

Evaluating the process and  
perceived impact of the Regional  
Paediatric Diabetes Network  
Coordinators: North West

Supporting, Improving, Caring

# Reader Page

<b>Title</b>	Evaluating the role and perceived impact of the Regional Paediatric Diabetes Network Coordinator in the North West.
<b>Author</b>	Dr. Louise Richards  Reviewed by: Dr Grace Sweeney Dr Gav Eyres Katherine Lewis Ruth Gordon Trudi Akroyd Dr Chris Cooper
<b>Publication Date</b>	May 2012
<b>Target Audience</b>	North West Regional Paediatric Network members, National Paediatric Diabetes Network members, members of other regional paediatric networks, and NHS Diabetes and Kidney Care Staff.
<b>Circulation List</b>	North West Regional Paediatric Network members, National Paediatric Diabetes Network members, members of other regional paediatric networks, and NHS Diabetes and Kidney Care Staff.
<b>Description/Purpose</b>	A report on the findings of an evaluation of impact of the North West Paediatric Network Coordinator role.
<b>Cross Reference</b>	<ul style="list-style-type: none"><li>• Evaluating the role and perceived impact of the Regional Paediatric Diabetes Network Coordinator in the East of England.</li><li>• Evaluating the role and perceived impact of the Regional Paediatric Diabetes Network Coordinator in the South Central region</li></ul>
<b>Superseded Documents</b>	N/A
<b>Action Required</b>	N/A
<b>Timing</b>	N/A
<b>Contact Details</b>	Dr. Louise Richards Louise.Richards@diabetes.nhs.uk Research and Evaluation Officer NHS Diabetes

# Section 1: Introduction

## NHS Diabetes

The overarching remit of NHS Diabetes is to ensure that the quality of care for people with diabetes in England is constantly improving. The organisation works with key stakeholders such as healthcare professionals, commissioners and people with diabetes to improve the quality of services.

## About the paediatric diabetes networks

NHS Diabetes has developed, funded and supported a programme of work to improve equity of care and service delivery for children and young people with diabetes. As a result, each NHS region in England now has a dedicated paediatric diabetes network. The regional networks offer support to healthcare professionals working with children and young people with diabetes by providing opportunities for shared learning and good practice.

The regional networks are underpinned by the National Diabetes Paediatric Network, which comprise representatives from each regional network, supported by programme managers from NHS Diabetes. The national network meet twice a year and shape the strategic direction of the network. They have identified the following outcomes for each regional paediatric network:

1. Raise the profile of the network and increase stakeholder engagement.
2. Undertake a health needs assessment within the network.
3. Gain agreement from all units in the region to participate and contribute to the network.
4. Establish a regional paediatric diabetes register<sup>1</sup>
5. Support commissioners to understand paediatric diabetes requirements and Payment by Results (PbR) tariff.

6. Take part in the National Paediatric Diabetes Audit (NPDA).
7. Establish clear governance arrangements with the strategic health authority (SHA) and long-term conditions (LTCs) groups/boards.
8. Work with a variety of stakeholders to improve the care children and young people with diabetes whilst at school.
9. Develop and implement a standardised service specification.

To support each network in achieving these aims NHS Diabetes has funded a regional paediatric network coordinator (PNC) role in each of the former SHA regions, with the exception of the North East who chose to focus on developing a regional register and employed a registry coordinator instead.

## PNC deliverables and responsibilities

The responsibility of the PNC post is to develop a local strategy that is aligned with national policy and the strategic priorities of NHS Diabetes, and as such, the PNC is expected to achieve the following deliverables:

1. A strategy to ensure effective communication within the network which is aligned with national policy and directives.
2. Agreed baseline for service development and network specific data collection.
3. Support the development of a regional register giving robust information which will be produced in a report format and feed into the national register (see endnote on previous page).
4. A gap analysis of children's diabetes services across the region in order to identify areas for service improvement and development.

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<sup>1</sup> Due to ongoing debate as to the value of establishing regional registers, this objective has recently been suspended.

