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Royal College of Paediatrics and Child Health

NHS

Diabetes

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Growing up with diabetes: children and young people with diabetes in England

Key Findings

- At least 22,947 0-17 yr olds have diabetes. The prevalence of diabetes of any type in children and young people is at least 209 per 100,000.
- Most children and young people have Type 1 diabetes whereas most adults have Type 2 diabetes. We can estimate from this survey that there are 40.000 people aged less than 25 years with Type 1 Diabetes - 60% more than previously suspected.
- There are at least 15,400 school children with diabetes in England who need support.
- There are 328 children and young people with Type 2 diabetes (3.0/100,000) but this is higher than that suggested by the only other UK study.
- There is a strong case to support a national register of childhood diabetes in England to facilitate equal care wherever you live, to monitor long term outcomes, to ensure appropriate resource allocation and to further research.

Introduction

The Department of Health commissioned the Royal College of Paediatrics and Child Health (RCPCH) to carry out a survey,[1] to find out how many children and young people under the age of 18 in England have diabetes.

This research was supported by and carried out in collaboration with NHS Diabetes, the British Society for Paediatric Endocrinology and Diabetes (BSPED), the Association of Children's Diabetes Clinicians (ACDC), Diabetes UK, the Royal College of Nursing, the National Diabetes Information Service (NDIS) and the Yorkshire & Humber Public Health Observatory and with the support of the National Clinical Director for Diabetes and the National Clinical Director for Children, Young People and Maternity.

By counting accurately how many children and young people have diabetes it should be possible to better understand the need for children's and adolescents' diabetes services to support them, their families and their schools consistently across the country.

The survey was sent out online in February 2009 and 97%, of hospitals who provide services to children and young people with diabetes in England, responded (244/251). Hospitals were asked to provide a 'snapshot' of the number of children and young people with diabetes less than 18 years old attending for routine diabetes care on 1st January 2009.

How many children and young people have diabetes?

There were 22,947 children and young people aged 0-17 years with diabetes in England on 1 January 2009.

Overall

- 51.1% are boys and 48.9% are girls
- 97% have Type 1 diabetes
- 1.5% have Type 2 diabetes and
- 1.5% have other types of diabetes.

As this was the first national survey of its kind, the results do not show if the number of new cases of diabetes (incidence) is increasing.

By age

Of those that responded with age groups it was found that most children and young people with diabetes are aged between 10-17 yrs (16318 out of 21136 = 77%):

- 77% of children and young people with Type 1 are aged 10-17 yrs
- Type 2 diabetes is very rare in children less than 10 years old
- 80% of children and young people with other types are aged 10-17 yrs
- 96% (827 out of 858) of children under 5 years with diabetes have Type 1
- 59% of children and young people with Type 2 are aged 15-17 yrs

Further analysis showed that the number of children and young people varied by region. To calculate the prevalence[2] for each SHA, the survey team used data from the 2007 National Statistics and found that prevalence by SHA ranged from 137 to 279 per 100,000 for 0 -17 yr olds.

For Type 1 diabetes, there are more children and young people in the North East and South East Coast SHAs compared to the East Midlands and London SHAs. For Type 2 diabetes, prevalence is higher in London closely followed by the North East and West Midlands whilst prevalence in the East of England SHA was lower than average.

This survey revealed 60% more children and young people with diabetes than estimated in the Department of Health 2007 report 'Making Every Young Person with Diabetes Matter'. This suggested that there were 25,000 people under 25 years of age with Type 1 diabetes. The current survey, however, implies that there are actually closer to 37,965 young people under 25 years of age with Type 1 diabetes.

Diabetes and schools

There are a total of 15,408 school age (5-15 years) children and young people with diabetes in England (a prevalence of 232 per 100,000). The report also showed there were further 5,177 children and young people aged 16 and 17 years.

This means there are at least 5,924 children and young people with diabetes in primary education (5-10) and 13,670 in secondary education (11-16). However as many young people stay in secondary or further education until the age of 18 the number is likely to be higher than this.

Children spend a third of their waking hours in school. They need support to help manage their condition to keep blood glucose levels as close to the normal range as possible. Assistance is also needed to help them minimise the risk of long term complications. It is essential that both PCTs and Local Education Authorities are aware of the specific needs of children in school with diabetes so that they and their families can be properly supported.

Type of diabetes

Recent evidence has shown that an increase in obesity has been linked to a rise in the number of children and young people with Type 2 diabetes.

This survey found there were at least 328 children and young people with Type 2 diabetes, a prevalence of 3.0 per 100,000 compared to previous estimates of 0.21 per 100,000 although the numbers of cases are still very small.

This compares with 97% of respondents having Type 1 diabetes, as previously mentioned.

In this survey, Type 2 made up 57% of all non-Type 1 cases. The survey did not collect information on "other" types of diabetes but this would include;

- Children with neonatal diabetes
- Maturity Onset Diabetes of the Young
- Diabetes as part of a syndrome or diabetes secondary to another condition
- Diabetes secondary to another condition such as cystic fibrosis

Towards a register

Almost 50% of paediatric diabetes services had not taken part in the National Diabetes Audit (NDA). This means the NDA omits the records of 9,477 children and young people. Reasons given for not taking part in the NDA included a lack of staff, lack of funding, lack of time & lack of clinical IT.

National Paediatric diabetes registers are already in existence in Scotland and Wales, but not in England however a number of regional registers are in existence in England.

A national register would help the NHS in England plan to ensure that services are delivered equally. It would also inform research into the changing incidence and demographics of children and young people with diabetes.

The Department of Health is looking into the feasibility of establishing a national paediatric diabetes register for England.

The Department will be in discussion with the Royal College of Paediatrics and Child Health and the survey's working group to see whether it is advisable to set up a national register as well as the current National Diabetes Audit and to discuss who would be best placed to carry out this work.

1 For a copy of the full survey report visit: http://www.rcpch.ac.uk/Research/Research-Activity/Current-Projects/National-Diabetes-Survey

2 Prevalence is the method used to estimate how common a condition is within a population over a period of time. It is worked out by dividing the total number of cases in a population by the total number of individuals in a population.

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