

National Children and Young People's Diabetes Network Delivery Plan 2020-25





FOREWORD BY
DR FIONA CAMPBELL
Clinical Lead, April 2020

Dear Colleagues

It gives me great pleasure to write the foreword to the National Children and Young People's (CYP) Diabetes Network Delivery Plan 2020-25. I would like to thank everyone involved for all their hard work in bringing it to fruition. The plan is designed to improve the quality of planning, commissioning, delivery and regulation of services in order to achieve better outcomes for children and young people living with diabetes and their families.

In 2009, 10 regional Paediatric Diabetes Networks were set up across England with support from NHS Diabetes. Together they formed the National Paediatric Diabetes Network. In 2015, Wales joined the Network as its 11th region. The membership of the Network recognised very early on that, to achieve good experiences of care and better outcomes for children with diabetes, the services that they provided

should be designed around the needs of those children and their families. Any newly designed services could not exist in isolation from the wider political, social and economic environment of the present day and resources needed to be used wisely to create safe and sustainable services for the future.

The driving force behind the development of the initial Service Improvement Delivery Plan 2013-2018 was to encourage all paediatric diabetes units to strive for continuous improvements driven by innovation, evaluation and the desire for continuous life-long learning. During those 5 years, we have taken a much closer look at what it takes to improve outcomes for young people and their families receiving care from the NHS consistently and sustainably. National Paediatric Diabetes Network members have gained a far better understanding of patient and family aims for their care. Clinicians are becoming more innovative and improving care quality based on their experience of delivering care and using data and networks to drive service improvements and share good practice ideas generated from home and abroad.

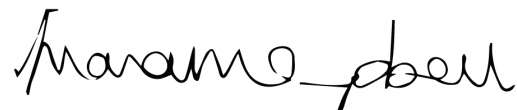
Over the past 10 years, the clinical outcomes measured by the National Diabetes Audit have greatly improved. We want to continue on this quality improvement journey and feel strongly that this can be done by the Network continuing to foster a culture, where patients and families, and the communities in which they live, work collaboratively with healthcare professionals and other providers in mutually beneficial partnerships to improve care.

The strategy outlined in our new National CYP Diabetes Network Delivery Plan 2020-25 is underpinned by the core value of high quality, person-centred care and focuses on building an integrated Network infrastructure that supports the

design and delivery of a comprehensive process of care from diabetes prevention through to diagnosis, effective disease management and optimisation of treatment. The annual NPDA, spotlight and local audits will continue to provide essential frames of reference for tracking our progress and identifying and understanding gaps in performance which could be addressed by diabetes teams using quality improvement methodologies taught in the Diabetes Quality Programme.

It is encouraging to note that in the NHS Long Term Plan, published in 2019, there has been a commitment to supporting the development of Clinical Networks for children with long-term conditions with diabetes named as being one of them. It has therefore never been more important that planners and commissioners of services, providers and their regulators, public, private and community sectors, families, practitioners and any community members, all work together to align services, to improve the health of children and young people and in so doing their quality of life.

I sincerely hope that this National CYP Diabetes Network Delivery Plan 2020-2025 helps us do what we know we must do and that is to continue to improve outcomes for our children and young people with diabetes and help them live complication free lives.



Dr Fiona Campbell
Clinical Lead
National Children and Young People's Diabetes Network
April 2020



Background

The National Children & Young People's Diabetes Network was formed in 2010. At the time there were high levels of variation in care processes and outcomes significantly lagged behind European and international counterparts. Clinical leaders made the case to NHS Diabetes (a former improvement organisation, funded by strategic health authorities across England), to support the development of a national clinical paediatric diabetes network. This development, in addition to more focus being put on the National Paediatric Diabetes Audit data, the introduction of a Best Practice Tariff and more recently the development and introduction of a National CYP Diabetes Quality Programme that consists of Quality Assurance (in the form of annual self-assessment against measures and peer review) and Quality Improvement (formation of Quality Improvement Collaboratives) has seen an impressive improvement in outcomes, in particular HbA1c values. Over the last 6 years, we have managed to significantly reduce our median HbA1c nationally towards the NICE recommended target of 48mmol/mol, yet it still remains behind those of many European countries. With lower HbA1c, comes a reduced risk of long-term complications, improved life expectancy and enhanced quality of life.



