

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

RESEARCH REPORT

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and Child Health



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**Royal College of Paediatrics and Child Health
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Foreword

Children and Young People with diabetes should have access to the best clinical care that empowers them to manage their condition on a day-to-day basis. This care should extend beyond hospital settings, to ensure children and young people with diabetes can lead their daily life at school and home in a way that is clinically optimal and personally and psychologically right for them.

The first step to making these improvements to health care and its provision is to have accurate data of how many children and young people in England have diabetes. Accurate, up-to-date knowledge is crucial to the planning and delivery of best quality health care. This report sets out the findings of a working group established to survey the number of children and young people in England with diabetes. This survey demonstrates the determination of all involved in diabetes care, to begin a process of quality improvement that will ensure the needs of children and young people with diabetes are met.

This survey brings exciting opportunities to address current diabetes health care provision and ensure that it is appropriate considering the numbers of affected children and young people. The organisation of care needs to be improved to ensure that all children, regardless of age or the region in which they live receive optimal health care. We are very fortunate to have an enthusiastic and committed workforce across all sectors, who are experts in making these improvements happen.

I would like to thank the working group that managed this project so successfully and who are enthusiastic about continued work with the Department of Health and the NHS to improve diabetes care. I would like to give special thanks to the Royal College of Paediatrics and Child Health (RCPCH) who have coordinated and managed the project so effectively. We now have the opportunity to address the care of children and young people with diabetes, both in professional health care settings and within the community, to ensure that our young people are able to lead full and productive lives regardless of their health care needs.



Sir Liam Donaldson
Chief Medical Officer

1. Introduction

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 these complications. However, there are anxieties around ensuring the standard of care for children and young people with diabetes is optimal and consistent. Following the concern expressed by Sir Liam Donaldson, Chief Medical Officer for the Department of Health, Dr Rowan Hillson (National Clinical Director for Diabetes) with Dr Sheila Shribman (National Clinical Director for Children, Young People and Maternity), commissioned a snapshot survey, financially supported by NHS Diabetes, with the aim of obtaining accurate numbers of children and young people with diabetes in England, the results of which would be used to inform and improve diabetes care.

The Department of Health commissioned the Science and Research Division of the Royal College of Paediatrics and Child Health (RCPCH) to undertake a project to establish the number of under-18 year olds with diabetes in England. This project has been 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. 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.

Caring for children and young people with diabetes involves a complex process of care provision with much emphasis on involving both the patient and their parents or carers in every step of decision making. Service provision has been improving in the United Kingdom but there are still variations in the standards of care of children and young people with diabetes. This survey is intended to help ensure added coordination and accurate knowledge to enable consistent, high quality care for all children and young people with diabetes across the country. The key areas that this project will help all involved in the care of children and young people with diabetes address are:

- How will health care provision support all children and young people diagnosed with diabetes?

- How can it be ensured that all school students with diabetes receive the best care during school hours?
- What is the geographic distribution of children and young people with diabetes?

2. Project Background

The project was undertaken by staff from the RCPCH Science and Research Division between January and March 2009. A project team was established to oversee the project which was run on a day to day basis by a project manager. The management structure ensured that the RCPCH was able to facilitate the access to paediatricians rapidly and effectively.

The specific aims of the project were:

- To establish the total number of infants, children and young people under the age of 18 (thereafter referred to as children and young people) in England with diabetes of any type on the 1st January 2009
- To establish the relative burdens of Type 1 and non-Type 1 diabetes and the age breakdown of children and young people with diabetes
- To inform the development of the national diabetes audit by exploring potential barriers to participation
- To inform the potential establishment of a national register of childhood diabetes

The project was initiated by a widespread information campaign to raise awareness within the clinical community using the following routes:

- The e-bulletin of the RCPCH President which is sent to over 10,000 members of the RCPCH
- Websites of the RCPCH, Diabetes UK, British Society for Paediatric Endocrinologists and Diabetologists (BSPED), the Association of Children's Diabetes Clinicians (ACDC), NHS Diabetes and the Royal College of Physicians
- The BSPED newsletter
- Diabetes UK Annual Professional Conference publication – The Daily Wire
- Department of Health Children and Maternity Services Bulletin

3. Survey Methodology

The tight project time-line (3 months) necessitated the use of an on-line survey programme *SurveyMonkey*¹ for this national survey. The aim was to achieve maximum case ascertainment by collecting a minimum of non-identifiable patient information, so as not to overburden participating clinicians many of whom had also submitted data in 2008 to the National Diabetes Audit² and to the Diabetes UK, ACDC, BSPED and ABCD survey of Paediatric and Adolescent Diabetes Services survey 2008³.

Previous surveys by Diabetes UK have established that the majority of children and young people with diabetes are cared for by paediatricians with a special interest in diabetes or endocrinology, most of whom are members of the ACDC or BSPED. However it was anticipated a small number would be cared for by general paediatricians or, depending on the age of transition to adult care, adult physicians. Therefore to maximise ascertainment the survey was targeted at an identified paediatric and adult physician lead in every hospital in England providing acute medical care.

Hospitals and individuals were identified using the membership lists of the ACDC, BSPED, the RCPCH 2007 workforce census, a list of consultants participating in the British Paediatric Surveillance Unit (BPSU), a list of hospitals participating in the National Diabetes Audit (NDA), the findings of the Diabetes UK 2008 Survey and from information provided in the Directory of Diabetes Care 2009⁴. These sources supplied the projects contacts spreadsheet which was updated and amended as the project progressed.

Before the survey was rolled out the National Clinical Director for Diabetes, the National Clinical Director for Children, Young People and Maternity and the RCPCH President sent an introductory letter to the identified paediatric clinical leads and to members of the Association of British Clinicians in Diabetes. The letter served to introduce the project, update the master contacts spreadsheet and identify invalid e-mail addresses.

3.1 Data Items

The agreed data items to be collected were compiled into an on-line survey form. In the first week of February 2009 a link to the online survey and a hardcopy of the

form was sent via email to the identified paediatric and adult diabetes leads in every hospital. Survey participants were initially given 2 weeks to return data although the deadline was subsequently extended by a week. Non-responders were then contacted by telephone. A project helpdesk was set up which responded to telephone or e-mail queries about the survey within 24 hours.

3.2 Inclusion Criteria

Participants were asked to provide numbers of children and young people with diabetes less than 18 years of age attending the service for their routine diabetes care on 1st January 2009. Clinicians treating children in more than one location were asked to identify the additional locations and provide the total across the service. Where the service provided joint adult and paediatric clinics for adolescents/young adults, participants were asked to ensure that children and young people were only included on either the paediatric or the adult return.

The mandatory data items for completion were:

- total number of children and young people with diabetes of any type on 1st January 2009
- total number of male children and young people with diabetes
- contact details of the reporting clinician
- specialty of clinician completing form

The survey also asked for:

- number of children and young people with diabetes by diabetes type (Type 1, Type 2 or other form) by age groups (0-4,5-9,10-14,15,16,17)
- where data were available – the number of children and young people with diabetes by type by year of birth
- whether the unit had submitted data for 2007 to the National Diabetes Audit (NDA)
- reasons for non-participation in the NDA if applicable

As the survey only asked for anonymised data the Multi-centre Research Ethics Committee and National Information Governance Board approval was not required.

4. Results

4.1 Response Rates

The survey form was initially sent to 607 clinicians (286 paediatricians and 321 adult physicians) in approximately 325 hospitals in England. Hospitals reporting that they did not care for any children and young people with diabetes or did not provide acute medical care were removed from the list.

Calculating an accurate response rate either in terms of hospitals or clinicians is difficult. This is because significant numbers of returns were joint hospital returns (i.e. from paediatric and adult services) and because several replies provided information for more than one hospital. However of the 251 hospitals identified by the RCPCH 2007 Workforce Census as having paediatric medical services 97% responded (244/251).

