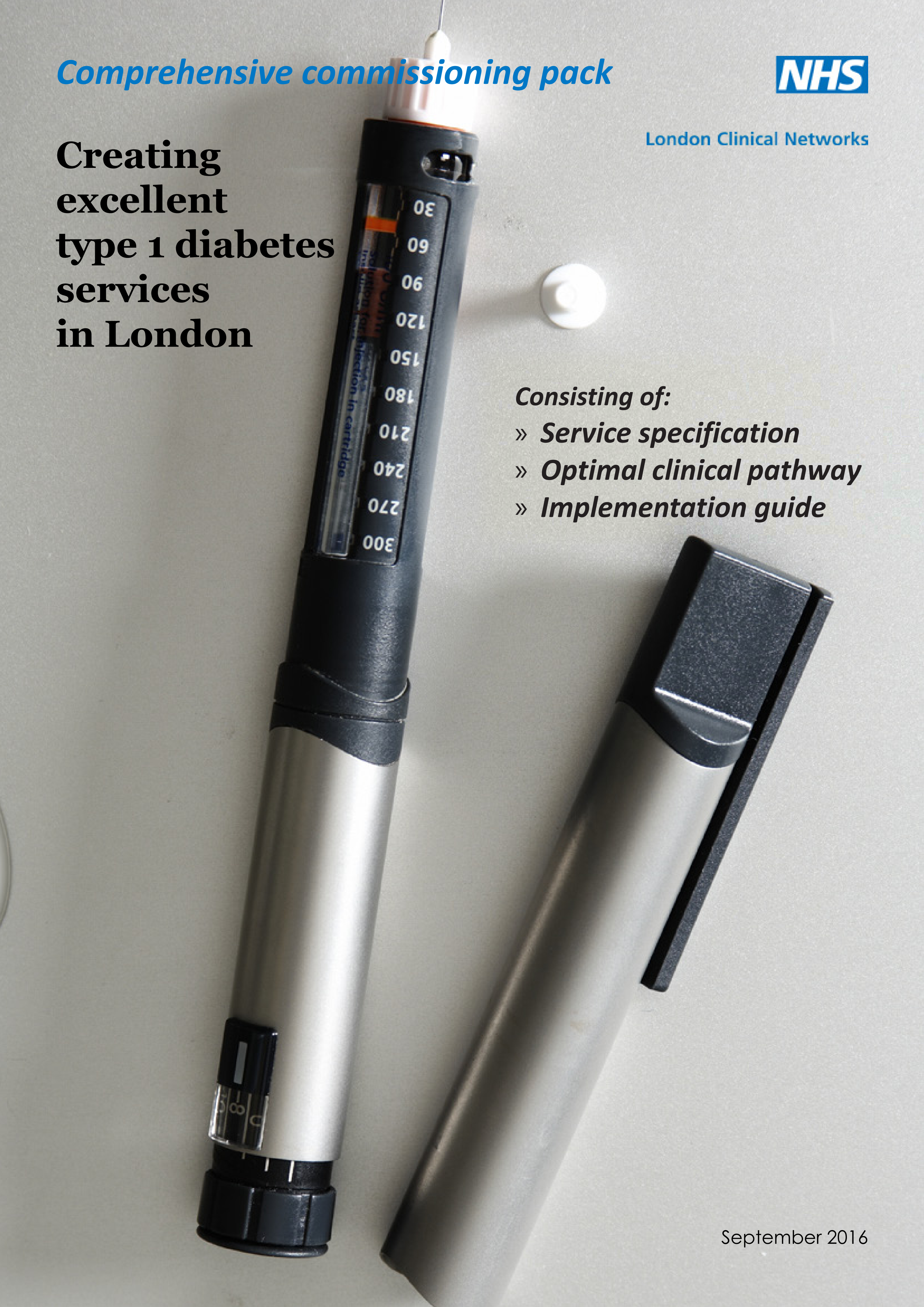
Comprehensive commissioning pack

NHS

London Clinical Networks

Creating excellent type 1 diabetes services in London



Consisting of:

- *Service specification*
- *Optimal clinical pathway*
- *Implementation guide*

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** (page 4) - 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** (page 26)- Aimed at providers, this document details the expected clinical care for type 1 diabetes.
- **Implementation guide** (page 68) - 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

Part 1 | **Service specification** | How to commission excellent type 1 diabetes services

COMMISSIONING DIFFERENTLY

Part 2 | **Optimal clinical pathway** | How to deliver excellent type 1 diabetes services

Part 3 | **Implementation guide** | Helping to create excellent type 1 diabetes services

Part 1 | *Service specification*

London Clinical Networks

How to commission type 1 diabetes services

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.

COMMISSIONING FOR TYPE 1 DIABETES

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, page 68*) 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 at 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.

