ANNUAL REPORT 2014

Diabetes Services at Great Ormond Street Hospital for Children and University College London Hospitals
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During 2014 we have continued to integrate the services between Great Ormond Street Hospital for Children and University College London Hospitals. In addition a large amount of work has been put into the creation of an Integrated Practice Unit for Paediatric Diabetes within North Central London. We have undertaken a series of events ranging from the Accelerated Solutions Environment with Cap Gemini, to larger patients soundings and individual work in the Barnet area. What the patients and families have told us is that they an exciting and vibrant place to meet for their diabetes care and that the big thing is that they want to create a Diabetes Community. Work is currently in progress with the Trusts and CCGs involved in NCL.

Welcome to Ashley Freeman and Emily Storr who started with us initially to cover maternity leave but are now firmly part of the team. Later in the year Laura Rose joined the nursing team with a specific focus on Transition to Adult Care. Further strengthening of the team will take place as we go through 2015.

The growth in the Children and Young People’s Diabetes Service continues. The clinic population continues to rapidly expand and the caseload is now at now at 484. During 2014, we have had 61 new referrals, where young people and their families have been looking to either start pump therapy or explore an alternative teams approach to support them in managing their diabetes.

We have continued to work to involve and engage patients and families in their care. This year we ran several Tree of Life sessions for young people ranging in age from 8 to 18 years. These now have young people leading them who are graduates from their own Tree of life session. Laura Bull, Rebecca Thompson and Peter Hindmarsh contributed to the annual Friends for Life Conference for parents and children with diabetes in Windsor.

Our School Pathway for care in schools developed jointly with London Borough of Camden has been adopted as an exemplar for use throughout Greater London.

The website won the best initiative for supporting self-care’ in the Quality in Care Awards in 2014 that Laura Bull and the team received. The site www.uclh.nhs.uk/T1 continues to be added to on a regular basis.

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 fifteenth successive year we have seen improvements in clinic glycosylated haemoglobin (Median 7.7%). 47% 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.

Peer Review took place in February 2014 and we did very well with only concerns over the IT system that needed attention.

Finally, congratulations to Peter Hindmarsh 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 2015. Congratulations also to Russell Viner who is now Clinical Director for Paediatrics with NHS England (London).
HOW WE ARE DOING?

Overview of UCLH Clinic Performance

Median HbA1c 7.7% compared to 8.5% Nationwide

47% of clinic achieving HbA1c less than 7.5% compared to 17% Nationwide.

1. National Quality Control of Glycosylated Haemoglobin Measurement

Over the year 2014 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 0.1% (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>2008</td>
<td>Median 9.0</td>
<td>Median 8.4</td>
<td>Median 10.0</td>
</tr>
<tr>
<td></td>
<td>(median 8.5)</td>
<td>Median 8.1</td>
<td>(median 9.3)</td>
</tr>
<tr>
<td>2009</td>
<td>Median 8.4</td>
<td>Median 8.2</td>
<td>Median 9.4</td>
</tr>
<tr>
<td></td>
<td>Median 8.2</td>
<td>Median 8.0</td>
<td>Median 8.7</td>
</tr>
<tr>
<td>2010</td>
<td>Median 7.8</td>
<td>Median 8.0</td>
<td>Median 8.4</td>
</tr>
<tr>
<td></td>
<td>Median 8.0</td>
<td>Median 7.6</td>
<td>Median 8.4</td>
</tr>
<tr>
<td>2011</td>
<td>Median 7.8%</td>
<td>Median 7.6</td>
<td>Median 8.5</td>
</tr>
<tr>
<td></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 7.7%</td>
<td>Median 8.4%</td>
</tr>
<tr>
<td></td>
<td>Median 7.8%</td>
<td>Median 7.7%</td>
<td>Median 8.4%</td>
</tr>
<tr>
<td>2013</td>
<td>Median 7.8%</td>
<td>Median 7.7%</td>
<td>Median 8.4%</td>
</tr>
<tr>
<td>2014</td>
<td>Median 7.7%</td>
<td>Median 7.5%</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 those 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.
Mode of Insulin Therapy and HbA1C

