol, North Somerset and South Gloucestershire	94%	78%	56%	28%
	Cornwall and The Isles Of Scilly	*	*	*	*
	Devon	97%	61%	14%	0%
	Dorset	94%	82%	53%	13%
	Gloucestershire	90%	80%	60%	0%
	Somerset	93%	93%	93%	0%
Wales	Aneurin Bevan Health Board	74%	89%	32%	0%
	Betsi Cadwaladr University Health Board	65%	85%	50%	6%
	Cardiff and Vale University Health Board	81%	90%	35%	0%
	Cwm Taf Morgannwg University Health Board	65%	94%	56%	4%
	Hywel Dda Health Board	91%	100%	61%	48%
	Swansea Bay University Health Board	*	*	*	*

1.7 Access to technologies

Respondents were asked to consider whether they had been offered different forms of diabetes related technologies by their diabetes team (Table 6).

Table 6: Responses to the question "Have you/Has your child been offered any of the following diabetes related technologies?" by technology and by respondent.

	Total responses (n = 2638)	Children and young people (n = 711)	Parents and carers (n = 1927)
Smart insulin pen			
Yes, and they use one	1708 (65%)	504 (71%)	1204 (62%)
Yes, but they don't want one	402 (15%)	50 (7%)	352 (18%)
No, but they would like to use one	90 (3%)	19 (3%)	71 (4%)
No, but they don't mind	316 (12%)	99 (14%)	217 (11%)
I don't know/can't remember	122 (5%)	39 (5%)	83 (4%)
Insulin pump			
Yes, and they use one	1021 (39%)	215 (30%)	806 (42%)
Yes, but they don't want one	534 (20%)	119 (17%)	415 (22%)
No, but they would like to use one	588 (22%)	183 (26%)	405 (21%)
No, but they don't mind	397 (15%)	149 (21%)	248 (13%)
I don't know/can't remember	98 (4%)	45 (6%)	53 (3%)
Flash glucose monitor			
Yes, and they use one	995 (38%)	342 (48%)	653 (34%)
Yes, but they don't want one	640 (24%)	142 (20%)	498 (26%)
No, but they would like to use one	37 (1%)	9 (1%)	28 (1%)
No, but they don't mind	769 (29%)	162 (23%)	607 (31%)
I don't know/can't remember	197 (7%)	56 (8%)	141 (7%)
Continuous glucose monitor (CGM)			
Yes, and they use one	1797 (68%)	422 (59%)	1375 (71%)
Yes, but they don't want one	171 (6%)	43 (6%)	128 (7%)
No, but they would like to use one	174 (7%)	55 (8%)	119 (6%)
No, but they don't mind	362 (14%)	142 (20%)	220 (11%)
I don't know/can't remember	134 (5%)	49 (7%)	85 (4%)
A hybrid closed loop system (artificial pancreas)			
Yes, and they use one	559 (21%)	118 (17%)	441 (23%)
Yes, but they don't want one	375 (14%)	78 (11%)	297 (15%)
No, but they would like to use one	507 (19%)	136 (19%)	371 (19%)
No, but they don't mind	809 (31%)	243 (34%)	566 (29%)
I don't know/can't remember	388 (15%)	136 (19%)	252 (13%)

68% of CYP were offered and used a smart insulin pen, while 40% used an insulin pump. **23%** were not offered an insulin pump but would like to use one. **41%** used a flash glucose monitor and **72%** used a continuous glucose monitor.

25% used a hybrid closed loop, while **23%** were not offered a hybrid closed loop but would like to use one. (Figure 9)

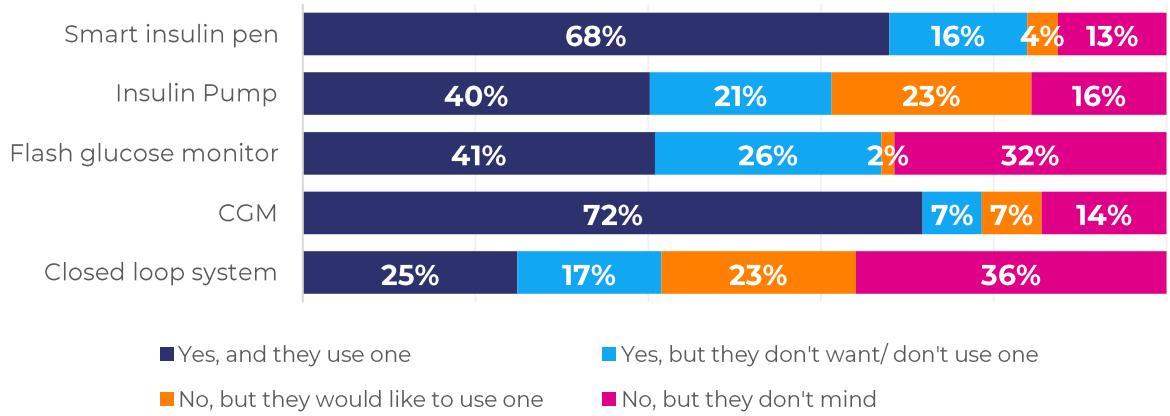


Figure 9: Responses to the question "Have you/Has your child been offered any of the following diabetes related technologies?" by technology, excluding "I don't know" responses. This question was asked to both parents/carers and CYP.

Children under the age of 12 were more likely to be offered an insulin pump and CGM compared to CYP over the age of 12 (Figure 10).

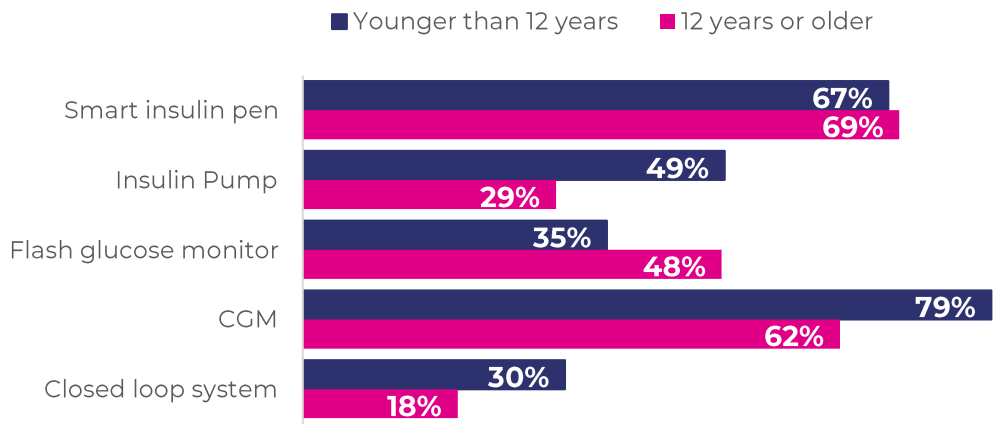


Figure 10: Access to diabetes related technologies by age.

Figure 11 shows the relationship between time since diagnosis and the percentage of "Yes, and they use one" responses to each diabetes related technology.

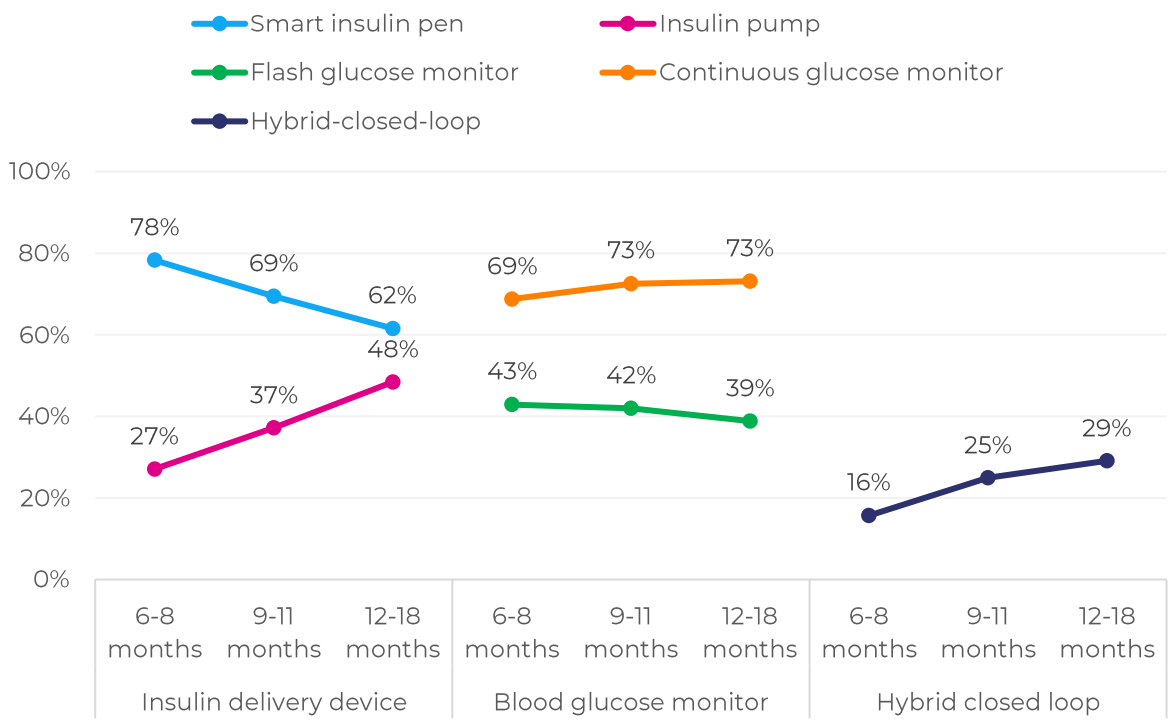


Figure 11: Use of each diabetes-related technologies by time since diagnosis.

Those who had been diagnosed 12-18 months before responding were more likely than those 6-8 months post diagnosis to be using an insulin pump and less likely to be using a smart insulin pen. Time since diagnosis was also related to use of a hybrid closed loop system.

Excluding missing and "I don't know" responses, **2.7%** of CYP were not offered either a flash glucose monitor or CGM and **6.6%** were not using either a flash glucose monitor or CGM.

1.8 Access to diabetes advice

Respondents were asked about how they had received support from their diabetes team and whether they were able to access appropriate advice about their child's advice during office hours and out-of-hours.

The vast majority of respondents (**98%** of parents and carers and **96%** of CYP) had received support via a face-to-face in-person clinic. **85%** of parents and carers also received support through telephone contact and **68%** by email contact (Figure 12).

