ANNUAL REPORT 2013

Diabetes Services at Great Ormond Street Hospital for Children and University College London Hospitals
## CONTENTS

Summary 3
Royal Visit 4
How are we doing?
- UCLH 5
- GOSH 10
What do you think of us
- UCLH 13
- GOSH 14
Peer Review 17
Schools and Nurseries 18
Type 1 Diabetes Website 20
Service at a Glance 22
Clinic Performance 26
Dietetics 29
Psychology 31
Play Specialist Report 33
African Group 34
Diabetes Charter 35
Finance 37
North Central London Paediatric Diabetes Health Care System 38
Diabetes Centre 40
Research 42
Publications 45
SUMMARY

2013 was marked with a visit from HRH the Duchess of Cornwall. The Duchess is the President of the Juvenile Diabetes Research Foundation. HRH visited the Service and met with staff, patients and families during a morning visit.

We have consolidated the integration between the services at Great Ormond Street Hospital for Children and University College London Hospitals and are now looking to bring all the Units in North Central London into a single managed centre. Work is currently in progress with the Trusts and CCGs involved in NCL. This is part of a bigger piece of work to create three centres within UCL Partners to deliver Paediatric Diabetes Care.

Welcome to Drs Billy White and Rakesh Amin who will be working in the Adolescent Diabetes part of the service. Rakesh will also be taking a lead on Research. Freya Brown was appointed to one of the UCLH Band 7 posts strengthening the nursing service to 3.8 Whole Time Equivalents. Laura Bull joined the team in January 2013 as the fulltime dietician.

The growth in the Children and Young People’s Diabetes Service continues. The clinic population is now 383 with 41 new referrals during 2013. The majority of referrals wish to extend their diabetes knowledge and skills so that they can commence insulin pump therapy but there is an increasing number referred because they are on pump therapy and need additional support.

We have continued to work to involve and engage patients and families in their care. This year we ran an ‘Expert Parent and Adolescent Day’ which included a Tree of Life session for young people. Parents were invited to attend the award session at the end of the day. Catherine Peters presented at Diabetes UK and Rebecca Thompson and Peter Hindmarsh continue to represent Paediatric Diabetes within Diabetes UK. Rebecca also contributed to the annual Friends for Life Conference for parents and children with diabetes in Glasgow.

We have also completed in conjunction with the London Borough of Camden our School Pathway for care in schools. Not only does this outline the care pathways but it also includes training and education provisions for staff and ways of delivering one to one support at critical stages of schooling.

We also have available our web site www.uclh.nhs.uk/T1 which contains information, blogs, webinars, videos and leaflets on all aspects of diabetes care. We will be expanding this further during 2014 with more useful hints and advice. All the school plans are now on the web so they can be downloaded easily for completion with the school.

We have continued to focus on improving diabetes care. We recognise that this is always in partnership with children and young people and their families. For the thirteenth twelfth successive year we have seen improvements in clinic glycosylated haemoglobin. 45% of children are now achieving an HbA1c less than 7.5%. Not only that but in the National Paediatric Diabetes Audit Patient Related Experience Measures families and patients rated the service we provide very highly with almost top scores on whether we would be recommended to other families with diabetes.

Finally, congratulations to Russell Viner who has taken over as Clinical Director for Paediatrics at UCLH. This is good for diabetes and we will be working closely with him to realise our clinical and research projects during 2014.
ROYAL VISIT

In January 2013 the Children and Young People’s Diabetes Service was host to a visit by HRH the Duchess of Cornwall. The visit was held jointly with the Juvenile Diabetes Research Foundation (JDRF). HRH has recently taken the position within the Foundation as President of the UK Branch.

The Royal Party was met by Professor Peter Hindmarsh as well as senior executives of JDRF. HRH was very keen to meet as many young people as possible during her visit and we used the public rooms on T12 ward to host the meetings. We provided three areas reflecting the work that JDRF does. In particular we were very proud to host with JDRF a section on Diabetes in the School Setting. Here JDRF showcased their new Schools Pack and we were able to introduce HRH to several families who outlined the problems that they face in having a child with diabetes at school.

In the young people’s section HRH met with staff and families across a wide age range and she talked at great length with the families and children about the problems they face on a day to day basis. For some of the young people there were even some tips on playing Table Snooker!!

After the visit to T12 a reception was held for supporters of JDRF along with Sir Robert Naylor (CEO of University College London Hospitals NHS Foundation Trust) and Richard Murley (Chairman of the Trust). HRH reiterated her commitment to push Paediatric Diabetes to the forefront both as part of her role at JDRF but also whenever she could within her other activities. The visit concluded with Professor Hindmarsh thanking HRH for taking the time to visit and emphasising how important that staff in the NHS were heartened by such visits.
HOW WE ARE DOING?

Overview of UCLH Clinic Performance

**Median HbA1c 7.8% compared to 8.6% Nationwide**

45% of clinic achieving HbA1c less than 7.5% compared to 18% Nationwide.

9.9 % of clinic achieving HbA1c greater than 9.5% (compared to 26% Nationwide)

1. **National Quality Control of Glycosylated Haemoglobin Measurement**

   Over the year 2012 monthly assessments were made of samples provided by the UK External Quality Assessment Scheme (EQAS). For UCLH HbA1c using the DCA1000 Siemens System in clinic over the range 5-10.9% there was a Bias of 0.12% (EQAS versus UCLH) with 95% limits of agreement of -0.48 to 0.72%.

2. **Glycosylated Haemoglobin Measurements Year on Year at UCLH**

   Overall Mean HbA1C (&) Clinic Performance for Years 2007 to 2013

<table>
<thead>
<tr>
<th>Year</th>
<th>All Clinics</th>
<th>Paediatric Clinic</th>
<th>Adolescent Clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007</td>
<td>8.9 (median 8.5)</td>
<td>8.2 (median 7.8)</td>
<td>9.4 (median 9.1)</td>
</tr>
<tr>
<td>2008</td>
<td>9.0 (median 8.4)</td>
<td>8.4 (median 8.3)</td>
<td>10.0 (median 9.3)</td>
</tr>
<tr>
<td>2009</td>
<td>Median 8.4</td>
<td>Median 8.1</td>
<td>Median 9.4</td>
</tr>
<tr>
<td>2010</td>
<td>Median 8.2</td>
<td>Median 8.0</td>
<td>Median 8.7</td>
</tr>
<tr>
<td>2011</td>
<td>Median 7.8</td>
<td>Median 7.6</td>
<td>Median 8.4</td>
</tr>
<tr>
<td>2012</td>
<td>Median 7.8%</td>
<td>Median 7.6</td>
<td>Median 8.5</td>
</tr>
<tr>
<td>2013</td>
<td>Median 7.7%</td>
<td>Median 7.7%</td>
<td>Median 8.4%</td>
</tr>
</tbody>
</table>

The general trend shows a steady all clinic improvement over time which is a continuation of a long term trend in clinic HbA1c over the years 1999-2013 which is shown in Appendix 1 (left panel). The right panel of Appendix 1 shows that the variation in the clinic is also decreasing with time. The decrease has taken place during a time when referral numbers and clinic size has continued to increase as has the clinic staffing. This would imply that internal consistency has been maintained.

These changes probably reflect an increasing use of protocols such as intensification of insulin therapy to improve care as well as policies that provide intensive follow up for those with HbA1c greater than 9.0%. The data have not been adjusted for the complexity of patients particularly these referred to UCLH who are struggling with their diabetes with history of recurrent presentation with Diabetic ketoacidosis prior to referral.

The effect of Mode of Insulin therapy on HbA1c is shown in below. Note we stopped recommending Twice Daily therapy for Children and Young People with Diabetes in 2004
UCLH now has 276 children and young people using insulin pump therapy. This represents 72.2% of our current caseload. We are able to resource for 48 new pump starts per year, enabling a supportive staged pathway from referral through to families feeling confident and competent to use this insulin regimen.

