

## ORIGINAL ARTICLE

## Diabetes services in the UK: third national survey confirms continuing deficiencies

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**Aims:** To determine the current level of diabetes services and to compare the results with previous national surveys.

**Methods:** A questionnaire was mailed to all paediatricians in the UK identified as providing care for children with diabetes aged under 16 years. Information was sought on staffing, personnel, clinic size, facilities, and patterns of care. Responses were compared with results of two previous national surveys.

**Results:** Replies were received from 244 consultant paediatricians caring for an estimated 17 192 children. A further 2234 children were identified as being cared for by other consultants who did not contribute to the survey. Of 244 consultants, 78% expressed a special interest in diabetes and 91% saw children in a designated diabetic clinic. In 93% of the clinics there was a specialist nurse (44% were not trained to care for children; 47% had nurse:patient ratio >1:100), 65% a paediatric dietitian, and in 25% some form of specialist psychology or counselling available. Glycated haemoglobin was measured routinely at clinics in 88%, retinopathy screening was performed in 87%, and microalbuminuria measured in 66%. Only 34% consultants used a computer database. There were significant differences between the services provided by paediatricians expressing a special interest in diabetes compared with "non-specialists", the latter describing less frequent clinic attendance of dietitians or psychologists, less usage of glycated haemoglobin measurements, and less screening for vascular complications. Non-specialist clinics met significantly fewer of the recommendations of good practice described by Diabetes UK.

**Conclusions:** The survey shows improvements in services provided for children with diabetes, but serious deficiencies remain. There is a shortage of diabetes specialist nurses trained to care for children and paediatric dietitians, and a major shortfall in the provision of psychology/counselling services. The services described confirm the need for more consultant paediatricians to receive specialist training and to develop expertise and experience in childhood diabetes.

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The management of diabetes in young people has become increasingly difficult as the incidence of type 1 increases,<sup>1,2</sup> type 2 diabetes emerges,<sup>3</sup> the case mix and treatment modalities become increasingly complex, and the quest for optimal control becomes more demanding.<sup>4,5</sup>

Previous surveys investigating the services provided for children and young people with diabetes in the UK identified deficiencies which were being addressed and improvements which were still required.<sup>6,7</sup>

Following publication of *The principles of good practice for the care of young people with diabetes*,<sup>8</sup> and the St Vincent Declaration working group reports,<sup>9</sup> the Youth and Families Advisory Committee of Diabetes UK (formerly the British Diabetic Association) agreed to carry out a further postal survey to establish the current provision of services.

## METHODS

During 1998 a list was compiled of clinicians considered to be caring for children and young people with diabetes in the UK. This was achieved from an amalgamation of lists used in the two previous surveys of diabetes services, a study of diabetic ketoacidosis in children, and names held by pharmaceutical companies. Visual inspection of the list identified 302 paediatricians and physicians most likely to be providing care to children with diabetes. A questionnaire was posted to 412 consultants (the total number on the list) and respondents were asked to identify any other consultant in their hospital trust also looking after young people with diabetes under 16 years of age.

The questionnaire sought information on staffing, personnel, clinic size, facilities, and patterns of care. Results were

compared with the two previous surveys,<sup>6,7</sup> and also to 10 key recommendations from *Principles of good practice for the care of young people with diabetes*.<sup>8</sup> The questionnaire also specifically asked about the numbers of young people with diabetes who required local authority care or residential special schooling.

## RESULTS

A total of 244 (81%) completed questionnaires were returned. Respondents identified a total of 17 192 young people (age 0–15 years) in their care and a further 2234 in the care of other consultants in the same hospital trust as the respondent.

Of the 17 192 children and adolescents in the respondents' clinics, 115 (0.7%) were in local authority care or in residential special schooling.

Table 1 summarises the results of the survey and comparisons with results from 1988 and 1994.

### Specialist interest of consultants

**Recommendation:** Children with diabetes should be under the care of consultants with a special interest and training in diabetes.<sup>8</sup>

Of the 244 consultants responding, 24 (10%) indicated that they were paediatric endocrinologists/diabetologists; 127 (52%) considered themselves to have a special interest in diabetes, and 56 (24%) a special interest in diabetes/endocrinology.