Seven hospitals known to provide care for children and young people with diabetes as part of the paediatric medical service did not participate in the survey. For two of these hospitals the numbers of CYP being cared for were obtained from the 2008 Diabetes UK survey.

4.2 Children and Young People with Diabetes in England

4.2.1 All England Prevalence

The survey established that there were 22,783 children and young people 0-17 years with diabetes in England on 1st January 2009. With a 2007 0-17 population of 10,994,788 (2007 ONS population data⁶) the all England prevalence of diabetes in children and young people is 207/100,000 (95% CI 180 – 240)/100,000). Including the 164 children identified from other sources (2008 Diabetes UK) the total of children and young people increases to 22,947, a prevalence of 209/100,000 (95% CI 180 –240)/100,000).

Just over half, 51.1 % (11,643/22,783), of the children and young people with diabetes are males.

4.2.2 Type of Diabetes

Classification of the type of diabetes was left to the discretion of the reporting clinician.

Type of diabetes was provided for 92.8% (21,136/22,783) of survey responses. Of these 97% (20,488/21,136) have Type 1, 1.5% (328/21,136) have Type 2 and 1.5% (320/21,136) have other types of diabetes. Using ONS data (2007 ONS population data⁶) the all England prevalence of Type 1 diabetes is 186.3/100,000 (95% CI 160 – 210)/100,000), for Type 2 is 3.0/100,000 (95% CI 2.68 – 3.3)/100,000) and for other types of diabetes is 2.9/100,000 (95% CI 2.62 – 3.62)/100,000). The overall non-Type 1 diabetes prevalence is 5.9/100,000 (95% CI 5.46 – 6.87)/100,000).

4.2.3 Age Breakdown

Age breakdown was also provided for 92.8% of all children and young people with diabetes and is illustrated in Table 1. For all types of diabetes the greatest number of children and young people are over 10 years of age; 77% of all children with Type 1 diabetes are in this age group; 98% of Type 2 and 80% of other types. Overall 4.1% (858/21,136) of children and young people were under 5 years of age, of whom 96.3% have Type 1 diabetes.

Table 1: Type of diabetes by age categories

Age	Type 1	% of Type 1	Type 2	% of Type 2	Other	% of other types	Total
0-4	827	4.0	0	0.0	31	9.7	858
5-9	3,920	19.1	6	1.8	34	10.6	3,960
10-14	8,715	42.5	128	39.1	114	35.6	8,957
15	2,327	11.4	72	22.0	45	14.1	2,444
16	2,498	12.2	71	21.7	51	15.9	2,620
17	2,201	10.7	51	15.6	45	14.1	2,297
Total	20,488		328		320		21,136

77% (183/239) of hospitals indicated that they were able to provide a breakdown of the numbers of children and young people by year of birth and data were received from 179 of these. Year of birth was therefore provided for 66.1% of the total of children and young people with diabetes in England.

4.2.4 Geographic Distribution

The list of hospitals participating in the survey grouped by Strategic Health Authority (SHA) is provided in Appendix 1.

4.2.5 SHA Prevalence

The number of children and young people with diabetes was analysed by SHA and prevalence calculated using 2007 ONS population data⁶. SHA prevalence of all types of diabetes ranged from 137 – 279 per 100,000 0-17 (Table 2).

The standardised morbidity ratios (SMR) were calculated for all diabetes cases and then separately for each type of diabetes in order to identify SHA's where the number of children and young people with diabetes is higher or lower than expected. The overall SMR by SHA was calculated by working out the number of cases which would be expected to occur in the SHA if the prevalence was the same as the all England prevalence (total cases/total 0-17 population x100,000) and then using this figure in the calculation as follows:

$$\text{SMR} = \text{Actual number of CYP in SHA} / \text{expected number} \times 100$$

Tables 2-5 and figures 1-3 illustrate the numbers, population prevalence's and SMR for all cases of diabetes and then separately for Type 1 and Type 2 diabetes. Figure 1 additionally shows the Type 1 prevalence by age group for each SHA.

The tables and figures illustrate the distribution of cases of diabetes. Table 2 and Figure 1 (all cases) and Table 3 and figure 2 (Type 1) show a similar geographic distribution; the North East and South East Coast SHA's have a higher number of cases than would be predicted whereas numbers in East Midlands and London SHA's are lower than expected. For Type 2 diabetes the distribution is different (Table 5 and figure 3). The highest SMR is found in London closely followed by the North East and West Midlands SHA's whereas East of England SHA has a lower number of cases than would be expected.

Table 2: All types of diabetes by age and Strategic Health Authority

Total types of diabetes	Age (years)							Total	0-17 population	Prevalence (per 100,000 0-17 year olds)	Expected number of cases (using England prevalence)	SMR% (0-17 year olds)
	0-4	5-9	10-14	15	16	17						
East Midlands	47	242	507	154	152	179	1,281	935,131	137.0	1,797.6	71.3	
East of England	81	383	866	250	238	234	2,052	1,226,621	167.3	2,357.9	87.0	
London	151	497	1039	266	266	233	2,452	1,627,757	150.6	3,129.0	78.4	
North East	48	268	631	184	191	166	1,488	532,289	279.5	1,023.2	145.4	
North West	100	532	1194	316	351	224	2,717	1,498,716	181.3	2,881.0	94.3	
South Central	74	398	786	218	259	234	1,969	880,131	223.7	1,691.9	116.4	
South East Coast	97	446	1103	267	353	233	2,499	924,546	270.3	1,777.3	140.6	
South West	108	421	909	252	286	231	2,207	1,056,866	208.8	2,031.6	108.6	
West Midlands	81	448	1042	279	304	285	2,439	1,199,997	203.3	2,306.8	105.7	
Yorkshire and The Humber	72	324	880	258	220	278	2,032	1,112,734	182.6	2,139.0	95.0	
							21,136	10,994,788				

Table 3: Type 1 diabetes by age and Strategic Health Authority

Type 1	Age (years)							Total	0-17 population	Prevalence (per 100,000 0-17 year olds)	Expected number of cases (using overall England prevalence for Type 1)	SMR% (0-17 year olds)
	0-4	5-9	10-14	15	16	17						
East Midlands	45	242	495	147	146	167	1,242	935,131	132.8	1,742.5	71.3	
East of England	79	380	841	242	228	224	1,994	1,226,621	162.6	2,285.7	87.2	
London	146	493	983	237	234	216	2,309	1,627,757	141.9	3,033.2	76.1	
North East	46	264	616	177	186	157	1,446	532,289	271.7	991.9	145.8	
North West	97	527	1153	302	338	213	2,630	1,498,716	175.5	2,792.7	94.2	
South Central	69	391	768	205	244	218	1,895	880,131	215.2	1,640.0	115.5	
South East Coast	94	445	1087	260	345	230	2,461	924,546	266.2	1,722.8	142.8	
South West	103	421	895	246	275	226	2,166	1,056,866	204.9	1,968.2	110.0	
West Midlands	78	439	1011	260	291	277	2,356	1,199,997	196.3	2,236.0	105.4	
Yorkshire and The Humber	70	318	866	251	211	273	1,989	1,112,734	178.7	2,073.0	95.9	
							20,488	10,994,788				

Table 4: Age related prevalence Type 1 diabetes

Type 1 Age Related Prevalence (per 1000,000 population) by Strategic Health Authority									
	Population	Cases	Prevalence	Population	Cases	Prevalence	Population	Cases	Prevalence
Strategic Health Authority	0-4	0-4	0-4	5-15	5-15	5-15	16-17	16-17	16-17
East Midlands	247,854	45	18.2	568,487	884	155.5	118,790	313	263.5
East of England	331,952	79	23.8	747,948	1,463	195.6	146,721	452	308.1
London	530,893	146	27.5	924,715	1,645	177.9	172,149	452	262.6
North East	140,598	46	32.7	323,899	1,058	326.6	67,792	343	506.0
North West	402,457	97	24.1	906,347	1,982	218.7	189,912	551	290.1
South Central	239,881	69	28.8	533,224	1,363	255.6	107,026	462	431.7
South East Coast	244,631	94	38.4	566,872	1,860	328.1	113,043	575	508.7
South West	271,738	103	37.9	649,708	1,562	240.4	135,420	501	370.0
West Midlands	327,354	78	23.8	723,848	1,710	236.2	148,795	568	381.7
Yorkshire and The Humber	301,045	70	23.3	672,341	1,435	213.4	139,348	484	347.3
England Totals	3,038,403	827	27.2	6,617,389	14,962	226.1	1,338,996	4,699	350.9