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5. Educational standards agreed for both clinicians and patients aligned with the PbR contracting framework and implementation of consistent policies, practice and service delivery across the region.
  6. Clear evidence of public and patient engagement.
  7. Evidence of development of links to other key strategies, e.g. Children's NSF<sup>2</sup>, 'Healthy Ambitions' programme<sup>3</sup>.
  8. For all PCTs/providers within their respective region to agree to fund and sustain this role going forward in order to deliver high impact service delivery.

### About this report

The overarching aim of the project, from which this report stems, is to evaluate the perceived impact of the regional PNCo role in achieving the outcomes as stipulated by NHS Diabetes, set out in the list above. This report presents the results of the evaluation of the North West PNCo and has been prepared for the North West Paediatric Network and its constituent parts.

### Methods used

A case study approach was used in this evaluation project. Interviews were conducted with the North West PNCo at monthly intervals. A total of six interviews were conducted between November 2010 and May 2011. An interview template consisting of 10 questions guided each interview (appendix) and spontaneous probes were used to capture further data. The first and last interviews were conducted face-to-face, with the remaining interviews being carried out by telephone. Each interview lasted for approximately one hour. Qualitative thematic analyses were conducted to identify the main themes for this report. In addition to the monthly interviews, the PNCo monthly progress reports to NHS Diabetes were analysed to capture further data and to triangulate evidence from the interviews.

The report was sense checked by the PNCo to ensure data had been accurately interpreted. Although this report reflects the personal views and experiences of the PNCo, the document was reviewed by the local network chair and local NHS Diabetes programme manager to ensure details about the network and network achievements were correct.

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<sup>2</sup> NSF for Children, young people and maternity services is available at: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4089100](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4089100)

<sup>3</sup> Details of the Healthy Ambition programme available at: <http://www.healthyambitions.co.uk/>

# Section 2: About the North West Paediatric Diabetes Network

The North West Paediatric Diabetes Network was established in October 2010 and was developed out of a pre-existing research network that covered part of the region. The network aims to bring together clinicians, commissioners and service users from across the region, to improve services and share good practice.

## About the North West region

The North West region comprises five counties: Cumbria, Lancashire, Greater Manchester, Merseyside and Cheshire. There are currently 28 paediatric diabetes centres in the region, which care for over 3000 children and young people with diabetes.

## Structure and function of the North West Paediatric Diabetes Network

The North West Paediatric Diabetes Network is chaired voluntarily by Dr Chris Cooper, Consultant Paediatrician at Stepping Hill Hospital, Stockport. The network formally consists of a lead clinician from each of the paediatric diabetes units in the area, an NHS Diabetes programme manager, a Diabetes UK regional manager and parent representatives. Additionally, all members of the multidisciplinary paediatric diabetes teams are kept informed of developments and invited to be involved in network activities. There are just over

100 clinical members of the network; a few of which geographically overlap with other networks and attend alternative meetings but are kept informed of the developments of the North West network.

Associate members of the network include academic researchers, representatives from pharmaceutical companies and commissioners. With the introduction of the best practice tariff (BPT)<sup>4</sup>, the network has developed a business element, in addition to the clinical aspects of the network.

The network meets on a quarterly basis, and reports to the Children's Board at the SHA on an informal, exception reporting basis.

## About the North West PNC

As set out above, the PNC post was created to support the development of the North West Paediatric Diabetes Network in order to deliver high quality services. The North West (NW) PNC came into post in October 2010 and worked part-time over 3 days (22.5 hours) per week. The PNC left the post in May 2011 due to the uncertainty around the sustainability of the role and the part-time nature of the post. The position was taken over by the PNC from the Yorkshire and Humber (Y&H) region.

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<sup>4</sup> Paediatric diabetes best practice tariff resources are available at: [http://www.diabetes.nhs.uk/networks/paediatric\\_network/](http://www.diabetes.nhs.uk/networks/paediatric_network/)

# Section 3: Key achievements of the North West PNC

The sections below detail the key achievements of the North West PNC and the impact these have had on the function of the North West Paediatric Diabetes Network.