3. **National and International Benchmarking**

UCLH Clinic Performance compared to UK National Paediatric Diabetes Audit 2012

<table>
<thead>
<tr>
<th>Mode of Insulin Therapy</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>BD</td>
<td>9.5 ± 0.4</td>
<td>10.9 ± 0.8</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MDI</td>
<td>9.7 ± 0.2</td>
<td>9.6 ± 0.2</td>
<td>Median 9.5</td>
<td>Median 8.6</td>
<td>Median 8.4</td>
<td>Median 8.5</td>
<td>Median 8.4</td>
</tr>
<tr>
<td>CSSI</td>
<td>7.7 ± 0.1</td>
<td>7.9 ± 0.1</td>
<td>Median 7.9</td>
<td>Median 7.9</td>
<td>Median 7.6</td>
<td>Median 7.6</td>
<td>Median 7.7</td>
</tr>
</tbody>
</table>

The overall percentage for target less than 7.5% at UCLH for 2013 was 45% for the whole clinic with 49% for paediatrics and 23% for adolescents. This compares with 17.4% for the National Paediatric Diabetes Audit 2012.
UCLH HbA1c Measures less than 7.5% and less than 8% 2004-2013

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;7.5%</td>
<td>18.8</td>
<td>29.4</td>
<td>32.5</td>
<td>33</td>
<td>34.6</td>
<td>28.9</td>
<td>35.2</td>
<td>45</td>
<td>39.7</td>
<td>45</td>
</tr>
<tr>
<td>&lt; 8%</td>
<td>23.5</td>
<td>37.5</td>
<td>40.6</td>
<td>45.9</td>
<td>47.4</td>
<td>41</td>
<td>52.6</td>
<td>55.4</td>
<td>59.7</td>
<td>65.4</td>
</tr>
</tbody>
</table>

General trend to more individuals hitting target area for HbA1c (as recommended by UK Department of Health less than 7.5%). For paediatric practice it has been suggested by the American Diabetes Association that 8% target should be used.

For the other end of the scale 9.9% of the UCLH clinic had HbA1c greater than 9.5% with 4.9% in paediatrics and 24.7% in adolescents. For the UK the overall figure was 26%. We are now planning three approaches to this population:

- audit of high HbA1c pathway effectiveness
- integration of CASCADE into routine clinic delivery
- trial of CSII in this population of CYP doing poorly

Translation of HbA1C into Relative Risk of Developing Complications using DCCT Complications Dataset

<table>
<thead>
<tr>
<th>Relative Risk</th>
<th>2010</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>HbA1C</td>
<td>% of Clinic</td>
<td>HbA1C</td>
</tr>
<tr>
<td>&lt; 8</td>
<td>52.6</td>
<td>&lt; 8</td>
</tr>
<tr>
<td>8-10</td>
<td>35.0</td>
<td>8-10</td>
</tr>
<tr>
<td>&gt; 10</td>
<td>12.4</td>
<td>&gt; 10</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Relative Risk</th>
<th>2012</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>HbA1C</td>
<td>% of Clinic</td>
<td>HbA1C</td>
</tr>
<tr>
<td>&lt; 8</td>
<td>59.7</td>
<td>&lt; 8</td>
</tr>
<tr>
<td>8-10</td>
<td>32.9</td>
<td>8-10</td>
</tr>
<tr>
<td>&gt; 10</td>
<td>7.4</td>
<td>&gt; 10</td>
</tr>
</tbody>
</table>

UCLP and National/International Benchmarking

<table>
<thead>
<tr>
<th>Site</th>
<th>Median HbA1c (%)</th>
<th>% with HbA1c less than 7.5%</th>
</tr>
</thead>
<tbody>
<tr>
<td>UCLH/GOSH</td>
<td>7.7</td>
<td>45.0</td>
</tr>
<tr>
<td>North Central London</td>
<td>8.5</td>
<td>16.0</td>
</tr>
<tr>
<td>England and Wales</td>
<td>8.6</td>
<td>17.3</td>
</tr>
<tr>
<td>Germany</td>
<td>7.7</td>
<td>33.8</td>
</tr>
</tbody>
</table>
### 4. Annual Review Performance

#### a). 2010

<table>
<thead>
<tr>
<th></th>
<th>PAEDIATRIC (0-12)</th>
<th>%</th>
<th>ADOLESCENTS (13-19)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eligible</td>
<td>N 176</td>
<td>147</td>
<td>142</td>
<td>100</td>
</tr>
<tr>
<td>Attended</td>
<td></td>
<td>100</td>
<td>110</td>
<td>77.4</td>
</tr>
<tr>
<td>Missed</td>
<td></td>
<td>47</td>
<td>32</td>
<td>22.5</td>
</tr>
<tr>
<td>DNA (invited)</td>
<td>2</td>
<td>1.36</td>
<td>4</td>
<td>2.8</td>
</tr>
<tr>
<td>New Referral</td>
<td>31</td>
<td>21.0</td>
<td>20</td>
<td>14.0</td>
</tr>
<tr>
<td>Too Young</td>
<td>22</td>
<td>14.9</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Local</td>
<td>2</td>
<td>1.36</td>
<td>6</td>
<td>4.2</td>
</tr>
<tr>
<td>Newly diagnosed</td>
<td>8</td>
<td>5.4</td>
<td>2</td>
<td>1.4</td>
</tr>
<tr>
<td>New referral with A/R</td>
<td>2</td>
<td>1.36</td>
<td>5</td>
<td>3.52</td>
</tr>
</tbody>
</table>

#### b). 2011

<table>
<thead>
<tr>
<th></th>
<th>PAEDIATRIC (0-2yrs)</th>
<th>%</th>
<th>ADOLESCENTS (13-19)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eligible</td>
<td>N 186</td>
<td>149</td>
<td>142</td>
<td>97.9</td>
</tr>
<tr>
<td>Attended</td>
<td>123</td>
<td>82.5</td>
<td>114</td>
<td>80.2</td>
</tr>
<tr>
<td>Missed</td>
<td>17</td>
<td>11.4</td>
<td>18</td>
<td>12.6</td>
</tr>
<tr>
<td>DNA (invited)</td>
<td>0</td>
<td>0.0</td>
<td>4</td>
<td>2.81</td>
</tr>
<tr>
<td>New Referral</td>
<td>4</td>
<td>2.68</td>
<td>3</td>
<td>2.11</td>
</tr>
<tr>
<td>Too Young</td>
<td>32</td>
<td>21.4</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Local</td>
<td>10</td>
<td>6.71</td>
<td>8</td>
<td>5.63</td>
</tr>
<tr>
<td>Newly diagnosed</td>
<td>5</td>
<td>3.35</td>
<td>3</td>
<td>2.11</td>
</tr>
</tbody>
</table>

#### c). 2012

<table>
<thead>
<tr>
<th></th>
<th>PAEDIATRIC (0-12yrs)</th>
<th>%</th>
<th>ADOLESCENTS (13-19yrs)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eligible</td>
<td>N = 204</td>
<td>161</td>
<td>147</td>
<td>98</td>
</tr>
<tr>
<td>Completed</td>
<td>91</td>
<td>61.5</td>
<td>86</td>
<td>61.2</td>
</tr>
<tr>
<td>Not completed</td>
<td>34</td>
<td>21.1</td>
<td>35</td>
<td>23.8</td>
</tr>
<tr>
<td>DNA (invited)</td>
<td>4</td>
<td>2.5</td>
<td>8</td>
<td>5.4</td>
</tr>
<tr>
<td>Newly diagnosed</td>
<td>5</td>
<td>3</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Too young</td>
<td>38</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>New Referrals</td>
<td>18</td>
<td>11</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### d). 2013

<table>
<thead>
<tr>
<th></th>
<th>PAEDIATRIC (0-12yrs)</th>
<th>%</th>
<th>ADOLESCENTS (13-19yrs)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eligible</td>
<td>N = 179</td>
<td>151</td>
<td>192</td>
<td>100</td>
</tr>
<tr>
<td>Completed</td>
<td>107</td>
<td>59.8</td>
<td>132</td>
<td>68.7</td>
</tr>
<tr>
<td></td>
<td>Not completed</td>
<td>DNA (invited)</td>
<td>Newly diagnosed patients</td>
<td>Too young</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td></td>
<td>45</td>
<td>25.1%</td>
<td>51</td>
<td>26.5%</td>
</tr>
</tbody>
</table>

We will be moving to use the Register record and also track on CDR through CDR/PRM which should help tighten this up. We also plan to link this into UCLID which is described in Research section.

5. **Admissions for Diabetic Ketoacidosis and Hypoglycaemia**

Admissions for Diabetic Ketoacidosis (DKA) and Hypoglycaemia are Key Performance Indicators within Peer Review and DKA admissions will also be part of the Best Practice Tariff from 2014. It is likely that the Tariff will only pay for up to 4 admissions per year per individual.

For 2013 there were 20 admissions coded of which 10 were new patients and 10 were already established patients with Type 1 Diabetes. Of the 10 established admissions 7 were by one individual. A clear plan is in place to help this young person and the number of DKA admissions is actually less than the previous year.