Our Vision

The National Children and Young Peoples Diabetes Network's (NCYPDN) ambition is to enable children and young people living with diabetes to achieve optimal health and social outcomes and enhanced quality of life through access to world-class diabetes services that offer consistent, high quality care no matter where it is delivered in England and Wales

To achieve this we will continue to work in partnership with parents, children, young and people alongside our colleagues in health, education, social care, charitable and voluntary sectors to develop a fully integrated care model that provides:



- **A highly trained, inter-disciplinary care team who understands the needs and preferences of CYP in addition to offering structured, comprehensive support for them up to the age of 25**
- **Good preparation for CYP moving from children's services into young adult services**
- **Equitable access to insulin pumps and CGM technology**
- **Face to face, one to one, group work or digital self-management learning and communication with their care team**
- **The ability to co-design their care plan during appointments, give feedback and have a say in service planning**
- **Access to 'diabetes trained' support in the community from social workers, youth workers, teachers and other supportive figures in their daily lives**
- **Knowledge of and ability to participate in research trials e.g. immunotherapies or new insulin delivery methods**
- **Psychological and emotional support for CYP , parents and families**

Diabetes in Children and Young People in England and Wales : Where are we?

DIABETES IN NUMBERS

28,597

There were 28,597 children and young people with Type 1 Diabetes being managed within PDU's in England and Wales in the 2018/19 National Paediatric Diabetes Audit

National median HbA1c fell from 64.0 mmol/mol to 61.5 mmol/mol between 2017/18 and 2018/19

61.5

- There is wide variation between Paediatric Diabetes Units (PDUs) in completion rates of all health checks, with the percentage of children and young people with Type 1 diabetes and a completed year of care receiving all 7 ranging from 3.3 to 95.8%
- There is an association between level of deprivation, ethnicity, gender and blood glucose control outcomes in children and young people with Type 1 diabetes
- There is a higher incidence of Type 2 diabetes in girls and young women of non-white ethnicity and living in deprived areas
- 39.1% of children with Type 1 diabetes who have recorded outcomes of accessing psychological services have been assessed to be in need of additional psychological or CAMHS support outside the MDT service.
- Usage of insulin pumps in therapy has increased year on year but so has the gap between usage rates in the most and least deprived areas – 29.5% versus 42.9% in 2018/19
- Increased pump usage is associated with female gender, younger age, living in least deprived areas and white ethnicity.¹

¹[NPDA report 2018/19](#);

What has been done so far?

The National Children and Young People's Diabetes Network (NCYPDN) was set up in England in 2010 (joined by Wales in 2015), in response to a report, published by the Department of Health, entitled "Making Every Young Person with Diabetes Matter". The NCYPDN, supported by the Families with Diabetes National Network (FWDNN), has been pivotal in the development and delivery of the key national initiatives designed to improve and standardise diabetes care for children and young people in the England and Wales:

- 1. The Children's Charter for Diabetes, published by Diabetes UK in 2009**, sits at the centre of clinical care for children and young people with diabetes in the UK. It sets out the basic rights and core values guiding all service design and delivery in children and young people's diabetes care.
- 2. The National Paediatric Diabetes Audit (NPDA), delivered by the Royal College of Paediatrics and Child Health** which, through its 100% completion rate by Paediatric Diabetes Units (PDUs) in England and Wales, provides reliable performance data and a benchmarking platform for services. The audit report also gives clear recommendations on how units can improve.
- 3. The National Diabetes Quality Programme (NDQP)** is delivered by the Royal College of Paediatrics and Child Health on behalf of the National Children and Young People's Diabetes Network. It consists of a Quality Assurance element and a Quality Improvement element with both working in conjunction with the NPDA; the aims of this Programme are to assist diabetes teams to improve outcomes by identifying ways to enhance multidisciplinary care within the NHS, reduce unwarranted variations and encourage more involvement of families in service design and improvement.
- 4. The Best Practice Tariff in England (BPT)** provides annual payment for the treatment of every child and young person under the age of 19 with diabetes as an incentivised payment mechanism that rewards clinical teams who deliver care of a specified quality, as evidenced by the NPDA and the Quality Assurance element of the NDQP.
- 5. The NHS Long-Term Plan commitments for children with long term conditions** makes several commitments to redesigning health services for children and young people that relate to improving care for children with long term conditions, including diabetes. Through developing the improvement capabilities, including QI skills and data analytics, systems will move further and faster to adopt new innovations and service models and implement best practices that can improve quality and efficiency in addition to reducing unwarranted variations in performance. To support the Quality Improvement methodology, from 2019-20 clinical networks will be rolled out to ensure the NHS improves the quality of care for children with long-term conditions. This will be achieved through sharing best clinical practice, supporting the integration of paediatric skills across services and bespoke quality improvement projects.