## Raising the profile of the network and stakeholder engagement

### *Developing an effective communication strategy*

Since the North West Paediatric Network has recently been established, one of the first key priorities for the PNC was to develop an effective strategy to engage stakeholders. Before formalisation of the network, clinicians in the region meet on an ad hoc basis to discuss specific issues, but a strategic approach to proceedings was lacking. Moreover, not all of the units and their respective leads were known to the network, therefore initially, the PNC invested a considerable amount of time identifying these units and establishing communication links.

The PNC felt it was important to build and manage relationships with network members before asking anything from them. Initial strategies included:

- Making initial contact with clinical and non-clinical stakeholders via email.
- Minimising contact with units to ensure clinical personnel were not overburdened with lengthy and irrelevant information.
- Using the first network meeting to introduce the PNC role.

To maintain and further develop engagement the PNC described how she:

- Used network meetings as networking opportunities and a forum to provide information about specific local objectives.
- Visited each unit on a regular basis.

- Telephoned stakeholders when appropriate.
- Produced monthly update emails, including information on: relevant publications, upcoming events, and details about particular network activities.

A contact database was established and included details of all communications between the PNC and the paediatric diabetes units. This enabled the PNC to keep track of replies and generate a picture of who from each unit was engaged with the network. The database also ensured problems were identified promptly, so the PNC could become more proactive or change approach if units did not appear to be engaged.

In addition to healthcare professionals, the PNC also sought to build relationships with other stakeholders; including, representatives from Diabetes UK, commissioners and academics.

### *Successful stakeholder engagement*

The PNC considered the relationships she built throughout the North West paediatric diabetes community one of her greatest achievements. The communication and engagement strategies the PNC adopted resulted in all paediatric diabetes units in the region becoming actively involved with the network, with none of the units opting out of the memorandum of understanding (MoU)<sup>5</sup> with NHS Diabetes.

Attendance rates at network meetings have been increasing since the PNC came into post (Table 1). Over half of the formal members attended the last network meeting; moreover, all of the remaining members sent apologies to the PNC, indicating a high degree of active engagement with both the network and the coordinator. Network meetings have been described as productive and proactive and a diverse range of stakeholders are now being represented, including:

<sup>5</sup> The MoU sets out the working relationship between NHS Diabetes and Kidney Care and the individual units, describing the responsibilities of each party and key deliverables.

- consultant paediatricians
- paediatric diabetes specialist nurses
- psychologists
- dietitians
- commissioners
- parent representatives

Date of network meeting	Number of people attending network meetings
October 2010	14
April 2011	28
October 2011	52

Table 1: Attendance rates at network meetings

The PNCo consistently reported high levels of motivation from within the network, and conveyed the importance of the PNCo role in organising the network, enabling the energy and enthusiasm to prosper. These positive reports have been verified by the Y&H PNCo, who reported how transition into the role was a straightforward process due to the systems the NW PNCo had put into place; furthermore, she felt like network members already knew her because of the good relationships the NW PNCo had fostered.

The coordinator reported being contacted regularly for advice or support on a variety of topics. Many queries could be readily answered over the phone or via email; however, more complex questions or those requiring specialist knowledge required additional input from the PNCo, for example:

- *Best practice tariff (BPT)*: invited BPT National Lead to a network event to directly address questions/concerns and consulted her directly about additional queries.
- *Commissioning*: liaised with NHS Diabetes programme manager and network chair.
- *National Paediatric Diabetes Audit*: searched for information on the audit website and contacted organisers directly when necessary.
- *Finance*: provided reference documents to help local business cases, shared information between units and offered to attend local meetings.

- *Insulin pump*: gathered information from various sources including other paediatric diabetes units and guidance documents.
- *Motivational interviewing*: sourced training, held meeting with trainer, proposed dates and secured funding.
- *Engagement with schools*: referenced work carried out by Diabetes UK, gathered information from two units that had cited good practice, identified potential barriers for local unit to focus on, and facilitated a discussion about working in schools at a network event.

Many of the enquiries related to how other units were undertaking various aspects of service provision and care, and the PNCo sought consent from units to share innovative and good practice amongst network members.

Excellent progress has been also made in connecting with the wider paediatric diabetes community. The PNCo reported being regularly contacted by external stakeholders for advice and networking opportunities. Representatives from pharmaceutical companies offered to fund network meetings, and the PNCo was invited to present her perspective on current paediatric diabetes service provision by the North West Paediatric Diabetes Research Study Group.