These data yield an established admission rate of 2.6% if simply based on admissions and 1.0% if considered on basis of number of individuals.

For admissions for severe hypoglycaemia there were three during the year. These were for evaluation of causes for the hypoglycaemia and were instgated by paediatricians in District General Hospitals.
HOW ARE WE DOING?

Overview of Great Ormond Street Clinic Performance

Patient referrals
The diabetes team at GOSH provide a service to children and young people aged 0-18 years with a range of less common forms of diabetes. These include Cystic Fibrosis Related Diabetes (CFRD), New Onset Diabetes after Transplant (NODAT), Steroid induced diabetes, and some monogenic forms of diabetes. The challenge for the patients, families and the team is that these types of diabetes may be transient, intermittent or progressive and are often in addition to another significant chronic disease.

The numbers of referrals to our service has increased as we have become established within the trust and as we have been more proactive in screening children with cystic fibrosis. Over the past year our numbers are recorded as follows:

<table>
<thead>
<tr>
<th>Type of Diabetes</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary diabetes provider</td>
<td></td>
</tr>
<tr>
<td>CFRD</td>
<td>10 + 1 transitioned</td>
</tr>
<tr>
<td>NODAT (lung for CF)</td>
<td>4</td>
</tr>
<tr>
<td>NODAT (Renal and Heart)</td>
<td>6</td>
</tr>
<tr>
<td>Monogenic</td>
<td>2 + 1 RIP</td>
</tr>
<tr>
<td>Autoimmune (type 1 overlap)</td>
<td>3</td>
</tr>
<tr>
<td>T2DM</td>
<td>1 transitioned</td>
</tr>
<tr>
<td><strong>Total 28</strong></td>
<td></td>
</tr>
<tr>
<td>Shared Care diabetes provider</td>
<td></td>
</tr>
<tr>
<td>CFRD</td>
<td>6 + 1 RIP</td>
</tr>
<tr>
<td>NODAT</td>
<td>5</td>
</tr>
<tr>
<td>Post pancreatitis (ALL)</td>
<td>2</td>
</tr>
<tr>
<td>Steroid related</td>
<td>3</td>
</tr>
<tr>
<td>Bardet-Beidl</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total 18</strong></td>
<td></td>
</tr>
<tr>
<td>Transient insulin dependence</td>
<td></td>
</tr>
<tr>
<td>Steroid related</td>
<td>3</td>
</tr>
<tr>
<td>Intermittent hyperglycaemia – active</td>
<td></td>
</tr>
<tr>
<td>monitoring and dietary advice</td>
<td></td>
</tr>
<tr>
<td>Cystic fibrosis</td>
<td>21</td>
</tr>
<tr>
<td>Glycogen storage disorder</td>
<td>2</td>
</tr>
<tr>
<td>Post transplant (heart/renal)</td>
<td>2</td>
</tr>
<tr>
<td>Other syndromic conditions</td>
<td>10</td>
</tr>
<tr>
<td><strong>Total 38</strong></td>
<td></td>
</tr>
</tbody>
</table>

Structure of Diabetes Service at GOSH
The GOSH site offers a service with a high inpatient commitment. Many of the children and young people have regular appointments and admissions for their underlying conditions and the diabetes team must therefore be flexible in timing and location for the delivery of the diabetes service.

In addition to the patients known to our service, diabetes reviews were requested for 31 inpatients over the past year. These were mainly children and young people with type 1 diabetes undergoing surgical procedures.
A weekly MDT meeting followed by a hospital ward round provides an opportunity to discuss all inpatients, outpatients and patient contact as well as discussions around service development. A quarterly joint CF/diabetes clinic is offered as well as routine MDT outpatient clinics, nurse led appointments and dietetic appointments.

Patients with CF are screened from the age of 10 years for CFRD with an OGTT. Those with indeterminate or impaired glucose tolerance will be offered CGMS and treatment with insulin is offered on the basis of the glucose profile. The use of CGMS in CF is leading to an increased number of referrals from the CF service.

**Education for children, young people and families**

All members of the team, apart from the psychologist, are certified pump trainers, for both the Medtronic and Roche pumps, and diabetes educators. The team are currently using material from the “Goals of Diabetes Education Package – structured education program” as an aid.

In addition the team have developed patient leaflets as below:

![Leaflets Image]

We have also produced several other information sheets for families including:

- **Carbohydrate Counting**
- **Hypoglycemia**
- **Cystic Fibrosis: Why does my blood glucose matter?**

In progress is a pictorial carbohydrate counting tool based on the foods served at GOSH and an information sheet on Diabetes and Exercise.

**Patient stories**


**Staff Education**

Samantha Drew and Rebecca Margetts have spent a great deal of time on staff education. This has been most effective if ward education is provided when the staff are managing inpatients with diabetes. Training of the Clinical Site Practitioners is also taking place.
Hannah Gordon has completed her Diabetes course at Birmingham and pump certification courses and has been working alongside Samantha Drew before starting her new role as Diabetes CNS in February to cover Samantha’s maternity leave.

Samantha and Rebecca were also able to join other medical members of the team at the annual BSPED meeting and presented a poster “Extreme hyperlipidaemia with poor glycaemic control in type 1 diabetes”.

**HbA1c results**

HbA1c results are less indicative of true glycaemic control in the GOSH patient set than in Types 1 and 2 diabetes. A normal HbA1c does not exclude significant hyperglycaemia. For this reason, we do not have HbA1c data for all our patients. However, a raised HbA1c is significant in these children and young people. The need to have HbA1c results in clinic for patient benefit and for Best Practice Tariff requirements has led to the trust acquiring a point of care HbA1c machine. This should be available for use in 2014.

**Results for April 2012- April 2013:**

65% of patients had HbA1c data available. Of these:

- **Average HbA1c = 6.91%**
- **Percentage <7.5% = 71%**
WHAT DO YOU THINK OF US?

UCLH

This year as part of the National Paediatric Diabetes Audit children and young people and their parents were asked to fill in a series of questionnaires at Great Ormond Street and University College Hospital on what they thought of the service.

The report was very complimentary to the service at both sites. We picked up on a couple of points:

Exercise

We are very aware that advice on exercise is an area that is often requested to be talked about at clinics. This is how you rated us (PZ203) with comparisons made to other London Centres and the average for England and Wales

![PREMS Q4E - Exercise Chart]

Overall this is quite good with 84.2% feeling that we provide helpful advice.

We feel however, that we have still not got this quite right so Rebecca Thompson has worked during the year on creating a special clinic which we will hold quarterly with Francesca Annan a Sports Dietician from Alder Hey Hospital in Liverpool. Francesca has seen over the years many of the families who attend our clinics in Liverpool to give advice. This has worked well but we felt that families and ourselves would get more out of consultations if we hosted them in London. Rebecca and Francesca held the first clinic in October and this was very successful with feedback of great outcomes from the first participants.
Schools and Nurseries

We were very pleased with the feeling that we are providing good support in terms of information, education and training for schools and nurseries. This is an area of considerable concern to families and although we have had uniformly good outcomes we have felt for a long time that more formal arrangements needed to be made with Council Educational Departments. Louise Potts started work in this area a few years ago and we are now pleased to announce adoption of our Schools Statement by Camden Council. More on this in the section on Schools.

GOSH

NPDA and PREMS

Over the past year, the GOSH service has been in a position to collect data and submit to the NPDA. We contributed to PREMS with small numbers and favourable results.

A larger number of patients were invited to contribute to the most recent PREMS audit with encouragement to use the online questionnaires. These results are awaited.
So in Summary what did you think?

It is always difficult to reduce a series of responses to a single number. Over the last two years or so we have used the NetProvider Question “On a scale of 1 to 10 where 1 is never and 10 highly likely would you recommend this service to a friend whose child has diabetes.”

The important point here is that we would want to score 9 plus and indeed we do pretty well with 90% giving us the 9 plus rating.

**UCLH**

![](image)

**GOSH**

The service scored a mean of 9.6 on the NetProvider score

We also got a lot of free ranging comments some of which are noted below

Good staff and nurses are a good help.
Very fun and kind staff, and helpful.
Very welcoming, understanding, never giving me a go but great at advice and generally care.
Because it's nice, clean and quick.
They are good
Friendly, helpful, good - knowledgeable in diabetes.
No problems whatsoever, very helpful.
(Child) enjoys coming to clinic.
The doctors and nurses give me enough time to talk about my condition and advice and are all really friendly.
This clinic is very good.
All the staff are really helpful and caring.
Really knowledgeable doctors and nurses.
Easy to talk to doctors and nurses and will always give you the time you need, answers any questions.
All of the doctors and nurses are very understanding and respectful and explain issues well.
It is really helpful.
High level of expertise

And for GOSH

Because very well explained and very helpful.