Together with the NICE guidelines and the NHS Long Term Plan, the above key national reports, initiatives and guidance provide a structure for PDUs across the country to design, evaluate and improve the care they provide.

The role of the NCYPDN and FWDNN

The NCYPDN and FWDNN have played an indispensable role in the process of national implementation of this improving care structure as they:

- a. Support PDUs to participate in national initiatives and achieve best quality care through improvement approaches**
- b. Work towards 100% of provider units utilising the Children and Young People's Diabetes Best Practice Tariff Service Specification and Self-Assessment Quality Standards**
- c. Develop mechanisms for best practice sharing to support standardisation across PDUs locally, regionally and nationally**
- d. Provide expert input on national priorities and key service gaps to build forward looking implementation plans**
- e. Continue to support the evaluation and further development of the National Children and Young Peoples Diabetes Quality Programme**

Since the inception of the Networks 10 years ago, diabetes care provision for children and young people in the UK has seen many advancements which have resulted in better resourcing, service outreach, quality of service, patient experience and, most importantly, better outcomes. The existence of the Networks as a national structure designed to improve care and outcomes, in addition to addressing the variation seen between services, has also enabled the development of many shared pathways, guidelines and resources, coordination of procurement, and liaison with NHS agencies and other organisations.

However, we can't sit still and some persistent challenges remain – most notably the wide variation in outcomes across the country as well as within certain socio-economic groups. Despite the existence of the BPT, there is also the issue of resourcing and coordination with other parts of the health service, including psychological support (outside the PDUs) as well as education, social services and transition from children's through to adult diabetes services.

There are also new challenges on the horizon – uncertainties over a sufficient level of available resources, adequate workforce provision with good knowledge and skills in diabetes and growing tensions over access to new technologies have all emerged in recent years.



Our Mission

To fulfill the Networks' ambition to improve the lives of CYP and families through sustainable development and an improvement focus, the NCYPDN and FWDNN aim to strengthen their mutual involvement by becoming more integrated. By working more closely together we will ensure that the clinical and family perspectives feed into joint strategic and operational decision-making.

It has been agreed that the FWDNN will be fully integrated into the NCYPDN. For the purpose of this Delivery Plan, the FWDNN will not be referred to separately and it will be implicit in the use of NCYPDN that there is family involvement. The FWDNN will nonetheless retain its identity, in the same way as regional networks, by having its own umbrella logo (turquoise).

This integrated Network will continue its function of supporting a more uniform service design and delivery, while undertaking developments needed to render it resilient and responsive to the ever changing circumstances of the NHS and the children and young people living with diabetes. To this end, and to fulfill its ambitious vision for children and young people living with diabetes, the NCYPDN will:

- a. Use the NPDA data to benchmark, review and drive Quality Improvement initiatives throughout the network;**
- b. Develop peer to peer review and accountability mechanisms and strong inter-regional communication links to ensure further integration of its structure and the services it represents;**
- c. Further develop its relationships with the NHS by becoming better connected with NHSE and NHS Wales to enhance and sustain the regional networks going forward, allowing them to play a key role in organising the delivery of networked diabetes care, as outlined**

in the NHS Long-term Plan, and share learning with other disease areas e.g. asthma and epilepsy;

