Service specification

NHS

London Clinical Networks

How to commission type 1 diabetes services

September 2016

How to use this pack

The London Diabetes Clinical Network has developed this comprehensive commissioning pack to ensure we deliver excellent type1 diabetes services for all Londoners. This pack contains recommendations to assist in the commissioning and delivery of excellent services, self-assessments to establish current gaps in commissioning and delivery, and performance targets expected which will ensure we deliver improved patient reported outcomes.

There are three parts to this commissioning pack:

- **Service specification** ***(this document)*** - Aimed at commissioners, this document details the care to be commissioned for adults with type 1 diabetes, including an overview of diabetes, elements of an excellent service plus commissioning recommendations.
- **Clinical management: Optimal pathway** - Aimed at providers, this document details the expected clinical care for type 1 diabetes.
- **Implementation guide** - This document provides the tools for both commissioners and providers to measure, analyse and develop improvement plans for their local diabetes service. It includes a summary of expectations and self assessments for commissioners and providers, performance targets and a sample patient reported outcome measures (PROM) form to collate patient feedback. It also highlights the type 1 care consultation tool (developed by Health Innovation Network and King's Health Partners), which can be used in the management of people with type 1 diabetes.

The London Diabetes Clinical Network, working with the academic health science networks in London, CCGs, Diabetes UK, JDRF (Juvenile Diabetes Research Foundation), Association of British Clinical Diabetologists (ABCD) and other stakeholders will support the implementation of this pack and the evaluation of local services. By identifying any gaps in service, we can work together to deliver excellent clinical outcomes in type 1 diabetes, which can be measured and validated by improved National Diabetes Audit participation and results.

Type 1 diabetes is a complex, long term condition, which requires individuals to own the condition for the rest of their lives, and take responsibility for their health and behaviours.

It is a condition which affects an individual in every way, every hour, every day, as glucose profiles and insulin requirements vary on a daily basis depending on multiple factors.

TABLE OF CONTENTS

COMMISSIONING DIFFERENTLY

FOREWORD

Dr Karen Anthony

Ensuring that all adults with diabetes in London receive high quality care is a key aim of the London Diabetes Clinical Network. The Strategic Clinical Leadership Group of the Network approves tools developed in its working groups to achieve this.

The Type 1 Diabetes Working Group is a dynamic group representing multidisciplinary clinicians, professionals, patients and charitable organisations. The energy and drive of this group led to the development of this service specification.

This service specification draws on work from National Institute for Clinical Excellence (NICE), Diabetes UK, INPUT and others, and brings together not only evidenced best practice, but also outlines innovative care, staffing and service delivery to meet the needs of patients with type 1 diabetes. It is a live document and will be reviewed as new evidence emerges or, at latest, in April 2018.

We look forward to working with clinical commissioning groups (CCGs), trusts, community health services, primary care and emerging GP federations, to begin implementing high quality diabetes services across London for those with type 1 diabetes.

We hope this service specification will assist commissioning decisions, combining all relevant guidance and standards in one document.

We would also like to thank those at the Association of British Clinical Diabetologists (ABCD) who have assisted with editing of this specification, and hope to use this as basis for a national document.

Finally, we would like to acknowledge essential support from the London Diabetes Clinical Network team of Dr Stephen Thomas for advice and guidance, and Ms Lesley Roberts for authoring of commissioning aspects, collation and editing of this document, supported by Andrea Marlow, Business Development Manager, London Clinical Networks.

Karen Anthony
Chair, Type 1 Diabetes and Insulin Pump Working Group
Consultant in Diabetes and Endocrinology,
Whittington Health NHS Trust

Dr Stephen Thomas

The impact of diabetes in London is well known. For people with diabetes, one of the biggest challenges is accessing good quality, integrated healthcare.

This is especially true for those with type 1 diabetes who are seeking appropriate insulin therapy, education/support, diabetes technologies and care for complications for their individual needs, as service provision varies across the capital.

The London Diabetes Clinical Network Type 1 Diabetes Working Group has collected and synthesised the best practice evidence and produced this service specification. This document builds on recommendations from the *Cardiovascular disease outcomes strategy*, NICE guidance , and responds to the challenges and aims of the *Five Year Forward View* and the work of *Better Health for London*.

I believe that this service specification will allow clinical commissioning groups (CCGs) to commission a service that delivers on the aims of integrated and holistic care across the patient pathway.

The specification has been developed with input and oversight from: the Strategic Clinical Leadership Group of the London Diabetes Clinical Network, including service user representatives; Professor Jonathan Valabhji, National Clinical Director for Obesity and Diabetes, NHS England; Dr Partha Kar, Associate National Clinical Director for Diabetes, NHS England; and members of the Association of British Clinical Diabetologists ABCD).

I would particularly like to thank Dr Karen Anthony and the group members for their effort in producing this service specification.

Dr Stephen Thomas
Clinical Director, London Diabetes Clinical Network
Consultant in Diabetes and Endocrinology,
Guy's and St Thomas' NHS Foundation Trust

Type 1 diabetes, an autoimmune disorder, leads to the failure of insulin production.
This means that people with type 1 diabetes are reliant on insulin treatment to stay alive. Nationally, type 1 diabetes accounts for 10 per cent of diabetes in adults and 95 per cent in children with diabetes[1]. Of the 4 million adults with diabetes in the UK, approximately 10 per cent -- more than 370,000 -- have type 1 diabetes. One challenge for commissioners is that there is currently no single source of data on the size of type 1 diabetes population in each CCG.

The National Diabetes Audit (NDA)[1] shows that diagnosis can occur at a very young age, even as young as a few months old.
Half of all patients with type 1 are diagnosed under the age of 15, and 90 per cent are diagnosed by the age of 30, although diagnosis can occur at any age. The 2012/13 NDA found just 3,000 of 6,800 newly diagnosed people were under 19 years of age. That means that more than half of those diagnosed have reached adulthood, with some initially misdiagnosed as having type 2 diabetes.

The incidence of type 1 diabetes is increasing.
Patients with symptoms of new onset type 1 diabetes may present to their GP or acutely to A&E. It is important that healthcare professionals in these settings are able to recognise the signs of type 1 diabetes. These include hyperglycaemia (excess glucose in the bloodstream), ketosis, rapid weight loss, age of onset is less than 50 years, body mass index (BMI) of less than 25 kg/m^2 and a personal/ family history of autoimmune disease. However, it is important not to discount type 1 diabetes for individuals with a BMI over 25 kg/m^2 or older than 50.

