

## NPDA spotlight audit report Diabetes-related technologies 2017-18

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### **Front Cover artwork:**

Sienna Leigh Ferguson, entrant of the NPDA art competition asking children and young people to design an image based on the theme of 'a good diabetes clinic visit'.

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## Foreword

I am very pleased to introduce the first National Paediatric Diabetes Audit (NPDA) spotlight report on support for use of diabetes-related technologies amongst children and young people with Type 1 diabetes. Type 1 diabetes is a complex and chronic condition which is accompanied by significant psychological and practical burdens for children, young people and their families. Optimal management of the condition reduces the risk of developing serious complications associated with diabetes and involves time-consuming and sometimes painful activities including frequent glucose monitoring, counting carbohydrate intake, and adjusting insulin dosage accordingly, whilst taking into account numerous environmental or individual factors that may influence how insulin is used by the body. This is in addition to the avoidance of serious complications of under- or overdosing on insulin. Previous NPDA national reports show many children and young people, particularly adolescents, struggle to adhere to the treatment plans associated with optimal management of Type 1 diabetes, which is perhaps not surprising given the other challenges that accompany growing up. New therapies and technologies therefore have huge potential to improve the lives of people with Type 1 diabetes both in terms of reducing complications of the condition and in improving quality of life.

This report provides an analysis of data submitted by healthcare professionals caring for children and young people with Type 1 diabetes in England and Wales about their support for the use of diabetes technologies. It provides evidence of the real improvements in diabetes management offered by use of insulin pumps and continuous glucose monitoring, whilst also demonstrating huge variation in technology-related diabetes outcomes between different clinics. It is clear that children and young people are benefitting more or less from using diabetes-related technologies to manage their condition depending on the paediatric diabetes service they attend, so the commitment of the NPDA to provide service-level analysis of pump outcomes in future rounds of audit is an important step towards identifying and sharing best practice, which will be necessary to close the performance gap.

I would like to thank all those involved in writing the report and developing its recommendations, including the NPDA Project Board, Methodology and Dataset Group, the audit team, and Clinical Lead, Professor Justin Warner. I would like to thank the paediatric diabetes teams across England and Wales for their support to the audit and for their efforts to make improvements in their local services.



**Russell Viner**  
**President, Royal College of Paediatrics and Child Health**

# Key terms used within this report

## **Artificial pancreas**

An externally worn insulin pump which communicates wirelessly to a continuous glucose monitor (CGM) worn as a patch on the skin. The CGM measures blood glucose levels and the result is fed into a small computer which calculates how much insulin (if any) needs to be delivered by the insulin pump. The dose is then delivered into the body, completing the cycle. (Diabetes UK)

## **Continuous glucose monitor (CGM)**

A continuous glucose monitor is a small device that you wear just under your skin. It measures your glucose (sugar) levels continuously throughout the day and night, letting you see trends in your levels and alerts you to highs and lows. (Diabetes UK)

## **DIY closed loop artificial pancreas**

'Do-it-yourself' artificial pancreas systems (DIY APS) use continuous glucose monitoring, insulin pumps and open source smartphone software (available freely on the internet) linking the former together so that they function as an 'artificial pancreas'.

## **Flash glucose monitoring**

A flash glucose monitor is a small sensor that you wear on your skin. It records your glucose (sugar) levels continuously throughout the day and you can access them by scanning the sensor whenever you want to. (Diabetes UK)

## **HbA1c**

The term HbA1c refers to glycated haemoglobin. By measuring glycated haemoglobin (HbA1c), clinicians are able to get an overall picture of what our average blood sugar levels have been over a period of weeks/ months. For people with diabetes this is important as the higher the HbA1c, the greater the risk of developing diabetes-related complications. (Diabetes.co.uk)

## **Insulin**

A hormone made in the pancreas, which is an organ in your body that helps with digestion. Insulin helps your body use glucose (sugar) for energy. When you have diabetes, sometimes your pancreas doesn't make any insulin, doesn't make enough or the insulin it makes doesn't work properly. That's why some people with diabetes are insulin-dependent, which means they need to take it as medication. Taking insulin helps you control your blood sugar levels. (Diabetes UK)

## **Insulin pump therapy**

An insulin pump is a small electronic device that gives your body the regular insulin it needs throughout the day and night. It is attached to your body by a tiny tube called a cannula which goes just under your skin. (Diabetes UK)

## **Multiple daily injection insulin therapy**

Multiple dose injection (MDI) therapy, also known as multiple daily injections, is an alternative term for the basal/bolus regime of injecting insulin. The therapy involves injecting a long acting insulin once or twice daily as a background (basal) dose and having further injections of rapid acting insulin at each meal time. (Diabetes.co.uk).

# Introduction

Diabetes mellitus occurs when blood glucose levels are elevated because the body is unable to metabolise it. Over 29,000 children and young people with diabetes are being managed by paediatric diabetes units (PDUs) in England and Wales, the majority of whom (95%) have Type 1 diabetes (RCPCH, 2019). With good diabetes care and blood glucose management, the risks of diabetes-related complications are reduced, enabling children and young people to enjoy a healthy and longer life.

The National Paediatric Diabetes Audit (NPDA) was established in 2003 to monitor the prevalence and incidence of diabetes in England and Wales, and to measure the quality of care provided by PDUs. It is funded by the NHS England and the Welsh Government, commissioned by the Healthcare Quality Improvement Partnership (HQIP) and delivered by the Royal College of Paediatrics and Child Health (RCPCH). Core NPDA annual reports focus on patient level data submitted by PDUs and report completion rates of healthcare checks and patient outcomes measured against standards of care produced by the National Institute for Health and Care Excellence (NICE, NG18). Reported here is a NPDA spotlight audit focusing on the use of diabetes technologies to manage the condition in children and young people attending PDUs in England and Wales in 2017-18.

## Aims of the diabetes-related technologies spotlight audit

NPDA core reports have shown wide variation in the quality of care and outcomes achieved by PDUs in England and Wales. Spotlight audits are aimed at providing the context to these findings. The core NPDA dataset measures implementation of NICE guidance for the management of children and young people with diabetes (NG18, NICE 2015), whereas the spotlight audits conducted by the NPDA for 2017/18 do not measure practice against any particular set of standards and seek instead to highlight variability in the way services differ in their structure and delivery of care. They provide insight into everyday practice and explore how this may be related to outcome. Where a question does relate to a standard, the standard is cited alongside the audit finding. Data is captured at PDU level through a series of questions answered by the PDU with mapping against that submitted to the 2017/18 NPDA patient level core audit where applicable.

This diabetes-related technology spotlight audit specifically aims to:

- Determine the prevalence of use of diabetes-related technologies amongst children and young people with Type 1 diabetes across England and Wales
- Highlight PDU level and regional differences in access to, and funding of such technologies, including:
  - Funding sources
  - Waiting times to initiation
  - Competency criteria needed for patient selection
  - Hospital Trust/Health Board policies for implementation and withdrawal
- Establish the type of support children and young people and their families receive when utilising diabetes-related technology, including:
  - Staff education
  - Ongoing clinical support
  - Access to technical support



- Enable benchmarking and comparison between nations, regions and PDUs of staff in terms of support for use of diabetes-related technologies for children and young people
- Establish relationships between diabetes related technology usage and patient outcomes.

The most recent national PDU-level insulin pump survey was conducted by Diabetes UK (DUK), the Juvenile Diabetes Research Foundation (JRDF), and the Association of British Clinical Diabetologists (ABCD, 2014). Since the 2014 audit, a wider range of technologies have become available. This report therefore provides a timely update on progress to providing NICE-approved technologies to children and young people with diabetes.

## Methodology

The diabetes-related technologies spotlight audit questions were adapted from the United Kingdom Insulin Pump Audit published by Diabetes UK (DUK), Juvenile Diabetes Research Foundation (JRDF), and the Association of British Clinical Diabetologists (ABCD, 2014). These were refined taking into account the National Diabetes Audit (adults) insulin pump and technologies audit running in parallel (NHS Digital, 2019). These were supplemented by questions prioritised by the multidisciplinary NPDA Dataset and Methodology Group (DSMG). Collection of the resultant dataset was then piloted by clinical members of the DSMG. Refinements were made before the spotlight audit survey was launched online with data collection between 14 September and 09 November 2018.