Table 5: Type 2 diabetes by age and Strategic Health Authority

Type 2					
Strategic Health Authority	Total	0-17 population	Prevalence (per 100,000 0-17 year olds)	Expected number of cases (using overall England prevalence for type II)	SMR% (0-17 year olds)
East Midlands	24	935,131	2.6	27.9	86
East of England	18	1,226,621	1.5	36.6	49
London	79	1,627,757	4.9	48.5	163
North East	24	532,289	4.5	15.9	151
North West	35	1,498,716	2.3	44.7	78
South Central	29	880,131	3.3	26.2	111
South East Coast	21	924,546	2.3	27.6	76
South West	25	1,056,866	2.4	31.5	79
West Midlands	52	1,199,997	4.3	35.8	145
Yorkshire and The Humber	21	1,112,734	1.9	33.2	63
	328	10,994,788			

Figure 1: Prevalence of diabetes (all types) per 100,000

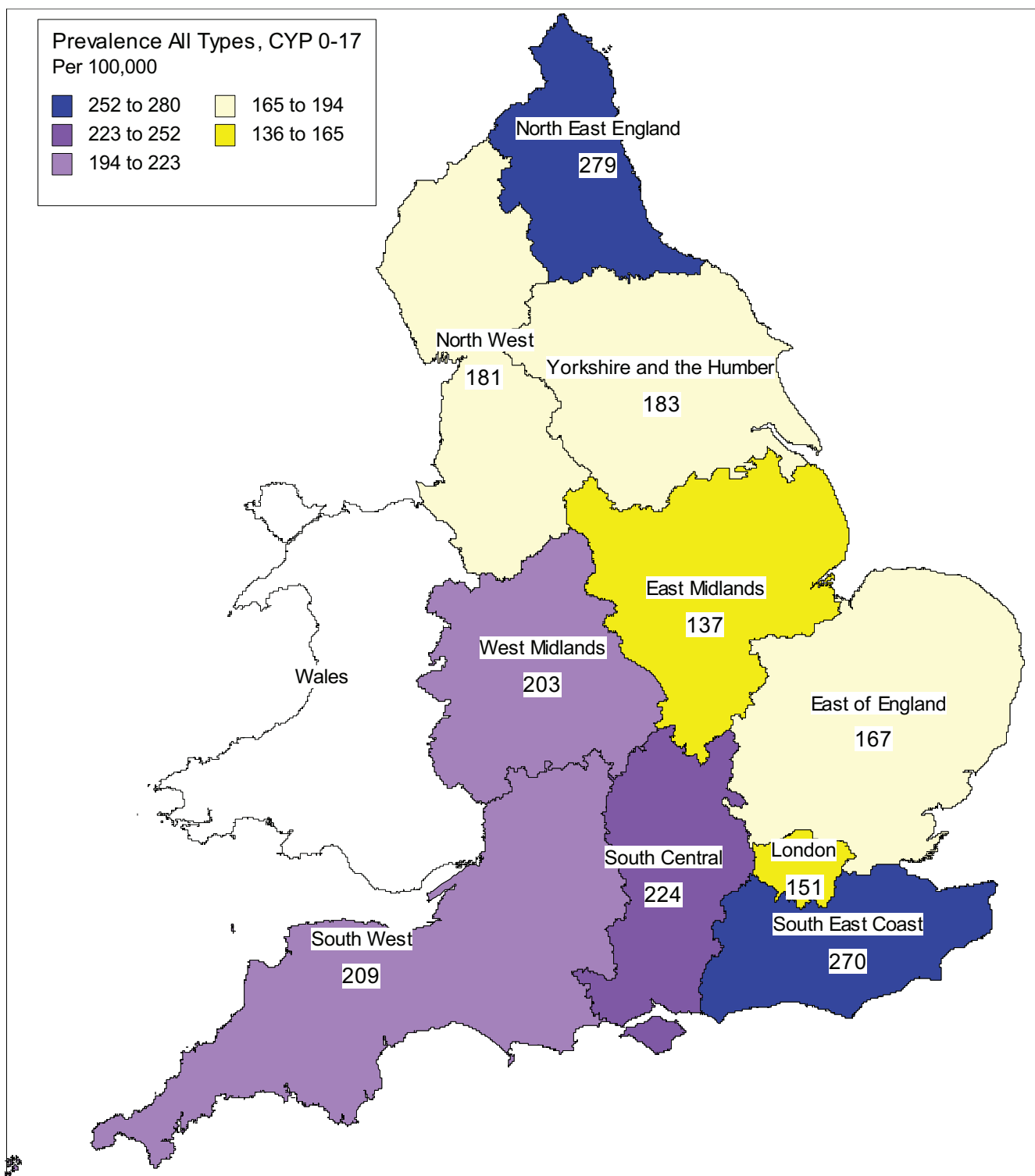


Figure 2: Standardised Morbidity Ratios by SHA for Type 1 Diabetes

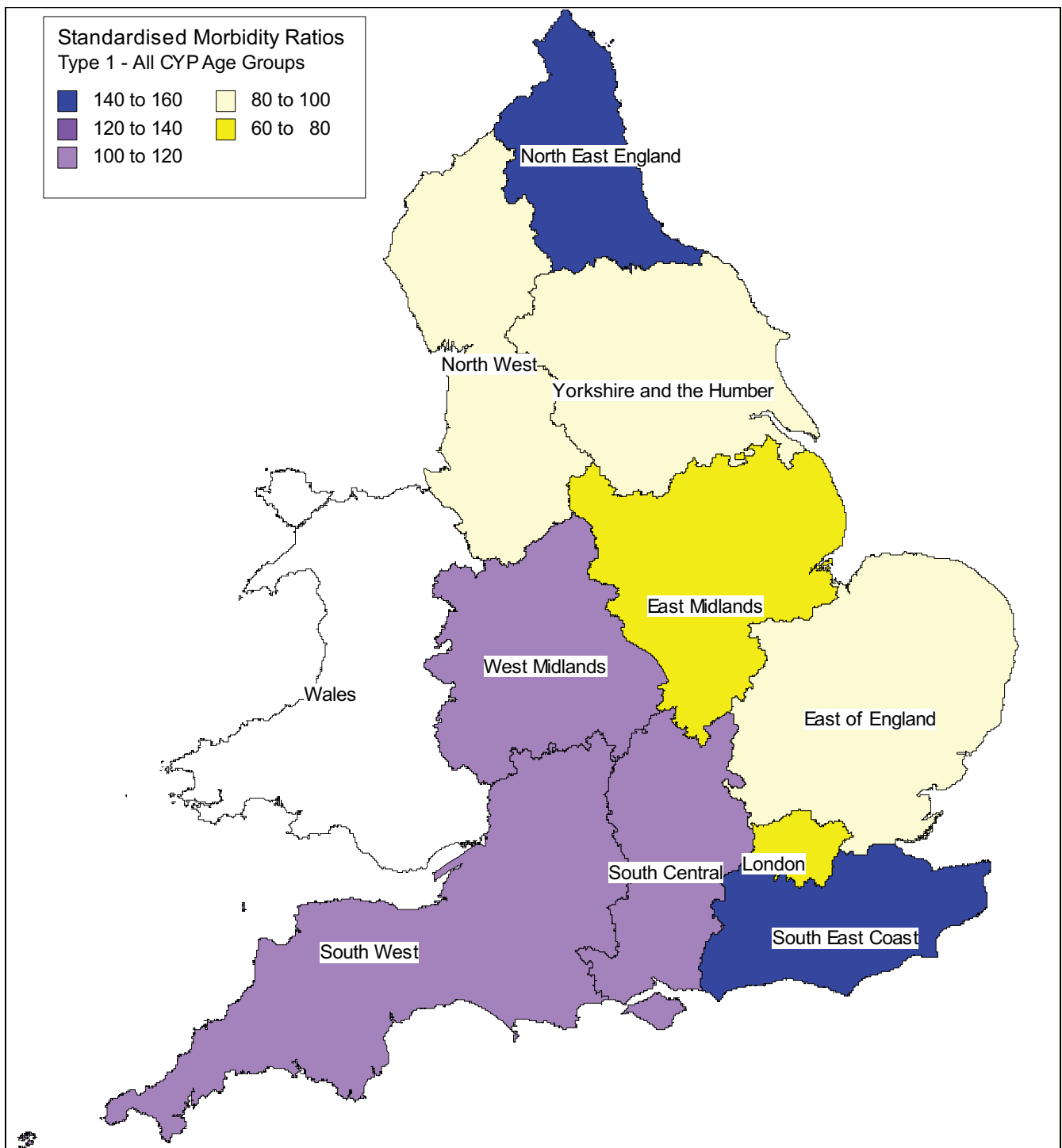
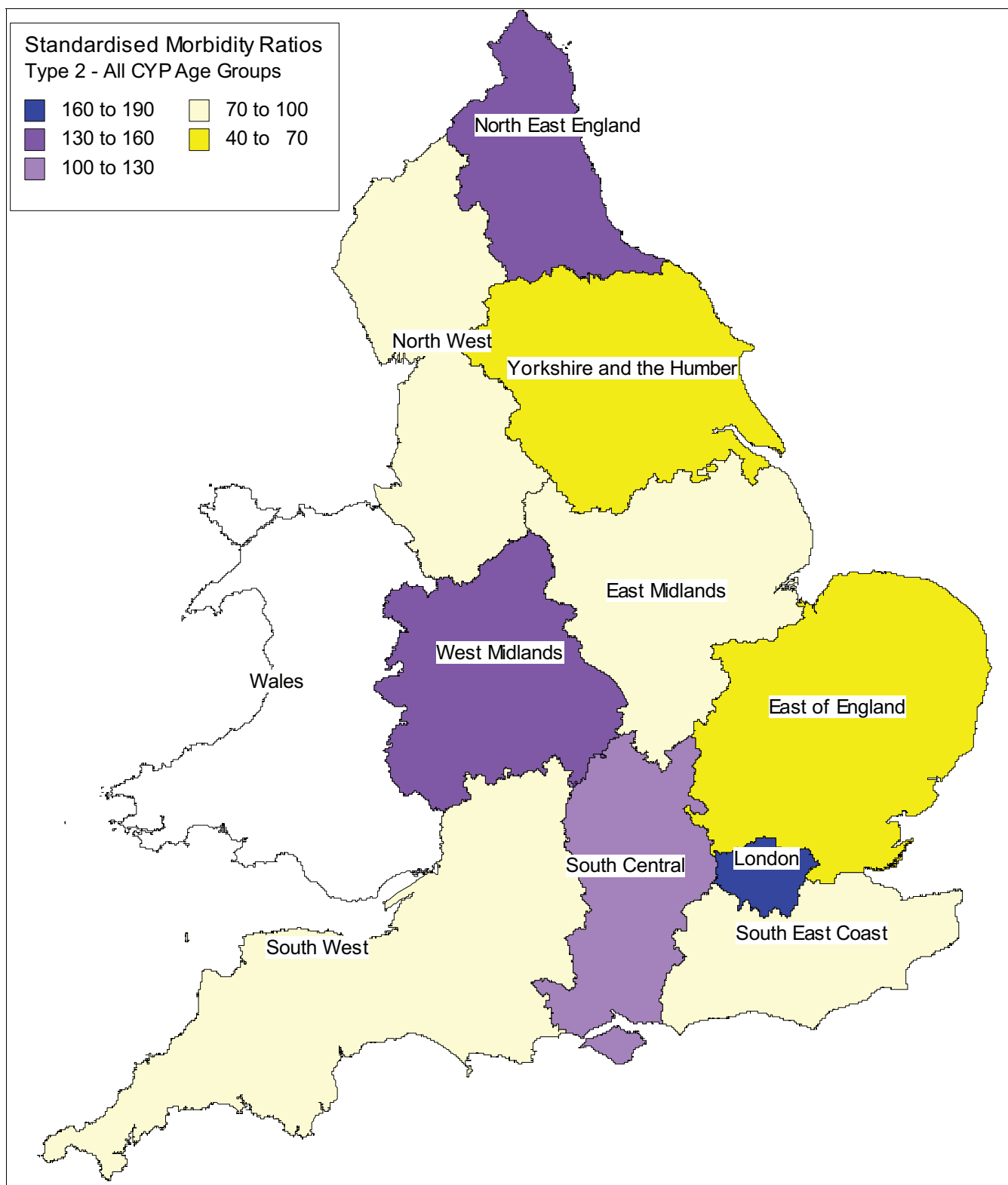


Figure 3: Standardised Morbidity Ratios by SHA for Type 2 Diabetes



5. Children and Young People with Diabetes in Education

As the peak prevalence of all types of diabetes is in the over 10 year olds, there will be a significant number of children and young people with diabetes attending schools or further education institutions. The survey established that there were a total of 15,408 school age (5-15 years) children and young people with diabetes in England, a prevalence of 232/100,000 (2007, ONS 5-15 population in England 6, 617,389⁶). There were a further 5,177 16 and 17 year olds. The distribution by SHA is provided in Table 6 (5-15) and Table 7 (16-17).

The year of birth breakdown data provided for two thirds of the total children and young people was used to estimate the numbers of children and young people in primary and secondary education. Twenty-six percent of this subgroup were between 5-10 years, and extrapolating this figure to the total children and young people with diabetes population suggests that there were 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 significantly greater than this.