It is important to design services to help people with diabetes stay as well as possible for as long as they can. In the years following diagnosis, uncontrolled high glucose levels can lead to tissue damage, resulting in complications of diabetes and disability such as loss of sight, kidney failure, amputation and premature cardiovascular death. The risk of complications is greatly reduced by treatment that enables glucose levels to be kept as near to normal as possible. In particular, glucose control in the 5-10 years after diagnosis, with early access to specialist teams and early structured education, has a huge impact on reducing expensive and life-shortening complications.

Additionally, hypoglycaemia (low blood glucose, occurring as a result of insulin therapy) can result in confusion, collapses, seizures and, in extreme cases, sudden death. It can affect every aspect of life in people with insulin-treated diabetes. A hypo, as an episode is commonly known, is unpredictable and potentially dangerous. It exerts psychological effects and is greatly feared by those affected and by their relatives, and can influence adherence to treatment and glycaemic control. Approximately 30 per cent of people with type 1 diabetes will experience a severe hypoglycaemic episode (a hypo requiring third party intervention to treat) in any one year, and 4-10 per cent deaths under the age of 40 in adults with type1 diabetes are attributable to hypoglycaemia[2]. Over a lifetime, the risk of death from a hypo is less than 2 per cent.

Insulin treatment is designed to mimic physiological insulin concentrations as closely as possible whilst supporting individual lifestyles and dietary preferences or requirements. Without careful and continuous management of their condition, people with type 1 diabetes face a reduced life expectancy of 11 to14 years[3].

The UK has one of the highest average HbA1c for adolescents in Europe[4] and this problem persists into adulthood. Data from the NDA shows that mean HbA1c for people with type 1 diabetes is around 72 mmol/mol (8.7%) and less than 30 per cent reach the 2004 NICE implementation standard of 58 mmol/mol (7.5%)[5]. When we extrapolate these data to those from a large Scottish cohort study, this suggests that life expectancy for type 1 diabetes is reduced by 11 to 12 years of life due to poor diabetes control[6]. However, it is not all gloom and doom. The DCCT - EDIC study group demonstrated that with seven years of intensive control early on, mortality at 30 years of diabetes can be reduced by 30 per cent[7].

Based on this, it is imperative that healthcare providers supporting people with type 1 diabetes must have in-depth knowledge of, and experience in, the use of insulin, and its physiology and action. Additionally, for patients with type 1 diabetes, getting the balance right between optimal glycaemic control and lifestyle also requires great skill. An important part of the role of healthcare professionals involved in the care of these people is recognising this and providing appropriate motivation, education, skills, training and professional support.

Our expectation is that all people with type 1 diabetes in London will be offered structured and ongoing education to improve their knowledge and self management skills, thereby delivering the personal and health economic benefits of reduced complications. NICE guidance TA60 (*Guidance on the use of patient education models for diabetes*[8]) gives guidance on the structured education models that can be commissioned, recognising that psychological services also need to be an integral part of care. Specialist psychological care must be made available for all people with type 1 diabetes. A psychologist should be a full time part of the MDT. Research from Canada suggests that 60 per cent of females with type 1 diabetes will develop a clinically significant eating disorder by the age of 25. Despite having access to free healthcare and technology, teens in the UK have the worst HbA1c in Europe, and type 1 females between the ages of 15 and 30 are nine times more likely to die than their non diabetes counterparts. (For males, that figure is four times as likely to die.) Diabetes-specific distress and high HbA1c can be predictors of eating disorders in people with type 1 diabetes.

Commissioners should therefore ensure that providers deliver holistic care[9] for their type 1 diabetes cohort, recognising it is a service that requires specialist staff, as patients often describe their lack of confidence in staff within primary and community care organisations to support their type 1 diabetes care.

TYPE 1 DIABETES IN LONDON

Care for adults with type 1 diabetes in London comes with unique challenges. The demographics of the London population are younger and more ethnically diverse than the rest of the country. The National Diabetes Audit[1] showed that people under 40 years of age with type 1 diabetes are less likely to receive all of their annual care processes. Young people with type 2 diabetes had similar findings, indicating a lack of engagement with this age group.

Although the risk of developing type 2 diabetes is much higher in certain ethnic minority populations in comparison to the Caucasian population, it has been generally assumed that ethnic minority populations would have a lower risk of development of type 1 diabetes compared to Caucasians. However, studies in migrant populations suggest that over time, the risk of type 1 diabetes increases for a native population, though varies greatly for migrant ethnic groups.

London also has a wide range of deprivation levels. Of the 32 London boroughs, 20 have a level of deprivation higher than the national average[10]. Overall, the population of London is rising and mobile, with considerable movement between boroughs. Additionally, individuals may choose to access healthcare outside of the borough in which they live (for example, close to work). Young people with diabetes attending university outside of London may feel they have inadequate support locally, at a difficult time of their life as they transition to adult services.

Additionally, commissioners are advised to ensure that their local providers link up with universities and colleges in London to ensure that type 1 diabetes support is in place for these young people near their place of study. This may require innovative GP practice-based diabetes clinics, run by specialist teams and open access to specialist diabetes clinics. These can be supplemented by jointly funded education sessions.

Introduction

This service specification aims to outline the care expected for adults with type 1 diabetes.

We appreciate that CCGs may be at different stages in developing their type 1 diabetes services; some may have services that already mirror this specification and others may need a year to get to this level. Data from the National Diabetes Audit illustrates why we must focus on implementation as soon as possible.

This specification takes into account the 2015 NICE guidance, *Type 1 diabetes in adults: diagnosis and management*[11], and goes further in detailing the following components of a clinical service for adults with type 1 diabetes.

Six components of a type 1 diabetes service

1. Diagnose early

Our primary aim is ensuring the correct diabetes diagnosis as early as possible so that clinical management can be appropriate.

2. Provide a pathway for management

A flexible pathway is necessary, which adapts to the needs of the individual with type 1 diabetes depending on circumstances, regardless of location and across CCG boundaries, and takes into consideration life events such as pregnancy, which can affect a woman's diabetes and the outcome for her baby.

3. Prevent or delay onset of diabetes-related complications

Diabetes services must aim to prevent amputation, retinopathy, neuropathy, nephropathy and cardiovascular complications such as myocardial infarction (MI) and stroke. Type 1 diabetes management should be delivered by trained diabetes specialists, advising on correct insulin management, perhaps advising an insulin pump (CSII), and supplying the patient with the tools for regular and frequent blood glucose monitoring so that educated patients have the requisite knowledge to act upon their own results.

