National Diabetes Quality Programme **Self-assessment report 2018-2022** 



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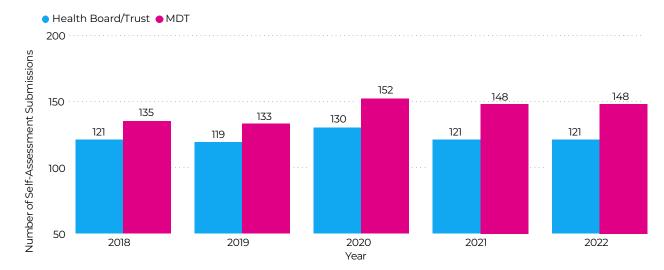
# **Overview**

The National Diabetes Quality Programme (NDQP) was established in 2018 in collaboration with the National Children and Young People's Diabetes Network and was delivered by the Royal College of Paediatrics and Child Health. The programme set out to help drive outcomes, improvements and encourage service change in paediatric diabetes care in England and Wales. The programme aimed to improve multidisciplinary care for children and young people with diabetes in the NHS, reducing unwarranted variations and involving families in service improvement in a developmental way.

Self-assessment measures were created by the NDQP in 2018 to evaluate the compliance of paediatric diabetes services across England and Wales in relation to NDQP and Best Practice Tariff (BPT) requirements.

Measures are broken down into several groups: 1) Health Board/Trust; 2) Multi-disciplinary team (MDT); and 3) Network measures. There are six key themes under Health Board/Trust measures, 27 key themes associated with MDTs, and 12 themes of Network measures. Several of the measures having sub-measures, Health Boards/Trusts are assessed against a total of 25 measures, there are 95 MDT measures in total, and 34 Network measures.

Self-assessment opens annually for 1-2 months per year and consists of MDT members submitting their compliance against the measures on behalf of their service and Health Board/ Trust. This data is signed off by the clinical lead and medical director of each Health Board/ Trust. In addition, network managers submit their compliance against the network managers, on behalf of their regional network. The total number of submissions varied per year (see Figure 1), which could be attributed to mergers between Health Boards/Trusts, MDTs who previously submitted together now submitting separately, and other competing MDT priorities and challenges, such as the Covid-19 pandemic.



The Peer Review programme associated with self-assessment, utilised external stakeholders to evaluate a service's compliance of the measures against their self-assessment scoring.

Figure 1: Number of services to have completed self-assessment per year

# Methodology

Self-assessment data was manually entered into Excel spreadsheets and analysed for the years 2018-2019. At this time, data collected could not be downloaded from the NDQP self-assessment portal. From 2020 onward, data from the portal was extracted directly and downloaded to Excel spreadsheets. Average compliance for each measure was calculated using the raw data derived from the Excel spreadsheets. Data was then uploaded to Power BI, allowing for it to be analysed. It must be acknowledged that some of the measures included in the 2018-2019 self-assessment were removed and the self-assessment was updated in 2020. Two transition and transfer measures were added in 2022, these measures were excluded from the impact report.

# Limitations

There were differences in how M.1 measures were recorded over the five years' time span. In 2018-2019, compliance was measured as a 'Yes' or 'No' for the whole MDT. From 2020 onwards, disciplines in the MDT were broken down, allowing for more complex analysis of staffing across services.

Furthermore, whilst the self-assessment data can provide insight on overall trends of compliance, actual compliance may not be reflected since the data is self-reported.

Examining the outcomes of services who were peer reviewed would provide a more accurate representation of compliance against NDQP measures, however, due to time constraints and limited resources, this was not possible for this report.

Data entered and analysed from 2018-2019 may contain entry errors due to the inability to download data directly from the NDQP portal which was achievable from 2020 onwards.

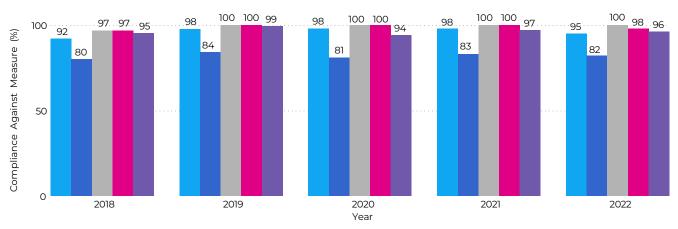
# Health Board/Trust Measures Overview

There are a total of 25 Health Board/Trust measures under six key themes (H.1.1-H.6.2) to assess compliance against NDQP and BPT standards.

Core BPT standards are marked with an asterisk (\*).

## H.1 Health Board/Trust wide Management Group

- H.1.1 There is a single, children's services management team responsible for the coordination, quality, safety and development of the service responsible for the care of CYP with diabetes in place.
- **H.1.2** Does the group meet at least quarterly (some teams may want to meet more frequently)?
- H.1.3 Membership must include the trust manager with responsibility for CYPD services
- H.1.4 Lead paediatric consultant for care of CYP with diabetes
- H.1.5 Lead paediatric specialist nurse for care of CYP people with diabetes



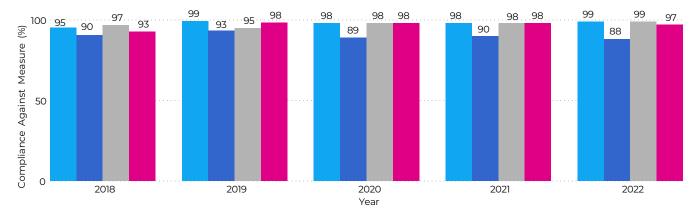
●H.1.1 ●H.1.2 ●H.1.3 ●H.1.4 ●H.1.5

### Figure 2: Compliance of H.1.1 to H.1.5 per year

- H.1.6 Lead paediatric specialist dietitian for care of CYP with diabetes
- **H.1.7** Lead clinical psychologist, trained specifically to look after children, and who has an interest in the care of CYP with diabetes
- H.1.8 Adult diabetes specialist consultant responsible for transition
- H.1.9 The group has a reporting mechanism to the trust/health board Clinical Governance/ Safety/Quality Committee(s)

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●H.1.6 ●H.1.7 ●H.1.8 ●H.1.9



### Figure 3: Compliance of H.1.6 to H.1.9 per year

#### H.1 Summary:

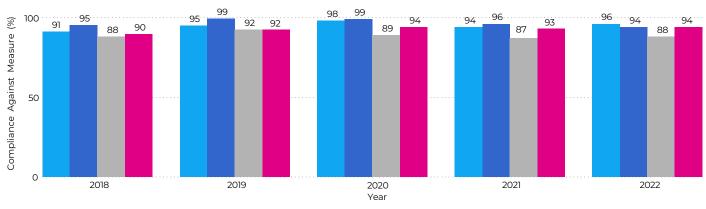
Compliance of H.1 measures stayed consistently high across the duration of the five years. H.1.3 and H.1.4 were the highest scoring measures with both scoring 96.8% in 2018 and then 100% from 2019 onwards.

### H.2 24-hour telephone advice services

**H.2.1** The hospital has agreed the CYPDN specification for 24 hours /seven day telephone advice services\*

The three levels of service are in place:

- H.2.2 For children/parents/carers\* -
- H.2.3 Forward-based staff provided by local paediatric diabetes team\*
- H.2.4 Escalation policy to a diabetes centre supported by an onsite paediatric intensive care unit?







#### H.2 Summary:

Consistent high scoring of H.2 measures were observed. Measure H.2.3 around access of 24-hour telephone advice for ward-based staff provided by local paediatric diabetes team was the lower scoring measure within this theme ranging from 87%-92% compliance. Some regions do not have formal policies for this service as observed on Peer Review which may be the reason the H.2.3 measure is not higher.

# **H.3 Device Download Facilities**

**H.3.1** There are facilities available in all clinics, on all sites, to enable the download of information from insulin pumps, continuous blood glucose monitors and blood glucose meters in time for results to be discussed with all patients at their clinic appointment.