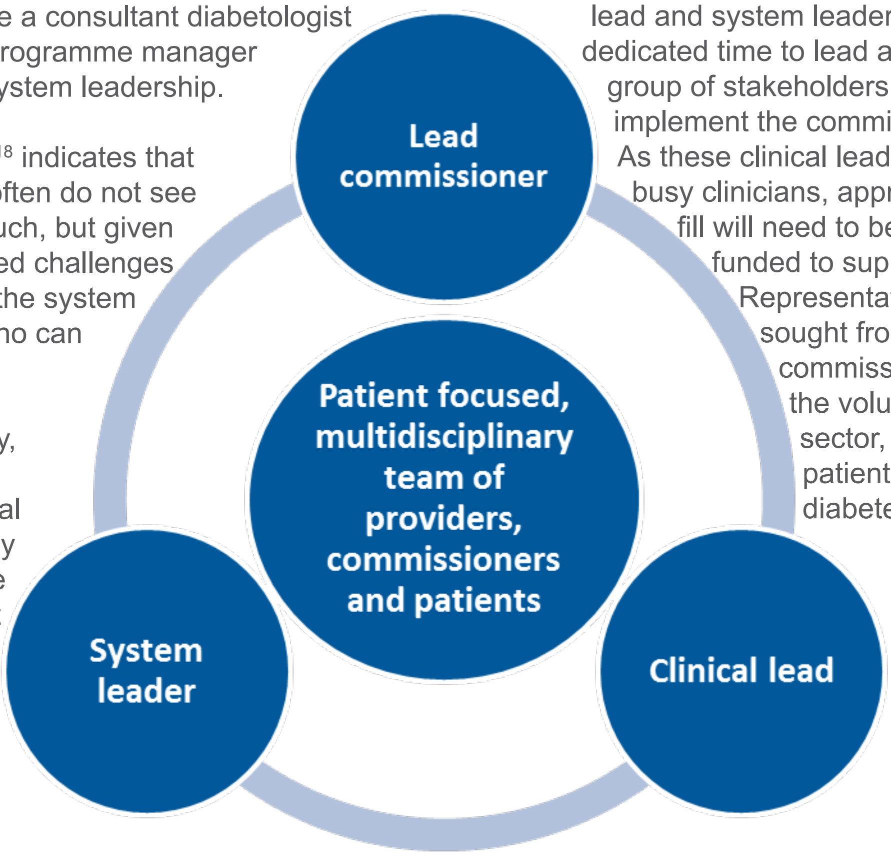


Figure 1: Structure of the Type 1 Diabetes Transformation Group

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.

COMMISSIONING DIFFERENTLY: LISTENING TO PATIENTS

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.*)

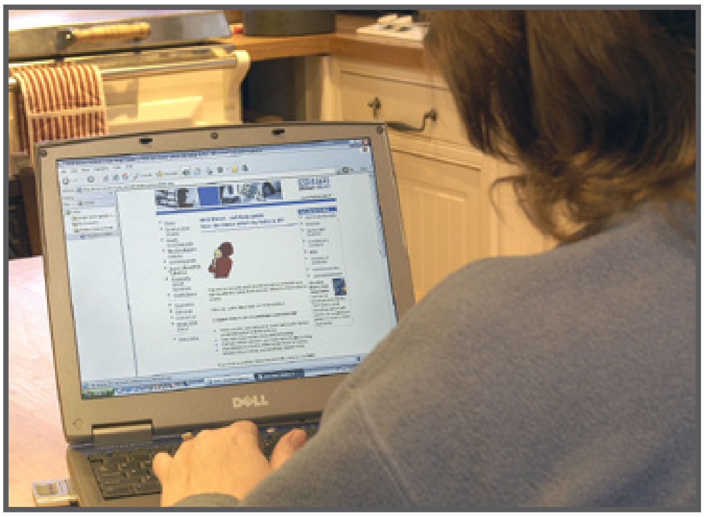
The survey found that of the respondents with type 1 diabetes, 65 per cent sought advice from social media to support them managing their condition. The authors concluded that additional support is needed for all people living with diabetes and their carers.

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 20*). 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.

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 at www.londonscn.nhs.uk.)

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.

See the implementation guide on page 68.

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.

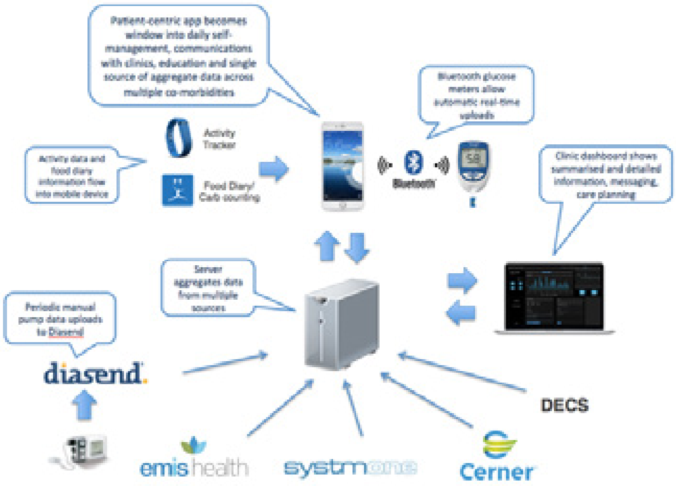
There are many categories of technology that can help people with diabetes, but integration between different areas of care and different technologies, in a way that provides a patient-centric view rather than a condition-centric view, is likely to move towards the goal of person-centred coordinated 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 53-62*).