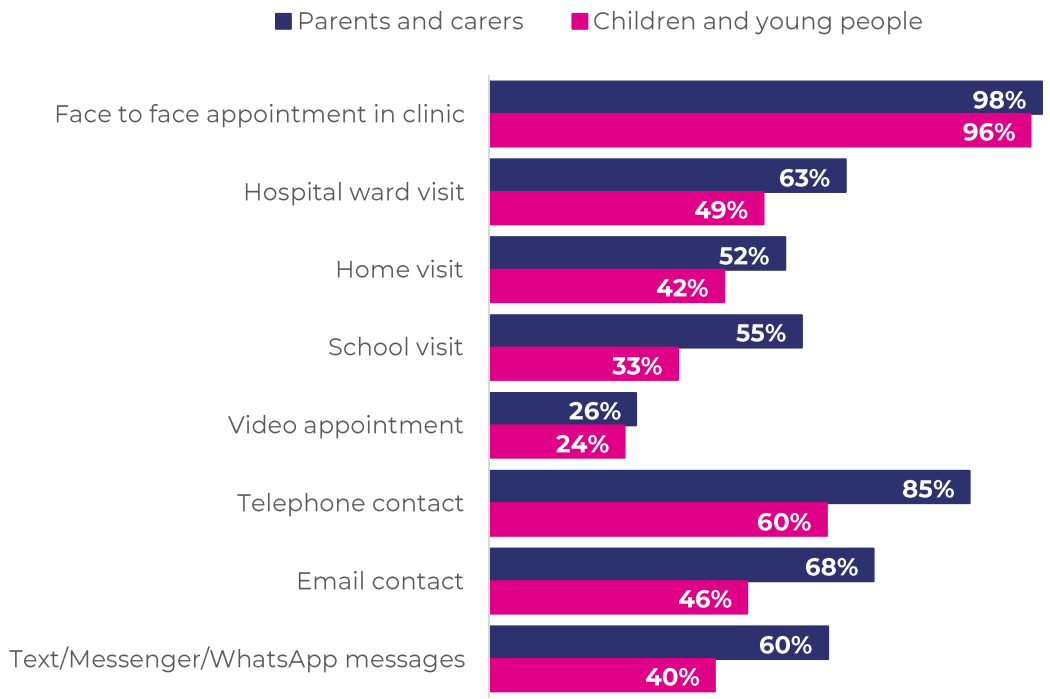


Figure 12: Responses to the question "Since diagnosis of diabetes, how have you received support from your diabetes team members?" by respondent.

Figure 13 shows that 82% of parents and carers could always contact a member of the diabetes team during core hours for advice, while **71%** could get appropriate advice about their child's diabetes from the hospital 24 hours a day.

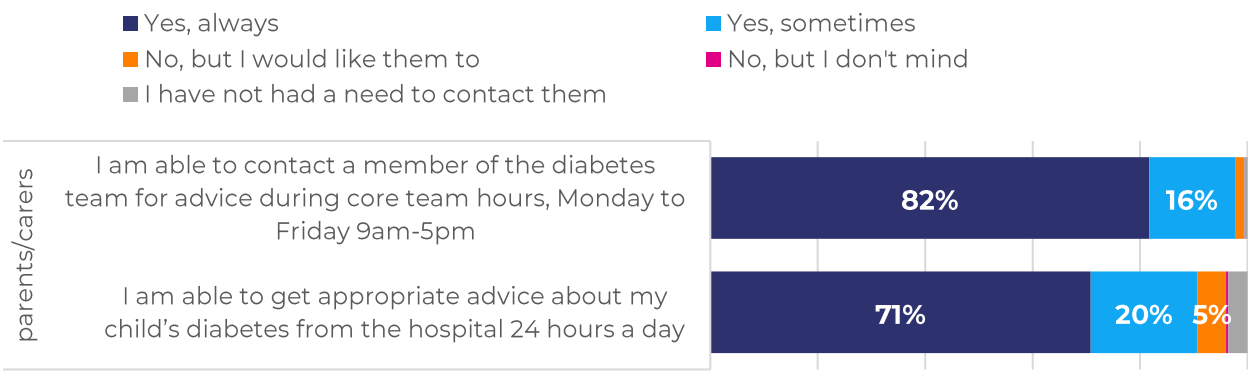
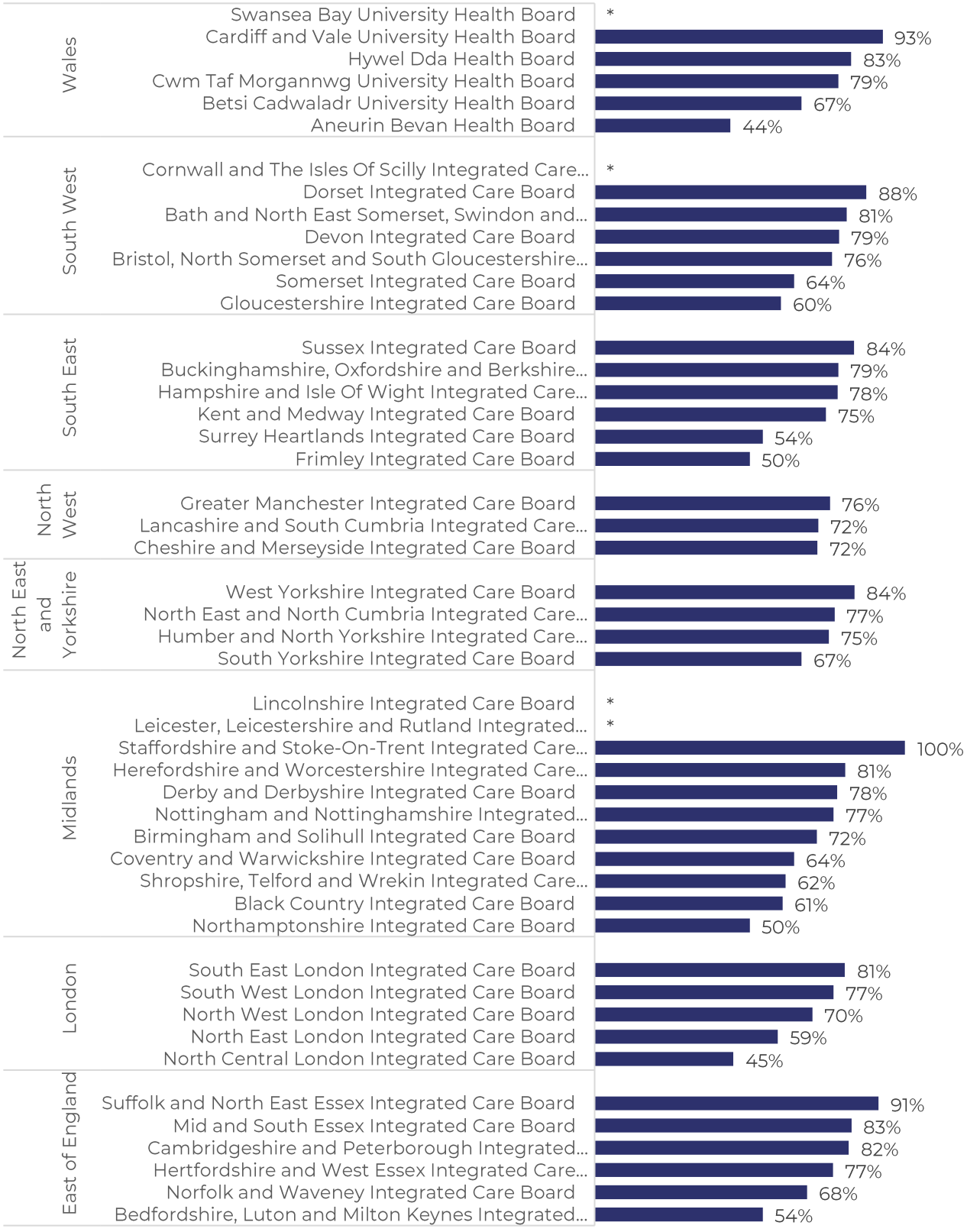


Figure 13: Ability to access diabetes advice. This question was only asked to parents and carers.

Table 7 shows access to out-of-hours advice by country, while Figure 14 shows the percentage of respondents who could access out-of-hours advice in each ICB and LHB.

Table 7: Ability to access diabetes advice. These questions were only asked to parents and carers.

	England and Wales (n = 1834)	England (n = 1710)	Wales (n = 124)
I am able to contact a member of the diabetes team for advice during core team hours, Monday to Friday 9am-5pm			
Yes, always	1497 (82%)	1390 (81%)	107 (86%)
Yes, sometimes	293 (16%)	279 (16%)	14 (11%)
No, but I would like them to	30 (2%)	28 (2%)	2 (2%)
No, but I don't mind	1 (0%)	1 (0%)	0 (0%)
I have not had a need to contact them	11 (1%)	10 (1%)	1 (1%)
I don't know	2 (0%)	2 (0%)	0 (0%)
I am able to get appropriate advice about my child's diabetes from the hospital 24 hours a day			
Yes, always	1290 (70%)	1200 (70%)	90 (73%)
Yes, sometimes	362 (20%)	343 (20%)	19 (15%)
No, but I would like them to	97 (5%)	88 (5%)	9 (7%)
No, but I don't mind	8 (0%)	8 (0%)	0 (0%)
I have not had a need to contact them	65 (4%)	60 (4%)	5 (4%)
I don't know	12 (1%)	11 (1%)	1 (1%)



* An asterisk (*) indicates fewer than 10 responses, which have been suppressed to protect confidentiality.

Figure 14: Ability to access diabetes advice 24 hours a day by Health Board and ICB.

1.9 Relationship with the diabetes team

Respondents were asked to rate their agreement with five statements about their relationship with their diabetes team.

The vast majority answered that they 'always' or 'sometimes' have a positive relationship with their diabetes team. Against all statements, parents and carers rated their relationship more positively than CYP (Figure 15).

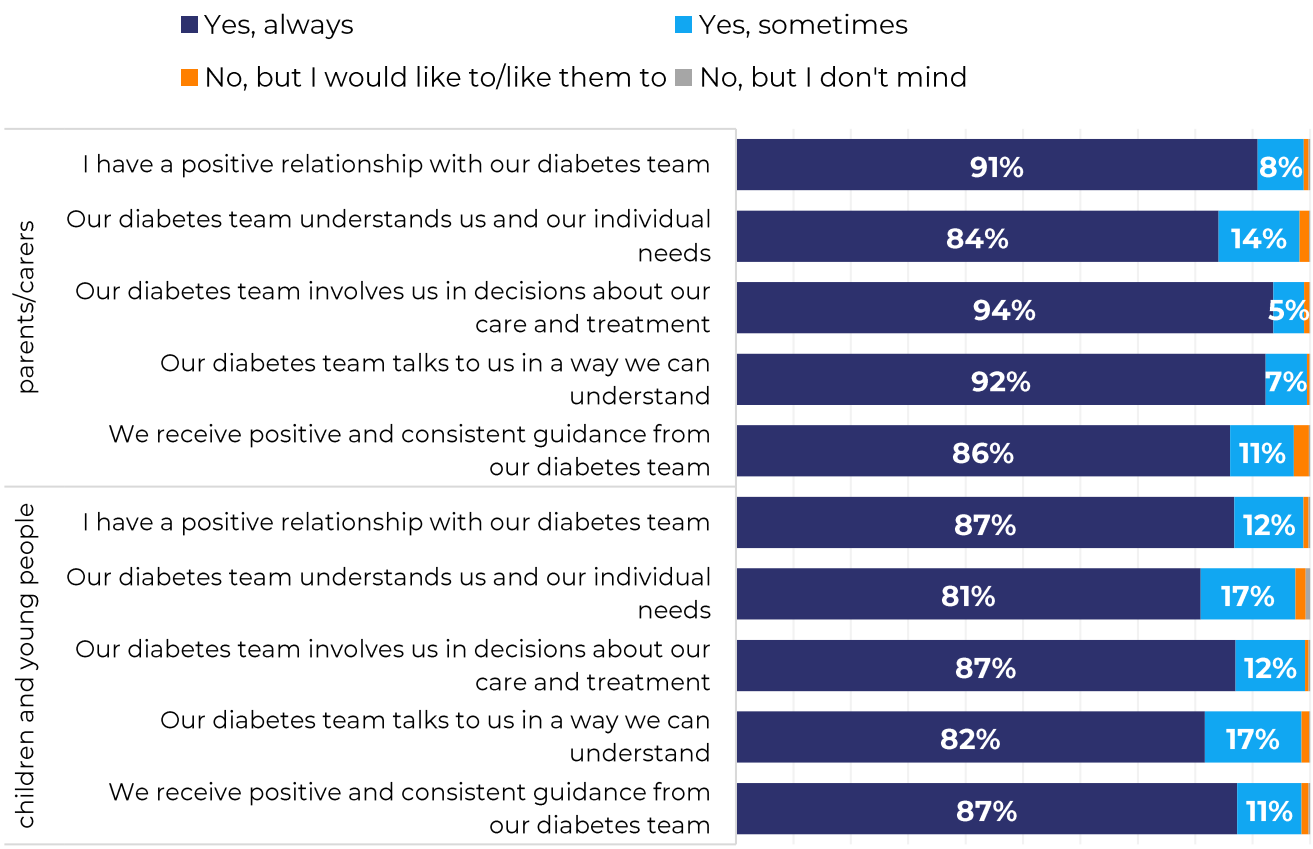


Figure 15: Relationship with the diabetes team by respondent, excluding *"I don't know"* responses.