Each PDU in England and Wales were requested to complete the survey, with the instruction that the questions should be answered based on the situation at their PDU on the 31 March 2018 - the last day of the 2017-18 NPDA audit year. This enabled comparison between the spotlight PDU level submission data, and the patient level data for children and young people from the 2017/18 core audit. It was recommended that the survey was completed as a multidisciplinary team, to ensure accuracy of submitted information. PDUs were asked to consider all children and young people that they had primary responsibility for in their responses, including those attending transition clinics if responsibility was retained for these.

One hundred and seventy-three submissions were received, covering all PDUs in England and Wales. Three PDUs who had previously submitted a combined submission to the NPDA sent data for three separate teams within their Trust, and three PDUs within the same Health Board in Wales submitted a joint submission.

## How to read this report

All responses to the spotlight survey received are presented in the data tables towards the end of this report, broken down by country and regional network. The 'Key Findings' section highlights the most notable results and provides further breakdowns to show regional variation on certain key metrics.

Where PDU practice is compared against outcomes, the outcome (HbA1c) data is taken from the patient-level data submitted by PDUs for the NPDA core audit (2017/18).

# Key findings

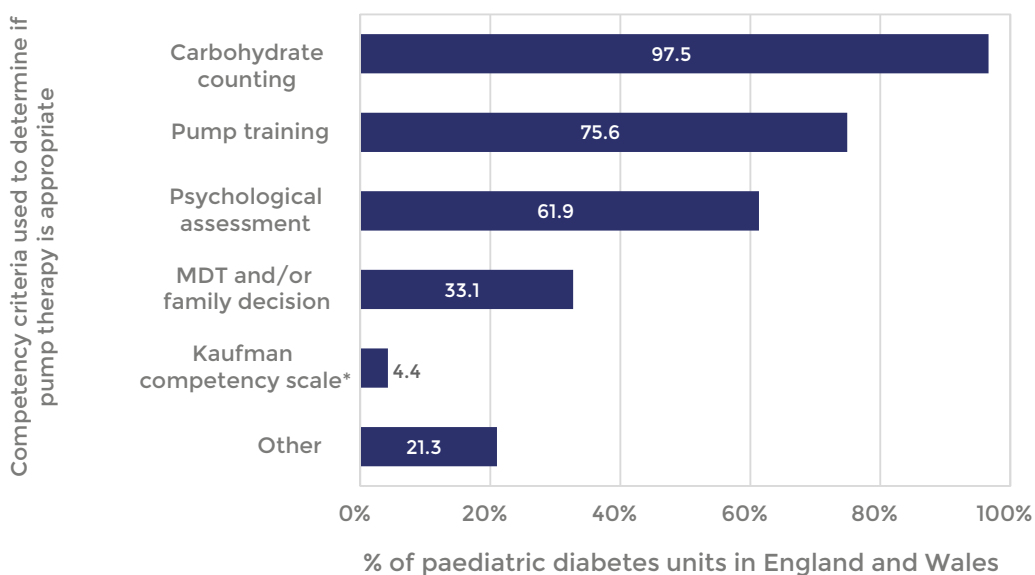
## Treatment regimen at diagnosis of Type 1 diabetes

- In the first month following diagnosis of Type 1 diabetes, the majority (81.5%) of PDUs reported that they typically managed their newly diagnosed children and young people with multiple daily injections (MDI), as recommended by NICE (NG18, 2015). One PDU reported that they typically used pre-mixed insulin, one other used a combination of MDI and pre-mixed insulin, and the remainder of PDUs (17.3%) reported that they typically used a combination of MDI and insulin pump therapy.
- No PDUs reported typically starting all newly diagnosed children and young people with Type 1 diabetes on insulin pump therapy within the first month of diagnosis.
- Over three-quarters (76.7%) of PDUs did not start any child or young person with Type 1 diabetes on insulin pumps within the first month of diagnosis.

## Initiating and discontinuing insulin pump therapy

- The spotlight audit reported 38.5% of children and young people with Type 1 diabetes as using insulin pump therapy on 31 March 2018. This is comparable to the findings of the 2017/18 NPDA core audit which found that for 35.7% of children and young people with Type 1 diabetes, the most recent insulin delivery regimen was recorded as insulin pump therapy within the audit year.
- Almost all (92.5%) PDUs reported that they required some form of competency criteria to be met to determine if insulin pump therapy was appropriate for both newly diagnosed or established children and young people with Type 1 diabetes.
- Of these (n=160), the most common criterion was a competency in carbohydrate counting (Figure 1):

**Figure 1: Percentage of PDUs using each competency criterion to determine if insulin pump therapy is appropriate for both newly diagnosed or established children and young people with Type 1 diabetes**



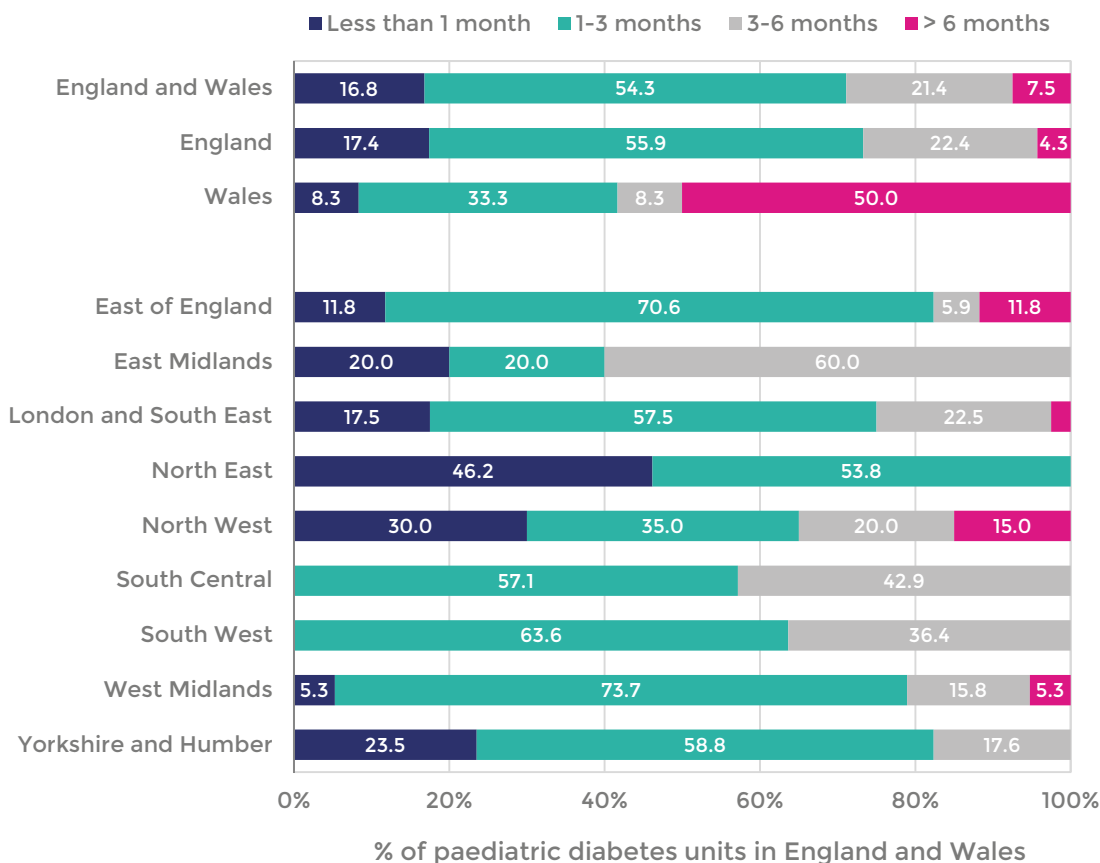
\*A set of standardised criteria developed by [Kaufman et al \(2001\)](#).

- One-sixth (16.8%) of PDUs reported a wait of less than one month between approval for insulin pump therapy and initiation of treatment. However, just over half (54.3%) reported a typical wait of one to three months, and 7.5% reported a typical wait of six months or greater.



- Waiting times for initiation of insulin pump therapy varied by country and region, with half of the 12 PDUs in Wales reporting a typical wait of six months or greater after approval compared to 4.3% of 161 English PDUs (Figure 2).