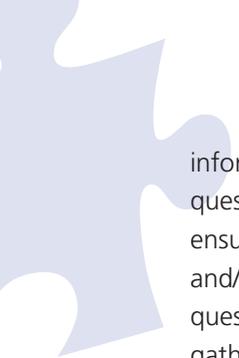
Being seen as a source of knowledge and facilitating the sharing of information not only between the units and network members, but also stakeholders from the wider diabetes community, suggests the role has become a valuable asset and a fundamental element to the structure of the network.

#### *Increasing participation in network activities*

The PNCo described how each of the units has different strengths, weaknesses and needs, and by allocating roles that individual units would find rewarding, the PNCo hoped all of the teams would contribute to the network.

#### *Increasing contributions to the network*

When it was necessary for network members to review and respond to information, the PNCo explained how she developed a system to manage the process effectively and efficiently. A form was prepared to collect the responses and included



information about the topic and the specific questions that required answering. This system ensured units were clear about the relevance and/or importance of the request, the correct questions were answered, and responses were gathered in a standardised manner, making the information easier to collate. The PNCo felt this was a good way to increase the number of responses to requests for feedback, and ensured the ideas and perspectives from all network members were considered.

### *Strategies to develop the network*

The PNCo described how working towards a common goal was an effective way to unite the network. Developing and carrying out a service evaluation and subsequent gap analysis would not only serve this purpose, but would also provide a baseline of current service provision for the region from which the network could build. An initial email providing succinct information about the service evaluation, what it would entail, and exactly how much time it would take, was distributed to all of the paediatric diabetes centres in the region. The PNCo believes this tactic was effective, as 24 units provided a prompt positive response to the email, and the planned follow-up telephone call to discuss the project was only necessary for the four that did not reply. Effective negotiation resulted in all units agreeing to participate; furthermore, a large number of units volunteered to pilot the service evaluation, which the PNCo described as a real measure of success.

### **Service evaluation and gap analysis**

The PNCo reported a lack of knowledge about levels of paediatric diabetes service provision in the North West due to the low percentage of units participating in national audits – putting the region at a disadvantage. Therefore, a service evaluation was imperative to provide accurate and up-to-date information on the current state of paediatric diabetes services in the region. This information would inform a gap analysis to identify areas for improvement, and would also ensure that units are prepared for the introduction of BPT.

The service evaluation covered all aspects of paediatric diabetes and diabetes care, from diagnosis, to transition into adult services. The PNCo described how she used her experience in audit and analytics to develop the questionnaire in conjunction with the network chair. The questions were devised using a range of resources, including: National Service Framework for Children and Young People, NICE clinical guidelines for type 1 diabetes, BPT discussions and other best practice guidance. The structure was based on DiabetesE, an online self-assessment tool, to make efficient use of the questions already developed. Stockport, Chester and Macclesfield were the first three units to express an interest in the project and were subsequently chosen as the pilot sites.

The PNCo described how she used the questionnaire to conduct semi-structured interviews with each of the units, thereby achieving a more open rather than fully structured service evaluation. The data was collated in a spreadsheet by representatives from each unit before the PNCo revisited each unit and invited them to review the information and amend as necessary. Units were supported at network meetings to identify specific areas of concern, enabling the network to work more strategically in addressing priorities at regional level. A report detailing the findings from the service evaluation is currently being drafted and will be available to the network later in the year.

All units in the region have carried out the service evaluation. The PNCo considered this positive and active response to the project, and the number of units eager to take part, to be a real achievement. She viewed this as evidence of how the PNCo can successfully facilitate the objectives of the national network while also motivating and supporting network members to take active steps towards improving and developing diabetes services for children and young people.

## Establishing work streams

To enable the network to meet some of the national objectives and other local priorities identified during network meetings, four work streams have been established and objectives have been set:

### *Dietetics and DSN resources*

- For all areas to outline how they plan to support schools in their care of children with diabetes; especially for newly diagnosed children.