CYP with Type 2 diabetes typically had lower agreement with each statement (Figure 16).

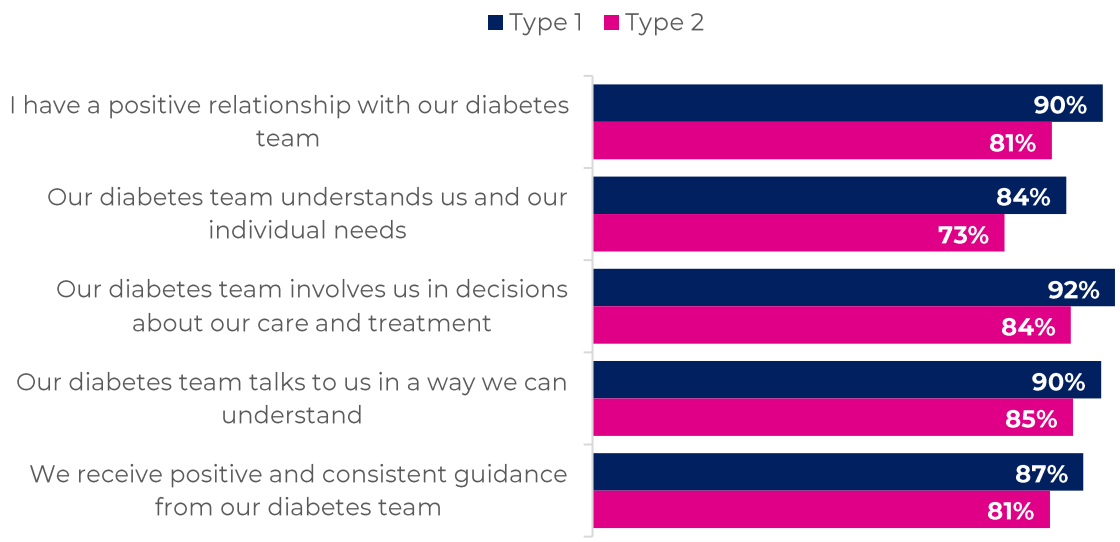


Figure 16: Percentage of respondents answering "*Yes, always*" to each statement about their relationship with the diabetes team, excluding "*I don't know*" responses, by type of diabetes.

White and non-white respondents had similar responses (Figure 17).

Figure 17: Percentage of respondents answering "*Yes, always*" to each statement about their relationship with the diabetes team, excluding "*I don't know*" responses, by ethnicity.

84% of parents and carers and **83%** of CYP responded that their diabetes team always told them their HbA1c result and gave them helpful advice on managing their blood glucose (Figure 18).

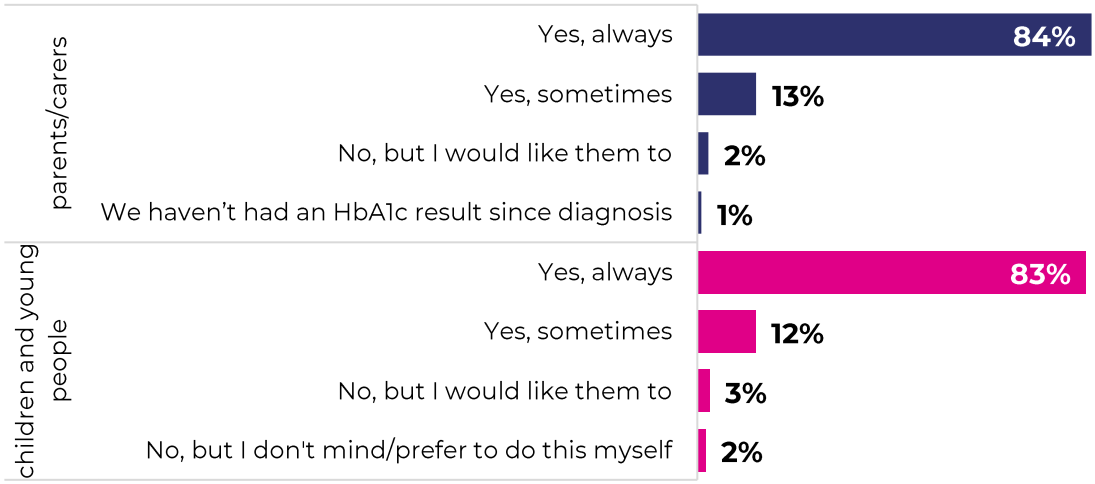


Figure 18: Responses to the statement "Our diabetes team tell me my/my child's HbA1c and use it to give me helpful advice on how to manage their blood glucose levels".

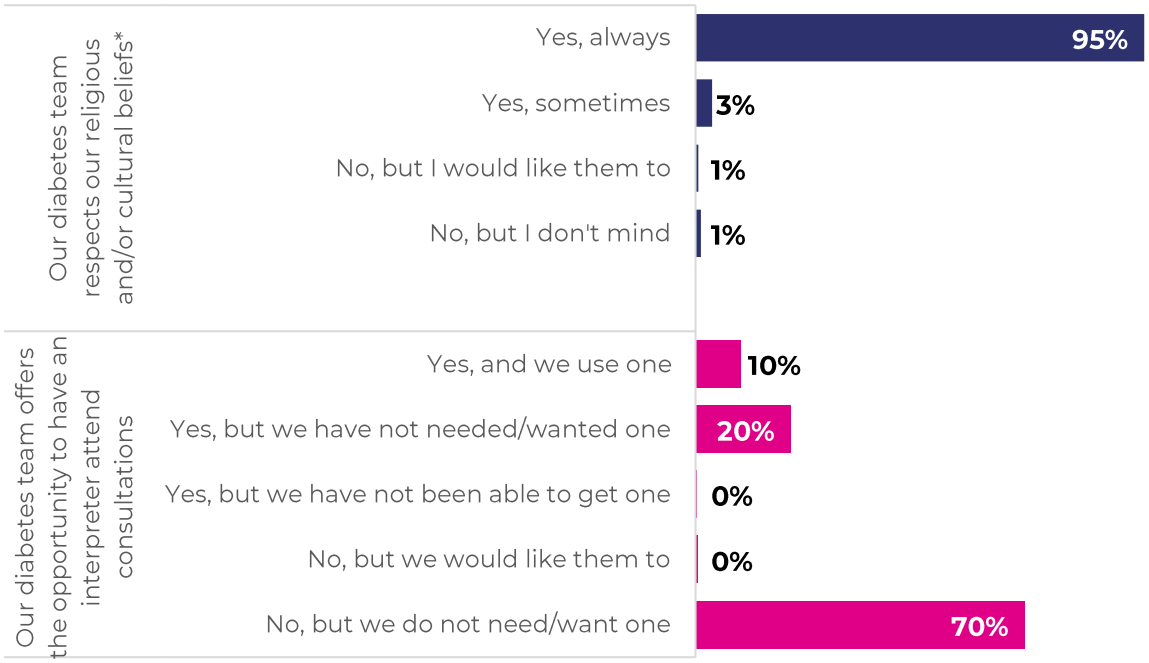
1.10 Culturally competent care

Parents and carers were asked whether their diabetes team respected their religious or cultural beliefs and whether they were offered an interpreter at their consultations (Table 8).

Table 8: Culturally competent care. These questions were only asked to parents and carers.

	England and Wales (n = 1834)	England (n = 1710)	Wales (n = 124)
Our diabetes team respects our religious or cultural beliefs			
Yes, always	1033 (56%)	961 (56%)	72 (58%)
Yes, sometimes	38 (2%)	37 (2%)	1 (1%)
No, but I would like them to	6 (0%)	6 (0%)	0 (0%)
No, but I don't mind	12 (1%)	11 (1%)	1 (1%)
Not applicable	745 (41%)	695 (41%)	50 (40%)
Our diabetes team offers the opportunity to have an interpreter attend our consultations			
Yes, but we have not needed/wanted one	176 (10%)	159 (9%)	17 (14%)
Yes, but we have not been able to get one	369 (20%)	341 (20%)	28 (23%)
Yes, but we have not been able to get one	4 (0%)	4 (0%)	0 (0%)
No, but we would like them to	9 (0%)	9 (1%)	0 (0%)
No, but we do not need/want one	1276 (70%)	1197 (70%)	79 (64%)

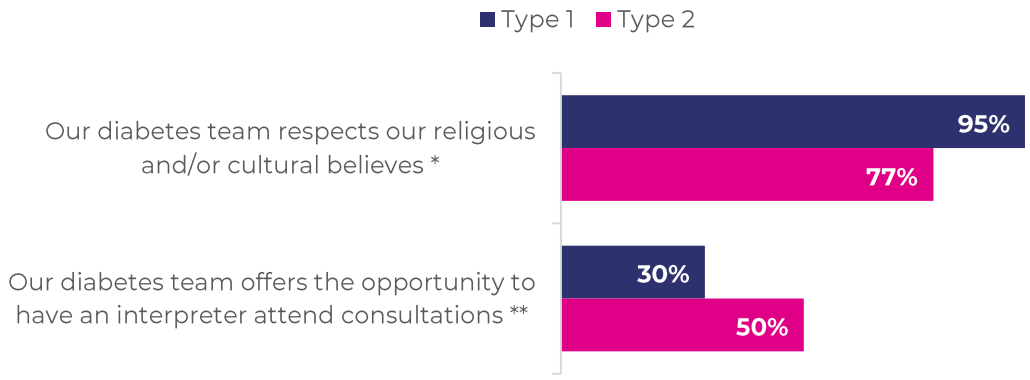
Figure 19 shows that **95%** of parents and carers always felt that their diabetes team respected their religious and cultural beliefs, excluding "Not applicable" responses.



*Excluding the response “Not applicable”.

Figure 19: Culturally competent care. These questions were only asked to Parents and Carers.

CYP with Type 2 diabetes were less likely to agree that their team respected their religious or cultural beliefs (Figure 20).



* Excluding “Not applicable” responses from the denominator.