Respondents did not use these terms as mutually exclusive, so they equate to 78% paediatricians who indicated some level

**Table 1** Comparison of results of three national surveys

	1988 <sup>6</sup>	1994 <sup>7</sup>	1999
Total number of consultant respondents	360	325	244
Consultant with a special interest in diabetes	32%	48%	78%**
Consultant caring for more than 40 young people	23%	45%	74%**
Designated paediatric diabetes clinic	63%	88%	91%*
Diabetes specialist nurse in clinic	61%	87%	93%**
Paediatric dietitian in clinic	37%	57%	65%**
Counsellor in clinic	9%	22%	22%*
Glycated haemoglobin at each visit	91%	90%	88%

\*Significant change 1988–1999.

\*\*Significant change 1994–1999.

of “special interest” in diabetes. Conversely 22% expressed no special interest in diabetes. The figures show a significant increase since 1994 in the proportion of consultant paediatricians caring for young people with diabetes who express a specific interest in diabetes (48%, 1994; 78%, 1999;  $\chi^2 = 87$ ;  $df = 2$ ;  $p < 0.001$ ).

### Clinic size

Recommendations: Children with diabetes should be seen in a designated paediatric diabetes clinic. In districts with fewer than 70 children with diabetes under the age of 16 years, they should all be under the care of a single designated consultant paediatrician.<sup>8</sup>

Ninety one per cent of respondents reported seeing young people with diabetes in a clinic dedicated to their care.

Twenty four per cent of consultants cared for more than 100 children and adolescents with diabetes; 50% cared for 40–100, with the remaining 26% caring for fewer than 40 young people with diabetes.

This represents a significant shift towards paediatricians involved in diabetes care being responsible for larger case loads since 1994 ( $\chi^2 = 87$ ;  $df = 2$ ;  $p < 0.001$ ).

### Diabetes specialist nurses (DSN)

Recommendations: Clinics should be supported and attended by a paediatric DSN with children’s and diabetes training and with a maximum caseload of 70–100 children per nurse (full time equivalent).<sup>10</sup>

Most services (93%) reported a DSN regularly attending clinic. This represents a significant increase since 1994 (87% in 1994;  $\chi^2 = 5.9$ ;  $df = 1$ ;  $p < 0.05$ ), but only 56% of these nurse specialists were trained as children’s nurses and 63% had undertaken a paediatric DSN course.

Many nurses did not specialise solely in paediatric diabetes, 19% were working in another subspecialty, and 42% were working in adult diabetes care.

### Dietetic support

Recommendation: Paediatric diabetes clinics should have regular attendance of a paediatric dietitian with diabetes expertise.<sup>8</sup>

Dietitians were reported to attend regularly at 86% of clinics, with 76% of these (158 of 209) being a paediatric dietitian. This is a significant increase in the percentage of paediatric dietitians providing diabetes care (57% in 1994;  $\chi^2 = 5.8$ ;  $df = 1$ ;  $p < 0.05$ ).

### Psychologist/counsellor services

Recommendation: The clinic has easy access to specialist services in child psychology/psychiatry,<sup>8</sup> or a counsellor with expertise in paediatric diabetes as part of the diabetes team.

Just over 25% of respondents reported that some form of “counsellor” regularly attended the children’s diabetes clinic, mostly psychologists ( $n = 47$ ), with other clinics supported by psychiatrists ( $n = 7$ ), nurse therapists ( $n = 4$ ), or other counsellors ( $n = 4$ ) such as psychotherapists.

The 1994 survey only considered psychologists and psychiatrists; comparing the figures for these professions shows no change.

### Chiropody services

Recommendation: Children’s diabetes clinics should have easy access to chiropody services.<sup>8</sup>

Just over half (55%) of respondents indicated that their clinic had easy access to chiropody services.

### Glycaemic control

Recommendation: Children’s diabetes clinics should have access to a measurement of glycated haemoglobin at each clinic visit.<sup>8</sup>

Eighty eight per cent of respondents indicated that glycated protein is routinely measured at each clinic visit, 84% using  $HbA_{1c}$ , 4% using  $HbA_1$ , and 1% using fructosamine; only two consultants reporting using more than one index.

Of those using  $HbA_{1c}$ , 86% (compared with 42% in 1994) are using a capillary method, indicating a significant move away from venous sampling since 1994 ( $\chi^2 = 119$ ;  $df = 3$ ;  $p < 0.001$ ); 70% reported that the result was available during the clinic.

