NHS

Diabetes

Evaluating the role and perceived impact of four regional Paediatric Diabetes Network Coordinators: The key findings

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Reader Page

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Foreword

Dear colleagues

I am delighted to have been asked to introduce you to this excellent report evaluating the role and perceived impact of four regional paediatric diabetes network coordinators (PNCos) in England. There is no doubt in my mind that the role of the PNCo is absolutely vital to the smooth running of the regional diabetes networks. They have been instrumental in ensuring individual paediatric diabetes delivery units have been supported in many ways to ensure the provision of good clinical care to the children and young people (CYP) with diabetes and their families who use our services.

Within this evaluation report, you will find out about the work of the National CYP Diabetes Network, alongside that of the 10 regional diabetes networks. Of particular importance is how the PNCos successfully engaged stakeholders within their region and encouraged partnership working thereby creating unified networks able to successfully deliver specific projects.

Finally, the report examines the future of the paediatric networks and the benefits of having the PNCos in post to help drive and coordinate service changes that will benefit our children and families.

I am in no doubt that these roles are crucial in the future. The findings of this evaluation suggest the PNCo role has become embedded in the structure of the regional networks. As we all know, the paediatric diabetes provider units must be a member of their regional network and actively participate in them in order to be eligible to receive the best practice tariff. In my view – if there is no PNCo, then there is no network, and no tariff. The PNCos are essential to the survival of the regional networks. 'Hosting' them along with developing arrangements for their on-going funding is a matter of priority.

Dr Fiona Campbell
National Clinical Lead for Paediatric Diabetes

Executive Summary

Living with a complex, chronic and potentially life-threatening long-term condition is challenging for anyone, but it is especially challenging for children and their families. For children and young people with diabetes, their needs are particularly complex and considerable variation exists in the number of recommended care processes this population receives. The NHS Outcomes Framework highlights the importance of preventing young people dying early from conditions such as diabetes and requires action to ensure improvements are made in this area.

It was against this background that NHS Diabetes set up ten regional paediatric diabetes networks across England. These networks ensure effective two-way sharing of the most up-to-date guidance, tools, best practice and resources. Led and supported by clinical leads and experts working in frontline diabetes services, they promote innovative and proactive approaches with the aim of improving the quality and cost effectiveness of diabetes services for children and young people, and their families. A national paediatric network was also established, and with funding and support from NHS Diabetes, a team of regional Paediatric Network Coordinators were recruited to support the delivery of the agreed priorities.

The strategic aims of the networks were to:

- Support implementation of the standards set out in the new Best Practice Tariff across the country.
- Raise the profile of the regional paediatric diabetes network and widen stakeholder engagement.
- Map the numbers of staff alongside their levels of training and competency in children's diabetes care in each provider unit.
- Support the development of 'Peer Review' in paediatric diabetes care initially with the roll out of 'self-assessment' against agreed 'measures'.
- Support professionals to improve the standards of care for young people moving through paediatric services towards young adult services, currently described as 'transitional care'.
- Encourage 100% data submission to the National Paediatric Diabetes Audit (NPDA).
- Support the future development of a regional and national registry for children and young people with diabetes.
- Assist the provider units to implement the nationally-agreed service improvement strategy with a view to seeing improved outcomes.
- Encourage provider units to utilise a standardised paediatric diabetes service specification.
- Work with partners on the European SWEET project (Better control in paediatric and adolescent diabetes: working to create centres of reference) to influence improved standards of care in England, bringing them in line with some other European Countries.

The purpose of the PNCo post was to develop a local strategy that was aligned with national outcomes and the strategic priorities of NHS Diabetes, and as such, the PNCo was expected to achieve the following deliverables:

- A strategy to ensure effective communication within the network which is aligned with national policy and directives.
- Agreed baseline for service development and network specific data collection.
- Support the development of a regional register.
- A gap analysis of children's diabetes services across the region in order to identify areas for service improvement and development.
- Educational standards agreed for both clinicians and patients aligned with the Payment by Results (PbR) contracting framework and implementation of consistent policies, practice and service delivery across the region.
- Clear evidence of public and patient engagement.
- Evidence of development of links to other key strategies e.g. Children's National Service Framework, 'Healthy Ambitions' programme.
- 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.

The outcomes delivered by both the networks and the PNCos have been considerable, as this evaluation report shows:

- 100% of the units in the National Paediatric Network agreed the criteria for the best practice tariff which is now being rolled out across the country. These are the first ever mandatory standards for paediatric diabetes care.
- The profile of paediatric diabetes has increased with the emergence of the National Paediatric Diabetes Network, the PNCo role and the roll out of the best practice tariff.
- An increase from 54% to 99% participation in the NPDA due to promotion by the PNCos across the country.
- A paediatric diabetes register has been established in the North East and East of England regions.

Furthermore, current projects include:

- A paediatric diabetes model for transition is now being rolled out across the country.
- The development of an e-learning module for all healthcare professionals looking after children and young people with diabetes.
- The formation of a National Parents Reference group which feeds into the National Paediatric Diabetes Network meetings.
- 100% of the paediatric units across the country are taking part in the self-assessment stage of peer review, funded by NHS Diabetes.

The PNCos have been instrumental in achieving these outcomes and a number of further benefits have also become apparent.

Stakeholder engagement has increased in all regions, and representation in the network from across organisations and professions has diversified.

Having established effective working relationships with paediatric diabetes stakeholders, the PNCos are now considered the first point of contact for the network. This provides the network with some familiarity and consistency. Being able to facilitate widespread sharing of knowledge and expertise puts the PNCo role at the heart of the network thereby creating a more collaborative and cohesive way of working.

The PNCos have helped the regional network deliver both national and regional projects by providing effective and efficient administrative and communication support. The role has also been the driver for many projects, helping to maintain the momentum of network activities, ensuring outcomes were delivered in a timely manner. Specific expertise or skills were also provided by many of the coordinators.

But what of the future? The dedicated funding for the PNCo posts provided by NHS Diabetes ceased at the end of June 2012 and unless further funding and support can be found, the NHS, and children and young people with diabetes, risk losing this effective resource.

Maintaining the regional networks has become imperative as active participation in a local paediatric diabetes network is one of the criteria for attaining best practice tariff. Receiving the payment is dependent on units achieving all thirteen specified criteria otherwise they will receive no money at all.

Although the networks have achieved so much, it is vital the regions continue to work together at a national level to ensure standards of care for children and young people with diabetes are improved across the country by sharing good practice, expertise, learning, tools and resources.

The findings of this evaluation suggest that the PNCo role has become embedded in the structure of the regional networks and is pivotal to the effective functioning of the networks. Retaining this role will help maintain the momentum of the regional and national networks to help drive towards achievement of the vision of the national network – to reduce variation of care and deliver better outcomes for children and young people with diabetes, their families and carers no matter where they live in England.

Section 1: Introduction

1.1 NHS Diabetes and Paediatric Diabetes

NHS Diabetes is a service improvement team working with managers, commissioners and providers of diabetes services to improve the quality of care for people of all ages with diabetes in England. As such, the organisation has developed, funded and supported a programme of work to improve equity of care and service delivery for children and young people with diabetes.