***Clinical management: Optimal pathway* begins on page 26.**

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

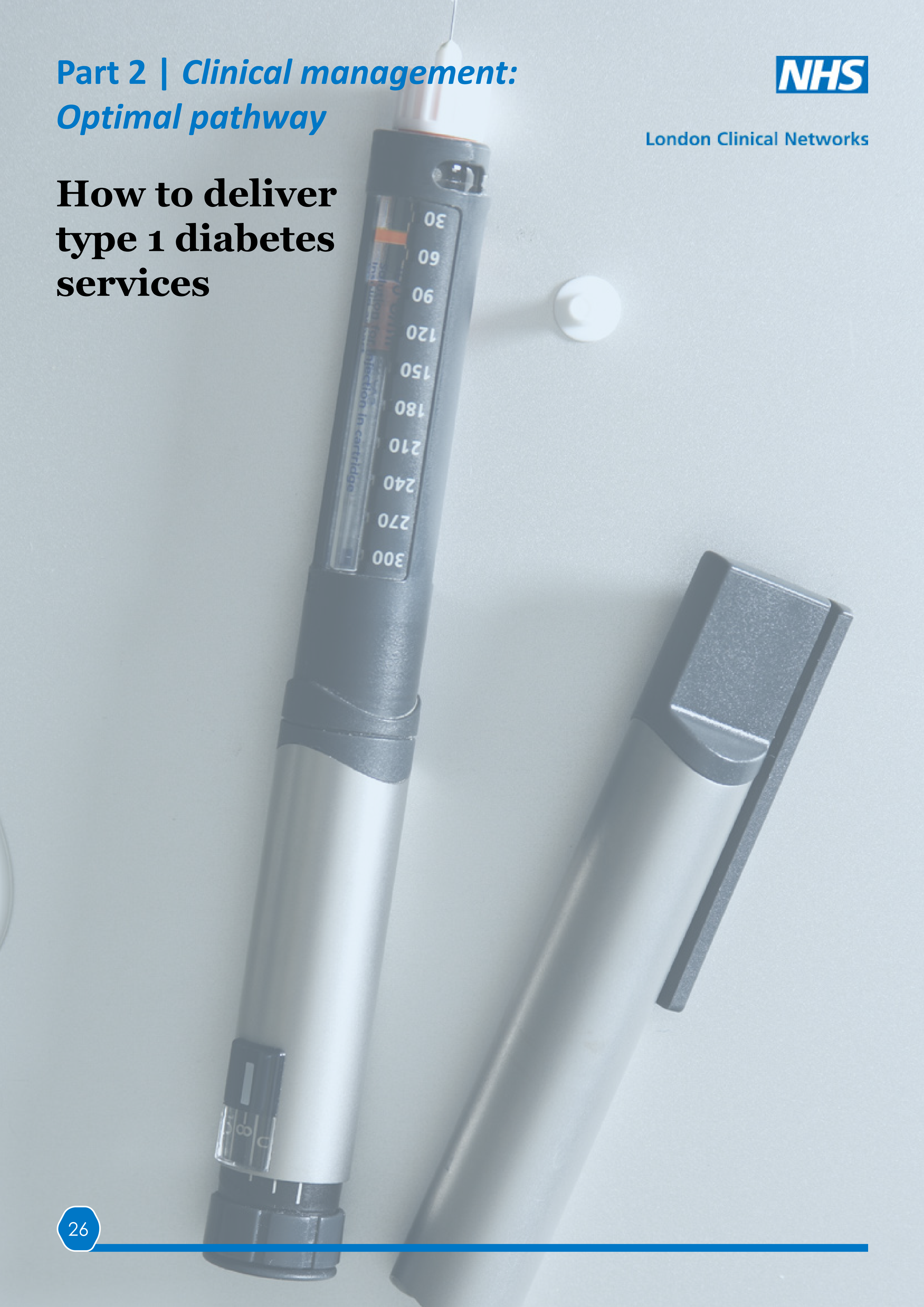
39. Pickup J. *Are pumps underutilized in type 1 diabetes? Yes.* Diabetes Care (2006) 29: 1449-1452.

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/



Part 2 | *Clinical management: Optimal pathway*

London Clinical Networks

How to deliver type 1 diabetes services

TABLE OF CONTENTS

Recommendation 1
Type 1 service

- All people with type 1 diabetes should have a patient-focused care plan. This should be shared with the patient and all staff caring for them.