Much better than my local hospital.

Because the nurses and doctors are very nice and very helpful.

I love it here.

The diabetes team so helpful.

And we really liked this one!!!

It's well sick innit! It's bangin'!
PEER REVIEW

In July 2012 we underwent the Peer Review process with a visit by the assessors from Yorkshire and the DQUINS Team. This process has now been established as a national process run from NHSIQ. The Peer Review process is important for Quality Assurance and is important component of the Best Practice Tariff.

The process is already underway and our review date will be February 24 2014. The Review will then repeated as a site visit every 5 years with yearly self assessments filling in in between.

As in 2012 we will be reviewed as a single service between Great Ormond Street Hospital and University College Hospital.
SCHOOLS AND NURSERIES

Having diabetes impacts on care given within schools and early year’s settings, with appropriate diabetes care necessary for the child’s immediate safety, long term well being, and optimal academic performance. Whilst some older children may be fully independent with their diabetes care, younger children are likely to need support and assistance from school staff during the school day to manage their diabetes on their behalf in the absence of their parents. It is therefore essential that all school staff have an awareness of this medical condition and the child’s needs during the school day.

Training for staff caring for young people with Type 1 Diabetes within schools and early years settings

At the start of 2013 we held a study day designed to develop the knowledge and skills of the school nurse in relation to supporting CYP with diabetes in the school setting, with the aim of increasing confidence and competence in this area. The day covered an introduction to diabetes and how it is managed, including MDI, insulin pump therapy and carbohydrate counting. It also covered the possible impact on cognitive function. There was an opportunity to look at different blood glucose monitoring and insulin delivery devices, and some hands on practical experience.

Overall, people felt their understanding/confidence had improved a small but significant amount following the training, and the final rankings were between 4-5 (0 being no understanding/confidence and 5 being completely confident) for all but the carbohydrate counting. Carbohydrate counting was the area that people felt least confident about before the training but showed the biggest improvement in understanding/confidence.

New School Year Study Days

UCLH then saw a flurry of activity this September with The Diabetes Team training over 230 members of school staff from 126 schools across the country.

The team ran two half day sessions on managing diabetes on pumps and one session on injections in schools. The sessions were attended by school teachers, school nurses and teaching assistants and included talks on 'What is Diabetes?', 'Managing high and low blood glucose levels', 'Diabetes and cognitive function' and 'Documentation, legislation and training needs'.

School staff with a duty of care to look after young people with diabetes felt the day gave them a better idea of what was expected of them legally and also practically. We had very positive feedback for both the pump and injection sessions with most people increasing their knowledge over the day. For those staff who have been coming every year they reported it being a useful reminder and update. Some of the feedback included:

"Thank you it was a very interesting course and I feel more confident about diabetes and the effects of it."
"Very good demo on insulin pump and settings"
"Excellent training- so helpful thank you!"

Due to high demand the team are running another course in January to train more staff and those who couldn't make it in September.

School Management plans can now be downloaded from the website and emailed to the nurses for signing off, once filled in by school staff and parents.
Written Position Statement on the care of CYP with Diabetes in schools and early years settings

The draft UCLH ‘School Position Statement’ was formally agreed by the Camden Special Educational Needs team in October 2013. This will now be easily accessible on the UCLH Diabetes webpage and help ensure consistency across schools in Camden.

The plan is that the diabetes team will host launch event in 2014 with presentations and invites to all the local schools in order to disseminate the publication of this document. We then plan to work with Camden CCG in particular to support their plan to reintroduce school nurses in all schools throughout the Borough.
A joint project with the UCLH communications department was undertaken to pilot dynamic web content this year. A small group from the diabetes team worked with the communication department, the specialist agency ‘Social and Local’ and two parents to develop our external webpage.

Following design of the new webpage, we tested the site with an online survey through the parent run facebook page. Feedback was used to update the site before it went live on the 3rd Sept. This feedback was incredibly positive with:

- a 96% net recommendation score
- 90% would return to the site again
- 74% rated the site as better than all other sites they have visited (including diabetes charities, NHS, commercial and US providers)
- Unique visitors in September – 893 (3611 page views)

In addition to links to useful websites, photos of staff members, advertisement about upcoming events, a blog and information relating to recruiting research studies, the site also hosts all the available written education material for children, young people, families and their carers.

This is supported by ‘how to’ videos aimed to support education provided in face-to-face appointments by the diabetes team. These videos show the diabetes nursing team demonstrating how to perform tasks associated with diabetes and have been one of the most positively evaluated aspects of the developed webpage.
We have been keeping track as to the number of times that these videos have been viewed. As of the end of October 2013, the numbers of views were:

- How to insert a MIO cannula – 270 views
- How to use an Enlite sensor – 450 views
- How to do an Insulin Injection – 281 views
- How to do a Glucagen injection – 1872 views
- How to do a blood glucose test – 113 views
The paediatric diabetes service at UCLH cares for children and adolescents aged 0-19 years. The service has specialist clinics for children (aged under 13 years) under the care of Professor Peter Hindmarsh and Dr Catherine Peters and clinics for adolescents (13-19 years) under Professor Russell Viner, and Drs Rakesh Amin and Billy White. The latter includes a specific transition programme into the adult diabetes service for 18-19 year olds. Rebecca Thompson provides services as a Nurse Consultant to both age groups.

The diabetes service has an inter-disciplinary team which work together with the aim to support the young person and their family living with the demands of diabetes.

The service offers an additional specialist service for adolescents struggling with their diabetes. Having a designated adolescent unit has enabled us to develop a 4-stage planned admission programme that allows young people who are really stuck with their diabetes, to start again and plan for a better future.

We are also a referral service for children and adolescents who wish to move onto an insulin pump. All team members are certified pump trainers and we continue to deliver our structured pump education pathway for these children and their carers.

We currently have a caseload of 383 children and young people with diabetes. Looking at our referrals into the service and the number of young people transitioning out to adult services each year, the service expands by approximately 25 children/ young people per year.

Accessing care

Children and young people have to live with the demands of diabetes 24-hours a day and the management impacts on every part of their life.

UCLH provides:

- an emergency department
- in-patient care (including a specialist adolescent unit for both emergency and planned admissions)
- out-patient care (includes interdisciplinary outpatient clinics, nurse-led clinics, nurse-led annual reviews, dietetic, podiatry and psychology clinics specifically focussed on CYP)
- education events (parent expert study days and workshops designed for school staff)
- ongoing support via telephone, SMS and email.

Inter-Disciplinary Group Meetings

The CYP IDG meets weekly on Tuesday between 13.00 and 14.00h at UCLH and between 10.00 and 11.00h on Thursdays at GOSH. Core members consist of one medical consultant, one clinical nurse specialist, a dietician and a psychologist. The following are discussed:

1. Current inpatients, including planned admissions, as well as newly presenting CYP with diabetes.
2. Recent inpatients review
3. Outpatients to be reviewed that week in clinical settings, along with any outstanding outpatient problems.
New referrals to the service, where consideration is given to attendance, either as an outpatient, the undertaking of a 4 stage plan, or a network meeting to better clarify the role for the Service in the care of the person with diabetes.

Decisions regarding treatment plans that need alteration are considered at the Clinical Nurse Specialist Team Meeting held each day at 08.00h.

For complex inpatients the Medical and Nursing Teams join the Thursday Paediatric and Adolescent Multi-Disciplinary Team Meeting

The weekly GOSH IDG consists of a medical consultant, clinical nurse specialist and dietician. Patient discussions have the same format as above. Due to the co-morbidities of the patients with diabetes that are managed at GOSH, psychology input is provided by the patient’s primary service ie CF team, transplant team, oncology team. Feedback to the psychology services from the meeting are provided where appropriate. Local liaison takes place in conjunction with the lead GOSH Speciality and involves the Secondary Care Paediatric Team and General Practitioner.