<table>
<thead>
<tr>
<th></th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>BD</td>
<td>10.9 ± 0.8</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MDI</td>
<td>9.6 ± 0.2</td>
<td>Median</td>
<td>Median</td>
<td>Median</td>
<td>Median</td>
<td>Median</td>
<td>Median</td>
</tr>
<tr>
<td></td>
<td></td>
<td>9.5</td>
<td>8.6</td>
<td>8.4</td>
<td>8.5</td>
<td>8.4</td>
<td>8.3</td>
</tr>
<tr>
<td>CSSI</td>
<td>7.9 ± 0.1</td>
<td>Median</td>
<td>Median</td>
<td>Median</td>
<td>Median</td>
<td>Median</td>
<td>Median</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7.9</td>
<td>7.9</td>
<td>7.6</td>
<td>7.6</td>
<td>7.7</td>
<td>7.6</td>
</tr>
</tbody>
</table>

UCLH now has 341 children and young people using insulin pump therapy. This represents 76% 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 2014

Percentage hitting Target HbA1C (< 7.5%) by Mode of Insulin Therapy at UCLH

<table>
<thead>
<tr>
<th></th>
<th>All</th>
<th>Paediatrics</th>
<th>Adolescent</th>
</tr>
</thead>
<tbody>
<tr>
<td>MDI</td>
<td>31.3</td>
<td>35.0</td>
<td>29.3</td>
</tr>
<tr>
<td>CSII</td>
<td>48.6</td>
<td>57.2</td>
<td>34.3</td>
</tr>
</tbody>
</table>
UCLH HbA1c Measures less than 7.5% and less than 8% 2005-2014

<table>
<thead>
<tr>
<th>Year</th>
<th>&lt;7.5%</th>
<th>&lt; 8%</th>
</tr>
</thead>
<tbody>
<tr>
<td>2005</td>
<td>29.4</td>
<td>37.5</td>
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<tr>
<td>2006</td>
<td>32.5</td>
<td>40.6</td>
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<tr>
<td>2007</td>
<td>33</td>
<td>45.9</td>
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<tr>
<td>2008</td>
<td>34.6</td>
<td>47.4</td>
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<tr>
<td>2009</td>
<td>28.9</td>
<td>41</td>
</tr>
<tr>
<td>2010</td>
<td>35.2</td>
<td>52.6</td>
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<tr>
<td>2011</td>
<td>45</td>
<td>55.4</td>
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<tr>
<td>2012</td>
<td>39.7</td>
<td>59.7</td>
</tr>
<tr>
<td>2013</td>
<td>45</td>
<td>65.4</td>
</tr>
<tr>
<td>2014</td>
<td>47</td>
<td>63</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 the other end of the scale 10.4% (up from 9.9% 2013) of the UCLH clinic had HbA1c greater than 9.5% with 3.2% (down from 4.9% in 2013) in paediatrics and 27.3% (up from 24.7% in 2013) in adolescents. For the UK the overall figure was 26%. We are now implementing an aggressive protocol for this population of increased contact along with integration of CASCADE into routine clinic delivery.

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>47.0</td>
</tr>
<tr>
<td>North Central London</td>
<td>8.3</td>
<td>27.4</td>
</tr>
<tr>
<td>England and Wales</td>
<td>8.5</td>
<td>17.1</td>
</tr>
<tr>
<td>Germany</td>
<td>7.7</td>
<td>33.8</td>
</tr>
</tbody>
</table>

4. 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 2014 there were 18 admissions coded of which 10 were new patients and 8 were already established patients with Type 1 Diabetes. Of the 8 established admissions 4 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.

There was only one admission for severe hypoglycaemia which was for evaluation of cause.
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.

Referrals of babies with neonatal diabetes have increased with five new cases in 2014-15.

The distribution of workload across GOSH specialties is illustrated in the figure below.

Figure: Distribution of patient workload across specialties at GOSH. Data based on 1111 hours of CNS patient contacts between April 14-March 15.
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.

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.

The newest leaflet in our patient education range is for hypoglycaemia:

![Hypoglycaemia in diabetes](image)
Clinical governance
Clinical governance projects have included those in the following figure:

Datix reporting of insulin prescribing and administration errors has increased with over half of the reports generated by the diabetes CNS team. This demonstrates robust checking by the team rather than an increase in true incidents and has served to be useful to highlight areas for improved staff education.

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.

We have seen dramatic improvements in HbA1c in CF patients placed on pump therapy and have demonstrated a useful role for the CSII in a select group of these patients.
WHAT DO YOU THINK OF US?

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.