### *Psychological support*

- By April 2013 all members of the North West network will have access to training on mental health assessment for young people and families.
- By April 2013 all members of the North West network will have access to validated mental health assessment tools for young people and families.

### *Patient involvement/transition*

- To develop a transition toolkit to assess, with young people, their competency in areas of transition.
- For a North West network meeting to showcase examples of good practice in engagement with young people and their parents.

### *Best practice tariff*

- All units to have had discussion regarding the specifics of tariff.

To assist the delivery of specific pieces of work, the PNCos provides administrative and communication support to the working groups and acts as the pivotal link between the various stakeholders. This support not only enables the efficient sharing of knowledge and information, but can also provide the drive and momentum to enable projects to be delivered in a timely manner. The current PNCos has reported that the work streams are progressing well and on course to achieve their objectives.

## Data submission to the National Paediatric Diabetes Audit

As previously discussed, participation in the National Paediatric Diabetes Audit (NPDA) in the North West region was poor, with only ~40% of units taking part in the 2008/09 NPDA<sup>6</sup>. Although barriers to submitting data were predominated by lack of IT resources and expertise, the PNCos also conveyed the reluctance of some units to submit data because of previous experiences; for example, poor organisation of the submission process. It was also reported that network members expressed concerns about the quality of the analysis and interpretation of data, as the findings were not perceived to be reflective of what is going on in the units.

Despite these barriers and reservations, the PNCos reiterated the importance of good quality data to the units and focused on developing the abilities of unit members to manage and utilise their own data. As a result, audit participation rates increased to 68% in 2009/10, and continued support from the subsequent PNCos has led to a 100% submission rate in 2010/11<sup>2</sup>. This has been a great achievement for both the North West region and the PNCos, and importantly, prepares the units for the impending BPT which requires all units to take part in the NPDA.

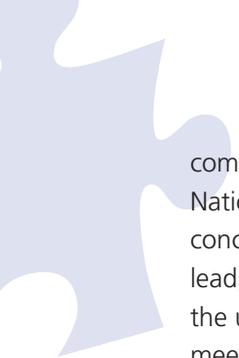
## Implementation of policies in line with BPT

### *Input into the development of best practice criteria*

Criteria to incentivise best practice for paediatric diabetes were developed by the national clinical leads and representatives from the regional networks<sup>7</sup>. The PNCos expressed concerns that units were not being consulted on the development of the BPT, and opted to distribute the consultation document to network members after each revision. Time was also set aside for units to discuss the tariff with the PNCos during the service evaluation meetings. The coordinator acted as a

<sup>6</sup> Available at: <http://www.ic.nhs.uk/nda>

<sup>7</sup> Details of BPT criteria are available at: [http://www.diabetes.nhs.uk/networks/paediatric\\_network/](http://www.diabetes.nhs.uk/networks/paediatric_network/)



communication link between the units and the National Clinical Lead for BPT; queries and concerns were collated then forwarded to the BPT lead, and detailed responses were relayed back to the units. The BPT lead also attended a network meeting where further discussions of the issues were facilitated by the PNC Co. The PNC Co believes some of the changes made to the draft tariff may have been in response to queries raised by the North West network, and without facilitation by the PNC Co the views of the units may not have been taken into account.

#### *Supporting units to understand BPT*

Although members of the North West network were not initially engaged with BPT, the PNC Co continually employed different tactics to ensure this matter became a priority for all units. At first, the PNC Co reported it was challenging for many teams to turn their attention from clinical topics to financial issues. Organisations were split between those managing financial matters and those managing clinical aspects of care. Therefore, the PNC Co focused on providing education on service management, including negotiating with commissioners, and identified internal resources to enable the units to redress the dissociation. To address the anxiety many of the units were communicating regarding the tariff, the PNC Co also pressed units to develop relationships and seek support from within their own organisation. For example, the PNC Co facilitated engagement between the paediatric diabetes units and financial teams to enable them to build business cases for the new tariff. The support and guidance provided by the network coordinator has ensured all paediatric units in the North West are fully aware of the impending changes to funding, empowering them to take the necessary action to ensure they receive the new payment.