Contacts

Diabetes Central Administrator  Tel: 020 344 79221
Janet.Taylor@uclh.nhs.uk

Diabetes Nurse Specialists  Tel: 020 344 79364
childrensdiabetesnurses@uclh.nhs.uk

STAFFING

Core Group

Medical Consultants
Dr Rakesh Amin
Professor Peter Hindmarsh
Dr Catherine Peters
Professor Russell Viner
Dr Billy White

Nurse Consultant
Rebecca Thompson

Diabetes Nurse Specialists based at UCLH
Kirsty Agostini
Freya Brown
Jennifer Pichierri
Louise Potts (Lead for Transition)

Diabetes Nurse Specialists based at GOSH
Samantha Drew (Lead for user issues)
Hannah Gordon
Dieticians
Laura Bull (UCLH)
Rebecca Margetts (GOSH)

Psychology Consultant
Dr Deborah Christie

Psychologist to Diabetes
Dr Lucy Casdagli
Dr Sharon McElroy (GOSH)

Diabetes Administrator
Janet Taylor (user issues contact)

Leads for Information Transfer and Technology
Professor Peter Hindmarsh
Dr Catherine Peters

Leads for User Issues and Information
Initial point of contact and directed as necessary
Kirsty Agostini (UCLH)
Freya Brown (UCLH)
Samantha Drew (GOSH)
Jennifer Pichierri (UCLH)
Louise Potts (UCLH)

Extended Groups

Adult Transition and Services
Dr Stephen Hurrell (UCLH)

Professor Stephanie Amiel (Kings College Hospital)
Geraldine Gallen (Clinical Nurse Specialist Kings College Hospital)

Play Specialist
Liz Wilkinson (UCLH)

Clinical Psychology
Glenda Fredman (UCLH)

Clinical Psychiatry
Simon Lewis (UCLH)

Social Worker
Gill Hardman (UCLH)
Ann Hunter (GOSH)

Ophthalmology at UCLH (Accredited Diabetes Retinal Service)
Mr Martin Harris
Currently we have seven Consultants in Paediatric Diabetes. Rakesh Amin, Peter Hindmarsh, Catherine Peters, Russell Viner and Billy White provide Medical Consultant input; Rebecca Thompson provides Nurse Consultancy and Deborah Christie provides Clinical Psychology input.

In addition to the consultants, the inter-disciplinary team include:

- **Clinical Nurse Specialists** – 2013 saw an increase in nursing time to 4 WTE at UCLH and 0.8 WTE at GOSH to provide advice, support and education Monday to Friday 08.00-18.00. All nurses have undertaken post graduate education within paediatric diabetes and are certified insulin pump trainers.
- **Paediatric dietician** – 2013 saw full time dietetic provision at UCLH and we continue with 0.7 WTE at GOSH
- **Paediatric Psychology** – Psychological services are an integrated component of the paediatric and adolescent diabetes service. Regular audit has demonstrated high levels of satisfaction with the service with over 50% of the case load having had an opportunity to meet with members of the psychology team. A range of psychological approaches are offered for individuals and families. The team works within a systemic framework and offers solution focussed, narrative and motivational interviewing as well as cognitive behavioural therapy. For complex cases network meetings are arranged in order to include members of the diabetes team, the family and other members of the network to join together to develop shared management plans.
- **Play specialists** who assist with pump preparation and intensive insulin schedules and help with annual reviews
- **Children and young people** are also able to access specialist advice for the ophthalmology and podiatry services, as part of their ongoing diabetes management.
CLINIC PERFORMANCE

General

The Service increased again during 2013 so that the total number in the service is 383. There were 44 new referral during 2013 and virtually all stayed within the service. The referrals fall into three main themes – families wishing to start insulin pump therapy; families already using pumps but looking for alternative support and education to enable them to get better outcomes and finally, young people generally struggling with living with diabetes.

Table 1 Clinic Size 2009-2012

<table>
<thead>
<tr>
<th>Year</th>
<th>Clinic Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>253</td>
</tr>
<tr>
<td>2010</td>
<td>298</td>
</tr>
<tr>
<td>2011</td>
<td>327</td>
</tr>
<tr>
<td>2012</td>
<td>348</td>
</tr>
<tr>
<td>2013</td>
<td>383</td>
</tr>
</tbody>
</table>

72.2% of the clinic population are on Insulin Pump therapy with the remainder on Multiple Daily Injection regimens and 3 remaining on Twice Daily therapies.

The current wait time for a Pump assessment Clinic is 2-3 weeks and pump starts are dependent upon the competence of the individual, on average 2 months. We offer immediate start on pump therapy to all newly diagnosed under the age of 5 years and to any sibling of a child already on insulin pump therapy.

Clinics Held

The number of clinics (face to face) held during the year increased overall by 5% reflecting the complexity of the case load along with the general increase in families wishing to have their care at UCLH. The addition of Drs Rakesh Amin, Catherine Peters and Billy White to the team has opened up a large area of flexibility to allow for more timely follow up appointments.

The General Diabetes Clinics have continued with the usual age banding. 2010 saw the introduction of the Teenage Transition Clinic held in parallel with the Adolescent Clinic. As transition is a continuous process this allows the 10-13 year age group to be seen in the same setting as the Adolescent Clinic and introduces them gradually to the concept and process of the Adolescent Clinic. Currently the Teenage Transition Clinic operates weekly.

The Nurse led clinic has continued on Wednesdays and continues to be a useful development for drop in and specific task focussed work. The telephone clinics are now well established and increased to twice weekly. These clinics from the clear agendas set for each consult. 2013 has seen a continued increase in e-mail communication which is now the most popular mode for interaction with the service.
Clinics Available for Children and Young People with Diabetes at UCLH 2013

<table>
<thead>
<tr>
<th></th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
</tr>
</thead>
<tbody>
<tr>
<td>AM</td>
<td>Paediatric Diabetes (weekly)</td>
<td>Pump School (2 a month)</td>
<td>Telephone clinic (weekly)</td>
<td>Additional Adolescent Clinic (monthly)</td>
<td>Annual Review and Education and Training Clinic</td>
</tr>
<tr>
<td>PM</td>
<td>Nurse consultant clinic (weekly)</td>
<td>Adolescent Clinic</td>
<td>Nurse Led Clinic (weekly)</td>
<td>Paediatric Diabetes (fortnightly)</td>
<td>Telephone clinic (weekly)</td>
</tr>
<tr>
<td></td>
<td>Adult Transition (3 monthly)</td>
<td>Teenage Transition (weekly) Psychology</td>
<td>Dietetic Clinic (weekly)</td>
<td>Adolescent clinic (fortnightly)</td>
<td>Dietetic Clinic (weekly)</td>
</tr>
</tbody>
</table>

Note: Psychology also conduct sessions throughout the week for CYP with Diabetes.

Timely service delivery is important and Table 7 shows how this has changed over the last few years in Paediatrics and Teenage Transition. Clinic size has increased and overall Did Not Attend (DNA) rates are low (versus 9-10% for Endocrinology at Great Ormond Street Hospital) and unchanged. Consultation times suggest that our 30 minute appointment schedule is correct with efficient use of time as shown by Face to Face times.

Timeliness of Service (Paediatrics)

<table>
<thead>
<tr>
<th></th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average Clinic Size</td>
<td>7.8</td>
<td>7.1</td>
<td>6.8</td>
<td>6.7</td>
</tr>
<tr>
<td>DNA Rate (%)</td>
<td>5.1</td>
<td>4.8</td>
<td>4.7</td>
<td>5.4</td>
</tr>
<tr>
<td>Wait time (mins)</td>
<td>15.5</td>
<td>12.8</td>
<td>12.4</td>
<td>12.5</td>
</tr>
<tr>
<td>Consultation time (mins)</td>
<td>26.5</td>
<td>25.6</td>
<td>25.5</td>
<td>24.9</td>
</tr>
<tr>
<td>% Face to Face Time</td>
<td>85.0</td>
<td>82.0</td>
<td>79.7</td>
<td>75.4</td>
</tr>
</tbody>
</table>

Timeliness of Service (Teenage Transition Clinic)
<table>
<thead>
<tr>
<th></th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average Clinic Size</td>
<td>5.4</td>
<td>5.3</td>
<td>5.9</td>
<td>5.96</td>
</tr>
<tr>
<td>DNA Rate (%)</td>
<td>3.4</td>
<td>6.0</td>
<td>6.8</td>
<td>3.4</td>
</tr>
<tr>
<td>Wait time (mins)</td>
<td>18.5</td>
<td>19.8</td>
<td>13.8</td>
<td>10.4</td>
</tr>
<tr>
<td>Consultation time (mins)</td>
<td>27.6</td>
<td>25.4</td>
<td>23.8</td>
<td>19.4</td>
</tr>
<tr>
<td>% Face to Face Time</td>
<td>76.9</td>
<td>75.9</td>
<td>77.8</td>
<td>79.8</td>
</tr>
</tbody>
</table>
DIETETICS AT GOSH/UCLH

GOSH

The children and young people's (CYP) diabetes service at GOSH has 0.4WTE dietetics provided by Rebecca Margetts. This includes inpatient and outpatient care, participation in weekly Diabetes MDT meetings, ward rounds, service development and delivery of a 2 day structured pump school with the Diabetes CNS.

