This report has been sent to all members of the Children and Young People's East Midlands Diabetes Network, all Chief Executives of member trusts, the National Clinical Lead for Paediatric Diabetes, NHS England, CCG's, Strategic Clinical Network for East Midlands.

Creation Date: September 2017
Renewal Date: August 2018
Figure 1: Map of the East Midlands

<table>
<thead>
<tr>
<th>Trust</th>
<th>Lead Clinician</th>
<th>Lead Nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chesterfield Royal Hospital NHS Foundation Trust</td>
<td>Dr Kiran Kumar</td>
<td>Gemma Bills</td>
</tr>
<tr>
<td>Derby Hospitals NHS Foundation Trust</td>
<td>Dr Dita Aswani</td>
<td>Nicki Sutton</td>
</tr>
<tr>
<td>Kettering General Hospital NHS Foundation Trust</td>
<td>Dr Gomathi Margabanthu and Dr Katie Govier</td>
<td>Karen Luck</td>
</tr>
<tr>
<td>Northampton General Hospital NHS Trust</td>
<td>Dr Anne Smith</td>
<td>Elizabeth Haase</td>
</tr>
<tr>
<td>Nottingham University Hospitals NHS Trust</td>
<td>Dr Louise Denvir</td>
<td>Vreni Verhoeven</td>
</tr>
<tr>
<td>Sherwood Forest Hospitals NHS Foundation Trust</td>
<td>Dr Ursula Ngwu</td>
<td>Helen Marsh</td>
</tr>
<tr>
<td>United Lincolnshire Hospitals NHS Trust (Lincoln Site)</td>
<td>Dr Dougie Thomas</td>
<td>Helen Warhurst</td>
</tr>
<tr>
<td>United Lincolnshire Hospitals NHS Trust (Grantham Site)</td>
<td>Dr Dougie Thomas</td>
<td>Helen Warhurst</td>
</tr>
<tr>
<td>United Lincolnshire Hospitals NHS Trust (Boston Site)</td>
<td>Dr Dougie Thomas</td>
<td>Helen Warhurst</td>
</tr>
<tr>
<td>University Hospitals of Leicester NHS Trust</td>
<td>Dr James Greening</td>
<td>Dawn Kitchener</td>
</tr>
</tbody>
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Introduction:
I am extremely delighted to present the Annual Report of the Children and Young People’s East Midlands Diabetes Network for 2016-17 which reflects the excellent work we have achieved as a network team.

The NPDA data for 2015 – 16 has grown from strength to strength in all outcomes of diabetes care. East Midlands fares well above the national averages for children with diabetes with tighter control, median HBA1c and all the 7 key care processes. The number of children with HBA1c less than 58mmol/l is much higher and children with poor control is significantly less which is a true testimony to the hard work by the teams across the region over the year.

BPT continues to make excellent progress with all the trusts in the regions to optimise teams with required personnel and expertise in providing the outcomes to a high calibre.

We have recognised the need to keep the momentum going with our diabetes control and hence QI projects have been envisaged. Quality improvement projects have been taken by all the units. The projects have been itemised within the network and are to be shared with network meetings and published on the website.

Information and communication is key in this information world. Our Network websites are constantly updated with all new events and materials on recent events, workshops, presentations and proves to be an excellent channel of continued communication through the network teams. Marie keeps the website continuously active with timely updates and has greatly championed the use social media for our patient groups. Twitter accounts continue to operate with posts updating events.

Parent groups are represented in every network meeting. They feedback on the success of group events that they have organised and keep the network informed of the issues raised at these meetings. User feedback has proven to be very valuable with our patient experiences. Three parent / carers events have been conducted well with excellent feedback; thanks to Marie who keeps the engine on drive mode. Parent representatives are geographically widespread to help understand the varied user views across the region.

The DEAPP phase of work has been almost completed and successfully piloted within the region. Structured education for all newly diagnosed patients has now reached a new level of learning which is one of its kind in the country. This will help iron out differences and provide a peer reviewed structured quality education for all our children and young people with diabetes.

Education and research has continued to progress and is a continued agenda item to keep the network teams fully informed of recent research progression and participation of individual units in rotation to share best experiences. CGM workshop was a huge success and a few more has been planned in the region to cater to the demand.

The network has done some work with transition across the Midlands as a whole. The young adolescents have been involved to get the user feedback to help understand the gaps in our transition service and address their needs. The data capture should be completed by the end of the year. Transition Booklet has been completed to help understand the transition services across the region.
Diabetes Registry has been taken up within the region and has kicked off to start with data collection.

We continue to work alongside national network goals contributing to the national strategy for paediatric diabetes. We continue in our efforts to engage with commissioners and service managers and circulate the agendas and minutes of network meetings.

We do have challenges in continuing to tighten our control of diabetes across the region with better HBA1c outcomes and all 7 key care processes. The other challenge is around recruiting children and young people themselves to get involved in remodelling transition services, and representing the views of their peers.

East Midlands regional teams are very proud of our achievements around diabetes care and outcomes ahead of the national standards for diabetes. We aim to target new and innovative ideas around Quality improvement frameworks to help constantly improve our outcomes with diabetes care, patient experiences and happy involved teams.

Dr. Gomathi Margabanthu
Consultant Paediatrician Diabetes, KGH
Chair for the Children and Young People East Midlands Diabetes Network
Background:
The CYPEMDN was established in 2009. In 2011 a network coordinator was appointed, funded by NHS Diabetes, and the network became more formalised and membership extended, and since September 2013 a new permanent network manager has been in post.

The East Midlands network meets 4 times a year, three times as the East Midlands Network and once a year the East and West Midlands join together for a meeting to share practices across the Midlands region. There has always been good attendance from units across the region at meetings and attendance continues to increase yearly with each meeting now attracting about 60 participants.

Membership
The membership of the network members is made up of representation from each trust as well as the lead people as below:

<table>
<thead>
<tr>
<th>Role</th>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chair</td>
<td>Dr Gomathi Margabanthu</td>
</tr>
<tr>
<td>Vice Chair</td>
<td>Dr Dita Aswani</td>
</tr>
<tr>
<td>Network Manager</td>
<td>Marie Atkins</td>
</tr>
<tr>
<td>Data Quality Manager</td>
<td>Nicky Virk</td>
</tr>
<tr>
<td>Lead PDSN of network</td>
<td>Vreni Verhoeven</td>
</tr>
<tr>
<td>Consultant diabetologist from adult services</td>
<td>Dr Mary Quinn</td>
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<tr>
<td>Strategic Clinical Commissioning and Senate for East Midlands</td>
<td>Sharon Verne</td>
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<tr>
<td>Lead Dietitian</td>
<td>Jen Calvert</td>
</tr>
<tr>
<td>Lead Psychologist</td>
<td>Dr Emily Bell</td>
</tr>
<tr>
<td>Parent and carer representatives</td>
<td>Kate Cullen, Rachael Cummings, Angela Stacey</td>
</tr>
<tr>
<td>Voluntary sector members</td>
<td>Peter Shorrick (Diabetes UK), Abi Clarke (JDRF)</td>
</tr>
</tbody>
</table>

Wider representation
Others with an interest in paediatric diabetes are also members of the network. This includes parents and carers, industry representatives and people from the voluntary sector.

Parental involvement and patient satisfaction
We have three parent representatives for the network. The parent representatives are volunteers and have their expenses paid to attend regional and national meetings by the network. The parent representatives attend the regional and national network meetings on a regular basis. They have a slot on the regional network meetings for them to discuss any issues that have been raised.

