



KALEIDOSCOPE
Health and Care

Case Study: The National Children & Young People's Diabetes Network

Kaleidoscope Health and Care

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Foreword

What does it take to improve outcomes for people receiving care from the NHS consistently and sustainably?

It's a central question for our improvement work at the Health Foundation. Part of the answer includes generating a deep understanding of patients' aims for their care, clinicians improving and innovating based on the experience of treating each patient, and applying the power of research, data and networks to learn from good practice at home and from around the world. And, importantly, this work would foster a culture where patients and the public work collaboratively with health care professionals and providers in mutually beneficial partnerships to improve care.

If you want to see an example of people working to make this happen, the National Children and Young People's Diabetes Network (the Network) is an excellent place to start.

The Network is made up of 173 paediatric diabetes units across England and Wales that apply the findings of the National Paediatrics Diabetes Audit to support improvements to care. It's a space for health care professionals, young people and families to share new ideas, learn from each other, collaborate on improvement initiatives and make their voices heard.

Over the past ten years, the clinical outcomes measured by the audit – and therefore the lives of children, young people and their families – have significantly improved. This report describes the contributions of the Network, which, along with other national initiatives such as the National Children and Young People's Diabetes Quality Programme, has supported dedicated local clinical teams to improve care.

The successes of the Network have been hard-won. They have depended on the commitment of the Network's members, and the vision and perseverance of its clinical leaders. Underpinning the achievements is a culture of psychological safety, trust and shared responsibility. As one parent representative comments in this report: 'I have never been made to feel anything other than an equal voice at the table.'

The Health Foundation is supporting the network to take the next steps in its development – bringing the clinical and public members of the Network closer together, and considering how to plan for sustainability. This is an important part of our wider effort to strengthen the evidence for how to build sustainable change across health care through collaboration between those who use services and those who deliver them.

Collaborative approaches to improvement of this kind hold great potential to transform the delivery of health care. We can start by learning from leading initiatives like the one described over the following pages – and creating the conditions for others to build on them.

Sarah Henderson

Assistant Director of Improvement Programmes at the Health Foundation

Network structure: five complementary and aligned components

1. Sharing framework

The Network has an effective meeting and communications structure to facilitate sharing of best practice, knowledge and knowhow. This accelerates improvement by enabling participants to adopt or adapt successful practices in their own context rather than developing them from scratch.



NDQP

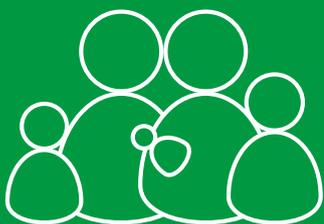
2. National Diabetes Quality Programme

The National Diabetes Quality Programme primarily consists of three parts:

- Self-assessment, using specific Network measures
- Peer review, by clinicians and parent representatives
- Quality Improvement Collaborative, involving training in quality improvement methodology and an applied project

3. Data and analytics

The Network partners with the National Paediatrics Diabetes Audit (NPDA) to offer robust data and analytics support to members. This enables paediatric diabetes units and regions to analyse their performance and progress as well as benchmark against their peers and national averages.



4. Family engagement

Each regional network has several parent representatives who support the development and delivery of improvement projects, and provide a forum for communication and support among families. The representatives attend the Network's national meetings to advocate for and represent the views of families.

5. Funding

The regional networks in England are primarily funded by the Best Practice Tariff (BPT), which provides paediatric diabetes units with an annual payment for every child or young person who meet the BPT criteria. Funding in Wales is allocated via the six Health Boards.



Introduction and context

With increasingly complex systems and pressured services, the health and care sector cannot afford to work in a fragmented way. ‘Collaboration’ is a current buzzword in health and care, but effective collaboration isn’t something that happens overnight. Meaningful collaboration takes time, resources and motivation – commodities that are in vanishingly short supply across much of the sector.

Networks are increasingly seen as a way to foster effective collaboration, as they can harness existing assets to accelerate improvement¹. For example, the NHS Long Term Plan (2019) placed much emphasis on networks: ‘from 2019/20 clinical networks will be rolled out to ensure we improve the quality of care for children with long-term conditions such as asthma, epilepsy and diabetes’².

We define networks as ‘cooperative structures where interconnected groups or individuals coalesce around a shared purpose on the basis of trust and reciprocity’³. While several models and examples of networks exist⁴, many have not realised their full potential⁵. This case study examines the story of the National Children & Young People’s Diabetes Network (‘the Network’), which bucked the trend by harnessing the commitment and enthusiasm of clinicians and families from 173 paediatric diabetes units (PDUs) across England and Wales to create a culture of sharing good practice and mutual learning, with a view to improving the outcomes of all children and young people living with diabetes. Since it was formed 10 years ago, variation in care processes among member PDUs has decreased and there have been impressive improvements in clinical outcomes⁶. While attributing these changes to Network activities is difficult, those involved in the Network believe that it has played a significant role in these improvements.

In this case study, we examine how the Network has brought together clinicians and families, and we explore the lessons and opportunities for policymakers, commissioners, administrators and clinicians seeking to harness the power of networks to improve care. We draw on data from a combination of interviews and workshops with Network leaders and members over nine months during 2019 (see Appendix).

¹ The Health Foundation. 2014. *Effective networks for improvement*. Available from: www.health.org.uk/publications/effective-networks-for-improvement

² NHS. 2019. *The NHS Long Term Plan*. Available from www.england.nhs.uk/long-term-plan

³ The Health Foundation. 2014. *Effective networks for improvement*. Available from: www.health.org.uk/publications/effective-networks-for-improvement

⁴ The Health Foundation. 2013. *Leading networks in healthcare*. Available from: www.health.org.uk/publications/leading-networks-in-healthcare

⁵ Ehrlichman, D., Sawyer, D. and Spence, M. 2018. Cutting through the complexity: a roadmap for effective collaboration. *Stanford Social Innovation Review*. Available from: ssir.org/articles/entry/cutting_through_the_complexity_a_roadmap_for_effective_collaboration#