- Services for adults with type 1 diabetes should have sufficient capacity to enable early frequent review of the newly diagnosed person with diabetes. Initial individual education by one or more appropriately trained members of the diabetes MDT should be provided in the following areas, taking account of the individual's home and work environment:
  - *What is diabetes?*
  - *Education on insulin regimen and injections*
  - *Self-monitoring and appropriate blood glucose targets*
  - *Recognition and management of hypoglycaemia*
  - *Initial dietary advice, introducing role of carbohydrate counting*
  - *Pre-conception planning*
  - *Everyday challenges (eg exercise)*
  - *Information about driving restrictions*
  - *Complications of diabetes (and avoidance) and the importance of regular screening*

Recommendation 2
Structured education / self management programme

- All staff caring for patients with type 1 diabetes should be trained in DAFNE (or a NICE compliant alternative).

- All adults with type 1 diabetes should be offered a diabetes structured education programme.

- 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:
  - All people newly diagnosed with type 1 diabetes within one year of diagnosis.
  - Those with problematic hypoglycaemia or an HbA1c above target.
  - All women of childbearing age with type 1 diabetes.
  - 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.

Across London we will need to understand the demand for education based on local populations with type 1 diabetes and develop strategies, which may include co-commissioning or using hub and spoke models to deliver capacity for structured education.

Recommendation 3
Carbohydrate counting

- All patients with a new diagnosis of type 1 diabetes should be taught an awareness of carbohydrate counting and the ability to adjust doses of insulin. The teaching of formal CHO counting can be daunting for some at the very beginning of their diagnosis and also not always suitable during the honeymoon phase. Therefore, the aim will be to initiate CHO counting within the first year where possible / when practical.

- All patients with a new diagnosis of type 1 diabetes should be encouraged to complete a structured education course within a year of diagnosis.

- Each CCG / specialist service should develop a clear strategy around how basic carbohydrate counting and structured education will be delivered to those patients who already are living with diabetes. (Note: DAFNE research clearly demonstrates that there is no difference in benefit from DAFNE based on duration of diabetes.)

- Planning for capacity should include networking with other centres to provide a single point of access for type 1 diabetes structured education across sectors.

- Patients who decline structured education should continue to be offered it, and all professionals should understand that this is the cornerstone of type 1 diabetes care. To increase uptake, providers and commissioners should collaborate to make structured education accessible to all patients. For example, DAFNE can be delivered over five consecutive days or one day for five weeks; not all providers offer both options. By enabling access to alternative delivery at other CCGs we would anticipate that more patients would access structured education.

- Structured education training should be considered mandatory training for those with type 1 diabetes.

Recommendation 4
Hospital insulin self management for adult inpatients with diabetes

- It is important that there are protocols in place that enable individuals with type 1 diabetes who are willing and able to self-manage their insulin either via injections or insulin pump, which also include information explaining when it is important for the healthcare professionals to temporarily take over.

- For an individual on an insulin pump, it may mean that they will temporarily be commenced on intermittent subcutaneous insulin injections, and sick patients may need their usual insulin replacement to be replaced with monitored intravenous insulin infusion.

Recommendation 5
Prevention of hypoglycaemia

- Services for people with type 1 diabetes should implement a screening strategy to identify those at high risk of problematic hypoglycaemia. The record should note: Hypoglycaemia frequency and severity, and awareness of symptoms using the *GOLD score.

- All episodes of severe hypoglycaemia requiring third party assistance, the frequency of glucose levels under 3.5mmol/l and awareness of hypoglycaemia using GOLD score, should be recorded in the patients shared record.

- Services for type 1 diabetes should have a pathway in place for patients identified as being at high risk of problematic hypoglycaemia (eg those with a GOLD score greater than 4 and/or severe hypoglycaemia in the preceding 12 months, the lower limit of the recommended glucose target for people with type 1 diabetes).

- Services for people with type 1 diabetes should create links with local ambulance providers, to enable referral of all patients with severe hypoglycaemia to the diabetes MDT.

- Links for psychology and specialist MDT support for all people with type 1 diabetes and recurrent hypoglycaemia should also be shared across all healthcare provider organisations.

Recommendation 6
Diabetes psychology pathway

- All type 1 diabetes services should have access to diabetes trained consultant clinical and health psychologists with a robust referral process to consultant psychiatrists within their structure. We recommend a tiered approach.

- The clinical psychologist, as part of the MDT, is crucial to ensuring that the whole team is trained in motivational interviewing and are aware of the needs of these vulnerable patients with the complex picture of type 1 diabetes and an eating disorder, to allow earlier identification.

Recommendation 7
Eye screening

It is imperative that all diabetes staff:

- Remain engaged with their local DESP service to ensure that patients don’t fall through the net due to multiple non attendances.

- Ensure that patients are not incorrectly coded or excluded from eye screening.

- Educate patients as to the importance of eye screening as patients can develop advanced levels of retinopathy and still remain asymptomatic. This can then increase the risk of subsequent blindness if untreated.

Recommendation 8
Type 1 services for women of childbearing age

The NICE guideline recommends that women with diabetes who are planning to become pregnant:

- Take 5mg/day folic acid prior to becoming pregnant and until 12 weeks of gestation to reduce the risk of having a baby with a neural tube defect.
- Aim to maintain HbA1c below 48 mmol / mol (6.5%), without causing problematic hypoglycaemia.
- Reassure women that any reduction in HbA1c level towards the target of 48 mmol/mol (6.5%) is likely to reduce the risk of congenital malformations in the baby.
- Strongly advise women with diabetes whose HbA1c level is above 86 mmol/mol (10%) not to get pregnant because of the associated risks.
- In accordance with NICE recommendations, diabetic eye screening should be offered to pregnant mothers (with pre-existing diabetes) at the first antenatal appointment and then again at 28 weeks gestation.