4. Education

Structured education (eg Dose Adjustment For Normal Eating, or DAFNE[12]) is needed for people with type 1 diabetes, as well as ongoing education and support from specialist type 1 teams to allow them to effectively self-manage their condition. This should be delivered to a minimum standard following a written curriculum, with trained educators, and should be quality assured and audited.

5. Targets

The specialist team should support adults with type 1 diabetes to aim for a target HbA1c level of 48 mmol/mol (6.5%) or lower, to minimise the risk of vascular complications. NICE recommends 53mmol/mol (7%) or less as the audit standard. This will all be documented and shared across the local health economy in a shared record that will feed the National Diabetes Audit.

6. Equity of access to services

Improving the patient experience of living with type 1 diabetes in providing the best possible care and support may require core type 1 services working together with larger centres providing enhanced care. Those centres that are still developing enhanced type 1 diabetes services are encouraged to develop two way flows and appropriate local commissioning arrangements with larger hub centres for increased education and support. With this, it is hoped that staff will work across the health economy and share resources between larger and smaller centres (eg structured education, pump therapy, CGM services, hypoglycaemia pathways and psychology services) creating access to high quality care across a wider geography.

CCGs should all move towards providing this level of care by March 2017.

The self-assessment documents (found in the *Implementation Guide*) can be used to measure performance in meeting this specification. Once the assessment is complete, services in 2017/18 can be commissioned with this specification in mind, with a focus on local priorities.

Nine commissioning recommendations

People with diabetes require nine regular checks to ensure their continued good health[13]. These nine commissioning recommendations are evidence based, and will result in high quality, cost effective type 1 diabetes services which achieve clinically effective outcomes.

1. All CCGs should be aware of the prevalence of their type 1 diabetes population, participating in the National Diabetes Audit to establish the incidence.

2. Commissioners should explore commissioning for value for type 1 diabetes services, using innovative commissioning models such as capitated outcomes based incentivised commissioning (COBIC)[14] or value based commissioning (VBC)[15].

3. Commissioners should identify a core team with dedicated time to redesign type 1 diabetes services and achieve better clinical and patient reported outcomes.

This team may consist of a commissioning lead for type 1 diabetes, a strategic clinical lead and a system leader. Commissioners should leverage this team to report into a wider multidisciplinary type 1 diabetes partnership group, network, collaborative, or integrated practice unit (IPU)[16].

These local groups should hold regular meetings, with the purpose of driving forward improvements in type 1 diabetes care. Strategic clinical leads for type 1 diabetes services are encouraged to direct these networks, incorporating people with diabetes and Diabetes UK as an integral part.

4. Commissioners should mandate participation in the National Diabetes Audit (NDA) and urgently develop a local process to establish the number of people with type 1 diabetes locally, consistently reporting their NICE diabetes care processes quarterly, so that these are available in the partnership group of commissioners, providers and service users, for better care.

5. Commissioners should ensure that for all people with type1 diabetes, services are designed to provide care coordination around their other health needs, recognising that their diabetes should be managed by specialists wherever possible. The service should ensure that all NICE diabetes care processes are collected routinely and acted upon, and have strong engagement with primary care and a shared record. We recommend developing services that link the collection of these care processes to the diabetes eye screening visit, to reduce patient appointments and cost. This should include a transition clinic.

6. Commissioners should ensure that all those with type 1 diabetes who meet the criteria are allowed to see if they can benefit from continuous subcutaneous insulin infusion (CSII) with support from a trained specialist team. It should be noted that many children and young adults moving into adult diabetes services will be treated with an insulin pump, and commissioners will need to account for this in the diabetes budget, as this will increase year on year.

7. Commissioners should ensure that all people with type 1 diabetes are offered structured education (eg DAFNE), and ongoing education as required. There should be a coherent CCG strategy to offer and deliver structured education to all patients with type 1 diabetes prioritising in the following way:

1. All newly diagnosed people with type 1 within one year of diagnosis
2. Delivery to those with problematic hypoglycaemia or an HbA1c above target
3. All women of childbearing age with type 1 diabetes
4. All patients with type 1 diabetes on an ongoing basis throughout their lives to ensure motivation is maintained and skills are refreshed and up to date with new developments.

8. Commissioners should ensure that all people with diabetes have access to technology to allow them to live safely. This includes:

- Access to a variety of capillary blood glucose (CBG) meters, including those with built in bolus calculators.
- Access to adequate CBG strips (The maximum of 10 per day or more to support them to achieve NICE recommended HbA1c targets is cost effective).

- Access to insulin pumps as per NICE (ref TA151) in patients who have problematic hypoglycaemia and/or HbA1c > 8.5% despite structured education.
- Access to a choice of insulin pumps as per individual needs.
- Policy for access to emerging technology such as continuous glucose monitoring (CGM) that may be valuable in individual circumstances.

There should be consideration of use of CGM. This is especially useful where insulin pump therapy without CGM has not been successful in reducing episodes of severe hypoglycaemia. Recent NICE guidance supports the use of CGM in this context. However, funding for this is currently patchy and variable. If these skills are not present within the team, an appropriate pathway for referral to this service should be in place.

We urge commissioners to develop a joint commissioning policy across London for funding CGM in local agreements to support those patients who meet the NICE criteria and continue to show an improvement in their condition as per NICE guidelines.

9. Commissioners should classify their service as ***core*** or ***enhanced*** *(see box, top right)*. This will also require providers to form strong referral and working relationships, especially with obstetrics, ophthalmology, renal services, podiatry, orthopaedics, vascular, psychology, rehabilitation, palliative care, community and primary care services. Innovative joint working should be developed with these services to make every contact count by also providing health promotion services, such as smoking cessation.

Providers should deliver type 1 services with a specialist multidisciplinary team with access to all other specialities (*see note, below right*) so that people with type1 diabetes have confidence in the care and support provided by healthcare professionals, as this is key to empowerment and self management and will achieve better outcomes for patients and for the NHS.

Core and enhanced classifications

Type 1 diabetes services will be classified as core or enhanced.

Enhanced will offer pump therapy (CSII) / continuous glucose monitoring and an integrated team approach to clinical psychology, including IAPT for Tier 1 and 2, clinical diabetes psychologist for Tier 3 and a consultant clinical psychologist for Tier 4 and clinical supervision.

