

# Is the NHS Best Practice Tariff for Type 1 Diabetes Applicable in the Irish Context?

## Abstract:

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## Abstract

The National Health Service in the UK has identified thirteen key standards of paediatric diabetes care. Funding depends on services meeting these standards. The aim of this study was to determine if these standards are applicable in an Irish setting. All patients attending the diabetes service during 2012 were included. Patient charts, electronic appointments, nursing notes and computerised results were used to ascertain relevant information for comparison with the NHS standards. Patients attended a mean 2.97 (SD 0.7) medical and 2.2 (SD 2.9) nursing appointments per year, with a median additional contacts of 8 nurse phone calls (range 0 - 125). Most standards were met by this service. In comparing our service to the NHS standard, we have identified a number of areas for improving our service provision. Limited resources and staff shortages make a number of these standards unachievable, namely annual dietetic review and three monthly outpatient appointments.

## Introduction

Over 95% of paediatric diabetes diagnoses in Europe are type 1<sup>1</sup>. The Diabetes Control and Complications Trial showed definitively that intensive therapy in type 1 diabetes mellitus improves glycaemic control, reducing the risk of long-term microvascular and macrovascular complications<sup>2,3</sup>. Achieving tight metabolic control is difficult and requires multidisciplinary input<sup>4</sup>. Best practice guidelines from the National Institute of Health and Clinical Excellence (NICE)<sup>5</sup> and the International Society for Pediatric and Adolescent Diabetes (ISPAD)<sup>6</sup> recommend that newly diagnosed children with type 1 diabetes should receive standardized care. This should include immediate referral to a multidisciplinary paediatric diabetes team; entry onto a national register; adequate diabetes education updates; 24 hour access to diabetic emergency management advice; screening for coeliac disease and thyroid dysfunction at diagnosis; routine assessment for retinopathy, microalbuminuria and hypertension from age 12, along with ongoing psychosocial support<sup>7</sup>. Recent audit of UK practice showed that diabetes control in childhood is sub optimal<sup>8</sup>. The National Diabetes Audit 2009-10<sup>9</sup> found that only 14.5% of children achieved the target glycosylated haemoglobin (HbA1c) of under 7.5% (58 mmol/mol), and this improved to 15.8% the following year<sup>10</sup>. 30.7% of children had HbA1c greater than 9.5% (80 mmol/mol) in 2009-10 and this improved slightly to 28.7% the next year<sup>11</sup>. To address this, the National Health Service developed thirteen key standards of paediatric diabetes care to be implemented from April 2012. If standards are not met, services have one year to improve, otherwise funding (£3,189 per child per annum) will be withdrawn<sup>12</sup>.

These standards also address the structure and training of the diabetes team. Newly diagnosed patients must be discussed with the specialist team within 24 hours, and seen by the team on the next working day. A structured education programme must be provided at diagnosis with updates and 24 hour access to advice on emergency management should be available. Patients must be offered four clinic appointments and HbA1c checks per year, with annual review as per the NICE guidelines. Patients should also have annual dietetic and psychological assessment. The diabetes team should partake in local meetings and national audit, and formal written policies must be in place for transition, poor glycaemic control, and non-attendances<sup>13</sup>.

Although a detailed national audit in Ireland has not been performed, it is likely that current practices are reflective of those in the UK. There are limited data available on the demographics of the Irish paediatric diabetes population. In 2006, twenty-nine consultants provided care for two thousand and forty patients with type 1 diabetes in nineteen centres across the Republic of Ireland, with only 50% of these consultants having a special interest in diabetes<sup>14</sup>. The average caseload per diabetes nurse specialist was 162, and per dietitian was 416. 70% of patients had no access to psychology services. No data on HbA1c levels was reported in this study<sup>15</sup>. A national paediatric diabetes audit group has recently been set up in Ireland. This aims to describe the services currently provided for children in Ireland with Type 1 diabetes, and the short-term outcomes in this population. As a pilot study for this national audit, we audited our service to determine if the UK tariff guidelines could identify areas for improvement in an Irish context.

## Methods

All children with type 1 diabetes attending the Children's University Hospital, Temple Street, were included in this retrospective chart review, which covered a period from January to December 2012. Patient charts, electronic appointments, diabetes nursing notes and computerised blood results were used to compile the relevant information. This service provision was compared with the NHS standards. This was subsequently analysed using Statistical Product and Service Solutions version 20.0 (IBM, New York, USA).

## Results

314 patients were attending the diabetes service on 31st December 2012, of whom 49 were diagnosed in 2012. Nineteen (of 314) had care shared with another centre. Demographics of these patients are shown in Tables 1 and 2. Service provision for all patients who had been followed up for at least 12 months in comparison to the NHS standards is shown in Tables 3 and 4.

