

# The National Paediatric Diabetes Audit

## Introduction

The National Paediatric Diabetes Audit (NPDA) for England and Wales is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). It reports highlights of the main findings on the quality of care for children and young people with diabetes mellitus and since 2011 has been managed by the Royal College of Paediatrics and Child Health (RCPCH). The NPDA should be considered as the measuring arm of an ongoing quality improvement programme for children and young people with diabetes and covers the components of the National Service Framework for Diabetes for England,<sup>1</sup> and Wales.<sup>2</sup> Outputs include details on the number of children and young people with diabetes, the care processes they receive and outcome measures, including inpatient admissions for diabetic ketoacidosis (DKA).

## Why is the NPDA important?

National audit programmes not only provide an overview of outcomes for given disease processes but also provide unbiased benchmarking data investigating variability among regional networks and, in the case of the NPDA, the Paediatric Diabetes Units (PDUs) where care is provided. Although local audit is important, the comparison with other PDUs providing the same service is paramount to maintaining quality and to provide the impetus for improvement. It also helps identify well performing and poorly performing centres so that lessons can be learnt and shared among PDUs. For the NPDA, the demographic, care process and outcome data are collected and submitted by individual PDUs but analysed centrally, making an unbiased comparison possible. In England, the last few years have seen the development of regional networks as well as a peer review quality assurance initiative that is partly driven by data from the NPDA.

Year	Age range (years)					Total
	0–4	5–11	12–15	16–19	20–24	
2008–09	719 (4.6)	5210 (33.4)	6098 (39.1)	3582 (22.9)		15 609
2009–10	875 (4.5)	6476 (33.1)	7937 (40.6)	4267 (21.8)		19 555
2010–11	677 (2.9)	6395 (27.2)	8672 (36.9)	7380 (31.4)	392 (1.6)	23 516
2011–12	1354 (5.4)	4861 (19.3)	10 987 (43.6)	7764 (30.8)	233 (0.9)	25 199

**Table 1.** Number of registered children and young people with diabetes (% of total) submitted to the NPDA between 2008–09 and 2011–12

## Who participates in the NPDA?

The NPDA collects data on all children and young people with diabetes receiving their care from a PDU in England and Wales from birth to 24 years. Most are under the age of 18 years since transition to adult diabetes services tends to occur around that age. The total number of children and young people with diabetes submitted to the NPDA has grown over the last few years with some evidence that numbers have begun to stabilise at around 25 000. Table 1 shows the numbers of submitted patients from 2008–2012 for England and Wales by age group.

In 2011–12 a total of 177 PDUs in England and Wales, where diabetes care is provided, participated in the NPDA. While there is a slight fluctuation in the number of participating PDUs year-on-year as units combine their clinical expertise into larger centres, the participation rate has gradually increased and now represents almost 100% of eligible PDUs. It seems likely that this trend will continue in future years.

## What data are collected?

In 2011 a dataset working group was convened by the NPDA to review the data being collected and lead on the development of an enhanced, more clinically meaningful dataset. Every item of data in the updated dataset is mapped against a standard of care as recommended by the National Institute for Health and Care Excellence (NICE). Many of these standards are evidence based but some are considered best practice.