### Complication monitoring

Recommendation: The diabetes clinic should have objective measures of monitoring microvascular complications, usually by systematic annual review.<sup>8</sup>

Two thirds of the 163 respondents to this question indicated that urinary microalbumin is regularly measured at clinic. Over half (56%) indicated that this occurred at least once yearly, with 4% reporting that it occurred at every visit (6% did not respond to this follow up question). Of those indicating that they routinely screen for microalbuminuria, 26% reported that this was limited to certain ages and/or duration of diabetes, although details were not requested.

**Table 2** Percentage of respondents meeting each of 10 key recommendations for paediatric diabetes care<sup>8</sup>

	%
Designated children's diabetes clinic	91
Glycated haemoglobin at each clinic visit	88
Retinopathy screening	87
Paediatrician with a special interest in diabetes	78
Joint or combined handover clinic to adult services	78
Paediatric diabetes specialist nurse	75
Consultant to patient ratio of >1:40	74
Screening for microalbuminuria	66
Paediatric dietitian	65
Paediatric diabetes specialist nurse: patient ratio of <1:100	53
Number of respondents meeting:	
1 recommendation	100
2 recommendations	100
3 recommendations	99
4 recommendations	98
5 recommendations	96
6 recommendations	93
7 recommendations	83
8 recommendations	58
9 recommendations	29
10 recommendations	12

Most (87%) respondents reported that retinopathy screening is performed on an annual basis, with 66% of those reporting that pupils were dilated for the examination. Of those screening for retinopathy 31% screen all children, 59% screen if over the age of 12 years, and 40% screen if the child is over the age of 12 and/or has a diabetes duration of more than five years.

### Clinic management

Recommendation: There should be a district diabetes register and regular audit of outcomes.<sup>8</sup>

As an aid to management of clinical data, 84 (34%) of consultants report using a computer database. "Twinkle" was the most widely used commercial diabetes database in 19 centres, with "Novonet" being used in five centres and "Diamond" in four centres. The majority of services were using a locally developed database.

Recommendation: Transfer to adult care should be structured with close cooperation between paediatric and adult diabetes services.<sup>8</sup>

Just over half (52%) of respondents have organised age stratified diabetes clinics, which usually meant a specific adolescent or young adult diabetes clinic (95%).

Young people are transferred to adult services between 14 and 16 years of age by 14% of respondents, at 16 years by 31%, and between 16 and 20 years of age by 45% of respondents. A further 2% report that handover occurs in response to patient preference. Just over half (53%) of respondents transfer young people into a young adult diabetes clinic. The process of handover is managed through joint or combined adolescent/young adult clinics by 78% of consultants; the remaining respondents did not indicate a system for planned handover to adult services.

### Meeting the recommendations

From the document *Principles of good practice for the care of young people with diabetes*,<sup>8</sup> 10 key recommendations for a paediatric diabetes service were analysed (table 2). Although 58% of respondents meet eight recommendations, only 12% of respondents meet all 10 recommendations.

### Services of consultants with and without a special interest in diabetes

The responses of the 22% of consultants who expressed no special interest in diabetes were compared with the responses from those who did express such an interest (table 3).

## DISCUSSION

From the outset of designing this survey it was disappointing that no specific list existed either within the professional bodies or the patient organisation (Diabetes UK) of paediatricians with special responsibility for children with diabetes. This is a defect that requires urgent and continuing attention by both the Royal College and Diabetes UK. Despite this, 302 consultants were identified, representing all the major hospital trusts. They were mailed the questionnaire, but only 81% (244) responded, despite a reminder letter. The 19% non-respondents might represent a group of paediatricians where the services are even less satisfactory than those reported.

The respondents identified a total of approximately 20 000 young people with diabetes; this figure approximates to the number estimated on the basis of population and current prevalence figures. The survey therefore should have given a fairly accurate indication of care for those individuals throughout the UK.

Another major deficiency at the time of the survey was that no national register of children with diabetes existed and only 34% of respondents had any IT support to their clinics. There is an urgent need to provide IT support to clinicians in the NHS to fulfil the recommendations of local diabetes registers and regular audit in the NSF Diabetes Standards.<sup>11</sup> This would facilitate the development of the recently developed national childhood diabetes audit and register,<sup>12</sup> which only covers about 30% of clinics so far.