NHS Diabetes established and manages a series of specialist networks to ensure effective sharing of the most up-to-date guidance, tools, best practice and resources amongst health care professionals[1]. The first of these, the National Paediatric Diabetes Network, was launched in June 2009[2]. This network aims to bring together healthcare professionals to reduce variation of care and deliver better outcomes for children and young people with diabetes, their families and carers no matter where they live in England.

The development of the network was instigated following a snapshot survey, which estimated there were almost 23,000 children and young people (0-17) with diabetes in England on 1st January 2009. The survey was commissioned by NHS Diabetes and carried out by the Royal College of Paediatrics and Child Health (RCPCH).[3]

1.2 About the National Paediatric Diabetes Network

At the time of writing, each of the ten former SHA regions now has a dedicated paediatric network. These regional networks are underpinned by the National Diabetes Paediatric Network, which is made up of representatives from each regional network and supported by programme managers from NHS Diabetes. The national network meets twice a year and shapes the strategic direction of the network. During 2010/12, the following outcomes for each regional paediatric network were identified:

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. Define and agree a local care pathway model.
5. Establish a regional paediatric diabetes register.
6. Map levels of staffing across the network.
7. Support commissioners to understand paediatric diabetes requirements and Payment by Results (PbR) tariff.
8. Take part in the National Paediatric Diabetes Audit (NPDA).
9. Establish clear governance arrangements with the strategic health authority (SHA) and long-term conditions (LTCs) groups/boards.

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[1] Information about these network is available at: Areas of care -> Networks - NHS Diabetes

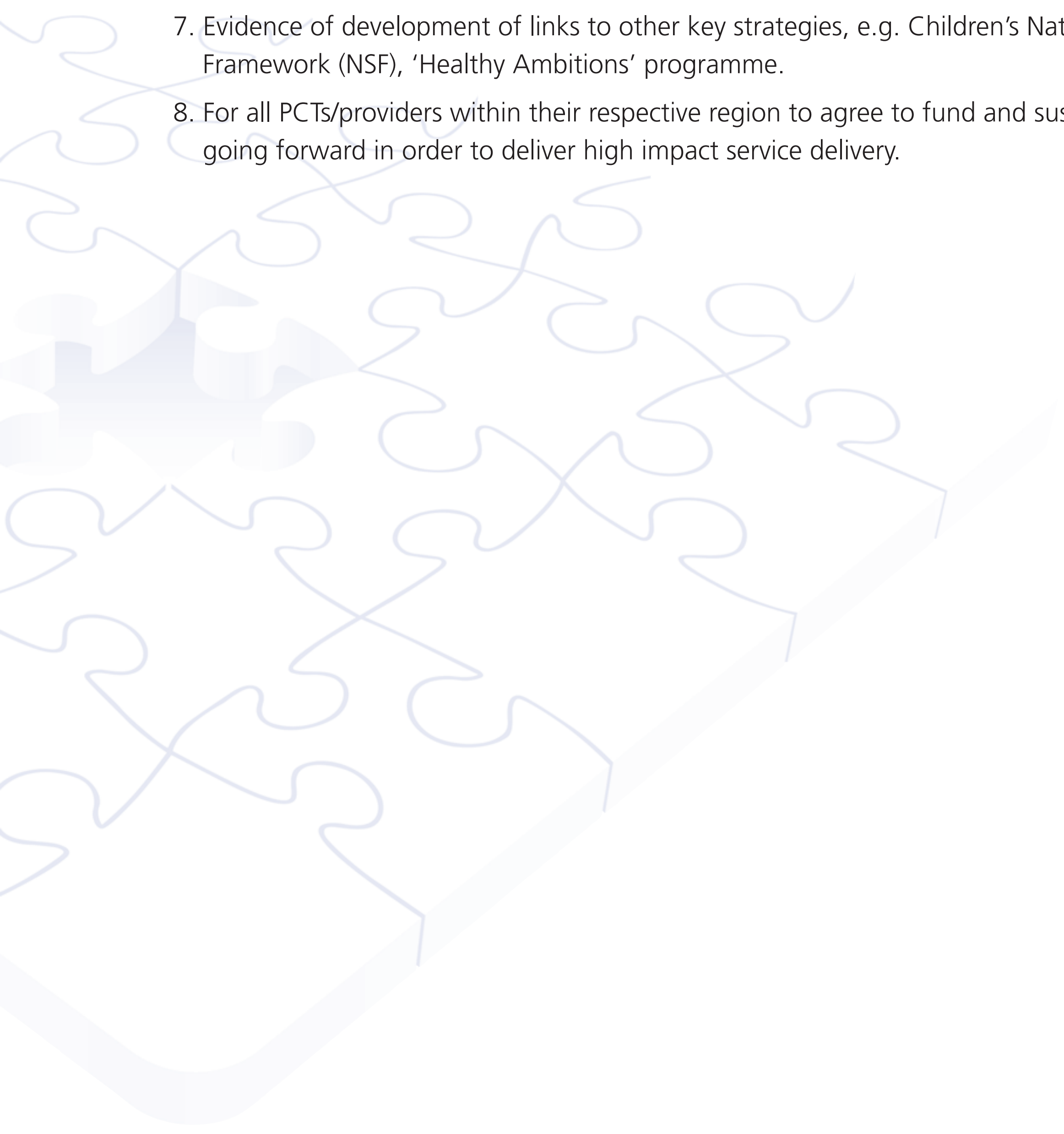
[2] Further details of the National Paediatric Diabetes Network are available at: Areas of care - Networks - Paediatric network - NHS Diabetes

[3] Report available at: http://www.rcpch.ac.uk/news/first-national-survey-finds-23000-children-diabetes-england-06-april-2009 or http://www.diabetes.nhs.uk/networks/paediatric_network/

1.3 About the PNCO POST

To support the regional networks deliver these national objectives, NHS Diabetes offered to fund a paediatric network coordinator (PNCo) role in each region. The purpose of the PNCo post was to develop a local strategy that was aligned with national outcomes and the strategic priorities of NHS Diabetes, and as such, the PNCo was 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.
4. A gap analysis of children's diabetes services across the region in order to identify areas for service improvement and development.
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 National Service Framework (NSF), 'Healthy Ambitions' programme.
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.



Section 2: About this Evaluation

2.1 What was the aim of this Evaluation?

The aim of this project was to evaluate the role and perceived impact of the regional PNCo in achieving the outcomes as stipulated by NHS Diabetes and the National Paediatric Diabetes Network.

2.2 What methods were used?

A case study approach was used to explore the perspectives of four regional PNCo roles. Due to time restraints, the first four coordinators that came into post were recruited into the study. Each of the participating PNCos was interviewed on a monthly basis over a six-month period. An interview template consisting of 10 questions guided each interview (Appendix 1) 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, the PNCo monthly progress reports to NHS Diabetes were analysed to capture further data and to triangulate evidence from the interviews.

A report was produced for each of the four participating regions[4] and sense checked by the PNCo to ensure data had been accurately interpreted. Although these reports reflect the personal views and experiences of the PNCos, the documents were reviewed by the respective regional network chairs and NHS Diabetes programme managers to ensure details about the network and network achievements were correct.

2.3 About this report

This overarching report presents the main themes that emerged from the four case studies. The views and experiences of the other PNCos and North West registry coordinator are also included which were captured via a focus group and face-to-face interview respectively.