A large UK-based study showed that an intensive pre-conception pathway for women with type 1 diabetes involving visits to a multidisciplinary clinic 1-3 times monthly reduced SAE from 10.2 to 2.9 per cent.

Additionally:

- Introduce a discussion about pre-conception in the annual diabetes care plan for all women of child bearing age with known pre-existing diabetes.
- All women to consider contraception if not actively trying for pregnancy.
- Refer all women considering pregnancy to the multidisciplinary pre-conception clinic if Hba1c level is equal or higher than 48 mmol/mol (>6.5%).
- Women will be seen in a multidisciplinary secondary care clinic for a new consultation and then seen 2-4 times monthly for follow up visits until they have achieved adequate glycaemic control. Some women will need more frequent clinic/telephone/email appointments.
- If women are not pregnant after 12 months, then consider referral for fertility services.

Recommendation 9
Transition to adult diabetes services

- A transition clinic should be commissioned with clinic appointments long enough for the person with diabetes to build up a relationship with the new team as they move from the familiar paediatric clinic to adult services. This should harness new technologies.

Recommendation 10
Technology

Patients who require it should have access to:

- A variety of CBG meters, including those with built-in bolus calculators.
- Adequate CBG strips (10 per day or more if needed where cost effective) to support them to achieve NICE recommended HbA1c targets.
- Insulin pumps as per TA151 in patients who have problematic hypoglycaemia or an HbA1c above 8.5 per cent, despite structured education.
- A choice of insulin pumps as per individual needs.

A policy should be in place for access to emerging technologies, such as continuous glucose monitoring, which may be valuable in individual settings.

Clinical pathway for type 1 diabetes

This section details the pathway for type 1 diabetes, including the care to be delivered by the provider. It is recognised that patients with type 1 diabetes will have differing requirements for specialist input at different stages of their diabetes journey, particularly if specific problems arise.

Diagnosis of type 1 diabetes

Diagnose type 1 diabetes[1] on clinical grounds in adults presenting with hyperglycaemia, bearing in mind that people with type 1 diabetes typically (but not always) have one or more of:

- Ketosis
- Rapid weight loss
- Age of onset before 50 years
- BMI below 25 kg/m^2
- Personal and/or family history of autoimmune disease

Do not discount a diagnosis of type 1 diabetes if an adult presents with a BMI of 25 kg/m^2 or above, or is aged 50 years or over.

Do not measure C-peptide and/or diabetes specific auto antibody titres routinely to confirm type 1 diabetes in adults.

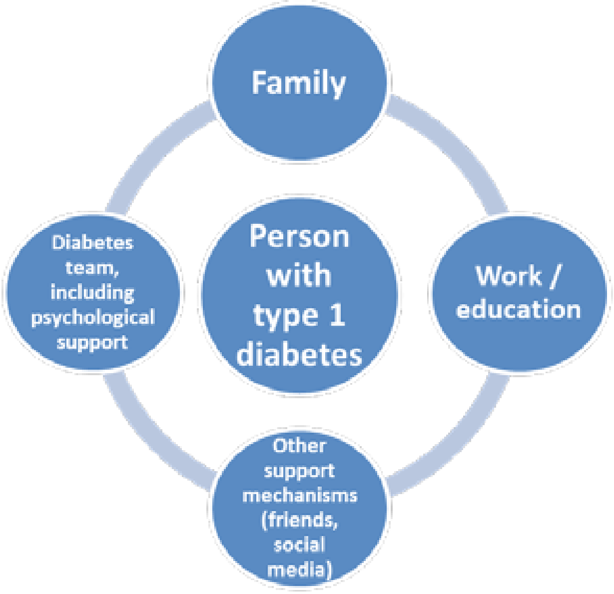
Consider further investigation in adults that involves measurement of C-peptide and/or diabetes specific auto antibody titres if:

- Type 1 diabetes is suspected but the clinical presentation includes some atypical features (for example, aged 50 years or above, BMI of 25 kg/m^2 or above, slow evolution of hyperglycaemia or long prodrome); ***or***
- Type 1 diabetes has been diagnosed and treatment started but there is a clinical suspicion that the person may have a monogenic form of diabetes, and C-peptide and/or auto antibody testing may guide the use of genetic testing; ***or***
- Classification is uncertain, and confirming type 1 diabetes would have implications for availability of therapy (for example, continuous subcutaneous insulin infusion [CSII] / insulin pump therapy).

Clinical review

People with type 1 diabetes should be offered at least an annual review by a specialist diabetes team experienced in the management of type 1 diabetes. Many people with diabetes will need multiple appointments each year; some will only need their annual review.