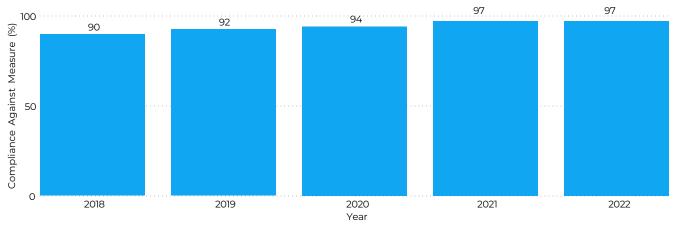


Figure 5: Compliance of H.3.1 per year

### H.3 Summary:

This measure steadily increased from 90% compliance in 2018 to 97% in 2022. Once facilities are in place, they are unlikely to be removed, however new technologies being released requires MDT to be active in ensuring latest facilities are available to aid downloads.

# H.4 Point of Care Testing for HbAlc

**H.4.1** There is point of care testing equipment available in all clinics, on all sites

**H.4.2** The point of care testing equipment used across the trust/health board for HbAlc measurement is tested regularly. This testing should be part of a recognised United Kingdom External Quality Assessment Service.

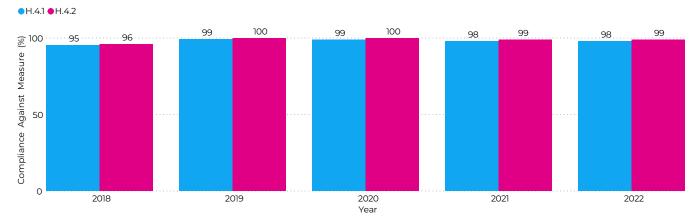


Figure 6: Compliance of H.4.1 to H.4.2 per year

**H.4.3** The point of care testing type.

The measure H.4.3 requesting the point of care testing type was added in 2020 and has remained at 100% compliance over the past three years.

### H.4 Summary:

Compliance of H.4 measures stayed consistently high across the duration of the five years. Higher compliance was observed for H.4.1 and H.4.2 in 2022 compared to 2018. H.4.3 was not included in Figure 6 since the question was asking which type of point of care testing machine a service utilised and once put in place, they are unlikely to be removed.

# H.5 Paediatric Ward Staff Training

- H.5.1 Management of children and young people newly diagnosed with diabetes\*
- **H.5.2** Use of all equipment used specifically for children and young people with diabetes including insulin pumps and glucose monitors
- **H.5.3** Principles of dietary management including offering Level 3 carbohydrate counting from diagnosis
- H.5.4 Management of hypoglycaemia\*

●H.5.1 ●H.5.2 ●H.5.3 ●H.5.4 ● H.5.5 ●H.5.6 ●H.5.7

- H.5.5 Management of children and young people in diabetic keto-acidosis (DKA)\*
- H.5.6 Care of children and young people with diabetes undergoing surgery
- H.5.7 Are complete staff training records kept?

97 \_99 98 96 96.96 97 95 96 94 93 93 93 93 92 89 90 90 87 88 87 87 87 84 86 87 86 Compliance Against Measure 82 81 | 82 82 81 I 82 50 0 2018 2019 2020 2021 2022 Year

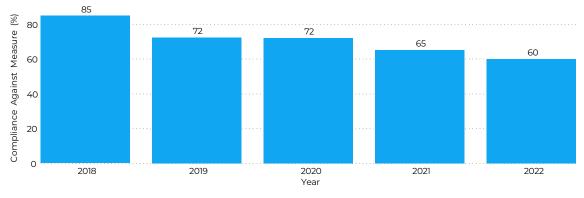
Figure 7: Compliance of H.5.1 to H.5.7 per year

### H.5 Summary:

The scoring remained consistently high, all above 80%, from 2018 to 2022. However, a small decrease was observed across all seven sub-measures from 2021 to 2022. This may indicate some services found it difficult to train ward staff due to an increase in nursing shortages as well as an increase in newly diagnosed patients and overall workload from 2021-2022.

# H.6 Outpatients' Clinic Management

H.6.1 At each clinic appointment, is the CYP offered consultation with all members of the multidisciplinary team (MDT), defined as including a doctor (please see the help definitions), paediatric diabetes specialist nurse, paediatric diabetes specialist dietitian and paediatric psychologist\*



### Figure 8: Compliance of H.6.1 per year



### H.6 Summary:

A noticeable decrease in the compliance for H.6.1 was identified from 85% in 2018 to 60% in 2022. This may reflect staffing decreases that were reported from the latest <u>paediatric</u> <u>diabetes staffing</u> dataset in comparison with the <u>NPDA 2017-2018 workforce spotlight audit</u>. Another factor could be more services completing a NDQP Peer Review and changing their scoring after their Peer Review identified that certain members of the MDT were not available at each clinic appointment, and therefore were not compliant with the measure. However, measure H.6.2 had increase of compliance from 91% in 2018 to 100% in 2022. It was observed during the NDQP Peer Review process that every service offered a minimum of 30 minute appointments to patients, with some services offering 40 minute appointments or more to better cater to their caseload.

# **MDT Measures Overview**

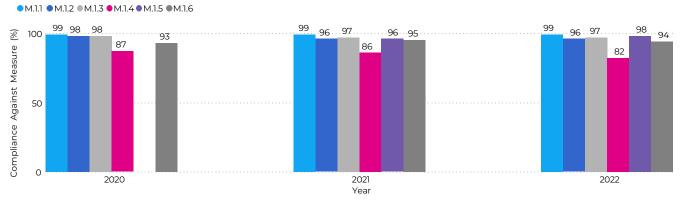
There are a total of 95 MDT measures under 27 key themes (M1.1-M.27.5) to assess compliance against NDQP and BPT standards.

Core BPT standards are marked with an\*

# M.1 MDT Membership

The core team must consist of the following health care professionals:

- M.1.1 Lead Consultant Paediatrician\*
- M.1.2 Lead PDSN\*
- M1.3 Lead Paediatric Diabetes Specialist Dietitian\*
- M.1.4 Lead Clinical Psychologist\*
- M.1.5 One of the four individuals above is identified as the single named lead clinician for the CYPD MDT. The lead clinician has an agreed list of responsibilities for the role of lead clinician and time specified in their job plan for the care of children and young people with diabetes.
- M.1.6 Secretarial / Administrative Support



### Figure 9: Compliance of M.1.1 to M.1.6 per year

- M.1.7 Other Consultant Paediatricians
- M.1.8 Staff Grade and Associate Specialist (Non-Consultant Career Grade)
- M.1.9 Other PDSNs
- M.1.10 Other Dietitians
- M.1.11 Other Clinical Psychologists
- M.1.13 Link for child safeguarding
- M.1.14 Inpatient ward link nurse
- M.1.15 Diabetes clinician for adult services

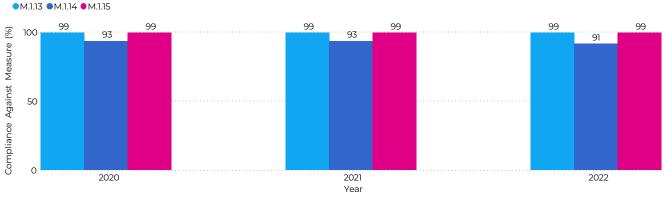


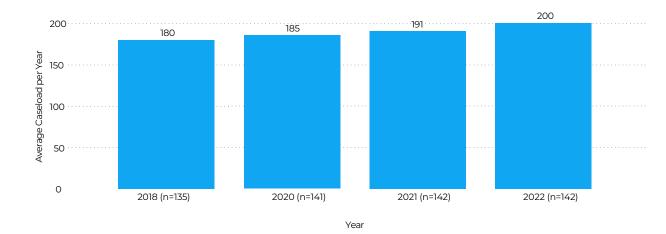
Figure 10: Compliance of M.1.13 to M.1.15 per year

### M.1 Summary:

Due to the change in format of the M.1 measures in the NDQP self-assessment from 2018-2019 to 2020-2022, only data from 2020-2022 was included in this report since it broke down MDT membership by staffing provision. Measures M.1.7 to M.12 (Other MDT core members and staff grade and associated specialists) and M.1.16 (Other extended MDT members) were not included in Figure 9 and Figure 10 nor this report since they were open text answers where services would submit the name and job title of the individual. Measure M.1.5 was also added in 2021, thus no data regarding if a service had a dedicated clinical lead was available prior.

Measures M.1.1 to M.1.3 and M.1.6 largely remained consistent over the three years. However, there was a 5% decrease in clinical psychology provision (M.1.5) being available within an MDT from 2020 to 2022. A factor contributing to this decline could be the increasing shortage of psychologists available within England and Wales. Furthermore, many services reported during their NDQP Peer Review that they did not have a clinical psychologist or overall psychology provision was not sufficient for the needs and size of their caseload. Measures M.1.13 to M.1.15 remained consistent over the three years, however, there was a slight decrease in services having an inpatient ward link nurse.

# M.2 MDT workload



M.2.1 How many CYP were registered for care on the 31 March during the review year?

Figure 11: Average caseload for a service per year

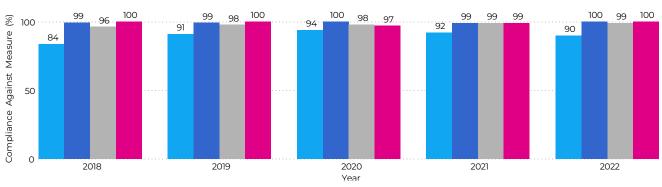
### M.2 Summary:

**Figure 11** reports the average caseload per service from 2018 to 2022. However, data from 2019 was unavailable. Average caseload was calculated by finding the sum of total reported patients per service and dividing it by the number of MDTs who completed the self-assessment that year. The findings from Figure 11 were in line with 2020-2021 NPDA report which stated that the incidence of Type 1 diabetes increased significantly in 2020-2021 amongst those aged 0-15 from 25.6 new cases per 100,000 in 2019-2020 to 30.9 in 2020-2021. The 2020-2021 NPDA reported an overall increase in 20.7% whilst the self-assessment data only reported an increase in 11.1% from 2018-2019 to 2020-2021. The difference in reporting could be due to the lack of data from 2019 and also service's not reporting their entire caseload on self-assessment data due to families opting out of being included in national reporting statistics. During the NDQP Peer Review process, many services reported higher caseloads to the Peer Review Team than what was recorded on their self-assessment. However, both the NPDA and NDQP results are evidence that the incidence rate of Type 1 diabetes is continually increasing in England and Wales.

# M.3 Clinical Guidelines

### The guidelines must include coverage of the following:

- **M.3.1** Have the clinical guidelines been reviewed by the regional CYPD Network as being in line with the most recent National Guidance?
- M.3.2 Care of children and young people newly diagnosed with diabetes, including that, for Type 1 diabetes, children and young people from diagnosis must be offered insulin therapy with multiple daily injections (MDI) and Level 3 carbohydrate counting.
- M.3.3 Care of children and young people with diabetes undergoing surgery.
- M.3.4 Care of children and young people with diabetic keto acidosis (DKA).



### ● M.3.1 ● M.3.2 ● M.3.3 ● M.3.4

- M.3.5 Care of children and young people with hypoglycaemia.
- **M.3.6** Care of children and young people with an HbAlc greater than 69 mmol/mol (8.5 %) in line with NICE.\*
- M.3.7 Sick day rules.
- **M.3.8** For Type 1 diabetes, the option of continuous glucose monitoring (either on -going or intermittently) should be offered to patients who meet the NICE criteria.

Figure 12: Compliance of M.3.1 to M.3.4 per year

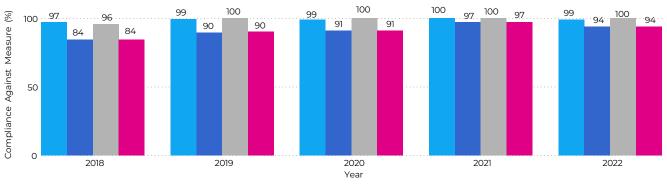


Figure 13: Compliance of M.3.5 to M.3.8 per year

### M.3 Summary:

M.3.5
M.3.6
M.3.7
M.3.8

From Figure 12, measure M.3.1 increased from 84% in 2018 to 90% in 2022 whereas all the other measures remained consistent. The increase in M.3.1 could be attributed to services not being in compliant to the measure in 2018 and seeking approval from their Network Manager to increase compliance with the NDQP measures over the five-year period. Findings from Figure 13 report that measures M.3.6 and M.3.8 had an overall increase in compliance of 10% from 2018 to 2022. Factors contributing to this could be the increased promotion of children and young people using advanced diabetes technologies such as insulin pumps and real time continuous glucose monitors (rt-CGM) to improve their blood glucose levels and overall quality of life. Over this same period, there have been guidelines published by NICE increasing the promotion and access that children and young people have to such technologies.

### **M.4 Patient Pathways**

The pathways should include coverage of the following:

- M.4.1 Have the patient pathways been reviewed by the regional CYPD Network?
- M.4.2 Referral of the newly diagnosed patient (aimed at primary care and general paediatric services). Including that on diagnosis, a young person's diabetes is to be discussed with a senior member of the paediatric diabetes team within 24 hours of presentation\*
- **M.4.3** That all new patients must be seen by a member of the specialist paediatric diabetes core team by the next working weekday.
- M.4.4 The management of complications of diabetes including DKA and hypoglycaemia\*
- **M.4.5** Final agreed pathways for the referral of newly diagnosed patients in primary care have been distributed to the CCGs/Health Board for onward distribution to GPs\*

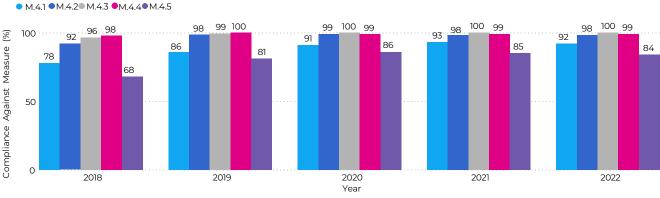


Figure 14: Compliance of M.4.1 to M.4.5 per year

#### M.4 Summary:

All of the measures associated with M.4 had an increase in compliance from 2018 to 2022. M.4.1 and M.4.5 had the most notable increases in compliance of 14% and 16% respectively. Similarly to measure M.3.1, increase in compliance in both measures could have been a result from services not meeting this measure in 2018 and seeking more support from their Network Manager in the following years.

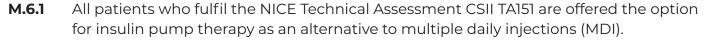
### **M.5 Primary Care Communication**

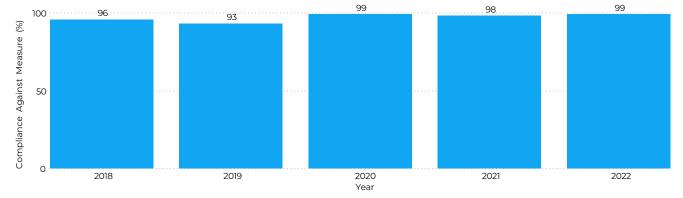
**M.5.1** The CYPD MDT has a policy whereby after a patient is given a diagnosis of diabetes, the patient's general practitioner is informed of the diagnosis and medication prescribed by the CYPD MDT by the end of the second working day after discharge from hospital.

#### M.5 Summary:

This measure had high compliance over the five years. There was an increase from 97% in 2018 to 100% in 2022. This could be attributed to several factors including the NDQP Peer Review identifying services who were not compliant with this measure and recommending them to implement this policy.

### M.6 Patient Choice of Insulin Pump Therapy







#### M.6 Summary:

M.6.1 had high compliance from all services who completed the self-assessment. As highlighted in Figure 15, there was a slight increase in compliance from 96% in 2018 to 99% in 2022. This increase could be due to a service's Clinical Commissioning Group (CCG), or now Integrated Care Board (ICB), enabling greater access to insulin pumps for patients by implementing guidance created by NICE as well as ensuring there is adequate funding for advanced diabetes technologies within the paediatric diabetes unit.

# M.7 Continuous Glucose Monitoring (CGM)

**M.7.1** All children and young people with type-1 diabetes who have frequent severe hypoglycaemia and all other criteria as listed in the most recent NICE guidance, are offered on-going real-time continuous glucose monitoring with alarms.

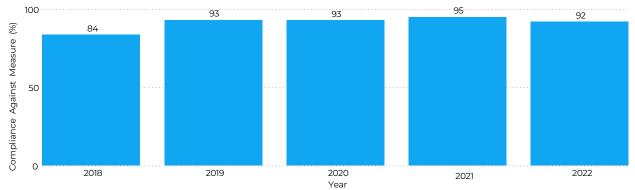


Figure 16: Compliance of M.7.1 per year

### M.7 Summary:

This measure has remained in over 90% every year since 2019. There was a small decrease from 95% 2021 to 92% 2022. The slight decrease may be due to a NICE guideline update being released in March 2022, which stated that all children and young people with Type 1 diabetes should have access to the CGM of their choosing. However, it was identified during several NDQP Peer Reviews in 2022 that services were no longer compliant with this measure because their local CCG or ICB had not implemented the latest NICE guidance.

## M.8 Four clinic appointments per year

**M.8.1** Each patient is offered a minimum of four clinic appointments per year with a MDT, defined as including a paediatric diabetes specialist nurse, a paediatric diabetes dietitian, paediatric psychologist, and doctor. At every visit, the patient must be seen by a doctor with appropriate training in paediatric diabetes and at least one other member of the MDT\*

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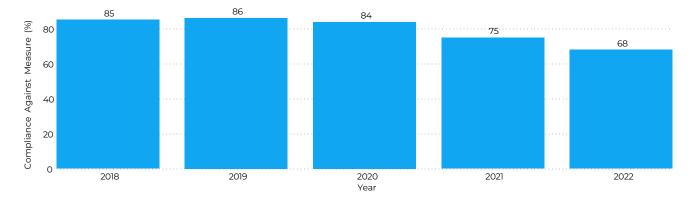


Figure 17: Compliance of M.8.1 per year

#### M.8 Summary:

A noticeable decrease in the compliance for M.8.1 was identified from 86% in 2019 to 68% in 2022. This may reflect staffing decreases during the pandemic that were reported in the 2021-2022 NPDA workforce calculations in comparison with the NDPA 2018 workforce spotlight audit. Another factor could be more services completing Peer Review and changing their scoring after Peer Review identified that certain members of the MDT were not available at each clinic appointment.

### M.9 Four haemoglobin HbA1C measurements per year

**M.9.1** Does the CYPD MDT offer each patient a minimum of four haemoglobin HbAlC measurements per year?\*

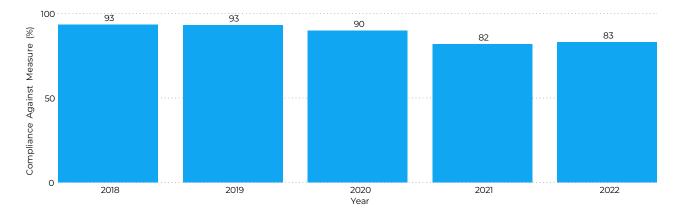


Figure 18: Compliance of M.9.1 per year

#### M.9 Summary:

There was a 10% drop in compliance of M.9.1 from 93% in 2019 to 83% in 2022. This coincides with a decrease in M.8.1 which may impact the ability to offer four haemoglobin measurements if the number of face-face clinics appointments are less available or if staff, such as PDSNs, are not able to attend all MDT clinic appointments.

# M.10 One additional appointment per annum with a paediatric dietitian

**M.10.1** Does the CYPD offer each patient at least one additional appointment per year with a paediatric dietitian with training in diabetes, who is a core member of the MDT.\*

### M.10 Summary:

Compliance was 90% or above for every year with a peak of 97% in 2019. However, results from the 2020-2021 NPDA reported lower compliance with this measure stating that only 82.6% of children and young people were offered an annual dietetic appointment in 2020-2021. The discrepancies in reporting are likely due to the fact that the NDQP self-assessment is self-reported and not externally verified.

# M.11 Annual psychological assessment

**M.11.1** Each patient must have an assessment at least annually by their MDT as to whether input to their care by a clinical psychologist is needed, and access to psychological support, which should be integral to the team, as appropriate.\*

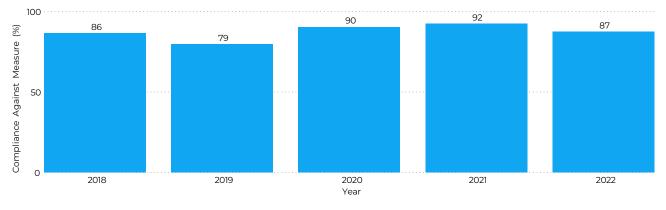


Figure 19: Compliance of M.11.1 per year

### M.11 Summary:

Compliance remains similar in 2022 (87%) to when self-assessment initiated in 2018 (86%). Similarly to measure M.10.1, the 2020-2021 NPDA reported a lower compliance of children and young people receiving an annual psychological assessment at 71.6% compared to the self-assessment report of 87% in the same year. However, both reports are evidence that psychology provision within MDTs is decreasing and is having an effect on the care that can be provided to children and young people with diabetes.

# M.12 Additional Contacts

M.12.1 All patients are offered a minimum of eight additional contacts annually. These contacts are in addition to the MDT clinic visits and may consist of telephone contacts, emails/texts, school visits, home visits, troubleshooting, advice, support etc.\*

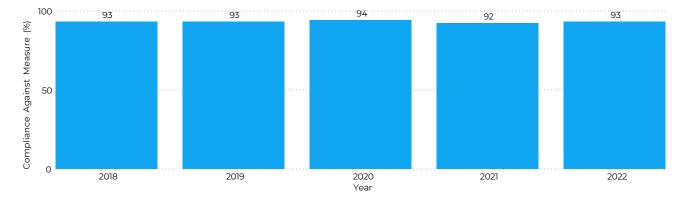


Figure 20: Compliance of M.12.1 per year

### M.12 Summary:

Measure M.12.1 remained consistent from 2018 to 2022, with compliance ranging between 92% and 94%. Despite the challenges services faced with the pandemic, implementing virtual and telephone clinic appointments, and staffing shortages, contact with patients was able to remain consistent. During the NDQP Peer Reviews, many services reported patients receiving more than eight additional contacts per year, with some as high as 20.

## M.13 Did Not Attend / Was Not Brought Policy

**M.13.1** There is a policy for the CYPD MDT for the management of non-attenders. The policy should take into account the trust/health board DNA/ WNB/Safeguarding Policy and Local Safeguarding Children Board (LSCB) guidance.\*

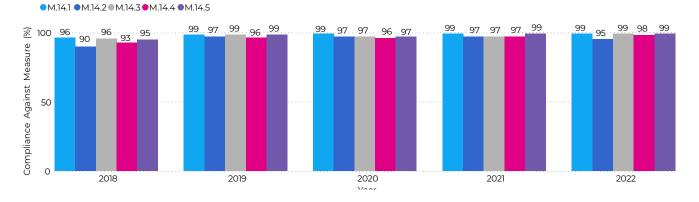
### M.13 Summary:

Compliance of M.13.1 ranged from 93% in 2018 to 96% in 2022, with the highest reported compliance in 2019 at 97%. Reasons for increased compliance could be attributed to services who did not have this policy in place in 2018 creating and ratifying a policy to be compliant with this measure in the following years.

# **M.14 Support for Children in Education**

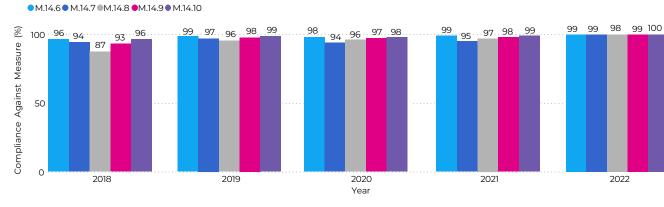
The policy must cover:

- M.14.1 Arrangements are in place for liaison with schools /academies and colleges.
- **M.14.2** Agreement of a school, academy or college care plan for each child that is reviewed at least annually.
- **M.14.3** Visits to the school, academy or college by a paediatric diabetes specialist nurse to discuss the care of each newly diagnosed child.
- **M.14.4** Training and assessment of competence of school, academy and college staff by the children and young people's diabetes team (including school day trips and residential trips).
- **M.14.5** Storage of medicines while in school, academy or college, including safe disposal of sharps.



### Figure 21: Compliance of M.14.1 to M.14.5 per year

- **M.14.6** The responsibilities of school, academy and college staff for supervising the delivery of/or administering insulin and the supervising of/or testing of blood glucose levels.
- M.14.7 Guidelines on care of children with diabetes while in school, academy or college.
- M.14.8 Carbohydrate counting of meals.
- M.14.9 Management of physical activity.





### M.14 Summary:

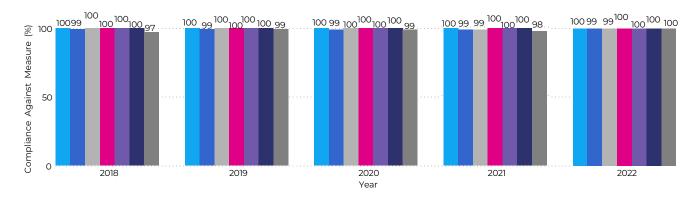
Compliance across all M.14 measures remained high and consistent despite the pandemic. During NDQP Peer Reviews, many services highlighted that they implemented virtual school staff training or developed training videos for school staff to ensure that children and young people were safe and protected in school. In Figure 21, measure M.14.2 had the highest increase in compliance from 90% in 2018 to 95% in 2022. Furthermore, M.14.8 increased 11% over the course of years as reported in Figure 22. Reasons for this could be paediatric diabetes dietitians being more involved in school staff training and providing and developing specialist resources targeted for school staff.

## M.15 Children and young people with diabetes must be offered annual screening according to current NICE guidance

In Type 1 disease, for:

- M.15.1 Coeliac disease at diagnosis
- M.15.2 Thyroid disease at diagnosis and annually thereafter until transfer to adult services
- M.15.3 Retinopathy screening annually from the age of 12 years\*

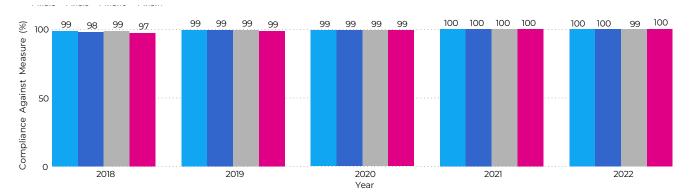
- M.15.4 Moderately increased albuminuria (albumin: creatinine ratio [ACR] 3-30 mg/mmol; 'microalbuminuria') from 12 years
- M.15.5 Standard anthropometric data
- M.15.6 Blood pressure annually from the age of 12 years
- M.15.7 Foot care advice for those under 12 years and assessment for those over 12 years



### Figure 23: Compliance of M.15.1 to M.15.7 per year

### In Type 2 disease, for:

- M.15.8 Hypertension annually starting at diagnosis
- M.15.9 Dyslipidaemia annually starting at diagnosis
- M.15.10 Retinopathy screening annually from age 12 years
- **M.15.11** Moderately increased albuminuria (albumin: creatinine ratio [ACR] 3-30 mg/mmol; 'microalbuminuria') from diagnosis



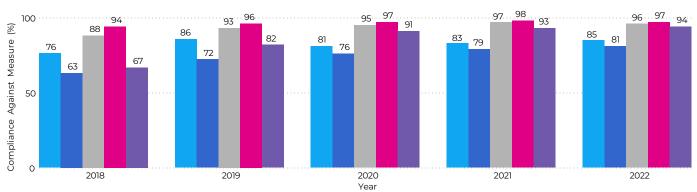
### Figure 24: Compliance of M.15.8 to M.15.11 per year

### M.15 Summary:

Compliance across all M.15 measures remained consistent despite the pandemic. Compliance for all measures ranged from 97% to 100%, with majority of measures being at 100% compliance in 2022. It must be acknowledged that services compliance of this measure was dependent upon them having policies and guidelines which stated that children and young people with Type 1 and Type 2 diabetes received an annual screening. However, the 2020-2021 NPDA reported that the percentage of children and young people with Type 1 diabetes aged 12 and up who received all six key health checks was 40.5%.

# M.16 Transition and Transfer Policy

- **M.16.1** Has the MDT implemented an up-to-date transition and transfer to adult services policy that is in line with current national guidance on transition
- M.16.2 At the start of transition there is a care plan that includes a person-specific programme of competencies to develop safe self-management of diabetes care prior to transfer.
- **M.16.3** There are individualised transition and transfer arrangements agreed for patients with additional or complex needs.
- **M.16.4** The decision about the age of transfer to the adult service is based on the young person's physical development, emotional maturity, local circumstances and patient choice.
- **M.16.5** There are clear protocols and guidelines in place for 16-18-year olds with DKA admissions that have been agreed jointly with adult services.



• M.16.1 • M.16.2 • M.16.3 • M.16.4 • M.16.5

### Figure 25: Compliance of M.16.1 to M.16.5 per year

### M.16 Summary:

M.16.1 to M.16.5 all showed an increase in compliance from 2018 to 2022. The greatest increase was in M.16.5, from 67% in 2018 to 94% in 2022. M.16.2 also saw a significant increase of 17% over the five years. Improving transition care for young people with diabetes was outlined as a key focus area of the NHS, which could be a contributing factor to service's being more compliant with the associated NDQP measures.

### In 2022 two additional M.16 measures were added.

- **M.16.6** Is the young person offered at least one joint clinic appointment involving both the paediatric and adult diabetes MDT prior to transfer to the care of the young adult diabetes team?
- **M.16.7** Are the DNA rates for young people that have moved from paediatric to young adult services reviewed jointly by both services within the first year of transfer?

### M.16.6 and M.16.7 Summary:

Compliance of M.16.6 was 87% whereas compliance of M.16.7 was only 20%. The lack of compliance for M.16.7 could be attributed to the increased workload of both paediatric and adult diabetes units and not having ringfenced time to review attendance rates in young adult clinics jointly.

## M.17 Attendance at the Network Group

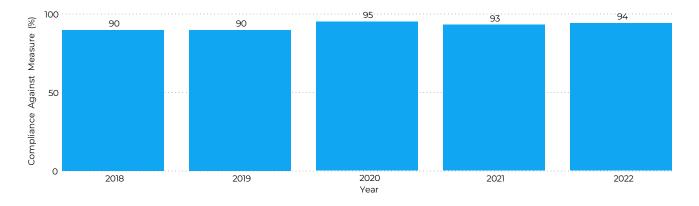
**M.17.1** At least one representative member of the CYPD MDT attends at least 75% of CYPDN regional network meetings.

#### M.17 Summary:

In 2018, compliance for this measure was at 100% and it slightly decreased to 98% in 2022. The decrease in compliance could be a result from MDT staffing shortages and members being unable to attend network meetings due to competing demands and priorities.

### M.18 Key Worker

**M.18.1** There is a single, named key worker for the patient's care at any given time is identified by the CYPD MDT for each individual patient and the name and contact number of the current key worker is recorded in the patient's case notes.



### Figure 26: Compliance of M.18.1 per year

#### M.18 Summary:

Compliance increased from 90% in 2018 to 94% in 2022. The increase in compliance could be attributed to the NDQP Peer Reviews, with services who completed a Peer Review in 2018-2019 not having this policy in place and a recommendation from the Peer Review team was to develop and implement a key worker policy for each patient.

## **M.19 Patient Information and Support**

**M.19.1** The CYPD MDT provides patients and carers with age/maturity appropriate written material, educational resources and a variety of support options.

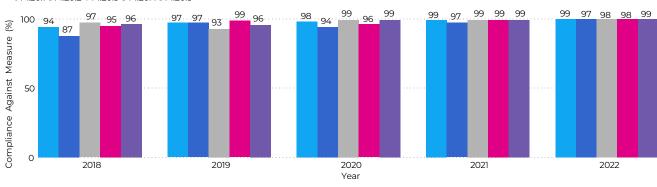
#### M.19 Summary:

This measure had high compliance over the five years, ranging from 98% to 100%. Despite the challenges services faced with the pandemic and staffing, it is evident that MDTs felt they were still able to provide education and appropriate resources to children and young people with diabetes.

# M.20 Individualised Life Style Objectives

# There is a policy whereby each child and young person has agreed individualised objectives, which are reviewed and updated regularly and cover the following items.

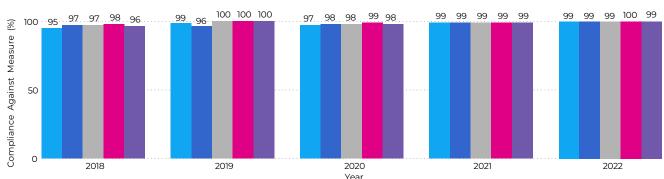
- **M.20.1** Explanations about the benefits and effects of exercise on blood glucose levels and about strategies for avoiding hypo- or Hyperglycaemia during or after physical activity.
- **M.20.2** Is there a system in place to establish if the CYP smokes and to offer referral to smoking cessation programmes?
- M.20.3 Target blood glucose levels and how to achieve this through insulin
- M.20.4 Therapeutic interventions (pharmacological and non-pharmacological).
- M.20.5 Self-care.



• M.20.1 • M.20.2 • M.20.3 • M.20.4 • M.20.5

### Figure 27: Compliance of M.20.1 to M.20.5 per year

- **M.20.6** Individualised healthy meal planning for the child/young person and their family including carbohydrate counting
- **M.20.7** Education and education plan covering, as a minimum, school attended, medication details, what to do in an emergency whilst in school, giving / supervision of injections by school staff and arrangements for liaison with the school
- **M.20.8** Early warning signs of problems, especially high and low blood glucose levels, and what to do if these occur
- M.20.9 Who to contact for advice and their contact details
- M.20.10 Planned review date and how to access a review more quickly, if necessary



● M.20.6 ● M.20.7 ● M.20.8 ● M.20.9 ● M.20.10

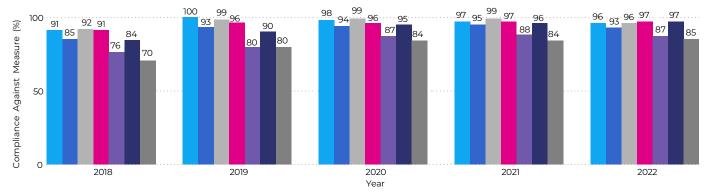
Figure 28: Compliance of M.20.6 to M.20.10 per year

#### M.20 Summary:

For all of the sub measures associated with M.20, they had high compliance over the five years ranging from 87% to 100%. As reported in Figure 27, M.20.2 had the highest increase from 87% in 2018 to 97% in 2022. Services who partook in an NDQP Peer Review often highlighted that individual lifestyle objectives were covered frequently in a patients quarterly MDT clinic appointment or during their annual review process.

## M.21 Diabetes Self - Management Education Programme

- **M.21.1** Do members of the CYPD MDT who have undertaken appropriate training paediatric diabetes and self-management education deliver the programme
- M.21.2 Is there a structured, written curriculum?
- **M.21.3** Is the programme adjusted to the personal preferences, emotional wellbeing and age and maturity of the child/young person?
- M.21.4 Does the programme fulfil the requirements of: NICE NG18 2015 & NICE QS125 2016
- **M.21.5** Does the programme have a named core member of the CYPD MDT who is responsible for organising the diabetes self-management education programme on behalf of the CYPD MDT?
- **M.21.6** Does the programme commence within 3 months of diagnosis and level 3 CHO counting within 2 weeks?
- M.21.7 Is the diabetes programme reviewed annually?



• M.21.1 • M.21.2 • M.21.3 • M.21.4 • M.21.5 • M.21.6 • M.21.7

#### Figure 29: Compliance of M.21.1 to M.21.7 per year

### M.21 Summary:

All measures displayed higher compliance in 2022 than when self-assessment was initiated in 2018. Notable increase includes the core BPT measure M.21.6 which increased from 84% in 2018 to 97% in 2022. However, it must be acknowledged that in several NDQP Peer Reviews, services highlighted that they are struggling to re-implement their structured education programme for on-going patients following recovery from the pandemic due to staff shortages and an increased demand in the service due to patients needing higher levels of support and the continual rise of newly diagnosed patients.

## M.22 Record of Care

M.22.1 Are all patients offered a record of care?

#### M.22 Summary:

This measure remained at high compliance from 2018 to 2022, ranging between 99% and 100%. During Peer Reviews, many services highlighted that patients receive letters following each clinic appointment containing a summary of the consultation and any further actions required.

## M.23 Patient Reported Experience Measure

- **M.23.1** The PREM results have been presented and discussed at a CYPD MDT meeting.
- **M.23.2** Action plans for improvement have been agreed and implemented as appropriate including feedback on results to CYP and families.

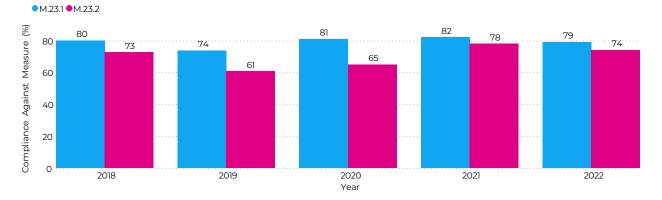


Figure 30: Compliance of M.23.1 to M.23.2 per year

#### M.23 Summary:

PREM results presented within a CYPD MDT (M23.1) has remained consistent around 80% compliance. M.23.2 saw a reduction in compliance from 2019-2020 but is back to 74% which was similar to the compliance in 2018.

# M.24 Patient/Carer Experience of Transition and Transfer

- **M.24.1** The results of the exercise (Parent/Carer have been presented and discussed at a CYPD MDT meeting.
- M.24.2 Action plans for improvement have been agreed and implemented as appropriate.

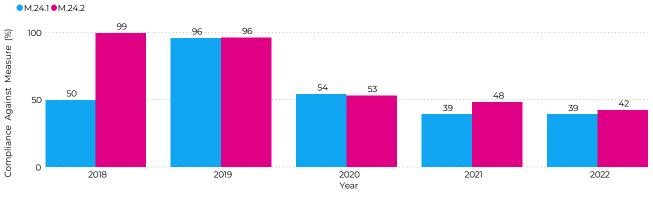


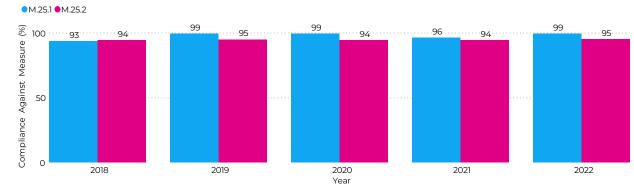
Figure 31: Compliance of M.24.1 to M.24.2 per year

### M.24 Summary:

Measures associated with M.24 were the lowest scoring self-assessment measures between 2020-2022. Despite a high peak of 96% for both in 2019 there was significant reduction in 2020 and compliance remained lower than other measures. Reasons for the decline in compliance could be attributed to the lack of standardisation in offering a patient/carer experience of transition and transfer survey. Some services may have completed this survey several years ago and are marking themselves as compliant in later years if the results are still relevant to improving the transition service offered to young people. Whereas other services who do not complete this yearly, may mark themselves as not compliant in later years. Additionally, during the NDQP Peer Review process, some services highlighted that they only conduct this survey when it is sent out by the NPDA.

# M.25 National Paediatric Diabetes Audit (NPDA)

**M.25.1** Having participated in the NPDA, the CYPD MDT has reviewed their individual unit report and annually submitted their NPDA results to the CYPDN for discussion and review of progress.



M.25.2 Agreed a programme for improvement.

Figure 32: Compliance of M.25.1 to M.25.2 per year

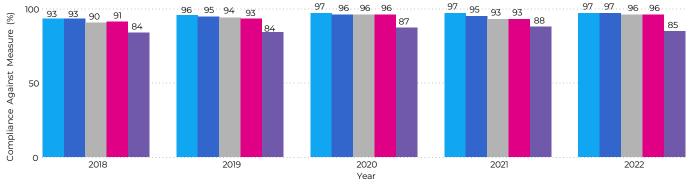
### M.25 Summary:

As highlighted in Figure 32, the percentage of services who participated in the NPDA and created an agreed programme for improvement following their results remained consistently high from 2018 to 2022. For services who partook in a NDQP Peer Review, they often had an Annual Workplan which comprised areas of improvement based off both NPDA reports and internal aspirations.

# M.26 Review of Children and Young People's Admissions

### CYPD MDT review of numbers of hospital admissions in the following categories:

- M.26.1 Those with newly diagnosed diabetes
- M.26.2 Children and Young People with DKA
- M.26.3 Children and Young People with hypoglycaemia
- M.26.4 Children and Young People for re-stabilisation
- M.26.5 Are reviews held at least quarterly and recorded?



• M.26.1 • M.26.2 • M.26.3 • M.26.4 • M.26.5

Figure 33: Compliance of M.26.1 to M.26.5 per year

### M.26 Summary:

Compliance for M.26.1 to M.26-4 remaining above 90% for all five years. M.26.5 was the lowest scoring sub measure remaining consistently between 84-87%. Reasons for this could include services reviewing hospital admissions data annually, rather than quarterly, and marking themselves as uncompliant with the measure.

- **M.27** Percentage of patients who were not brought/did not attend their hospital appointments
- M.27.1 Have DNA/WNB rates been reviewed across all clinics?
- M.27.2 Are DNA/WNB rates reviewed across different age bands?
- **M.27.3** Have DNA/WNB rates been discussed at the trust/health board management group (ref question H1)
- M.27.4 Have actions been taken to improve patient surveillance
- M.27.5 Have the DNA/WNB rates been discussed at CYPDN?

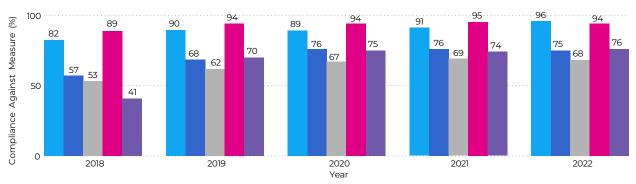




Figure 34: Compliance of M.27.1 to M.27.5 per year

#### M.27 Summary:

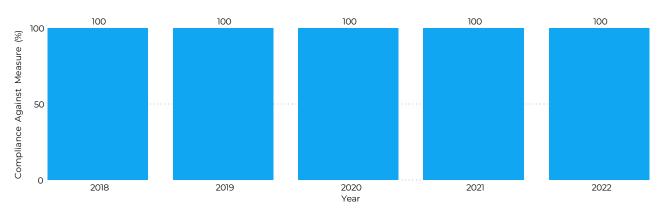
All M.27 sub measures increased in compliance since the start of the NDQP. As reported in **Figure 34**, several measures had significant increases from 2018 to 2022 including M.27.2 (18%), M.27.3 (15%), and M.27.5 (35%). These increases could be attributed to the overall increase in data capturing that is now required of paediatric diabetes units for submissions to both local and national audits. Furthermore, many services have implemented databases such as Diamond or Twinkle, which are specifically designed to cater to the data capturing needs of a paediatric diabetes service.

# **Network Measures Overview**

There are a total of 34 Network measures under 12 key themes (N.1.1-N.12.1) to assess compliance against NDQP standards.

## **N.1 Network Configuration**

N.1.1 The list of the regional Children and Young People Diabetes (CYPD) service provider hospitals and CYPD MDTs, within a trust/health board in the network, has been updated and agreed annually in consultation with the lead clinicians of each hospital trust/health board.



### Figure 35: Compliance of N.1.1 per year

### N.1 Summary:

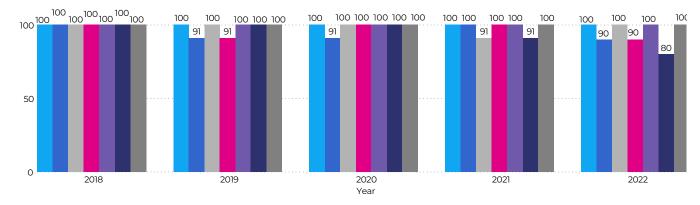
This measure remained at 100% over the course of five years.

# **N.2 Regional CYPDN Membership**

### Must include the following membership:

- N.2.1 Chair of the regional CYPDN.
- **N.2.2** Vice chair of the regional CYPDN.
- N.2.3 CYPDN manager.
- **N.2.4** Lead consultant paediatrician with an interest in diabetes.
- N.2.5 Lead paediatric diabetes specialist nurse for the CYPDN
- N.2.6 Consultant diabetologist from adult services.
- **N.2.7** Lead clinician or a nominated deputy from the core team from each CYPD MDT within the CYPDN.

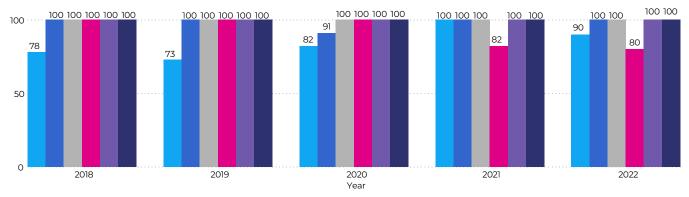
#### National Diabetes Quality Programme: Self-assessment report 2018-2022



● N.2.1 ● N.2.2 ● N.2.3 ● N.2.4 ● N.2.5 ● N.2.6 ● N.2.7

#### Figure 36: Compliance of N.2.1 to N.2.7 per year

- N.2.8 At least one representative from commissioners / health boards, drawn from and acting on behalf of the commissioning group(s) / health boards relevant to the CYPD within the catchment area of the network.
- **N.2.9** Must include the following membership: Lead paediatric diabetes specialist dietitian for the CYPDN.
- **N.2.10** Lead psychologist for the CYPDN.
- N.2.11 At least two patient/parent/carer representatives.
- N.2.12 The regional CYPDN has agreed a description of the role of the CYPD chair.
- N.2.13 Terms of reference have been agreed for the regional CYPDN.



N.2.8 • N.2.9 • N.2.10 • N.2.11 • N.2.12 • N.2.13



#### N.2 Summary:

As shown in Figure 36, measures N.1.1, N.2.3, N.2.5, and N.2.7 remained at 100% between 2018 and 2022. Both N.2.2 and N.2.4 decreased from 100% in 2018 to 90% in 2022. There was a significant decrease in measure N.2.6 from 100% in 2018 to 80% in 2022. This decrease could be a result from an increased pressure on adult diabetes services and a lack of consultant time to participate in their associated regional paediatric diabetes network. Similarly, Figure 37 shows that measures N.2.10, N.2.12, and N.2.13 remained at 100% over the five year period. There was an increase in compliance of 12% for measure N.2.8, which is evidence of increased participation between paediatric diabetes services and the CCG/ICBs in the surrounding area. However, there was a 20% decrease in measure N.2.11 relating to a minimum of two parent/carer representatives being present at network meetings. It is imperative that this group is represented as they are being directly impacted by the decisions and policies created within a given region.

## **N.3 Regional Network Meetings**

**N.3.1** The regional CYPDN meets at least three times a year (some may wish to meet more frequently).

#### **N.3 Summary:**

This measure remained at 100% over the five years, despite the challenges presented by Covid-19.

### **N.4 Annual Report**

N.4.1 An annual report has been prepared and sent to constituent trusts, units, local authorities, statutory healthcare providers and commissioners / health boards to inform them of service improvements and/or developments the CYPDN has achieved or has planned.

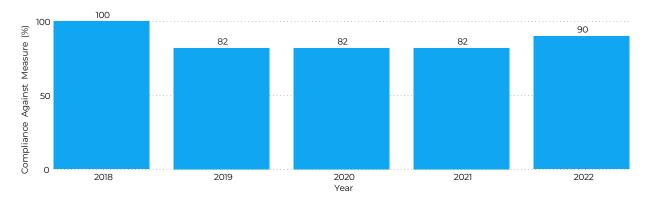


Figure 38: Compliance of N.4.1 per year

#### N.4 Summary:

This measure decreased from 100% in 2018 to 82% from 2019 to 2021. However, N.4.1 increased to 90% in 2022. A decrease in this measure could be attributed to the lack of time clinical staff have to prepare an annual report due to competing demands and priorities within the service.

### **N.5 Annual Service Development Proposals**

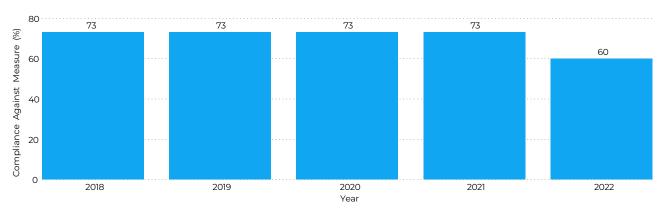
**N.5.1** Service development proposals have been produced by the CYPDN that are reviewed annually.

