

The National Diabetes Paediatric Audit

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ARTICLE POINTS

1 The National Paediatric Diabetes Audit describes key clinical outcomes from paediatric services across the UK.

2 Data from 11 696 children and young people with diabetes inform the audit.

3 Most children and young people in the study had an average HbA_{1c} above the national target of 7.5%.

4 Many children and young people have levels of hyperglycaemia that put them at serious risk of long-term complications.

5 Blood glucose control deteriorates with age and in the first five years of living with diabetes.

6 Diabetic ketoacidosis, a serious condition that is preventable, is experienced by one in 20 children and young people with diabetes a year.

KEY WORDS

- Audit
- Paediatric diabetes
- Hyperglycaemia
- Diabetic ketoacidosis

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Introduction

The National Paediatric Diabetes Audit was a joint initiative between Diabetes UK, the Royal College of Paediatrics and Child Health, the British Society for Paediatric Endocrinology and Diabetes and the Royal College of Nursing. It describes key outcomes of diabetes services for children and young people in the UK – its aim is to support the development of these services by charting their progress towards national service standards. The 2002 audit reveals a widespread failure to achieve agreed national targets. Considerable investment is still needed to ensure that children and young people with diabetes suffer a minimum of health problems, both now and in the future.

Clinical audit is a process of investigation, learning and change. The methods of audit can sometimes be complex, but the underlying process is intuitive to any healthcare professional who is keen to improve service quality. The questions at the heart of the clinical audit cycle are:

- What are we trying to achieve?
- Are we achieving it?
- Why are we not achieving it?
- What can be done to improve practice?
- Have we made things better?

The National Paediatric Diabetes Audit surveyed paediatric diabetes clinics across the UK to inform the improvement of service quality through an investigation into current practice (i.e. it asks the second of the above questions). The results of the audit can be used by healthcare professionals, in conjunction with local audit and management information, to assess their priorities and identify changes that are of direct benefit to patients. Copies of the full report are available at: www.diabetes.org.uk/audit (accessed 17.02.05). Although this initiative is no longer being run by Diabetes UK, the National Clinical Audit Support Programme has taken over the work and roll-out of the diabetes audit has begun. We encourage all paediatric diabetes centres to participate – further details of

how to register are available at: www.nhsia.nhs.uk/ncasp/pages/audit_topics/diabetes (accessed 17.02.05).

The 2002 audit: method

The 2002 Audit was carried out in the last year of a four-year audit process supported by Diabetes UK, the Royal College of Nursing, the Royal College of Paediatrics and Child Health and the British Society for Paediatric Endocrinology and Diabetes. In England, data were submitted from 111 hospitals out of a possible 190. Data from the registers in Wales, Northern Ireland and Jersey are included for comparison where possible.

Anonymised data from individual children were submitted to Diabetes UK by clinicians and diabetes specialist nurses. Results for each centre were analysed first in order that each hospital could act quickly on local priorities. The national comparative data provide a broader view of variations in quality and local strengths and weaknesses.

Results: the cohort of children with diabetes

Data were obtained from 11 696 children and young people aged between 0–16 years. On average, centres in England treated 91 children each, with a range from 24–281 children.

In 2002, 1423 children in England and

123 children in Wales were diagnosed with diabetes. The incidence rate is therefore 14.9 children per 100 000, up from 13.5 children per 100 000 in 2001.

There were slightly more boys (52%) than girls (48%) in the cohort as a whole. Their average age was 11 years, the average age at diagnosis was seven years and the average length of time living with diabetes was four years.

The great majority (98.4%) of the children in the cohort had type 1 diabetes, but 102 children (0.9%) had type 2 diabetes. Although this latter figure represents a significant increase on the 75 children with type 2 diabetes in the 2001 audit, the difference may be due to increased recognition rather than to a true increase in prevalence. The small proportion of remaining children had other illnesses.

Table 1 outlines the ethnicity of the children in the cohort. The ethnic categorisation dates back to the 1991 census; the 2001 categorisation will be used in future national audits. The ethnic breakdown of the cohort is similar to that of the general population: 7.0% of the cohort were non-white compared to 7.9% of the general population, as recorded by the 2001 census.