- d. Support the families living with diabetes and diabetes charities to engage with the National CYP Diabetes Network to ensure the voice of service users is heard;**
- e. Continue to strengthen its relationships with other key stakeholders, including the Department of Health, Welsh Government, Royal Colleges, adult diabetes networks, diabetes charities and research organisations;**
- f. Ensure sustained base funding and explore new funding models (outcomebased funding) and sources;**
- g. Drive a shift to value-based commissioning based on a validated Quality of Life measure and family drivers in the system;**
- h. Become an instrument of community-integrated care by establishing strategic links with new partners including schools, colleges, social services, primary care, CCGs (LHBs Wales) and the new Integrated Care Systems (ICS) and other relevant stakeholders;**
- i. Establish themed, cross-working groups to provide pockets of expertise on different aspects of CYP diabetes care;**
- j. Strengthen the National CYP Diabetes Network structure, providing a shared framework and mechanisms for the regional CYP Diabetes networks to feed into;**
- k. Develop a communication strategy and plan with a clear message and communication channels for target audiences;**

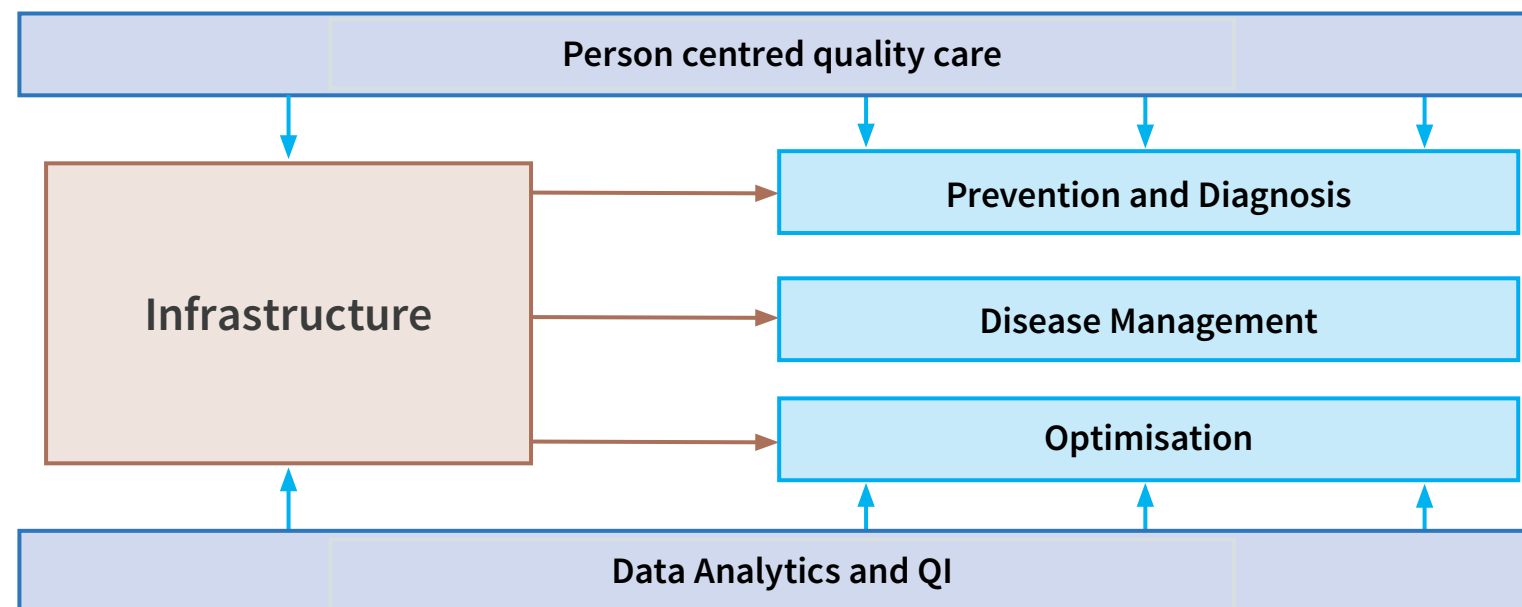


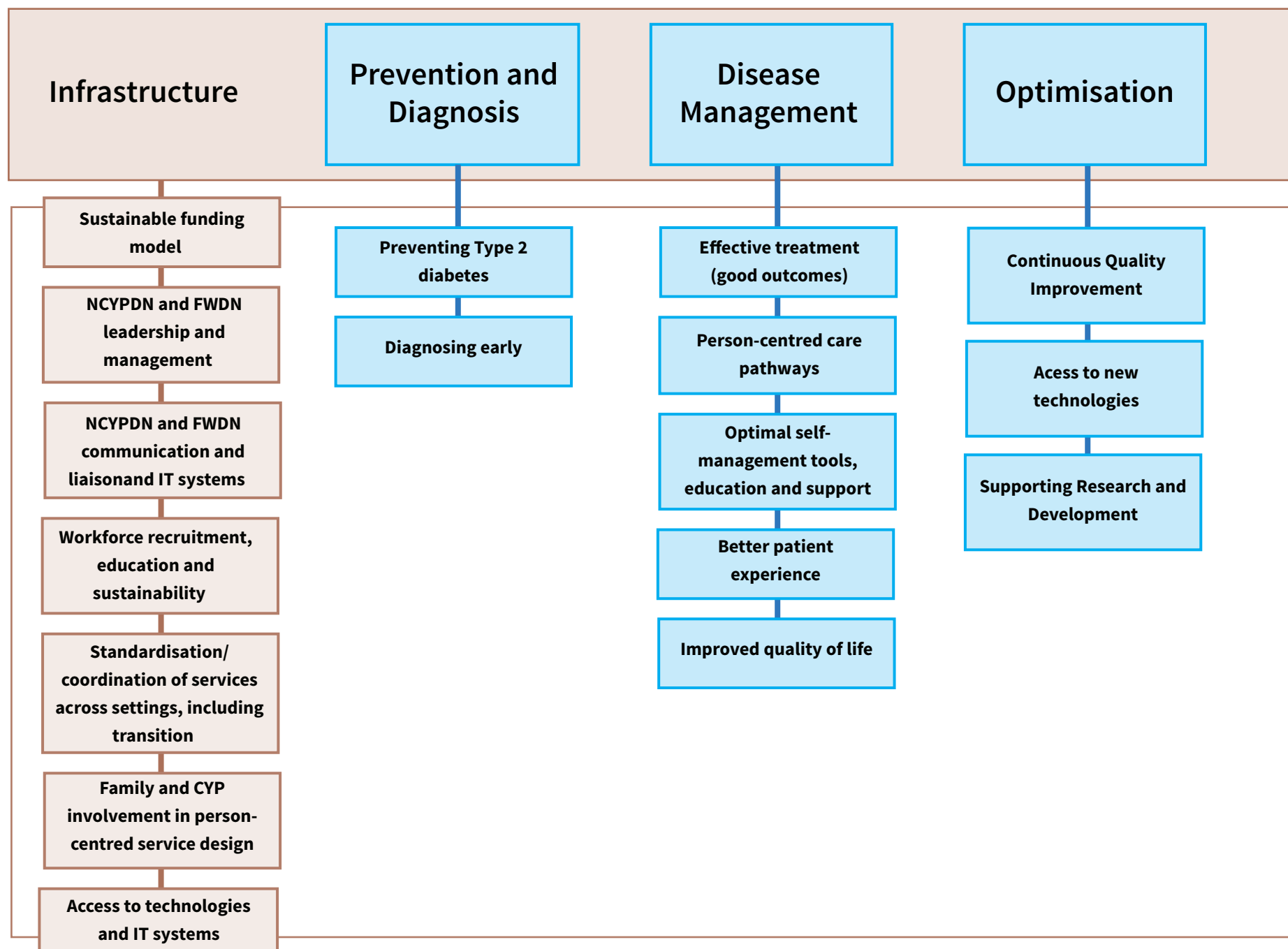
Our Strategy

Our new strategy for the integrated Network is underpinned by the core value of person-centred quality care, and focuses on the following key steps:

- 1. To build a robust service infrastructure enabling effective care design and delivery.**
- 2. To support the design and delivery of a comprehensive process of care from prevention, through diagnosis and effective disease management, to optimisation of treatment.**

We plan to focus our efforts under these listed headings in the next 5 years. We will first strengthen the diabetes infrastructure as the foundation – and the area of immediate priority – on which effective diagnosis and treatment can be delivered, sustained and optimised. The Quality Improvement agenda will be driven by robust analysis of data. The annual NPDA, spotlight and local audits will continue to provide frames of reference for tracking progress, identifying and understanding performance gaps and helping us adapt our strategic approach accordingly. This information will be supplemented by the information gathered by the CYP Diabetes Quality Programme.