UCLH (PZ203)

The overall report is provided as Appendix 2
The service scored a mean of 9.64 on the NetProvider score

<table>
<thead>
<tr>
<th>Percentage</th>
<th>PZ203</th>
<th>London</th>
<th>England and Wales</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>0.0%</td>
<td>0.2%</td>
<td>0.3%</td>
</tr>
<tr>
<td>1</td>
<td>0.0%</td>
<td>0.1%</td>
<td>0.2%</td>
</tr>
<tr>
<td>2</td>
<td>0.0%</td>
<td>0.1%</td>
<td>0.3%</td>
</tr>
<tr>
<td>3</td>
<td>0.0%</td>
<td>0.6%</td>
<td>0.5%</td>
</tr>
<tr>
<td>4</td>
<td>0.0%</td>
<td>0.5%</td>
<td>0.7%</td>
</tr>
<tr>
<td>5</td>
<td>0.5%</td>
<td>2.5%</td>
<td>2.5%</td>
</tr>
<tr>
<td>6</td>
<td>0.5%</td>
<td>1.8%</td>
<td>2.0%</td>
</tr>
<tr>
<td>7</td>
<td>2.3%</td>
<td>4.4%</td>
<td>5.1%</td>
</tr>
<tr>
<td>8</td>
<td>5.1%</td>
<td>12.6%</td>
<td>12.6%</td>
</tr>
<tr>
<td>9</td>
<td>13.8%</td>
<td>18.5%</td>
<td>17.9%</td>
</tr>
<tr>
<td>10</td>
<td>76.0%</td>
<td>55.6%</td>
<td>55.8%</td>
</tr>
<tr>
<td>Invalid/no response</td>
<td>1.8%</td>
<td>3.0%</td>
<td>2.0%</td>
</tr>
</tbody>
</table>

| Mean | 9.64 | 9.09 | 9.04 |

A score of 9 or 10 (green) indicates a high level of satisfaction.
A score of 5-8 (amber) indicates a medium level of satisfaction that requires attention.
A score of <5 (red) indicates a poor level of satisfaction and is cause for concern.

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 us 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
It's well sick innit! It's bangin'!
Forward thinking!
I don't leave crying from clinic (my other hospital always made me cry).
Compared to care I had locally this has been really good.
I have been given good service.
It has been a good service that I have been given.
Friendly, knowledgeable and accessible.
HbA1c has gone down significantly since we moved to this clinic.
Standard of service and support excellent.

GOSH (PZ196)

The overall report is provided as Appendix 3
The service scored a mean of 9.6 on the NetProvider score

<table>
<thead>
<tr>
<th>Percentage</th>
<th>PZ196</th>
<th>London</th>
<th>England and Wales</th>
</tr>
</thead>
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<td>0.0%</td>
<td>0.2%</td>
<td>0.3%</td>
</tr>
<tr>
<td>1</td>
<td>0.0%</td>
<td>0.1%</td>
<td>0.2%</td>
</tr>
<tr>
<td>2</td>
<td>0.0%</td>
<td>0.1%</td>
<td>0.3%</td>
</tr>
<tr>
<td>3</td>
<td>0.0%</td>
<td>0.5%</td>
<td>0.5%</td>
</tr>
<tr>
<td>4</td>
<td>0.0%</td>
<td>0.5%</td>
<td>0.7%</td>
</tr>
<tr>
<td>5</td>
<td>0.0%</td>
<td>2.5%</td>
<td>2.6%</td>
</tr>
<tr>
<td>6</td>
<td>0.0%</td>
<td>1.8%</td>
<td>2.0%</td>
</tr>
<tr>
<td>7</td>
<td>0.0%</td>
<td>4.4%</td>
<td>5.1%</td>
</tr>
<tr>
<td>8</td>
<td>20.0%</td>
<td>12.6%</td>
<td>12.6%</td>
</tr>
<tr>
<td>9</td>
<td>0.0%</td>
<td>18.5%</td>
<td>17.9%</td>
</tr>
<tr>
<td>10</td>
<td>80.0%</td>
<td>55.6%</td>
<td>55.8%</td>
</tr>
<tr>
<td>Invalid/no response</td>
<td>0.0%</td>
<td>3.0%</td>
<td>2.0%</td>
</tr>
</tbody>
</table>

| Mean       | 9.60  | 9.09  | 9.04              |

A score of 9 or 10 (green) indicates a high level of satisfaction.
A score of 5-8 (amber) indicates a medium level of satisfaction that requires attention.
A score of <5 (red) indicates a poor level of satisfaction and is cause for concern.

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

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.
In February 2014 we underwent the Peer Review process with a visit by assessors from 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.

As in 2012 we were reviewed as a single service between Great Ormond Street Hospital and University College Hospital.

The final report is still awaited on the DQUINS site as publication was deferred until the process was completed for England and Wales. It is unclear at this stage whether this large exercise will be repeated on a yearly basis and it is more likely that this will be a 5 yearly cycle.