Note: The London Diabetes Clinical Network is clear that any commissioning decisions to allow those with type 1 diabetes to be cared for by non specialist staff in conjunction with a specialist MDT team, should be carefully risk assessed, as it is very challenging to ensure that there is a consistent level of staff competences commensurate with the complexity of type 1 diabetes. We see this as risky and suboptimal.

COMMISSIONING STRUCTURE FOR IMPROVING DIABETES

NHS England recommends the following commissioning structure for optimal type 1 diabetes care, outcomes and value for money.

We would like to aim for a service similar to the Finnish model[17].

Commissioning for type 1 diabetes requires a very different commissioning focus than for other types of diabetes. It is for this reason that this specification has been developed, with the following suggested commissioning structure.

Note that there would be no need to change to this particular structure if your CCG can show that there is a specific team driving forward type 1 diabetes transformation, and achieving the outcomes identified in this specification.

1. Commissioning lead for type 1 diabetes - It is expected that commissioning organisations will assign a commissioning lead for type 1 diabetes who will ensure the implementation of this specification.

2. Clinical lead and system leader - We recommend identifying a clinical lead and a system leader. This is likely to be a consultant diabetologist supported by a programme manager experienced in system leadership.

The King's Fund[18] indicates that system leaders often do not see themselves as such, but given the unprecedented challenges facing the NHS, the system needs leaders who can motivate staff and managers to work differently, across service and organisational boundaries. They believe this is the only way to meet the needs of the growing number of people with complex and long term conditions, many of whom rely on care and support from different services. Commissioners are advised to dedicate a system leader who can work within provider organisations to:

- Start with a coalition of the willing, build a local type 1 evidence base, determining the number of people with type 1 diabetes in your population (or developing a strategy to do so building outwards). It is vital to engage clinicians in understanding the need for change and to lead efforts to achieve that change.
- Co-design services with people with type 1 diabetes and their carers; they have an invaluable role to play in helping to identify which services need to be redesigned.
- Strike the right balance between constancy of purpose and flexibility by facilitating conversations about what needs to change and how; being flexible about how that might be achieved; and ensuring the momentum is there to deliver change despite any opposition.
- Pursue stability of leadership.

3. Type 1 diabetes transformation group - It is anticipated that each CCG will set up a Type 1 diabetes transformation group. The commissioning lead for type 1 diabetes will work with the clinical lead and system leader with dedicated time to lead a representative group of stakeholders to transform and implement the commissioning aspirations. As these clinical leads are likely to be very busy clinicians, appropriate clinical back-fill will need to be funded to support this. Representation should be sought from service providers, commissioners and CCGs, the voluntary and third sector, social care and patients with type 1 diabetes.

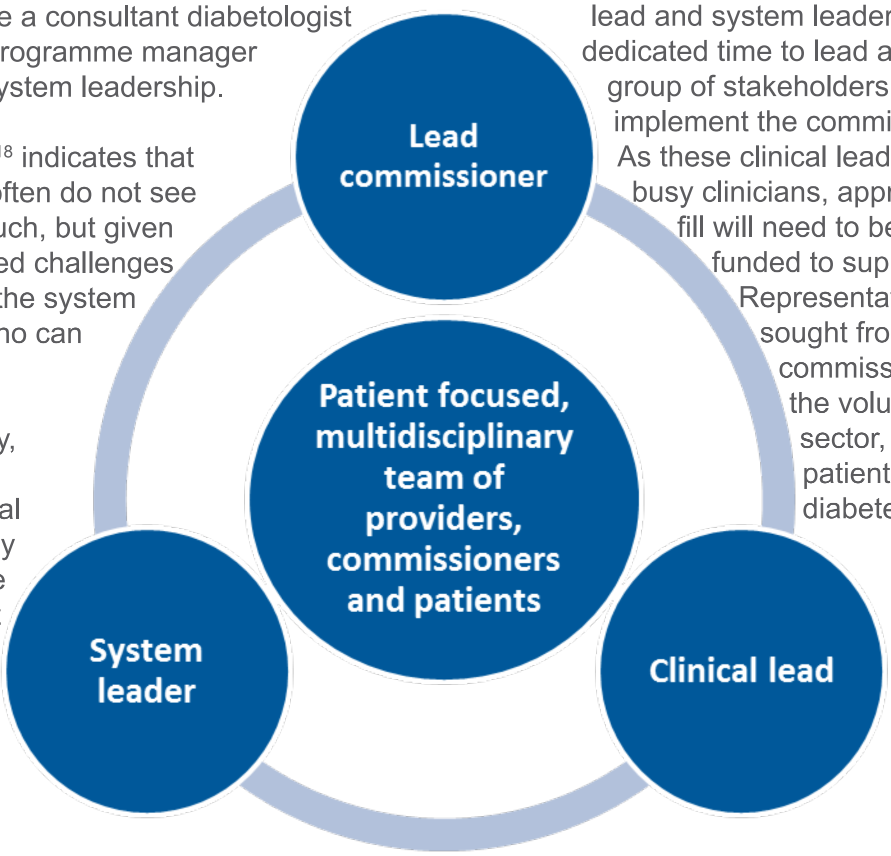


Figure 1: Structure of the Type 1 Diabetes Transformation Group

Stakeholders who represent community groups and patients with type 1 diabetes should be encouraged to attend this group. A process should be set up to train and reimburse patients who sit on advisory panels to ensure we value their contribution in driving forward services change. The transformation group should drive forward the implementation of this service specification for type 1 diabetes in adults.

A positive experience can lead to improved outcomes. The Patient Experience group of the London Diabetes Clinical Network gathered people's views about living with diabetes in London through an online survey[19]. The survey asked about the services they use, the level of support available and how their experiences could be enhanced by improving access to high quality care and thus, improve patient outcomes. Of the 180 respondents, 63 per cent had type 1 diabetes. Of these, 79 per cent preferred all their diabetes care to be hospital-based. (*We have interpreted this as referring to the specialist diabetes teams skills, rather than the venue of clinics.*)

The survey found that of the respondents with type 1 diabetes, 65 per cent sought advice from social media to support them managing their condition. The authors concluded that additional support is needed for all people living with diabetes and their carers.