The PNC Co described how people had been contacting her independently for assistance and advice about resourcing and BPT, demonstrating

that progress on the issue was becoming unit led, rather than PNC Co led, providing further evidence that the network coordinator role has become important for facilitating network objectives.

#### *Supporting commissioners to understand PbR tariff*

Although the majority of units were ready to engage with commissioners about BPT, the current reorganisation of the PCTs meant there was uncertainty amongst commissioners as to who would be responsible for paediatric diabetes. Furthermore, the PNC Co reported that at the time of the interviews, commissioners were not prioritising children and young people with diabetes or the new tariff until the best practice criteria became mandatory. Consequently, contact with commissioners was de-prioritised until this issue had been resolved by PCTs.

The current PNC Co worked with the SHA to schedule an event to engage commissioners with BPT which took place in December 2011. The NHS Diabetes programme manager reported that all of the commissioning groups and the SHA were represented, and that whilst the information was largely well received, it was evident that considerable work was needed to ensure all stakeholders were ready for the introduction of the new tariff.

### **Patient and public involvement**

There was a reported lack of patient and public involvement in paediatric diabetes across the North West region. The Diabetes UK service user involvement team was contacted by the coordinator to try and find ways to address this issue, and she reported having input into the Diabetes UK North West Family Day. The PNC Co spoke of her intention to design innovative ways to increase the number of service users involved in network activities, and a work stream was set up to showcase examples of good practice in engagement with young people and their parents.

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<sup>8</sup> Information on the 'Join Us on Our Journey' project is available at: [http://www.diabetes.nhs.uk/about\\_us/research\\_and\\_evaluation/join\\_us\\_on\\_our\\_journey/](http://www.diabetes.nhs.uk/about_us/research_and_evaluation/join_us_on_our_journey/) and <http://www.leedsmet.ac.uk/gettingsorted/61165D76C64C4A85BA0548AC0FE6DCB3.htm>

<sup>9</sup> Available at: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_073674](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_073674)

Establishing creative ways to engage children and young people, and methods of how units can listen to patients and carers are currently in development. For example, units have engaged well with the parents and children and young people from the 'Join Us On Our Journey' (JUOOJ)<sup>8</sup> project. This was a three-year research project commissioned and supported by NHS Diabetes and carried out by Leeds Metropolitan University. The aims were to develop a model of care that will deliver the aspirations of the policy document 'Making Every Young Person with Diabetes Matter'<sup>9</sup> and improve provision of care for children and young people with type 1 diabetes, and representatives from the JUOOJ group feed into the network.

The current PNCo is consulting with a local adult diabetes network that has successfully embedded service user involvement<sup>10</sup>, on how best to implement a patient expert reference group, where service users can be consulted on specific pieces of work. It is hoped that this approach will result in meaningful and valuable service user input into the improvement and development of paediatric diabetes services in the North West region.

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<sup>10</sup> Information on the 'User Involvement in Local Diabetes Care' project is available at: [http://www.diabetes.nhs.uk/about\\_us/research\\_and\\_evaluation/an\\_independent\\_evaluation\\_of\\_the\\_user\\_involvement\\_in\\_local\\_diabetes\\_care\\_project1/](http://www.diabetes.nhs.uk/about_us/research_and_evaluation/an_independent_evaluation_of_the_user_involvement_in_local_diabetes_care_project1/) and [http://www.diabetes.nhs.uk/areas\\_of\\_care/user\\_involvement1/](http://www.diabetes.nhs.uk/areas_of_care/user_involvement1/)

# Section 4: Challenges

The PNC Co has, understandably, faced some challenges during the initial months of the post. Many have been resolved or lessened following discussions with network stakeholders, or through careful time management.

## Time constraints

One of the biggest challenges the PNC Co reported were time constraints; not only on the PNC Co role but also other members of the network. Coordinating diaries to schedule meetings between the various stakeholders was not always easy as clinical duties were understandably prioritised over the network.

The PNC Co reflected on previous roles and felt that the deliverables of the post were unrealistic within the timeframe, and that the development of the networks should be more gradual. The PNC Co conveyed her belief that time was needed to build solid stakeholder relationships which needed to be firmly in place before asking network members to embark on tasks that would possibly take time away from their clinical commitments. However, as previously described, the PNC Co successfully built strong relationships with the network, evidenced by increased attendance rates at network meetings and 100% engagement in the service evaluation project. Therefore, this challenge has been overcome and the coordinator can focus on facilitating the network in achieving their objectives.