The draft review was highly complimentary to the services on the two sites. We had one adverse comment on the IT that we use. This will be addressed with our move to the InfloFlex system and redesign within the Electronic Health Record Systems that will be put out to Tender in 2015 at both sites.
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

UCLH continues to offer a dedicated training programme for school and nursery staff, with a 3 hour programme designed around the impact of diabetes in school. During the last school year, 140 people have attended this training. Attendees continue to evaluate the workshop incredibly well and due to requests, the team have increased the frequency of the programme, offering it twice a year.

The next training dates are as follows:

9th September 2015 (children on injections)
To book a place go to: https://diabetes-injections-uclh.eventbrite.co.uk

10th September 2015 (children on insulin pumps)
To book a place go to: https://diabetes-pump-uclh.eventbrite.co.uk

7th January 2016 (children on insulin pumps)
12th September 2016 (children on insulin pumps)

School Management plans are in the process of being revised based upon comments from parents and will be able to be downloaded from the website

Freya Brown has led on developing our guidance on exams for young people with diabetes. This document has been reviewed by users of our service and the final version is now available on the webpage.
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.

The web site was nominated for the 2014 QIC Awards and won its category for the best initiative for supporting self-care

Well done to Laura Bull, Rebecca Thompson and the communications department.
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.

**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.
4. 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
Freya Brown
Kirsty Dring
Ashley Freeman
Jennifer Pichierri
Louise Potts
Laura Rose (Lead for Transition)
Emily Storr

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 Casdagili
Dr Hannah Duncan
Dr Sharon McElroy (GOSH)

Diabetes Administrator
Janet Taylor (user issues contact)

Leads for Information Transfer and Technology
Dr Billy White

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
Sue …….(UCLH)

Clinical Psychiatry
Simon Lewis (UCLH)

Social Worker
Gill Hardman (UCLH)

Ophthalmology at UCLH (Accredited Diabetes Retinal Service)
Mr Martin Harris

Nephrology
Dr Stephen Marks (GOSH)
Professor Robert Unwin (Royal Free Hospital)

Gastroenterology
Dr Sara McCartney (UCLH)
Dr Keith Lindley (GOSH)
Neuropathy (Autonomic)
Professor Chris Mathias (National Hospital)

Exercise and Diabetes Consultant
Francesca Annan (Alder Hey Hospital, Liverpool)

Link Nurses
Laura Taylor (UCLH Ward T11)
Hannah Gordon (GOSH Rainforest)

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 – 2014 saw an increase in nursing time to 6 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 dietitian – 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 2014 so that the total number in the service is 484. There were 61 new referrals during 2014 and virtually all stayed within the service. From looking at our past few months of activity, we project that the number of new patients over the whole of 15/16 will be 72.

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>
<tr>
<td>2014</td>
<td>484</td>
</tr>
</tbody>
</table>

76% of the clinic population are on Insulin Pump therapy with the remainder on Multiple Daily Injection regimens and several 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 2014

<table>
<thead>
<tr>
<th>AM</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
</tr>
</thead>
<tbody>
<tr>
<td></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</td>
</tr>
<tr>
<td></td>
<td>Adolescent Diabetes clinic (3 a month)</td>
<td></td>
<td></td>
<td>Psychology and monthly Network Meetings</td>
<td>Clinic (monthly)</td>
</tr>
<tr>
<td></td>
<td>Pump School (2 a month)</td>
<td></td>
<td></td>
<td>Sensor training clinic (monthly)</td>
<td></td>
</tr>
<tr>
<td>PM</td>
<td>Nurse consultant clinic (weekly)</td>
<td>Adolescent Clinics (weekly)</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)</td>
<td>Dietetic Clinic (weekly)</td>
<td>Adolescent clinic (fortnightly)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Psychology</td>
<td></td>
<td>Dietetic Clinic (weekly)</td>
<td></td>
</tr>
</tbody>
</table>

Note psychology also conduct sessions throughout the week for CYP with Diabetes

Timely service delivery is important and the Table below 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>2011</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average Clinic Size</td>
<td>7.1</td>
<td>6.8</td>
<td>6.7</td>
<td>6.9</td>
</tr>
<tr>
<td>DNA Rate (%)</td>
<td>4.8</td>
<td>4.7</td>
<td>5.4</td>
<td>4.3</td>
</tr>
<tr>
<td>Wait time (mins)</td>
<td>12.8</td>
<td>12.4</td>
<td>12.5</td>
<td>11.7</td>
</tr>
<tr>
<td>Consultation time (mins)</td>
<td>25.6</td>
<td>25.5</td>
<td>24.9</td>
<td>24.5</td>
</tr>
<tr>
<td>% Face to Face Time</td>
<td>82.0</td>
<td>79.7</td>
<td>75.4</td>
<td>76.9</td>
</tr>
</tbody>
</table>
### Timeliness of Service (Teenage Transition Clinic)