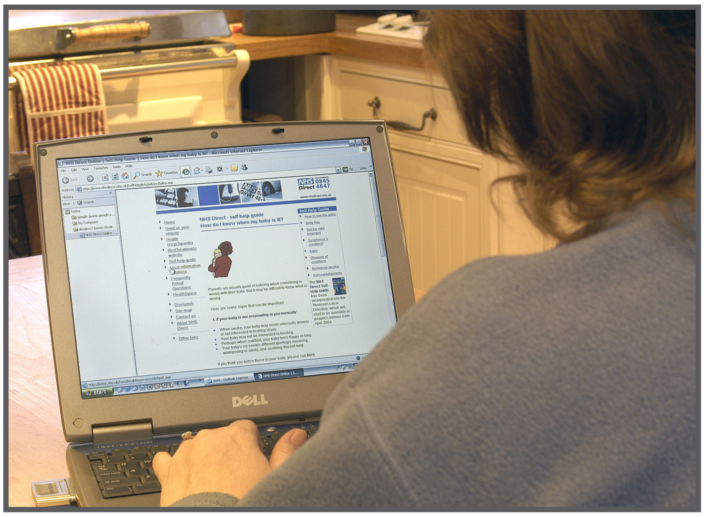
Taking account of their preferred channels for information (eg online peer support versus healthcare professionals in primary care), support may need to be configured differently for this cohort of adults. It is particularly important to take into account younger adults, as they begin their journey toward building self-management skills, staying well informed and living positively with their long term condition.

It should be noted that the survey was publicised via social media so it may over represent the views of people currently benefiting from online peer networks.

Living with diabetes in London: the patient experience; G Snell, E Warren, P Trevatt, M Holloway and S Thomas

Commissioning differently: Peer support

Effective, lifelong self-care is the cornerstone of survival for people with diabetes. Their support needs - and those of their families - go far beyond what NHS services normally provide, particularly following diagnosis when any life challenges arise.



Interactions with healthcare providers are necessarily limited, so patients have much to gain from joining communities, sharing experiences, being signposted to new information, joining social media networks and attending peer support meetings. Peer support can play a crucial role in enhancing wellbeing by complementing the clinical support provided by primary and secondary care services.

The international Diabetes Online Community (#DOC) can be accessed 24/7 on Facebook, Twitter and YouTube. It provides timely peer-to-peer support that can improve the effective utilisation of NHS resources. Telephone helplines, meetings and courses can provide life-enhancing information and support.

Type 1 diabetes service providers are encouraged to highlight these support avenues to their patients and their families, whilst acknowledging that the quality of advice will vary, and judgment should be applied to any advice where the source is not moderated or regulated. Commissioning support to produce information for signposting to local, national and international peer support is recommended.

T1 Resources

T1 Resources was designed as a set of signposts for anyone wanting to explore social media and online information to help them manage type 1 diabetes.
www.t1resources.uk

COMMISSIONING DIFFERENTLY: INNOVATION AND DEVELOPMENT

Providers are expected to continually develop and improve their services and care for people. This should be achieved through improving services in line with the recommendations of the *Five Year Forward View*[20] and employing innovative approaches to provide flexible and high quality care.

Providers should seek to establish integrated diabetes budgets with commissioners to be able to provide innovative commissioning arrangements and not be restricted by traditional activity and tariff arrangements. This will allow more flexible staffing and integration with other diabetes services

For example beginning in 2013, Camden Diabetes Integrated Practice Unit[21] implemented a value based commissioning approach (*see case study, page 18*). This uses a capitated outcomes based incentivised commissioning (COBIC)[22].

Providers should attempt to deliver increased access to the service, supported by improved outreach and joint working with primary care and other community services. Innovative approaches to education and continuing professional development are also needed.

COMMISSIONING DIFFERENTLY: CONTINUOUS IMPROVEMENT

Commissioners should expect providers to have an internal quality assurance and risk management process that assures them of their ability to manage the risks of running the service.

Providers will:

- Ensure that appropriate failsafe mechanisms are included across the whole pathway
- Review and risk assess the service
- Work with the Commissioner and Quality Assurance teams to develop, implement, and maintain appropriate risk reduction measures
- Ensure that mechanisms are in place to regularly audit implementation of risk reduction measures and report incidents
- Ensure that appropriate links are made with internal governance arrangements, such as risk registers
- Ensure regular staff training and development is undertaken. (See *Building the right workforce for diabetes care: A toolkit for healthcare professionals* guidance document)

Providers will participate fully in any local or national quality assurance (QA) processes and respond in a timely manner to recommendations made. This will include the submission to QA teams and commissioners of:

- Data and reports from external quality assurance schemes
- Minimum data sets as required
- Self-assessment questionnaires / tools and associated evidence
- Audits or data relating to nationally agreed internal quality assurance processes.

Where national recommendations and acceptable / achievable standards are not currently fully implemented providers will be expected to indicate in service plans what changes and improvements will be made over the course of the contract period. They will be expected to submit data to the National Diabetes Audit.

The provider shall develop a continual service improvement plan (CSIP) in line with the performance indicators and the results of internal and external quality assurance checks. The CSIP will address any performance issues highlighted by the commissioners, with consideration of concerns raised via any service user feedback. The CSIP will contain action plans with defined timescales and responsibilities, which will then be agreed with the commissioners.

Need help? Check out the *Implementation guide*

This document provides the tools for both commissioners and providers to measure, analyse and develop improvement plans for their local diabetes service. It includes a summary of expectations and self assessments for commissioners and providers, performance targets and a sample patient reported outcome measures (PROM) form to collate patient feedback. It also highlights the type 1 care consultation tool (developed by Health Innovation Network and King's Health Partners), which can be used in the management of people with type 1 diabetes.

Download the implementation guide

As can be seen in the Diabeter example (*next page*), those with type 1 diabetes need to be seen by a skilled healthcare professional. This will be someone who can provide evidence of the following:

- In-depth understanding of type 1 diabetes
- High level of competence in choice and actions of insulins and regimens
- Appreciation of psychological aspects of living with type 1
- Expertise in carbohydrate counting
- Have attended type 1 structured education course

These competencies will demonstrate an understanding of the complexity of minimising complications and managing type 1 diabetes well.

Type 1 diabetes care is best managed by professionals with considerable experience and competencies of this condition. These professionals need to continually develop their competence in choice and actions of insulins and regimens. They will work in a coordinated approach, as part of a multidisciplinary specialist team. Often a common environment (eg a diabetes centre) is seen as an important resource[24] in allowing a diabetes multidisciplinary team to work and communicate efficiently while providing consistent advice.