Rebecca is able to see CYP in a variety of settings. Education is largely provided at ward level as this is when diagnosis is made. She provides support in the Diabetes MDT outpatient setting as well as reviewing patients opportunistically as they attend CF clinic, transplant clinic or daycase procedures. There is also email and telephone support for CYP and their families in between hospital visits.

The role of the dietitian is largely one providing education to CYP and their families, working in a diabetes educator role. The team has started to use the Goals of Diabetes Education, structured education programme for CYP with diabetes. Education is delivered on a 1:1 basis. Group education is often not possible as CYP are not able to mix due to their medical conditions. Each CYP has different education goals as they often have different types of diabetes and different medical backgrounds.

Rebecca is also available to provide education for a range of staff throughout the hospital, which is provided throughout the year.

UCLH

A full time Dietitian was employed for the UCLH Children's and Young Peoples Diabetes team in January 2013. The Dietitian is present at all MDT clinics and has set up two Dietetic clinics each week, with activity in these clinics gradually rising. All patients were invited in writing for an annual Dietetics review and will continue to be offered this annually. Since April 2013, 150 patients have received an individual dietetic review. Referral paths include the annual dietetic review, high HbA1c (>9%), patients newly diagnosed, patients new to the service or patients commencing insulin pump therapy. The Dietitian delivers a session during every pump school on advanced bolus options. The Dietitian has been trained to deliver the CASCADE structured education course alongside the nursing staff, and will begin delivery of CASCADE in February 2014.

Dietetic project and development work includes input to the development of the team website, which involved the development of numerous patient information leaflets and two blog posts for Halloween and Christmas. Carbohydrate counting resources have been developed for the children and adolescent inpatient wards at UCLH, which are due to be launched shortly.

The Dietitian has accessed peer support from the GOSH Children's Diabetes Dietitian, the UCLH Adult Diabetes Dietitian and is part of the London and South East Diabetes Dietitian Network, who hold quarterly meetings. Training attended includes The British Dietetic Association Diabetes Management and Education Paediatric Group Update, The Cambridge Advanced Insulin Pump Course, a Coeliac Disease update and in-house Psychology training.

A specialist Children's Diabetes and Sports Dietitian, Francesca Annan, ran a very successful Diabetes and Sports clinic. More clinics will be arranged for 2014. The UCLH
Dietitian completed the IOC Diploma in Sports Nutrition and hopes to receive specialist training in the area of sports and diabetes management in order to continue the clinics longer term.
PSYCHOLOGY AT GOSH AND UCLH

GOSH

Referrals to psychology are usually made at the weekly diabetes MDT meeting. Any member of the team can refer. Many children already have input from psychology due to their underlying condition and therefore each referral is assessed to determine who is best to see that child – diabetes psychologist, cystic fibrosis psychologist or local psychologist.

At present there is 0.2 WTE psychology through Dr Sharon McElroy offering CBT, systemic therapy, mindfulness and solution focused therapy. Group work is generally not appropriate as the CYP are often unable to mix with patients of the same diagnosis.

Currently we offer patients with diabetes the opportunity to complete a range of questionnaires including PedsQL, diabetes PedsQL, problem areas in diabetes, PI-ED, Strengths and difficulties questionnaire, diabetes family responsibility questionnaire, DEPS-R. The aim is to examine the psychological impact of a second chronic disease and to focus therapy appropriately.

UCLH

The Psychology Team continue to offer an integrated psychosocial service to children, young people and families attending the diabetes clinic.

Referrals to psychology continue to increase year on year with an 30% increase in referrals this year.

Families are seen 3 - 12 times following the initial referral depending on the reason for referral. Individual, family and parental support is available as well as Network meetings which bring together the UCLH Diabetes Team, families and local services including schools.

A specialist neuropsychological assessment service is also offered to young people who may have cognitive difficulties as a result of poor metabolic control. This specialist assessment is discussed with children, young people and families as well as liaising with schools and the education authorities.

Tree of Life is an award winning programme offered to young people aged 9-19 years old. In October 2013 the project was nominated as a finalist by the Quality in Care Programme for the ‘Best initiative supporting a positive patient experience and equality of care in ‘hard to reach’ groups’.

The ‘Tree of Life’ is an innovative day event which invites young people to meet together to build strength and resilience, share knowledge and experiences of living with diabetes. It enables young people to build positive views of themselves, with an identity separate from diabetes thereby enhancing self-esteem and empowering them to feel it is possible to reduce the negative influence of diabetes in and on their lives.

In the last 3 years 39 young people have taken part in 8 groups. One consultant clinical psychologist, one clinical psychologist and two assistant psychologists run the day along with previous participants who join as co-facilitators. Young people shape the project through feedback and have designed a leaflet to promote future days.

Evaluation has been extremely positive. Young people describe the day as having helped them to develop positive views of themselves and feel less isolated by connecting, learning from and sharing knowledge with others living with diabetes.
In 2014 we plan to run two more groups as well as a patient expert programme in order to train patients who have already taken part in the project to co-facilitate future groups.

Number of Diabetes Referrals and Total Psychology Appointments Offered by Year
40% of the play specialist workload is from diabetes. The work includes supporting all children newly diagnosed with diabetes. This involves education plus awareness of the treatment and developing a positive attitude.

This is achieved in young patients through creating a safe environment where play activities are used to help facilitate expression of feelings such as anxiety and confusion. With adolescent patients reflective listening is used with some relaxation techniques or guided imagery to help cope with some aspect of their treatment eg blood tests. Children with additional needs such as autism have been supported during intensification of insulin therapy.

Sibling support continues to be offered both as pre-booked individual or group sessions or during routine clinic appointments. Approximately 12 siblings have been seen over 2013 with referral either from the Diabetes Team or parents. Siblings were also invited to participate in the Expert Pump Day where 100% of them expressed their enjoyment of the session. Advice and support is offered to parents as required in the form of practical advice, referral to other professionals or reflective listening.

Routine clinic visits are frequently used to introduce families to one another to help establish contacts to provide mutual support. Clinic time is also used to measure progress.

Events organised this year included the family outing to Popham Airfield and a Summer Party at a London farm sponsored by the Starlight Children’s Foundation. These were in addition to the Christmas Party where the children were entertained by “Mr Lolly” and a visit from “Santa.”

We have been working closely with Pat Thomson who is providing pouches for pumps which are now available even for pump trials.

It is a privilege to have explored and found effective ways of helping our young patients adapt to their life with Type 1 Diabetes.
AFRICAN GROUP – Jennifer Pichierri

The work involves improving the outcomes for Children and Young People with diabetes treated at UCLH, specifically from African backgrounds. We have identified that children and adolescents from African backgrounds have poorer glycaemic control compared to the white Caucasian population treated at UCLH. (Caucasian mean HbA1c 7.8%; African mean HbA1c 9.4%).

Jen has taken this work further in the last 18 months creating and running an African group. The support group was held within the children’s outpatient clinic in a non-clinical meeting room apart from one cookery session, which was held outside in a local community hall. The support group ran from 10:00 – 13:00 and parents were encouraged to come and go as they pleased. During these exercises in conjunction with the Play Specialists participants were given the opportunity to share the feelings and emotions surrounding their condition (both siblings and patients).

The teaching sessions within the support group covered a range of topics guided by what the participants felt they needed. These were: food; family support; the difficulties of looking after a child with diabetes; basic diabetes anatomy; carbohydrate counting; and managing exercise, illness, and diabetes in school. The parents showed a huge interest in insulin pump therapy and this was something that was discussed on numerous occasions. One of the sessions was held in a local community hall with a small kitchen where a hands-on cooking and carb counting session was held with the paediatric diabetes dietician.

The data from this suggest that there may be an improvement in HbA1c due to the support group intervention. There was a 0.9% decrease in average HbA1c following the intervention, compared to 0.3% increase in those who attended fewer than two sessions.

We think that this intervention is worth continuing and plan to expand the process into other groups as we go through the next 2 years.
DIABETES CARE CHARter

Our Mission Statement, “To develop and deliver a high quality and responsive diabetes service that maximise health and well-being for children, young people and families” captures what we believe we should be striving for.