⁶ Royal College of Paediatrics and Child Health. 2019. *National Paediatric Diabetes Audit 2017/18: care processes and outcomes*, Version 2: updated 30 May 2019. Available from: www.rcpch.ac.uk/sites/default/files/2019-05/NPDA-national-report-2017-18_v2-updated-2019-05-30_0.pdf



The Network was formed in 2009. At that time, there were high levels of variation in the outcome HbA1c and in the measurements of care processes (cholesterol, blood pressure, blood creatinine, urinary albumin, body mass index, eye screening and foot examination)^{7,8}. Furthermore, clinical outcomes significantly lagged behind European and international counterparts⁹. Clinical leaders made the case to NHS Diabetes (a former NHS Improvement organisation, funded by strategic health authorities (SHAs) across England) to support the development of a clinical paediatric diabetes network. By targeting paediatrics, the Network aimed not only to directly improve outcomes for children early in life, but also to mitigate longer-term complications and morbidity – thereby reducing costs and improving overall quality of life throughout the life course^{10,11}. A network model was chosen because a learning network was seen as an effective and efficient way of sharing good practice and improving outcomes quickly. The network model was piloted by Yorkshire and the Humber SHA then replicated in all other nine SHAs across England.

“There were huge differences in how services were staffed, delivered and supported across the country, and it was felt that this was something that had to change; the same standards of care and access to services should apply no matter where you live. Developing those universal standards of care became one of the main priorities of NHS Diabetes and the Network.”

Tabitha Randell, Consultant in Paediatric Endocrinology and Diabetes,
Nottingham University Hospitals NHS Trust

As a result, NHS Diabetes supported the creation of 10 regional paediatric diabetes networks across England. These comprise multidisciplinary diabetes professionals, family representatives and essential managerial support. In 2015, Wales joined as the 11th regional network and together they form the National Children & Young People’s Diabetes Network, with membership from 173 PDUs across England and Wales, caring for more than 27,000 children and young people with diabetes.

⁷ Royal College of Paediatrics and Child Health. 2012. *National Paediatric Diabetes Audit Report 2010–11*. Available from: www.rcpch.ac.uk/resources/npda-annual-reports

⁸ NHS RightCare. 2011. *NHS atlas of variation in healthcare for children and young people*, pp 40–42. Available from: <https://fingertips.phe.org.uk/profile/atlas-of-variation>

⁹ National Children & Young People’s Diabetes Network. 2017. *Paediatric diabetes Best Practice Tariff criteria – for paediatric diabetes units in England. Frequently asked questions*. Available from: www.cypdiabetesnetwork.nhs.uk/files/6815/2051/6740/180110__FAQ_for_BPT_paediatric_diabetes_for_England_ONLY_V3.pdf

¹⁰ Stratton I.M., Adler A.I., Neil H.A.W., Matthews D.R., Manley S.E., Cull C.A., Hadden, D., Turner, R.C., Holman, R.R. 2000. Association of glycaemia with macrovascular and microvascular complications of type 2 diabetes (UKPDS 35): prospective observational study. *BMJ*; 321(7258): 405–412.

¹¹ Baxter M., Hudson R., Mahon J., Bartlett, C., Samyshkin, Y., Alexiou, D. and Hex, N. 2016. Estimating the impact of better management of glycaemic control in adults with Type 1 and Type 2 diabetes on the number of clinical complications and the associated financial benefit. *Diabetic Medicine* 33:1575–1581.

¹² Randell T. 2012. Developing a best practice tariff in paediatric diabetes: can we improve services and outcomes for children and young people with diabetes in England? *Diabetes Care for Children & Young People* 1(1). Available from: www.diabetesonthenet.com/uploads/resources/dotn/_master/2190/files/pdf/dccyp1-1-23-6.pdf



A core feature of the Network is the close partnership it has built with the Families with Diabetes National Network, which consists of family representatives from each of the 11 regions. The family representatives play an important role in setting the direction and priorities of the Network and have been instrumental in developing its delivery plans.

“Our family representatives have ensured we stay focused on what matters most to those we serve.”

Dr Fiona Campbell, Chair, National Children & Young People’s Diabetes Network

In 2011, with support from the Department of Health, NHS Diabetes established a Best Practice Clinical Pathway Tariff¹³ for paediatric diabetes for English PDUs. The tariff specifically recognises the value of the Network and provides funding for regional and national meetings, modest clinical leadership time for regional network chairs, Network management support, and the National Diabetes Quality Programme¹⁴. In addition, the tariff provides funding for increased clinical staffing to more accurately reflect the cost of paediatric diabetes care provision.

The Network has made significant progress in meeting its core aims of sharing good practice, and setting and maintaining high-quality standards for the treatment and care of children and young people with type 1 diabetes¹⁵. The impact of its work is described below.

¹³ National Children & Young People’s Diabetes Network. *Best Practice Tariff*. Available from: www.cypdiabetesnetwork.nhs.uk/national-network/best-practice-tariff

¹⁴ Royal College of Paediatrics and Child Health. *National Diabetes Quality Programme*. Available from: www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/diabetes-quality-programme

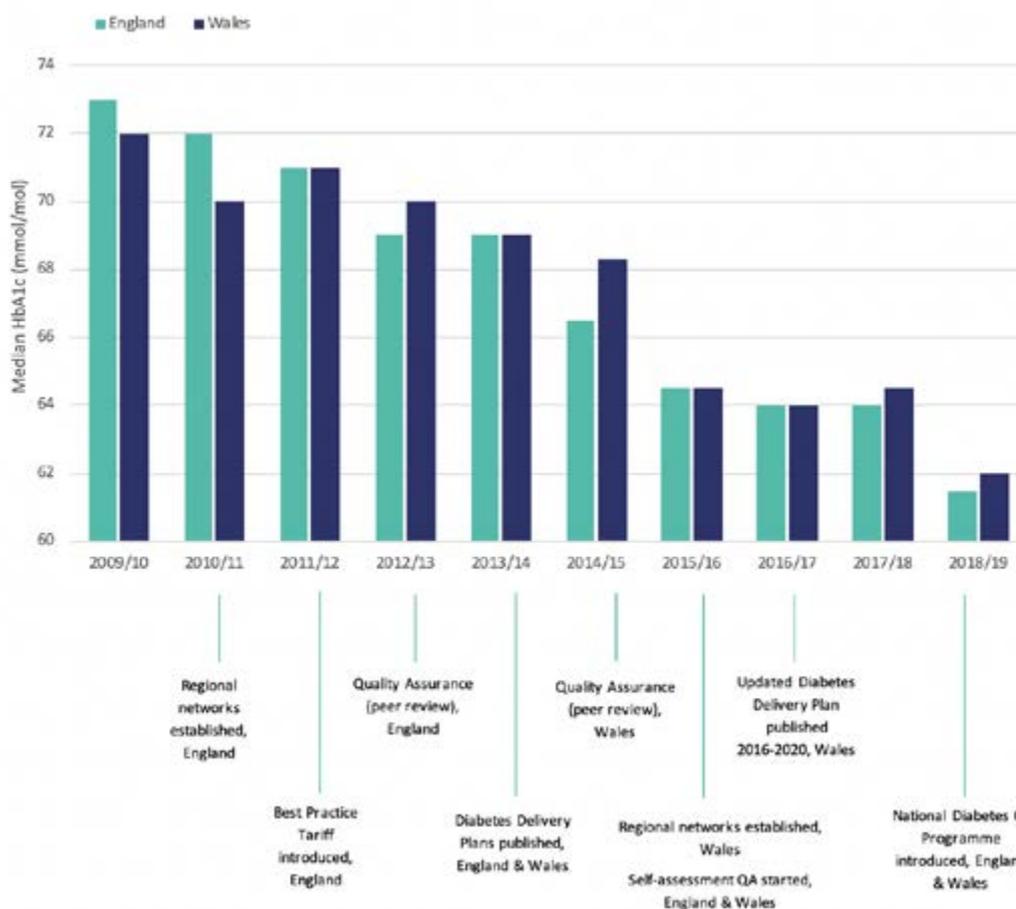
¹⁵ National Children & Young People’s Diabetes Network. *About us*. Available from www.cypdiabetesnetwork.nhs.uk/national-network/about-us

Impact

Since the Network was set up, there have been significant improvements in outcomes for children with type 1 diabetes. Figure 1, from the 2018/19 National Paediatric Diabetes Audit (NPDA)¹⁶, shows that since 2009/10 national median HbA1c has decreased by 10mmol/mol, reducing the life-time risk of developing a microvascular complication by an estimated c. 25%¹⁷.

Care processes have also improved in this same time period, including a year on year increase in the completion of the recommended health checks for children and young people with type 1 diabetes¹⁸.

Figure 1: Median HbA1c for children and young people with all types of diabetes in England and Wales 2009/10 to 2018/19 with associated NHS policy and/or paediatric diabetes delivery structural changes Source: *National Paediatric Diabetes Audit 2018/19*



¹⁶ Royal College of Paediatrics and Child Health. 2020. *National Paediatric Diabetes Audit 2018/19: care processes and outcomes*, 12 May 2020. Available from: www.rcpch.ac.uk/sites/default/files/2020-03/final_npda_core_report_2018-2019.pdf

¹⁷ Stratton I. M., Adler A. I., Neil H. A. W., Matthews D. R., Manley S. E., Cull C. A., Hadden, D., Turner, R. C., Holman, R. R. 2000. Association of glycaemia with macrovascular and microvascular complications of type 2 diabetes (UKPDS 35): prospective observational study. *BMJ*. Aug 12; 321(7258): 405-412.

¹⁸ Royal College of Paediatrics and Child Health. 2020. *National Paediatric Diabetes Audit 2018/19: care processes and outcomes*, 12 May 2020. Available from: www.rcpch.ac.uk/sites/default/files/2020-03/final_npda_core_report_2018-2019.pdf



While some outcomes had already started to improve before the Network was created, this case study explores how the Network has contributed to subsequent improvements in the NPDA measures. Determining cause and effect within a complex system such as paediatric diabetes care is always challenging, as complex systems behave in non-linear ways and any change in one area of the system could have effects throughout. Furthermore, since we cannot compare current outcomes to those in a counterfactual world where the Network does not exist, it is impossible to quantify exactly how much of the improvement is attributable to Network activities.

However, those closest to the Network believe that many of the observed improvements are a direct result of its activities. Several Network members also noted that it has made improvement efforts more efficient by increasing the pace at which best practices spread, especially beyond the larger academic centres.

“Yes, clearly the establishment of networks has been one of the contributing factors to improvement. Networks provide an overarching influence on change supported by audit data, the quality of which has got better and better with improved unit-level reports demonstrating change over time...”

Justin Warner, Clinical Data Lead, National Children & Young People’s Diabetes Network

“Without the Network we’d all be working very much in silos and independently. It would mean quite a lot of variations for our families.”

Raphaella Rookes, Chair, Children & Young People’s South West Diabetes Network

Collaborations and networks primarily create value in three overlapping ways¹⁹:

- **Shared learning** – networks enable members to learn from each other. This enables sharing of best practice and avoids duplication of efforts and repetition of mistakes.
- **Shared voice** – the larger and more diverse the group, the more powerful its advocacy and influencing efforts are. Networks amplify and strengthen the voices of their members when advocating for resources and seeking to influence policy.
- **Shared delivery** – networks enable diverse members to work together to develop, test and implement new products or services.

During the interviews and workshops we conducted with Network leaders and members, we used this framework to explore how the regional networks and the national Network have impacted care and outcomes. The following themes emerged, with examples for each.

¹⁹ Adapted from Malby, B. and Anderson-Wallace, M. 2016. *Networks in healthcare: managing complex relationships*. Emerald Group Publishing Limited.



1. Sharing learning

- **The Network spreads learning across PDUs.** The Network has developed a sharing framework (see component 1 below). This includes a national and regional meeting structure that enables sharing of ideas and potential solutions, and provides a forum for PDUs to share learning from improvement projects. Many Network members noted that communication has significantly improved since the Network began, providing for the first time forums for sharing best practice.

“There’s a lot of shared practice. The dietitians within the Network all meet up together; the nurses all meet up together; we, as parent reps, all meet up together virtually. It’s sharing what we’re all doing in the different regions so then we can all report back to our regions if someone’s doing something that we think is a good idea.”

Jenny Dias, Parent Representative, Children & Young People’s
South East Coast and London Diabetes Network

“It was almost like a lightbulb moment because we’re talking about coeliac disease and it was one of those moments of, ‘Oh, you’re doing that here. Well, we’re doing this here. Why are we doing this here when all of the patients get sent to the same centre? Actually, we should all be doing the same thing. It’s the same set of patients. Well, we should all have one guideline. We should all have one pathway because it will lead to the same endpoint.’”

Jennifer Hoare, Network Manager, Children & Young People’s
Thames Valley Diabetes Network

- **The Network offers a safe space and opportunity to ask questions and receive answers from the community.** Both regional and national meetings offer a psychologically safe space²⁰ where attendees are comfortable talking openly about what is not working so well in their PDU, free from the scrutiny of performance management and regulatory pressures. Several participants reported that without the Network they would not have developed relationships with colleagues from other PDUs whereby they can pick up the phone and get valuable advice about a challenging clinical case or delicate administrative situation.

“The Network is there to provide an open channel for everyone to communicate with one another, to reduce replication of the same work.”

Jennifer Hoare, Network Manager, Children & Young People’s
Thames Valley Diabetes Network

²⁰ Edmondson, A.C. 2018. *The fearless organization: creating psychological safety in the workplace for learning, innovation, and growth*. Wiley.



“I’ve been consciously trying to give everybody an equal voice. In the way that we structure our [regional] network meetings, and in the way that we make decisions. I’ve worked really hard to make sure that, because although everyone kind of comes and contributes and feels ownership, that doesn’t necessarily mean that everybody speaks.”

Chris Anderson, Network Chair, Children & Young People’s Wessex Diabetes Network

- **The Network enables members to learn from NPDA data to drive improvement.** The regional and national Network structure offers an important framework for reviewing and reflecting on NPDA data. Network meetings include presentations and discussions of the data, as well as the implications for clinical practice. Regional networks use NPDA data to identify PDUs that need additional support to improve their care processes.

2. Sharing voice

- **The Network adds clout to local requests for funding for resources and multidisciplinary team members.** The Network supports individual PDUs to advocate for additional resources. This typically takes place at the regional level where relationships, guidelines and benchmarking with similar PDUs are used to develop and strengthen the case for additional resources.

“It gives them the opportunity to share with their management and say, ‘Look, at the other unit in the Network you’ve got a paid dietician three days a week. We’ve only got one, one day a week. Look at what they are being able to achieve for their patients.’ It gives them that leverage to evidence what other units are doing now.”

Mary Bance, Former Network Administrator, East of England
Children & Young People’s Diabetes Network

- **The Network gives voice to children and young people and their family members.** Through the Families with Diabetes National Network and regional family representatives, the Network has provided a structure for families to work with clinical leaders to determine its priorities, contribute to improvement initiatives, and collaborate with clinical teams. Furthermore, children and young people with diabetes and their families have used the Network infrastructure to develop regional communities, including Facebook groups with several thousand members offering peer support and information.

“I have never been made to feel anything other than an equal voice at the table... and the difference this meaningful engagement makes can be seen across the audited outcomes of the Network. By working together, we identify the areas that need bolstering and address these, but also celebrate the huge achievements and successes that are apparent.”

Annie Astle, Regional Parent Representative

²¹ Astle, A. 2019. The Families with Diabetes National Network: working with clinicians to improve care. *Diabetes Care for Children & Young People* 8(3): 27–33.

“I have anecdotal evidence that people who come and speak at regional meetings with my teams subsequently find it easier to engage in a personal level with their diabetes and see their HbA1c come down, because you’ve given them a voice and you’ve given them the chance to get out there and talk about it. For me, that is huge.”

Jon Matthias, Network Manager, Children & Young People’s
Wales Diabetes Network (and Brecon Group)

“One parent’s voice is not that strong. Hundreds of parents’ voices are really strong.”

Jenny Dias, Parent Representative, Children & Young People’s
South East Coast and London Diabetes Network

3. Sharing delivery

- **The Network offers resources to educate children and young people with diabetes, their families, schools and clinicians.** It has developed numerous and wide-ranging educational resources (some created by individual regional networks or PDUs and others by cross-PDU working groups). All are freely available on the Network’s website²².
- **The Network co-develops guidelines, pathways and standards in order to reduce unintended variation in care.** It has created more than 100 guidelines, pathways and standards, which are often reviewed and discussed at Network meetings. These are developed by the Network’s Guideline Advisory Group, which is responsible both for reviewing external guidelines for Network members to use and for developing new guidelines²³. The health checks (care processes) that are measured and reported on by the Network are those recommended by the National Institute for Health and Care Excellence (NICE) in its guidance for the diagnosis and management of children and young people with type 1 and type 2 diabetes.

“We’ve had guidelines absolutely. We’ve emphasised which guidelines are important for clinical safety. We’ve set a whole set of standards. There are 130 standards embedded within the peer review, self-assessment document, which went out for consultation and were agreed on by the whole of the Network. We’ve built our own standards and are working towards delivering them in all diabetes units across the country.”

Fiona Campbell, Chair, National Children & Young People’s Diabetes Network

²² National Children & Young People’s Diabetes Network. Education resources. Available from: www.cypdiabetesnetwork.nhs.uk/education-tools-resources/education-children

²³ National Children & Young People’s Diabetes Network. Guideline Advisory Group. Available from: www.cypdiabetesnetwork.nhs.uk/national-network/guideline-advisory-group



Network structure: five complementary and aligned components

We have discussed how the Network has impacted care and sought to improve outcomes by sharing learning, voice and delivery. We also wanted to understand what constitutes the Network and learn about its structure. Through workshops and interviews, we found that the Network consists of five broad components that operate in a highly complementary way.

1. Sharing framework

Effective networks accelerate improvement by facilitating the sharing of best practice, knowledge and expertise²⁴. They enable participants to adopt or adapt successful practices and interventions into their context rather than developing them from scratch. The Network has an effective meeting and communications structure to support this sharing and spread of ideas at both the national and regional level.

Nationally, the Network holds biannual meetings that include data-led discussions on progress and opportunity areas. The highlights of these meetings are often presentations by clinicians on best practice and learning from recent improvement projects. Peer breakout sessions are held to enable multidisciplinary team members to discuss issues relevant to their practice; and time is allocated specifically for discussion and networking, enabling valuable relationship-building and more informal collaboration. These national meetings also enable sharing and alignment across the regional clinical networks, both for clinicians and parent representatives. Several interviewees noted that these meetings offer a trusting environment where participants feel comfortable raising and seeking advice about challenging cases and situations.

In addition, each regional network has developed its own meeting and communication structure. These typically involve more frequent meetings to explore intra-regional variation in care processes and resources, and a forum to plan regional events for families.

“Each hospital has a section in a meeting, which has the opportunity to say, ‘This is our outcome. This is what we’ve done in the past year that we’re proud of, this is what we’re really struggling with at the moment.’ And then have the entire [regional] network say, ‘That’s a great idea, can we borrow that, please?’ Or ‘we’ve got this really good idea, which might help that problem that you’ve got.’ It means that each unit has centre stage for a little while.”

Chris Anderson, Network Chair, Children & Young People’s Wessex Diabetes Network



²⁴ See, for instance, Greenhalgh, T. 2017. *How to implement evidence-based healthcare*. Ch. 10, pp. 182–202.



Many participants reported that the most valuable part of the sharing framework is that the frequency and format of the Network's face-to-face meetings have enabled members to foster and develop trusting relationships. This provides clinicians with the comfort and familiarity to be able to pick up the phone to colleagues across the country to discuss specific cases, and receive advice and peer support.

“The clinicians will just pick the phone up to one another and chat about ideas, they're really open with each other.”

Lucy Powell, Network Manager, Children & Young People's Wessex Diabetes Network

2. National Diabetes Quality Programme

The Network has partnered with the Royal College of Paediatrics and Child Health (RCPCH) to develop and implement an ambitious National Diabetes Quality Programme²⁵. It is based on evidence from Sweden where paediatric diabetes outcomes (as measured by HbA1c levels) have improved as a result of national quality improvement collaboratives and peer review²⁶.



Participation is voluntary but strongly encouraged by the Network's leadership, and so far approximately 90% of PDUs have committed to participate. The programme is funded by the PDUs themselves via funding they receive from the Best Practice Tariff (see below). It is administered by the RCPCH, which has strong expertise and experience in developing improvement capability.

The National Diabetes Quality Programme consists of three parts:

- **Self-assessment** by every participating PDU, in the form of an annual survey. This offers a structure to enable PDUs to reflect on their strengths and opportunity areas of practice. Network members developed the measures used for this assessment.
- **Peer review programme** – these data-driven standardised visits to PDUs are conducted by a multidisciplinary team of clinicians and parent representatives. They provide 'external eyes' to identify improvement areas and offer ideas, coaching, and support to prioritise and guide improvement efforts. These visits render the host PDU quite vulnerable, as they must expose their workings and practices to external reviewers; however, the process serves to further build trust and respect across the clinical diabetes community.

²⁵ Royal College of Paediatrics and Child Health. National Diabetes Quality Programme. Available from: www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/diabetes-quality-programme

²⁶ Peterson, A., Hanberger, L., Åkesson, K., Bojestig, M., Andersson Gäre, B. and Samuelsson, U. 2014. Improved results in paediatric diabetes care using a quality registry in an improvement collaborative: a case study in Sweden. *PLoS ONE* 9(5): e97875.

- **Quality Improvement Collaborative** – this is a relatively new programme (which started in October 2017) that involves training in quality improvement (QI) methodology and delivering an applied improvement project (examples include testing and implementing self-management resources and improving the outpatient clinic experience). PDUs participate in the QI Collaborative in waves. The aim is that at least 100 PDUs will have participated in a collaborative by 2021. Pilot results are encouraging, with participating PDUs reporting an accelerated decrease in median HbA1c levels over the course of their involvement in the collaborative²⁷.

3. Data and analytics

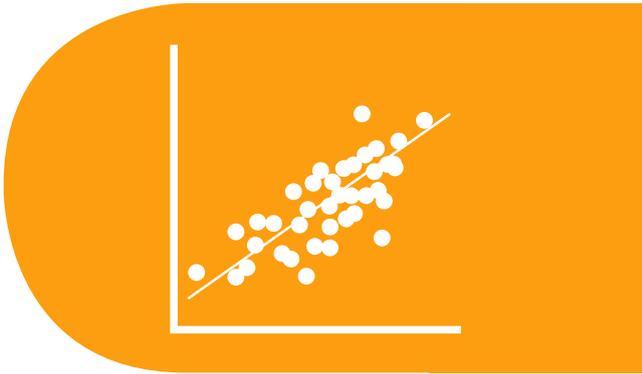
The Network encourages PDUs to submit data annually to the NPDA. There is 100% PDU participation in this audit, which offers highly valued, robust data and analytics support to Network members, at any time throughout the year. This enables PDUs and regions to analyse their real-time performance and progress, and to benchmark against their peers and national averages, enabling them to assess whether their QI interventions are beneficial. The audit is commissioned by the Health Quality Improvement Partnership (HQIP), funded by NHS England and the Welsh government, and is managed by the RCPCH.

The data are collected from all 173 PDUs and summarised in annual reports that explore trends, examine variation, and offer recommendations. The data and reports are used at the PDU, regional and national levels to assess progress and establish priority areas. Key measures are depicted as funnel charts²⁸ so that positive deviants can easily be identified and learned from, and negative outliers can receive more coaching and support. The NPDA also offers and highlights resources showing how PDUs have improved specific measures – including, for example, how the Sunderland Royal Hospital PDU reduced HbA1c by focusing on carb counting and staff education.

The reports and data are fully transparent, publicly accessible, and viewed as robust by clinicians. An interactive reporting tool enables stratification by PDU, clinical commissioning group (CCG) or region²⁹, and individual PDUs and regional networks are encouraged to review their data regularly. Clinical leaders report that the audit data drive improvement and inform decision making.

“... it’s a combination of having that data, understanding it and being able to use it in some sort of way to improve.”

Justin Warner, Clinical Data Lead, National Children & Young People’s Diabetes Network



²⁷ Royal College of Paediatrics and Child Health. Diabetes Quality Programme – Quality Improvement Collaborative. Available from: www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/diabetes-quality-programme/qi-collaborative

²⁸ HAELO Innovation and Improvement Science Center. Understanding a funnel plot. Available from: www.haelo.org.uk/funnel-plot

²⁹ Royal College of Paediatrics and Child Health. NPDA Results Online. Available from: npda-results.rcpch.ac.uk/ccg-data.aspx



The NPDA also produces an annual Parents and Carers Report³⁰, which summarises the key findings in an accessible way and includes a glossary to help those without a clinical background understand clinical and analytics terminology. Spotlight audit reports have also recently been produced, focusing on specific aspects of diabetes care and seeking to explore and learn from the variation in the structure of the care delivery system³¹. The initial spotlight reports used data from 2017 to 2018 and focused on ‘Diabetes Related Technologies’ and the ‘Workforce in Paediatric Diabetes Units’. These have been used by several PDUs to help advocate for additional resources.

To explore and understand young people’s and parents’ experiences of care, Patient Reported Experience Measures (PREMs) are periodically collected and analysed. The PREM questionnaire is distributed via PDUs and allows parents and children and young people with diabetes to provide direct feedback on their experiences of care. The PREM audits performed in 2012, 2013, 2015 and 2019 captured the experiences of between 7,500 and 13,100 children and young people and their parents in each round.

4. Family engagement

Parents and families of children with diabetes are an important part of the Network. Each regional network has several parent representatives who support the development and delivery of improvement projects and provide a forum for communication and support among families. The regional parent representatives attend the Network’s national meetings to advocate for and represent the views of families across all 11 regions. The parents also help set the Network’s priorities for workstream developments. There is a parent representative role description; recruitment is by formal application to the regional network manager and clinical lead.



While there is variation in how each region works with and engages children, young people and their families, they all offer an opportunity for families to present at meetings and contribute to improvement and advocacy efforts. This structure brings parents together, coordinating action and amplifying their voices as well as enabling the Network to harness the passion and enthusiasm of parents who want to contribute to the diabetes community.

“ [Families] are the real experts, they’re dealing with this all the time... I learn an awful lot speaking to them... it’s a very unique perspective. ”

Lucy Rowe, Network Manager, Children & Young People’s South West Diabetes Network

³⁰ Royal College of Paediatrics and Child Health. 2019. *NPDA parents and carers report 2017–2018*. Available from: www.rcpch.ac.uk/resources/npda-annual-reports

³¹ Royal College of Paediatrics and Child Health. 2019. *National Paediatric Diabetes Audit (NPDA) spotlight audit reports*. Available from: www.rcpch.ac.uk/resources/npda-spotlight-audit-reports



Each region has an online forum (typically a Facebook group comprising several hundred members) for parents of children with diabetes, where they can share experiences and engage with other parents. As well as offering support and connection, these forums enable the Network to test ideas with the community and quickly gather family perspectives, often adding weight to local requests for resources.

The Families with Diabetes National Network has used the online forums to administer numerous surveys and research, which the Network has used to help shape its priorities. These surveys have had a profound impact. For example, the survey based on the question ‘What worries you most about diabetes?’ changed many clinicians’ perspectives by clearly showing that reducing HbA1c levels is a low priority for many children and young people with diabetes³². The ‘Survey to establish accessibility to “Glucogen Hypokit” among parents/carers and schools’ received more than 880 responses and prompted the Network to issue a position statement explaining when a school requires training in glucagon administration³³.

“He’d gone in with a slide that we produced in the Families with Diabetes National Network, showing the percentage of people who had issues at schools, and he got a nurse funded to go to schools specifically just for that job and train schools. Actually, I always remember that, because that was one of the best moments for me. It came years down the line, but it really made me realise it was work that was useful and was actually getting things done.”

Kate Fazakerly, Parent Representative, Children & Young People’s South East Coast and London Diabetes Network, and Former Chair of the Families with Diabetes National Network

Regional family representatives play an important role in communicating and organising with other local parents. Several regional networks partner with local and national diabetes charities to run educational and social activities for their member families, including (for example) camps for children and young people with diabetes, film screenings and bowling nights.

“They might be the only child in their school with type one diabetes... But on the camp weekend, there were 30 of them together. They’ve all got the same things to deal with, and it’s a chance for them to feel normal for the weekend... It’s a really good opportunity for the children to just be able to be free and be themselves.”

Mary Bance, Former Network Administrator, East of England
Children & Young People’s Diabetes Network

The Network’s family engagement efforts have enabled productive relationships to be formed and sustained between parents and Network leaders. This has led to parents participating in the Network’s most important initiatives, including the National Diabetes Quality Programme, and informing the sharing framework and NPDA processes.

³² Astle, A. 2019. The Families with Diabetes National Network: working with clinicians to improve care. *Diabetes Care for Children & Young People* 8(3): 27–33.

³³ Families with Diabetes National Network. Survey to establish accessibility to ‘Glucogen Hypokit’ among parents/carers and schools. Available from: www.cypdiabetesnetwork.nhs.uk/files/3314/2796/7834/Survey_to_establish_accessibility_to_Glucagen_Hypokit.pdf

5. Funding

The regional networks in England are primarily funded by the Best Practice Tariff (BPT). This was introduced in April 2012 and comprises 13 national mandatory standards of care³⁴. The BPT provides PDU with a tariff (payment) for every child or young person who receives care that meets the annual criteria. As well as funding Network activities, including the provision of a paid regional Network manager and support for meetings, the BPT represents a substantial increase in funding for paediatric diabetes services, which more accurately reflects the actual costs incurred in delivering paediatric diabetes care³⁵. Network leaders advocated for the BPT and co-developed the criteria, which include:

- expert support within 24 hours of diagnosis
- a structured diabetes education programme
- four multidisciplinary clinic appointments with eight additional contacts per year
- an annual dietetic appointment
- quarterly HbA1c measurements
- annual psychiatric assessments
- 24-hour expert advice and support for those with high HbA1c³⁶.

Network leaders have developed an expanded range of new criteria, which were implemented in 2019³⁷.

Funding in Wales is allocated via the six health boards and enables Welsh PDUs to have their own regional network and to participate in national meetings, the NPDA, and the National Diabetes Quality Programme.



³⁴ Randell, T. 2012. Developing a best practice tariff in paediatric diabetes: can we improve services and outcomes for children and young people with diabetes in England? *Diabetes Care for Children & Young People* 1(1). Available from: www.diabetesonthenet.com/uploads/resources/dotn/_master/2190/files/pdf/dccyp1-1-23-6.pdf

³⁵ National Children & Young People's Diabetes Network. 2017. Paediatric diabetes Best Practice Tariff criteria – for paediatric diabetes units in England, frequently asked questions. Available from: www.cypdiabetesnetwork.nhs.uk/files/6815/2051/6740/180110__FAQ_for_BPT_paediatric_diabetes_for_England_ONLY_V3.pdf

³⁶ Newton, R., Dunn, S., Neail, C., Brown, C., Diegnan, J., Thalava, R. and Puttha, R. 2017. G161(P) The best practice tariff in paediatric diabetes – patient views and preferences. *Archives of Disease in Childhood* 102(1).

³⁷ NHS. 2017/18 and 2018/19 national tariff payment system. NHS England and NHS Improvement. Available from: improvement.nhs.uk/documents/1044/2017-18_and_2018-19_National_Tariff_Payment_System.pdf



Aligning and connecting the components



While the five components are important individually, many Network leaders and members reported that much of the Network's value is in aligning and connecting what would otherwise be disparate initiatives. Elements of the five components might exist individually without the Network; however, by aligning and connecting these efforts, the Network significantly increases their impact. It is a case of the whole being far greater than the sum of its parts.

We explored this with Network members during a workshop at a recent Network meeting (see Appendix) where attendees discussed how additional value is created by elements of the components working together. Examples included the following:

- **Increasing the effectiveness of funding requests**

The Network adds clout to local requests for additional funding for PDUs. These requests are typically made by clinical leaders to trusts and CCGs. The Network has strengthened these requests by facilitating the use of insights from surveys conducted by families involved in the regional and national networks, data from PREM surveys, benchmarking data from the NPDA spotlight reports, and by referencing the standards of care and best practices developed by the Network.

- **Enabling data-driven learning and improvement**

Network leaders use data and analysis from the NPDA to determine the measures and associated care processes most worthy of discussion at regional and national meetings. They also use these data to identify the PDUs that are positive deviants and ask them to share their practices and learning at Network meetings. Network committees and working groups also use the NPDA data to inform the development of care standards and pathways.

- **Informing and empowering families**

Network leaders led the development of the BPT criteria and used the Network's infrastructure to publicise the criteria to families via the regional family representatives. This has made families aware of what they should expect from their local service, and has empowered them to support local improvement and advocacy efforts.



Implications and opportunities for the Network

The Network has created a structure and culture that enables shared learning, voice and delivery across the paediatric diabetes community. This has made those involved feel that the Network has had a profound impact on paediatric diabetes care. However, in England and Wales, paediatric diabetes outcomes still lag behind several of our European counterparts³⁸.

It is therefore an important time for the Network to reflect on its progress and determine its future priorities. The interviews and workshops we conducted enabled Network members and leaders to surface several opportunity areas. The Network has recently embarked on a development project to consider these and other opportunities in order to focus and prioritise efforts for the next five years. These discussions will influence the content of the Children & Young People's Diabetes Delivery Plan 2020–2025, which is currently being developed. Already several themes have been recognised to be addressed as priorities:

- **Governance and leadership:** The current governance structure is too dependent on a small number of highly committed, predominantly volunteer, clinical leaders. This presents a risk to the Network if current leaders were to leave or reduce their commitment. It also limits the Network's ability to scale up its efforts, and raises important questions around succession planning and sustainability. The Network is currently considering how to transition to a more distributed leadership structure and develop more clinical leaders. With the recent publication of the NHS Long Term Plan and its emphasis on children's networks of care for diabetes, asthma and epilepsy, this gives the Network the opportunity to link more closely with the NHS England National Clinical Director for Children, Young People and Transition.
- **Cross-regional variation and learning:** Each regional network has considerable autonomy and there is variation in their structures and priorities. Ensuring efficient, effective communication across the regions is thus challenging, with duplication of effort reported. This presents an opportunity for the Network to foster more cross-regional learning and collaboration.
- **Engaging families:** While most regions have successfully engaged and integrated family partners into their teams, in some regions family partners play only a minimal role, and efforts to engage families have been limited and largely unsuccessful. The Network has an opportunity to support those regions and further develop standards and best practice.

³⁸ Charalampopoulos, D., Hermann, J.M., Svensson, J., Skrivarhaug, T., Maahs, D.M., Akesson, K., Warner, J.T., Holl, R.W., Birkebæk, N.H., Drivvoll, A.K., Miller, K.M., Svensson, A., Stephenson, T., Hofer, S.E., Fredheim, S., Kummernes, S.J., Foster, N., Hanberger, L., Amin, R., Rami-Merhar, B., Johansen, A., Dahl-Jørgensen, K., Clements, M. and Hanas, R. 2018. Exploring variation in glycaemic control across and within eight high-income countries: a cross-sectional analysis of 64,666 children and adolescents with type 1 diabetes. *Diabetes Care* 41(6): 1180–1187.

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- **Engaging young people:** The Network currently has no formal national representation from young people with diabetes. There is now an opportunity to incorporate young people with diabetes into its leadership structure and develop an approach to engage them fully in Network activities. This will ensure that the Network is more inclusive and transparent, and that its goals are better aligned with the needs of the people it serves. This will be especially important when developing diabetes services for young people in transition (those being prepared to move from paediatric to young adult services).
 - **Online training and support materials for families and clinicians:** The Network has a nascent partnership with an online platform (DigiBete) that offers educational resources for children and their families³⁹. The Network could use this platform more widely and work on improving self-management, as well as developing digital training and education to improve the skills and knowledge of those involved in diabetes care.
 - **Type 2 diabetes:** The Network has recently established a working group to support teams to achieve improvements in care and outcomes for children and young people living with type 2 diabetes. This initiative could have a growing impact as the prevalence of type 2 diabetes continues to increase and the opportunities for training, learning and sharing increase accordingly.

³⁹ DigiBete. Available from: www.digibete.org/

Conclusion

The National Children & Young People's Diabetes Network shows what can be achieved when clinicians and family members work together towards a common purpose in a formal structure. It demonstrates that for collaboration to be meaningful and support improvement, commitment and resources are necessary. It is not surprising that at a recent workshop, Network members rated 'funding' as the most important of its five components, noting that it is crucial in making the other components possible.

Since the Network was set up, its leaders have had a strong vision: to share good practice and maintain high-quality standards in the treatment and care of children and young people with type 1 diabetes. However, making progress towards this vision has required perseverance. The funding and partnerships that have enabled the Network were not readily available from the outset, and Network leaders have had to be opportunistic, advocating for and taking advantage of opportunities as they presented amidst a shifting policy landscape. This has meant that the five components were not integrated as part of a deliberate strategic plan, but rather were developed and incorporated as part of the Network more organically. This situation is suboptimal and has created uncertainty for the Network's members and staff. It has also resulted in too much precious leadership time being spent justifying and advocating for resources to external stakeholders at the expense of focusing on realising the Network's purpose.

Despite this, the Network is a powerful example of a successful collaboration that has led to improvements in outcomes and processes, and we believe that the Network's structure could serve as a blueprint for those working on other long-term conditions to learn from and adapt. Our hope is that by documenting the Network's achievements and journey, we can provoke increased debate around whether and how we might ensure that every long-term condition has a network to support its improvement.

It is encouraging that the NHS has committed to supporting clinical networks for children with long-term conditions⁴⁰. However, if this reflects a serious intention to replicate and accelerate the approach behind the Network, it will need consistent and sustained funding to develop the components and infrastructure necessary for such networks to form and thrive.

Finally, the success of the Network as a pioneer is credit to its leaders who, since the beginning, have believed in what they were doing, maintained a positive mindset, and remained committed to delivering their vision. In doing so they have inspired colleagues and family members living with diabetes to make innumerable contributions to both the Network and paediatric diabetes care in general.

⁴⁰ NHS. 2019. *The NHS Long Term Plan*. Available from: www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf



“It’s about finding people who have got the drive and motivation to bring about improvements in care for children and people with whatever condition and getting those like-minded people together. That kind of joined-up working prompts enthusiasm, and spreads enthusiasm. If you’ve got that, then I think you can make a success of a network. But it’s really hard work. You have to be tenacious, and you have to be ready to fight because there are people who don’t believe in it, but actually in the end, the outcomes are what matters. And it’s working.”

Jenny Foster, Network Manager,
Children & Young People’s Yorkshire and Humber Diabetes Network



Appendix: Methods (interviewees and workshop)

In order to get the views of a representative group of Network participants, we designed an engagement approach that included attending, facilitating and observing Network meetings, alongside in-depth, semi-structured interviews conducted between June and September 2019.

Data collection

Network meeting observation

We attended two meetings. We attended and observed the Network meeting on 4 June 2019, which was also attended by regional network managers, chairs and other stakeholders, including colleagues from the RCPCH. During this meeting we facilitated a session that explored the Network's journey to date and the value and impact it has created. The output from that session was summarised and is available as a synthesis pack⁴¹.

Then, on 24 September 2019, we attended, observed and facilitated a half-day session at a meeting of the Network attended by 24 participants, including the national and regional network chairs, regional network managers, and parent and family representatives. During this meeting, we facilitated a session that validated the synthesis pack from the June meeting⁴² with attendees and shared the preliminary findings from the interviews. We also discussed the Network components and their impact on diabetes care. The output from that session was summarised and is available as a synthesis pack⁴³.

Semi-structured interviews

We designed a semi-structured interview guide based on background reading, the outputs from the session we observed and facilitated on 4 June 2019, and discussions with the Network Chair, Dr Fiona Campbell (Consultant Paediatric Diabetologist at Leeds Teaching Hospitals Trust). Dr Campbell supplied us with a stakeholder list of 21 potential interviewees. This list included all key representative groups: regional network managers, regional network chairs, the regional network administrator, data lead, and parent or family representatives. We approached all stakeholders on the list and were able to interview 17 participants between 25 June and 11 September 2019.

⁴¹ Reflection & collaboration workshop synthesis pack. 4 June 2019. Available from: bit.ly/2BpEgXy

⁴² Reflection & collaboration workshop synthesis pack. 4 June 2019. Available from: bit.ly/2BpEgXy

⁴³ National Children & Young People's Diabetes Network Meeting. 24 September 2019. Available from: bit.ly/2MM7cOw



We carried out six face-to-face interviews on 25 June 2019, while stakeholders were gathered at the Network managers' meeting. Ten interviews took place by telephone and one other interview took place face-to-face. Each interview took approximately 45 minutes. Interviews were audio recorded using smartphone voice recording applications and transcribed using a transcription service.

Analysis

The meeting synthesis packs and the qualitative interview data were coded using OneNote and organised into *a priori* themes, with emerging themes discussed between the research team and included throughout the analysis phase.

Presentation and validation of findings

We presented and explored preliminary findings at the second Network meeting (24 September 2019) with the 24 attendees (regional network chairs, regional network managers, and parent and family representatives).

Case study write-up

The case study was written up into a report format in October 2019 with iterative feedback included from the Network chair and the Health Foundation.

About Kaleidoscope

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About the Health Foundation

This work was supported by the Health Foundation, an independent charity committed to bringing about better health and health care for people in the UK.

Kaleidoscope Health and Care
604 Cannon Wharf
Pell Street
London, SE8 5EN

hello@kscopehealth.org.uk