Elements of good diabetes control, where blue elements are those that people with type 1 diabetes deal with every day.

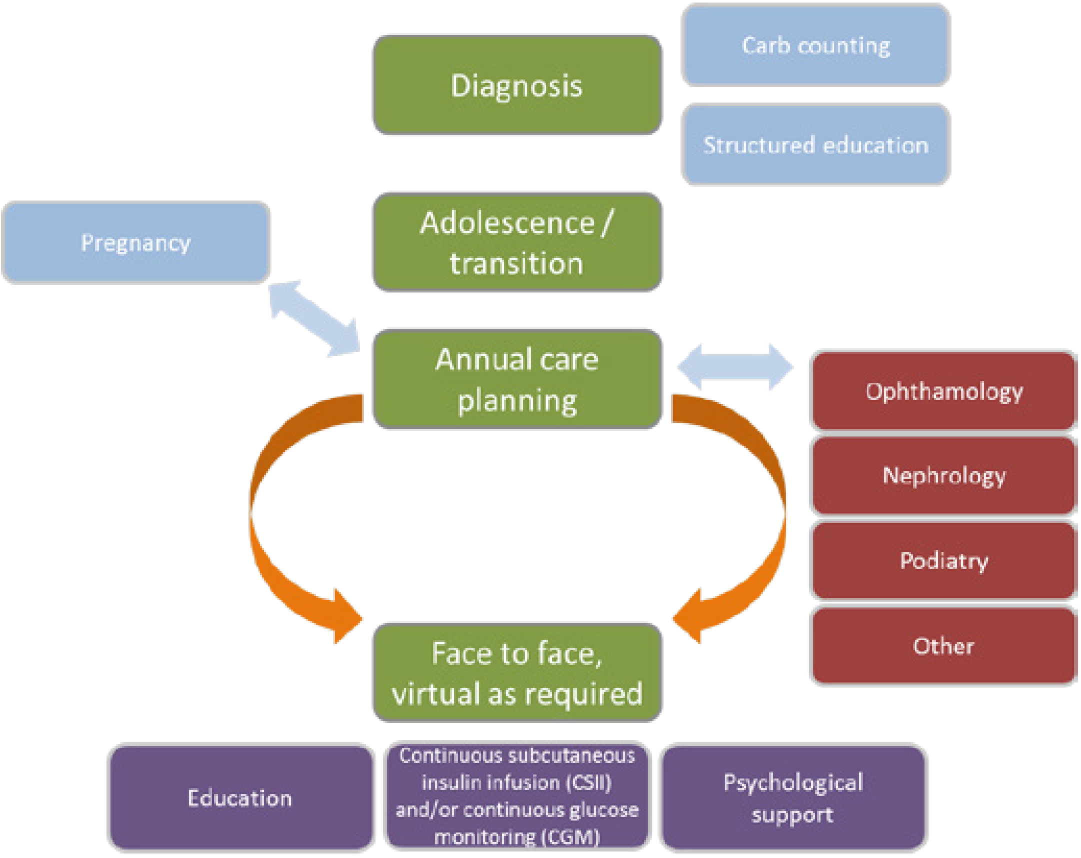


Everything surrounding a person with type 1 diabetes.

Recommendation | Clinical review

The clinical review will culminate in production of a care plan. The review should include the following:

- Motivational interviewing and coaching styles of appointment using care and support planning, ensuring a focus on identifying any areas of concern, (particularly diabetes related distress) that the patient wishes to discuss, including their potential need for psychological support.
- Review of self-monitoring and HbA1c.
- Review of self-management skills and any new or ongoing educational needs.
- Assessment of hypoglycaemia frequency, severity, awareness, potential causes and management.
- Confirmation that screening for microvascular complications and cardiovascular risk has occurred, been shared with MDT and that the results have been acted upon.
- Review of insulin regime, injection technique, needle length, usage and injection site inspection.
- Following review, an individual care plan should be agreed. This will include follow up plan such as education and review by members of the multidisciplinary team (MDT), the regularity of follow-up will depend on patient requirements. For example, some patients prefer a structured review by a diabetes specialist nurse at regular intervals, but others may prefer to contact the team only if problems arise or if they have specific needs. Clinical services should explore the potential benefits of developing remote access to expertise, such as scheduled virtual clinics, reviewing data shared by electronic download at home, etc.
- Any test results should be routinely shared with patients and ownership of these encouraged.



Care planning

The establishment of a care plan is an integral part of type 1 care. NICE guidance Type 1 diabetes in adults: diagnosis and management (NG17) states that clinicians should "set up an individual care plan jointly agreed with the adult with type 1 diabetes, review it annually and modify it, taking into account changes in the person's wishes, circumstances and medical findings, and record the details[1]."

The plan should include aspects of diabetes education, including:

- Nutritional advice
- Insulin therapy (including dose adjustment),
- Self-monitoring
- Avoiding hypoglycaemia and maintaining awareness of hypoglycaemia for women of childbearing potential
- Family planning, contraception and pregnancy planning (see the NICE guideline on diabetes in pregnancy[2])
- Cardiovascular risk factor monitoring and management
- Complications monitoring and management
- Means and frequency of communicating with the diabetes professional team
- Frequency and content of follow-up consultations, including review of HbA1c levels and experience of hypoglycaemia
- Next annual review.