This year we have translated this broader mission statement into a series of statements that describe what you can expect of us from the time of diagnosis and then through our general care processes. We imagine that these will change with time as we receive feedback.

At Diagnosis we will:

1. Always respect your views on your child and work with you to provide the best care possible
2. Remember that this a stressful time for you and provide extra help when needed to deal with the problems that arise
3. Introduce you to the Diabetes Team and explain the way that we help people manage diabetes.
4. Help you start insulin therapy and understand how insulin works and how to give insulin.
5. Instruct you on how to measure blood glucose using a meter and explain what high and low blood glucose measurements mean.
6. Show you how to deal with high blood glucose values by giving extra insulin
7. Show you how to deal with low blood glucose values by giving carbohydrate or reducing insulin
8. Review your family meals and think about how diabetes will fit in

When you go Home we will:

1. Keep in daily contact for the first 10 days
2. See you on a weekly basis in our clinics until you are confident about diabetes
3. Ensure that there will be Community support for you at home
4. Liaise with nursery/school so that they know how to help you when your child goes back to nursery/school

What Care you should expect in the long term. We will:

1. Encourage and support you to develop into an Expert Diabetes Carer
2. Deliver advice and support in a way that is helpful to you
3. Expect you to work with us in a collaborative way to enhance your skills
4. Use clinic appointments or telephone sessions to develop your skills and help you find solutions to any problems that arise
5. Keep you updated on new developments in diabetes care
6. Make sure that we check for long term problems on a regular basis

RELATIONS WITH FAMILY DOCTORS

We are conscious also that we need to work well with colleagues in primary care. Paediatric Diabetes Care is recognised by all to be best delivered through Paediatric Diabetologists but we recognise the important role that Family Doctors play in providing holistic care.
We hope to improve our interactions with Family Doctors through our web solution. However it is useful to also outline what the UCLH diabetes team is responsible for and what your family doctors/GPs can do.

**Hospital Responsibilities**

We will provide:-

- Quarterly review of diabetes care and goal setting to develop the competence of the patient and family
- Annual review checks for complications of diabetes
- Provide various modes of access for information and advice such as telephone clinics, email and the UCLH Diabetes Portal
- Update you by whatever mode of communication you prefer after every consultation
- Liaise with nursery/school to ensure that staff are trained in managing diabetes in nursery/school
- Provide in-house experienced psychologists who are specifically trained in dealing with the problems children and young people with Type 1 Diabetes can often experience.

**General Health**

From the Family Doctor/GP standpoint we would like you to provide:

- General health care as you would in any child without type 1 Diabetes
- The full range of immunisations and developmental checks
- Prescriptions for the requisite supplies: insulin, needles, ketone strips, needle disposal, Glucogel and Glucagon injections, etc. We will provide this list at diagnosis for you and update as needed.
- Sufficient blood glucose testing strips. With the intensive insulin regimens that we recommend, patients need to test many times per day and the average is 8-10. We find that this achieves a high level of control which is consistent with research findings.

**Emergency Care**

There are several aspects that we welcome help with:

1. Supporting ourselves and the family in ensuring “Ease of Access” with the local Paediatric Team to avoid unnecessary delays in Accident and Emergency.
2. Ensuring that your practice has easy access to our information on Sick Day rules and the Management of Hypoglycaemia. All these are on our Web Portal (see below).
3. That the patient’s condition is flagged on your system, so locum doctors and practice nurses are alerted that the patient has Type 1 Diabetes.
4. Encourage the young person to wear a medic alert. We realise that we cannot enforce this but a bit of additional reinforcement can be helpful.
FINANCE

For all patients under our outpatient care, we receive an annual tariff set by the Department of Health called the Diabetes Best Practice Tariff.

The Best Practice Tariff is awarded on the following criteria:

On diagnosis, a young person with the diagnosis of diabetes is to be discussed with a senior member of paediatric diabetes team within 24 hours of presentation.

All new patients must be seen by a member of the specialist paediatric diabetes team on the next working day.

Each provider unit can provide evidence that each patient has received a structured education programme, tailored to the child or young person’s and their family’s needs, both at the time of initial diagnosis and ongoing updates throughout the child or young person’s attendance at the paediatric diabetes clinic.

Each patient is offered a minimum of four clinic appointments per year with a multi-disciplinary team (MDT), i.e. a paediatric diabetes specialist nurse, dietitian and doctor.

Each patient is offered additional contacts by the diabetes specialist team for check-ups, telephone contacts, school visits, e-mails, trouble shooting, advice, support etc. Eight contacts per year are recommended as a minimum.

Each patient is offered at least one additional appointment per year with a paediatric dietician with training in diabetes (or equivalent appropriate experience).

Each patient is offered a minimum of four haemoglobin HbA1C measurements per year. All results should be available and recorded at each MDT clinic appointment.

All eligible patients should be offered annual screening as recommended by current NICE guidance.

Each patient should have an annual assessment by their MDT as to whether input to their care by a clinical psychology input is needed, and access to psychological support as appropriate.

Each provider must participate in the annual Paediatric National Diabetes Audit.

Each provider must actively participate in the local Paediatric Diabetes Network. A minimum of 60% attendance at regional network meetings needs to be demonstrated.

Each provider unit must provide patients and their families with 24 hour access to expert advice on diabetes management.

Each provider unit must have a clear policy for transition to adult services.

Each unit will have an Operational Policy, which should include within it a structured ‘high HbA1C’ policy, a clearly defined DNA/was not brought policy taking into account local safeguarding children board (LSB) policies and evidence of patient feedback on the service.

Funding for the Insulin Pump Service is not covered by the Tariff and this will continue to be charged separately on the basis of a new start rate of 48 per year. There have been recent changes in commissioning which have led to uncertainty in who currently funds patients requiring full time sensors. We are currently working to resolve this with NHS England.
NORTH CENTRAL LONDON PAEDIATRIC DIABETES HEALTH CARE SYSTEM

The North Central London Paediatric Diabetes Health Care System is a grouping of Commissioners and Paediatric Diabetes practitioners which aims to deliver a value-based diabetes health care system to the current 750 children and young people (CYP) with diabetes in North Central London. The Hospitals involved are Barnet and Chase Farm Hospitals NHS Trust, Great Ormond Street Hospital for Children NHS Foundation Trust, Royal Free Hospital NHS Trust, University College London Hospitals NHS Foundation Trust and Whittington Health NHS Trust.

The delivery of care varies between the participating centres. Only the service at UCLH approaches the benchmark measures of Germany, internationally recognised as providing the best quality of care. Access to intensive insulin regimens such as pump therapy, which provides the best control, is variable across the sector with 64% of patients at UCLH on pump therapy versus 8% at the other sites. All participating trusts cover similar areas of social deprivation and ethnic diversity and attaining a standard of equitable care is a major challenge.

Based on these data the Paediatric Diabetes Clinical Teams we have all got together to deliver a patient centred high value service to all CYP with Diabetes in North Central London.

We plan to do this by:

✓ Creating high performing diabetes teams to deliver the vision individualising care on the basis of personal needs, beliefs and priorities and delivering care in suitable environments.
✓ Ensuring that the needs of the family are met and that we reach those at risk of exclusion, such as children in care or from ethnic minorities. Equitable care for all
✓ Delivering a high value service based on the 6 markers of Quality Care which is cost-effective maximising the quality of healthcare while releasing savings
✓ Use already designed innovative ways to provide services on a 24/7 basis using specialist assessment and treatment protocols, inter-disciplinary teams, outreach and IT systems
✓ Providing services that are age-appropriate and emphasise prevention, earlier diagnosis, better treatment and better coordination.

This is part of a larger drive which we are the lead for through the area that is part of UCL Partners. UCL Partners is an Academic Health Centre charged with improving care for all in North Central and North East London. Our service is the prototype for this service development and we will be working on this throughout 2014.

Currently we have a Steering Group and 4 Working Groups established and are working to create a final Document for consideration by NCL Commissioners.
### Key milestones:

<table>
<thead>
<tr>
<th>Milestone</th>
<th>Expected completion date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agree final business case</td>
<td>June 2014</td>
</tr>
<tr>
<td>Acquire and renovate site</td>
<td>Sept 2014</td>
</tr>
<tr>
<td>Staff team agreed and contractual arrangements in place</td>
<td>Dec 2014</td>
</tr>
<tr>
<td>Supporting functions agreed and in place (including IT)</td>
<td>Dec 2014</td>
</tr>
<tr>
<td>Centre operational</td>
<td>Jan 2015</td>
</tr>
</tbody>
</table>
DIABETES CENTRE

In order to better deliver what we do at UCLH and to deliver services better for children in North Central London we need to organise everything into a single Diabetes Centre. The general thinking and needs are shown below and Catherine Peters and Peter Hindmarsh are looking at siting options.