The parent representatives for the East Midlands Network, set up an East Midlands Paediatric Diabetes Parents Facebook page, which continues to steadily grow in numbers, currently having 239 members from across the whole region. We ask all trusts to inform their parents and carers about this group. Each team have been sent flyers to promote it and we have also asked the network to include this group in their newly diagnosed information booklets as and when they are updating them. This group is aimed for parents/carers of children with Diabetes to help with networking across the East Midlands and also to help raise any concerns from the various parents/carers across the region. These views are collated by the parent representatives and they raise them with the Chair and Network
Manager. The parent representatives will also feedback from the regional and national meetings to all the parents/carers in the region. The parent representatives who attend the meetings are members of well-established local groups and through these groups feedback to other parents and seek their views on aspects of the network’s work. All the parents are also members of the Families with Diabetes National Network.

We continue to use Skype to support the parent representatives. Calls take place before the quarterly meetings and allow parents to feed into the agenda and obtain the views of other parents across the region via social media. There is also a follow up call after the meeting to go through any issues arising from the network meeting.

We have a twitter account for the Midlands Diabetes Network, for both East and West and we are increasing our followers on a regular basis. Whilst we understand that everybody is not on social media this is the easiest method to communicate with vast numbers of parents and carers across a big geographical area. Ideas continue to be discussed about how we can engage parents and carers that do not use social media.

We have successfully run four parents/carers and family days across the East Midlands since April 2015. The latest one was in Northampton in October 2016. There is another planned for June 2017 in Leicester and we aim to run a joint East and West Midlands Family day in conjunction with JDRF in October 2017. We plan to involve JDRF in one event annually.

The family days have been well attended; with on average 20 families attending on each occasion. The day is centred around the children doing organised activities, such as bug hunting, pond dipping, learning about mummification, archaeological digging etc, whilst the parents have sessions on their areas of interest.

We run the days around the needs of the parents, we ask them for ideas on what sessions they would like to learn about and then we locate speakers on the relevant subjects. We have been very successful in the rotation of the meetings across the region, this is to try and ensure that people from all areas across the network are able to attend these events if they wish. It is encouraging to see that some families that are attending each meeting, which we take as a sign of success on the benefit and relevance that these meetings have. It is a great way for parents and carers and children to learn from each other and have peer support. We continue to have our children's panel in the meeting, which is a very informal session, and if the children are willing, are asked questions in regards to diabetes, sometimes with unusual and funny responses. We try to listen to what they say and ask them what they would like to do at future meetings in order to incorporate these ideas into the meetings.

This is all in addition to the work that individual units do to understand the needs of those who attend their service. All Trusts have been encouraged to increase their patient and parent involvement and many run successful parents’ groups. This has been further supported by the network as information on initiatives such as PREMS linked to the NPDA has been presented and promoted at the network.

**Communication**

Because of the size of the region the main communication methods are not face to face apart from at meetings and sub-group (task and finish) meetings. Good use of phone calls, emails and Skype is made for sharing information and answering specific questions. Each month, a newsletter is sent to all members of the network plus other interested parties.
There is also the national network website which was established in March 2015. It contains national information about guidelines, news, events, education both for HCPs and for families. There are also pages within each network home page, which contain all the documents/meetings/resources etc. that are specific to that region. Other documents/resources/information that are not network specific can be accessed 24/7.

**Who is involved?**

**Chair**
Dr Gomathi Margabanthu is the Chair of the network she works with the network manager to set the agenda for each meeting and then to chair the network meeting itself and follow up relevant actions from it. She works to the job description shown in Appendix 1 and has a key role in providing clinical authority to the meeting and supporting the network manager. The network manager reports to the Chair.

**Vice Chair**
Dr Dita Aswani is the Vice Chair and her role is to help in the development of the network. The vice chair will deputise for the chair as necessary and is active in network projects.

**Network Manager**
The network manager is Marie Atkins. She carries out the majority of the day to day work of the network. Alongside the chair she sets the agenda and meeting dates. She also coordinates the meetings and chairs the work of the task and finish groups that come from the agreed work programme. She also fulfils the secretarial role of the network including booking venues and ensuring attendance, sharing agendas and writing and sharing the minutes. This role is a joint network manager role with the West Midlands network.

The network manager acts as the central point of communication for all network related information. This includes answering specific queries, especially from team members and also being the point of contact for industry, voluntary sector and parents and carers. Finally, they are responsible for creating many of the key documents for the network such as locally agreed service specifications and also draft policies and other documents that teams can then adapt and use locally.

**Data Quality Manager**
We welcomed Nicky Virk into the network as the new Data Quality Manager in June 2016; Nicky’s role is to support the East Midlands registry project.

**Past and present funding**
At present, the Network funds the manager’s role, the data quality role as well as the costs for the network meetings, when we are unable to achieve industry support, and parents’ meetings. Costs are shared equally by all trusts within the network and an annual subscription pays for its continuation. This has been reflected in the wording of the tariff standards. The details of the MOU and payment required from each Trust are shown in Appendix 2. The network has been clear with members that they must pay this Trust subscription to attend the network and that without it they will be unable to attend and thus will be unable to claim tariff payments. This top sliced money not only secures the role of the network manager and data quality manager but will also allow other streams of funding for network activities. East and West Midlands have come together to appoint one person to cover both networks. The two networks already work closely together with joint meetings.
and close collaboration between the chairs. The post is hosted by Birmingham Children’s Hospital.

Regional and National links
Nationally, the CYPNCos meet together several times a year to share progress, receive updates and learn from one another. Additionally, every six months the chairs, managers and parent representatives of each network come together nationally to hear about national changes related to diabetes, including updates on structured education, best practice tariff and transition updates.

The West and East Midlands regional networks meet annually with a joint education meeting.

The work of the network
Improving outcomes of care
The focus of all the work of the network is to improve the quality of care for children and young people with diabetes. This has been achieved in many ways including:

- Ensuring that all Trusts are working to ISPAD/BSPED/ACDC policies and guidelines.
- Ensuring Trusts are updated on new cutting edge practice including research and technology.
- Supporting units to share their good practice.
- Supporting units and clinicians to share concerns about challenging cases.
- Bringing in nationally recognised speakers for network meetings.
- Updating on national research and advances in knowledge.
- Ensuring investment in Trusts through the achievement of Best Practice Tariff.

Achievements so far
All Trusts are fully aware of the requirements of Best Practice Tariff (BPT) for paediatric diabetes and the standards within it. Each trust in the East Midlands is now achieving all of the BPT standards and all are now in receipt of the money. This is a great achievement. Going forwards all trusts are offered support from the network in relation to BPT if needed.

Transitional care
The network has had transition as an area of focus over the last few years. Nationally there has been a lot of work occurring in this area. We launched a service user questionnaire with the West Midlands in December 2016 and this will until October 2017. The results of this will be discussed at the joint East and West Midlands meeting in December 2017. These outcomes will then focus the project over the next 2-3 years worth of work. We are also in the process of developing the transition booklet that the West Midlands Network have written which outlines each hospital’s transitional arrangements, and offered services. Eventually the aim is for this booklet to be incorporated into a national document covering all regions.

24 hour care
The topic of providing 24 hour care has been an agenda item at several network meetings over the years. Assurance has been sought from each unit that they are able to provide support for their patients at any time. Within the network some Trusts have come together to share on-call arrangements, and the tertiary consultants at Nottingham and Leicester staff a rota to provide ‘expert advice’ (as defined in BPT criteria) for all hospitals in the East Midlands Network area.
Technology, Data and Information
The use of technology has been a key part of the way of working for the network. As it is mainly a virtual network, members have to rely on communication via technology rather than just face to face meetings. Effective use of email, webinars and teleconferencing has made the work of the network possible. The Children and Young People’s with Diabetes National Network website continues to be a massive achievement for the national network and hosts a wealth of resources and information for healthcare professionals and parents/carers.