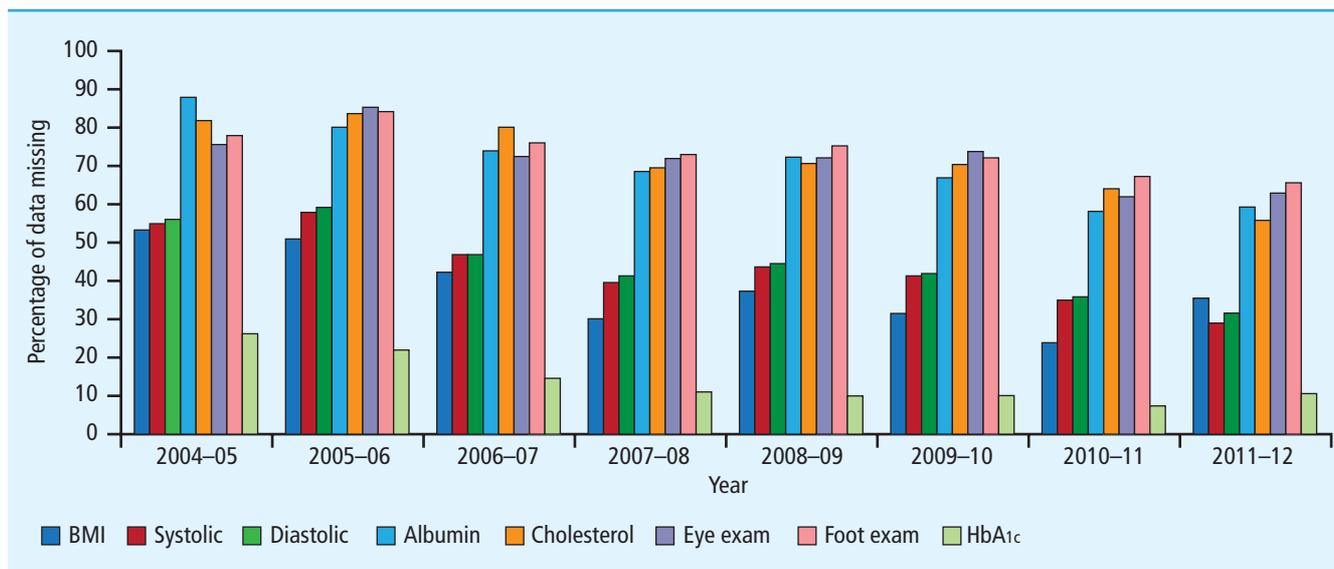
The current NPDA dataset can be reviewed on the NPDA website at: [www.rcpch.ac.uk/npda/datasubmission](http://www.rcpch.ac.uk/npda/datasubmission). Each PDU submits demographic data for each of their patients as well as the results of care processes and outcome data obtained over the 12-month audit cycle. The NPDA has approval under Section 251 of the NHS Act 2006 to collect patient identifiable information without written consent, although PDUs are provided with information leaflets about the NPDA for distribution to their patients and parents or carers. The collection of patient NHS numbers allows the NPDA to potentially link with other datasets where this unique identifier is also collected. Currently, inpatient episodes (DKA and hypoglycaemia) are analysed by linkage with the Hospital Episode Statistics in England (HES) and the Patient Episode Database for Wales (PEDW).

## Highlight results from the NPDA Care processes and outcomes

The NPDA collects information on the key care processes recommended by NICE for children and young people with diabetes<sup>3</sup> and measures the completion rate of the processes below:

- Glycated haemoglobin A<sub>1c</sub> (HbA<sub>1c</sub>).
- Body mass index (BMI).
- Blood pressure.
- Urinary albumin.
- Cholesterol.
- Dye screening.
- Foot examination.