<table>
<thead>
<tr>
<th></th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Average Clinic Size</strong></td>
<td>5.3</td>
<td>5.9</td>
<td>5.96</td>
<td>5.21</td>
</tr>
<tr>
<td><strong>DNA Rate (%)</strong></td>
<td>6.0</td>
<td>6.8</td>
<td>3.4</td>
<td>5.3</td>
</tr>
<tr>
<td><strong>Wait time (mins)</strong></td>
<td>19.8</td>
<td>13.8</td>
<td>10.4</td>
<td>11.6</td>
</tr>
<tr>
<td><strong>Consultation time (mins)</strong></td>
<td>25.4</td>
<td>23.8</td>
<td>19.4</td>
<td>24.4</td>
</tr>
<tr>
<td><strong>% Face to Face Time</strong></td>
<td>75.9</td>
<td>77.8</td>
<td>79.8</td>
<td>70.3</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 runs two Dietetic clinics each week, activity within these clinics has continued to grow and is reaching capacity. All patients continue to be offered an annual Dietetic review. The Dietitian has conducted 253 individual reviews with patients over the last year.

Referral paths include the annual dietetic review, high HbA1c (>9%) and admissions to the ward for a four-stage plan, 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.

Two further specialist sports and exercise clinics, run by Specialist Dietitian, Francesca Annan have been organised over the last year. 12 patients have therefore received individual sports and nutritional advice and feedback from these sessions has been very positive. Further sessions have been planned and the UCLH Dietitian continues to develop skills in this area. The UCLH Dietitian has also completed the Teaching Skill’s for Healthcare Professionals module and attended the National Children’s Diabetes Dietitian study day for peer support.

Other development work includes the development of further patient resources as part of our team website and the use of combined multidisciplinary clinic letters.
Carbohydrate counting and nutrition training continues to be provided to ward staff and students and the ward carbohydrate counting resources have been updated with the change in menus.

100 parents and young people completed a user questionnaire to establish what parents and young people want from the Dietitian and to plan future development work. General themes that emerged were that parents prefer contact with the Dietitian during the MDT clinics, by email, by telephone and on the website more than arranging a separate Dietetic clinic appointment. Particular areas of interest where further support is required is managing exercise, advanced bolus options and helping younger children start to gain independence with carbohydrate counting. There was some interest in running educational activities for children and young people during clinics on topics relating to them, although this was not unanimous. Future plans for the coming year are therefore to update advanced bolus and fat and protein counting resources, continue to run sports clinics, organise sports and exercise practical activity sessions and develop some clinic education sessions.

The UCLH Dietitian has also been invited to speak at the Friends for Life Children with Diabetes Conference and teach on the Advanced Diabetes Educator Masters course on the Food, Nutrition and Health Module.
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 Fionna Bathgate 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 Pedsqol, diabetes Pedsqol, 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
NORTH CENTRAL LONDON PAEDIATRIC DIABETES

The North Central London Paediatric Diabetes Health 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 Great Ormond Street Hospital for Children NHS Foundation Trust, Royal Free Hospital NHS Foundation 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:

Defining our Vision

To develop and deliver a high quality Paediatric Diabetes service that maximises the health and well-being of children and young people and their families

Defining our Values

Inspirational
Pioneering
United

With Business Consultants Shirlaws we have identified agreed areas to work on:

- 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.
Appendix 4 outlines the Business Case for the Integrated Practice Unit which will deliver this development and provides in detail new models of care where we have placed the patient at the centre of all activity.
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 have completed the next phase in the Artificial Pancreas Project in Cambridge with Roman Havorka. Further families enrolled in the Home use of the algorithm with the closed loop functioning for 3 months overnight. Next year we hope to be involved with the at home algorithm that is being developed to work with the new Medtronic 640g pump.

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 has looked at how this marker changes with short term changes in blood glucose and we have also identified two further markers Megalin and Cubulin that seem to be early markers of renal tubule malfunction.

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.

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 2015.

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 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.

**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. In conjunction with a Company she is also about to start the evaluation of home oral glucose tolerance testing for patients 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


2013


2014


APPENDIX 1.  UCLH HbA1c MEASURES FROM 1999 to 2014

Left Panel shows the control plot for the clinic from 1999-2014 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