Data and Information
Data and information has been used effectively by the network on many levels. Discussion of the NPDA outputs (and their validity) is now a standard item on our meetings and once a year a whole meeting is dedicated to this discussion.

<table>
<thead>
<tr>
<th>CYPEMDN Network Median % achieving Care Processes</th>
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<tbody>
<tr>
<td><img src="image" alt="Graph showing Median % achieving Care Processes" /></td>
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</tbody>
</table>

CYPEMDN network has out done the previous years achievements in achieving all the 7 key care processes. There has been an increase from 40.6% from the previous year to 49.9% well ahead of the national average of 35.5% with particular increase with foot examination, thyroid screening and albuminuria screening. Total cases reported were 1712 compared to 1770 the previous year.

Mean adjusted A1C has decreased from 68.6mmol/mol from the previous year to 65.8mmol/mol comparable to a national average of 68.3mmol/mol, reflecting good standards of care within the region.

Diabetes control with HbA1c outcomes has again outdone the previous year targets for A1C less than 58mmol/mol from 24.6% to 32.3% comparable to national average of 26.6%. Interestingly the overall numbers with poor control has also decreased from 16.1% to 14.6% comparable to a national average of 17.9%. This is reflective of the MDT hard work and effort over the last year.
Data collection and Database systems and NPDA Submission

Ensuring that MDTs are supported to collect relevant patient data has been a key piece of work for the network. All Trusts have been successful at submission of the NPDA since 2011. We also welcomed Nicky Virk the new Data Quality Manager who is available to help units with any data issues they are experiencing. Nationally the network coordinators meet with the RCPCH twice a year to ensure that future submissions for both the NPDA and PREMs are of a high standard and we work together to support any units that are struggling in the region with submission.

Audit analysis

Audits have been initiated locally. We as a network encourage units to conduct local audits and present these at future network meetings.

Education and Research

Education and research forms part of the agenda for each Network meeting (e.g. four days per year). There has been an education schedule in place where each trust takes it in turns to be in charge of providing the education. The network manager helps with the logistics of the meeting, but it is up to the individual trust to source topics and speakers to deliver this session. This has been in place since September 2014 and has been working very well, with varied topics for each meeting. The focus of the joint East and West meeting each year in December is education and this is delivered usually over a three hour period.

Research is on every agenda for the network and an update is given on any trials or research studies that are currently being undertaken.

The network aims to provide opportunities for all members of the MDT to be updated locally on best practice and cutting edge research and also for people to share their own good work. Other courses and education events, including those run by academic institutions and industry, have been advertised and promoted through the network both via the meetings and also the monthly newsletter. There is also a whole section on the national website that is dedicated to education for healthcare professionals.
The Regional register
In April 2014 the network signed up to a regional register in conjunction with Newcastle University. This regional register will be linked to the already established Northern registers. We have experienced significant delays with the regional register however this was reported last year and was out of our control as it was due to ethics and the research application needed to be amended. We appointed the new Data Quality Manager in June 2016 and the main aim for her is to engage with units and the registry to facilitate this project.

Service development

Work programme
The work programme has provided a focus for the network and is used for two main purposes:
- To inform and shape the agendas for the network meetings.
- To prioritise the work through task and finish groups.

What has been achieved?
The main achievement for the East Midlands Network has been that we were successful in our bid with The Health Foundation on our newly diagnosed App for patients and families. This has been much of the work of the network for the last 18 months and is a massive achievement for the East Midlands. We have designed an app that families can use in newly diagnosed patients, it is based on the concept of flipped learning where the learner (newly diagnosed patient or parent) learns about their diagnosis and diabetes self management independently using resources on an ipad, and subsequently HCPs test the knowledge acquired by the patient/family. This method has been found to better consolidate learning for the long term.

There are five pilot sites across the East Midlands using this app until December 2017. We will then evaluate the results, and if successful, will be able to roll it out to the rest of the East Midlands network as well as nationally. We have already had interest from other networks about this project and hope to present the results at the national meeting in December 2017.

There has been a strong working group of members from the five pilot sites of Chesterfield, Derby, Nottingham, Leicester and Sherwood Forest. This group of people have worked tirelessly along with De Montfort University who we have commissioned to design the app with us.

Since the last annual report the network continue to achieve a lot. We undertook another around of self assessment during 2016; the reports were published however it is fair to say the detail in the reports was not of a high enough standard to be able to use as effectively as any of the units or the network wished to. There are currently plans to redesign the peer review system and comments will be asked for nationally as plans develop. The network continues to support all of the units with peer review and any issues that they experience.

We have successfully run another 2 parents/carers and family days across the region and our numbers continue to grow in the attendance of these events. We are currently working with JDRF to run a Midlands wide event that will be run once a year in conjunction with JDRF. This is scheduled to run in autumn 2017.
Plans for the future and future developments
Our main focus for the next year as a network is to continue with our newly diagnosed DEAPP project. We are running the pilot until December 2017 and then will be rolling it out to the rest of the East Midlands Network and nationally.

We continue to streamline processes, by the effective use of Task and Finish groups producing good outputs. These groups are chaired by the Network manager and will be made up of a small number of volunteers including parent and carer representatives. Using the support of the network manager, outputs and outcomes will be achievable without the need for a huge input of clinical time. The use of technology such as sharing draft documents by email and also teleconference facilities to discuss issues, will allow the work to move forward apace whilst still ensuring full engagement from clinicians.

We continue to have transition as one of our main areas to improve services across the region as well as aligning ourselves with the work that has already been done nationally. As discussed earlier in this report we are in the process of running a patient satisfaction survey and these results are due to be discussed at the December joint East and West Midlands Meeting. Subject to these results and findings, this will focus the work on transition across the region for the next few years.

The key role for the network over the coming years is to ensure the work programme is completed and most importantly ensure that the network continues to engage clinicians and through them continues to drive the standards of paediatric diabetes care. The key priorities for the network are listed above but also include:

- Formalising the structure and governance of the network.
- Developing work streams informed by the national network.
- Formal feedback and network wide shared learning from the peer review process.
- Supporting paediatric diabetes teams to meet and continue to meet BPT standards.
- Working with an academic team at Newcastle University to commence the regional paediatric diabetes register.
- Regional analysis of NPDA and PREMs submission and monitoring of these action plans.
- Conducting a region wide audit of paediatric diabetes care.
- Continue to update guidelines based on national/international developments
- Providing regional opportunities for CPD for paediatric diabetes teams.
- Ensuring stakeholder representation.
- Continuing and more involvement in regional paediatric diabetes education resources for parents, carers, children and young people.

This annual report will be shared with all the members of the network including parents and carers, all Chief Executives of the network member trusts, the voluntary sector, industry and commissioners.

Guidelines

Primary
Currently there are no network primary care guidelines. As a network we feel the useful areas to look at would be around a care pathway, referral routes and transition in particular. Input and engagement from the commissioners will be required for success.
Secondary

The use of BSPED/ISPAD and ACDC guidelines for local adaptation has been agreed within the network meetings, we now have network approved guidelines for the network and these are based on either national/international guidelines or bespoke ones written by the network for the region.

Patient numbers for each trust

Below is a breakdown of patients per trust and shows how many new diagnoses there were and the numbers of patients on pump therapy.