**Figure 2: Typical wait time for insulin pump initiation following approval by country and region, 2017/18**

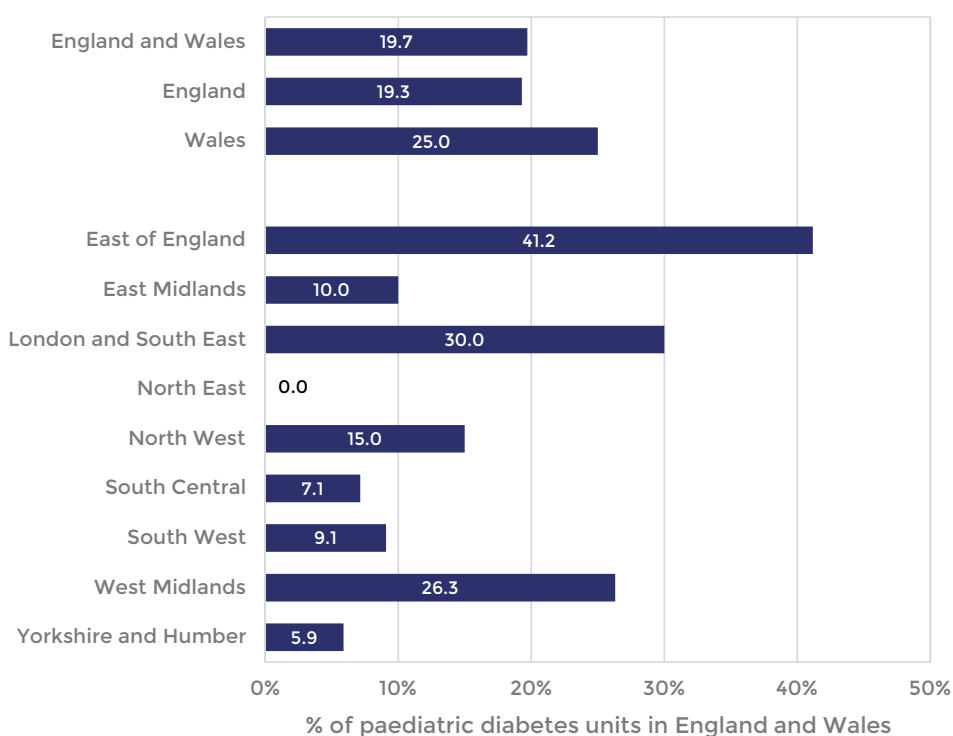


- A quarter (24.3%) of PDUs reported that they had had to suspend insulin pump initiation within the previous two years, with the most common reasons being a lack of paediatric diabetes specialist nurse (PDSN) workforce (88.1%) and lack of dietetic workforce (26.2%).
- There was no significant difference in PDSN or dietitian caseload between PDUs that had suspended insulin pump starts in the previous year.
- Most (89.6%) PDUs utilised the assistance of an insulin pump company representative at insulin pump therapy initiation, with 49.1% reporting that they were always present, and 40.5% reporting that they were sometimes present.
- At PDUs where a company representative is always or sometimes present at insulin pump therapy initiation, healthcare professionals were also always present at all but two PDUs.
- Just over a third (38.7%) of PDUs had a written policy or guideline for insulin pump therapy discontinuation or withdrawal when it is ineffective or unsafe.

## Insulin pump usage and support

- A fifth (19.7%) of PDUs had a dedicated insulin pump therapy clinic but there was considerable regional variation (Figure 3). PDUs with dedicated insulin pump clinics overall tended to have a lower proportion of children and young people with Type 1 diabetes on insulin pump therapy (33.6%) compared to those that had no such service (39.7%).

**Figure 3: Percentage of PDUs with a dedicated insulin pump therapy clinic by country and region, 2017/18**



- In all PDUs, 100% of PDSNs were involved in ongoing training for children and young people and parents and carers on insulin pump therapy use, with 78.6% of dietitians, 71.1% of consultants, and 43.4% of insulin pump company representatives also being involved in such training.
- Children and young people at all but two PDUs (one without provision and one with missing data) had access to 24-hour technical (non-clinical) support for using insulin pump therapy.
- Where provided, 24-hour technical (non-clinical) insulin pump support was most commonly provided by insulin pump companies (at 98.2% of PDUs), followed by PDSNs (at 23.4% of PDUs).
- The majority (89.0%) of PDUs reported replacing insulin pumps immediately once beyond their warranty date (normally 4 years).

## Insulin pump use during a hospital admission

- Two thirds (65.1%) of PDUs had a written policy and/or guideline for the management of children and young people with diabetes on insulin pump therapy who are admitted to hospital, and 95.8% had a written policy/guideline for those undergoing a surgical procedure.
- Almost all (99.4%) of PDUs had provision for children and young people with diabetes on insulin pumps for their parents to continue to self-manage (when clinically appropriate) after admission to hospital.

## Insulin pump training within the MDT

- The majority of consultants (89.9%), PDSNs (91.6%) and dietitians (75.5%) working in PDUs had attended a recognised insulin pump training programme.
- In PDUs who reported psychology support (n= 154), 14.3% had at least one psychologist who had been insulin pump trained. In PDUs with a diabetes educator (n= 19), 63.2% had at least one diabetes educator that had been insulin pump trained.

## Use of glucose monitoring technologies (continuous and flash glucose monitors)

- One-tenth (9.7%) of the 25,687 children and young people from 162 PDUs who provided data were using a continuous glucose monitor (CGM) with alarms (not including flash glucose monitoring or DIY closed loop systems). This was similar to the percentage of children and young people with Type 1 diabetes reported to the 2017/18 NPDA core audit using CGM with alarms (9.4%).
- The majority (78.5%) of patients using CGM were receiving insulin via an insulin pump. This is similar to the results of the 2017/18 core audit where 76.4% (1,519/1,988) of children and young people with Type 1 diabetes using CGM were on insulin pump therapy.
- In PDUs providing numbers, 2,505 (12.9% of the total caseload) children and young people with Type 1 diabetes were reported as using Freestyle Libre. However, a quarter (24.3%) of PDUs did not know how many of their caseload were using such devices.
- Twenty-nine children and young people in total for England and Wales were reported to be using a DIY closed loop artificial pancreas to manage their diabetes (an unapproved system used outside of a clinical trial). Nine PDUs were unaware if any children and young people within their caseload were using such a system.

## Funding for diabetes technologies

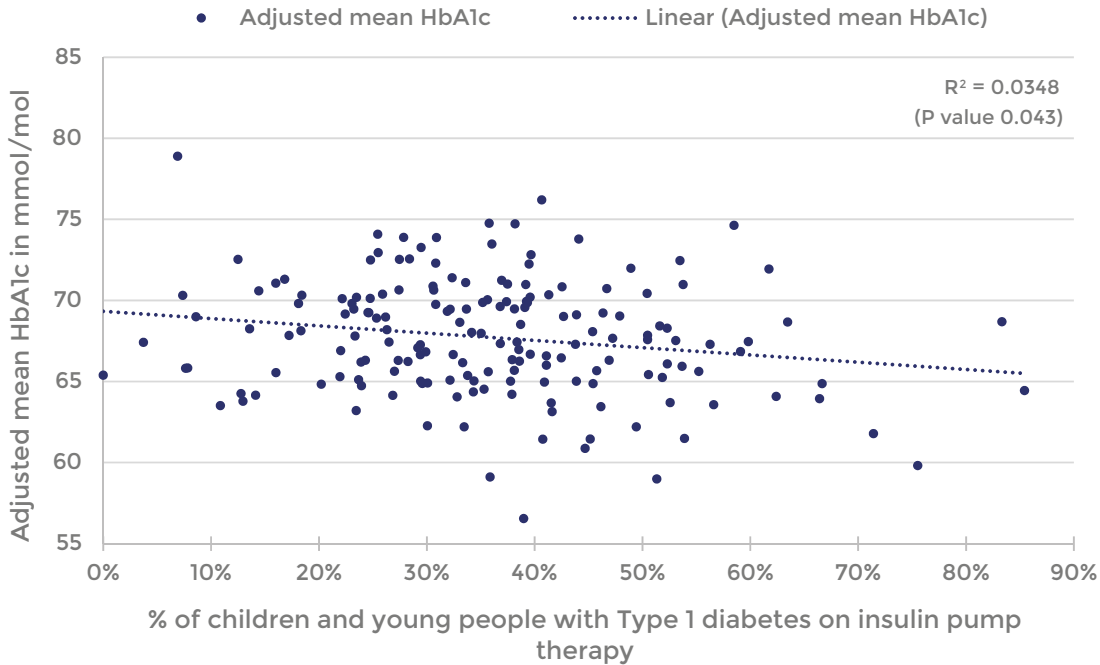
- Almost all (99.9%) children and young people with Type 1 diabetes managed on insulin pump therapy had their insulin pump funded by the NHS. The majority (85.4%) of those using CGM were funded by the NHS, with most of the rest being self-funded (11.4%).