The Health Innovation Network (HIN) recognised the need for a holistic care plan for people with type 1 diabetes which meets the needs of the individual as well as provides valuable data on patient outcomes. Many care plans were in place throughout London, however none considered the unmet demand for the acknowledgement, assessment and support for people who are suffering psychologically with the demands or living with diabetes. Alongside this, no agreed single care plan was in place across the south London network. As such, data at an aggregated population level could not be used to identify opportunities for collaboration.

The HIN therefore developed the Type 1 Care (T1C) Plan. The T1C uses the GOLD score to assess an individual's awareness of hypoglycaemia and the Diabetes Distress 2 (DDS-2) screening tool to identify those patients with elevated diabetes distress. There are e-learning pages on the King's Health Partners' Learning Hub[3] for more information on the relationship between diabetes and depression.

Newly diagnosed patients (up to 1 year post diagnosis)

Healthcare professionals in primary and acute settings should be aware of the need to refer the suspected newly diagnosed patient urgently (same day) to diabetes specialist services. Many newly diagnosed patients can be managed in the outpatient setting. However, a minority will be acutely unwell with diabetic ketoacidosis, requiring hospital admission.

The role of the specialist team is to confirm the diagnosis of type 1 diabetes and instigate appropriate management. In a small proportion of cases the diagnosis of type 1 diabetes will not be clear and the knowledge of the diabetes specialist team with regard to the role and interpretation of additional diagnostic tests (such as specific auto-antibodies and C-peptide) should guide the use of these tests, which should not be requested by primary care.

There are data to support tracking of glucose control, suggesting that HbA1c achieved in the first year of diagnosis are predictive of long term control, highlighting the importance of providing patients with support, education and skills required to achieve this soon after diagnosis[4].

Adults with a new diagnosis of type 1 diabetes should be started on a multiple daily injection (MDI) regimen with basal insulin detemir (BD) or glargine and mealtime fast-acting insulin aspart, lispro or glulisine. Adults with a new diagnosis of type 1 diabetes should not be initiated on continuous subcutaneous insulin infusion (CSII) or continuous glucose monitoring (CGM). The need for psychological support should be considered and offered and information about on and offline peer support provided to the patient and their family.

Recommendation | Type 1 service

- All people with type 1 diabetes should have a patient-focused care plan. This should be shared with the patient and all staff caring for them.
- Services for adults with type 1 diabetes should have sufficient capacity to enable early frequent review of the newly diagnosed person with diabetes. Initial individual education by one or more appropriately trained members of the diabetes MDT should be provided in the following areas, taking account of the individual's home and work environment:
  - What is diabetes?
  - Education on insulin regimen and injections
  - Self-monitoring and appropriate blood glucose targets
  - Recognition and management of hypoglycaemia
  - Initial dietary advice, introducing role of carbohydrate counting
  - Pre-conception planning
  - Everyday challenges (eg driving, exercise)
  - Complications of diabetes (and avoidance) and the importance of regular screening

NICE guidance on structured education

Structured education as can be seen in NICE TA60[5] is key in supporting individuals with type 1 diabetes to manage their condition effectively. Such programmes (eg Dose Adjustment for Normal Eating, or DAFNE) are effective at any duration post diagnosis. They are commonly offered after 6-12 months, but may be delivered later, especially if the honeymoon* period is prolonged. While there are no specific evidence based educational interventions for this early stage of the condition, one-to-one support from trained diabetes educators is key to the person with type 1 diabetes in developing safe self-care strategies and, importantly, a good relationship with their condition. It is vital that those with type 1 diabetes are followed up by teams trained and experienced in the principles of flexible insulin therapy and carbohydrate counting so that the principles are reinforced at each subsequent visit in order to maintain the benefit. It is highly important that referrals to structured education are made by a clinician who has good knowledge of the course content and its benefits. This improves a patient's understanding of the course and its importance as a key part of their care which will lead to better health outcomes.

**The honeymoon period (ie partial remission of type 1 diabetes mellitus) is characterised by reduced insulin requirements while good optimal HbA1c is maintained.*

The NICE guideline on type 1 diabetes in adults[1] (recommendation 1.3.4) states that any structured education programme for adults with type 1 diabetes should include the following components:

- It is evidence based, and suits the needs of the person.
- It has specific aims and learning objectives, and supports the person and their family members and carers in developing attitudes, beliefs, knowledge and skills to self-manage diabetes.
- It has a structured curriculum that is theory driven, evidence based and resource effective, has supporting materials, and is written down.
- It is delivered by trained educators who have an understanding of educational theory appropriate to the age and needs of the person, and who are trained and competent to deliver the principles and content of the programme.
- It is quality assured, and reviewed by trained, competent, independent assessors who measure it against criteria that ensure consistency.
- Outcomes are audited regularly.