<table>
<thead>
<tr>
<th>Trust</th>
<th>Patient numbers</th>
<th>No of new patients</th>
<th>No of patients transferred/leave service</th>
<th>No of patients on MDI/other regimen</th>
<th>No of patients on pumps</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chesterfield</td>
<td>167</td>
<td>12</td>
<td>86</td>
<td>81</td>
<td></td>
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<tr>
<td>Derby</td>
<td>241</td>
<td>39</td>
<td>29</td>
<td>177</td>
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<td>Kettering</td>
<td>168</td>
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<tr>
<td>Leicester</td>
<td>337</td>
<td>28</td>
<td>18</td>
<td>187</td>
<td>150</td>
</tr>
</tbody>
</table>
Chesterfield Team Key Achievements, Challenges and Aims for next year

Team Key Achievements:
- Following the Diabetes National Peer Review, the Diabetes Team have reviewed their operational policy and updated it reducing the gaps in services that were being offered in keeping with the best practice tariff.
- Currently meeting with all parameters for achieving the best practice tariff.
- Having started insulin pump therapy for children with Type 1 diabetes in May 2012 the Diabetes MDT has now over 50% of the children and young people on insulin pumps. Children with diabetes on insulin pumps have 24 hour access to member of diabetes MDT.
- Developed more meaningful individualised health care plans for children within the clinic setting including easy to follow Hba1c graph.
- Guidelines for all aspects of Paediatric Diabetes now on intranet. Information leaflets on various aspects of diabetes care are available on the ward and children’s outpatient department.
- Capturing all contacts and clinical information on to Diamond database for children’s diabetes service with administrative support.
- Downloading the blood sugar results using Diasend and making clinic visits more meaningful for the family.
- Extending the transitional services to the age of 19 years and psychology services to the age of 20 years
- Introduction of Nurse lead clinics

Key Challenges:
- Improving diabetes control by reducing the number of children with HbA1c above 75mmol/mol and increasing number of children with HbA1C less than 53 mmol/mol.
- Examining new ways to work efficiently and reduce costs.
- Continue to maintain the Diamond database for accurate submission to the National Diabetes Audit
- To introduce virtual clinics.
- To provide 24 hour diabetes consultant cover for out of hours and weekend for the MDT.
- To reduce the number of children cancelling and not attending clinic appointments.
- To arrange for regular transition clinics
- Introduction of CGMS

Aims for April 2017 – March 2018

- Structured education Programme for Children – evaluate the effect of DEAPP training
- Paediatric Staff Training – To ensure that nursing staff have a diabetes training package to be completed every 3 years. To ensure that all paediatric doctors get an update with regards to various aspects of diabetes management during induction
- Diabetes Camps – To organise outdoor events for children including Camps.
- To ensure that best practice tariff is achieved and peer review process is completed with excellence.
- To reduce the number of children with HbA1c above 75 mmol/mol to less than 64mmol/mol
- To increase the number of children with HbA1C less than 58 mmol/mol to above 30%.
- To reduce the cancellation rates to less than 10% and DNA rates to less than 5%.
Derby Team Key Achievements, Challenges and Aims for next year

Achievements

- Improved clinic median HbA1c (see activity data).
- Strong teamwork during periods of gaps in staffing.
- Recruitment to 3 new permanent nursing posts, with resultant expansion from 1.96 to 4.96 WTE PDSNs.
- Expansion in nursing team allows 8am to 8pm cover for 7 days a week.
- Recruitment of an additional dietitian.
- Recruitment of an additional psychologist.
- Increase in pump patients and reduction in pump waiting list.
- Reduced length of stay for most newly diagnosed admissions (non-DKA) because of greater capacity to deliver ward education and next day follow up home visit.
- Continuation of school staff education sessions delivered in group sessions in the hospital, using diabetes staff time efficiently, and ensuring that time is protected for school personnel as they are off-site. These sessions have received good feedback.
- Technology event held for patients and carers in response to 2015 PREM report feedback.
- Maintaining complete consistency amongst multi-disciplinary team members regarding clinical blood glucose targets for patients.
- Removal of reporting of HbA1c in percentages from point of care testing machine and laboratory results. HbA1c now only reported in mmol/mol.
- Standards met to maintain Best Practice Tariff for paediatric diabetes.
- Cooking sessions for young people run by dietitians and supported by Assistant Practitioner.
- Enhanced support for ward staff with mandatory training sessions and additional sessions on hypoglycaemia on the wards.
- Ward drop in sessions with targeted learning points initiated following insulin errors on wards.
- Continuing Derby Diabetes Fun Club monthly for under 11 year olds.
- Regular newsletter publication.
- Obtaining retinopathy screening results from the local programme, greater yield of results available for National Audit.
- Change in referral process to retinopathy from April 2017. Referral now to be made from secondary care at diagnosis rather than from primary care. Change prompted by large numbers of patients without timely referrals.
- Level 3 carbohydrate counting now initiated from diagnosis in response to NICE NG18 2015.
- Approval for CGM funding (from 1st April 2017).
- Renewal of exercise guidance.
- New improved DKA guideline with flowchart.
- Successful recruitment to trialnet research trial.
- Regular data tracking for HbA1c for new patients, alongside high HbA1c cohort, aiming for a preventative rather than reactive approach.
- Patient information folder updated.

Current challenges

- Continue current pump expansion and ensure waiting list contained.
- Team expertise required in education and use of CGM.
- Work with CCG on process for CGM funding ensuring that NICE criteria and ACDC guidance met, and that there is clarity for withdrawal of devices appropriately.
- Provide a mechanism whereby ward errors are followed up with enhanced levels of mandatory training (packages are being currently reviewed).
- Clinic capacity of young adult service is limiting discharge of transition patients.
- Ensure transition service meets NICE specifications in terms of adult team presence.
- Additional adult transition physician post approved, but remains vacant.
- Additional transition nursing post approved, but remains vacant.
- When posts in place, plan for transfer of paediatric patients to young adult clinic from 19 years instead of 18 years. This will alleviate capacity issues in adult clinic, and allow longer time for relationship to develop between young person and adult team, with the aim of greater retention within secondary care at a vulnerable stage of development.
- Final year of BPT income would then be anticipated to be split between adults and paediatrics with the proviso that adult nurse takes over as key contact and keyworker when young person is 18 years and ensures 8 additional annual contacts as well as provision of emergency advice, as if not adhered to, extra one year could cause strain on existing paediatric nursing capacity.
- Improving outcomes for patients with high HbA1c with new lower target HbA1c of 48mmol/mol or less.
- Accuracy of data extraction from Twinkle database for NPDA collection
- Patient data collection required for National Registry, extensive dataset which will be very time consuming to collect

Aims for next year

- Increase proportion of patients on pumps who meet NICE criteria where there is clinical indication and consider wider patient choice.
- Streamline CGM application, commencement and withdrawal process.
- Build team expertise in CGM.
- Improve accuracy of data collection and extraction for National Audit.
- Reduce clinic HbA1c further.
- Progress on structured education curriculum and with expansion of nursing team, to provide group education evening sessions with a rolling curriculum.
- Residential weekend away for patient group.
Kettering Team Key Achievements, Challenges and Aims for next year

