FIRST NATIONAL SURVEY FINDS 23,000 CHILDREN WITH DIABETES IN ENGLAND

- Survey to support better care for children with diabetes -

The Royal College of Paediatrics and Child Health (RCPCH) has found that almost 23,000 children and young people have diabetes in England – a figure higher than previous estimates.

The snapshot survey, ‘Growing up with Diabetes: children and young people with diabetes in 2009’ commissioned by the Department of Health, gives accurate numbers of children and young people under the age of 18 with diabetes of any type in England.

The report also shows that:

- The majority of children and young people have Type 1 diabetes (97 per cent) – this is in contrast to adult populations where numbers of cases of Type 2 far exceed Type 1
- A very small percentage of children and young people have Type 2 diabetes (1.5 percent) but prevalence of Type 2 is probably increasing in children as in adults
- The greatest number of children and young people with diabetes are aged between 10-14 years (just under 9,000)
- The burden of diabetes in school age children is high. There are at least 15,361 children (age 5-15) in schools in England with diabetes – this has significant implications for schools and families
- There are differences in numbers of cases between Strategic Health Authorities (SHAs). The numbers with Type 1 are higher than would be expected in the North East and South East Coast SHA’s. For Type 2 diabetes, numbers were much higher than average in London, the North East and the West Midlands.

The Department of Health and healthcare providers will use the results of the audit to help to plan and deliver high quality care for children and young people wherever they live in the country. This will include the organisation of healthcare, and the accommodation of children’s needs, in schools as well as in clinical settings.

The Department of Health commissioned the Royal College of Paediatrics and Child Health Research Department to establish the number of under-18 year olds with diabetes in England. The project was funded by NHS Diabetes. It was 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 is supported by the National Clinical Director for Diabetes and the National Clinical Director for Children, Young People and Maternity and the Chief Medical Officer. This survey will supplement the National Diabetes Audit (NDA) managed by the NHS Information Centre and the Diabetes UK survey of Paediatric and Adolescent Diabetes Services.
Diabetes is a serious life long condition that can lead to multiple complications and premature mortality. Effective care on a daily basis can greatly improve the quality of life of children and young people with diabetes and reduce the risk of them developing complications.

**RCPCH President, Professor Terence Stephenson said,**

“For the first time we know that at least 23,000 children and young people have diabetes in England and it confirms that most cases are Type 1 diabetes.

“With such a high response rate to our survey, this also is a testament to both to the efficiency and to the willingness of paediatricians nationally to collaborate and the ability of the Royal College of Paediatrics and Child Health to conduct important research.

“All children with any type of diabetes should be able to lead their daily life with the best support and medical care so that they can manage their condition. Effective care on a daily basis can greatly improve the quality of life of children and young people with diabetes. This survey may prompt questions about the standard and provision of care around the country and we hope that the Government looks at this immediately.”

**Dr. Rowan Hillson, National Clinical Director for Diabetes said,**

“I want to ensure that all of the 23,000 children and young people with diabetes in England can lead the same full, active lives as children without diabetes.

“I commissioned this survey to help us to plan and deliver the best quality healthcare clinically and within schools and the community.

“A better understanding of the numbers of children and young people with diabetes will help us to enable them to grow up unimpeded by their condition, avoiding complications such as kidney disease and eye problems”

“I would like to thank everyone involved in this major project for their enthusiastic hard work and support.”

**Dr. Sheila Shribman, National Clinical Director for Children, Young People and Maternity said,**

“Improving children's health is a top priority for the Government.

“The results of this audit will be valuable in helping us to meet the pledge, to improve the organisation of diabetes care, made in our strategy, Making Every Young Person with Diabetes Matter.

“We are working with the Department for Children, Schools and Families to help ensure that children with diabetes are properly supported whilst they are in school.

“We are committed to helping diabetes teams to offer a co-ordinated service, delivered through networks, that supports children and young people in managing their diabetes, enabling them to experience the best possible quality of life.”
NHS Diabetes, Director, Anna Morton said:

“This comprehensive study will help to give healthcare professionals the chance to really get a grip on planning diabetes care for children and young people, as you can not plan ahead if you do not know the size of the problem.

“So ultimately this work should result in the standards of care for children and young people being raised. I would like to see these results collected annually as part of the National Diabetes Audit, which currently has a 60% response rate.”

Ends

Notes to editors:

1. The full RCPCH report is available at http://www.rcpch.ac.uk/Research/Research-Activity/Current-Projects/National-Diabetes-Survey
2. The survey was carried out by the RCPCH Research Department, with an almost complete response rate of 97% (244/251) from hospitals with acute paediatric medical services. (Acute paediatric medical services as defined by RCPCH Workforce Census 2007).
3. Type 1 diabetes develops if the body is unable to produce any insulin. This type of diabetes usually appears before the age of 40 and it is not preventable.
4. Type 2 diabetes develops when the body can still make some insulin, but not enough, or when the insulin that is produced does not work properly. Type 2 diabetes is usually linked with being overweight.
5. Other types of diabetes include children with neonatal diabetes, Maturity Onset Diabetes of the Young, diabetes as part of a syndrome (either recognised or unrecognised) or diabetes secondary to another condition, most commonly cystic fibrosis.
6. The figure for the number of under-18s with diabetes exceeds previous estimates with Diabetes UK figures suggesting 20,000 children and young people have diabetes in the whole of the UK.
7. Just over half, 51.1% (11,643/22,783), of the CYP with diabetes are boys.
8. The report shows that
   a. 97% (20,488) of under-18s with diabetes have Type I
   b. 1.6% (328) of under-18s with diabetes have Type 2
   c. 1.5% (319) of under-18s with diabetes have other types of diabetes
9. NHS Diabetes works to raise the quality of diabetes care by supporting healthcare professionals.