Blood glucose results

The glycated HbA_{1c} result is the core clinical monitoring indicator for children and young people with diabetes. The International Society for Pediatric and Adolescent Diabetes (ISPAD) defines a target HbA_{1c} of ≤7.5% for children and their healthcare professionals (ISPAD, 2000), which is supported by the National Institute for Clinical Excellence (NICE) clinical guidelines for type 1 diabetes (NICE, 2004).

The average HbA_{1c} of the children in the cohort in England was 9.0%, with a range of 3.9%–20.0%. In Northern Ireland, the national average was 8.7%. Results were not available for Wales. Table 2 describes the results by strategic health authority in England. As these results have not been standardised for age, sex, ethnicity or deprivation, they should not be seen as a description of

differences in the quality of care. Instead, each result should be used locally as a marker for ongoing quality improvement.

No strategic health authority achieved an HbA_{1c} average within the recommended range to prevent long-term complications. Among children aged nought to five years, 20% achieved the NICE target of below 7.5%; among those aged six to ten years, 18% achieved the target; and among those aged 11 to 16 years, 14% achieved the target.

If the target HbA_{1c} is set higher, at 9.0% maximum, these results inevitably improve. Among children aged nought to five years, 69% achieved the target; among those aged six to ten years, 65% achieved the target; and among those aged 11 to 16 years, 52% achieved the target.

The wide range of the results in Table 2 indicate that while many children and young people face a high risk of long-term complications from persistent hyperglycaemia, others may be managed too strictly, risking serious hypoglycaemia.

Demographic differences

In general, HbA_{1c} results become worse with the age of the children in the cohort. However, the slight difference between boys and girls tends to disappear with age. At nought to five years, boys have an

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Table 1. Ethnicity of children in the cohort

Ethnic group	Frequency	Valid %
White	9 420	92.0
Black Caribbean	97	0.9
Black African	74	0.7
Black other	47	0.5
Indian	162	1.6
Pakistani	180	1.8
Bangladeshi	30	0.3
Chinese	10	0.1
Other Asian	68	0.7
Other	154	1.5
Sub total	10 242	100.0
Not recorded	1 454	
Total	11 696	

Table 2. HbA_{1c} by strategic Health Authority in England

Strategic Health Authority	HbA _{1c} (%)		
	Mean	Min	Max
Shropshire & Staffordshire	8.0	4.9	12.0
Norfolk, Suffolk & Cambridgeshire	8.5	4.9	13.8
Coventry, Warwick, Herefordshire & Worcestershire	8.6	5.3	14.6
South West London	8.7	5.2	14.0
Cheshire & Merseyside	8.7	5.2	15.2
South East London	8.8	5.1	13.7
South Yorkshire	8.8	4.5	15.2
Greater Manchester	8.8	4.7	16.7
Birmingham & Black Country	8.9	3.9	14.2
Thames Valley	8.9	4.8	15.2
South West Peninsula	8.9	5.2	15.4
North & East Yorkshire & Northern Lincolnshire	8.9	5.4	16.1
Trent	9.0	5.2	14.2
Hampshire & Isle of Wight	9.0	4.7	14.1
Dorset & Somerset	9.0	4.5	15.9
Cumbria & Lancashire	9.0	5.0	17.2
County Durham & Tees Valley	9.0	5.4	15.9
North East London	9.1	4.3	16.9
Kent & Medway	9.1	5.3	15.1
Northumberland, Tyne & Wear	9.1	4.6	18.0
West Yorkshire	9.1	4.8	20.0
Bedfordshire & Hertfordshire	9.2	4.6	19.0
Surrey & Sussex	9.2	5.0	17.1
North Central London	9.2	4.7	16.5
Leicestershire, Northamptonshire & Rutland	9.3	5.5	16.6
Avon, Gloucestershire & Wiltshire	9.3	4.7	16.4
Essex	9.3	6.1	14.0
North West London	9.8	5.3	16.1
England	9.0	3.9	20.0

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1 There were small but statistically significant differences in average HbA_{1c} levels between white and non-white children in the cohort.

2 In 2002, 7.5% of the cohort of children and young people had no recorded HbA_{1c} test.

3 Almost one in 20 (4.7%) of the children in the cohort were hospitalised at least once for DKA in 2002.

average HbA_{1c} of 8.4% whereas girls have a higher average of 8.6%. At six to ten years, boys average 8.6% and girls 8.7%, but by 11 to 16 years both sexes average 9.2%.