2.4 What are the limitations of this study?

There are limitations associated with the methodology used in this study. Firstly, the nature of this evaluation does not allow us to establish a cause and effect relationship between the PNCo role and the regional networks achieving the prescribed outcomes set nationally. The experiences of the four regional coordinators may not be representative as case study subjects were selected on a first in post basis. As the data was self-reported, it may be subject to participant bias, social desirability for example. It also relies upon the memory or recall of events and potentially, details that may have been pertinent to the research questions may not have been communicated to the researcher. Although the reports were verified with the respective NHS Diabetes Programme Manager and Regional Network Chair, the information was not validated or triangulated with hard data sources and therefore may be prone to error. Finally, this evaluation has only identified short term impact of the PNCo role. The long term impact would have to be identified through future research.

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[4] Individual evaluation reports are available at:
http://www.diabetes.nhs.uk/about_us/research_and_evaluation/regional_paediatric_diabetes_network_coordinator/

Section 3: Regional paediatric diabetes networks and the PNCOS

3.1 Were regional networks in place before the National Paediatric Diabetes Network was established?

Before the advent of National Paediatric Diabetes Network, several regional paediatric diabetes groups existed. Some were described as clinical networks encompassing the whole or part of the region, whilst others were educational or research groups. Many held regular meetings but the frequency varied between groups ranging from every six weeks to every six months, and in some instances, on an *ad hoc* basis. Consequently, each of the regional networks started from a different position when the national network was established (Table 1).

3.2 Do all of the regional networks have a PNCO?

Nine of the ten regional networks opted to employ a Paediatric Network Coordinator (PNCo). Most coordinators were employed on a part time basis, (Figure 1) with some covering more than one region. London and the South East Coast share one full-time coordinator working across both regions.

In the North East, a functional paediatric diabetes network has been in existence for a number of years. As this region considered establishing a regional register a priority, the network felt a registry coordinator, rather than a PNCo, was a more appropriate use of resources.

Region	Number of paediatric diabetes units	Status of network when PNCo came into post	Time in PNCo post* (months)	Time allocated to PNCo role each week
East Midlands	10	Newly formed in Sep 09.		13 27 hrs
East of England	18	Developed out of long-running education meetings. Lead paediatric consultant appointed Sep 09 and established working groups.	#24	22.5 hrs
London South and East Coast	43	Comprised of 5 clinical networks and an overarching Partnership Board.		17 37.5 hrs
North East	13	Clinical network had been in existence for many years.	24 (Registry Coordinator) ‡4 (PNCo)	1 day 1 day
North West	28	Established in Oct 10 out of a pre-existing research network which covered part of the region.	7 ‡14	3 days 1 day
South Central	14	Comprises two networks: North & South. South network was well established and North network was formed in Sept 09.	11 #6	22.5 hrs 1 day
South West	11	A network, previously called a forum, had been in operation for many years with bi-annual meetings that predominantly focused on education.	18	22.5 hrs
West Midlands	20	Established a year before PNCo came in to post.	16	37.5 hrs
Yorkshire and the Humber	18	Clinical network had been active for many years.	‡18	2 days (split between 2 coordinators)

*Table 1: Characteristics of the regional paediatric networks and PNCo roles (*as of July 2012; ‡/# posts held by the same PNCo)*

SECTION 4: What is the nature of the PNCO role?

This section of the report will explore what the PNCo role entailed and how the coordinators went about achieving the deliverables of the post. Discussion points will include:

- How the PNCos engaged paediatric diabetes stakeholders and the communication strategies they adopted.
- How the PNCos helped their networks to work collaboratively.
- The mechanisms the coordinators put in place to support the networks deliver regional and national projects.
- What helped the PNCos carry out the role.

4.1 Stakeholder engagement

Engaging members of the paediatric diabetes community is one of the most important functions of the PNCo role. All of the coordinators consider the relationships they built with network members one of their greatest achievements. Moreover, all of the PNCos have reportedly gained endorsement for the role from their respective network(s).

4.1.1 How did the PNCOS build relationships with multidisciplinary paediatric diabetes teams?

Networks have the potential to improve services by promoting a whole system approach[5]. To achieve this, networks require representation from all organisations and professions involved in commissioning and delivering diabetes services. Initially, consultants reportedly dominated network membership in most, if not all regions. Carrying out stakeholder mapping exercises to identify the key members of the multidisciplinary team (MDT) in each paediatric diabetes unit was the first step many coordinators took to establish a representative network.

'There was something like a network, but it was very consultant based…they would discuss clinical practice and research and that sort of thing, and share some news. There was not really any governance or equity in terms of representation across the region, not everyone knew about it, and of course DSNs and dietitians weren't involved…Our biggest achievement is really actually getting such a cohesive group of people across the teams, not just the consultants, but nurses and dietitians, psychologists, we have had all sorts coming.' [PNCo 2]

Visiting individual units was a common approach for identifying members of the MDT. Most of the coordinators believed face-to-face contact was the most effective way to build relationships, particularly with healthcare professionals. These visits reportedly provided opportunities to reach the wider diabetes team, such as dietitians and psychologists, as communication channels to these professional groups were not always easy to access.

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[5] Beyond Boundaries: A guide to diabetes networks (2006). Available at: http://www.diabetes.nhs.uk/our_publications/archived_publications/

The role and responsibilities of the national network and PNCo post were commonly introduced during initial visits. Some PNCos described how they used health needs assessment or gap analysis questionnaires to gain a greater understanding of the strengths and weaknesses of the paediatric diabetes units. This enabled the coordinators to establish how they, and the network, could support each unit.

Many of the coordinators continue to visit units on a regular basis to ensure relationships are maintained. Given the part time nature of the role however, other coordinators felt that once rapport had been established this could be sustained through more time efficient methods. Moreover, in regions where visits to individual units were not logistically possible, the PNCos have successfully adopted other approaches to build and maintain relationships with clinical teams.

4.1.2 How did the PNCOS engage commissioners of paediatric diabetes services?

Commissioners were commonly reported as being hard to engage. Some PNCos described how the NHS reforms and associated disbanding of PCTs made it difficult to identify the relevant commissioners. Frequent changes in personnel reportedly led to uncertainty amongst some commissioners as to who would be responsible for paediatric diabetes. Several PNCos also communicated that commissioners were not prioritising children and young people with diabetes.

Lack of commissioner engagement was not universal however. A few coordinators relayed that commissioners had been part of their network from the outset and that relationships were good. Commissioners in these regions regularly attended network meetings and participated in network activities, for example by producing a best practice tariff (BPT) tool for commissioners and developing service specifications. The reasons why commissioners in these regions were more engaged than others are not clear, but the coordinators suggest a number of possible explanations:

- Clear structures within particular PCTs made it apparent who the relevant commissioners were.
- Commissioners were assigned tasks to make them feel part of the network.
- Commissioners previously holding clinical roles, particularly those within paediatric diabetes, already knew members of the network and had an interest and understanding of the issues.
- Having a proactive diabetes or long term conditions lead at the SHA who facilitated engagement with commissioners.

Most of the PNCos report commissioners have become more engaged with the network, although many acknowledge more work needs to be done to increase the commitment of this stakeholder group to the network.

4.1.3 how did the PNCOS encourage service user involvement?

Levels of service user involvement in the regional paediatric networks were poor when the PNCos first came into post. Some of the coordinators reported that although the networks realise the importance of service user input and are keen to involve young people with diabetes and their carers in network activities, debate continues about the most effective way to achieve this.