The specialist MDT should comprise staff with relevant complementary skills who work either together or in close communication with each other, including (or with ready access to) specialist groups. This core team must include: consultant diabetologist, diabetes specialist nurse, diabetes specialist dietitian and diabetes specialist podiatrist, clinical psychologist and diabetes screening team. This team will ensure expert input in the principles of flexible insulin management and technology use, and management of type 1 diabetes. They will work closely with the renal, cardiac and emergency teams.

Commissioners and providers should also ensure people admitted for emergency treatment are cared for by a specialist multidisciplinary team of health professionals. Additionally, a team should be commissioned to deal with inpatient care of those with diabetes to prevent excessive length of stays and readmissions[25].

There needs to be an integrated pathway for all people with diabetes, but type 1 requires a specific focus. This may result in a unique service for this type than other diabetes services, yet still fully linked by excellent communication across the wider hospital, community and primary care teams.

With patient consent, the specialist team will carry out the complication screening of the NICE care processes, using this information to inform management and treatment plans. Healthcare professionals managing any aspect of care for those with type 1 diabetes, regardless of setting, should have access to these results through a comprehensive shared patient record.

Case study: *Diabeter*

London type 1 diabetes services should aspire to achieve clinical results akin to the Diabeter service in the Netherlands. This is a state of the art service commissioned differently, with costs comparable to the type1 diabetes tariff, but achieving extraordinary clinical results and engagement of young people with diabetes who want to work with clinicians and change their self-management, from the excellent support they receive through the Diabeter team. The Diabeter HbA1c levels are significantly better than those currently achieved in London. In Holland, the national HbA1c target value for children and young adults is to be less than 58 mmol/mol (7.5%). For adults, the aim is to get this lower than 53mmol/mol (7%).

More than half (58.4 per cent) of Diabeter patients had an insulin pump in 2012.Of these patients, 36.8 per cent reached an HbA1c level between 58.5mmol/mol and 80.3mmol/mol (7.5 and 9.5%), and 19.4 per cent of patients even reached a HbA1c lower than 53mmol/mol (7%). Patients who used both a pump and a continuous glucose sensor gained even better results. Of those, 58.5 per cent reached an average HbA1c level lower than 58.5mmol/mol (7.5%) and 31.7 per cent of this patient group even managed an average HbA1c level of less than 53mmol/mol (7%) . The results Diabeter achieves compare favourably to international best practice.

They also have achieved a reduction in their patients admitted to hospital for acute diabetes related problems. The Diabeter service has an average of just 3 per cent of diabetes-related hospital admissions per year as compared to the Dutch national average of 20 per cent. The Diabeter service is clearly making an impact on care.

For more information, see the Diabeter website, diabeter.nl/en.

Image source: Diabeter website, diabeter.nl, *used with permission*

COMMISSIONING DIFFERENTLY: CO-LOCATION OF SERVICES

Commissioners and providers should consider the optimal location for delivery of care for people with type 1 diabetes. Many will require additional care for diabetes and other chronic conditions, including mental health. In line with *Five Year Forward View*[20] guidance, services should consider providing care to service users within the same facility as renal and kidney dialysis services, retinal screening services and specialist chronic disease services in hospital and the community.

It is important that the person with type 1 diabetes is seen by a specialist. The location is less important, as long as there is linkage between services and a holistic approach to improving type 1 care.

Ensuring equitable access to high quality patient care is a vital attribute of good service for patients with diabetes. This includes ensuring equitable access for vulnerable groups such as people with type 1 diabetes who:

- Do not speak English
- Are house bound
- Are physically disabled
- Live in a care homes
- Are homeless
- Have a mental health issue, including eating disorders
- Are in prison
- Are visually impaired
- Are elderly (who may have challenges with cognition, mobility, dexterity, vision, hearing, depression and chronic pain)
- Have learning difficulties*

* There has been a lack of expertise when planning for, and meeting the health needs of, adults with learning disabilities. In particular, there is little comprehensive education material available for the teaching of diabetes self-management to adults with learning disabilities.

Case study: Camden Diabetes IPU

In line with the *Diabetes guide for London*[26], and following the value based commissioning work of Professor Michael Porter of Harvard Business School[27], the Camden Diabetes Integrated Practice Unit (IPU) is an innovative and complex commissioning investment to improve the care of all adults with diabetes in Camden.

This is a value based commissioning / capitated outcomes based incentivised contract (COBIC) to build an integrated diabetes team across primary, community and hospital diabetes care, delivering improved patient and productivity outcomes. The integration has standardised and streamlined clinical processes, reduced duplication, improved communication between all providers and delivered cost-effective, evidence-based, patient-focused diabetes care -- irrespective of provider.

Additionally, co-location of diabetes and renal services at St Pancras Hospital allows those receiving dialysis to have diabetes care at the same time, if required. Additionally, podiatry, diabetic retinal screening, dietetics, clinical psychologists, nursing and medical staff (from all providers), are all co-located with shared admin support. This enables weekly MDT clinics for complex patients and education meetings to develop staff.

Case study: *Hillingdon diabetes eye screening and specialist nurse team*

In 2015, the diabetes specialist nurse in Hillingdon devoted two sessions a week of the working with the retinal service. Within the ophthalmology service, the nurse could see patients waiting for review, creating another touch point with a different focus. It is a nurse-led service, and the HbA1c recruitment was those patients with > 75 mmol, (due to capacity). Although the cohort was mostly type 2 patients, it illustrates the benefit of joint working.

Preliminary data for the first three months:

- 65.5 per cent of patients were purely under GP care.
- 116 patients seen 09/03/2015 to 10/12/2015.
- Median age 58 years.
- 69 patients on insulin initially, 47 not.
- 76 patients under GP only care.
- Mean HbA1c = 91.8; Median = 90 (Mean repeat HbA1c = 75.2; Median = 73).
- Mean HbA1c difference = 16.1; Median = 13.
- Mean follow up period = 3.3 months; Median = 3 months.

Interventions needed:

- 51 patients had insulin titrated.
- 34 patients had medications changed.
- 15 had insulin started.
- No care was altered unless clinically indicated (eg co-existent untreated proteinuric nephropathy that needed intervention).

Case study: *Diabetes and me*

The Walsall Health Facilitation Team has sought to address this by developing the Diabetes and me information pack, aimed at educating people with learning disabilities about diabetes and self-management of the condition in an easy-to-read, accessible format, which has led to health and quality-of-life improvements in this population.