The monitoring of such processes is important as this helps to detect

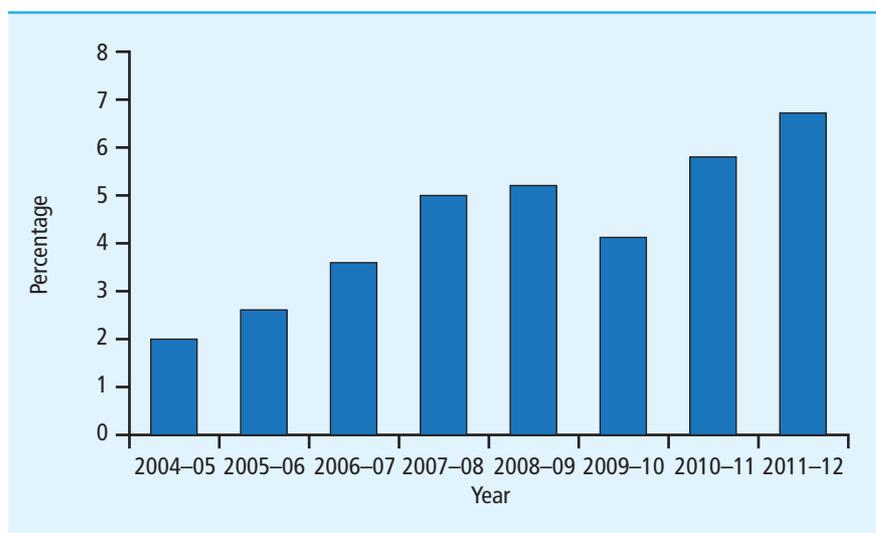


**Figure 1a.** Percentage of children and young people with diabetes with missing or incomplete individual care processes, as reported to the NPDA between 2004–05 and 2011–12

long-term complications at the earliest treatable stage. Although complications of diabetes are rarely seen in childhood, it is a lifelong condition and so attention to continuous screening throughout the patient's life remains essential. Current guidelines for the UK specify a starting age of 12 years for commencing all care process monitoring, with the exception of HbA<sub>1c</sub> which should be recorded for all ages.

The number of children receiving the individual care processes has steadily increased over the years as demonstrated by the decline in missing or incomplete care process data submitted to the audit (Figure 1a). However, the percentage of those receiving all care processes within an audit year remains unacceptably low with only 6.7% of children and young people with diabetes recorded as having received all seven care processes in 2011–12 (Figure 1b). This proportion falls far short of similar data from the National Diabetes Audit 2011–12 for adults which reports a comparable figure of 42.4% for type 1 diabetes.<sup>4</sup>

The NPDA can only report on the data submitted by the PDU and cannot therefore distinguish between care processes that are genuinely incomplete for an individual patient and data that are missing due to the incompleteness of a PDU's submission. The ability to make this distinction would require sub-auditing at an individual PDU level. Furthermore, the NPDA is unable to quantify



**Figure 1b.** Percentage of children and young people with diabetes aged 12 years and over having all care processes recorded, as reported to the NPDA between 2004–05 and 2011–12

instances of incomplete care process data that are the result of poor attendance by patients, leading to a failure in completing the care process within the audit year which is outside the control of the PDU.

The NPDA reports HbA<sub>1c</sub> outcome as this is recommended as the best indicator of long-term diabetes control and correlates with adverse outcome.<sup>3</sup> In 2011–12, 17.4% of children and young people with diabetes achieved the NICE recommended HbA<sub>1c</sub> target of <58mmol/mol (7.5%) with the greatest numbers of patients having an HbA<sub>1c</sub> between 58–80mmol/mol (7.5–9.5%), and 25.1% having a value >80mmol/mol (9.5%); (Figure 2a). The percentage

achieving an HbA<sub>1c</sub> of <58mmol/mol (7.5%) has increased marginally from 14.5% in 2009–10 and 15.8% in 2010–11, but there still remains considerable variability across the two nations between individual centres and is suboptimal compared to some other European countries. Data from the German and Austrian registry demonstrate that ~35% of children and young people with diabetes have an HbA<sub>1c</sub> <58mmol/mol (7.5%).<sup>5</sup> Figure 2b shows the change in overall median HbA<sub>1c</sub> by year and by nation. There has been little improvement in this value for several years, with perhaps a trend towards improvement over the last three years that the audit has reported. Again, there is much