Diabetes UK has been an invaluable source of expertise for many of the coordinators. The charity has provided advice and support on how to promote and embed service user involvement within the regional networks, including:

- Sharing of user representative role descriptions.
- Advising on recruitment and selection processes.
- Providing funding for local service user engagement events and projects.

Although the extent of user involvement varies between the networks, all of the coordinators felt that progress has been made within their regions, examples include:

- Encouraging representatives from diabetes charities to be part of the network.
- Inviting a parent representative to attend network meetings and act as a communication link to other parents or parent groups in the region.
- Consulting with established local paediatric diabetes user groups on specific network activities or projects.
- Establishing a regional parent network that reportedly fully represents the local paediatric diabetes population and integrates with the regional network.

The PNCos acknowledged that user involvement needed to reflect their regional diabetes population. While most of the coordinators reported input from parents and/or carers, most believe improvements could still be made, particularly with regard to the diversity of representation. Some PNCos also highlighted the need for more involvement of children and young people with diabetes.

4.1.4 How did the pncos communicate with network members?

All the PNCos emphasised the importance effective communication. Keeping stakeholders informed about regional and national developments not only ensured individuals or teams could respond to information in a timely manner, but it also gave members a sense of inclusion in the network. Methods of communication were the similar for all of the coordinators but how they were used, and how frequently, often varied.

Network meetings/events

Influencing network meeting agendas reportedly provided some PNCos the opportunity to keep network members updated about national initiatives. Many gave presentations and/or facilitated workshops or learning sessions. The coordinators often invited external speakers to provide expertise on current topics such as best practice tariff, service user involvement, motivational interviewing and setting up a paediatric register. By providing administrative support at network meetings and events, such as taking and disseminating meeting minutes, the coordinators ensured the wider network remained informed of developments.

Email

All of the coordinators routinely used email. Some disseminated information as it came to light, whilst others sent weekly or monthly updates/newsletters. A few PNCos highlighted the limitations of this form of correspondence, reporting that emails were easy to overlook or ignore. Developing contact databases so messages could be targeted to specific professional or working groups ensured members were not overburdened with irrelevant information. Monitoring replies also reportedly allowed some PNCos to assess engagement and adapt communication methods where necessary.

'Every time I send out communications I keep track of replies…I have an overall picture of who from each unit is engaged…so it is easy for me to measure that everyone was highly engaged and that engagement is spread across the region fairly reasonably. It helps me identify problems quite quickly. If we are not hearing from this particular unit I need to be a bit more proactive or to change an approach' [PNCo 3]

Regional network web pages

The benefits of using regional paediatric diabetes network web pages as a communication tool were realised by a few coordinators who described their rationale for promoting this way of keeping network members informed:

- Posting documents on a website rather than via email reduces coordinator workload, reduces inbox, and was considered a key strategy for promoting sustainability of network activities should the PNCo post not be retained.
- Discussing individual issues via the website leaves more time at meetings to address wider issues.
- Best practice, learning and experiences can be shared with the whole network rather than just those attending meetings.
- Network members can just access the information that is of interest or relevant to them.
- Information is stored in one place and can be accessed at a time convenient to network members.

Each regional paediatric diabetes network had a web page on the NHS Diabetes website. As an alternative, some coordinators preferred to use NHS Networks as their primary web interface. The amount of information and resources available on these sites varied between regions. Most contained a basic overview of the regional network, links to newsletters, and information about best practice tariff (BPT), but a few coordinators further developed their sites to include a wide range of items, such as:

- a secure document library (e.g. internal and external reports, minutes from meetings)
- national and regional network news
- diary dates
- a secure discussion forum
- links to external resources (e.g. professional education courses)

Utilisation of the regional networks pages on NHS Diabetes and NHS Networks websites was variable (Appendix 2) and appears to be correlated to the amount of content. Some coordinators felt web pages were not an effective way to communicate, but others believed that if time was taken to explain the benefits and the pages are kept up to date, network members could be persuaded to use the resource.

4.1.5 What factors had an impact on stakeholder engagement?

The ease and pace at which the coordinators engaged stakeholders in their region appeared to be dependent on a number of factors, including: status of the network when the coordinator came into post (Table 1), perceptions about the network and the PNCo role, and previous experience of the coordinators.

With less well established networks the amount of time the coordinators needed to spend on stakeholder engagement increased. PNCos working with pre-existing networks more commonly reported that building relationships with clinical teams was more straightforward. Suggested reasons for this included:

- Contact lists were established or details of key stakeholders were readily available.
- Clinical teams were used to being part of a network and working together.
- Network members were keen to formalise their network and be part of a national strategy to improve diabetes care for children and young people.
- Network members, particularly the regional network chair, were supportive of the PNCo role.
- Enthusiasm and dedication of individual network members, particularly the regional network chair.

Irrespective of how developed the network was, many PNCos faced barriers engaging stakeholders to some degree, these reportedly included:

- Difficulties in identifying key contacts.
- Scepticism amongst some network members about the value of the national network.
- Lack of support or misconceptions about the PNCo role.

Given the differences between the networks, each PNCo developed a stakeholder engagement strategy that reflected the needs of their network.

The coordinators came from a variety of backgrounds and each brought different knowledge and skills to the role. Those with senior management, cross-organisational and/or extensive NHS experience, reported fewer challenges engaging stakeholders compared with those from other backgrounds, or PNCos with less working experience.

4.2 How did the PNCOS help their network to work collaboratively?

For the networks to function effectively, members of each paediatric diabetes unit needed to work collaboratively across their region, but creating this ethos was not necessarily straightforward. Although clinical teams were passionate about improving care for children and young people with diabetes, many of the coordinators reported that some individuals or teams were reluctant to work in partnership with other teams in their area.

4.2.1 What were the barriers to partnership working?

The most commonly cited reasons for resistance to collaborative working included:

- Geographically too far apart to collaborate.
- Conflict and/or competition between paediatric diabetes units.
- Perception that differences between the units (for example size of units and population demographics) rendered cross-team working futile.

- Current or historical politics.
- Insecurity or lack of confidence.
- Personality clashes.

4.2.2 How did the PNCOS overcome barriers to partnership working?

Identifying and understanding the barriers to partnership working enabled the coordinators to develop strategies to facilitate collaboration. Finding common ground and inviting teams to participate in projects with a universal goal were frequently reported ways of promoting a more unified way of working. Some of the coordinators recognised that each paediatric diabetes team had different strengths and weakness, and used this information when persuading units to take part in network activities. By allocating tasks that reflected the skills and needs of the units the coordinators hoped to reassure teams, irrespective of size or population demographics, that they each had something to offer and gain from participating in the network.

Some of the coordinators sought to capitalise on the competitive spirit of the units. By keeping the network informed of the achievements of regional and national projects, those not participating reportedly began to feel left behind which led them to become more interested in being involved.

The geographical spread of the units still poses a challenge for many of the PNCos and networks, particularly in areas with poor road infrastructure and transport links. Coordinators tried to address this issue in a number of different ways. Some booked meetings or events at the most convenient location for the majority, whilst others rotated the location. Alternating venues also served to promote a sense of fairness and impartiality, as well as ownership and engagement. The frequency and length of meetings have also been adapted in many cases to maximise attendance rates.

Being independent from the units enabled the coordinators to step back from the politics and personal/unit issues and assess the needs of each paediatric diabetes centre objectively. This autonomy also puts the PNCos in a good position to provide strategic direction to the region, ensuring they work as a network rather than individual units.

'I think that we are big enablers, bringing people together, and I don't think that would happen without us…also, managing the political landscape and bringing people together. Diplomacy and the continual communication and keeping the discussion open is really, really important part of the role and without that the units would operate in silos, and continue to do their thing the way that they do it. There would be no cohesive plan across the region for the way that services are going to be delivered'. [Focus group]

4.2.3 What skills did the PNCOS need to promote partnership working?

Building and maintaining relationships with clinical teams and promoting partnership working required the PNCos to have effective interpersonal skills, including:

- ability to listen and understand the needs of individuals and teams
- diplomacy
- negotiation and facilitation skills
- ability to motivate others

- assertiveness
- being enthusiastic and having a positive outlook
- empathetic

Equally, having confidence, particularly when communicating and working with senior clinical staff, was considered essential by some coordinators.

The coordinators reportedly devoted a lot of time forming links and supporting the development of relationships between the different clinical teams. The PNCos had to first earn the trust of the care teams, before the teams were able to trust each other and have the confidence to discuss issues without fear of exposure.

'I would say my biggest role is keeping lines of communication open through all the different disciplines within a multi-disciplinary team and also with commissioners…I also find myself to be sort of a middle man if anyone has a query…we are now feeling like a network in the sense of people talking to each other…people going to people and asking things without any concern. They feel now that we are doing everything as a team and it not that somebody is trying to beat someone else…they are now having conversations… previously it was very much putting an email out there and hoping that people would answer, whereas now we have people that we can go to to answer questions. I think that is quite a success.' [PNCo 2]

4.3 How successful have the PNCOS been in engaging the paediatric diabetes community and creating a unified network?

The success of the national and regional paediatric diabetes networks is dependent on the willingness of the paediatric diabetes community to take part in network activities. Since the introduction of the PNCo role, stakeholder engagement has increased in all regions, to a greater or lesser extent, and representation across organisations and professions has diversified, examples include:

- A memorandum of understanding agreed between all of the paediatric diabetes units and NHS Diabetes.
- Increased number of people on network membership lists and/or contact databases.
- Improved attendance rates at network meetings.
- Greater representation of the MDT on network boards and/or at network meetings including consultants, PDSNs, dietitians and psychologists.
- Increased representation of other stakeholder groups involved in the network including:
    - commissioners
    - service users
    - business and/or finance managers
    - representatives from the SHA
    - academic research groups
    - charitable organisations
- Links with other networks, such as local adult diabetes networks and the Insulin Pump Network[6], have also been established in some regions.

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[6] Information about the National Insulin Pump network is available at: Networks - Insulin pump network - NHS Diabetes

- Sponsorship from pharmaceutical companies for network meetings and events.

'I think that this [requests for additional network meetings] shows how valuable they now feel that the network is, and that these meetings aren't actually just talking about things…things are happening' [PNCo 2]

Having established effective working relationships with paediatric diabetes stakeholders, the PNCos are now reportedly considered as the first point of contact for the network. This provides the network with some familiarity and consistency. Being able to facilitate widespread sharing of knowledge and expertise puts the PNCo role at the heart of the network thereby creating a more collaborative and cohesive way of working.

The commitment demonstrated by members of the paediatric diabetes community has enabled the regional networks to deliver most, if not all, of the outcomes set by the national network (see section 5). In addition, many local projects have also delivered (see section 5.5 for further details).

4.4 How do the PNCOS support their network to deliver projects?

Although the pre-established networks or other paediatric groups met on a regular basis before the PNCos come into post, they reportedly operated on an informal basis. In depth discussions of current clinical and/or research issues took place but little happened as a result. Establishing the national network provided strategic direction for the regional networks and having the PNCo post provided the administrative support to enable the networks to work in a more formal and structured way.

'I think that our relationship that we have with each of the people in the individual trusts and their relationships with us is sometimes what brings them along to meetings. It gives them the confidence and faith that the work is going to happen that they have not had in the past' [Focus group]

4.4.1 Providing administrative support

Many of the coordinators feel they provide much of the drive and motivation behind network activities. Most perform secretariat duties for network meetings by setting agendas, taking minutes and following up actions. This clerical support reportedly reduces the burden of administrative duties on clinicians and ensures discussion points are acted upon and projects progress, allowing the networks to function more effectively and efficiently.

'The PNCo is crucial for keeping communication links open, keeping the momentum going, chasing things up – clinicians don't have the time to do this' [Network chair region 3]

4.4.2 Establishing project or profession-specific groups

Many of the coordinators set up and administered Task and Finish or working groups as a way of delivering projects. During the initial months of the post, some of the coordinators reported that finding volunteers to sit on the groups was challenging. However, once key members of the MDT had been identified and relationships with the clinical teams became stronger, finding volunteers became easier.

Some of the coordinators described how the impact of many paediatric diabetes issues is often different for healthcare professionals such as PDSNs, dietitians and psychologists, compared with consultants. To ensure these groups were provided with a supportive environment to discuss the issues that affect their roles, some of the PNCos established and ran profession-specific groups or meetings. Many of these groups also act as forum for sharing new initiatives and good practice that feed into wider network activities, in addition to delivering network specific projects.

4.5 What has helped the PNCOS carry out their role?

4.5.1 Peer support

Several PNCos, particularly those with less working experience, initially found the autonomy of the role challenging and expressed feelings of isolation and uncertainty. Two of the coordinators first employed in the post made regular contact with each other to discuss experiences and share learning. For at least one of these coordinators, this peer support led to improved self-confidence. To extend this support network, these coordinators offered inductions for new appointees, and established a peer mentoring group which they hoped would go some way to negate any feelings of isolation new PNCos may experience.

This group has continued and provides a forum for the coordinators to discuss work, obtain advice and support, as well as promoting a greater sense of team working. A couple of the coordinators believe that the group should now develop further and adopt a more strategic function.

'My vision is actually that what we start to do is to work smarter as a bunch of network coordinators…and we are actually not trying all to do the same thing…also then you have got quality assurance because you can then pass it [pieces of work] on to other network coordinators and say, 'this is what we have created; have a look guys and ask your Chairs what they think' and you have automatically got that critical friend there, so I think that it becomes a learning set of network coordinators, and that would be really positive' [PNCo 2]

4.5.2 Support from the network

High levels of dedication, enthusiasm and motivation from within the network were reportedly invaluable. Many of coordinators described how they were able seek information and advice from a variety of network members, in particular, the network chairs. The NHS Diabetes regional managers were also regarded as a good source of information and support by several of the coordinators.

4.6 In summary

Interviews with the coordinators suggest that development of the regional networks has been driven, at least in part, by the PNCos. The coordinators have helped bring together clinicians from across the region and are now seen at the first point of contact within their region, putting them in a good position to facilitate sharing of information and resources. By administering meetings, establishing working groups, and facilitating discussions between various stakeholder groups, the PNCos have enabled clinical teams to work together as a region and in line with the national strategy.

Section 5: Impact of PNCo role on the achievements of the regional network

The primary purpose of the PNCo role was to support the regional networks deliver the outcomes stipulated by the National Paediatric Diabetes Network, ensuring alignment between the national and regional strategies. Defining achievement of these outcomes is not necessarily straightforward as many are open to a certain degree of interpretation and subjectivity, and some are on-going tasks.

As previously discussed, this evaluation does not allow us to determine a cause and effect relationship between the PNCo role and ability of the networks to achieve the outcomes stipulated by the national network. However, all of the regions can demonstrate considerable progress towards achieving most, if not all, of these outcomes (Appendix 3). The evidence suggests the PNCos played a pivotal role in coordinating and delivering many of the projects, many of which may not have been delivered or would have been delayed without the role.

5.1 National Paediatric Diabetes Audit

One of the greatest achievements of the networks has been 100% submission rates to the 2010/11 National Paediatric Diabetes Audit (NPDA) in all but one region (Appendix 4). The number of units participating in the audit has more than doubled since the formation of the national network and the introduction of the PNCo role (Figure 1).

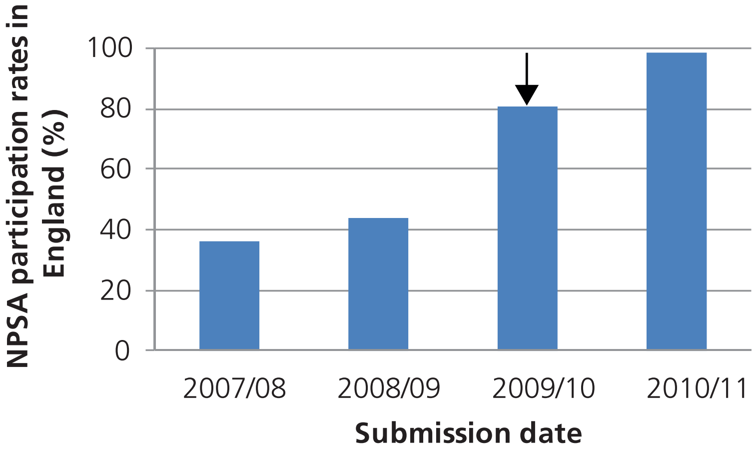

Figure 1: Paediatric diabetes unit participation in the NPDA[7] *(↓marks the introduction of National Paediatric Diabetes Network and PNCo role)*

Most coordinators reported it was often challenging for many units to submit data for a variety of reasons:

- lack of or inefficient IT systems
- lack of paediatric templates
- different data items stored in different databases
- many units relied upon paper records (at least in part)

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[7] Data from NPSA reports available at: http://www.ic.nhs.uk/nda

Some coordinators also reported scepticism from units about the value of submitting data to the NPDA. There were concerns about the quality the data submitted to the audit and the analysis and interpretation of the data, as the findings were not perceived to be reflective of what is going on in the units. Furthermore, poor past experiences of the submission process also hampered enthusiasm for the audit.

Despite these barriers, the PNCos encouraged all units to participate in the NPDA by emphasising the importance of having national data and offering their support before and during the submission period. The assistance provided by the PNCos varied not only between units but also between regions and included:

- communicating submission dates and sending reminders
- simple facilitation activities such as dealing with the loss of login details and passwords
- answering general queries about the submission process
- collecting data
- resolving issues when submitting data
- submitting data on behalf of units that do not have the necessary resources
- working with IT departments to develop electronic systems for data collection

'Getting all of the units to buy into the network and network activities, like the NDA for example is a fantastic achievement, as at the beginning we didn't know who the centres were [Network chair region 3]'

Participating in the NPDA is one of the criteria for BPT and will inevitably be a driver for data submission in the future. However, as many of the barriers to submitting data remain, it is likely that many units will require additional support from the PNCos to meet this tariff requirement.

5.2 Establishing a paediatric diabetes registry

The *Yorkshire Register of Diabetes in Children and Young People* was established over 20 years ago and enables the region to monitor changes in outcomes associated with service development, in addition to being a data source for research into the aetiology of paediatric diabetes. Some members of the national network aspired to develop such a registration system in each region that would eventually feed into a national database, and as such, it was included as an outcome for the regional networks.

During the initial months of the post, many PNCos reportedly worked on aspects of the registry project but were faced with three main barriers[8]:

- Complex and time-consuming process for obtaining legal and ethical approvals.
- Lack of integrated, or inefficient, IT systems.
- Lack of support from network members.

Consequently, some regions reportedly felt there were more pressing issues that needed to be addressed and the amount of resources required to establish and maintain a registry were unjustifiable. Furthermore, insufficient evidence suggesting that such databases support service improvement was also cited as a reason for lack of commitment to the project. These reports were

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[8] Further information about the set-up procedure and a discussion of the issues surrounding the barriers to establishing regional registries can be found in the forthcoming *Setting up a regional paediatric diabetes registry: Lessons from the NE report*.

corroborated by some of the network chairs. In light of these views, a few regions decided to postpone or abandon the registry initiative.

Despite the reported barriers, several regions were and remain supportive of the project, and two regions, the North East and East of England, have successfully established registers of children and young people with diabetes. The first of these was the North East which was granted approval in April 2011. Having a dedicated registry coordinator in this region put them in a great position to lead the way with this work.

5.2.1 Shared learning between the registry coordinator and the PNCOS

As previously stated, the ethical and legal requirements for setting up such a database are complex and time-consuming. Although attaining the necessary approvals has become more rigorous since the creation of the *Yorkshire Register of Diabetes in Children and Young People*, the registry coordinator sought the knowledge and expertise from the PNCo who established this register in 1990 as part of an earlier post. The registry coordinator worked with a variety of stakeholders to develop the necessary accompanying resources, and processes for collecting and moving patient information between sites.

Considering the complexities of the project and the amount of time it took to gain legal and ethical approval, the registry coordinator felt it was important to share the experiences from the North East with the other regions and described how she passed on this learning to the PNCos:

- Produced a detailed protocol for the application of the ethical and legal approval, including a step-by-step flow-diagram, and disseminated to all of the regional PNCos.
- Shared the supporting resources, such as the age-banded patient information sheets, assent and consent forms developed by the coordinator.
- Delivered a series of webinars to provide an overview of how the North East region had successfully sought approval for their registry and how barriers had been overcome.
- Presented at the East of England, South West and West Midlands network meetings.

The coordinator hoped this would avoid duplication of work and help the other regions to address many of the challenges, thereby hastening their ability to develop a database.

In the East of England, the PNCo supported an academic team at the Department of Paediatrics, University of Cambridge, who set up, manage and now host this registry since approval was granted in December 2011.

5.3 Health needs assessment and peer review

Each of the regions approached the health needs assessment (HNA) in a different way, consequently the amount of work required by individual PNCos varied. In some regions, this work was carried out by the SHA with little or no input from the coordinator. In other regions, an HNA and subsequent gap analysis was led and carried out by the coordinator. This included liaising with the clinical lead and other stakeholders to develop the questionnaire, conducting interviews with the clinical team, and analysing, reporting and presenting the data.

Some of the coordinators developed additional questionnaires to gain a greater understanding of each paediatric diabetes team and to prepare units for the introduction of best practice tariff. One of the PNCos explained that conducting semi-structured interviews rather than using a fully structured questionnaire allowed for open discussions of the issues. This also provided the PNCos with an insight into the concerns and needs of the teams enabling the coordinator to identify where support was required.

As an alternative to the traditional HNA, a peer review process was adopted by one region which allowed paediatric diabetes teams to identify the strengths and gaps in existing services, in addition to exposing them to alternative approaches to service delivery. The coordinators in this region played a pivotal role in promoting, coordinating and administering this process.