Key Achievements

- New Admin/Clinical band 4 started Aug 2016 and left Dec 2016. New appointment to start around Jan 2017 (permanent May 2017) for clinic support and maintaining the database and cater to NPDA, BPT and patient communications.
- New DSN has completed the Diabetes module with the Birmingham course.
- Dietitian has completed the Diabetes module in 2015 at Birmingham.
- New DSN to start June 2017 to help with transition.
- PDSN band 7 uplift completed
- SPIN training in Diabetes alongside LRI to be in place and KGH recognised as a training centre.
- We have achieved the BPT over the last 3 years with multiple staffing challenges and team have really worked hard to work at par with national standards.
- We have tried hard to work along with commissioners and have organised meetings twice a year to keep us in close communication.
- Annual Review clinic both paediatric and Transition in place April/May and June start of financial year as a one-stop clinic.
- We have near patient HbA1C testing in place with POCT in place alongside ketone meters with NEQUAS and WEQUAS in place in close liaison with the biochemistry department.
- We do quite a lot of fun sessions, adventure sessions and Christmas parties which children enjoy. We also did diabetes teaching with team day out for the younger ones at the farm and the older ones as activity workshop in Grendon. The educational content was well appreciated with our models recently purchased.
- Increased number of patients on insulin pumps, insulin pump schools developed (43 of which 6 were new pump starts the last year. We have total of 4 Omnipods, 3 ROCHE and rest are Medtronic pumps with 1 self-funded CGMS. Quite a few are on Free style Libre.)
- We offer a Variety of pumps – Medtronic, Omnipod and Roche
- High A1C clinic on once a month basis, High A1c leaflet used. There is a steady decline in the numbers around 17% comparable to national average as evidenced by the NPDA results.
- Virtual Insulin Pump clinic twice weekly as evidenced by the excellent A1c results compared to national standard as detailed in the NPDA results.
- Dietetic led Annual Clinics in place and involves structured education that is age banded.
- Twinkle database has been in use over the last three years.
- Transition leaflet introduced and used effectively.
- Self- management plan used.
- Ketone leaflet introduced.
- Hypo guidance has been updated to current review standards.
- Insulin passport introduced to all patients.
- Formalised education programme is in place for school staff with refresher training and support available throughout the year with excellent feedback.
- There is a wide of collection of reference books that are loaned to people to help with their self-management of diabetes
- On-call for weekends and bank holiday by the Diabetes team in place on Pro rota basis.
- We continue to effectively participate in the yearly NPDA and PREM audits.
• We continually do yearly admission audit that is discussed 3 monthly in our team meeting for review and feedback to our service needs.
• We are actively involved in multiple national research projects.
• 100% of patients on downloadable meters that are downloaded on Diasend every clinic and in between clinics and reviewed by the PDSN and dietitian.
• Availability of a variety of pump and Meter download and review in clinic
• TWINKLE database maintained
• Ketone meter and Point of care HbA1c machine purchased and in use- EQA with NEQAS and WEQUAS
• Quality assurance in place and monitored by GM/ KL

Key Challenges
• Increase in dietetic time from 0.6 to 0.8 by SLA to be completed 2017 September.
• Lead diabetes PA/ diabetes on-call rota/virtual pump clinic/ transition to be reflected in consultant Job Plan.
• SLA needs developing as currently psychology support services without clinic presence
• Increase in patient numbers and hence increase in follow up/ new patients and transition slots for the service and time for the team to be recognised in the job plan.
• Robust staff education on the paediatric wards and pump schools to be more structured.
• Structured education using the new guidance to be established.
• NPDA and PREM action plan to be completed.
• Trained Education is difficult to achieve for the service.

Aims for the next year
• Services delivered to be recognised in the job plan of the consultants.
• Transition clinic number to be double for the year with two clinics a month. Nurse led drop-in clinics to be imitated.
• Robust ward staff trainings
• Structured pump schools, review sessions, carbohydrate counting sessions, diet and psychology focus group sessions.
• Structured Education to be well established in annual review clinic and follow up clinics
• Nurse led clinics to be set in all areas once monthly to help with the high A1c patients
• 24/7 on call to be in place with new qualified PDSN.
Leicester Team Key Achievements, Challenges and Aims for next year

Key Achievements
1. A business case for additional dedicated psychology provision has been submitted and agreed with interviewing September 2017.
2. The result is improvements in and attainment of most of the PREMs outcomes as seen in the action plan. As well as delivery on areas of service design. This year focusing on
   a. Revision of the high HbA1c pathway and nurse led clinics
   b. Changes to the young adult clinic. With recruitment of dietitians additional medical support. As well a moving toward delivery of tariff for the young adult service and the setting up of a SKYPE clinic.
   c. Carb counting at diagnosis and changes to structured education starting home visits.
   d. Launch of structured education APP “DeAPP” at diagnosis as part of the innovation for improvement grant from the healthcare foundation. Providing e-learning at diagnosis and educational resources for the healthcare team.
3. Setting up dedicated clinics for
   a. Pre-insulin pump assessment
   b. CGMS / FGM/ i-port
4. Diabetes Schools training
   a. Rolling program of teacher training
   b. 2016-17 : 363 from 94 schools -teachers and allied staff being trained
5. Peer group support:
   a. Coffee mornings around the county
   b. The highs and lows diabetes choir.
   c. Camp Charnwood residential diabetes camp

Key Challenges
The key challenge this last year has been service redesign for the young adult clinic, submission of the business case for a dedicated psychologist that is now through. Coping with the increase demand for insulin pumps and integration of sensor augmented pumps and CGMS as well as strengthening our pre-pump selection.

1. Reduction of the High HbA1c > 9 % in at risk patient groups adolescents and ethnic minorities. as identified by the NPDA. Service re-design of the high HbA1c pathway.
2. Continued Service redesign for the young adult clinic.
3. We have work in collaboration with our adult colleagues to develop a service that fulfils both the NICE guidance for transition and diabetes and fulfils the national diabetes tariff. The adults have invested in the service for additional nursing. Consultant and dietetic support.
4. We are aiming to improve the environment of clinic with drop clinic and starting a SKYPE clinic in an effort to reduce DNA rate and improvement HbA1c.
5. Integrate the substantive psychology post into the team. Interviews are in September 2017 with the post holder due to start up to 3 months after that period. This will allow the reduction of waiting time as well as a psychologist present in clinic. So that the psychologist is seen as part of the team and the norm.
6. Insulin pumps / sensors and CGMS

We continue to see rising demand for all of the above. With now 40% (150) of the clinic on insulin pumps. We now have a waiting list that is 6 months with some patient waiting longer. We now have streamlined the patient pathway with a pump pre-assessment clinic. So
patients are fully informed of the expectations of pump patients and their glycaemic control. We have started using Animas pumps as well as Medtronic still initiating patient via a pump school the same way we have used the Equip program. We remain on track with our 3-5 year target for pump recruitment and high cost therapies budgets.

**Aims for next year**

- Increase capacity for insulin pumps / appropriate CGMS
- Appointed dedicated psychologist and embed in the team.
- Look at outcome in line with new NICE criteria to reduce mean HbA1c. Instituted now goal setting sheet in clinic to audit outcomes
- Concentration of High HbA1c patient in the adolescent and ethnic minority groups.
- Improve transitional service and pathway into adult services.
- Support structured education programs in the team.
- Work with the East Midlands diabetes network to ratify network polices and guidelines.
- Continued focus at MDT meetings, greater focus on patient with HbA1c >9.0%

The team have had a successful year in delivery of patient care, improving service delivery and developing new ways of working with new core members of the team in the face of recruitment challenges.
Northampton Team Key Achievements, Challenges and Aims for next year

Key team achievements
- Continuing compliance with the Best Practice Tariff
- Submission to the National Diabetes Audit for the 13th year running
- Improvement in our median HbA1C, sustained for the last 3 years, now 63mmol/mol (a decrease of 6mmol/mol in the last 3 years)
- All PDSN posts are recruited into
- Multiple training and education events for children and young people and their families
- Active involvement in the East Midlands diabetes network
- Revision and updating of all guidelines in line with the East Midlands network guidelines, and the new NICE guidelines (NG18)
- Monthly MDT outreach clinics in Danetre Hospital, Daventry
- Engagement of ward staff in diabetes training
- 2 RSCNs have completed the BCH diabetes course over the past year
- Children’s ward training is now mandatory for all ward staff
- We have secured significant funding to undertake a research project on the use of a transition nurse in the transition of young people from the paediatric to the adult clinic at the Northampton General Hospital
- Embedding of one of our parent reps into the East Midlands Diabetes Network meetings
- Initiation of a parent support group managed by our parent reps
- Closer links with the adult team, with whom we now have quarterly MDT meetings
- Development of a pump panel with the adult team