OUR STRATEGY

1

INFRASTRUCTURE



In order to develop standardised, high- quality, person-centred services for patients, a strong national networked infrastructure is needed with the appropriate resources to allow the well- educated, multidisciplinary and adaptable workforce, equipped with the right tools and technologies to deliver the care and support to young people and their families to help them improve their self-care and outcomes including emotional health and well-being. These need to be inter-connected with other parts of the health service and social support mechanisms including social care, schools as well as a supportive digital environment such as the DigiBete platform. Patients and families must be involved in care review and design at a national, regional and local level to ensure that it matches their needs.

OUR STRATEGY

2

PREVENTION AND DIAGNOSIS

Partnering with stakeholders in a wide-reaching campaign, targeting primary care, schools, pharmacies and the wider society needs to be put in place to raise the awareness of all forms of diabetes. Early diagnostics must be promoted to help to reduce complications from late diagnosis.

3

DISEASE MANAGEMENT

Young diabetes patients must receive NICE recommended care standards in a process which accounts for wider social determinants of health outcomes and provides tailored pathways, including the right tools, knowledge, clinical and social support.

4

OPTIMISATION OF CARE

Continuous improvement and innovation must go hand in hand with care delivery. Patients must be given access to new technology and clinical trials where it can support their individual progress.



Our Delivery Plan 2020-25



A I M S

Within our strategic area of **INFRASTRUCTURE**, we have identified key wins that we will be working to accomplish in collaboration with NHS England and NHS Wales by the end of 2025, which will become the foundation on which **optimal care and innovation** will be built. We will aim to:

1

Ensure that every child with diabetes has equal access to the same level of diabetes care and education, that allows effective self-management through the delivery of a national standard programme supported by diabetes teams that include psychologists and social workers.

3

Develop nationally defined and enforced paediatric diabetes job descriptions for all roles, exemplar business cases, staffing ratios and educational standards.

2

All children and young people with diabetes have access to clinically appropriate technology.

4

Ensure we will have full parent, children and young people representation and voice in diabetes services.



OUR DELIVERY PLAN 2020 - 25: AIMS

1

AIM 1: By 2025, we can ensure that every child with diabetes has equal access to the same level of diabetes care and education, that allows effective self-management through the delivery of a national standard programme supported by diabetes teams that include psychologists and social workers.

How will we know we have been successful?

Our clinical data and patient reported outcome and experience measures show minimal variation in outcomes across regions and services.

How will we do it?

We will focus our work firstly on trying to understand variation, its causes and effects, where it needs to be eliminated and where it adds value in order to strike a balance between providing equitable, high standards of care nationally and matching the needs of local children and young peoples and the resources of the clinics that serve them. We will develop clear guidelines and standards in key processes of care, including at diagnosis, self-management as well as transitioning to other parts of the health service (adult hospital services, primary care and community specialist care).

1. System

- Understanding variation within regions and identifying where there should be no variation and how to address the gaps
- Standardising the language and key messages for children, young people and their families across the system

2. Diagnosis

- Developing guidance on early diagnosis and prevention of DKA
- Providing a standard package at diagnosis, including key guidelines, evidence-based core content education programme delivered by staff trained to the same level
- Providing standard access to specialist support from trained staff (standard minimum level of support)

3. Treatment and self management support

- Developing clear pathways for GPs (particularly around prescribing)
- Agreeing standards for transition to adult services and ensuring that they are operationalised
- Developing wider community-based support via schools, social care, housing and other agencies via targeted information and training packages and local engagement mechanisms
- Providing access to technology and ongoing e-learning for patients



OUR DELIVERY PLAN 2020 - 25 : A I M S

2

AIM 2: By 2025, all children and young people with diabetes have access to clinically appropriate technology.

How will we know we have been successful?

All children and young people are assessed for their eligibility to use appropriate technology and supported in its use via standard training and support packages

How will we do it?