5.4 Supporting commissioners to understand paediatric diabetes requirements and best practice tariff

A specific paediatric diabetes tariff has been introduced to improve standards of care for all children and young people with diabetes. Receiving the payment is subject to centres meeting the stipulated minimum standards of care which were developed by the National Paediatric Diabetes Network and representatives from the regional networks[9]. The national network worked in collaboration with the Department of Health Best Practice Tariff Working Party to cost and roll out the tariff which becomes mandatory in April 2013.

Supporting commissioners to understand paediatric diabetes requirements and best practice tariff was one of the outcomes set by the national network. However, some of the PNCos reported that before the networks could do this, clinical teams needed to understand the practicalities and implications of the new tariff themselves.

During the development of the best practice criteria, the coordinators acted as a communication link between their regional network and the National Lead for BPT. Sometimes this entailed collating the responses of network members to consultation documentation; on other occasions, the national lead or other speakers were invited to network meeting to address the queries and concerns of the units. In addition, some of the PNCos reported that many clinical staff were not confident negotiating with commissioners and therefore the coordinator facilitated these discussions.

'…it is far greater than an administration role. They need to have a good background of the NHS, how it works etc. and knowledge of diabetes. They also need business knowledge to have high-level conversations with commissioners because clinicians don't have the expertise to do this… it needs a high calibre person…' [Network chair region 3]

Now that best practice tariff has been implemented, most of the PNCos report that commissioners have become more engaged with the network, but many feel more work needs to be done to ensure readiness for when the tariff becomes mandatory in April 2013.

5.5 Region-specific projects

Each of the networks identified regional priorities, although how these were established was dependent on the network. Some adopted structured approaches such as a health needs assessment and/or gap analysis, others used less formal approaches, relying on the clinical experience of individuals or teams to make decisions.

Regional workstreams have included:

- Establishing an out-of-hours service.
- Developing a psychology assessment tool.
- Running efficiency clinics.

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[9] Details of the tariff are available at: Areas of care - Networks - Paediatric network - NHS Diabetes

- Developing an electronic paediatric template.
- Improving transition services and experiences.
- Carrying out local audits.
- Developing patient information in languages other than English.

The PNCos have reportedly been instrumental in managing and delivering many of these projects. Tasks have varied between networks and between projects but include:

- Establishing and managing working groups/Task and Finish groups
- Liaising or consulting with a variety of stakeholders including: clinical and academic teams; financial teams/business managers; IT personnel; and commissioners.
- Analysing and reporting data.
- Writing service specifications.
- Negotiating with commissioners.
- Developing business plans.
- Drafting end of year reports to demonstrate network achievements.

5.6 How did the PNCos ensure the national and regional networks remained aligned?

Understandably, there will have been some lack of synergy between local and national priorities. As previously discussed, the most contentious national outcome was establishing the paediatric diabetes register. Most of the PNCos realised the importance of adopting a national approach but some also expressed the need for giving consideration to regional projects. Many felt time restraints and the remit of the role occasionally hindered the support they could offer local initiatives.

All of the coordinators reportedly supported the delivery of local projects, but devised ways to ensure the national projects remained at the forefront of network activity. This usually entailed putting national items on the agenda at network meetings or setting up working groups. Having strong communication skills and being assertive reportedly helped the PNCos steer the network back towards the national outcomes when too much time was being devoted to region-specific projects.

5.7 In summary

The PNCos have reportedly helped the regional network deliver both national and regional projects by providing effective and efficient administrative and communication support. The role has also been the driver for many projects, helping to maintain the momentum of network activities, ensuring outcomes were delivered in a timely manner. Specific expertise or skills were also provided by many of the coordinators.

Resources developed by some of the regional networks have been shared with other regions via the PNCos. By continuing to work in this manner, it is hoped duplication of work will be reduced, saving time and money which will benefit the paediatric diabetes community as a whole.

Section 6: Scope of the PNCo role

6.1 Remit of the PNCo role

This study has raised a number of questions about the scope of the PNCo role, particularly with regard to balancing regional priorities with national objectives. Some of the coordinators, particularly those with less working experience, initially described feelings of uncertainty and insecurity. This is perhaps understandable as no precedent had been set by previous post holders. Moreover, it is likely the role evolved rapidly as the networks developed. Some of the coordinators also felt there was confusion about the responsibilities and accountability of the post. This appeared to be related to the complexities of the funding and governance of the post. Although the posts were commissioned by NHS Diabetes, the PNCos were employed by local hospital trusts, SHAs or PCTs, but the day-to-day work was carried out on behalf of the regional networks. Managing the expectations of these key stakeholder groups was, and continues to be, challenging for many of the coordinators, requiring diplomacy, strong communication and negotiation skills.

6.2 Time restraints and resources

Many of the PNCos thought the deliverables of the post were unrealistic within the original specified timeframe. Before clinical personnel could be expected to carry out network activities, the coordinators needed to build relationships and gain the trust of paediatric diabetes teams. The coordinators explained this level of stakeholder engagement takes a considerable amount of time to achieve and consequently, many felt the role should have been full time to allow for greater devotion to this aspect of the role.

6.3 Differences between the regional PNCo roles

Differences between the regional networks will have inevitably impacted on what was required from each PNCo and how the role was carried out. However, some coordinators felt disadvantaged because of the nature of their network(s), role and/or region, for example:

- being employed part time (some were employed full time)
- large number of paediatric diabetes units in their region
- geographically large area to cover
- poor transport links within the region
- working for more than one network

On balance, most of the coordinators were presented with a challenge relating to these issues which will have impacted on the amount of time they could spend on any given task. A few coordinators described how they overcame their respective challenges by developing alternative ways to effectively communicate with their network. Furthermore, one of the coordinators described how they took advantage of working for more than one network by allocating different elements of a workstream across two regions to share the workload and hasten delivery of the project.

Section 7: The future

7.1 Paediatric Diabetes Networks

Maintaining the regional networks has become imperative as active participation in a local paediatric diabetes network is one of the criteria for attaining best practice tariff. Receiving the payment is dependent on units achieving all thirteen specified criteria otherwise they will receive no money at all. The rationale for this is to encourage trusts to provide paediatric diabetes services with the appropriate resources to meet the criteria. Without this incentive, there is a risk trusts will continue as they are and not invest in services to improve patient care[10].

The rationale for a national network steering the regional networks was to reduce variation of care nationally and to improve outcomes for children and young people with diabetes irrespective of where they live in England. As described in section 5, many of the original objectives set by the national network have been achieved and work continues in areas where deliverables are outstanding. Furthermore, additional national priorities have been identified and work to address these has commenced, including:

- Roll out of the self-assessment stage of peer review across all paediatric diabetes units in England.
- Formation of a National Parents Reference Group which feeds into the national network meetings.
- Development of an e-learning module for all healthcare professionals caring for children and young people with diabetes.
- A paediatric diabetes model for transition is being rolled out across England.
- Working with partners on the European SWEET project to influence improved standards of care in England, bringing them in line with some other European Countries.

Although the networks have achieved so much, it is vital the regions continue to work together at a national level to ensure standards of care for children and young people with diabetes are improved across the country by sharing good practice, expertise, learning, tools and resources.