Key Challenges
- Insufficient clinic slots due to clinic day being a Monday and losing clinics due to bank holidays
- Due to staff sickness and staff leaving, our PDSN has been far below establishment and have been unable to provide the level of care that the team would like over the course of the year
- Poor in-patient and out-patient estate and environment
- Increase in number of patients with significant safeguarding concerns
- Achieving the targets we have set ourselves as a team
- Reducing our in-patient admission rate
- Reducing the number of DNAs/late cancellations
- Continuing to improve our yearly screening

Aims for April 2017 – March 2018
- The team have set targets of
  - 10% of C&YP with an HbA1C >80mmol/mol
  - 45% C&YP with an HbA1C < 58mmol/mol
  - 15% of C&YP with an HbA1C < 48mmol/mol
- Change the clinic day from a Monday
• Decrease the number of DNAs
• Continue to provide education and training sessions which are geared towards C&YP
  o Provide a pump show and tell event
  o Education event about the transition from primary to secondary school
  o Education event for up to 5 year olds
  o Education event for 7 – 11 year olds
  o Education event for 12 – 14 year olds
• Charity fundraise to increase the number of CGMS devices the clinic has, with the aim of giving all our C&YP the opportunity to have CGMS monitoring twice a year
• Improve efficiency through the service by finding innovative new ways of working as an enhanced team
• Embed the new PDSN into the MDT team. With the return to work of a PDSN who has been on sick leave, this will bring our PDSN establishment up to capacity.
• Commence our research project into the use of a transition nurse
• Continue to actively engage in National research projects
• Continue to decrease the number of long term patients who are readmitted to hospital
• Set up meetings with our counterparts in the North of the county to enhance our cross county working
Nottingham Team Key Achievements, Challenges and Aims for next year

Key Achievements:

- Hosts - British Society for Paediatric Endocrinology and Diabetes (BSPED) Annual National Conference 2016 - Dr Tabitha Randell was the Lead local convenor, supported by Jo Benson, paediatric endocrine nurse and Caroline Saddington, paediatric diabetes nurse.

- East Midlands Network won sponsorship for development of a new patient education project DEAPP (Diabetes Education App) involving ‘Flipped learning’ of which we are a pilot site for this project.

- Patient Outcomes: NICE recommends HbA1c < 48 mmol/mol Nottingham Children’s Hospital’s and National outcomes have been improving year on year, most notably since the introduction of the Paediatric Best Practice Tariff in 2012.

- Adjusted mean HbA1c is the best outcome measure calculated from data submitted to the National Paediatric Diabetes Audit (NPDA).

- Most recent NPDA data collected for the year 2015-2016 and published 28/02/17 showed: Nottingham Children’s Hospital now ranks number 1 in England, having the best mean adjusted HbA1c and number 2 in England and Wales, having the second best mean adjusted HbA1c in England and Wales.

- Paediatric Diabetes Best Practice Tariff Standards of Care have been achieved again for this year ending April 2016. We have met these standards since their inception in April 2012. Income generated is around £3000 per patient per year of care, if all strict standards are met. It includes payment for any hospital admissions where the primary reason for admission was diabetes. Presently this equals around £1,050,000 income per year.

- Education and Training of Junior Medical Staff attached to the diabetes team GRID Trainee – trained and supported to successful application for a Consultant Post in Paediatric Endocrinology and Diabetes Birmingham Children’s Hospital from August 2017

- Adolescent Registrar Trainee – trained and supported in the management of long term diabetes and endocrine conditions as well as the impact of growth and puberty and psycho-social circumstances on young people

- Registrar currently undertaking research with diabetes and endocrine patients into brown fat metabolism supported in clinical exposure and tutorials in preparation for GRID application (diabetes and endocrinology) ST1-3 – trained and supported to enable exposure to as much clinical experience as allowed due to split responsibilities with general paediatrics. Supported to undertake specialty audits and service improvement projects leading to publications and presentations. This will have given both recent trainees a good grounding in preparation for GRID applications in diabetes and endocrinology

- Medical Student (Nottingham Link Initiative) - serves to allow keen medical students interested in academic research links with academics offering short term projects in and around the hospital/medical school. There are 6 projects currently underway and the aim is to present these at BSPED 2017.

  - Review and Audit of children and young people with diabetes (CWD) using Continuous Glucose Monitoring System (CGMS) / Flash Glucose System (FGS)
  - Effects and side effects of transition to the updated national DKA guideline 2017
  - Stabilisation and intensive re-education in T1DM patients with High HBA1c - aims, process and long term outcomes
o A retrospective review of patients admitted with Diabetic Ketoacidosis (DKA), their HbA1c and engagement with the diabetes team pre and post transition to young adult care.
o A review of our patients with T1DM and autism: diagnosis, challenges and glycaemic control
o Evaluation of the experience of the conventional education package offered at diagnosis to patients with Type 1 diabetes.

**Key Challenges**

Nottingham Children’s Hospital Diabetes Team has achieved improved outcomes year on year and now ranks at number 1 in England and Wales. To maintain these high standards and to continue to improve on these. The areas of need are:

- Transition and Young Adult Service
- Requires increased staff specialising in this area – particularly transition worker, youth team worker, psychosocial support
- Improving health in diabetes through sport and exercise. Requires support for current staff to further develop expertise in this area
- Team efficiencies and workload and staff development. Requires increased understanding of the service and roles from outside the diabetes team
- Requires increased admin support, improved admin systems as the first step
- Social support services - Children’s Hospital or Diabetes Team Social Worker would improve communication across agencies, decrease risk and improve efficiencies
- CAMHS support services - Improved and increased access to PLS/CAMHS support when needed
- IT and Technologies support services - Needed to enable in and out of hospital access to appropriate IT systems involved in patient care, education and patient feedback
- Patient experience - Improvement in clinic administrative systems, communication and environment required
- Research - Clarity of funding streams, so that funds are appropriately received to enable on-going levels of research in diabetes
- Public/professional awareness of diabetes - In order to improve early diagnosis and to improve understanding the impact of diabetes on day to day life and vice versa requires increased and improved collaboration with primary care

**Aims for next year**

- Improved Strategies to Support Young People with Diabetes in Transition and Young Adulthood
- Development of Sport and Exercise in Diabetes Service with the aim of improving access and support for all young people with diabetes to exercise and sport.
- Implementation of DEAPP (Diabetes Education App) with evaluation of success compared to standard new patient education.
- On-going high activity levels in Research
- Systemic Psychotherapist Service Evaluation – Part 2 planned this year looking at the impact of psychotherapy on glycaemic control and outcomes
- Events to support young people with diabetes in Nottingham will be planned
- Audits and Projects
- Improved carbohydrate counting in schools
- Staffing levels to increase need:
  - Transition worker
  - Youth Worker
  - Administrative increase in banding and time
  - Social worker time
Sherwood Team Key Achievements, Challenges and Aims for next year