Concept
- Central umbrella paediatric diabetes centre operating across GOSH and UCLH trusts with option for other trusts to participate by local agreement
- Centre focused on needs of Children and Young People (CYP) and moving away from traditional medical clinic models
- The majority of staff situated in one clinical centre to improve communication and collaboration and for greater working efficiency
- Opportunity for holistic care of CYP with various forms of diabetes eg type 1 and cystic fibrosis related diabetes
- Strong clinical and basic science collaboration

Structural Needs
- Open reception and resource area
- 8 appointment rooms Each 4m x 3m
- Treatment room with lab equipment/stores 4m x 3m
- Educational seminar rooms opening into larger lecture area Each 5m x 5m
- Open plan office to accommodate nursing staff, dietitians, medical staff, psychologists, administrative staff involved in care of CYP with diabetes 6m x 6m

Desirables
- Separate adolescent and child facilities
- Kitchen/coffee bar area with wall mounted ovens and microwave for dietetic sessions

Activities
- Outpatient MDT activity
- Outpatient consultations with nursing staff, dietitians, psychology
- Daily rapid access referral clinic for new and current patients
- Transition clinics
- Pump school
- Diabetes educational programmes for CYP & family
- Seminars for teaching staff
- Seminars for parents & CYP on range of topics
- Staff educational programmes and study days
- Dietetic group work for weight management/celiac disease with potential for cooking/recipe resources
- Opportunities for walk in use of resources
- Reception staff/PA role to be amalgamated so that they are friendly face of clinic, allowing patient-admin staff interaction and full membership of diabetes team
- Use of space for weight management programmes in context of type 2 diabetes
Potential for CYP with co-existing morbidities to mix with other CYP with diabetes who do not pose health risks ie CF CYP in pump school with T1DM. Preventing cross infection between CF patients, but allowing shared learning.
RESEARCH

UCLH Children and Young People’s Diabetes Service have an active research programme ranging from beta cell studies, clinical research studies and large scale motivational behaviour trials.

This year we were very pleased to be involved with the Artificial Pancreas Project in Cambridge with Roman Havorka. Further families went to Cambridge to participate in the studies in 2013 and the results show amazing control overnight with the closed loop algorithm. Several patients have returned this year to complete a short study on how the algorithm copes with missed boluses and also the younger patients participated in study of different dilutions of insulin. Next year we hope to be involved with the at home algorithm.

Measuring Oxidative Stress
In conjunction with Dr Kevin Mills at Institute of Child Health, Professor Hindmarsh has been looking at the development of markers of oxidative stress in urine. Diabetes is associated with high glucose values in the blood and these lead to damage to blood vessels through a process known as oxidative stress. Currently we try to keep blood glucose normal to reduce these problems but we know that problems still occur. As a result we are looking at ways of measuring oxidative stress as this may be another factor, like HbA1c, that we should control. So far we have identified a marker in urine which is a by-product of the body’s metabolism of Vitamin E which is generally higher in those with diabetes. Our research centres on how this might relate to other markers of blood vessel health. This is now moving into field studies with Chloe Bulver currently analysing samples collected during 2013.

We are also identified with Victoria Mainwaring two new urine measures of kidney function which initial studies suggest might be of value. Chloe will be extending her studies in 2013 to evaluate the usefulness of these markers.

Diabetes Care in Different Communities
Delivering care equitably is a hallmark of a Quality Service. We have started to look at this in our clinic population. What we have found is that the background of the person, particularly their ethnicity, is important in how well they do with their diabetes. We showed that deprivation played a small role in this. From this, we have started to look at how we might better address the needs of different ethnicities. More specifically, Rakesh Amin is developing this concept further with projects to assess differences in cardiovascular risk markers between ethnic groups.

CASCADE
This was a structured intensive psycho-educational programme developed at University College London Hospitals Trust, with the randomised control trial complete this year. Results showed a minimal impact overall of the programme. More importantly the study revealed that success of the intervention was highly dependent on the involvement of the whole paediatric diabetes team at the trial sites.

This approach of delivering education has now been integrated into our clinical service with 2 groups run in 2013 and a further 2 planned for the first half of 2014.

To view full details about the project visit www.hta.ac.uk/1669

TRIAL NET
Trial Net is a large multi-national study that is addressing how to diagnose Type 1 Diabetes earlier. It contains several aspects in particular early detection using antibody measurements in siblings of someone affected by Type 1 Diabetes. In addition there are a number of intervention studies aimed at preventing or delaying the onset of symptoms.
Great Ormond Street and University College London Hospitals joined up in 2013 and we hope to have this part of the study functioning by mid 2014.

**UCLID (UCL Investigation of Diabetes)**

In the next 12 months, we will be starting the UCLID Study, which is a very ambitious long-term study with the objective of determining the pathogenesis of diabetes complications. We will aim to collect clinical information, blood and urine during annual reviews and also DNA, and these samples will be stored in a repository called the UCL BioResource. We will also be asking if other family members would provide a blood and urine sample. We will aim to develop new tests that better diagnosis the development of complications than current tests. We are currently seeking funding for research nurses and a study coordinator.

**B-cell death and the development of diabetes**

Dr Rakesh Amin is developing and validating the measurement of serum methylated insulin DNA as a direct marker of B-cell death during the development of diabetes and its complications and will evaluate whether it is a better measure of impending diabetes than current measures. This will link with the UCLID study above and will involve undertaking frequent blood measurements in newly diagnosed children with Type 1 Diabetes. We are currently seeking funding for a PhD fellow to undertake these studies.

**Paediatric HOMA**

A simple measure of insulin resistance called HOMA is often used in large research studies or in a clinic setting to determine future risk of developing Type 2 Diabetes, however this measure was derived from adults. Dr Rakesh Amin is attempting to recalculate HOMA using information from well children in order to provide a more accurate measure of insulin sensitivity in this age group.

**A Cardiovascular Disease (CVD) Prediction Tool for Type 1 Diabetes**

CVD is the major cause of death in people with diabetes. GPs use CVD Risk Scores to predict 10 year risk of heart problems in the general population, but these scores are inaccurate for people with Type 1 Diabetes. We aim to develop a new formula to predict CVD specifically for people with T1D. This formula will be derived from information obtained from primary care databases in the UK and will be made freely available as a web-tool. Dr Rakesh Amin is currently seeking funding in order to undertake this three year project.

**Diabetes as a second chronic condition**

Dr Catherine Peters is using questionnaires to examine the psychological impact of the diagnosis of diabetes as a second long term condition.

**Cystic fibrosis (CF) related diabetes**

Dr Catherine Peters is looking at the use of continuous glucose monitoring as part of this screening process for diabetes in children with CF.

**PREMS and Acute Outcomes**

We are using the National Paediatric Diabetes Audit dataset to examine the relationship between patient experience and acute complications risk. This is being undertaken in conjunction with researchers funded by the Children Policy Research Unit and is being led by Professor Terence Stephenson.

**Tracking of HbA1c and Complications Risk**

We are using the National Paediatric Diabetes Audit dataset to examine the extent to which HbA1c levels track from the first year of diagnosis and whether this associates with complications risk. In adults this is called the metabolic memory and, if present in children, has important implications for the clinical management of newly diagnosed children. This is
being undertaken in conjunction with researchers funded by the Children Policy Research Unit and is being led by Professor Terence Stephenson.
PUBLICATIONS

2009


2010


2011


Thompson, R. Adolescents and pump therapy – Maintaining success CSII therapy. Diabetes Digest 2011 (Suppl); 10 :6-8

Thompson, R. Get going and stay going’ with pump therapy. Educating adolescents about pumps. Paediatrics and Child Health 2011; 21: 431-433

2012


Senniappan S, Hine P, Tang W, Campbell J, Bone M, Sankar V, Robinson M, Smith C, Cooper C, Amin R. The Effect of Socioeconomic Deprivation on Efficacy of Continuous


2013


2014


APPENDIX 1.  UCLH HbA1c MEASURES FROM 1999 to 2013

Left Panel shows the control plot for the clinic from 1999-2013 with HbA1c expressed as mean value. Dashed lines are at 3 sigma

Right Panel shows the standard deviation of the mean plotted over time indicating degree of variation