We will concentrate our work on trying to ensure that technology is equally accessible. This will include working directly with commissioning services to provide the IT systems, data collection and analysis and education and training needed to enable access, making sure that every service is capable of assessing patients and offering them clinically appropriate technology. We will work with the diabetes community on changing mindsets about the use of technology, highlighting its benefits.

1. Funding

- Developing a national funding policy and programme, with strict criteria for funding tied with educational packages
- Pooling and evidencing business cases
- Working directly with CCGs and LHBs towards resourcing teams adequately on a region by region basis

2. Equipment

- Providing IT access to clinics, child health professionals and patients (via links with schools or community in case of lack of personal resource)

3. Education

- Developing clear pathways for GPs (particularly around prescribing and annual screening)
- Providing adequate training and subsequent upskilling for staff on how to use technology, interpret and apply data
- Providing training packages for parents, children and young people
- Providing awareness-raising and mindset changing tools for staff to deal with resistance to technology and highlight its benefits
- Working with schools via staff training, drop-in clinics and increasing PDSN support to schools (enabling direct communication between schools and MDTs)

4. Data and systems

- providing a uniform system for clinic data downloading and interpretation
- Facilitating local and national data collection, analysis and benchmarking



OUR DELIVERY PLAN 2020 - 25 : A I M S

3

AIM 3 : By 2025, there are nationally defined and enforced paediatric diabetes job descriptions for all roles, exemplar business cases, staffing ratios and educational standards.

How will we know we have been successful?

There is a clear process and template documentation in place supporting the recruitment of paediatric diabetes workforce. Every member of staff is given the same training opportunities and education standards to support them in their role at its commencement and on an ongoing basis.

How will we do it?

We will concentrate our work on developing a standard process and templates to guide the recruitment, training, retention and support of staff, supporting the services to become adequately staffed and the staff to be trained to the same high standard.

1. Recruitment

- Standardising job descriptions for all members of a multidisciplinary team (MDT) and administrative staff
- Providing guidance on minimum staffing ratios and out of hours support
- Providing a pool of exemplar business cases to support recruitment
- Facilitating the showcasing of jobs via NHS Recruitment and recruitment fairs

2. Training

- Providing discipline specific training standards (using NHS Diabetes Curriculum)
- Embedding Best Practice Tariff training in the job description
- Providing training opportunities (including blended learning) in collaboration with the RCPCH, RCN, DMEG, BPPN

3. Retention and Support

- Providing staff upskilling opportunities (including training in type 2 diabetes in paediatrics and technology training)
- Facilitating innovation and quality improvement sharing
- Enabling flexibility of workforce
- Developing mechanisms for the evaluation of roles on an ongoing basis
- Including support from the RCPCH recruitment and retention campaign



OUR DELIVERY PLAN 2020 - 25: AIMS

4

By 2025, we will have full parent, children and young people representation and voice in diabetes services.

How will we know we have been successful?

There is 100% family representation in the regional networks and individual PDUs and clear mechanisms for families to feed into service design, delivery and evaluation, as evidenced by PREMs and satisfaction surveys.

How will we do it?

We will concentrate our work on ensuring adequate representation and feed-in mechanisms at a PDU, regional network and national NCYPDN and FWDNN level. We will further grow the integration between NCYPDN and FWDNN, providing a clear remit for the family representative role and training to ensure that families and child health professionals can collaborate to the best effect. We will develop mechanisms whereby the health service can be held to account for the quality, efficiency and efficacy of the diabetes care it provides to children and young people.

1. Family representation at a PDU level

- Ensuring each PDU has a parent and a young person representative feeding into their regional FWDNN representative
- Developing pathways for children, young people and parents to feed into their services, as appropriate

- Providing PDU-level, spotlight PREMs to collect feedback related to the execution of these pathways and the experience of service
- Providing rewards for involvement

2. Family representation in FWDNN

- Developing a standard role description for parent and young people members (including provisions on leadership, confidentiality, safeguarding)
- Providing standard training for members (either face to face via a local provider or online)
- Developing clear mechanisms for families to feed into PDUs and the NCYPDN

3. Accountability

- Ensuring family representation at Trust/LHB-wide meetings
- Providing patient and family feedback to CCGs, Trust Boards and LHBs