** Percentage combines all positive responses: "Yes, and we use one", "Yes, but we have not needed/wanted one" and “Yes, but we have not been able to get one”.

Figure 20: Percentage of respondents giving positive responses to each statement about culturally competent care, by type of diabetes.

1.11 Information and advice

Respondents were asked if they had received enough information from their diabetes team to manage different areas of diabetes care effectively and to rate the overall amount of information provided.

The vast majority of respondents 'always' or 'sometimes' received information about diabetes management (Figure 21).

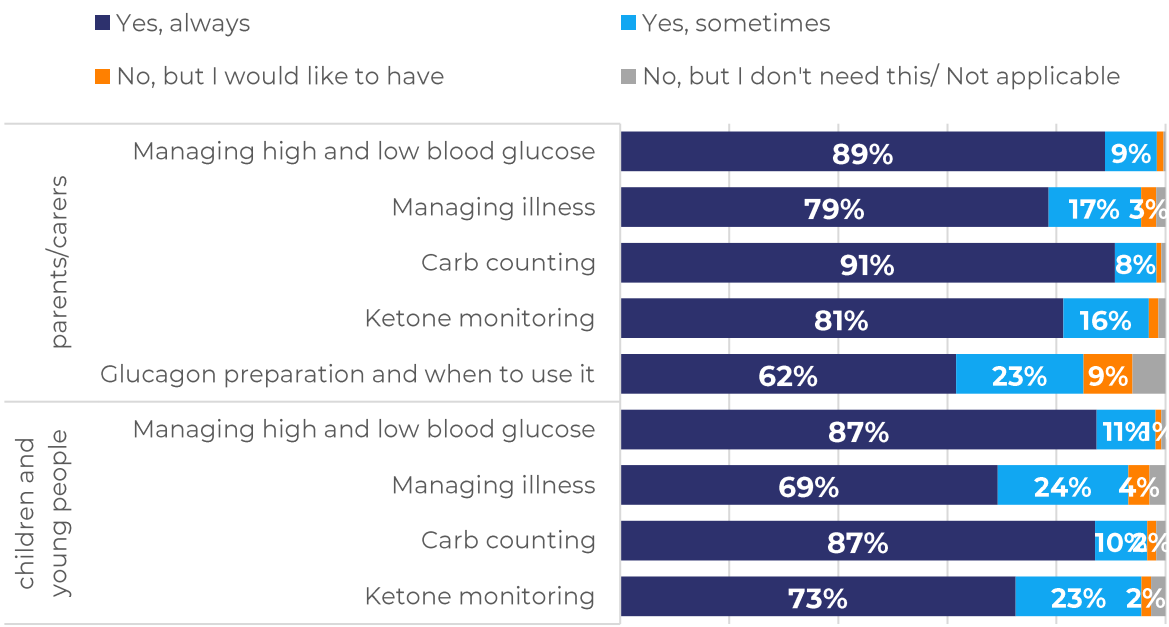
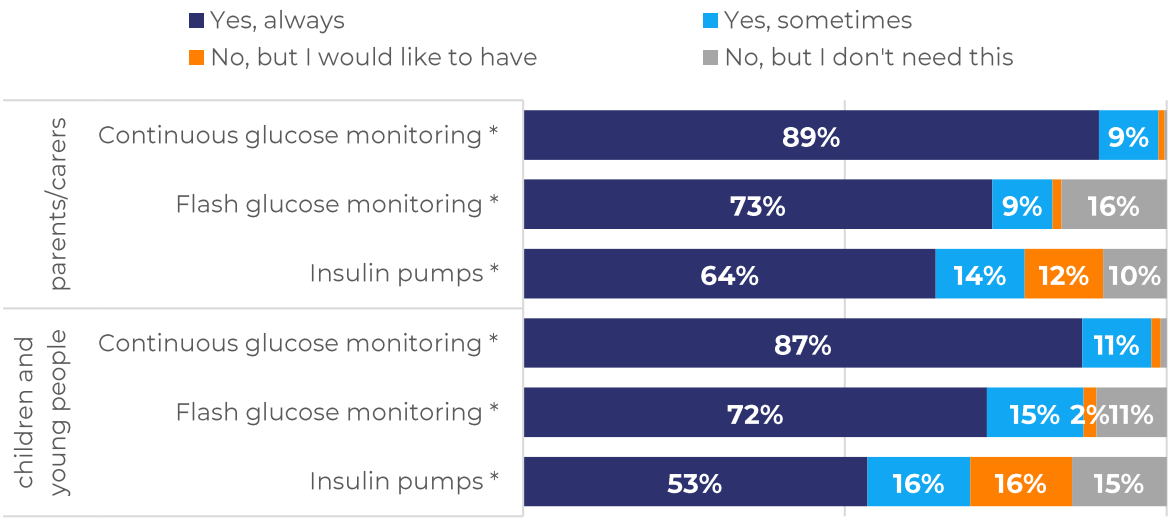


Figure 21: For information about diabetes management, response to the question "Since diagnosis, have you received enough information from your child's diabetes team to manage the following areas effectively?".

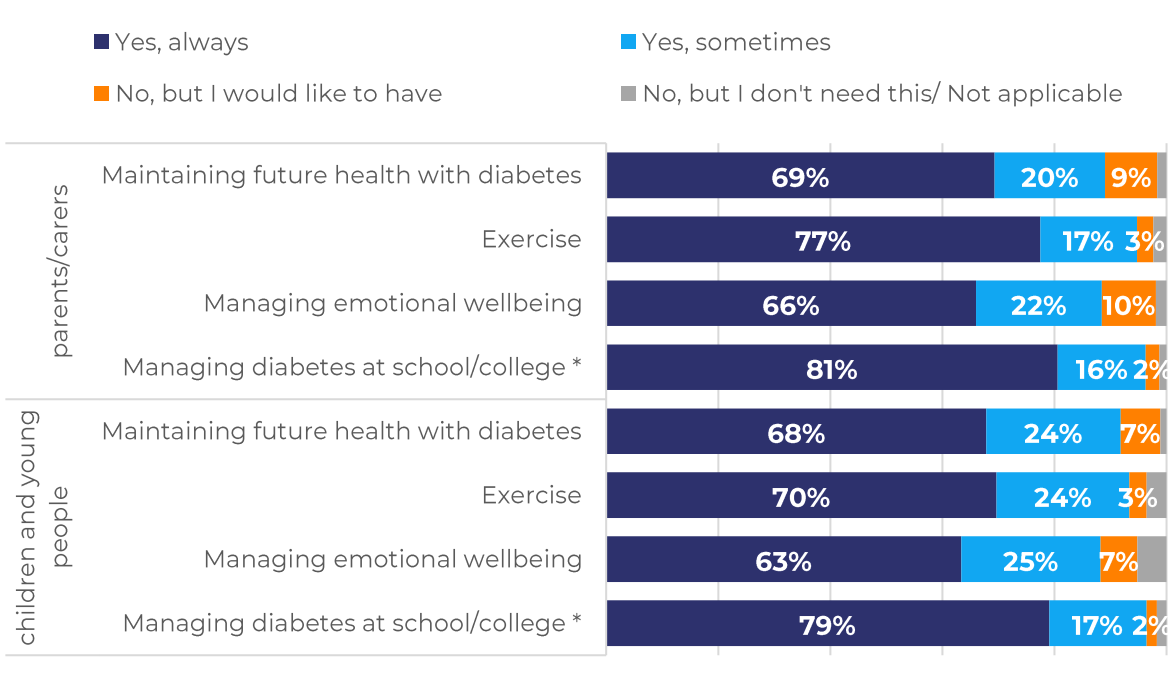
Most respondents received information about continuous glucose monitoring, but fewer received information about flash glucose monitors and insulin pumps (Figure 22).



*Excludes 'Not applicable' answers.

Figure 22: For information about diabetes technologies, response to the question *"Since diagnosis, have you received enough information from your child's diabetes team to manage the following areas effectively?".*

When it came to information about maintaining well-being, most respondents 'always' or 'sometimes' received enough information (Figure 23).



*Excludes 'Not applicable' answers.

Figure 23: For information about maintaining wellbeing, response to the question *"Since diagnosis, have you received enough information from your child's diabetes team to manage the following areas effectively?".*

Overall, **73%** of parents and carers and **69%** of CYP 'strongly agreed' that they received enough information since diagnosis to manage their condition (Figure 24).

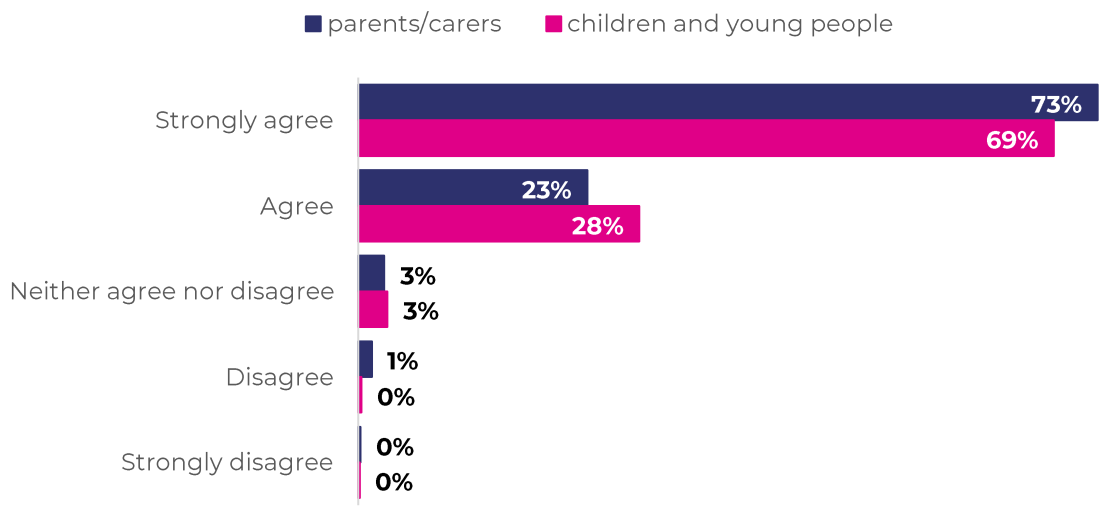


Figure 24: Response to the question "Overall, since diagnosis, have you received enough information to help you understand and manage your/your child's condition?" by respondent.

1.12 Family support

Respondents were asked to rate whether their diabetes team supported the whole family.

Figure 25 shows that **81**% of parents and carers and **75**% of CYP reported that their diabetes team always supported the whole family. **3**% of parents and carers and **1**% of CYP said that the team did not support the whole family, but they would like them to.

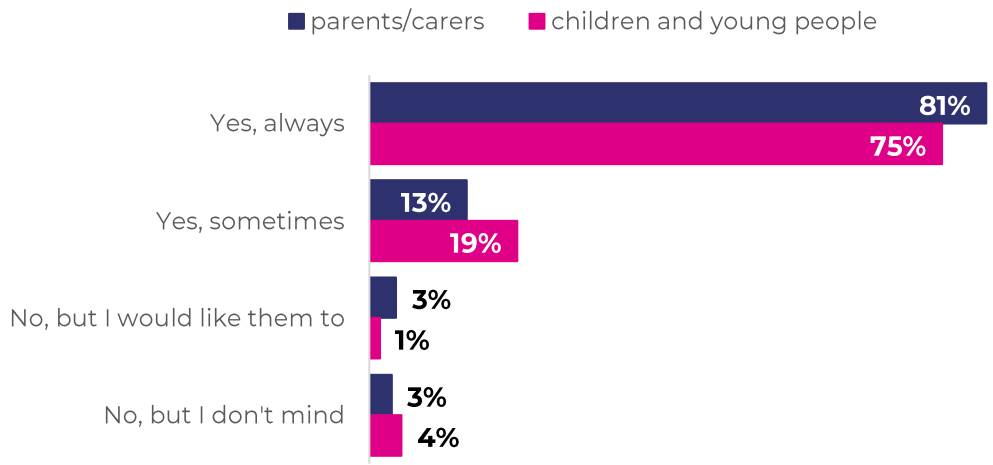


Figure 25: Responses to the statement "*Our diabetes team supports the whole family*" by respondent

CYP with Type 2 diabetes and their parents/carers were less likely to answer 'yes always' to diabetes team support to the whole family (Figure 26).

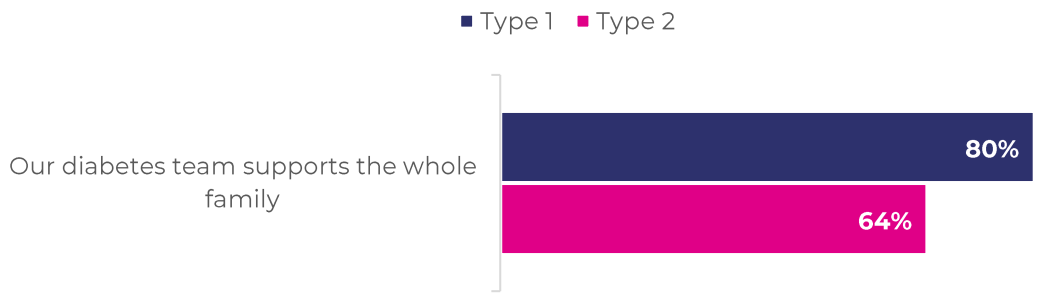


Figure 26: Percentage of respondents answering "*Yes, always*" to "*Our diabetes team supports the whole family*", excluding "*I don't know*" responses, by type of diabetes.

1.13 Managing diabetes at school or college

Respondents were asked to consider whether their diabetes team ensured that staff at their/their child's school/college have the necessary information about their diabetes in order to help them.

77% of parents and carers and **70%** of CYP felt that their teams always ensured that their school/college were informed (Figure 27).

5% of CYP felt that staff at their school/college were not informed but they would like them to be.

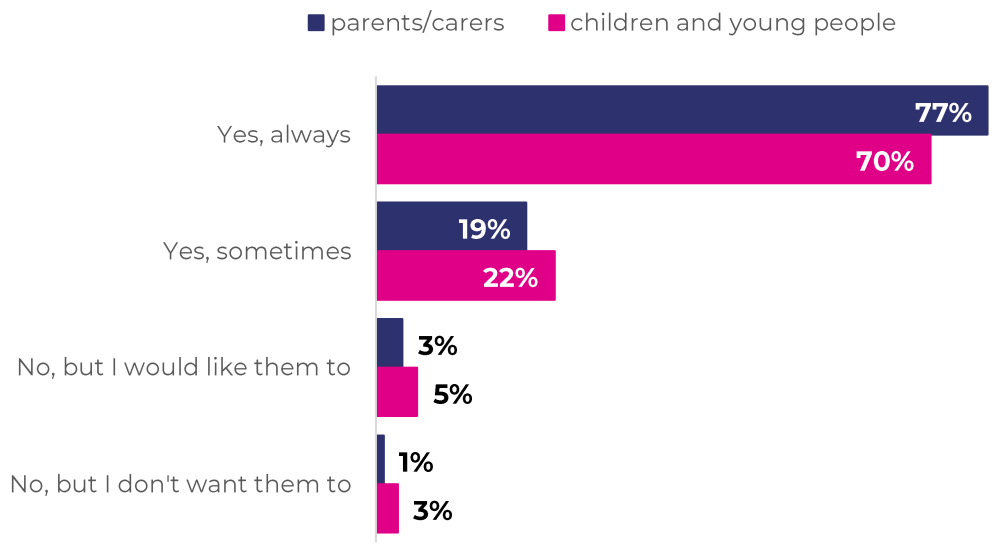


Figure 27: Responses to the statement "Our diabetes team ensure that staff at my/my child's school/college have the necessary information about my/their diabetes in order to help me/them", excluding "I don't know" and "Not applicable" responses, by respondent.

1.14 Peer support

Respondents were asked whether their diabetes team make it possible for them to connect with other young people or parents of young people with diabetes.

63% of CYP and **67%** of parents and carers reported that their diabetes team made it possible to connect with peers (Figure 28).

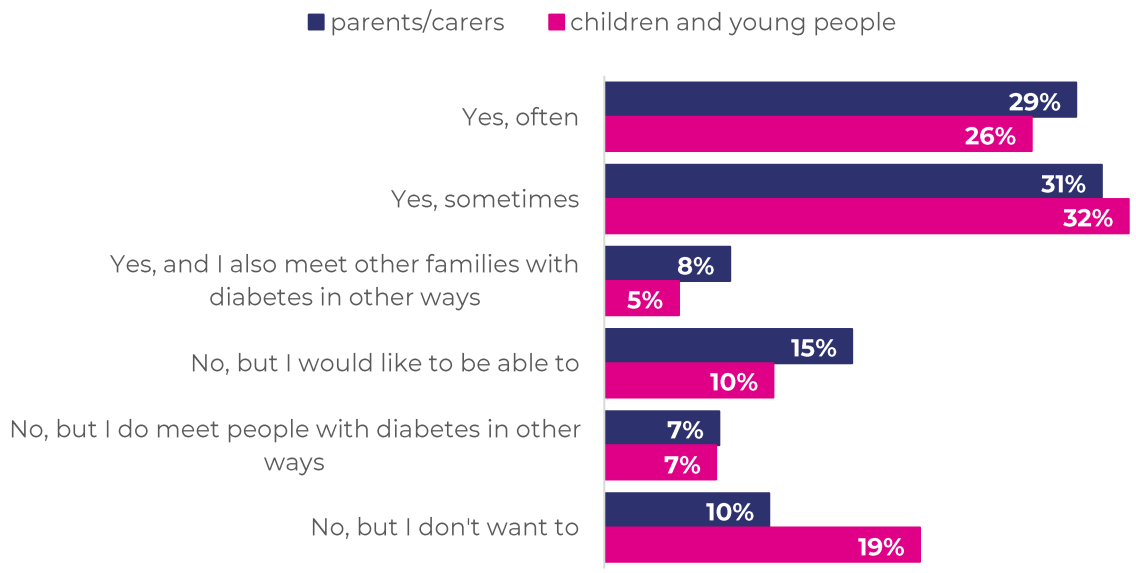


Figure 28: Responses to the statement "Our diabetes team make it possible for me to connect with other (parents of) young people with diabetes" by respondent.

1.15 Financial challenges

Parents and carers were asked whether their diabetes team asked them about any financial challenges their family faced that may impact on their child's diabetes management or access to care.

36% of parents and carers reported that they were asked about any financial challenges they faced, while **48%** said they did not want to be asked about financial challenges (Figure 29).

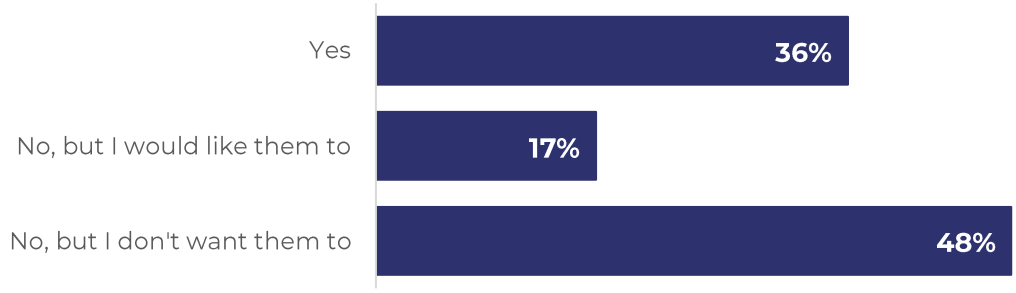


Figure 29: Responses to the question "*Have your team asked you about any financial challenges faced by your family that may impact your child's diabetes management/access to care*", excluding "*I don't know*" responses. This question was only asked to parents and carers.

30% of families in England were asked about financial challenges, compared to **23%** in Wales (Table 9).

Table 9: Discussion of financial challenges by country. This question was only asked to parents and carers.

	England and Wales (n = 1820)	England (n = 1696)	Wales (n = 124)
Have your team asked you about any financial challenges faced by your family that may impact your child's diabetes management/access to care?			
Yes	532 (29%)	504 (30%)	28 (23%)
No, but I would like them to	248 (14%)	229 (14%)	19 (15%)
No, but I don't want them to	716 (39%)	668 (39%)	48 (39%)
I don't know	324 (18%)	295 (17%)	29 (23%)

1.16 Impact of diabetes diagnosis

Parents and carers were asked whether their child's diabetes care needs impacted on their sleep or employment.

47% of parents and carers reported sleep disturbance three or more times a week due to attending to their child's diabetes health care needs, while **37%** reported sleep disturbance three or more times a week due to stress relating to their child's health (Figure 30).

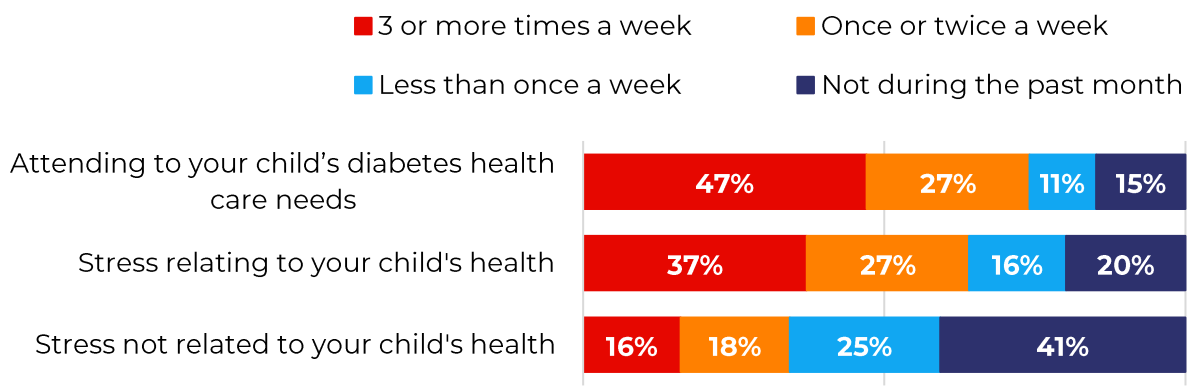


Figure 30: Responses to the question "*Compared with your sleep before your child's diabetes diagnosis, has there been a disturbance to your normal sleep pattern, either quality of sleep or length of sleep*" by reason for disturbed sleep. This question was only asked to parents and carers.

Sleep disturbance was greater in families with younger children with diabetes (Figure 31) and mothers were more likely than fathers to report sleep disturbance (Figure 32).

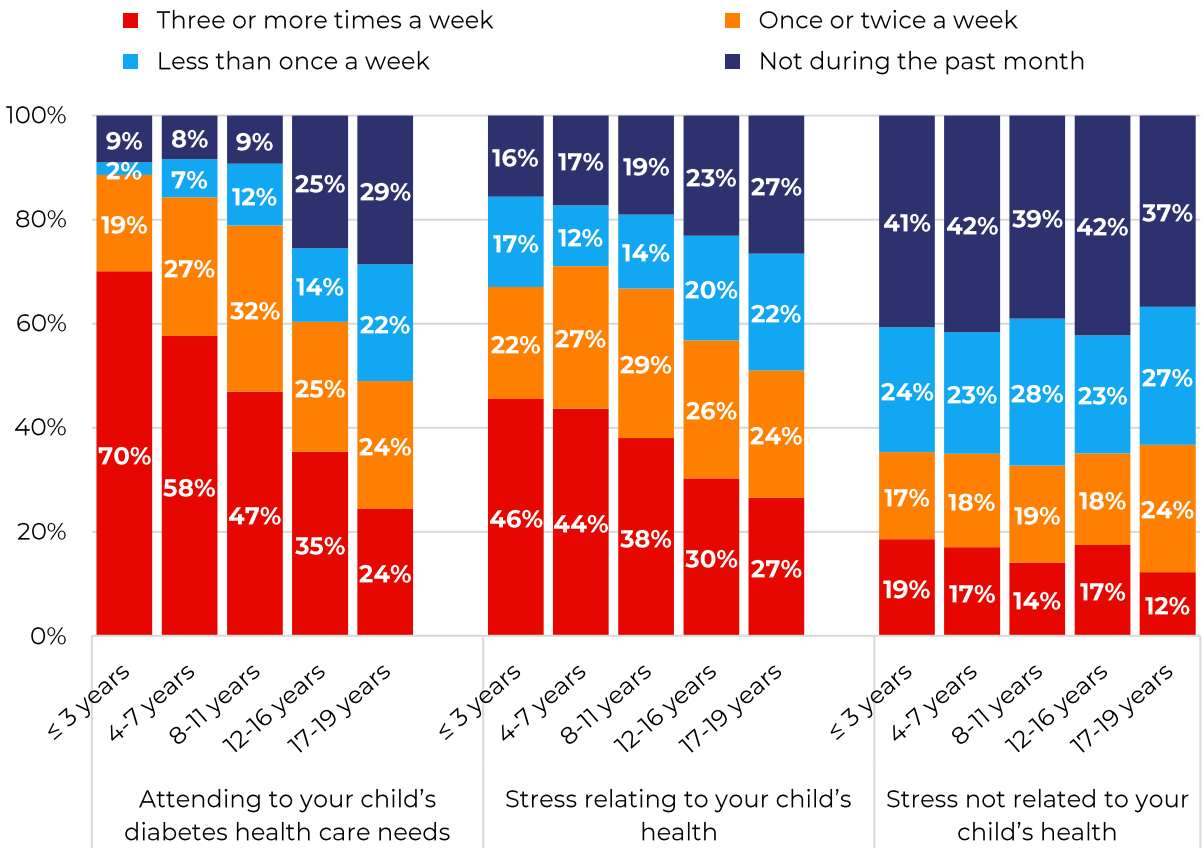


Figure 31: Sleep disturbance by the age of the child or young person. This question was only asked to parents and carers.

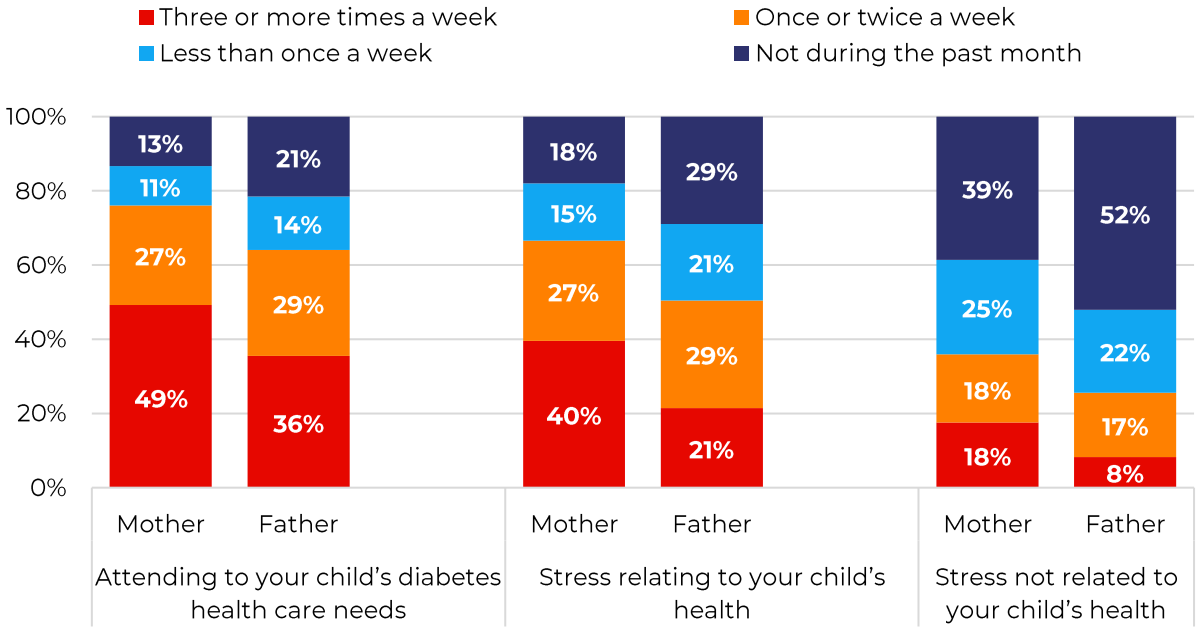


Figure 32: Sleep disturbance by the respondent's relation to the child with diabetes. This question was only asked to parents and carers.

Families with regular access to a psychologist within diabetes appointments experienced less sleep disturbance (Figure 33).

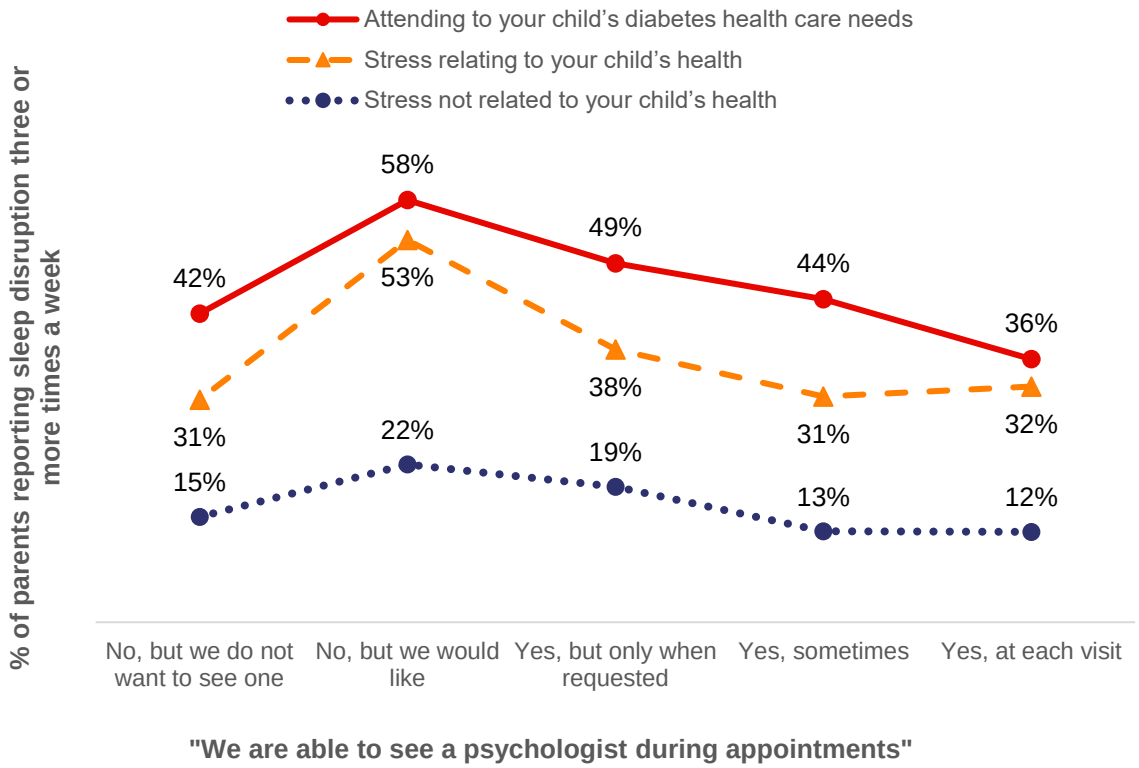


Figure 33: Percentage of parents and carers reporting sleep disruption three or more times a week, by access to Psychologist.

11% of parents and carers reported that they or their partner had left employment, while **30%** reported a reduction in working hours (Figure 34).

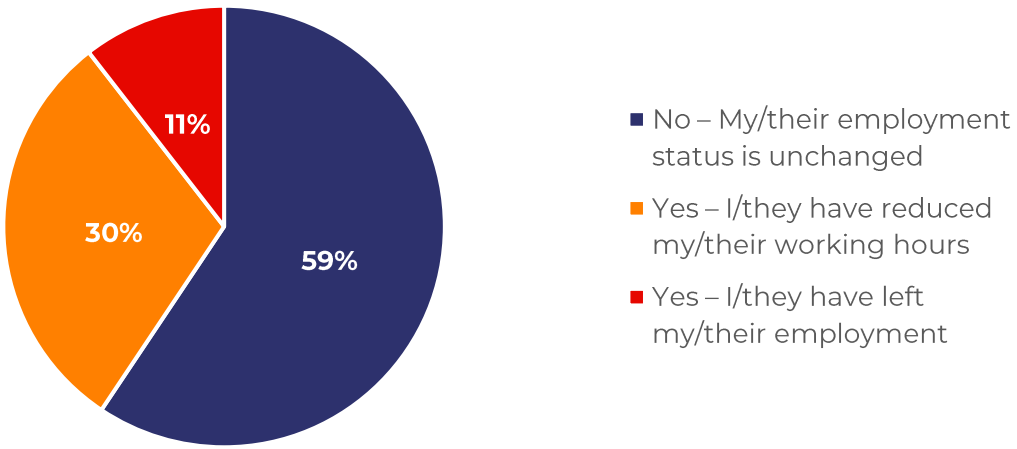


Figure 34: Reponses to the question "*Have the diabetes care needs of your child impacted on your/your partner's employment?*", excluding "Not applicable" responses. This question was only asked to parents and carers.

Families with younger children with diabetes were more likely to report a change in employment (Figure 35).

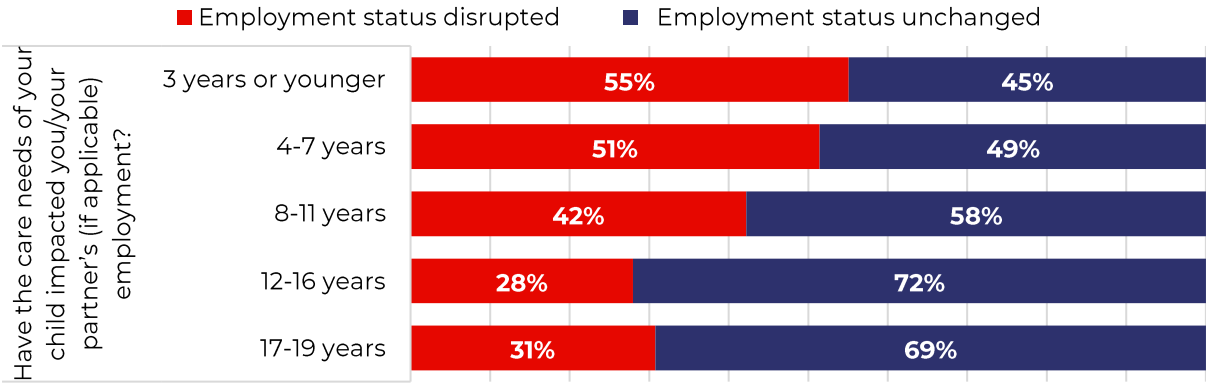


Figure 35: Impact of child's diabetes needs on parent or carer's employment by the age of the child or young person, excluding "Not applicable" responses. This question was only asked to parents and carers.

Families experiencing greater sleep disruption were more likely to experience a change in employment status (Figure 36), as were ethnic minority families (Figure 37). There was little difference between England and Wales (Table 10).

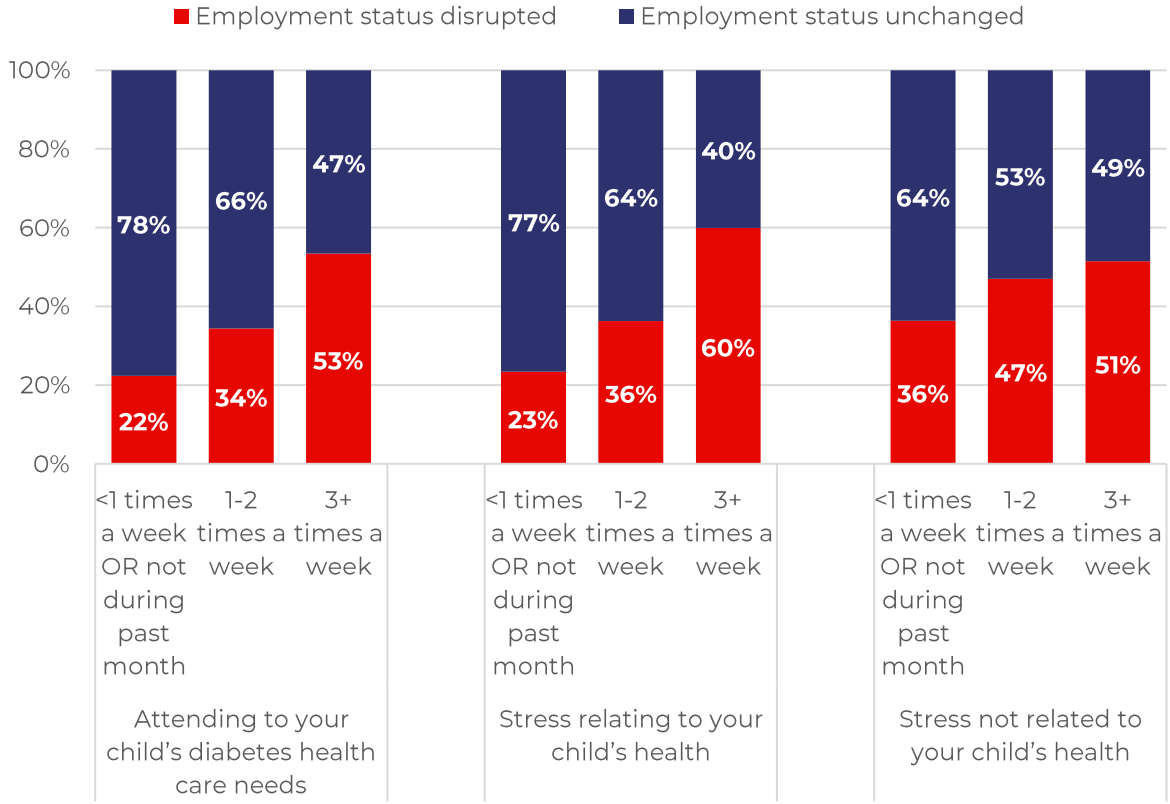
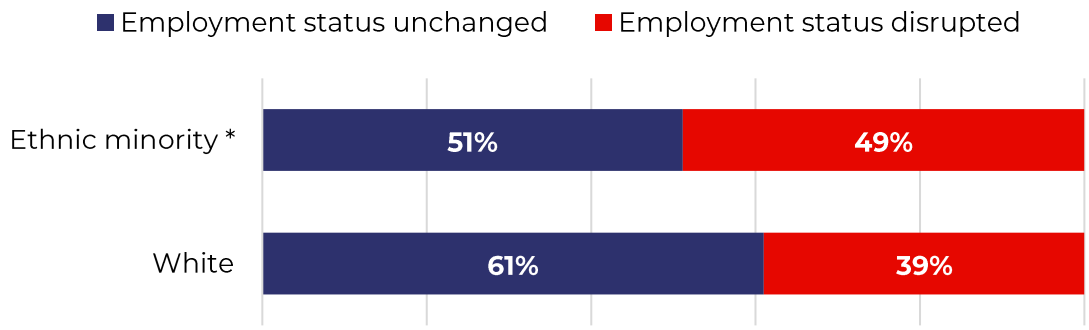


Figure 36: Association between sleep disruption and employment, excluding "Not applicable" responses.



* Ethnic minority includes Asian, Black, Mixed, Other and 'Prefer not to say' responses.

Figure 37: Impact of child's diabetes needs on parent or carer's employment by ethnicity, excluding "Not applicable" responses. This question was only asked to parents and carers.

Table 10: Impact of diabetes care needs on employment by country. This question was only asked to parents and carers.

	England and Wales (n = 1820)	England (n = 1696)	Wales (n = 124)
Have the diabetes care needs of your child impacted your/your partner's employment?			
Yes – I/they have reduced my/their working hours	927 (52%)	865 (52%)	62 (51%)
Yes – I/they have left my/their employment	470 (26%)	445 (27%)	25 (21%)
No – My/their employment status is unchanged	164 (9%)	152 (9%)	12 (10%)
Not applicable	239 (13%)	217 (13%)	22 (18%)

1.17 Overall

Respondents were asked how they felt after appointments with the diabetes team and whether they would recommend their diabetes team to a friend or other family who has a child with diabetes.

53% of parents and carers and **37%** of CYP report feeling 'Very happy' after their appointments with the diabetes team (Figure 38). Overall, **87%** of respondents reported feeling 'Happy' or 'Very happy' after their appointments.

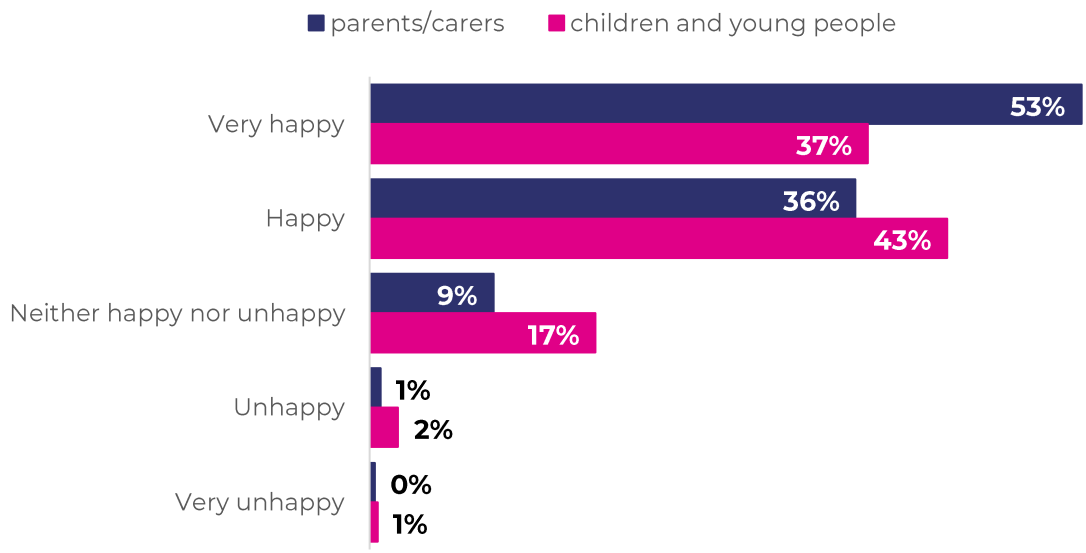


Figure 38: Responses to the question "How do you usually feel after your appointments with the diabetes team?" by respondent.

CYP with Type 2 diabetes and their parents/carers were less likely to report feeling 'Happy' or 'Very happy' after their appointments (Figure 39).

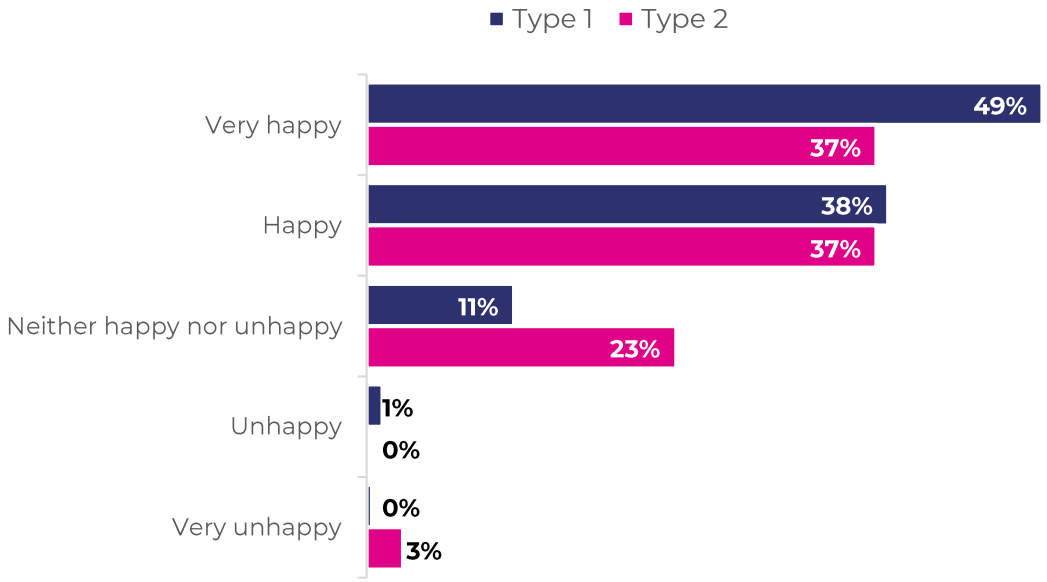


Figure 39: Responses to the question "How do you usually feel after your appointments with the diabetes team?" by diabetes type.

Figure 40 shows that **92%** of parents and carers and **87%** of CYP agreed 'a lot' that they would recommend their team, excluding "I can't decide/I don't know" responses.

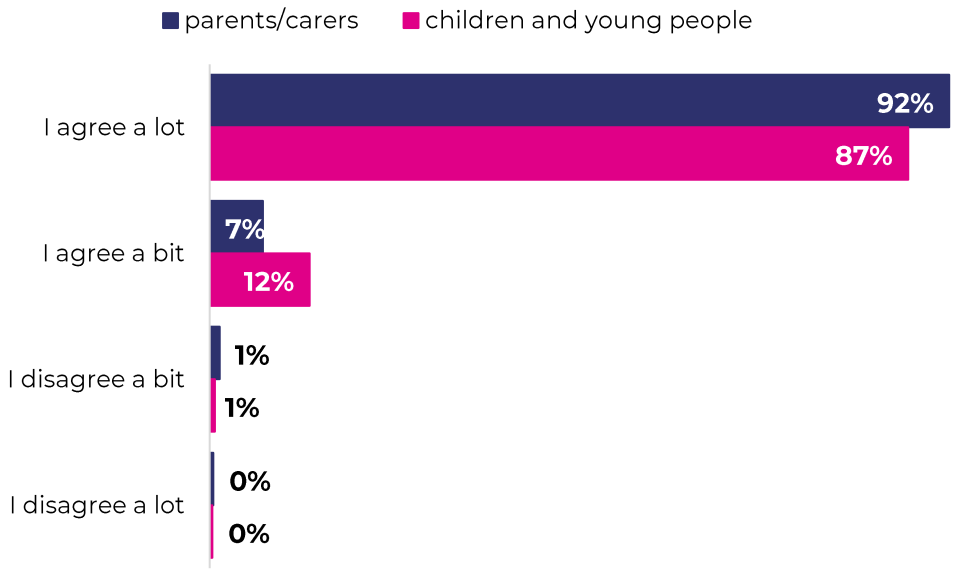


Figure 40: Responses to the statement "I would recommend our diabetes team to a friend or other family with a child who has diabetes", excluding "I can't decide/I don't know" responses, by respondent.

1.18 PREM Score

An overall PREM score[1] was calculated to facilitate comparison of performance between PDUs. PDUs with less than 10 responses in total were excluded from these analyses. There was an overall average PREM score of **75%,** compared to 81% in the 2021 PREM (which was open to all CYP receiving care from paediatric diabetes units). There was little variability in PDU performance, ranging from **60%** to **89%** (Figure 41) or by regional network (Figure 42)

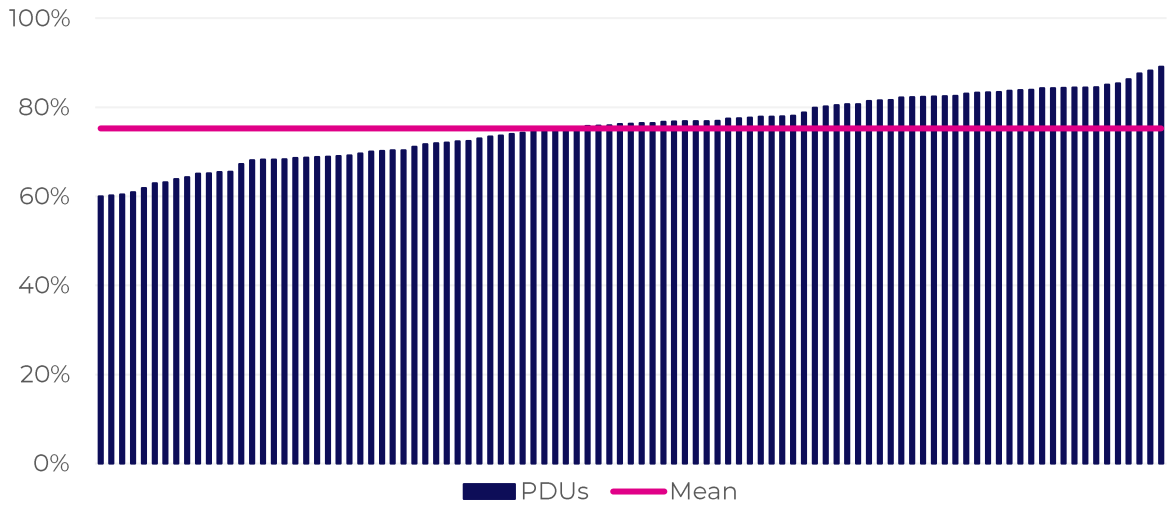


Figure 41: PREM scores by PDU. This only includes PDUs with at least 10 responses.

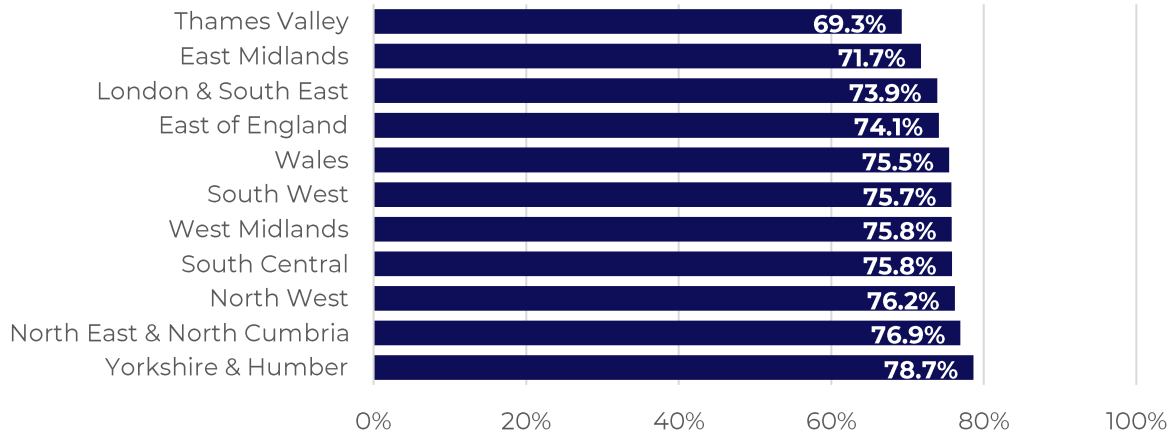


Figure 42: Mean PREM score by diabetes regional network.

[1] These scores were calculated from a selection of questions measuring performance or experience, with clear positive or negative response options. 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*

2. List of Tables

3. List of Figures

4. Methodology

The questionnaires used in this First Year of Care PREM survey were the same as derived from those developed and utilised in the 2019 PREM data collection, with the questions adapted to focus on experiences within the first year of care.

The survey was only open to CYP who have had diabetes for between 6-18 months at the point of completing a survey and their families. To support services in identifying eligible CYP, an Excel diagnosis duration checker was provided.

The surveys were available online (via Survey Monkey Enterprise) between **24th July 2023 and 23rd January 2024**. PREM leads in each PDU were 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. Digibete, a digital content platform for diabetes related education, was also commissioned to promote the survey via their app.

Translations of the survey were provided in a PDF format to support participation amongst those whose first languages are Welsh, Urdu, Punjabi, Polish and Ukranian.

Flyers and posters for the surveys including a QR code linking to the questionnaires were distributed to the teams and promoted via the NPDA's Twitter account. Participation rates per PDU were published fortnightly during this period to enable teams to monitor the results of their efforts to encourage participation.

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.

5. Glossary of terms and abbreviations

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.

CYP
Children and young people

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

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.

Hybrid closed loop (HCL)
Hybrid closed loop systems link continuous glucose monitors to insulin pumps to automatically adjust insulin delivery based on blood sugar levels. This is sometimes referred to as an “artificial pancreas”.

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.

Type 1 diabetes
An autoimmune condition where the body can no longer produce insulin, so insulin injections or infusions are needed.

Type 2 diabetes
A condition with both genetic and lifestyle factors, where the body is unable to make enough insulin, or where the insulin that is produced doesn't work effectively.

Standard deviation
A statistic indicating the dispersion of data points relative to the mean

6. Acknowledgements

NPDA Clinical Lead

- Professor Justin Warner, Clinical Lead, RCPCH and Consultant in Paediatric Endocrinology and Diabetes, Cardiff and Vale University Health Board

NPDA Project Team

- Dr Cillian Brophy, NPDA Analyst, RCPCH
- Calvin Down, Head of Audits, RCPCH
- Simon Duncan, Audit Administrator, RCPCH
- Tom Kellier, Audit Administrator, RCPCH
- Amani Krayem, NPDA Manager, RCPCH
- Natasha Long, NPDA Coordinator, RCPCH
- Saira Pons-Perez, Audit Senior Analyst, RCPCH
- Holly Robinson, NPDA Manager, RCPCH
- Richard Shepherd, NPDA Coordinator, RCPCH

NPDA Project Board

- Dr Fiona Campbell, Consultant in Paediatric Endocrinology and Diabetes, Leeds Teaching Hospitals NHS Trust
- Kate Cullen, Parent Representative
- Dr Mark Deakin, Consultant in Diabetes and General Paediatrics, Alder Hey Children's NHS Foundation Trust
- Professor Paul Dimitri, Vice President for Science and Research, RCPCH
- Vivien Dunne, Project Manager, NCAPOP, HQIP
- Rachel Harris, Paediatric Diabetes Specialist Nurse, Cardiff and Vale University Health Board
- Dr Neil Hopper, Consultant Paediatrician, South Tyneside and Sunderland NHS Foundation Trust
- Simon Lewthwaite, Parent Representative
- Dr Kemi Lokulo-Sodipe, Specialty Registrar in Paediatrics, Southampton Children's Hospital
- Caroline Schmutz, Research Partnerships Manager, JDRF
- Charlotte Skinner, Senior Case Manager, NHS Digital
- Anthony Walker, Policy Lead, Diabetes UK
- Rachael Ward-Sample, Associate Director for Quality and Improvement, NCAPOP, HQIP
- Professor Justin Warner, Clinical Lead, RCPCH and Consultant in Paediatric Endocrinology and Diabetes, Cardiff and Vale University Health Board

NPDA Methodology and Dataset Working Group

- Francesca Annan, Clinical Specialist Paediatric/Adolescent Diabetes Dietitian, University College London Hospital NHS Foundation Trust
- Dr Nivedita Aswani, Consultant in General Paediatrics and Diabetes, Sheffield Children's NHS Foundation Trust
- Dr Fiona Campbell, Consultant in Paediatric Endocrinology and Diabetes, Leeds Teaching Hospitals NHS Trust
- Dr Alex De Costa, Speciality Registrar in Paediatrics, Queen Mary University
- Dr Mark Deakin, Consultant in Diabetes and General Paediatrics, Alder Hey Children's NHS Foundation Trust
- Dr Halina Flannery, Clinical Psychologist, University College London Hospital NHS Foundation Trust
- Robert Grant, Statistician, Bayes Camp
- Dr Dee Khaira, Clinical Psychologist, Barts Health NHS Trust
- Nicky Moor, Paediatric Diabetes Lead Specialist Nurse, Barts Health NHS Trust
- Professor Justin Warner, Clinical Lead, RCPCH and Consultant in Paediatric Endocrinology and Diabetes, Cardiff and Vale University Health Board

HQIP Support

- Grace Cuff, Project Manager, NCAPOP, HQIP
- Rachael Ward-Sample, Associate Director for Quality and Improvement, NCAPOP, HQIP