The PNC Co reported having strong time-management skills but stated that the part-time nature of the post had impacted negatively on her ability to effectively carry out the role. For example, the frequency of visits to paediatric diabetes units had to be limited due to the extensive travel time between the hospitals. This reportedly not only hindered the building of relationships with unit staff, but also impacted on the delivery of the service evaluation. The PNC Co expressed strong

feelings that the role should be full-time, particularly as the post is continually developing and the PNC Co position has become more involved with the network and network activities.

## Differences between national and local priorities

The PNC Co reported conflict between the outcomes set at a national level and local priorities. For example, the PNC Co described how the BPT, submission to the NPDA and the development of a registry were perceived by the network to be small issues compared with the reorganisation of provider services in the North West. Given that the objectives for the network were set nationally after consultation with each of the ten regions it is understandable that national and regional priorities may not be completely aligned. As previously discussed, despite the challenges and misgivings about submitting data to the NPDA and engagement with BPT, the PNC Co has ensured that these outcomes have been achieved. Progress has also been made establishing a regional register (see below).

However, the PNC Co expressed her concern that focusing purely on nationally set outcomes limited capacity for addressing additional regional issues. For example, the PNC Co described how the reorganisation of services could further exacerbate the inequality of service provision in many areas across the North West. The PNC Co felt confident, capable and happy with what she was doing regionally, but felt there was something missing in terms of national structure and objectives and how local and national needs fit together.

### *National Register*

The PNC Co conveyed that some members of the network were keen to submit data to a national database; however, members of the network expressed reservations about the value of a regional register, particularly if data items collected

by the NPDA are improved. A number of other barriers, predominantly IT related, were also identified. Paediatric diabetes units in the North West use several different databases, and patient data is collected in a variety of formats, with some units using paper records. Many units were also reportedly apprehensive about their knowledge and the resources required to maintain a local database.

As described in the earlier East of England PNCo evaluation report<sup>11</sup>, one of the other main barriers to establishing a registry has been obtaining ethical approval which has caused considerable delays to the project. However, a regional register has recently been launched in the North East, and the North East Paediatric Registry Coordinator has

been supporting the regional PNCos with the set-up process, particularly applying for ethical approval. It is hoped that this shared learning will hasten the ability of the other regions to establish a registry in the future.

Although these compounding factors have led to the North West network to deprioritise the registry, the PNCo reported working with units to improve capacity such as standardising methods of data collection, improving data collection processes, and identifying funding and training, to enable units to submit data to a registry should the network consider a regional database valuable in the future. Furthermore, these initiatives will allow units to submit data to the NPDA more readily.

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<sup>11</sup> Available at: [http://www.diabetes.nhs.uk/about\\_us/research\\_and\\_evaluation/regional\\_paediatric\\_diabetes\\_network\\_coordinator/](http://www.diabetes.nhs.uk/about_us/research_and_evaluation/regional_paediatric_diabetes_network_coordinator/)

# Section 5: Enablers

## *Previous experiences*

The PNC Co felt very confident in the role because of her previous experience. Having worked with networks in the past, the PNC Co realised the need to build relationships before demanding anything from them, and used this knowledge to formulate strategies to successfully engage network members. The PNC Co believed that her analytical and audit background within the NHS provided the network with the expertise to develop and carry out the service evaluation. Previous employment in the North West region was also described as an advantage, as the PNC Co already knew the people she would need to contact to get specific information.

## *Support from the network*

As previously discussed, the PNC Co reported high levels of enthusiasm and motivation from within the network. This proactive attitude enabled her to seek information and advice from a variety of stakeholders, in particular, the network chair. With regard to the BPT, the NHS Diabetes regional manager was regarded as a good source of information and always responded to emails in a timely manner. Assistance was also available from outside the network, for example, the chair reported that the department manager at Stockport Hospital 'helped her to settle and find her feet'. Having this level of support from both within and outside the network has made it easier for the PNC Co to carry out the role efficiently and effectively, which in turn, has had a positive impact on the network and contributed to its success.