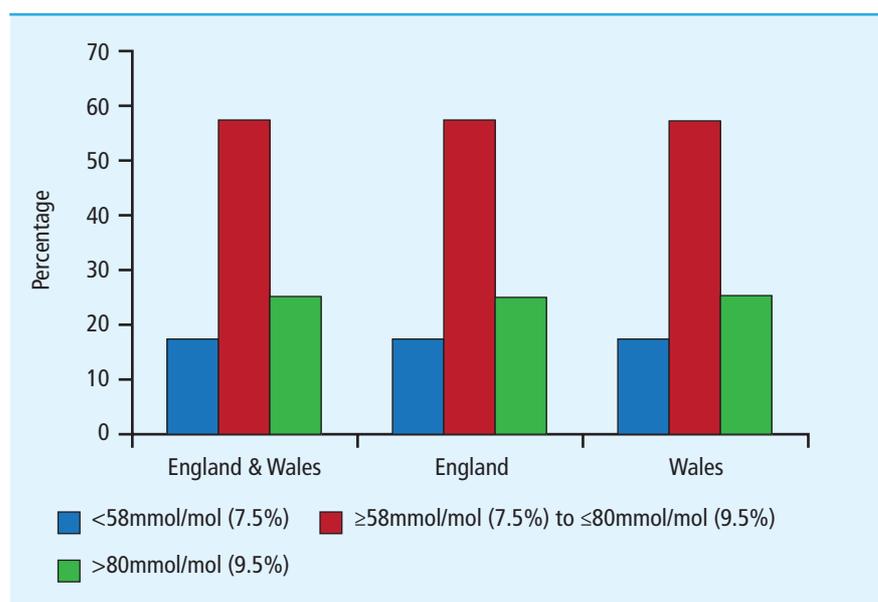
variation in this figure by region and by individual PDU – the data for which can be accessed by reading the NPDA reports.<sup>6</sup>

### Inpatient admissions

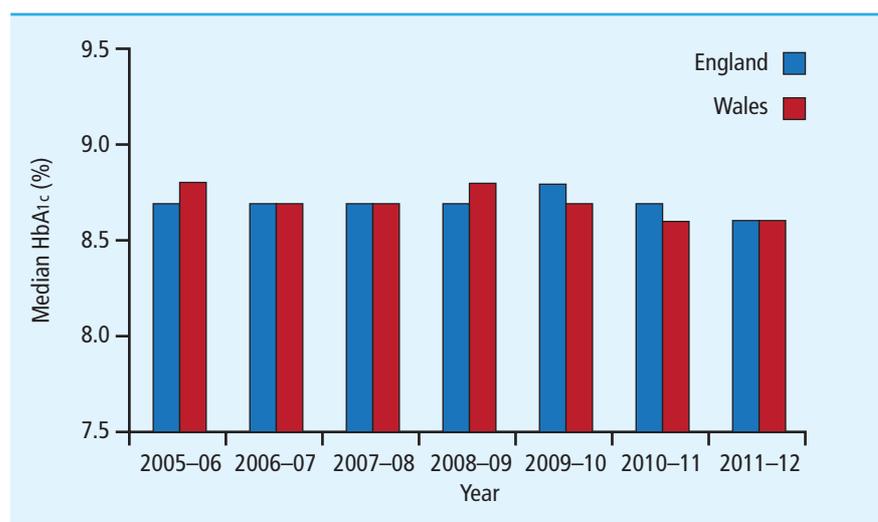
The NPDA has for many years reported on admissions with DKA and, for the first time, in 2011–12 included admissions with hypoglycaemia and admissions to hospital where the cause of admission was unknown (coded as ‘without complications’). NHS numbers from the NPDA submission are linked to HES and PEDW databases so that any admissions for that particular patient are recognised.<sup>7</sup> In 2011–12 there were 6210 admissions to hospital in children and young people with diabetes and these were broken down into the three categories shown in Figure 3a. The cause of admission in those coded as ‘without complications’ remains unknown, but a considerable number probably represent children with newly diagnosed diabetes who do not present with DKA or patients admitted for stabilisation of their diabetes.

In both England and Wales there has been an increase in the incidence of DKA emergency admissions from 2005–6 to 2010–11 which is most marked in the 15–19 year age range. In 2011–12, in some age categories, there has been a slight decline in the number of DKA admissions which is encouraging but it is too early to say whether this represents a true downward trend (Figure 3b).