On the positive side the results show improvements in a number of aspects of paediatric diabetes care. Fewer consultants look after inappropriately small numbers of children and

**Table 3** Comparison of services of paediatricians with a special interest in diabetes with those with no special interest

	Paediatrician with stated special interest in diabetes	Paediatrician without special interest in diabetes
Number of patients aged under age 16 years; mean (SD)	75 (53)	29 (28)*
Number of patients aged over 16 years; mean (SD)	11 (16)	2 (5)*
Patients per 1 WTE DSN; mean (SD)	130 (111)	40 (31)
Presence of paediatric dietitian	93%	68%*
Psychological/counselling support in clinic	30%	9%*
Glycated haemoglobin at each clinic visit	88%	74%*
Screen microalbuminuria	78%	44%*
Screen retinopathy	97%	80%*
Number of Diabetes UK recommendations met	8.2	5.8*

\*Significant difference (p<0.005).

substantially more run designated diabetic clinics; this reflects the higher percentage of consultants stating a special interest in diabetes. Most clinics (86%) now provide capillary sampling methods, making the measurement easier for children and having results available in clinic to facilitate discussion of changes in management. The provision of paediatric diabetes specialist nurses and paediatric dietitians has increased since the previous surveys.

On the negative side there are serious continuing deficiencies. The results described are only from consultants who replied to the questionnaire and of these there are still at least 22% who claim no special interest despite their continuing responsibilities for children with diabetes. Twenty six per cent have small clinic populations of fewer than 40 children, making it less likely that the multidisciplinary team attends the clinic, and inexplicably 12% of clinics still do not regularly measure HbA<sub>1c</sub>. This figure is even worse (26%) for those clinics where the paediatrician does not express a special interest in diabetes. Glycated haemoglobin is the only evidence based measurement related to long term microvascular complications,<sup>4,13</sup> and the positive move towards its almost universal use should facilitate the introduction of a nationally agreed DCCT aligned assay method.<sup>14</sup> Routine annual complication screening has also not been universally adopted as recommended in international guidelines.<sup>13</sup>

This survey has found that many of the "diabetes" nurses have to cover other subspecialties and/or are part of adult diabetes services. Just under half of these nurse specialists are identified as not being trained as children's nurses, and one third are reported to have not undertaken a paediatric DSN course. Recommendations state that all children should be looked after by appropriately trained children's nurses.<sup>15</sup>

Further major defects are that 35% of clinics do not have the support of a paediatric dietitian and 78% of clinics do not have easy access to any sort of psychological counselling services. Both these provisions would seem to be essential in such a complex disorder with so many nutritional and psychological problems.

As shown in the previous surveys there are highly significant differences in the services offered by the diabetes team of a consultant with a special interest in diabetes (table 3). One paradox<sup>16</sup> is confirmed: that the whole time equivalent of paediatric DSN support per family is less in the clinics of paediatricians with a "special interest" by virtue of larger caseloads. It may be argued that this might compromise overall care, but the greater specialisation and experience of the clinicians and nurses probably outweigh the disadvantage.

Close cooperation between the adult and child services is highly recommended.<sup>13</sup> The survey shows 47% do not transfer teenagers with diabetes into a clinic specifically designed for young adults with diabetes. Similarly only 52% of the respondents have age stratified clinics, even though the majority (76%) manage their teenagers with diabetes into middle to late adolescence before transferring to adult services.

Diabetes UK has been interested in the provision of services to young people with special needs, particularly those in local authority care or in special residential schooling. The survey identified a small (0.7%) group requiring special educational help, complex support systems, and monitoring. These children often add significantly to the burden on the already overloaded diabetes teams.

### Conclusions

The results of this survey indicate significant improvements, but also show continuing important organisational deficiencies including:

- (1) The provision of appropriately trained and adequate numbers of specialised staff for children's diabetes teams, particularly consultant paediatricians with specialised training, specialist diabetes children's nurses, and paediatric dietitians specialising in diabetes is inadequate. Support from psychology services is particularly poor.
- (2) Sizes of many clinics remain too small to allow multidisciplinary team representation and specialisation.
- (3) There are serious inadequacies in information technology, audit, and evaluation of care (particularly in non-specialist clinics, in the regular assessment of vascular complications, and the utilisation of HbA<sub>1c</sub> measurements).

Paediatricians who claim to have a special interest in diabetes must increase their involvement in and work more closely with local diabetes specialist advisory groups,<sup>17</sup> hospital and primary care trusts, the Royal Colleges, and Diabetes UK to eradicate these deficiencies and to improve the services for children and young people with diabetes.

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