# Section 6: Influences on the sustainability of the PNC Co role and networks



The uncertain future of PCTs and SHAs is the major influence on the sustainability of networks and the PNC Co role. Currently, networks are devising strategies to address these impending changes. The current PNC Co is in the process of writing a sustainability paper which will be presented to the North West network early 2012.

# Section 7: Conclusion and next steps

The PNCo role has been pivotal in facilitating the achievements in the network, and are summarised in the table below.

<b>Network and PNCo deliverables</b>	<b>Outputs / Outcomes</b>
Effective communication strategy with the network and increased stakeholder engagement	Attendance at network meetings has increased almost four-fold since the first network meeting in October 2010 All members of the multidisciplinary paediatric diabetes team, commissioners and service users are represented in the network Regional network page on NHS Diabetes website 100% engagement with the service evaluation project All units have agreed a MoU with NHS Diabetes
Baseline for service development and network specific data collection	100% participation in the service evaluation
Submission to NPDA	100% submission to the 2010/2011 audit
Regional Register	Working to standardise data collection Liaising with North East Registry Coordinator
Implementation of consistent policies, practice and service delivery	BPT work stream established Input into the development of the criteria to incentivise best practice Paediatric diabetes units and commissioners are fully informed of BPT Psychological support work stream established Dietetics and DSN workstream established
Public and patient involvement	Patient involvement work stream established Links with Diabetes UK service user team Input into Diabetes UK North West family days Links with local adult diabetes network that have embedded service user involvement
Standardised service specification	Service specification developed by Yorkshire and the Humber network is being implemented
Schools work	Dietetics and DSN workstream established
Sustainability of the role	Sustainability paper being drafted

Table 2: Achievements of the North West Paediatric Network facilitated by the Paediatric Diabetes Network Coordinator

Successful engagement between the PNCos and the network members has contributed to the achievements of this newly established network. The greatest achievements have been the development and participation in the service evaluation, and submission of data to the NPDA by all paediatric diabetes units in the North West region; particularly as not all of the units and their respective clinical leads were known to the network when the PNCos first came into post. Findings from the audit and service evaluation will provide invaluable information about the current state of paediatric diabetes services in the North West region, enabling clinical teams to identify the gaps in the services they provide and inform them of improvements that need to be made.

Having the role of the network coordinator has ensured network members and commissioners are informed of the impending BPT, and this work continues to ensure that all stakeholders are fully prepared for implementation of the tariff which becomes mandatory in 2013/14.

Work also continues to engage service users in the development of paediatric diabetes services in the North West region. Parent representatives now attend network meetings and the network hope to implement a patient expert reference group in the near future.

The network coordinator has helped the network deliver these objectives by providing effective and efficient administrative and communication support, facilitating between the network and key internal and external stakeholders. The role has been the driver for many projects and has helped maintain the momentum of several network activities, ensuring outcomes are delivered in a

timely manner. The North West PNCos also provided specific expertise in areas such as audit, analytics, service management and development, which provided the network with the capability of achieving some of the more specialist network objectives.

The current PNCos continues to develop strong links established by the PNCos not only with network members but other paediatric diabetes stakeholders, which have been the key to successfully addressing the strategic priorities of the network.

#### *Scope of the role*

The interviews with the NW PNCos raised a number of questions about the scope of the role. The post has only recently come into fruition, and it is understandable that the role will evolve. The PNCos embarked on numerous additional initiatives to further develop the network, many of which have arisen as a result of her previous experiences. In future, these projects may prove beneficial to the network; however, given that one of the major challenges has been time-constraints, at this current time the focus of the role should be aligned with priorities set by the national network.

#### **Next steps**

The final interviews have been conducted with the PNCos in the Yorkshire and the Humber region which will conclude the four PNCos role case studies, and a report similar to this one will be produced for that network and its constituent parts. Subsequently, an overarching report of findings will be produced and published on the NHS Diabetes website.





[www.diabetes.nhs.uk](http://www.diabetes.nhs.uk)

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