The DKA rate in newly diagnosed children and young people with diabetes reported by the NPDA in 2011–12 is unacceptably high at 15.7% of all newly diagnosed children. However, this figure is substantially less than the 25% recently quoted following a prospective study of newly diagnosed children.<sup>8</sup> It is difficult to make a direct comparison between the NPDA data and this report, owing to the differences in the way the data were collected. The study by Lokulo-Sodipe *et al.*<sup>8</sup> was hypothesis driven and specifically designed to capture all newly diagnosed children with diabetes in order to understand the pathway to diagnosis and achieve a better understanding of whether there were shortfalls along that pathway that could be



**Figure 2a.** Percentage of children and young people achieving the NICE recommended HbA<sub>1c</sub> target of <58mmol/mol (7.5%), ≥58mmol/mol (7.5%) to ≤80mmol/mol (9.5%), and >80mmol/mol (9.5%), by country, 2011–12



**Figure 2b.** Change in overall median HbA<sub>1c</sub> for England and Wales from 2005 to 2012

targeted to reduce the incidence of DKA at diagnosis. The NPDA is not hypothesis driven, rather a representation of data collected on patients with diabetes. However, the fact that the two statistics differ requires further observation and a continued awareness that DKA at diagnosis still presents a very real problem.

### Patient Reported Experience

There has been increasing emphasis within the NHS of the importance of the Patient Experience in terms of designing and delivering high quality care and ensuring that patients have a positive experience. Furthermore, Patient Experience is

part of the fourth domain of the Department of Health outcomes framework. The NPDA conducted a Patient Reported Experience Measure (PREM) survey in 2012–13 which was completed by 13 118 families in England and Wales. A series of themed questions were posed, which were developed through focus groups and expert advisory groups.<sup>9</sup> Figure 4 shows the results for the penultimate survey question: ‘On a scale of 0–10, how likely is it that you would recommend this clinic to a friend or another family with a child who has diabetes?’ Although there was large variation in response to the PREM questions between PDUs and

# Short report

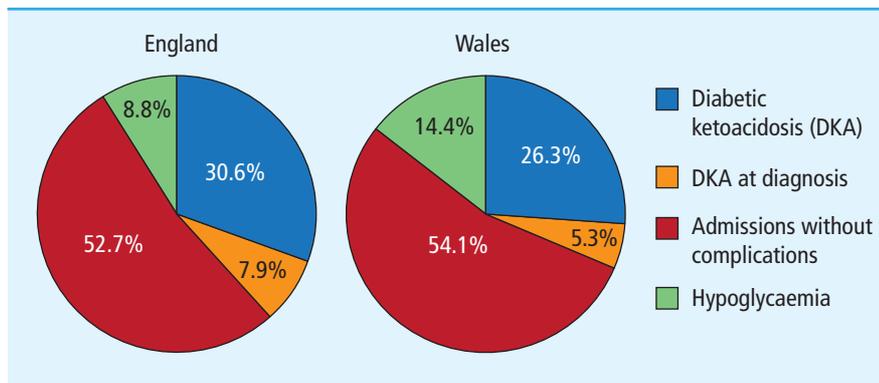
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regional networks, the Patient Experience of care at diabetes clinics was generally perceived to be good. PREM data for individual PDUs can be accessed using the reporting tool available on the RCPCH website:

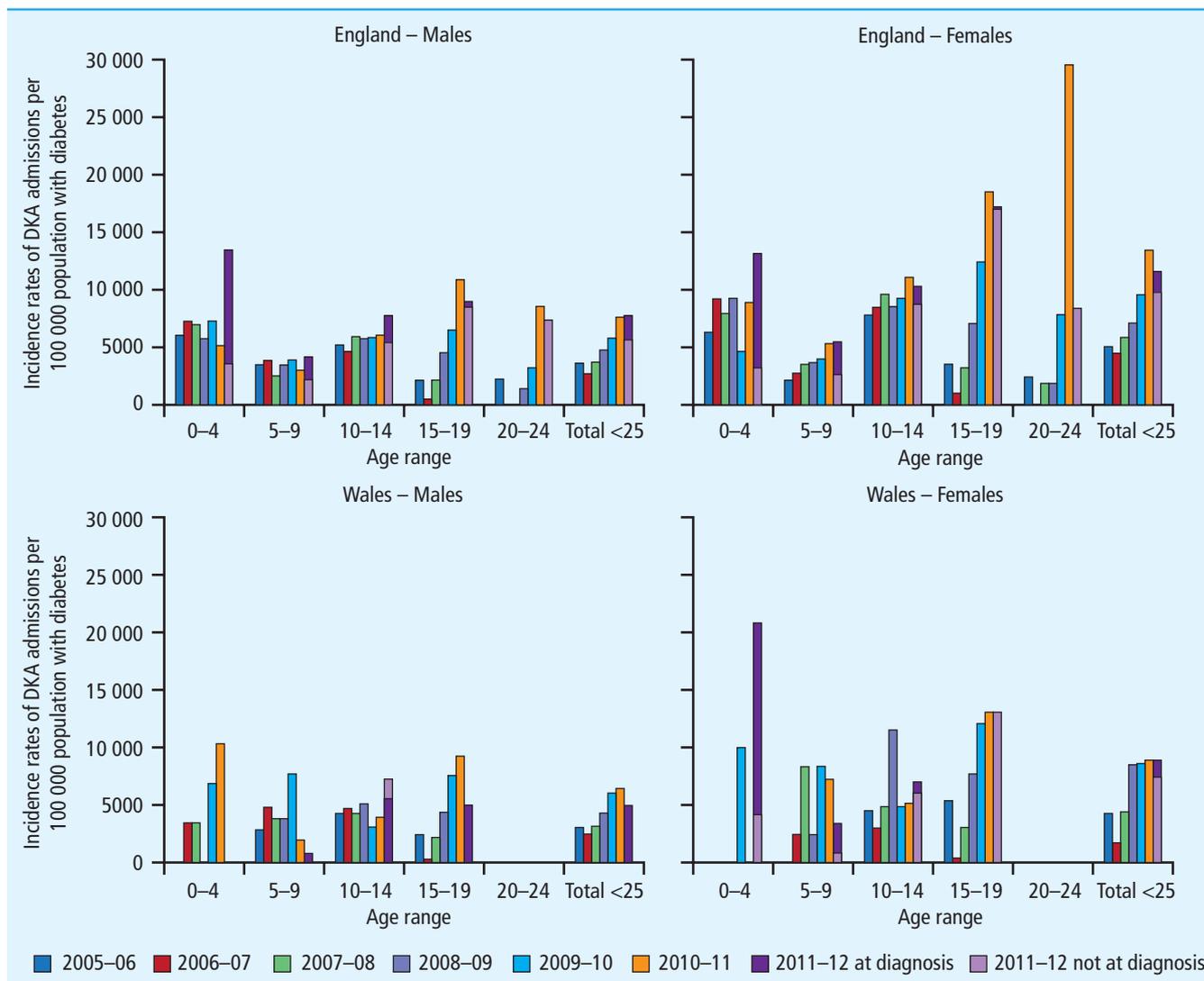
[www.rcpch.ac.uk/npda/PREM](http://www.rcpch.ac.uk/npda/PREM). The NPDA is also in the process of developing a Patient Reported Outcome Measure to assess patients' quality of life. At the time of writing the use of this tool remains at a piloting stage.