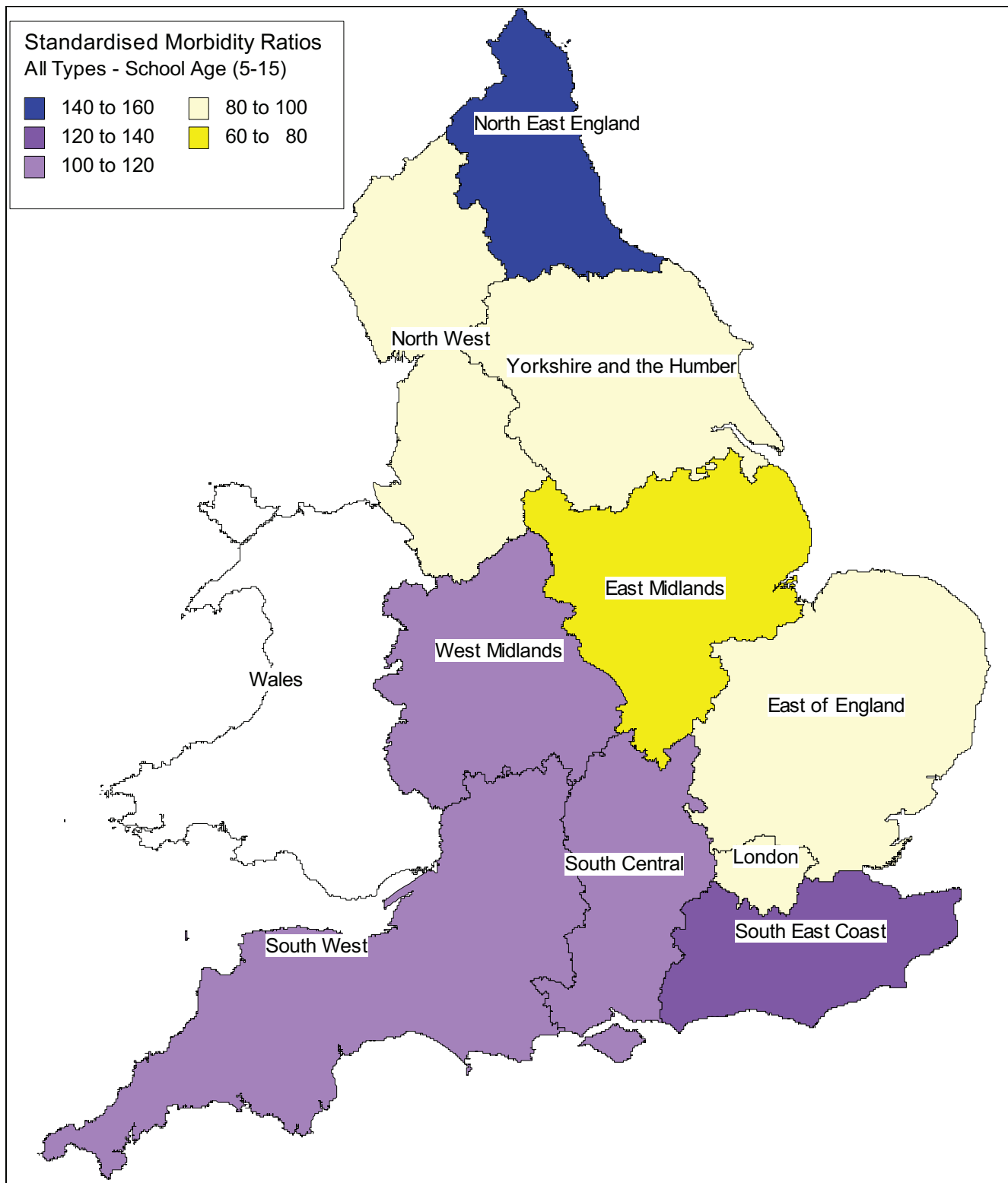
Table 6: 5-15 year olds with diabetes within each Strategic Health Authority

Strategic Health Authority	School Children (5-15 years old)	5-15 population	Prevalence (per 100,000)	Expected number of cases	SMR %
East Midlands	903	568,487	158.8	1,323.7	68
East of England	1,499	747,948	200.4	1,741.5	86
London	1,846	924,715	199.6	2,153.1	86
North East	1,083	323,899	334.4	754.0	143
North West	2,042	906,347	225.3	2,110.3	97
South Central	1,402	533,224	262.9	1,241.6	113
South East Coast	1,820	566,872	321.1	1,315.1	138
South West	1,582	649,708	243.5	1,512.8	105
West Midlands	1,769	723,848	244.4	1,685.4	105
Yorkshire and The Humber	1,462	672,341	217.4	1,565.5	93
Total	15,408	6,617,389			

Table 7: 16 and 17 year olds with diabetes within each Strategic Health Authority

Strategic Health Authority	Young Adults (16-17 years old)	16-17 population	Prevalence (per 100,000)	Expected number of cases	SMR %
East Midlands	331	118,790	278.6	436.2	76
East of England	472	146,721	321.7	538.8	88
London	466	172,149	270.7	632.2	74
North East	357	67,792	526.6	248.9	143
North West	575	189,192	303.9	694.7	83
South Central	493	107,026	460.6	393.0	125
South East Coast	619	113,043	547.6	415.1	149
South West	517	135,420	382.8	497.3	104
West Midlands	589	148,795	395.8	546.4	108
Yorkshire and The Humber	498	139,348	357.4	511.7	97
Total	4,917	1,338,996			

Figure 4: Standardised Morbidity Ratios for all types of diabetes in school age children (5-15) by SHA



6. Clinician Speciality

One of the recommendations made by Diabetes UK is that children and young people with diabetes should be under the care of consultants with a special interest and training in diabetes. The fourth national Diabetes UK services survey in 2005 found that 88% (165/187) of clinic responses indicated that a paediatrician with a special interest in diabetes was the lead clinician⁵.

As shown in Table 8, 95% (230/243) of paediatric responses were from individuals who considered themselves to be either a paediatric diabetologist or endocrinologist or had a special interest in diabetes. Of the 191 answers from adult physicians 82% (157) were either an endocrinologist/diabetologist or had a special interest in diabetes.

The survey suggests that 21,509 children and young people are being cared for by paediatric services and 1,149 by adult physicians although this information should be interpreted with caution because it is based on the identified specialty of the lead individual completing the survey form. For 16 and 17 year olds 18.2% (895/4,917) are being cared for by the adult service and 81.8% (4,022/4,917) by the paediatric service.

Table 8: Breakdown of reporting clinician speciality

Speciality	Total
Paediatric Diabetologist	7
Paediatric Endocrinologist/Diabetologist	45
Paediatrician with special interest in diabetes	178
General Paediatrician	13
Adult Endocrinologist/Diabetologist	124
Adult Physician with special interest in diabetes	33
General Adult Physician	4
Total	434

7. Participation in the National Diabetes Audit

Units were asked if they had submitted 2007 data to the NDA; 51.8% (115/222) of those answering this question indicated that they had. The 107 units not submitting data to the NDA but participating in the survey cared for 9,477 children and young people with diabetes, indicating that the national audit is missing information for 41.6% (9,477/22,783) of all children and young people with diabetes

For participating units, there is a match between the number of children and young people with diabetes ascertained by the two methods (Paediatric NDA 2007-8 13,026; survey January 2009 13,306). This provides reassuring validation for the survey figures as a whole.

Among the 40% of survey respondents who do not participate in the NDA very few indicated that this was because of negative views about the NDA (2% each for ‘not useful’, ‘dataset too large’, ‘technical problems’). Rather, almost 90% reported barriers to participation – mainly lack of staff, lack of funding, lack of time & lack of clinical IT. This resonates with the feedback received each year by the NDA team when they contact non-participating units. It is also consistent with the observation that among specialist services paediatric units are least likely to have electronic care records.

These results suggest that with a small investment in struggling services there would be overwhelming support for universal participation in the paediatric NDA. This would obviate the need for any future independent surveys to determine the number of children with diabetes and it would enable all services to participate in collaborative quality improvement.

Table 9: Reasons for non participation in the National Diabetes Audit

Reasons for non participation	Total	% of total number
Lack of staff	58	23.8
Lack of funding	34	13.9
Lack of time	56	22.9
Lack of IT	53	21.7
No access to data	9	3.7
Don't think the results are useful	4	1.6
NDA dataset is too large	6	2.5
Unsure of reason/new to post	5	2.1
Not applicable	1	0.4
Not contacted	12	4.9
NDA technical fault	5	2.1
Poorly designed	1	0.4
	244*	

**Numerous responses indicated more than one reason for non participation*

8. Survey Completeness

Although the survey obtained a very high response rate, it was appreciated from the outset that we would be unlikely to capture 100% of children and young people with diabetes. There were 5 hospitals with acute medical paediatric services for which data could not be obtained from any source; two were London teaching hospitals which may explain the lower than expected number of cases in the London SHA. The survey would also not have captured the children and young people receiving all their care from their GP though this is likely to be a very small number. There may also be a very small number of patients receiving all their diabetes care privately who would not have been recorded in the survey.

As the survey collected non-identifiable information it is also possible there was a small amount of double counting. This was most likely for the children and young people managed in more than one unit and those being managed jointly by adult and paediatric services. These risks were identified from the outset and efforts made to minimise the likelihood which included giving clear inclusion criteria and guidance to participants particularly those hospitals with joint adult and paediatric clinics. In addition the data submitted were regularly monitored to identify duplicate data entries.