Key Achievements:
- The percentage of patients with a target HbA1C below 58mmols/l is 36.9% which is higher than the national average of 26.6% and is also an improvement on the 31.5% we achieved the previous audit year.
- The new HbA1c target set by NICE of below 48mmol/mol was achieved in 10.7% of our patients compared to 6.5% nationally and exceeds our achievement last year of 7.4%.
- The completion rates of all individual care processes as well as the combined rate for all seven care processes achieved by SFHT are higher than the national and regional averages.
- Education group session carried out by PDSN and Dietitian within the summer holidays for all CYP moving up from primary to secondary school including use of a diabetes board game covering relevant issues regarding this transition.
- Continuation of insulin pump service with 30% of caseload on insulin pump therapy including dietetic involvement.
- An Insulin Pump Education Day was organised and delivered on 28th February 2017. This was offered to all families with a CYP with diabetes managed on an insulin pump.
- Involvement in Trialnet research study and Address 2 continues.
- Participation in SWEET-EU project.
- Obtained 10 hours administrative support for diabetes.
- Involvement in the regional health award project to develop a diabetes education app for newly diagnosed patients (DEAPP).
- Achievement of Best Practice Tariff
- Structured education - All diabetes education is structured within education plans along with the rationales for the education given and commenced on the ward at diagnosis. In addition to this, education is given throughout the year on a one to one basis according to individual need and continues throughout the patient’s journey. As part of each child’s annual review a specific topic of education is reviewed alongside the appropriate education plan and education delivered. The child/family’s knowledge is assessed by way of an annual review quiz prior to the session. This ensures all children have had the same education within the year.
- Dietetic structured education programme is commenced on the ward at diagnosis. Structured carbohydrate counting level 3 education with a written curriculum is offered from diagnosis.
- Psychology – the service includes a WTE CAHMS worker who is available within clinic and on referral will also deliver direct one to one consultations with patients and families. At each child’s annual review, a health and well being assessment is carried out and if appropriate referrals are made to CAHMS. Referrals will also be made to specialist CAHMS services if necessary.
- Annual review clinics – annual proforma in place to ensure and evidence annual criteria/screening is carried out and achieved for each patient.
- HbA1c testing equipment- DCA advantage HbA1c analyser available within Kings Mill and Newark clinics to provide HbA1c results within the clinic appointment.
- Dietetics- additional appointment offered at annual review, annual dietetic assessment also performed.
- Submission of data to National Paediatric Diabetes Audit.
- Recommended additional contacts have been offered by diabetes specialist team.
- Attendance of team members to all regional network meetings and involvement with East Midlands Paediatric Diabetes Network above the recommended 60%.
Children and Young People’s East Midlands Diabetes Network Annual Report 2016-2017

- Participation in self-assessment of Peer Review Process.
- All newly diagnosed patients have been discussed with a senior member of the diabetes team within 24 hours and seen on the next working day.
- All patients are offered a minimum of 4 MDT out-patient appointments per year.
- A senior member of the diabetes team is on-call for telephone advice 24 hours, 7 days per week and is accessed via the paediatric ward.
- Transition clinics take place every 3 months with involvement and collaboration of the adult diabetes team. A young adult clinic exists within the adult service.
- High HbA1c policy carried out on patients whose HbA1c is above 75 mmol/mol and patients offered 3 weekly contact and support between clinic appointments by the diabetes team.

Key Challenges:
- Achievement of recommended contacts due to one of the PDSN’s (0.8WTE) on sick leave for 4 to 5 months.
- Reducing number of patients with a high HbA1c above 75 mmols/mol.
- Collating the evidence to get commissioners to pay the mandatory Best Practice Tariff.
- Administrative support for the service remains limited.
- Retinal screening - problems with accessing results for Derbyshire patients affecting NPDA results.
- To increase the number of patients with HbA1c at or under the new NICE target of 48mmols/l.
- Purchase of new Diamond database- security of patient data / audit purposes. Progress underway to complete.
- Transition- No adult DSN involved in transition. Placed on the Risk Register for adults and paediatrics.
- Explore ways to reduce the number of DNA’s within transitional clinic.

Aims for next year
- To reduce number of patients with high HbA1c above 75mmols/mol.
- Improve patient / carer involvement within service.
- To continue to achieve Best Practice Tariff
- Explore the development of a structured education group for newly diagnosed patients.
- To explore methods of training for ward staff with the aim to increase participation to teaching sessions/material provided.
- To undertake a survey looking at patient and parent/carer experience of transition and transfer process.
- Develop clear written pathway for transition
- Participation in DEAPP, involvement in the development of a diabetes education app with the regional network along with a health innovation award for newly diagnosed patients and becoming a pilot site.
- To have monthly team meetings to include discussion of management for patients with high HbA1c.
United Lincolnshire Team Key Achievements, Challenges and Aims for next year

Key Achievements:

- **IT initiative** - Over the past year we have introduced a new IT initiative. We have purchased 8 I pads for the DSN to use for education purposes. Trust wide presentations and teaching have been put onto I pads to ensure consistent reproducible teaching for patients and carers at home and school. Looking ahead, we intend to use the I pads to engage families in filling out their PREMS questionnaires.

- **Psychology Services** - The psychologist has developed a High impact, High HbA1c joint clinic with DSNs. This new clinic is to specifically target children, young people and their families that have a high Hb1Ac – initially starting with our young people with the highest HbA1c results but then to target anyone with a HbA1c over 75mmols. The clinics have been running for about a year now and the structure is being reviewed, and the team have recently given feedback on the clinics, which has been positive and hopefully clinic capacity will increase.

- **School Education Program** - The team have developed a new education training day for the local schools. This is to maximise cost efficient training and provide peer support within the education sector. This is designed as a half day education event including power point presentation, practical sessions and workshops. Feedback from the schools involved to date has been very positive. PDSNs continue to roll out this training, and have recently created events through Eventbrite to advertise the sessions available and be able to monitor attenders. Usual problems with timings of sessions and getting staff to book on the training but the team continue to book dates up and encourage attendance.

- **Residential Trip**. For 5 consecutive years the whole MDT have been involved in taking 7 to 10 years olds (approximately 20 each year) to a local farm park for a 3 day/overnight residential trip. This is our local version of a diabetes camp and we have found it invaluable for increasing the Children’s confidence and diabetes management. In addition the hands on experience it beneficial to the teams understanding of living with Diabetes. We have attempted to evaluate this intervention but the response rate has been low this year. Also, in the past we have fund raised to subsidise the cost of attending for families. This year we have finances to only attend two full days and one night and be able to offer the trip at reduced costs. Planned for September 2017. Again our psychologist has prepared a pre and post trip questionnaire to evaluate the project.

Key Challenges

- **Medical Staff** - Over the year we have had a number of challenges. One of the diabetes clinicians left the trust and prior to appointment of a new consultant the remaining consultant undertook a number of additional clinics to ensure patients continued to be seen appropriately. This temporary arrangement continued for 4 months. However we are pleased to announce that we were successful in appointing a fantastic new clinician to this post. She is presenting a business case for point of care testing for all three hospitals and Twinkle.

- **Nursing staff** - In addition one of the experienced DSN left the trust. Unfortunately during budgeting and cost improvement by the trust the funding for this vacant post was removed leaving the DSN service significantly stretched. This post was advertised eventually and a nurse recruited in April this year, based over at Boston site. We need to compile a business case for more health care support hours and for diabetes admin to support the nursing team county wide.

- **IT issues** - The ability to download pumps and meters had been compromised due to lack of working Laptops. We have now purchased new laptops at all three hospital sites to be able to download meters and pumps in clinic and at home visits.
• **National Audit** - As our trust does not have a database that can submit to the NPDA there are significant demands put on the staff (PDSN / HCSW) to input data. This is not sustainable in the long term. There is no dedicated admin support for the team. There is an admin worker who looks after county wide community children’s medical equipment ordering. She is going to commence the audit for the next year for all three sites and we will have to monitor her progress but we need to compile a business case for diabetes admin.

• **Dietetic Services** - Despite the excellent service offered - the advent of the new Best practice Tariff dietetic requirements are difficult to achieve. Between 2012 and 2015 this was achieved by prioritising paediatric diabetes cover at the expense of other services. As highlighted in previous reports due to number of staff the dietetic services had to temporality stop coming to clinics from April 2016 and target specific patients only. These posts have now been recruited to and dietitians are now attending all clinics again.