## HbA1c outcomes by treatment regimen and CGM usage

- The 2017/18 NPDA report (RCPC, 2019) showed that insulin pump use and use of CGM is more prevalent amongst children and young people with characteristics associated with lower HbA1c including younger age, shorter duration of diabetes, White ethnicity and living in the least deprived areas. It also showed that on average, users of insulin pump therapy and CGM achieved lower HbA1c targets. However, the NPDA has not previously examined whether better outcomes associated with insulin pump and/or CGM usage are attributable to the characteristics of the children and young people with diabetes using these technologies.
- Data from the NPDA 2017/18 core audit showed that there was a small, yet statistically significant, inverse relationship between the case mix adjusted mean HbA1c and the percentage of children and young people with Type 1 diabetes using insulin pump therapy within each PDU (Figure 4). This means that there was a slight trend towards lower HbA1c at PDUs with higher percentages of insulin pump users once the case mix factors recorded by the audit had been controlled for (Figure 4). However, only 3.5% of the variability of mean adjusted HbA1c could be accounted for by the proportion of insulin pump users.
- There was no significant relationship between (unadjusted) median PDU HbA1c and the

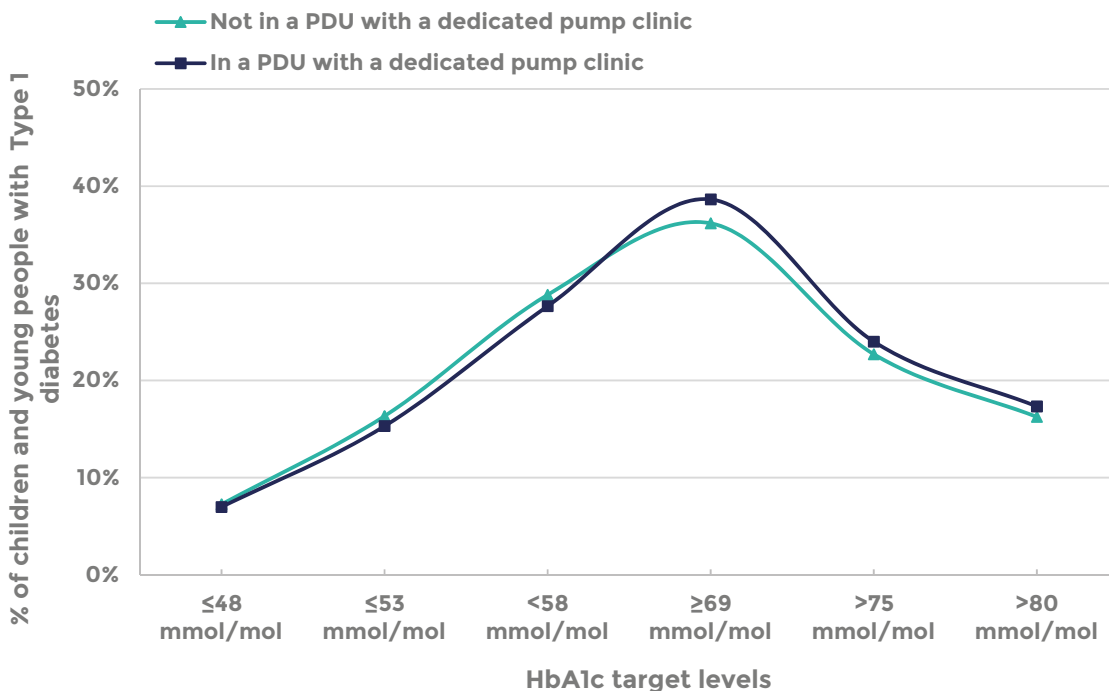
proportion of patients with Type 1 diabetes using an insulin pump within each clinic, with an R-squared 0.020 (P value 0.077).

**Figure 4: Case mix adjusted mean HbA1c and percentage of children and young people using an insulin pump by PDU, 2017/18**



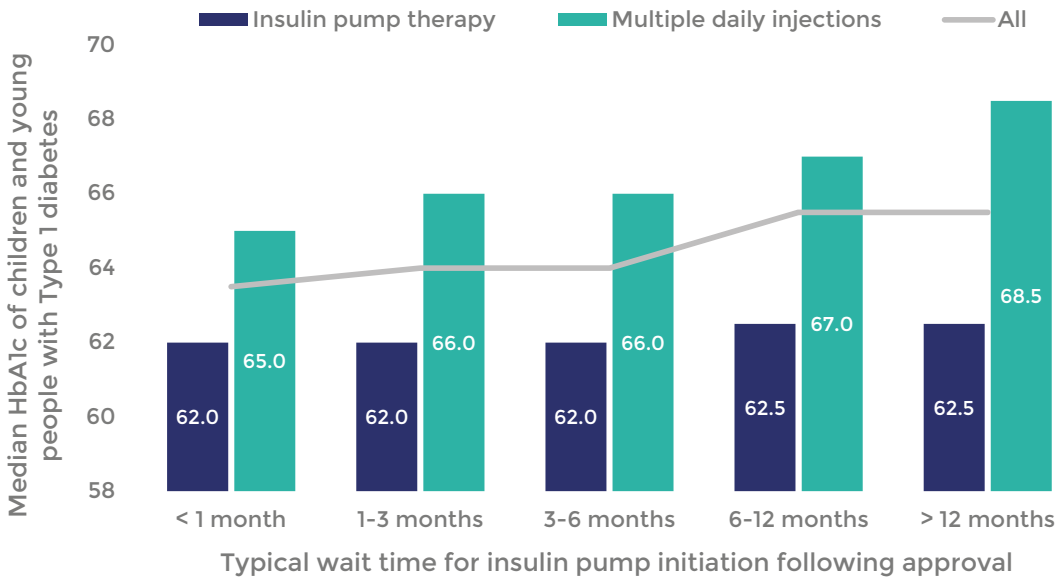
- There was no difference between achievement of HbA1c targets between children and young people using insulin pump therapy attending a PDU with a dedicated insulin pump clinic and those attending a PDU without one (Figure 5).

**Figure 5: Percentage of children and young people with Type 1 diabetes achieving HbA1c targets by PDUs with a dedicated insulin pump clinic or not, 2017/18**



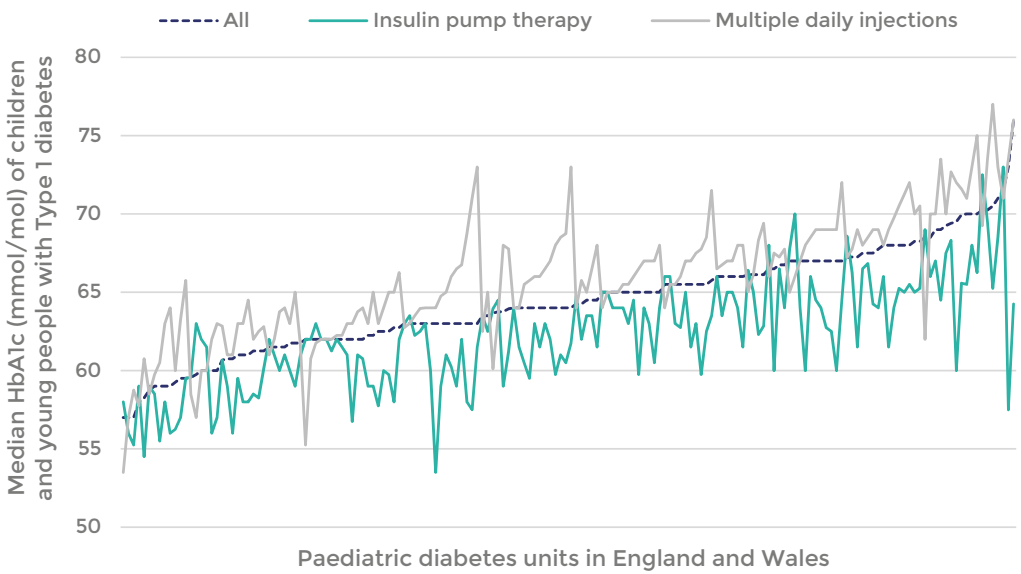
- In PDUs where the wait for initiation of insulin pump therapy was longer, there was a trend towards a higher median HbA1c amongst children and young people with Type 1 diabetes using MDI. The median HbA1c of children and young people already using insulin pump therapy did not tend to vary according to waiting time for insulin pump initiation (Figure 6). There are likely many factors contributing to this difference in outcomes.