7.2 Benefits of the PNCo role

The changing NHS landscape is the major influence on the sustainability of networks and the PNCo role, and networks are currently devising strategies to address these impending changes. The PNCos reportedly ensured this issue was maintained on the agenda at network/board meetings and events. Some of the coordinators described how they produced a sustainability paper or business plan which detailed the achievements of the network, benefits of the coordinator role and a financial plan for sustaining the post and network activities.

This evaluation has revealed the PNCo role has been beneficial for at least some of the regional networks. With the BPT becoming mandatory in April 2013, the role could prove vital to the units' ability to receive the new payment.

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[10] Further information about the paediatric diabetes best practice tariff is available at: http://www.diabetes.nhs.uk/networks/paediatric_network/best_practice_tariff_for_paediatric_diabetes/?#sg_anchor_

In summary, the PNCo role can:

- Support paediatric diabetes units to attain BPT criteria and payment of the tariff by:
    - o continuing to support units to submit data to the NPDA;
    - o maintaining and further developing stakeholder engagement ensuring the networks are sustained;
    - o providing communication and administrative support allowing the networks remain functional.
- Provide effective communication links between the national and regional networks to ensure strategies remain aligned.
- Act as a first point of contact for the region to provide consistency and stability for the network.
- Be a conduit for disseminating and sharing good practice, information, knowledge and resources between paediatric diabetes units and regional networks.
- Facilitate improvements in involving service users to ensure the views of children and young people and their families and carers are taken into consideration during service development projects.
- Ensure partnership working continues across the region by acting as a communication link and facilitating discussions between units to overcome any potential barriers.
- Provide momentum for workstreams by managing and coordinating the delivery of projects and carrying out effective and efficient administrative duties.
- Maintain and further develop relationships with pharmaceutical companies to ensure support for meetings and events sponsorship.

7.3 Should the PNCo post be retained?

The findings of this evaluation suggest that the PNCo role has become embedded in the structure of the regional networks and is pivotal to the effective functioning of the networks. Retaining this role will help maintain the momentum of the regional and national networks to help drive towards achievement of the vision of the national network – to reduce variation of care and deliver better outcomes for children and young people with diabetes, their families and carers, no matter where they live in England. Therefore, NHS Diabetes recommends the PNCo role should be retained.

However, as NHS Diabetes is not in a position to continue funding the PNCo role, continuation of the post will need to be determined by each regional network. With the advent of best practice tariff, it is hoped that each paediatric diabetes unit will have the financial ability and willingness to contribute to the maintenance of this resource.

7.4 What should be the future remit of the PNCo role?

The coordinators expressed differing views about the future remit of the PNCo role. At one end of the spectrum, a few coordinators felt the role had developed into a full time managerial position requiring additional secretarial or technical support; at the other end, some PNCos thought that less input may be required in their area as clinical teams were now engaged and the networks were functioning effectively.

Decisions about the future scope of a PNCo or similar role will need to be decided regionally and will be dependent on the needs of the individual networks.

Appendix 1: Interview questions

1. [First interview only] Could you talk through your background, previous experiences that might be relevant to this work and what motivates you to undertake this post?

2. Describe your role and the responsibilities of this post. Have these changed as the months progressed?

3. What are your objectives and how will you try to achieve them? Have these changed as the months progressed?

4. What are your measures of success and how will you capture, record and report them? Have these changed as the months progressed?

5. Can you discuss and reflect upon your key achievements over the past month?

6. Has anything unexpected happened over the past month? New initiatives? New opportunities? Links or relationships?

7. Can you discuss and reflect upon the main challenges that you've faced over the past month? How have you overcome these?

8. [First and final interview only] What has been the most significant thing to happen since you've taken on this work?

9. What are the key things you want to achieve or work on during the next month?

10. Is there anything else you'd like to add at this stage?

Appendix 2: Regional Paediatric Diabetes Network webage activity

Region	Number of web-hits for each NHS Diabetes paediatric diabetes network page								Number of members on NHS Networks regional paediatric diabetes site
	Nov 2011	Dec 2011	Jan 2012	Feb 2012	Mar 2012	Apr 2012	May 2012	Jun 2012	
East Midlands	0	0	0	0	2	3	3	32	N/A
East of England	43	51	82	48	51	87	64	48	N/A
London & South and East Coast	68	45	66	48	62	60	55	48	172
North West	74	41	86	58	46	58	53	30	N/A
South Central	37	32	82	45	32	39	32	19	10
South West	39	22	71	33	58	73	46	35	48
West Midlands	33	37	78	26	49	70	57	43	10
Yorkshire & the Humber	236	139	179	265	155	147	160	143	7

Table A1: Visits to the NHS Diabetes regional paediatric network web pages and membership to NHS Networks regional paediatric diabetes website

Appendix 3: Regional Paediatric Diabetes Networks achievements dashboard

Key: 🟩 Outcome on track 🟧 Outcome delayed

Outcomes	**East of England**	**London**	**South East Coast**	**South Central**	**South West**	**East Midlands**	**West Midlands**	**North East**	**North West**	**Yorkshire & the Humber**
Increased stakeholder engagement	🟩 complete	🟩 complete	🟩 complete	🟩 complete	🟩 complete	🟩	🟩	🟩	🟩 complete	🟩 complete
Health needs assessment completed	🟩 complete	🟩 complete	🟩 complete	🟩 complete	🟩 complete	🟩	🟩	🟩	🟩 complete	🟩 complete
MOU signed by all units in the regional network	🟩 complete	🟩 complete	🟩 complete	🟩 complete	🟩 complete	🟩	🟩	🟩	🟩 complete	🟩 complete
Establish a regional register	🟩	🟧	🟧	🟧	🟧	🟧	🟩	🟩 complete	🟧	🟩 complete
Commissioners to understand PbR/best practice tariff	🟩 complete	🟩	🟩	🟩	🟩 complete	🟩	🟩	🟩	🟩	🟩 complete
100% submission to the NPDA	🟩 complete	🟩	🟩	🟩 complete	🟩 complete	🟩	🟩 complete	🟩 complete	🟩 complete	🟩 complete
Establish clear governance links to the SHA/LTC boards	🟩 complete	🟩	🟩	🟩	🟩 complete	🟩 complete	🟩	🟩	🟩 complete	🟩 complete
Evaluation of the PNCo role	🟩 complete	🟩	🟩	🟩 complete	🟩	🟩	🟩	🟩 complete	🟩 complete	🟩 complete
Schools work	🟩	🟧	🟧	🟧	🟩	🟩	🟧	🟧	🟧	🟧
Standardised service specification	🟧	🟧	🟧	🟧	🟩 complete	🟩	🟧	🟧	🟩	🟩 complete

Appendix 4: National Paediatric Diabetes Audit Submission Rates

Region	***Approximate submission rates to NPDA (%)**			
	2007/2008	**2008/09**	**2009/10****	**2010/11**
East Midlands	72	33	82	100
East of England	35	35	81	100
London South and East Coast	51	53	82	88.3
North East	45	67	100	100
North West	54	43	70.0	100
South Central	50	60	100	100
South West	67	86	93	100
West Midlands	26	50	75	100
Yorkshire and the Humber	85	100	100	100

*Figure 2: Submission rates to NPDA (*calculations based on number of units registered for the audit rather than actual number of units in the region. Data may also be skewed by boundary changes; **Time period when PNCos came into post*

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