Technology: A changing landscape

The NHS is undergoing a digital transformation of both the digital infrastructure and support for creating a digitally professional clinical workforce. At the most fundamental level, NHSmail 2[27] enables clinicians to communicate digitally and most importantly, securely, with other clinicians and with patients. When members of the clinical team use NHSmail 2 email systems in to communicate with patients using the patient's own email address, this communication will be secure. Similar security is offered to enable video conferencing (eg Skype) consultations between patients and clinicians. This offers considerable opportunity for access to diabetes care to be increased for patients to make it timely and appropriate and importantly when needed. Personal health records are similarly being established slowly across NHS services, and a clinical team's engagement with these will be essential to engaging people with diabetes with personal health records. The Digital Professional is on the horizon and this provides a timely backdrop to the evolution of technology to help people live well with their diabetes.

Treatment and monitoring of type 1 diabetes is continually changing. Over recent years technological developments in both diabetes monitoring and insulin delivery have progressed rapidly. Technology is used to ensure complications are prevented, reduced or managed and to improve quality of life, even reducing sick days[28]. Diabetes technologies support self-management and are effective as an adjunct to ongoing education and support.

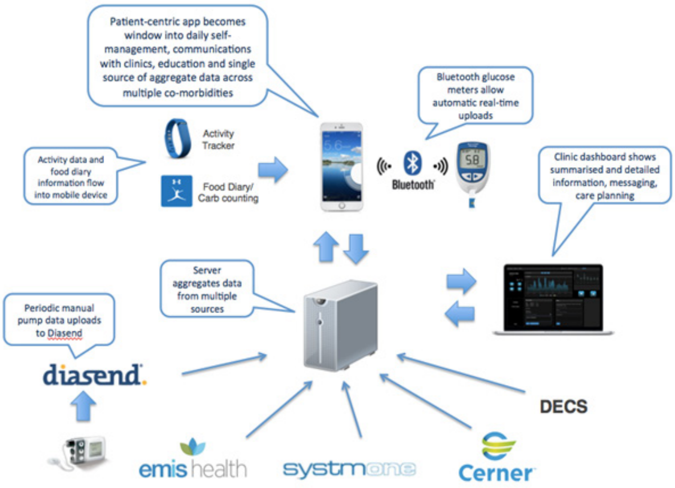
There are many categories of technology that can help people with diabetes, but integration between different areas of care and different technologies, in a way that provides a patient-centric view rather than a condition-centric view, is likely to move towards the goal of person-centred coordinated care as part of the *House of Care*[29] model. The diagram below shows a sample technology ecosystem.

Want more information?
Check out *Clinical management: Optimal pathway*

Aimed at providers, this document details the expected clinical care for type 1 diabetes and has an extensive guide to harnessing technology (*see pages 27-35*).

Download
Clinical management: Optimal pathway

We would urge commissioners to work with clinicians to develop a pathway that would allow access to new technology to patients where appropriate costs and benefits have been appraised on an individual basis.



Above: Sample technology ecosystem

REFERENCES

1. NHS Digital, National Diabetes Audit
www.hscic.gov.uk/nda

2. Cryer PE, *Severe hypoglycemia predicts mortality in type 1 diabetes*. Diabetes Care (2012); 35: 1814-1816.

3. SJ Livingstone, on behalf of the Scottish Diabetes Research Network epidemiology group; Diabetes Epidemiology Unit, University of Dundee, Dundee, UK (2013); *Life expectancy in type 1 diabetes: a Scottish Registry Linkage study*
http://jama.jamanetwork.com/article.aspx?articleid=2088852

4. Diabet Med, *Glycaemic control of type 1 diabetes in clinical practice early in the 21st century: an international comparison* (2015) Aug;32(8):1036-50 McNight et al |
www.ncbi.nlm.nih.gov/pubmed/25510978

5. HSCIC, HQIP, Diabetes UK, N*ational Diabetes Audit 2013-14 and 2014-15* (slide deck)
www.hscic.gov.uk/catalogue/PUB19900/nati-diab-rep1-audi-2013-15.pdf

6. Livingstone et al, *Estimated life expectancy in a Scottish cohort with type 1 diabetes, 2008-2010* JAMA 2015 Jan 6; 313(1):37-44
http://jama.jamanetwork.com/article.aspx?articleid=2088852

7. DCCT/EDIC research group, *Association between 7 years of intensive treatment of type 1 diabetes and long-term mortality*, JAMA. 2015;313(1):45-53
http://jama.jamanetwork.com/article.aspx?articleid=2088851

8. NICE, *TA60: Guidance on the use of patient-education models for diabetes* (2015)
www.nice.org.uk/guidance/ta60?unlid=69190705201621533424
Note: Replaced by *NG17 Type 1 diabetes in adults: diagnosis and management* (2016)
www.nice.org.uk/guidance/ng17

9. Diabeter, a certified centre, based in the Netherlands, dedicated to provide comprehensive and individualised care for children and young adults with type 1 diabetes
https://diabeter.nl/en/

10. London Clinical Networks, *Understanding diabetes in London* (2015)
www.londonscn.nhs.uk/wp-content/uploads/2015/02/dia-understanding-ldn-challenges-022015.pdf

11. NICE *NG17 Type 1 diabetes in adults: diagnosis and management* (2016)
www.nice.org.uk/guidance/ng17

12. Dose Adjustment for Normal Eating (DAFNE) programme, a working collaborative of 75 diabetes services from NHS trusts and health boards across the UK and Southern Ireland
www.dafne.uk.com

13. NHS England, *Action for diabetes* (2014)
www.england.nhs.uk/wp-content/uploads/2014/01/act-for-diabetes.pdf

14. Right Care Casebook Series, *What organisation is necessary for commissioners to develop outcomes based contracts? The COBIC case study*
www.rightcare.nhs.uk/downloads/RC_Casebook_cobic_final.pdf

REFERENCES

15. NHS Camden Clinical Commissioning Group, *Value based commissioning* webpage www.camdenccg.nhs.uk/what-we-do/vbc.htm

16. Harvard Business Review, *The strategy that will fix healthcare*, (2013) https://hbr.org/2013/10/the-strategy-that-will-fix-health-care

17. American Diabetes Association, *Diabetes in Finland: What can happen when a country takes diabetes seriously* (2009) http://spectrum.diabetesjournals.org/content/22/3/188.full

18. The King's Fund, *The practice of system leadership* (2015) www.kingsfund.org.uk/publications/practice-system-leadership

19. London Clinical Networks, *Living with diabetes: What support is needed?* (2015) www.londonscn.nhs.uk/publication/report-living-with-diabetes-what-support-is-needed/