**Figure 6: Median HbA1c of children and young people with Type 1 diabetes by current treatment regimen and typical wait time for pump initiation following approval.**



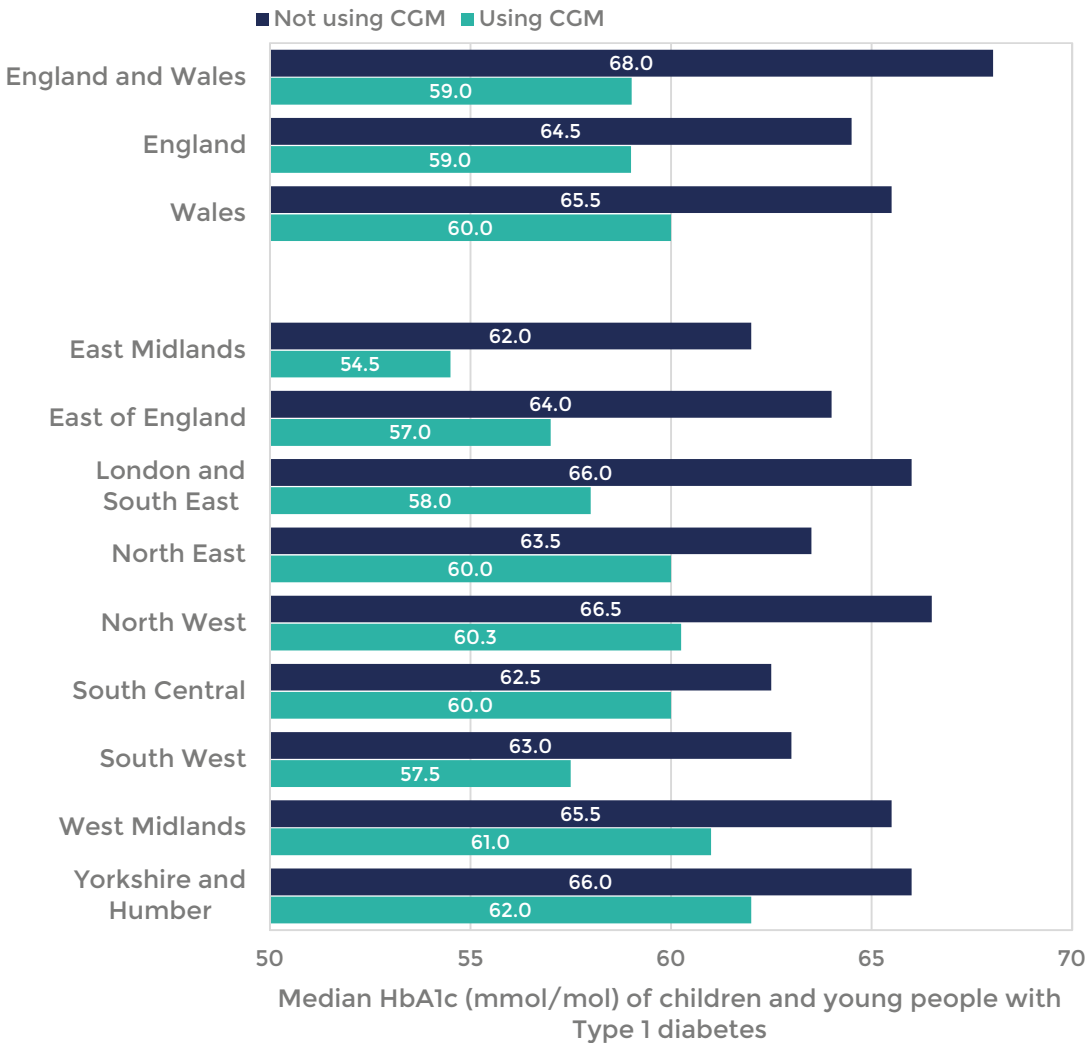
- The median HbA1c was lower amongst those on insulin pump therapy compared to MDI in the majority of PDUs (82.6%). Figure 7 shows the median HbA1c of children and young people with Type 1 diabetes by PDU in England and Wales in 2017-18, and the median HbA1c of those on insulin pump therapy and MDI within each. There is a trend for PDUs with lower overall median HbA1c to have lower median HbA1c amongst both insulin pump and MDI users, with a greater difference in PDUs with a higher overall median HbA1c.

**Figure 7: Median HbA1c of all children and young people with Type 1 diabetes by PDU, broken down by those using insulin pump therapy and MDI, in England and Wales 2017-18**



- Data from the NPDA 2017/18 core audit shows that median HbA1c was lower amongst those using CGM compared to those not using CGM in England and Wales, and in all regions. This was found in almost all (144 out of 155) of the PDUs where children and young people with Type 1 diabetes were using CGM.

**Figure 8: Median HbA1c of children and young people with Type 1 diabetes using CGM or not by region and country, 2017/18**



- A multiple regression model was constructed to examine the effect of treatment regimen type and CGM usage on the HbA1c of children and young people with Type 1 diabetes. After controlling for the effect of different demographic and social characteristics, compared to children and young people using MDI without CGM, mean HbA1c was lower amongst children and young people with Type 1 diabetes who were:
  - using MDI and CGM
  - using insulin pump therapy without CGM
  - using insulin pump therapy and using CGM
- Use of insulin pump therapy combined with CGM was associated with the greatest difference in mean HbA1c, with a reduction of 6.4 mmol/mol (P-value <0.001), compared to those using MDI without CGM. This was followed by use of insulin pump therapy without CGM, with a difference 5.0 mmol/mol (P-value <0.001).
- Children and young people on MDI and CGM had, on average, a lower HbA1c of 2.6 mmol/mol (P-value =0.001), compared to those who were not using CGM.



**Table 1: Results of regression analysis of mean HbA1c by treatment regimen compared to MDI alone taking into account measurable socio-demographic co-factors.**

Variable	Change in mean HbA1c (mmol/mol) (95% CI)	P-value
<b>Treatment regimen and CGM usage (cf to MDI alone)</b>		
On MDI and using CGM	-2.57 (-4.06 to -1.07)	0.001
On insulin pump therapy and not using CGM	-4.94 (-5.44 to -4.44)	0.000
On insulin pump therapy and using CGM	-6.36 (-7.24 to -5.47)	0.000
<b>Male (cf female)</b>		
Male (cf female)	-1.27 (-1.71 to -0.84)	0.000
<b>Age (in whole years)</b>		
Age (in whole years)	0.74 (0.68 to 0.81)	0.000
<b>Duration (in whole years)</b>		
Duration (in whole years)	0.83 (0.76 to 0.9)	0.000
<b>Ethnic group (cf White)</b>		
Asian	0.35 (-0.65 to 1.35)	0.489
Black	5.69 (4.47 to 6.9)	0.000
Mixed	2.25 (0.85 to 3.64)	0.002
Other	-0.54 (-1.98 to 0.91)	0.467
Not stated or unknown	-0.03 (-1 to 0.93)	0.945
<b>Deprivation (cf most deprived)</b>		
Second most deprived	-1.85 (-2.53 to -1.17)	0.000
Third least deprived	-2.83 (-3.52 to -2.14)	0.000
Second least deprived	-3.93 (-4.62 to -3.23)	0.000
Least deprived	-5.73 (-6.43 to -5.04)	0.000
<b>Constant</b>		
Constant	60.17 (59.27 to 61.07)	0.000
Adjusted R-squared 14.4%		
N = 19,932 includes all children and young with Type 1 diabetes reported to the 2017/18 NPDA with a valid record for: treatment regimen of insulin pump therapy or multiple daily injections; CGM usage; gender; age; duration; ethnicity; and deprivation.		

- It is important to note that this analysis was conducted using patient-level data collected as part of the NPDA 2017/18 core audit. NPDA data is descriptive rather than experimental data which means that we are unable to fully control for all confounding factors. As a result, there are likely other factors that are not accounted for in the model (including information about use of flash glucose monitoring systems not collected as part of the NPDA patient level dataset) which are contributing to the difference in outcomes.

## Discussion

This PDU level spotlight audit on the usage of diabetes related technology has demonstrated huge variation in practice across England and Wales. Although over 80% of PDUs generally start all newly diagnosed children and young people with Type 1 diabetes on MDI regimens, the trend is towards increasing use of diabetes related technologies with nationally just over 1 in 3 children with Type 1 diabetes using an insulin pump and 1 in 10 using CGM. It is important therefore, that those prescribing and initiating the use of such technologies at great cost to the NHS are using them to their full capability.