Our Operational Model

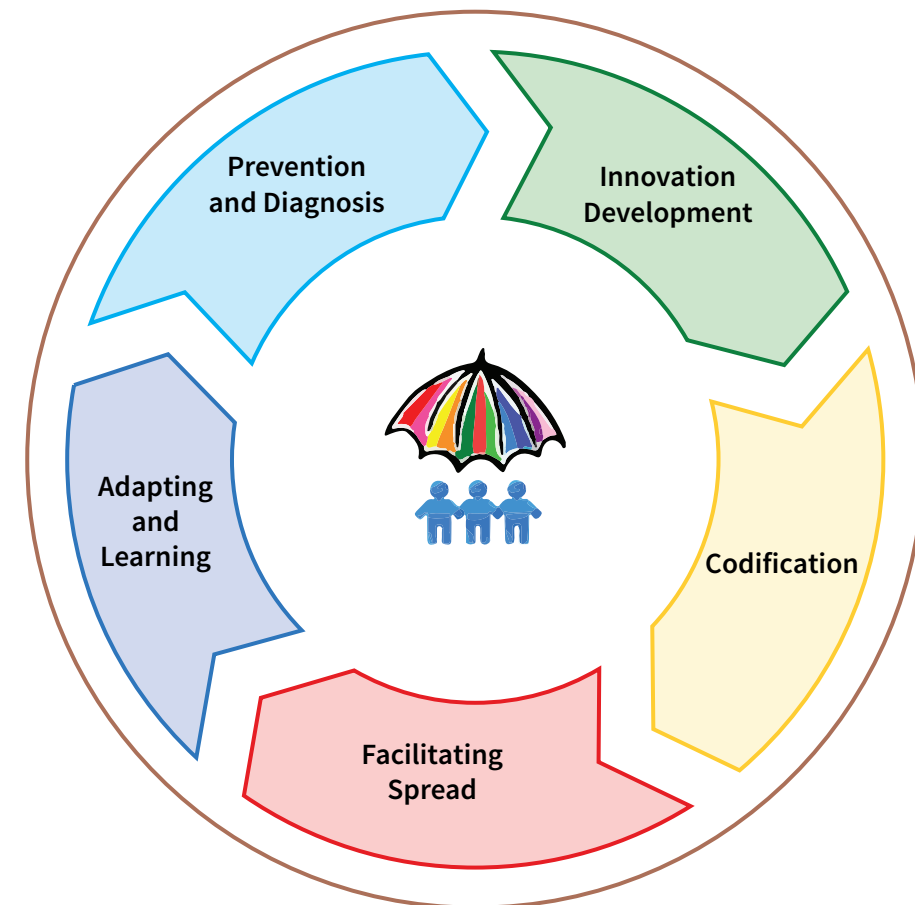


Building on an existing example of a Type 2 Diabetes Working Group within the NCYPDN, and in order to work towards the completion of our 4 big aims, we will develop an operational model consisting of cross-national action groups- each responsible for advancing the work of one of the big aims, starting from evidence and best practice review in a given area, through developing and trialling solutions, codifying them as replicable interventions, spreading in a coordinated programme of work and adapting for local practice.²

How will we do it?

Each action group will include core membership from across the NCYPDN as well as satellite membership inputting specific expertise as and when needed. While independent of each other, the groups will all report to the National Network and they will be able to draw on collective resources of the Network members to advance their work.

The action groups will also be supported by regional network teams in each region, who will be responsible for ensuring that the pathways, guidelines, standards or solutions developed by each action group are built into a spread project format and are subsequently disseminated to PDUs and adapted for local practice. They will also collate learning from local adaptations and feed back to the action group in question to enable continuous improvement.



²Health Foundation. (September, 2018). [The Spread Challenge](https://reader.health.org.uk/the-spread-challenge/): <https://reader.health.org.uk/the-spread-challenge/>

Additionally, there will also be a **National CYP Diabetes Network Board** developed to oversee the national integration and performance optimisation of the NCYPDN and FWDNN as well as its strategic links with NHS England, NHS Wales, Department of Health, Welsh Government, RCPCH, RCN and other key stakeholders (in line with the Networks’ Mission as outlined earlier in this document). See diagram.