8.1 Wales Register Data

Information collected by the Wales Diabetes Register, which has an estimated 97% ascertainment rate, was provided to the project in order to estimate the completeness of the England data. In Wales there are 1,373 0-17 year old children and young people with diabetes on the register, of whom 53.1% are male. With a 0-17 population of 636,961 the prevalence in Wales is 216/100,000 which suggests that this 2009 survey has a slight under ascertainment rate, which is likely to be mostly explained by the missing data from the two large London hospitals. However the breakdowns of types of diabetes are comparable; 96.8% of the total children and young people with diabetes in Wales have Type 1 (1,329/1,373), 1.8% have Type 2 (25/1,373) and 1.4% (19/1,373) have other types which is very similar to that found in the 2009 England survey.

9. Discussion

The 2009 survey of the prevalence of diabetes in children and young people achieved an excellent response from clinicians caring for children and young people with diabetes. It provides unique information about children and young people with diabetes in England in 2009. Although the study only collected anonymised data so that double counting cannot be ruled out, the high response rate and comparison with other national data suggests a very high level of case ascertainment.

In recent years the diabetes community has participated in several paediatric audits and surveys most notably the National Diabetes Audit (NDA) managed by the NHS Information Centre and the five yearly Diabetes UK survey of paediatric and adolescent diabetes services. The response rates have not always been comprehensive with 65% response rate for paediatric involvement in the NDA audit. The success of the 2009 survey can be attributed to the continuing commitment of clinicians to improving the care of children with this chronic life-long condition as well as to the fact that the survey was undertaken by the RCPCH with its access to a comprehensive network of paediatricians and was supported by NHS Diabetes, the Department of Health, Diabetes UK, BSPED, ACDC and all the major professional groups of diabetes clinicians.

The survey established that there are at least 22,947 children and young people with diabetes in England in 2009, a minimum prevalence of 209/100,000 (0-17 year olds). Although type of diabetes was not provided for all cases, 97% (20,488) have Type 1, meaning an all England Type 1 prevalence of 186.3/100,000. In the Department of Health 2007 report “Making Every Young Person with Diabetes Matter”⁷ it was estimated that approximately 25,000 people under 25 years have Type 1 diabetes. The current survey suggests that the actual number is higher than this. Assuming that the population of all reported cases has the same breakdown of diabetes type as the 93% for whom diabetes type was provided, it can be estimated that there are 21,865 CYP with Type 1 under 18 years of age. Survey data on the number of cases by individual year of age showed there were almost 2,300 17 year olds; if there is a similar number for each year group between 18-24 year olds then the total with Type 1 0-25 year olds is 37,965.

Of the cases reported just over half were in boys although sex-specific prevalence has not been calculated. The majority of cases identified in the survey were over 10 years of age and the peak age for diagnosis of Type 1 has been found to be 10-14 years of age⁷. There were however a very small number of cases of diabetes reported

in children under one year, and it is important that infants with diabetes are not forgotten.

The survey has established a minimum prevalence for diabetes in England and as this was the first national survey of its kind, the results do not establish whether or not the number of new cases of diabetes (incidence) is increasing.

The evidence suggests that the incidence of Type 1 in children and young people increased between the 1970's and 1990's⁸⁻¹². In 1988 a study of the UK incidence of insulin dependent diabetes in children under 15 years found that it had increased since 1973-4 when it was 7.7/100,000 to 13.5/100,000 in 1988¹⁰. In 1999 a study reported UK incidences from different centres of 7.8 – 21.6/100,000 and used an additive regression model to predict that the UK incidences would range from 21 – 34.9/100,000 in 2010¹². There is also evidence of changing patient demographics. In a study of the UK prevalence and incidence trends over 10 years it was shown that the fastest rate of increase was in the under 5 year olds⁹.

The survey established that there are over 15,300 school age children with diabetes in England, a figure that may increase in the future. It is important that both PCTs and Local Education Authorities are aware of the specific needs of children in school with diabetes so that young people and their families can be supported to manage their condition and resources are allocated appropriately. Both the Department of Health and Diabetes UK are able to supply supportive documents on how to care for children and young people with diabetes in schools.

Type 2 diabetes in children and young people in the UK has only emerged relatively recently as a clinical concern but there is evidence from other countries that the incidence is rising fast due to the growing prevalence of childhood obesity. This 2009 survey established that there were at least 328 children and young people with Type 2 diabetes, a prevalence of 3.0 per 100,000. These data seem to confirm that the number of children with Type 2 diabetes is increasing relatively rapidly as an earlier study estimated the minimum UK prevalence to be 0.21/100,000¹³ although the authors acknowledged that this was likely to be an underestimate. A study of first hospital admission for Type 2 diabetes in under 18 year olds also found that the incidence rose significantly between 1996-7 and 2003-04¹⁴. In 2005 Type 2 UK incidence was 0.53/100,000 per year, two and a half times higher than suggested by the earlier UK study¹⁵. Despite this, it is reassuring that the number of children and young people with Type 2 diabetes is still low.

In the current survey, Type 2 made up 57% of all non-Type 1 cases. No additional information was collected as to what diagnoses were classified as “other” types but in the UK study of non-Type 1 incidence, this group consisted of 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 fibrosis¹⁵. However data from the current survey about children and young people with non-Type 1 diabetes should be interpreted with caution as reporting clinicians were not given any diagnostic criteria. Identifying Type 2 diabetes can be clinically challenging in children and young people; in the survey cited, 34 reported cases could not be classified as either Type 2 or as any other non-Type 1 category.

One of the most interesting survey findings is the geographic variation in the numbers of cases of diabetes in children and young people. This finding needs further exploration as it may be due to local pockets of under-ascertainment but it would seem that numbers of children and young people with Type 1 are higher than would be expected in the North East and South East Coast SHA’s whereas numbers of Type 2 are greater than would be expected for London, followed by the North East and the West Midlands. The distribution of Type 2 diabetes may be explained by the ethnic breakdown of the local population; in the UK study incidence of Type 2 was significantly higher in children from an ethnic minority background¹⁵.

10. Diabetes Register

The case for a national register of children with diabetes is overwhelmingly strong. Diabetes is a life-long condition with significant morbidity and the monitoring of long-term outcomes is crucial to improving clinical management. Universal registration of cases would not only help to ensure that all children and young people receive the same high standard of care but would also facilitate the epidemiological study of this disease. It is becoming increasingly clear that both the incidence and patient demographics are changing in childhood diabetes and the establishment of a national register would enable these changes to be more closely monitored so that resources are allocated appropriately.

As well as improving the outcomes for children and young people with diabetes today, a national register would facilitate the research which is essential to understand the disease, alleviate the long term health consequences and possibly ultimately prevent this chronic disease. Regional registers of childhood diabetes such as those in Oxford and Yorkshire, have already contributed significantly to the understanding of the variations and changes in incidence in Europe¹¹.

National registers of children with diabetes already exist in Scotland and Wales. Children and young people and their families living with diabetes in England today, deserve their own national register to ensure that future services are designed appropriately.

11. Conclusion

The snapshot survey of diabetes in children and young people in England in 2009 achieved a very high response rate. Although it is difficult to ascertain the data completeness it is likely that it has captured data on the majority of children and young people with diabetes in England. There are a number of key survey findings:

- There are at least 22, 947 children and young people in England with diabetes.
- The prevalence of diabetes of any type in children and young people is at least 209/100,000 in the 0-17 population.
- The majority of children and young people have Type 1 diabetes. This is in contrast to adult populations where numbers of cases of Type 2 far exceed Type 1.
- Although the number of children with Type 2 diabetes is numerically very small, at 3.0/100,000 the prevalence is significantly higher than that suggested by the only other UK study.
- The burden of diabetes in school age (5-15) children is high. There are at least 15,400 children in schools in England with diabetes. This has significant implications for schools and families.
- There are differences in numbers of cases of diabetes in children and young people between SHA's. Numbers of cases of Type 1 are higher than would be expected in the North East and South East Coast SHA's and lower than expected in the East Midlands and London. For cases of Type 2, numbers were much higher than expected in London, the North East and the West Midlands but were very low in the East of England SHA.
- There is a strong case for a national register of childhood diabetes in England to facilitate improved standards of clinical care, monitoring of long term outcomes, ensure appropriate resource allocation and further research.