There were small but statistically significant differences in average HbA_{1c} levels between white and non-white children in the cohort. For whites, the average was 8.9%, compared to 9.2% for Indian, Pakistani and Bangladeshi, 9.3% for African Caribbean and 9.2% for other ethnicity.

Similarly, children from the least deprived backgrounds have an average HbA_{1c} of 8.9%, compared to 9.2% for those from the most deprived backgrounds. The indicator used here is the Carstairs Deprivation Index (Carstairs and Morris, 1989).

Frequency of blood glucose testing

Diabetes UK guidelines recommend that

children and young people with diabetes should be assessed every three to six months using the HbA_{1c} test (British Diabetic Association, 1996). In practice, there is great variability in the frequency of testing.

In 2002, 7.5% of the cohort of children and young people had no recorded HbA_{1c} test. Unfortunately, it is not known whether these children were not recalled, had moved away or lacked a test due to poor recording. Given the importance of the test, and the value of tracking test results over time, clinics should ensure that this recording is rigorous.

For half of the cohort (50.1%), only one HbA_{1c} test was submitted for the audit, although in some cases more than one test may have been conducted in practice. Among those who were definitely tested more than once, 29% had two tests, 35% had three tests, 26% had four tests and 10% had five tests or more. In general, children should not receive more than four tests a year.

Diabetic ketoacidosis

Diabetic ketoacidosis (DKA) is a severe condition that typically leads to hospital admission. As such, it is a very strong indicator of poor glucose control and the associated risks of long term complications.

Almost one in 20 (4.7%) of the children in the cohort were hospitalised at least once for DKA in 2002. This excludes admissions at diagnosis. More girls were admitted for DKA than boys (5.3% vs 4.0%).

Among those who were admitted for DKA, the majority (73%) only had one experience. However, 14% were admitted twice and 8% were admitted three times. As all DKA admissions more than a year after diagnosis are avoidable, there is considerable scope for reducing the physical, emotional and financial costs of these admissions (Dunger et al, 1999).

Discussion

The results of this national audit provide a context for interpreting local audit information and for defining goals in service

development. They provide a general indication of the scale of the challenge faced by clinicians, nurses and other professionals in the pursuit of national targets for children and young people with diabetes.

The experience of running the audit provided Diabetes UK with invaluable insight into the technical challenges of gaining accurate data over time from a national cohort. In particular, the use of the NHS number in future audits is recommended as a means of improving data quality.

NICE guidelines (NICE, 2004) and the National Service Frameworks for diabetes (Department of Health 2001; 2003) provide the strategic direction for improvements in the care, education and involvement of children and young people with diabetes. In terms of the audit cycle questions described earlier, it should be clear 'what we are trying to achieve'. The results from this audit indicate that this achievement still lies some way off. These results are therefore key indicators for change that ought to be invaluable to the efforts of local diabetes teams and networks to improve services for children and young people.

A minority of children and young people with diabetes – less than a fifth – currently achieve target HbA_{1c} results. The majority have unsatisfactory or poor glucose management. One in 20 children with diabetes are hospitalised with DKA every year. These are the principle indicators that have to shift if the long-term outcomes of children living with diabetes in the UK are to improve.

There is a clear pattern of deterioration in glucose control both with age and with time after diagnosis. This is likely to be related to many factors including the challenges of adolescence and identity-formation. Healthcare professionals must be wary of treating 'routine' appointments as a series of routine interventions, without full regard for the changing needs of young people. Particular efforts must be made to regularly engage with young people whose results are consistently high.

There are a number of indicators that are a cause for concern: the apparent rise in type 2 diabetes, the proportion of children not receiving any HbA_{1c} test, and the variations between the sexes, white and non-white children and children from high and low deprivation backgrounds. All of these issues should be carefully considered in local audits and future national audits.

Conclusion

Overall, the results of the audit provide a clear benchmark against which local services can monitor the improvement of their services. Local health commissioning bodies need to prioritise paediatric diabetes care to bring services into line with nationally-agreed standards and ensure that children and young persons with diabetes are enabled to achieve a quality of life and life expectancy similar to that of the general population. ■

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