20. NHS England, *Five year forward view* (2014) www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf

21. Royal Free London NHS Foundation Trust, *Camden Diabetes IPU* webpage www.royalfree.nhs.uk/services/services-a-z/diabetes-camden-ipu

22. NHS England, COBIC solutions, *COBIC explained: Transforming the quality and value of healthcare* www.nhsiq.nhs.uk/media/2590529/cobic_explained.pdf

23. London Clinical Networks, *Building the right workforce for diabetes care: A toolkit for healthcare professionals* (2016) www.londonscn.nhs.uk/publication/workforce-toolkit-for-diabetes-care

24. Day JL, Metcalfe J, Johnson P, *Benefits provided by an integrated education and clinical diabetes centre: a follow-up study,* Diabet Med. 1992 Nov;9(9):855-9. www.ncbi.nlm.nih.gov/pubmed/1473327

25. Cavan, D A, Hamilton, P, Everett, J and Kerr, D; *Reducing hospital inpatient length of stay for patients with diabetes*. Diabetic Medicine, 18:162–164 doi:10.1046/j.1464-5491.2001.00420.x (2001)

26. Healthcare for London, *Diabetes guide for London* (2011) www.londonprogrammes.nhs.uk/wp-content/uploads/2011/03/Diabetes-Guide.pdf

27. NHS Digital, *Keeping customers informed* webpage http://systems.digital.nhs.uk/nhsmail/informed

28. Healthline, *The best diabetes apps of 2016* webpage www.healthline.com/health/diabetes/top-iphone-android-apps

29. NHS England, *Enhancing the quality of life for people living with long term conditions: House of Care* www.england.nhs.uk/house-of-care/

30. NICE, *DG21 Integrated sensor-augmented pump therapy systems for managing blood glucose levels in type 1 diabetes (the MiniMed Paradigm Veo system and the Vibe and G4 PLATINUM CGM system)* (2016) www.nice.org.uk/guidance/dg21

REFERENCES

31. Miller KM, et al, *Evidence of a strong association between frequency of self-monitoring of blood glucose and hemoglobin A1c levels in T1D Exchange Clinic registry participants* Diabetes Care. (2013) Jul;36(7):2009-14
www.ncbi.nlm.nih.gov/pubmed/23378621

32. Simmons JH; *Differences in the management of type 1 diabetes among adults under excellent control compared with those under poor control in the T1D Exchange Clinic registry*, Diabetes Care (2013) Nov;36(11):3573-7
www.ncbi.nlm.nih.gov/pubmed/24026543

33. Rabbone, I, et al; *Carbohydrate counting with an automated bolus calculator helps to improve glycaemic control in children with type 1 diabetes using multiple daily injection therapy: an 18-month observational study*, Diabetes Res Clin Pract. (2014) Mar;103(3):388-94 Diabetes Care 2013 Nov; 36(11): 3613-3619

34. Huang, ES, et al, *The cost effectiveness of continuous glucose monitoring in type 1 diabetes* (2010)
http://care.diabetesjournals.org/content/33/6/1269.full

35. Roze, S et al, *Health-economic analysis of real-time continuous glucose monitoring in people with type 1 diabetes* (2015)
http://onlinelibrary.wiley.com/doi/10.1111/dme.12661/abstract

36. NICE press release, *NICE guidance recommends integrated automated glucose monitoring system for people with type 1 diabetes* (2016)
www.nice.org.uk/news/press-and-media/nice-guidance-recommends-integrated-automated-glucose-monitoring-system-for-people-with-type-1-diabetes

37. NICE *TA151 Continuous subcutaneous insulin infusion for the treatment of diabetes mellitus* (2008)
https://www.nice.org.uk/Guidance/TA151

38. JDRF, ABCD, Diabetes UK, *The United Kingdom insulin pump audit – service level data*
www.diabetes.org.uk/Documents/News/The_United_Kingdom_Insulin_Pump_Audit_May_2013.pdf

39. Pickup J. *Are pumps underutilized in type 1 diabetes? Yes.* Diabetes Care (2006) 29: 1449-1452.

40. NICE *DG21 Integrated sensor-augmented pump therapy systems for managing blood glucose levels in type 1 diabetes (the MiniMed Paradigm Veo system and the Vibe and G4 PLATINUM CGM system)* (2016)
www.nice.org.uk/guidance/dg21

41. NICE *MIB51 MiniMed 640G system with SmartGuard for managing blood glucose levels in people with type 1 diabetes* (2016)
www.nice.org.uk/advice/mib51

42. Healthline, *Meet beta bionics: New business structure for iLet bionic pancreas* (2016)
www.healthline.com/diabetesmine/meet-beta-bionics

43. NHS England, *Newham diabetes Skype pilot success increases young people's clinic attendance* (2016)
www.england.nhs.uk/2016/01/newham-diabetes-pilot-scheme/

ABBREVIATIONS

ABCD	Association of British Clinical Diabetologists
BMI	Body mass index
CBG	Capillary blood glucose
CCG	Clinical commissioning group
CGM	Continuous glucose monitoring
COBIC	Capitated outcomes based incentivised commissioning
CSII	Continuous subcutaneous insulin infusion
CSIP	Continual service improvement plan
DAFNE	Dose Adjustment For Normal Eating
DDS	Diabetes distress scale
DKA	Diabetic ketoacidosis
#DOC	Diabetes online community
HES	Hospital episode statistics
HIN	Health Innovation Network
IPU	Integrated practice unit
JDRF	Juvenile Diabetes Research Foundation
MDT	Multidisciplinary team
MI	Myocardial infarction
NDA	National Diabetes Audit
NICE	National Institute for Clinical Excellence
PAID	Problem areas in diabetes scale
PBRe	Payment by Results exclusion
QA	Quality assurance
VBC	Value based commissioning

About the London Clinical Networks

The London Clinical Networks bring together those who use, provide and commission the service to make improvements in outcomes for complex patient pathways using an integrated, whole system approach.

The Clinical Networks work in partnership with commissioners (including local government), supporting their decision making and strategic planning, by working across the boundaries of commissioner, provider and voluntary organisations as a vehicle for improvement for patients, carers and the public. In this way, the networks will:

- Reduce unwarranted variation in services
- Encourage innovation in how services are provided now and in the future
- Provide clinical advice and leadership to support their decision making and strategic planning.

London Clinical Networks | NHS England (London Region)
londonscn.nhs.uk | england.london-scn@nhs.net