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Appendix 1: Participating hospitals by SHA*

*The hospitals listed represent the main site of service and may have submitted data on behalf of additional hospitals. Additional hospitals are represented under the main hospital in italics.

**Sourced from Diabetes UK Data

Strategic Health Authority	Hospital
East Midlands	
	Bassetlaw Hospital District General Hospital, Doncaster
	Chesterfield Royal Hospital
	Derbyshire Children's Hospital
	Derbyshire Royal Infirmary
	Grantham and District Hospital, Lincolnshire
	Kettering General Hospital
	King's Mill Hospital, Nottinghamshire
	Leicester Royal Infirmary
	Lincoln County Hospital
	Northampton General Hospital
	Pilgrim Hospital, Boston
	Queen's Medical Centre, Nottingham <i>Nottingham City Hospital,</i> <i>Newark Hospital</i>
East of England	
	Addenbrooke's Hospital, Cambridge
	Basildon & Thurrock Hospital, <i>Orsett Hospital</i>
	Bedford Hospital
	Broomfield Hospital, Essex
	Colchester General Hospital
	Hemel Hempstead General
	Princess Alexandra Hospital
	Ipswich Hospital
	James Paget Hospital, Norfolk
	Luton & Dunstable Hospital
	Norfolk & Norwich University Hospital, <i>Cromer Hospital</i>
	Peterborough District Hospital, <i>Edith Cavell Hospital</i>
	Southend General Hospital
	Queen Elizabeth Hospital, Kings Lyn
	Queen Elizabeth II, Hertfordshire, <i>Lister Hospital,</i> <i>Hertford County</i>

Strategic Health Authority	Hospital
	St John's Hospital, Essex
	West Suffolk Hospital
London	
	Barnet General Hospital
	Central Middlesex Hospital
	Chase Farm Hospital
	Chelsea and Westminster Hospital, <i>Royal Brompton Hospital</i>
	Ealing Hospital
	Hillingdon Hospital
	King George Hospital
	Kings College Hospital, London
	Kingston Hospital
	Mayday University Hospital
	Newham General Hospital
	North Middlesex University Hospital
	Northwick Park Hospital
	Orpington Hospital <i>Beckenham Beacon Hospital</i>
	Queen Elizabeth Hospital, Surrey
	Queen Mary's Hospital for Children <i>St Heliers Hospital</i>
	Queen Mary's Hospital, Sidcup
	Queen's Hospital Romford
	Royal Free & University College Hospital, London
	Royal London Hospital <i>Homerton Hospital</i>
	St George's Hospital, Tooting
	St Mary's Hospital London <i>Charing Cross Hospital, Hammersmith Hospital</i>
	University Hospital Lewisham
	University College London, <i>Great Ormond Street Hospital</i>
	West Middlesex University Hospital
	Whipps Cross University Hospital
North East	
	Bishop Auckland General Hospital, County Durham
	Darlington Memorial Hospital

Strategic Health Authority	Hospital
	Friarage Hospital
	James Cook University Hospital, Middlesbrough
	North Tyneside General Hospital, <i>Wansbeck Hospital</i>
	Queen Elizabeth Hospital, Gateshead
	Royal Victoria Infirmary, Newcastle <i>Newcastle General Hospital</i>
	South Tyneside District Hospital
	St Luke's Hospital Middlesbrough, <i>Bradford Royal Infirmary</i>
	Sunderland Royal Hospital
	University Hospital of North Durham
	University Hospital of North Tees <i>Hartlepool General Hospital,</i> <i>University Hospital Hartlepool</i>
North West	
	Arrowe Park, Wirral <i>Wirral University Teaching Hospital</i>
	Blackpool Victoria Hospital
	Booth Hall Hospital
	Burnley General Hospital
	Countess of Chester Hospital
	Cumberland Infirmary
	Fairfield General Hospital
	Halton General <i>Warrington General Hospital</i>
	Leighton Hospital
	Macclesfield District General Hospital
	Manchester Royal Infirmary <i>Manchester Diabetes Centre</i>
	Rochdale Infirmary <i>Milnrow Health Centre</i>
	Royal Albert Edward Infirmary, Wigan <i>Wigan Infirmary</i>
	Royal Blackburn
	Royal Bolton Hospital <i>Bolton Diabetes Centre</i>
	Royal Lancaster Infirmary <i>Furness General Hospital,</i> <i>Westmoreland General Hospital</i>
	Royal Liverpool Childrens Hospital, <i>Walton Hospital</i>
	Royal Manchester Children's Hospital

Strategic Health Authority	Hospital
	Royal Oldham Hospital
	Royal Preston Hospital <i>Chorley & South Ribble Hospital</i>
	Salford Royal Hospital
	Southport & Formby District General Hospital <i>Ormskirk & District General hospital</i>
	St Mary's Hospital for Women and Children, Manchester
	St. Helens Hospital
	Stepping Hill Hospital, <i>Buxton Cottage</i>
	Tameside General Hospital
	Trafford General Hospital
	West Cumberland Hospital
	Whiston Hospital
	Wythenshawe Hospital <i>University Hospital of South Manchester;</i> <i>Withington Hospital</i>
South Central	
	Basingstoke & North Hampshire Hospital <i>North Hampshire Hospital</i>
	Horton General Hospital, Oxfordshire
	Milton Keynes General Hospital
	John Radcliffe Hospital
	Queen Alexandra Hospital, Portsmouth <i>St Marys Hospital,</i> <i>Royal Haslar Hospital</i>
	Royal Berkshire Hospital
	Royal Hampshire County Hospital
	Southampton General Hospital
	St Marys Hospital Newport
	Stoke Mandeville Hospital
	Wexham Park Hospital <i>Heatherwood Hospital,</i> <i>St Marks Hospital</i>
	Wycombe Hospital
South East Coast	
	Conquest Hospital
	Darent Valley Hospital

Strategic Health Authority	Hospital
	East Surrey Hospital <i>Crawley Hospital,</i> <i>Horsham Hospital</i> <i>West Sussex Queen Victoria Hospital</i>
	Eastbourne District General Hospital, <i>East Sussex Hospital</i>
	Frimley Park Hospital <i>Farnham Hospital,</i> <i>Aldershot Centre for Health,</i> <i>Cambridge Military Hospital</i>
	Maidstone General
	Medway Maritime Hospital, Gillingham
	Pembury Hospital <i>Kent & Sussex Hospital</i>
	Princess Royal University Hospital, Kent
	Royal Alexandra Children’s Hospital
	Royal Surrey County Hospital
	Royal Sussex County Hospital
	St Peter’s Hospital, Surrey, <i>Ashford Hospital</i>
	St Richard’s Hospital, West Sussex
	William Harvey Hospital, Kent <i>Queen Elizabeth the Queen Mother Hospital,</i> <i>Buckland Hospital,</i> <i>Kent & Canterbury Hospital</i>
	Worthing Hospital
South West	
	Bristol Royal Hospital for Children, <i>Weston General Hospital</i>
	Bristol Royal Infirmary
	Derriford Hospital, Plymouth
	Dorset County Hospital
	Gloucestershire Royal Hospital <i>Cheltenham General Hospital</i>
	Great Western Hospital, Swindon <i>Cirencester Hospital</i>
	Musgrove Park Hospital, Somerset
	Nobles Hospital, Isle of Man
	North Devon District Hospital
	Poole Hospital, Royal Bournemouth Hospital
	Royal Cornwall Hospital