### Conclusion

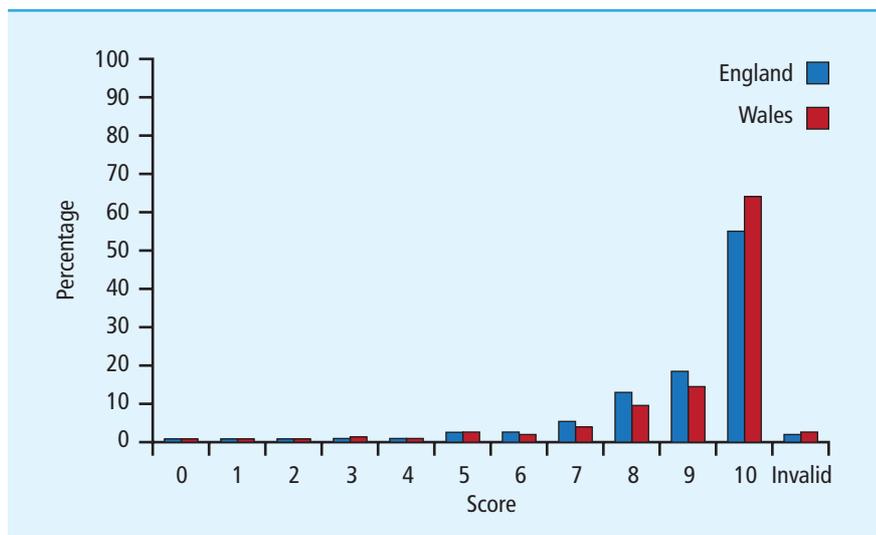
The NPDA is a powerful benchmarking tool and is an essential part of a long-term quality improvement programme for children and young people with diabetes. Since the inception of the audit, there has been little improvement in outcomes of care and participation in care processes in England and Wales, and an alarming increase in the number of children and young people being admitted with DKA. However, there may be emerging evidence in the last three years that the tide has changed in favour of improvement. It is accepted that significant change will not be immediate but that a constant trend in the right direction is vitally important. The NPDA has to recognise that some of the perceived poor adherence to care processes may not be a true reflection



**Figure 3a.** Percentage of hospital admissions in children and young people with diabetes for different complication categories for England and Wales 2011–12



**Figure 3b.** Age and sex specific crude incidence rates of DKA admissions per 100 000 children and young people with diabetes, England and Wales 2005–06 to 2011–12. (The % incidence rate can be calculated by dividing the crude incidence rate per 100 000 children and young people with diabetes by 1000)



**Figure 4.** Mean PREM (Patient Reported Experience Measure) score for England and Wales for the question 'On a scale of 0–10, how likely is it that you would recommend this clinic to a friend or another family with a child who has diabetes?' (0 = would not recommend at all, 10 = highly recommend). Scores of 9 or 10 are considered excellent and scores of 4 or less are considered a cause for concern. Scores of 5–8 are considered as requiring attention

of a failure to perform these processes, but may instead reflect the inadequate IT resources that many PDUs have to collect and submit their NPDA data.

These poor outcomes cannot be allowed to continue and the time has come for a concerted effort to improve quality of care for children and young people with diabetes. Investment in care for the young will ultimately reduce the risk of long-term complications and their associated cost to the NHS but also improve long-term quality of life. There have already been many changes in the way services are structured and delivered over the last few years. In England, with the help of the former NHS Diabetes, 10 Regional Networks have been established, geographically located in former Strategic Regional Health Authorities. The development of such networks has already resulted in improved participation in the NPDA by way of facilitating the collection of annual audit data and providing a facility for the monitoring and benchmarking of services within a region. The ultimate aim of this Regional Network approach is to improve quality of care across a region and remove inequalities of service provision.

The last few years have seen a move towards intensification of therapy, including insulin dose adjustment for carbohydrate intake using multiple daily injections and/or continuous subcutaneous insulin infusions. There

is also recognition of the need for continuous structured education programmes starting at diagnosis and continuing throughout childhood, adolescence and transition into adult services. In the last two years the Best Practice Tariff has been introduced in England to enhance the funding of paediatric diabetes services, with the aim of driving up the quality of care and improving outcomes for children and young people with diabetes. Participation in the NPDA is one of the key requirements to receiving the Best Practice Tariff and data for individual centres are utilised as part of a 'peer review' quality assurance programme. There are moves to introduce the quality assurance programme in Wales.

The RCPCH recognises that participation in the NPDA is a time consuming process, particularly where there is a lack of resource and/or computer software to aid data collection. Furthermore, there is a need to interrogate the audit dataset in a more meaningful manner and provide centres with additional outcome data that can be utilised to improve quality of care. To this end, work is currently underway to explore the possibility of including casemix adjustment as outcomes can undoubtedly be influenced by variables such as, age, gender, duration of diabetes and deprivation.

The NPDA is keen to engage patients, clinicians and other

stakeholders in England and Wales in order to improve outcomes for children and young people with diabetes, and would like to thank all those who have participated in data collection and submission, without which the NPDA would not be possible.

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