Although NICE (NG18, TA151) recommends use of insulin pumps and CGM in certain cases, the benefits in terms of improved blood glucose levels and HbA1c are often small and financially costly. However, this must be carefully balanced against potential improvements in quality of life and reduced burden of disease in children and young people and their families and the potential reduction in long term risks of future complications. The importance of the data from this audit is that this is a natural experiment rather than a controlled trial. This makes the findings of better glycaemic control in those using these technologies even more powerful. However, there remains much to learn from the variability in practice and how this impacts on quality improvement.

It is reassuring to know from this audit that almost all PDUs (>90%) are applying some form of competency/ training programme before initiating insulin pump therapy in an aim to ensure appropriate selection of patients and education. It is also good to see that in nearly all PDUs, NHS funding is now provided for those requiring diabetes-related technology. However, there remains a large variation in outcomes between PDUs despite the use of such selection criteria. More needs to be done to ensure efficient usage of limited resources. It is notable that the majority of PDUs are utilising the assistance of insulin pump company representatives at the initiation of pump therapy. PDUs should provide a wide choice of pumps in order to facilitate shared decision making around pump choice, but there is potential for constraints around this if PDUs have stronger relationships with particular pump companies over others.

Cost benefit remains difficult to calculate in children with Type 1 diabetes as no studies have followed the whole life course of individual patients. Although not within the remit of audit, there is evidence that such interventions and intensification of therapy may provide long term savings. For example, Herman et al., (2018) undertook an economic analysis of the results from the diabetes control and complications trial/epidemiology of diabetes interventions and complications (DCCT/EDIC) and found evidence of value for money when the least expensive intensive therapy needed to safely achieve treatment goals for patients with Type 1 diabetes is used. This is important as not all children and young people need such technologies to achieve excellent outcomes. In this audit, Figure 7 shows us that PDUs who achieve well overall in terms of median HbA1c achieve comparatively better results for both MDI and insulin pump users. This tends to suggest there are circumstances where MDI and insulin pump users can do equally well. In order to identify and support best practice in education and management for users of insulin pumps and MDI the NPDA will break down unit level HbA1c outcome by treatment regimen in future rounds of audit.

Waiting times in excess of 6 months must be frustrating and unacceptable to most families who have made a decision to use diabetes-related technology. The evidence from this audit that PDUs with longer waits are associated with poorer HbA1c is worrying. It suggests that there is something intrinsically different in the way such services with longer waits are managed that leads to poorer outcomes. Every PDU needs to examine their waiting lists and explore the reason behind long waits.

The finding of an association between median HbA1c and the proportion of children and young people in a PDU using insulin pump therapy is of interest, but it only accounts for 3.5% of the variability

suggesting intrinsic differences in the way individual PDUs are using and managing such technology. This is further confounded by the finding that running dedicated insulin pump services within a PDU makes no difference to the achievement of target HbA1c levels. This tends to suggest that there is a lot to learn from each other regarding the optimal usage of technologies that are designed to improve diabetes control and quality of life and does not support the hypothesis that increasing technology usage in a PDU will improve average HbA1c. PDUs need to explore their operating procedures before embarking on a 'technology for all' strategy. Following future rounds of audit, and where numbers allow, the NPDA will publish PDU-level HbA1c data taking into account case-mix for those on insulin pumps and MDI separately as well as combined in order to identify which PDUs are achieving the best outcomes for children and young people using insulin pumps. This will enable identification of PDUs whose practices are supporting the best outcomes for those using insulin pumps and will support the identification and sharing of best practice.

One in eight children were using flash glucose monitoring as a method for monitoring glucose control. However, it is of concern that a quarter of PDUs did not know how many of their caseload were using such devices. It was not possible to explore outcomes for those using flash glucose monitoring using NPDA data as it is not collected at patient level. It is likely that use of flash monitoring has increased significantly since these spotlight audit data were collected since flash glucose monitors have become available on prescription in England and Wales for children and young people meeting necessary criteria in the meantime.

Twenty-nine children and young people in total for England and Wales were reported to be using a DIY closed loop artificial pancreas system to manage their diabetes (an unapproved system used outside of a clinical trial). This may represent an underestimate as many PDUs were unaware if any of their families were using this technology.

Finally, in this large cohort of children and young people, the regression modelling clearly demonstrates improvements in HbA1c with the use of insulin pump. This improvement is augmented further by combining the use of insulin pump with CGM and is reassuring when one considers the financial outlay for new technologies. This effect has also been demonstrated in other parts of Europe (Mönkemöller, 2019) and the USA (Foster, 2019). However, the regression model also evidences inequalities in outcomes as children or young people living in the least deprived areas can be expected to have an HbA1c that is 5.7 mmol/mol lower than a patient living in the most deprived areas. Furthermore, some black and minority ethnic (BME) groups collectively have higher HbA1c compared to those of white ethnicity which needs addressing. Since only 14.4% of the variation in HbA1c is explained by the model, there are likely other factors which are contributing to the difference in outcomes that were not included in the analysis, such as clinic level factors, individual and family factors, and wider socio-economic factors. This requires ongoing surveillance through quality assurance programmes to ensure PDUs are supported in their goal to achieve better outcomes for children and young people with diabetes who deserve nothing less.

## Conclusion

This diabetes related technology audit has uncovered large variability in practice across PDUs in England and Wales in both usage and outcomes. Although the modelling suggests that the use of an insulin pump and CGM might lead to an improved HbA1c, it is not clear how optimal usage of such technologies within a PDU or across PDUs might be achieved so that everyone has that opportunity. Unmeasurable clinic factors must come into play to account for the variability which need open discussion through national and local networks.

# Recommendations

## For PDUs:

1. Each multidisciplinary team should review their practice in the usage and outcomes associated with use of diabetes related technology in comparison to national and regional findings in this report, using the unit level summaries published alongside this report.
2. Each PDU should understand and take into account the potential benefits that insulin pump therapy and CGM might provide individual patients with Type 1 diabetes regardless of their demographics.
3. PDUs with longer waiting times for insulin pump initiation should discuss with their funding bodies to ensure a more timely pathway to initiation.
4. All PDUs should have a written policy or guideline for insulin pump therapy discontinuation or withdrawal when it is ineffective or unsafe.
5. All PDUs should have a written policy and/or guideline for the management of children and young people with diabetes on insulin pump therapy who are admitted to hospital, and all should have a written policy/guideline for the those undergoing a surgical procedure.

## For regional networks:

6. Discussion of the variability in the usage and outcomes associated with use of diabetes related technology should be added to regional network meeting agendas with a view to reducing inequities between PDUs and maximising potential benefits.
7. Discussions at regional and national meetings should be added to their respective agendas to establish best practice for utilising the support of insulin pump company representatives at the initiation of insulin pump therapy to maximise the benefits of their input whilst also ensuring real patient choice in the selection of pump.

## For commissioners:

8. Commissioners should note the potential benefits of use of insulin pumps and CGM and facilitate access when clinically indicated.
9. Commissioners should support PDUs to enable timely initiation of insulin pump therapy once requested by clinical teams.

## Data tables

For patient level data, the total number of patients in the denominator will be the total number of patients reported by the clinics returning data for each question.

Q no.	Question	Data item	England and Wales	England	Wales
	Number of paediatric diabetes units who submitted spotlight data	Total - n	173	161	12
	Number of patients with Type 1 diabetes receiving treatment within PDUs on 31st March 2018.	Total - n	25847	24549	1298
	Number of patients with other types of diabetes receiving treatment within PDUs on 31st March 2018.	Total - n	1243	1205	38
	Number of patients with all types of diabetes receiving treatment within PDUs on 31st March 2018.	Total - n	27090	25754	1336
	Number of newly diagnosed children with Type 1 diabetes receiving care from a PDU within the audit year (1st April 2017 to 31st March 2018)	Total - n	3267	3072	195
18	At diagnosis (within the first month), which best describes your unit's practice with regards to how newly diagnosed children and young people with Type 1 diabetes are managed?	Multiple daily injections using a basal bolus regimen - % (n/N)	81.5 (141/173)	81.4 (131/161)	83.3 (10/12)
		Premixed insulin - % (n/N)	0.6 (1/173)	0.6 (1/161)	0 (0/12)
		Insulin pump therapy - % (n/N)	17.3 (30/173)	17.4 (28/161)	16.7 (2/12)
		A combination of multiple daily injections and/or insulin pump therapy - % (n/N)	0.6 (1/173)	0.6 (1/161)	0 (0/12)
		Other - % (n/N)	0.0 (0/173)	0.0 (0/161)	0.0 (0/12)
19	Within the previous year (1st April 2017- 31st March 2018), how many children and young people with Type 1 diabetes started on pumps within a month of diagnosis?	Percentage of units with a known response - % (n/N)	94.2 (163/173)	94.4 (152/161)	91.7 (11/12)
		Percentage of units where at least one child or young person with Type 1 diabetes started on pumps within a month of diagnosis- % (n/N)	23.3 (38/163)	24.3 (37/152)	9.1 (1/11)
		Total - % (n/N)	2.7 (83/3084)	2.8 (81/2919)	1.2 (2/165)
		rate per 10,000 patients	200.6	201.1	189.8