### N.5 Summary:

Compliance of this measure remained at 100% from 2018 to 2022.

# **N.6 Clinical Guidelines**

**N.6.1** Clinical guidelines of the CYPD MDTs within the regional CYPDN have been reviewed and the relevant parties have agreed the final guidelines.



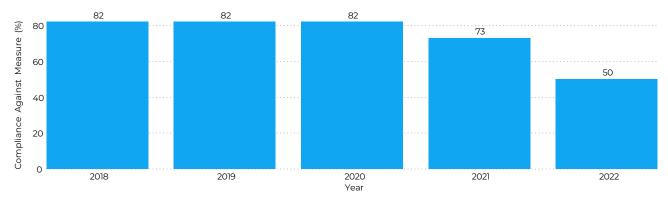
#### Figure 39: Compliance of N.6.1 per year

#### N.6 Summary:

Compliance was 73% between 2018-2021 but decreased to 60% in 2022. Factors contributing to this decline could be a lack of dedicated time for service improvement and development to update clinical guidelines and have them certified by the MDTs regional network manager. During several NDQP Peer Reviews, this was highlighted as a challenge for some services due to a lack of clinical staff capacity and the need to prioritise patient care.

### **N.7 Patient Pathways**

**N.7.1** Patient pathways listed in the measure M4 for the regional CYPDN MDTs have been reviewed and the relevant parties have agreed the final pathways.



### Figure 40: Compliance of N.7.1 per year

### N.7 Summary:

Compliance was 82% between 2018-2020 then decreased to 73% in 2021, with a further decrease to 50% in 2022. The decline in this measure could be due to similar reasons as stated in the **N.6 Summary.** 

# **N.8 Transition and Transfer Policy**

**N.8.1** The regional CYPDN is responsible for ensuring that a transition and transfer policy has been devised and agreed by the adult and paediatric teams within an individual trust/health board. This policy must align with NICE NG43 and QS140, and in England, the NHS England Diabetes Transition Specification (published Jan 2016) and in Wales, the NHS Wales National Standard.

### N.8 Summary:

Compliance for this measure remained stagnant at 73% between 2018 to 2021. However, a significant increase to 90% was reported in the 2022 self-assessment. As stated in the **M.16 Summary**, reasons for this improvement could be linked to the NHS stating that improving transition care for young people with diabetes is a key focus area.

## **N.9 Patient Experience**

- **N.9.1** The most recent Patient Reported Experience Measures (PREMS) report has been discussed and reviewed.
- **N.9.2** Patients' and carers' experience of transition has been discussed, reviewed.
- **N.9.3** Any other patient experience gathering exercises, which have been undertaken have been discussed and reviewed.
- **N.9.4** An improvement programme from all exercises undertaken has been agreed and any remedial actions reviewed.

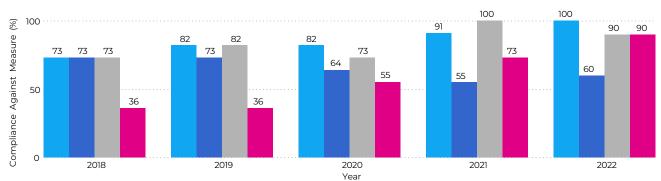




Figure 41: Compliance of N.9.1 to N.9.4 per year

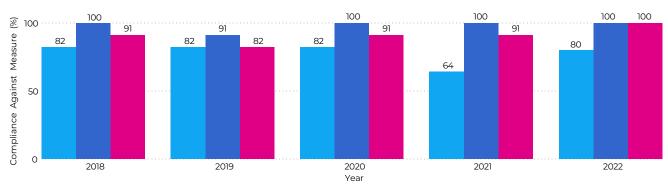
### N.9 Summary:

Measure N.9.1 steadily increased from 2018 to 2022 which is evidence of paediatric diabetes units presenting their PREMs results to other services in their network. Measure N.9.2 decreased from 73% in 2018 to 60% in 2022, which is in line with the decreases also observed in measure M.24.1. A 17% increase in measure N.9.3 was reported between 2018 to 2022 and a 54% increase was reported in measure N.9.4 over the same period.

# **N.10 Twenty-four Hour Advice Services**

# Twenty-four hour / seven-day advice services are agreed and in place for the following three levels:

- N.10.1 Advice on diabetes management for CYP/parents/carers.
- **N.10.2** Advice for ward-based healthcare professionals provided by local paediatric diabetes team on the management of CYPs with diabetes admitted to hospital
- **N.10.3** Is there a clear, agreed escalation policy for local teams for advice/transfer to a diabetes centre supported by paediatric intensive care facilities?



#### ●N.10.1 ●N.10.2●N.10.3

Figure 42: Compliance of N.10.1 to N.10.3 per year

### N.10 Summary:

Measures N.10.2 and N.10.3 remained largely consistent over the five years, with both having a decrease in 2019 from the previous year. Compliance of measure N.10.1 was 82% in 2018 and 80% in 2022. However, in 2021, N.10.1 was reported to be only 64% compliant which could be a result from the staffing challenges paediatric diabetes and acute services faced during the pandemic.

# **N.11 Clinical Outcomes Indicators and Audits**

- **N.11.1** Submission of data to the National Paediatric Diabetes Audit (NPDA) has been completed by all constituent MDTs.
- **N.11.2** Outcomes and progress as published in the most recent NPDA report have been discussed and documented at a team meeting.
- **N.11.3** The results of the local reviews of children and young people's admissions to hospital have been reviewed.
- **N.11.4** The results of the local reviews of Did Not Attend (DNA) or Were Not Brought (WNB) rates have been reviewed.
- N.11.5 The CSQM results for the units have been reviewed and publicised
- **N.11.6** Any additional audits for hospital practice, which the regional CYPDN has agreed relevant, across its associated MDTs have been reviewed.

#### National Diabetes Quality Programme: Self-assessment report 2018-2022

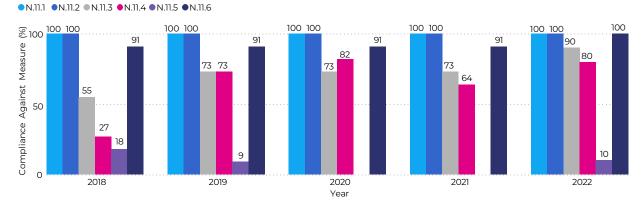


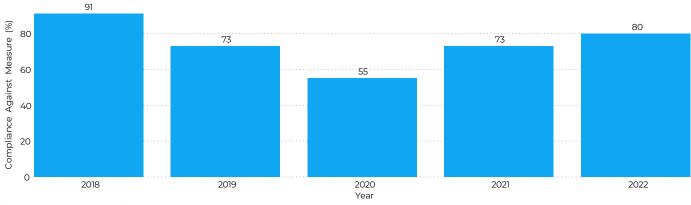
Figure 43: Compliance of N.11.1 to N.11.6 per year

#### N.11 Summary:

Compliance for N.11.1 and N.11.2 remained consistently at 100% over the five year period. Measure N.11.13 reported a significant increase in compliance from 55% in 2018 to 90% in 2022 which could be attributed to the increase in data reporting required from paediatric diabetes services. Similarly, compliance of N.11.4 significantly increased from 27% to 80% from 2018 to 2022 as also reported in measure M.27.5. Compliance of N.11.5 remained low over the five year period, with 2020 to 2021 reporting a 0% compliance and 10% in 2022. **Figure 43** also displays high compliance of measure N.11.6 between 91% and 100%.

### **N.12 Self-assessment and Peer Review**

**N.12.1** The CYPDN has discussed the findings of the most recent self-assessment/peer review visit programme and has ensured that action/improvement plans have been put in place within each unit.





#### N.12 Summary:

Compliance of this measure varied of the five years of the self-assessment with the highest compliance at 91% in 2018 and the lowest compliance at 55% in 2020. Since 2020, compliance of measure N.12.1 increased to 73% in 2021 and had an additional increase of 7% in 2022.

# Acknowledgements

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