

# Children and young people diabetes networks: Where are they now and where are they going?

The children and young people diabetes networks (CYPDNs) were set up in 2009 with the aim of providing consistent, high-quality diabetes care to our children, young people, and their families. There are 10 regional networks across England and together they form the national CYPDN. Working in conjunction with NHS Diabetes and the Department of Health, the CYPDN is developing a national paediatric diabetes strategy. Embedded initiatives within the strategy will ensure that our diabetes services are efficient and effective in a sustainable way and will facilitate improvements in health outcomes that matter the most to our children, young people, and their families. The importance of improving outcomes has recently been highlighted in a report prepared for the Secretary of State for Health by the Children and Young People's Health Outcomes Forum (Department of Health, 2012), which was established to respond to the challenges set out in Sir Ian Kennedy's report published in 2010, entitled "Getting it right for children and young people" (Kennedy, 2010). We eagerly await the Government's response to this report, which is likely to form the basis of the development for the Children and Young People's Outcome Strategy. In addition, one of the roles of the NHS Commissioning Board is to drive improvements in quality and outcomes, as measured at a national level through the NHS Outcomes Framework 2012–13 (Department of Health, 2011). It is clearly important that our plans for changes to diabetes care for children and young people are developed in line with NHS Strategy.

Recently, there have been some notable successes in improving the quality of diabetes services that we are delivering, which can be directly attributed to the development of the CYPDNs.

The first successful initiative has been to assist in the development of the 13 care standards set out in the best practice tariff (NHS Diabetes, 2012).

This tariff, introduced in April 2012, has enabled paediatric diabetes to become a commissioning priority. Paediatric diabetes units (PDUs) across England are currently in negotiation with provider and commissioning managers to secure investment in clinical diabetes services in order to achieve the high standards of the tariff that the children and families should rightly expect, no matter where they live.

The second successful initiative has been the development of the National Peer Review Quality Assurance Programme, supported by NHS Diabetes. In 2011, 18 PDUs across Yorkshire and Humber participated in a pilot study commissioned by the Yorkshire and Humber Strategic Health Authority. The regional CYPDN was also subject to peer review, involving self-assessment against written standards, external validation and peer-review visits. The peer-review programme was based on that which had been developed in cancer services and delivered by the National Cancer Peer Review team. A similar pilot is also being undertaken in the West Midlands at the present time. Peer review encourages individual teams to engage in reflective practice and to seek ways to improve their effectiveness. As a result of these pilots, a plan to roll out self-assessment and external validation across all PDUs and CYPDNs in England has been formulated. This quality-assurance programme will commence in October 2012 and reach completion by May 2013.

The third success has been the recent development of the NHS Diabetes Parent Reference Group. Parents will play an integrated part in the development of all the local CYPDNs and PDUs as they move forward. A key role of the group will be to improve communication with parents in the local CYPDNs and bring forward the critical issues that parents face concerning the care of their children. These challenges can then be faced collectively.



**Fiona Campbell**

Consultant Paediatric Diabetologist, Leeds Children's Hospital, and Clinical Lead for Children and Young People, NHS Diabetes



**Sheridan Waldron**

Education Lead for Children and Young People, NHS Diabetes

*“It is now time to move on and focus our attention on how we can improve the health outcomes that matter the most to our children and families.”*

It is true to say that since 2009 the CYPDNs have had a major focus on the process of diabetes care, and network members and stakeholders should be justly proud of their accomplishments.

Alongside the key successes, there has been a great deal of work to standardise care and share good practice, including activities such as:

- Sharing service specifications.
- Setting care standards.
- Supporting team performance.
- Promoting active engagement with our service users and professional colleagues.
- Using resources effectively and imaginatively.

It is now time to move on and focus our attention on how we can improve the health outcomes that matter the most to our children and families. There is little doubt that continuing to work in a networked model of care will help us to achieve this and so we must turn our attention to how we can support the networks to flourish. The 10 CYPDNs are all at different stages of maturity. Assessing each network's strengths and areas for growth and development is going to be an essential part of keeping them all “fit” to perform their role. The peer-review programme will greatly assist in this process.

In the future, regional network members need to share a common purpose with clear objectives and strategic goals that are reflected in each network's work plan and annual report. The network's performance should be repeatedly examined to ensure that all members are working jointly to advance the network goals, reduce variation in clinical outcomes (RightCare, 2012) and continue to add value to each other's work. Robust pathways of communication between each PDU both within and between regional networks, and across the national network, will be an essential component of their ongoing success. Operationally, the chairs, coordinators and parent representatives of the CYPDNs will perform vital leadership roles, encouraging members to communicate and collaborate to achieve more together than they could achieve alone. In time, the networks will need fully effective governance structures, with individual accountability amongst members, using agreements and understandings. An increase in material resources will undoubtedly be needed, and network members will need to develop new skills and connections in order to achieve their goals and objectives. This structure will assist the networks

in reviewing their strategic direction. Additional national working groups will also be required to cover specific topics. For example, a new system of care is currently being developed for the transition from paediatric to adult services.

We should welcome the recent guidance set out in the publication “The Way Forward: Strategic Clinical Networks” published by the NHS Commissioning Board (2012). The guidance provides clear recognition of the large-scale changes that are required across very complex pathways, involving many professional groups and organisations. It is clear that a coordinated approach to commissioning, workforce planning and service delivery is needed to improve quality, safety and outcomes. In order to ensure the delivery of safe, quality-driven services in a sustainable way, we need to develop and maintain a network of key stakeholders that links strong professional and clinical leadership with formal governance arrangements, and the ability to influence planning and decision-making.

We should continue to acknowledge the impact and value that the CYPDNs have had in supporting this drive for the changes to our service design and delivery. The described changes will undoubtedly help to improve clinical outcomes in line with our European and global counterparts and maximize the quality of life for our children and young people. ■

Department of Health (2011) *The NHS Outcomes Framework 2012/13*. DH, London. Available at: <http://bit.ly/up3lKS> (accessed 24.09.12)

Department of Health (2012) *Report of the Children and Young People's Health Outcomes Forum*. DH, London. Available at: <http://bit.ly/P1wzEM> (accessed 24.09.12)

Kennedy I (2010) *Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs*. Department of Health, London. Available at: <http://bit.ly/cR582d> (accessed 24.09.12)

NHS Commissioning Board (2012) *The way forward: Strategic clinical networks*. NHS, London. Available at: <http://bit.ly/N5dn8u> (accessed 24.09.12)

NHS Diabetes (2012) *Best Practice Tariff for Paediatric Diabetes (diabetes in children and young people aged 18 and under) – information for parents, children and young people*. NHS Diabetes, Newcastle Upon Tyne. Available at: <http://bit.ly/HZaPaX> (accessed 24.09.12)

RightCare (2012) *NHS atlas of variation in healthcare for children and young people*. RightCare, UK. Available at: <http://bit.ly/QyF50t> (accessed 24.09.12)