The diabetes team at Children's University Hospital, Temple Street comprised 0.6 working time equivalent (WTE) consultant, 1 WTE specialist registrar, 1 WTE intern, 0.3 WTE Senior Health Officer, 2.2 WTE diabetes nurses, 0.5 WTE social worker, 0.3 WTE dietitian, 0.5 WTE psychologist, and 0.1 WTE psychiatrist. The consultant, specialist registrar, intern and senior house officer workload was split between diabetes and endocrinology. In this service, outpatient appointment frequency was reduced to four monthly in 2010 to allow more time per consultation as patient numbers increased. Where necessary, additional outpatient appointments or diabetes nurse appointments were offered. The mean number of outpatients appointments attended were 2.97 (SD 0.7) and diabetes nurse appointments were 2.2 (SD 2.9). The median number of additional contacts provided was 8 nurse phone calls (range 0-125).

20.3 % of patients achieve the target HbA1c of <7.5%. Almost 30% of our patients had a HbA1c below 8%, and only 10% had a HbA1c of greater than 9%. 19.4% had a dietetic review, 43% a psychology review, and 90% had an ophthalmology review during the study period. While 246 patients attended the service in Temple Street in 2012 and were diagnosed with diabetes for > 1 year, complete 2012 data was not available for all as some patients transitioned to newly established services locally and to young adult services during the study period. Complete data on service provision was available for 222 patients, as seen in Table 3.

\* Of the 9 patients with one or less appointments, 1 was based in another country for a year, 2 were seen as inpatients when attending with other comorbidities and 6 have care shared with other centres. One is a true non-attender, which was addressed.

## Discussion

Auditing our practice against the NHS tariff has been a useful exercise for our department. Despite our suboptimal resources, we are mostly compliant with the NHS standards. These include the diabetes team composition, structured education programme, number of contacts per year and psychosocial assessment as required. However, we are not meeting all criteria. This is reflective of UK practice, where a recent study<sup>12</sup> of 21 paediatric diabetes services revealed that no centre met all NICE guidelines regarding resource recommendations<sup>12</sup>. Increasing patient numbers and limited resources have necessitated modifications in our practice. In order to maximize the benefit of each outpatient encounter, and avoid the overbooking of clinics, we have reduced outpatient frequency to four monthly. Patients identified to be having difficulties are offered focused extra medical or nursing appointments. We feel that this has been a successful intervention, but it has reduced our average outpatient appointments attended to 2.97 per patient per year. Diabetes Specialist Nurse appointments and frequent phone calls bring our average number of contacts per patient per year far above the guideline number of 8.

While our clinic average HbA1c remains sub optimal, and this remains a constant focus area for improvement, 20.33% of our patients achieve HbA1c <7.5% (56 mmol/mol), compared to only 15.8% of UK patients in the 2010-11 audit. Our patient population includes a relatively large proportion of socially disadvantaged patients, where achieving optimal control is more challenging<sup>12</sup>. Adolescents in our service are less successful at maintaining good control and on reviewing the data from this audit, we are planning to see teenagers every 3 months rather than the clinic standard of 4 monthly. Our patients aged over 16 have a significantly higher HbA1c (mean 8.7 % (71 mmol/mol)), and this is largely affected by selection bias. Patients are generally transitioned to the adult services at 16 years of age, but patients with poor glycaemic control are often held for a further year to optimize their control in advance of transition. A specific area for improvement identified by this audit is the streamlining of annual assessment investigations. Full lipid profiles are not performed in all patients over 12 years of age, despite most having annual blood tests done. Depending on correct form completion, the biochemistry laboratory will perform either a full lipid profile or a single cholesterol test. The magnitude of this discrepancy was not previously identified and will be addressed. Furthermore, international guidelines suggest checking for microalbuminuria in children >5 years from diagnosis and annually from puberty but in our service urinary microalbumin/creatinine ratio is tested unnecessarily in most patients under 12 years. Ophthalmology assessment is also performed when not indicated in children under 12 years.

Dietitian availability for children with type 1 diabetes in Ireland is a significant issue, with only 19.4% receiving dietetic review during the study period. Despite our large patient numbers, we have just 0.3 WTE dietitian but this very committed and efficient individual has facilitated newly diagnosed education and carbohydrate counting for pump initiation for a large group of patients during this study period. It is not possible to offer an appointment to each patient annually in this context, and patients who have acquired full carbohydrate counting skills may not want or require an annual dietitian review. Regarding psychological review, we are compliant with the standards, whereby patients are asked at annual review if they would like to access psychological services. While our service had informal policies in place to address poor diabetes control and recurrent non attendance, after this audit identified deficiencies, we have put formal policies in place.

In order to identify these potential areas for improving our service, patient charts and blood results were meticulously analysed. This process was extremely time consuming and limited by a reliance on accurate documentation. It is likely that all appointments and contacts are an underestimation of the true number as they depended on manual data entry. This issue is not confined to our service and was a common<sup>8,9</sup> problem in the National Paediatric Diabetes Audit 2009-10 whereby the accuracy of the paper records was questioned<sup>8,9</sup>. This audit shows the benefit that a service can accrue from systematic evaluation. An automated national computerised system would allow the prospective collection and audit of performance indicators. However, the implementation of such a system that integrated with clinical practice, would require significant financial investment. We found that auditing our service against the NHS standards has reassured us in the quality of care that we provide, and also identified a number of potential areas for improvement. Little is known about the provision of care for children with type 1 diabetes in Ireland, and a national audit is currently in progress.

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