• **Transition** - The service is attempting to make changes to improve provision for young people moving from paediatric to adult diabetes services across ULHT sites. Currently the team recognises the inequity of service provision across the county, with young people in Boston and Grantham moving over to the adult teams at a younger age and with a less robust transition support process in place due to challenges in providing joint paediatric-adult clinics at different sites. The earlier transition age means that they do not have the same access to paediatric services such as psychology provision. With this concern in mind we are in communication with colleagues in the adult services and we are hoping to attend County wide forums to discuss these issues further. Currently in Boston we are meeting with adult colleagues and the business unit to set up our new transition service. In Grantham some transition clinic dates have now been set up. This work is on-going.
Appendix 1 - Job Outline for the role of Chair of East Midlands Paediatric Diabetes Network

Aim
To chair the East Midlands Paediatric Diabetes Network effectively ensuring that the network works well with good stakeholder engagement and develops a work programme that helps to improve the diabetes care in the East Midlands region for children and young people with diabetes.

Objectives
- To effectively chair network meetings (4 times a year). Providing strategic and clinical leadership to the network.
- To work with the network manager to ensure that there is an effective work programme for the network and that this is delivered across the region.
- To ensure that the work programme meets Department of Health requirements e.g. Best Practice Tariff and is in tune with national guidance such as recommendations from NHS England, the National Network.
- To work with the network manager to support all units across the region to achieve all of Best Practice Tariff standards including 100% NPDA submission and effective monitoring of attendance at the network to demonstrate attendance at 60% of meetings.
- To work with the network manager to ensure that meetings are booked, minuted and that the agendas are relevant to the work programme and stakeholders.
- To work with the network coordinator to ensure that there is good stakeholder engagement and communication including involving parents and carers, industry and charities such as DUK and JDRF.
- To work with the network manager to ensure that there is regular proactive communication including a monthly newsletter sent to an up to date list of contacts.
- To work to support the network manager in responding to reactive communications such as requests for information. This will include supporting units who request help such as providing advice, sharing good practice, undertaking a visit or writing letters.
- To work with the network manager to ensure that the work programme is delivered by being involved in or chairing task and finish groups (small sub groups of the wider network that are undertaking specific pieces of work).
- To work with Paediatric Epidemiology to help continue the register across the region and support its development.
- To lead on work such as consolidating views on regional audit priorities and the role for a registry in the East Midlands, examining data and liaising with research leads.
- To attend regional and national meetings as appropriate.

Supporting Evidence
We will be looking for specific examples to evidence the criteria detailed below.

<table>
<thead>
<tr>
<th>Factors</th>
<th>Description</th>
<th>Essential</th>
<th>Desirable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge, Training and Experience</td>
<td>Knowledge of current diabetes issues including being in clinical practice in the East Midlands region.</td>
<td>√</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Understanding of aims of current healthcare policy in diabetes and appreciate the impact of this on the network.</td>
<td>√</td>
<td></td>
</tr>
</tbody>
</table>
An appreciation of the relationship between the Department of Health, the Strategic Health Authority and individual provider and commissioning organisations.

<table>
<thead>
<tr>
<th>Communication Skills</th>
<th>Able to effectively chair meetings.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Able to negotiate with senior stakeholders on difficult issues, presenting complex and sensitive information to large and influential groups.</td>
</tr>
<tr>
<td></td>
<td>Able to represent the CYPEMDN at national and regional meetings.</td>
</tr>
</tbody>
</table>

| Analytical | Ability to analyse complex facts and situations and develop a range of options. |
|           | Takes decisions on difficult and contentious issues where there may be a number of courses of action. |

| Planning Skills | Demonstrate capability to plan over short, medium and long-term timeframes and adjust plans and resource requirements accordingly. |

| Management Skills | Able to direct activities of network coordinator. |

| Autonomy Freedom to Act | Experience of identifying and interpreting National policy. |
|                         | Experience of interpreting best practice to make successful changes to a system. |

| Physical Skills | Have sufficient time (estimated to be about a session per month) to undertake the work of the network and represent the network at regional and national meetings. |

| Equality and Diversity | Have an understanding of and commitment to equality of opportunity in terms of day-to-day working practices and also in relation to management systems for diabetes. |
|                        | Evidence of equality and diversity training. |

| Financial and Physical Resources | Support the network manager to manage a non-pay budget and work with industry to ensure that meetings are supported. |

| Other | Demonstrate a strong desire to improve performance across the East Midlands region for children and young people with diabetes. |
Appendix 2 - Memorandum of Understanding

Introduction:
This memorandum sets out the framework for a working relationship between the East Midlands Paediatric Diabetes Network (hosted by Birmingham Children's Hospital NHS Foundation Trust, Steelhouse Lane, Birmingham, B4 6NH) and ? NHS Foundation Trust. It sets out the principles on which both parties work together in the course of their day to day working relationship.

Responsibilities:
1. The East Midlands Paediatric Diabetes Network is responsible for ensuring that they:
   - Organise and facilitate a minimum of 4 East Midlands paediatric diabetes network meetings per year. Minutes for these will provided to all members within 3 weeks of the meeting.
   - Chair, supervise and support any network projects through task and finish groups.
   - Communicate regularly with all units, answer queries and offer support by phone, email or in person as appropriate.
   - Support units in their discussions with commissioners regarding the implementation of the Best Practice Paediatric Diabetes Tariff.
   - Organise and support parent representation in network meetings.
   - Organise and support industry representation in network meetings.
   - Support units in participating in the regional paediatric diabetes register and National Paediatric Diabetes Audit (NDA).
   - Liaise with local commissioners to raise awareness of funding issues pertinent to paediatric diabetes services.
   - Arrange education days on topics relevant to paediatric diabetes for diabetes teams and any other healthcare professionals involved in the care of young people with diabetes (e.g. Hospital ward staff).
   - Support units and the network in the completion of peer review process and share learning from it.
   - Continuously facilitate and increase engagement with stakeholders and raise awareness of paediatric diabetes healthcare and service issues.
   - Link into the diabetes national agenda and represent the region at relevant stakeholders meetings and ensure that national objectives are met.
   - Arrange (via the network executive) for all funding pertaining to the East Midlands Paediatric Diabetes Network to be held and managed in a trust fund at the host Trust (BCH) and to ensure that this money is used solely for the business and purposes of the East and West Midlands Paediatric Diabetes Network.
   - Invoice all participating units in the network via BCH for their annual network contribution.

2. ? NHS Trust is responsible for ensuring that they:
   - Make an annual financial contribution (2016/17 - £4904.30) towards the running costs of the network (this figure to be reviewed on an annual basis).
   - Send a Trust representative to 60% of all network meetings.
   - Send apologies for all network meetings that they cannot attend.

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1 The Paediatric Diabetes Network is made up of representatives from all paediatric diabetes units across the East Midlands and is the forum where all network business and work plans are set and discussed.

2 This needs to be a member of the diabetes team; however, business managers are also welcome to attend.
· Support the aims and objectives of the Network and those set out nationally and incorporated into the networks annual plan of work.
· Actively participate in the network’s working groups.
· Actively participate in the national self-assessment and peer review process.
· Should network posts need to be made redundant to share associated costs.
· Maintain their own local paediatric diabetes register and contribute their data to the Regional Paediatric Diabetes Register and submit data to the National Diabetes Audit.

Statement of Support:
We as the Clinical Leads and Business Managers for our local paediatric diabetes service, and on behalf of our paediatric diabetes team, agree to this memorandum and to work in partnership with the CYPEMDN towards enhancing diabetes care across the region and support the commissioners to improve the quality of care for all children and young people with diabetes.

Signatories to the memorandum of understanding: