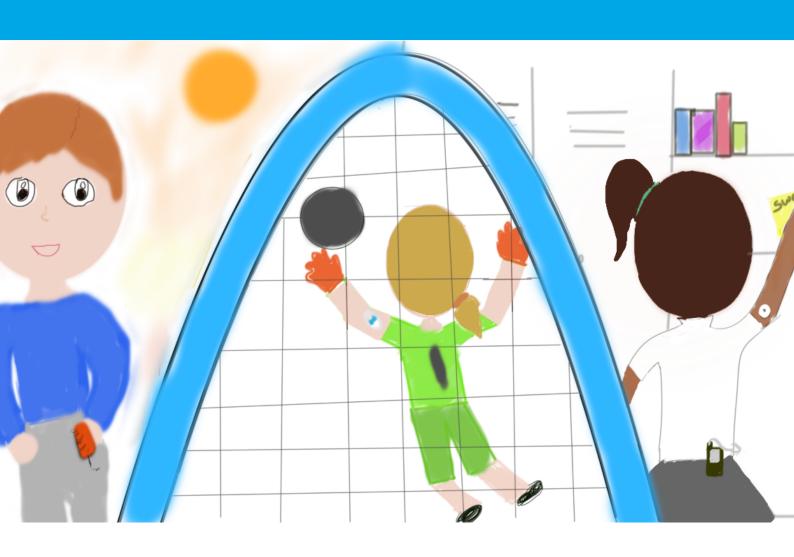




National Paediatric Diabetes Audit (NPDA) Report on Care and outcomes 2021/22







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FRONT COVER ART COMPETITION

Cover image Winner: Erin K

Introduction

The National Paediatric Diabetes Audit (NPDA) is managed by the Royal College of Paediatrics and Child Health (RCPCH) and commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing, and National Voices. Its aim is to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage, and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies www.hqip.org.uk/national-programmes.

The NPDA has been reporting for 19 years. Data is submitted by healthcare professionals in Paediatric Diabetes Units (PDUs) in England and Wales about the care received by the children and young people with diabetes using their service. The effectiveness of diabetes care is measured against NICE guidelines (NG18, NICE 2015) and includes treatment targets, health checks, patient education, psychological wellbeing, and assessment of diabetes-related complications including acute hospital admissions, all of which are vital for monitoring and improving the long-term health and wellbeing of children and young people with diabetes. In 2021/22, 100% of paediatric diabetes teams participated in the NPDA.

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

https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/national-paediatric-diabetes-audit/about-national-paediatric-diabetes-audit

Expanded analysis of 2021/22 data, PDU level reports and posters, a glossary of terms used in this report, a line of sight table describing the evidence base for the recommendations made in this report, and links to Excel files of data at PDU, regional network and integrated care system level are available within our annual reports page:

https://www.rcpch.ac.uk/resources/npda-annual-reports

PDU level, regional, local health board and ICS level data is available at: https://npda-results.rcpch.ac.uk/

Key messages

- The increase in incidence of Type 1 diabetes observed in the first year of the COVID-19 pandemic has been followed by a continuing increase in the numbers newly diagnosed with the condition in 2021/22. There were 3,883 new diagnoses of Type 1 diabetes in 2021/22 managed within a PDU, compared to 3,662 in 2020/21. This is 1,010 more than the average number newly diagnosed and being managed in a PDU between 2013/14-2019/20, before the start of the pandemic. This increase in the numbers newly diagnosed since 2020, based on the pre-pandemic average, is the same as the caseload of five averagely sized PDUs.
- There has been continuing improvement in national median HbA1c. There has also been an increase
 in the use of diabetes technologies associated with lower HbA1c. Use of a closed loop system was
 associated with the best HbA1c outcomes.
- Almost all (98.2%) of those with Type 2 diabetes were overweight or obese, and almost half (46.1%) had a diastolic or systolic blood pressure in the hypertensive range. Two fifths (42.3%) of those with Type 1

diabetes were also overweight or obese, with a third (29.9%) having a diastolic or systolic blood pressure in the hypertensive range.

- Despite reductions in the percentages recorded as requiring additional support between 2020/21 and 2021/22, over a third of children and young people were assessed as requiring additional psychological support outside of multidisciplinary team meetings (39.0% of those with Type 1 diabetes and 48.3% of those with Type 2 diabetes).
- Inequalities persist in terms of the use of diabetes-related technologies by ethnic group and deprivation quintile, with a fifth (22.2%) of those with Type 1 diabetes and Black ethnicity using a rtCGM, (a technology associated with lower HbA1c whether used in combination with injections or a pump) compared to almost a third of those of Mixed (31.3%) or White (30.8%) ethnicity. However, the usage gap between White and Black children and between the most and least deprived quintiles has reduced markedly since 2019/20, when the usage rate of rtCGMs was half that of White children amongst Black children and young people with Type 1 diabetes.

National recommendations

1. Commissioners should ensure adequate staffing of full multidisciplinary diabetes teams to manage the increasing numbers of cases of Type 1 and Type 2 diabetes observed since 2020, who are trained to facilitate the optimal use of new diabetes-related technologies.

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

2. Children and young people with Type I diabetes should have equitable access to diabetes care, irrespective of social deprivation, ethnicity or geography. They should be offered a choice of diabetes technology that is appropriate for their individual needs with families being made aware of the potential differences in outcome with different modalities of insulin delivery and blood glucose monitoring.

Action by: Integrated Care Boards across England in line with the aims for diabetes care set out within Core20PLUS5 – the national NHS England approach to reducing health inequalities for children and young people. Health Boards and Regional Partnership Boards across NHS Wales and Public Health Wales. The RCPCH, to provide a better understanding of ethnic and social deprivation variability.

3. Health checks for children and young people with diabetes are essential for early recognition of complications. The need for tests and the results should be clearly communicated to families as part of their individual care package, and completion rates of checks should be monitored through the year.

Action by: Clinical teams within Paediatric Diabetes Units in NHS Health Boards and Trusts across England and Wales.

4. Awareness of diabetes symptomatology amongst the public should be enhanced to avoid newly diagnosed children and young people presenting with Diabetic ketoacidosis (DKA).

Action by: The Office for Health Improvement and Disparities, NHS England, Public Health Wales and NHS Wales supported by the National Children and Young People's (CYP) Diabetes Network, and diabetes charities (Diabetes UK and JDRF).

5. Studies should be funded to derive evidence for interventions supporting pre-diabetic children young people to avoid progression to Type 2 diabetes.

Action by: Funding bodies such as the National Institute for Health and Care Research, Diabetes UK.

2021/22 Results Summary

There were **33,251** children and young people receiving care from a PDU in 2021/22: 31,685 (95.3%) in England and 1,566 (4.7%) in Wales.

SECTION 01

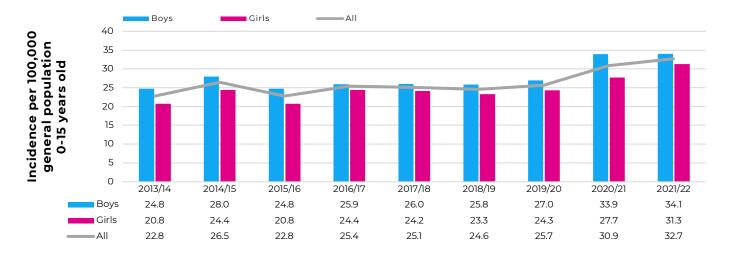
How many children and young people were receiving care from paediatric diabetes services in England and Wales in 2021/22?



Country	Total number of children and young people with diabetes	Type 1 diabetes	Type 2 diabetes	Other rare forms
England	31,685	29,838 (94.2%)	1,116 (3.5%)	731 (2.3%) *
Wales	1,566	1,511 (96.5%)	28 (1.8%)	27 (1.7%) *
England and Wales	33,251	31,349 (94.3%)	1,144 (3.4%)	758 (2.3%) *

^{*}Includes cystic fibrosis diabetes, Maturity-onset diabetes of the young (MODY) and "unknown/unspecified" types of diabetes.

Incidence of Type 1 diabetes (0-15 years) increased from **25.7** new cases per 100,000 in 2019/20 to **30.9** in 2020/21 and **32.7** in 2021/22, with **3883** new cases diagnosed and managed in PDUs in 2021/22. This represents an excess of **789** and **1001** new cases in 2020/21 and 2021/22 respectively compared to the average from previous years. This increase in the numbers newly diagnosed since 2020, based on the pre-pandemic average, is the same as the caseload of five averagely sized PDUs.



Sex and audit year

Figure 1: Incidence of Type 1 diabetes per 100,000 general population 0-15 years old in England and Wales, from 2013/14 to 2021/22

There were **281** children and young people newly diagnosed with Type 2 diabetes in 2021/22 – an increase from 230 in 2020/21.

What percentages of children and young people received all six recommended health checks in 2021/22?



59.7% of those with Type 1 diabetes aged 12 and above received all six 'key' health checks (HbA1c, BMI, blood pressure, thyroid test, albuminuria screening, and foot checks), compared to 40.2% in 2020/21).

33.0% of those with Type 2 diabetes aged 12 and above received all six 'key' health checks (HbA1c, BMI, blood pressure, cholesterol, albuminuria screening, and foot checks), compared to 24.1% in 2020/21.



^{*} health checks completed for children and young people aged 12 or older.

N.B. Eye screening was reduced to biennial frequency in many NHS Trusts from 2020/21 and has been excluded from compound 'key annual check' reporting by the NPDA since.

Figure 2: Percentage of children and young people with Type 1 diabetes receiving individual health checks, 2015/16 to 2021/22

What percentage of all recommended health checks were delivered by PDUs in 2021/22?



In 2021/22 the overall completion rate (the total number of the six key health checks actually completed divided by the total that should have been provided), for key health checks received by children and young people aged 12 and above with Type 1 diabetes was **87.2%** (up from 70.2% in 2020/21), although completion rates varied between PDUs:

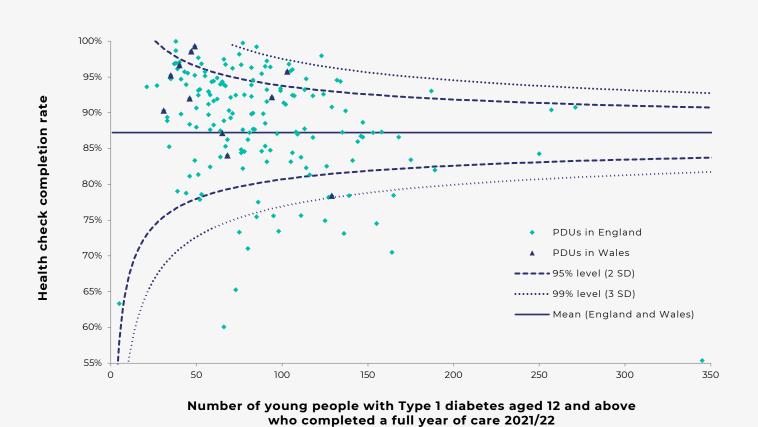


Figure 3: Funnel plot of health check completion rates by PDU for those aged 12 and above with Type 1 diabetes

What percentages of children and young people with Type 1 diabetes received recommended checks at diagnosis in 2021/22?



85.9% received level three carbohydrate counting education within a fortnight of diagnosis, compared to 82.1% in 2020/21.

91.2% received screening for thyroid disease within three months of diagnosis, compared to 86.6% in 2020/21.

87.0% received screening for coeliac disease within three months of diagnosis, compared to 83.8% in 2020/21.

SECTION 05

Has there been longitudinal improvement in national HbAlc?



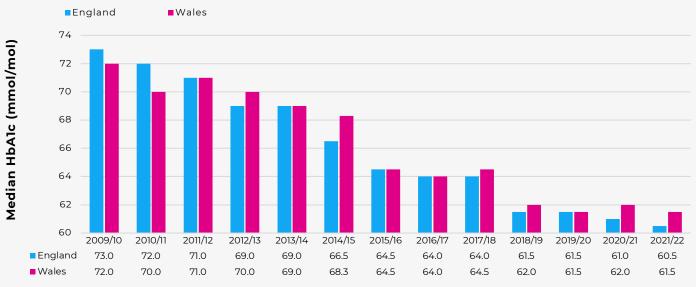


Figure 4: Median HbA1c for children and young people with all types of diabetes in England and Wales, 2009/10 to 2021/22

The national overall median HbA1c for children and young people with all types of diabetes was **60.5 mmol/mol** (60.5 mmol/mol for England and 61.5 mmol/mol for Wales), down from 61.0 mmol/mol in 2020/21.

The national median HbA1c for Type 1 diabetes was **61.0 mmol/mol** (unchanged from 2020/21). The median HbA1c at PDU level ranged from 54.0 mmol/mol to 69 mmol/mol.

The national median HbA1c for Type 2 diabetes was **50.0 mmol/mol**, down from 53.0 mmol/mol in 2020/21.

Figure 5 shows considerable variation at PDU level in terms of case mix adjusted mean HbA1c for those with Type 1 diabetes.

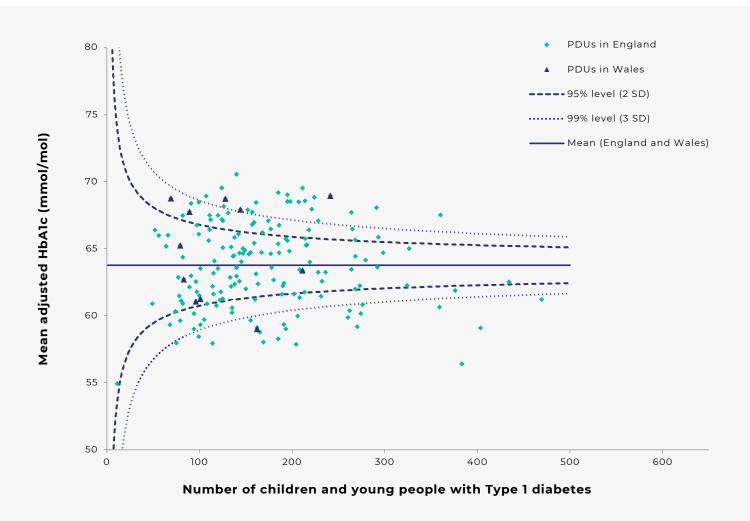


Figure 5: Funnel plot of mean adjusted HbA1c by PDU for those with Type 1 diabetes.

What percentages of children and young people with diabetes were at risk of macrovascular and microvascular complications in 2021/22?



TYPE 1 DIABETES	TYPE 2 DIABETES
29.9% (aged 12 and above) had a diastolic or systolic blood pressure in the hypertensive range (>98th centile after correction for age and gender), compared to 31.0% in 2020/21.	46.1% (all ages) had a diastolic or systolic blood pressure in the hypertensive range (>98th centile after correction for age and gender), compared to 49.3% in 2020/21.
19.0% (aged 12 and above) had a total blood cholesterol of 5mmol/I or higher, compared to 19.8% in 2020/21. (Cholesterol is no longer included in the health checks specified for Type I diabetes by NICE, however the NPDA continues to report the outcomes of the cholesterol tests undertaken and submitted as some PDUs consider it to merit continuing scrutiny).	27.9% (all ages) had a total blood cholesterol of 5mmol/l or higher, compared to 26.8% in 2020/21.
42.3% (all ages) were overweight or obese (BMI>85 th centile after correction for age and gender), compared to 42.9% in 2020/21.	92.8% (all ages) were overweight or obese (BMI >85th centile after correction for age and gender), compared to 92.0% in 2020/21.
11.4% (aged 12 years and above) had an abnormal retinopathy screen, compared to 16.9% in 2020/21.	8.4% (aged 12 years and above) had an abnormal retinopathy screen, compared to 3.5% in 2020/21.
11.5% (aged 12 years and above) had micro- or macro- albuminuria, compared to 10.3% in 2020/21.	20.6% (all ages) had micro- or macro-albuminuria, compared to 23.4% in 2020/21.

What percentages of children and young people with Type 1 were using diabetes-related technologies in 2021/22?



IN ENGLAND AND WALES:

40.3% were using an insulin pump, compared to 38.5% in 2020/21.

7.5% were using a closed loop system (data not collected in 2020/21).

30.0% were using a real time continuous glucose monitor (rtCGM); either combined with insulin injections or a pump), compared to **27.9%** in 2020/21.

43.7% were using a flash glucose monitor or a modified flash monitor (data not collected in 2020/21).

Country	Insulin pump	Closed-loop system	rtCGM	Flash glucose monitor or modified flash monitor
England	40.2%	7.4%	29.5%	44.3%
Wales	42.6%	9.4%	40.8%	30.1%
England and Wales	40.3%	7.5%	30.0%	43.7%

SECTION 08

What was the average HbA1c for children and young people with Type 1 diabetes using different diabetes-related technologies in 2021/22?



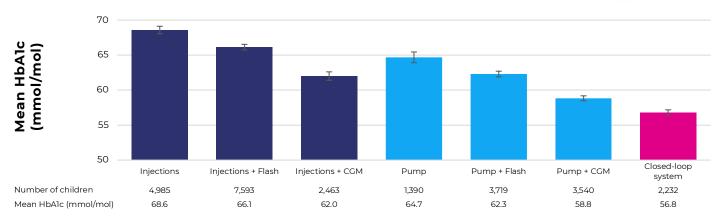


Figure 6: Mean HbA1c for children and young people with Type 1 diabetes using different combinations of treatment regimen and glucose monitoring in 2021/22.

What percentages of children and young people with Type 1 diabetes had diabetes related hospital admissions in in 2021/22?



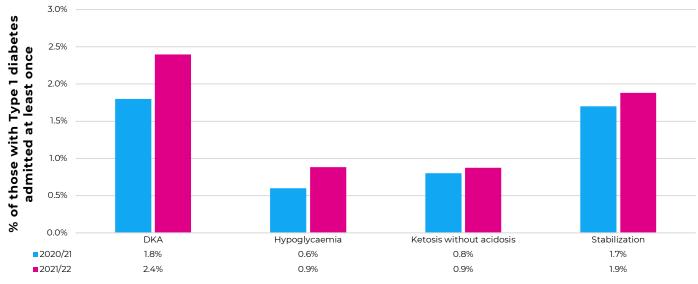


Figure 7: Percentage of children and young people with Type 1 diabetes admitted at least once for a diabetes-related cause not associated with diagnosis, 2020/21 and 2021/22

25.6% of children and young people newly diagnosed with Type 1 diabetes presented with DKA at diagnosis in 2021/22 compared to 25.8% in 2020/21.

SECTION 10

How many children and young people with diabetes were assessed as requiring additional psychological support following assessment in 2021/22?



39.0% of those with Type 1 diabetes and known outcome of psychological assessment (n=21,616) were assessed as requiring additional psychological support outside of multidisciplinary team meetings compared to 46.5% in 2020/21.

48.3% of those with Type 2 diabetes and known outcome of psychological assessment (n=636) were assessed as requiring additional psychological support outside of multidisciplinary team meetings compared to 59.5% in 2020/21.

Spotlight on inequalities

NPDA results have shown persistent inequalities in HbAIc outcomes and use of diabetes-related technologies associated with age, sex, deprivation and ethnicity.

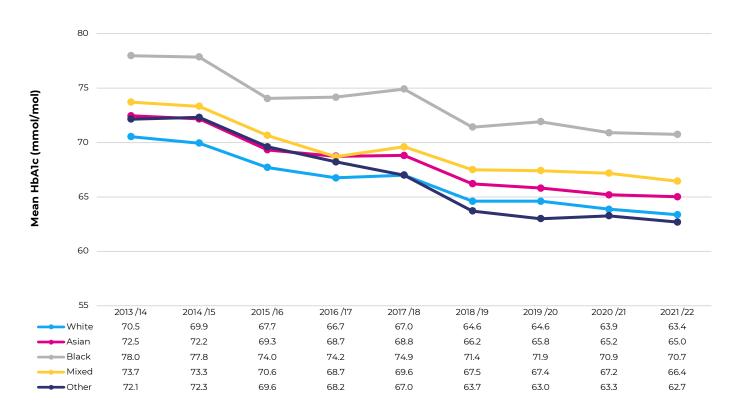


Figure 8: Mean HbAlc by ethnic group for those with Type 1 diabetes, 2013-2022.

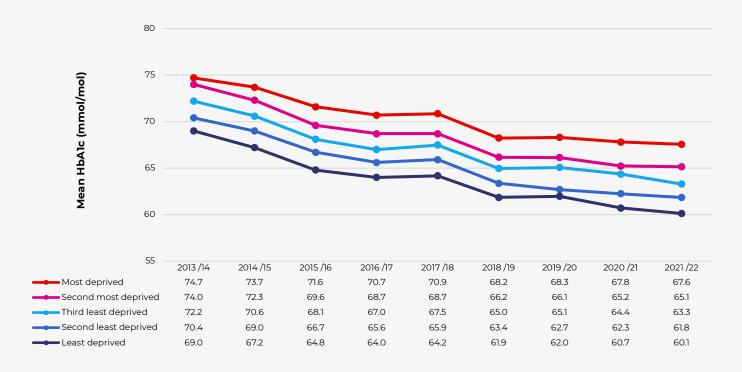


Figure 9: Mean HbAlc by deprivation quintile for those with Type 1 diabetes, 2013-2022.



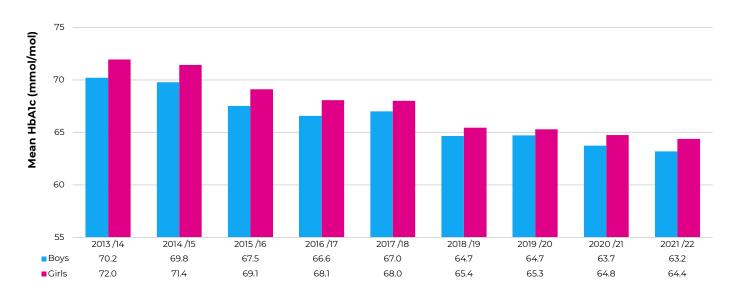


Figure 10: Mean HbAlc by sex for those with Type 1 diabetes, 2013-2022.

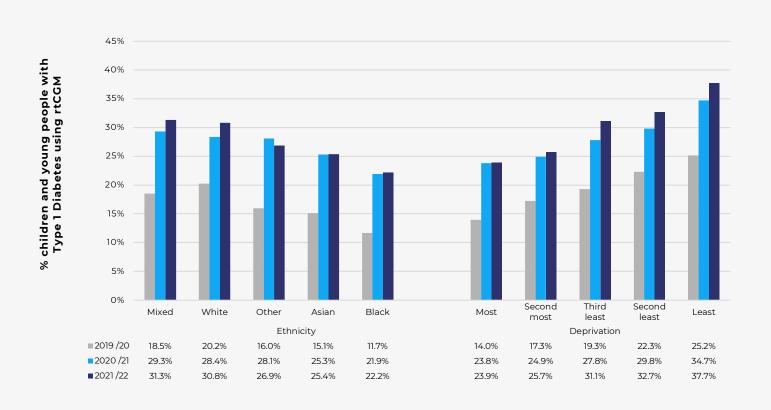


Figure 11: Use of rtCGM by ethnic category and deprivation quintile amongst those with Type 1 diabetes: 2019- 2022.

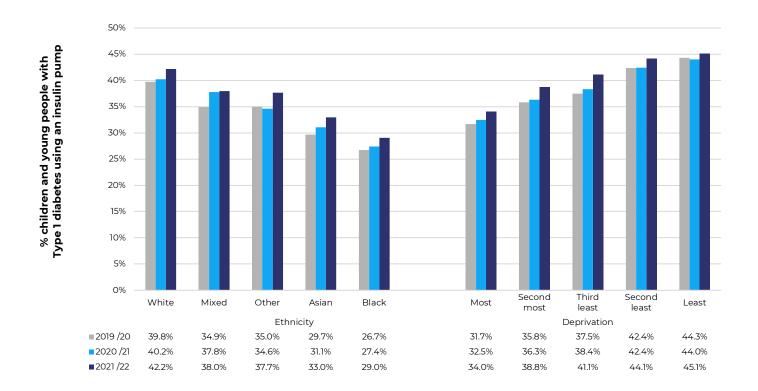


Figure 12: Use of insulin pump therapy by ethnic category and deprivation quintile amongst those with Type 1 diabetes: 2019-2022

Patient story: Using a closed loop system

The 2021/22 report has demonstrated that use of a closed loop system is associated with the lowest average HbA1c compared to other insulin delivery and glucose monitoring combinations. Here, Katie L aged 17 shares her experience of using this technology.

I was diagnosed with Type I diabetes aged 13.

I moved relatively quickly from multiple daily injections to an insulin pump including access to a Freestyle Libre from early on following the diagnosis.

I did not anticipate that diabetes would change my life as much as it would and that participating in all the sport I had before was a lot harder than expected. Staying in sport was initially the most important thing for me, however, I've learnt that staying active is also a huge part of living well with diabetes and controlling blood sugars. Participation in sport, particularly prolonged events, is not easy with Type I diabetes. Despite frequent testing and careful planning of meals and snacks, it was difficult to avoid hypoglycaemia during and after exercise, or to manage the pre-race hyperglycaemic nerves. My sugar was frequently low overnight after particularly active days.

My diabetes team suggested that I try a closed loop system. With their help, I began using one.

This has been a fantastic step forward for me. My HbAlc has improved a little but, more importantly, my time in target has significantly improved. This is because I am having less hypoglycaemic episodes, during the day and overnight. In fact, my overnight blood sugar readings are commonly a completely straight line – previously unheard of! This gives me the confidence to remain active during the day and I rarely worry about my blood sugar overnight.

My experience of closed loop systems is that they require considerable confidence and motivation to use, and consistent access to Bluetooth wireless technology. The systems are not yet familiar to the wider population so can require quite extensive explanations, for example at school / college, during sports events, and, more recently for me, during driving lessons and tests.

I would like diabetes teams and policy makers to work with young people and families to develop better education and support for families new to these devices. I am sure that there is a growing number of young people familiar and confident with closed loop systems who would be keen to share their experiences and expertise with others, perhaps with the support of the diabetes charities.

Quality Improvement resources

- The <u>RCPCH Diabetes Quality Improvement Website</u> provides multidisciplinary teams with the tools to identify, design and analyse their own interventions specific to the needs of the children and young people and their families that they care for.
- A slide deck is available on the <u>NPDA reports page</u> for teams to customise with their own results, with prompts for team discussions around results, and links to relevant QI resources.

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