Q no.	Question	Data item	England and Wales	England	Wales
21	On 31st March 2018, how many of your Type 1 patients (in total: new and follow up) were you managing on insulin pump therapy?	Percentage of units with a known response - % (n/N)	100.0 (173/173)	100.0 (161/161)	100.0 (12/12)
		Percentage of units managing children or young people with Type 1 diabetes on insulin pump therapy on 31 March 2018- % (n/N)	100.0 (173/173)	100.0 (161/161)	100.0 (12/12)
		Total - % (n/N)	38.5 (9957/25847)	38.6 (9477/24549)	37 (480/1298)
		rate per 10,000 patients	85.4	85.7	79.3
22	Of the total number of Type 1 diabetes patients managed on insulin pump therapy, please enter the number of patients who had their pump funded by each method below:	<b>NHS funded</b>			
		Percentage of children and young people - % (n/N)	99.9 (9947/9957)	99.9 (9467/9477)	100 (480/480)
		Number of PDUs -n	173	161	12
		<b>Self-funded</b>			
		Percentage of children and young people - % (n/N)	0.04 (4/9957)	0.04 (4/9477)	0 (0/480)
		Number of PDUs -n	3	3	0
		<b>Other methods</b>			
		Percentage of children and young people - % (n/N)	0.04 (4/9957)	0.04 (4/9477)	0 (0/480)
		Number of PDUs	2	2	0
		<b>Don't know</b>			
	Percentage of children and young people - % (n/N)	0.02 (2/9957)	0.02 (2/9957)	0.02 (2/9957)	
	Number of PDUs	1	1	1	
23	Do you have a dedicated insulin pump therapy clinic (for patients on pump only)?	Yes - % (n/N)	19.7 (34/173)	19.3 (31/161)	25 (3/12)
		No - % (n/N)	79.2 (137/173)	80.1 (129/161)	66.7 (8/12)
		Don't know - % (n/N)	1.2 (2/173)	0.6 (1/161)	8.3 (1/12)
24	When starting a patient on an insulin pump do you require competency criteria to be met to determine if pump therapy is appropriate for newly diagnosed or established patients with Type 1 diabetes?	Yes - % (n/N)	92.5 (160/173)	94.4 (152/161)	66.7 (8/12)
		No - % (n/N)	6.9 (12/173)	5.6 (9/161)	25 (3/12)
		Don't know - % (n/N)	0.6 (1/173)	0 (0/161)	8.3 (1/12)
25	What competency criteria do you require to determine if pump therapy is appropriate? (Select all that apply):	Pump training - % (n/N)	75.6 (121/160)	75.7 (115/152)	75 (6/8)
		Psychology - % (n/N)	61.9 (99/160)	61.8 (94/152)	62.5 (5/8)
		MDT and/or family - % (n/N)	33.1 (53/160)	33.6 (51/152)	25 (2/8)
		Kauffman - % (n/N)	4.4 (7/160)	4.6 (7/152)	0 (0/8)
		Carbohydrate counting - % (n/N)	97.5 (156/160)	97.4 (148/152)	100 (8/8)
		Other - % (n/N)	21.3 (34/160)	21.7 (33/152)	12.5 (1/8)



Q no.	Question	Data item	England and Wales	England	Wales
26	How long do your established patients typically wait for pump initiation following approval?	Less than 1 month	16.8 (29/173)	17.4 (28/161)	8.3 (1/12)
		1-3 months	54.3 (94/173)	55.9 (90/161)	33.3 (4/12)
		3-6 months	21.4 (37/173)	22.4 (36/161)	8.3 (1/12)
		6-12 months	6.9 (12/173)	4.3 (7/161)	41.7 (5/12)
		> 12 months	0.6 (1/173)	0 (0/161)	8.3 (1/12)
27	Within the past two audit years (1st April 2016 – 31st March 2018) has your service had to suspend insulin pump starts?	Yes - % (n/N)	24.3 (42/173)	19.9 (32/161)	83.3 (10/12)
		No - % (n/N)	75.1 (130/173)	79.5 (128/161)	16.7 (2/12)
		Don't know - % (n/N)	0.6 (1/173)	0.6 (1/161)	0 (0/12)
28	If your service suspended insulin pump starts, what was the reason for this? (Select all that apply)	Lack of PDSN resources - % (n/N)	88.1 (37/42)	84.4 (27/32)	100 (10/10)
		Lack of dietetic resources - % (n/N)	26.2 (11/42)	18.8 (6/32)	50 (5/10)
		Lack of funding - % (n/N)	14.3 (6/42)	12.5 (4/32)	20 (2/10)
		Lack of diabetes educator resources - % (n/N)	4.8 (2/42)	3.1 (1/32)	10 (1/10)
		Lack of medical resources - % (n/N)	4.8 (2/42)	6.3 (2/32)	0 (0/10)
		Other - % (n/N)	11.9 (5/42)	12.5 (4/32)	10 (1/10)
29	Are insulin pumps in your service which are beyond their (normally 4 years) warranty replaced immediately (if still clinically appropriate)?	Yes - % (n/N)	89 (154/173)	90.1 (145/161)	75 (9/12)
		No - % (n/N)	8.1 (14/173)	7.5 (12/161)	16.7 (2/12)
		Don't know - % (n/N)	2.9 (5/173)	2.5 (4/161)	8.3 (1/12)
30	Is a company representative present at your insulin pump therapy starts?	Yes, always - % (n/N)	49.1 (85/173)	50.3 (81/161)	33.3 (4/12)
		Yes, sometimes - % (n/N)	40.5 (70/173)	39.8 (64/161)	50 (6/12)
		No - % (n/N)	9.8 (17/173)	9.3 (15/161)	16.7 (2/12)
		Don't know - % (n/N)	0.6 (1/173)	0.6 (1/161)	0 (0/12)
31	If a company representative is always or sometimes present at your insulin pump therapy starts, is a healthcare professional also always present?	Yes - % (n/N)	98.7 (153/155)	98.6 (143/155)	100 (10/155)
		No - % (n/N)	0.6 (1/155)	0.7 (1/155)	0 (0/155)
		Don't know - % (n/N)	0.6 (1/155)	0.7 (1/155)	0 (0/155)
32	Which of the following members of staff provide ongoing training for patients/parents/carers on insulin pump therapy use? (Select all that apply)	Consultant - % (n/N)	71.1 (123/173)	71.4 (115/161)	66.7 (8/12)
		PDSN - % (n/N)	100 (173/173)	100 (161/161)	100 (12/12)
		Dietitian - % (n/N)	78.6 (136/173)	78.3 (126/161)	83.3 (10/12)
		Psychologist - % (n/N)	16.2 (28/173)	15.5 (25/161)	25 (3/12)
		Diabetes educator - % (n/N)	4.05 (7/173)	3.73 (6/161)	8.33 (1/12)
		Pump company representative - % (n/N)	43.4 (75/173)	42.2 (68/161)	58.3 (7/12)
33	Does your unit have a written policy/guideline for the management of children and young people with diabetes on insulin pump therapy who are admitted to hospital?	Yes - % (n/N)	65.1 (110/169)	65.6 (103/157)	58.3 (7/12)
		No - % (n/N)	33.1 (56/169)	32.5 (51/157)	41.7 (5/12)
		Don't know - % (n/N)	1.8 (3/169)	1.9 (3/157)	0 (0/12)
		N/A - n	4	161	12