Strategic Health Authority	Hospital
	Royal Devon and Exeter Hospital Wonford
	Royal United Bath Hospital <i>Trowbridge Hospital</i>
	Salisbury District Hospital
	Southmead Hospital
	St Michael's Hospital, Bristol
	Torbay Hospital
	Yeovil District Hospital
West Midlands	
	Alexandra Hospital
	Birmingham Children's Hospital
	George Eliot Hospital, Warwickshire
	Good Hope Hospital, Birmingham
	Heartlands Hospital, Birmingham <i>Solihull Hospital</i>
	Hereford County Hospital
	Kidderminster General Hospital
	Manor Hospital, Walsall
	New Cross Hospital, Wolverhampton
	Princess Royal Hospital, West Midlands, <i>Royal Shrewsbury Hospital</i>
	Queen's Hospital Burton
	Russell's Hall Hospital, Dudley
	Sandwell Hospital
	Staffordshire General Hospital <i>Cannock Chase Hospital</i>
	University Hospital Coventry
	University Hospital of North Staffordshire
	Warwick Hospital** DUK
	West Birmingham Hospital – City Hospital
	Worcestershire Royal Hospital
Yorkshire and The Humber	
	Airedale General Hospital
	Barnsley District General Hospital
	Calderdale Royal Hospital, Huddersfield Royal Infirmary
	Dewsbury & District Hospital** DUK
	Diana, Princess of Wales Hospital

Strategic Health Authority	Hospital
	Doncaster Royal Infirmary, <i>Montagu Hospital</i>
	Harrogate District Hospital
	Hull Royal Infirmary
	Leeds General Infirmary, <i>St James University Hospital</i>
	Northern General Hospital, Sheffield, <i>Royal Hallamshire Hospital</i>
	Pinderfields General Hospital
	Pontefract General Infirmary
	Rotherham General Hospital
	Scarborough Hospital, <i>Bridlington and District Hospital</i>
	Scunthorpe General Hospital
	Sheffield Children’s Hospital
	Wharfedale Hospital
	York District Hospital

Glossary

Association of British Clinical Diabetologists (ABCD) – The national professional organisation of consultant physicians who specialise in Diabetes Mellitus with the aim of preserving and supporting diabetes specialist care.

British Paediatric Surveillance Unit (BPSU) – A unit responsible for undertaking active surveillance of rare conditions in children.

British Society for Paediatric Endocrinologists & Diabetologists (BSPED) – An organisation that aims to advance education in paediatric endocrinology and related subjects by promoting research and disseminating the results of research.

Diabetes Mellitus – A complex disorder of carbohydrate, fat and protein metabolism that is primarily a result of a deficiency or complete lack of insulin secretion by the beta cells of the pancreas or resistance to insulin.

Diabetes Type 1 – Insulin dependant diabetes mellitus (IDDM Type 1) is having little or no ability to produce the hormone Insulin.

Diabetes Type 2 – Non-insulin dependent diabetes mellitus (NIDDM Type 2) is when the pancreas can still make some insulin, but not enough, or when the insulin that is produced does not work properly (known as insulin resistance).

Diabetes UK – The largest charity in the UK devoted to the treatment and care of people with diabetes with the purpose of improving the quality of life for people with the condition.

Incidence – The number of new cases of a potential condition within a specified period of time.

Multi-centre Research Ethics Committee (MREC) – A committee mandated to decide if a trial or research is ethical to do and whether it can go ahead or not.

National Diabetes Audit (NDA) – An audit developed and delivered by the National Clinical Audit Support Programme (NCASP) part of The NHS Information Centre and provides an infrastructure for the collation, analysis and benchmarking of local clinical data to support diabetes clinical audit across the NHS.

National Information Governance Board (NIGB) – An organisation that provides leadership, promotes consistent standards for information governance and considers ethical issues in the interpretation and application of the law in information governance.

National Diabetes Information Service (NDIS) – A coordinated diabetes information service, which supply's commissioners and providers with comprehensive information in order to plan and improve services for the local population.

NHS Diabetes (Previously the National Diabetes Support Team) – Part of NHS Diabetes & Kidney Care, a national team that works with frontline staff in both the diabetes and kidney communities to implement the respective National Service Frameworks.

NHS Information Centre – A special health authority that provides facts and figures to help the NHS and social services run effectively. The National Clinical Audit Support Programme (NCASP) is one of its key components.

Office of National Statistics (ONS) – Is the executive office of the UK Statistics Authority, a non-ministerial department which is the UK Government's single largest statistical producer.

Prevalence – The total number of cases of a disease in the population at a given time, or the total number of cases in the population, divided by the number of individuals in the population. It is used as an estimate of how common a condition is within a population over a certain period of time.

Primary Care Trust (PCT) – A type of NHS trust that provides primary and community services or commissions them from other providers and are involved in commissioning secondary care.

Project Team – A team consisting of clinical and key stakeholder representatives with the purpose of completing the project successfully

Register (medical) – A population based medical register is a method of monitoring disease and can be used for the planning and provision of local health services.

Standardised Morbidity Ratio (SMR) – Widely used indices which are applied when a number of areas are to be compared in relation to a baseline population.

Strategic Health Authority (SHA) – Is responsible for enacting the directives and implementing fiscal policy as dictated by the Department of Health at a regional level. Each SHA area contains various NHS trusts which take responsibility for running or commissioning local NHS services. The SHA is responsible for strategic supervision of these services.

SurveyMonkey – Web based software tool used to create and publish custom surveys and then view results graphically and in real time.

Yorkshire and Humber Public Health Observatory – Part of the Public Health capacity building function for the Yorkshire and Humber region, creating a network of public health data and evidence to develop knowledge and transfer knowledge into practice.

References

1. Surveymonkey – <http://www.surveymonkey.com>
2. National Diabetes Audit, The NHS information Centre – <http://www.ic.nhs.uk/services/national-clinical-audit-support-programme-ncasp/audit-reports/diabetes>
3. Diabetes UK, ACDC, BSPED and ABCD, survey of Paediatric and Adolescent diabetes services, 2008, unpublished.
4. Diabetes UK 2009. Directory of Diabetes Care. CMA Medical Data
5. Edge J A, Swift P G F, W Anderson, Turner B. Diabetes Services in the UK: Fourth national survey; are we meeting NSF standards and guidelines? *Arch Dis Child* 2005; 90: 1005 – 1009.
6. Office of National Statistics – <http://www.statistics.gov.uk/statbase/Product.asp?vlnk=15106>
7. Department of Health: “Making Every Young Person with Diabetes Matter”: HMSO 2007 – http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_073674
8. Rangasami J, Greenwood D, McSparran B, Smail P, Patterson C, Waugh N. Rising incidence of Type 1 diabetes in Scottish children, 1984–93. *Arch. Dis. Child.* 1997;77;210-213
9. González E, Johansson S, Wallander M-A, Rodríguez L. Trends in the prevalence and incidence of diabetes in the UK: 1996 – 2005. *J Epidemiol Community Health.* 2009; 63: 332-336
10. Metcalfe MA & Baum JD. Incidence of insulin dependant diabetes in children aged under 15 years in the British Isles during 1988. *BMJ.* 1991; 302: 443-447
11. EURODAIB ACE Study Group. Variation and trends in incidence of childhood diabetes in England. *Lancet* 200; 355: 873-876
12. Onkamo, P, Vaananen S, Karvoenen M and J Tuomilehto. Worldwide increase in incidence of Type 1 diabetes – the analysis of the data on published incidence trends. *Diabetologia* 1999; 42: 1395-1403.
13. Ehtisham S, Hattersley AT, Dunger DB & Barrett TG. First UK survey of paediatric Type 2 diabetes and MODY. *Arch. Dis. Child.* 2004;89:526-529
14. Aylin P, Williams S Bottle A: Obesity and type 2 diabetes in children 1996-7 to 2003-4. *BMJ* 2005; 331: 1167
15. Haines L, Wan KC, Lynn R, Barrett TG & Shields JPH. Rising incidence of Type 2 diabetes in children in the U.K. *Diabetes Care* 30:1097-1101, 2007.

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