Q no.	Question	Data item	England and Wales	England	Wales
34	Does your unit have a written policy/guideline for the management of children and young people with diabetes on insulin pump therapy who are undergoing surgery?	Yes - % (n/N)	95.8 (160/167)	96.8 (150/155)	83.3 (10/12)
		No - % (n/N)	3.6 (6/167)	2.6 (4/155)	16.7 (2/12)
		Don't know - % (n/N)	0.6 (1/167)	0.6 (1/155)	0 (0/12)
		N/A - n	6	161	12
35	Is there provision for children and young people with diabetes on pumps or their parents to continue to self-manage (when clinically appropriate) after admission to hospital?	Yes - % (n/N)	99.4 (169/170)	99.4 (157/158)	100 (12/12)
		No - % (n/N)	0.6 (1/170)	0.6 (1/158)	0 (0/12)
		Don't know - % (n/N)	0.0 (0/170)	0.0 (0/158)	0.0 (0/12)
		N/A - n	3	161	12
36	Do you have a written policy/guideline for insulin pump therapy withdrawal when it is ineffective/unsafe?	Yes - % (n/N)	38.7 (67/173)	37.3 (60/161)	58.3 (7/12)
		No - % (n/N)	59.5 (103/173)	60.9 (98/161)	41.7 (5/12)
		Don't know - % (n/N)	1.7 (3/173)	1.9 (3/161)	0 (0/12)
37	Do your patients on insulin pump therapy have access to 24-hour technical (non-clinical) support?	Yes - % (n/N)	98.8 (171/173)	99.4 (160/161)	91.7 (11/12)
		No - % (n/N)	0.6 (1/173)	0.6 (1/161)	0 (0/12)
		Don't know - % (n/N)	0.6 (1/173)	0 (0/161)	8.3 (1/12)
38	Who provides this technical support for your patients on insulin pump therapy? (Select all that apply)	Consultant - % (n/N)	8.2 (14/171)	8.7 (14/160)	0 (0/11)
		PDSN - % (n/N)	23.4 (40/171)	25 (40/160)	0 (0/11)
		Dietitian - % (n/N)	0.6 (1/171)	0.6 (1/160)	0 (0/11)
		Pump company - % (n/N)	98.2 (168/171)	98.1 (157/160)	100 (11/11)
		Another insulin pump site - % (n/N)	1.2 (2/171)	1.3 (2/160)	0 (0/11)
		Other - % (n/N)	0.6 (1/171)	0.6 (1/160)	0 (0/11)
39	As of 31st March 2018, enter the number of consultants within your service who have ever attended a recognised insulin pump therapy training session	Total - n	356	333	23
		Percentage of consultants who have ever received pump training - % (n/N)	89.9 (356/396)	89.5 (333/372)	95.8 (23/24)
		Percentage of units that had at least one consultant who received pump training - % (n/N)	96 (166/173)	96.3 (155/161)	91.7 (11/12)
40	As of 31st March 2018, enter the number of PDSNs within your service who have ever attended a recognised insulin pump therapy training session	Total - n	513	484	29
		Percentage of PDSNs who have ever received pump training - % (n/N)	91.6 (513/560)	92.4 (484/524)	80.6 (29/36)
		Percentage of units that had at least one PDSN that received pump training - % (n/N)	98.8 (171/173)	98.8 (159/161)	100 (12/12)

Q no.	Question	Data item	England and Wales	England	Wales
41	As of 31st March 2018, enter the number of dietitians within your service who have ever attended a recognised insulin pump therapy training session	Total - n	213	200	13
		Percentage of dietitians who have ever received pump training - % (n/N)	75.5 (213/282)	75.8 (200/264)	72.2 (13/18)
		Percentage of units that had at least one dietitian who received pump training - % (n/N)	83.2 (144/173)	84.5 (136/161)	66.7 (8/12)
42	As of 31st March 2018, enter the number of psychologists within your service who have ever attended a recognised insulin pump training session	Total - n	23	20	3
		Percentage of units that had at least one psychologist who received pump training - % (n/N)	12.7 (22/173)	11.8 (19/161)	25 (3/12)
		Percentage of units with a psychologist that had at least one psychologist who received pump training - % (n/N)	13.8 (22/152)	12.5 (18/144)	37.5 (3/8)
43	As of on 31st March 2018, enter the number of diabetes educators within your service who have ever attended a recognised insulin pump training session	Total - n	38	36	2
		Percentage of units that had at least one diabetes educator who received pump training - % (n/N)	10.4 (18/173)	9.9 (16/161)	16.7 (2/12)
		Percentage of units with a diabetes educator that had at least one diabetes educator who received pump training - % (n/N)	66.7 (12/18)	62.5 (10/16)	100.0 (2/2)
44	On 31st March 2018, how many of your patients with all types of diabetes were using CGM (not including flash glucose monitoring/DIY closed loop systems)?	Percentage of units with a known response - % (n/N)	94.8 (164/173)	95 (153/161)	91.7 (11/12)
		Percentage of children and young people - % (n/N)	9.7 (2492/25687)	9.5 (2325/24426)	13.2 (167/1261)
		Percentage of PDUs caring for CYP with all types of diabetes who were using CGM	98.2 (161/164)	98 (150/153)	100 (11/11)
45	On 31st March 2018 how many of your patients using CGM (not including flash glucose monitoring/DIY closed loop systems) fell into the following categories.	Type 1 insulin-dependent diabetes mellitus - % (n/N)	9.81 (2406/24515)	9.61 (2239/23291)	13.64 (167/1224)
		All other types of diabetes - % (n/N)	3 (35/1172)	3.1 (35/1135)	0 (0/37)
		Don't know - % (n/N) of total CYP	0.2 (51/25687)	0.2 (51/24426)	0 (0/1261)
46	On 31st March 2018 how many of your patients using CGM (not including flash glucose monitoring/DIY closed loop systems) delivered insulin by the following methods?	Insulin pump - % (n/N)	80.3 (2001/2492)	82.3 (1913/2325)	52.7 (88/167)
		Daily injections - % (n/N)	14.9 (371/2492)	13.8 (322/2325)	29.3 (49/167)
		Don't know - % (n/N)	4.8 (120/2492)	3.9 (90/2325)	18 (30/167)

Q no.	Question	Data item	England and Wales	England	Wales
47	Of your patients using CGM, please enter the number of patients who had their CGM device funded by each method below:	NHS funded - % (n/N)	85.4 (2128/2492)	84.9 (1973/2325)	92.8 (155/167)
		Self-funded - % (n/N)	11.4 (284/2492)	11.7 (272/2325)	7.19 (12/167)
		Other methods - % (n/N)	0.1 (2/2492)	0.1 (2/2325)	0 (0/167)
		Don't know - % (n/N)	3.1 (78/2492)	3.4 (78/2325)	0 (0/167)
48	On 31st March 2018, how many of your patients were using a DIY closed loop artificial pancreas to manage their diabetes (i.e. an unapproved system used outside of a clinical trial)?	Percentage of units with a known response - % (n/N)	94.8 (164)	94.4 (152)	100 (12)
		Percentage of children and young people - % (n/N)	0.1 (29/25218)	0.1 (28/23882)	0.1 (1/1336)
		Number of PDUs - n	18	17	1
49	On 31st March 2018, how many of your patients with diabetes were using a Freestyle Libre?	Percentage of units with a known response - % (n/N)	75.7 (131)	76.4 (123)	66.7 (8)
		Percentage of children and young people - % (n/N)	12.9 (2505/19360)	12.8 (2367/18434)	14.9 (138/926)
		Number of PDUs - n	127	119	8
50	Of those using a Freestyle Libre, please enter the number of patients who had their Freestyle Libre funded by each method below:	<b>NHS funded</b>			
		Percentage of units with a known response - % (n/N)	89 (154/173)	90.7 (146/161)	66.7 (8/12)
		Percentage of children and young people - % (n/N)	39 (961/2463)	36.2 (842/2325)	86.2 (119/138)
		Number of PDUs - n	53	48	5
		<b>Self-funded</b>			
		Percentage of units with a known response - % (n/N)	77.5 (134/173)	77 (124/161)	83.3 (10/12)
		Percentage of children and young people - % (n/N)	63.9 (1570/2457)	66.9 (1551/2319)	13.8 (19/138)
		Number of PDUs - n	110	107	3
		<b>Other methods</b>			
		Percentage of units with a known response - % (n/N)	75.1 (130/173)	75.8 (122/161)	66.7 (8/12)
		Percentage of children and young people - % (n/N)	1 (22/2223)	1.1 (22/2085)	0 (0/138)
		Number of PDUs - n	3	3	0

# Acknowledgements

## Report Editors

- Ms Lisa Cummins, Audit Analyst, RCPCH
- Professor Justin Warner, Clinical Lead, RCPCH and Consultant in Paediatric Endocrinology and Diabetes, University of Wales Hospital
- Ms Holly Robinson, NPDA Project Manager, RCPCH

## Data Analysis

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