Diabetes structured education improves glucose control, reduces hypoglycaemia, improves quality of life and is cost effective within four years. It is clear that patients need reinforcement of those messages and support to keep implementing what they have learnt, as there is an inevitable loss of those skills over time. Therefore, ongoing educational support is required throughout the life long journey of patients with diabetes to ensure self management skills are maintained and up to date with new developments.

Such programmes require considerable resource from the diabetes specialist nurse and dietitian, and are therefore costly to deliver, but they are cost effective[6] through improving diabetes control, reducing acute complications and also risk of long term complications and improving mental health[7] and quality of life[8]. Commissioners should therefore ensure that appropriate funding is provided for such education. DAFNE costs less than £500 per patient and is cost effective within two years from reduced hospital admissions alone, irrespective of the benefit on mild hypos and HbA1c.

The cost quoted to put a patient through DAFNE at £500 includes staff time. All services delivering DAFNE in the UK were surveyed, and of the 70 per cent who responded, none had received additional staff resource to deliver DAFNE courses. This means they are delivering DAFNE from existing resource, achieved by service redesign as in the words of one respondent, they *stop doing things that don't work and do something that is proven to work instead*.

Therefore the only additional cost of delivering DAFNE above existing care is the annual contribution to audit and quality assurance, which works out at £50 per patient in a service delivering one course per month to eight patients per course. All diabetes services have a choice as to how to use their staff, and this is a very cost effective way to use them.

The QIPP analysis of DAFNE on the NHS Evidence database[9] shows that if DAFNE is delivered to all eligible type 1 adults there will be a recurrent savings of £93,000 annually per 100,000 population. Therefore, if you have a population of 5 million people with type 1 diabetes, and all eligible adults are offered a DAFNE course, there could be a realised savings of nearly £5 million per annum on reduced complications, acute admissions from DKA, and severe hypoglycaemia episodes, for example[69].

Evidence shows that if DAFNE is delivered to all eligible type 1 adults there will be a recurrent saving of £93,000 annually per 100,000 population.

The national DAFNE audit suggests that diabetes teams that have a homogeneous approach (where all clinicians are DAFNE trained) can get more than 40 per cent of patients under HbA1c 58 mmol/mol (7.5%). This is more than double the national average, compared to units where only one or two clinicians are DAFNE trained.

Equipping staff with DAFNE training (or other structured education courses) is mandatory for them to be able to manage patients with type 1 diabetes. This will assist them to help people with diabetes in their knowledge of carbohydrate counting, insulin to carbohydrate ratios, correction factors, sick day rules, basic understanding of psychological skills such as motivational interviewing and person centred, empowerment techniques.

Case study: *DEHKO*

Given the wide geographic distribution and low population density, patients from all over Finland come to a centralised location, purpose-built for providing diabetes education, coordinated by the Finnish Diabetes Association. Here, every week there are 3-4 group education sessions where nurse educators facilitate small (6-8 person) groups through their national diabetes education programme, DEHKO, in conjunction with medics, and dietetic support.

The philosophy is that coming to the centre gives patients the opportunity to focus on diabetes away from the pressures and burdens of everyday life, and also makes providing the education efficient for the system across a large area, without compromising care elsewhere[10].

Case study: *King's College Hospital*

Data suggest the need for refresher courses for structured education to maintain the effect over multiple years. At King's College Hospital, the team provide ongoing support for patients who have undergone structured education in three ways:

- All team members who see patients with type 1 diabetes are trained in structured education for type 1 diabetes and the principles are reinforced at each visit.
- The team runs small groups of DAFNE follow-up slots to help with dose adjustment and cover key areas such as carbohydrate counting and exercise.
- The team runs large *DAFNE refresher* days with up to 100 patients attending each time, with lectures, and small group workshops to address key issues patients are having.

Recommendation | Structured education / self management programme

- All staff caring for patients with type 1 diabetes should be trained in DAFNE (or a NICE compliant alternative).
- All adults with type 1 diabetes should be offered a diabetes structured education programme.
- 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 people newly diagnosed with type 1 diabetes within one year of diagnosis.
  2. 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.

Across London we will need to understand the demand for education based on local populations with type 1 diabetes and develop strategies, which may include co-commissioning or using hub and spoke models to deliver capacity for structured education.

Carbohydrate (CHO) counting

Carbohydrate counting training is an integral part of structured education. We recommend that services also consider offering standalone carbohydrate counting courses for patients unable to commit to attendance at the full structured education programme or as a refresher. Educational needs should be considered as part of annual review.

NICE states that all information about treatment and care, including a structured patient educational programme, should take into account age and social factors, language, accessibility, physical, sensory or learning difficulties, and should be ethnically and culturally appropriate. It should also be accessible to people who do not speak or read English. If needed, people with diabetes should have access to an interpreter or advocate.

For patients with poor literacy skills for whom the term structured education may be off putting, it may be helpful to use other language to describe this support. It is vital that strong motivational skills are employed to persuade patients to attend. Use of enthusiastic peers with type 1 diabetes who have already benefited from courses could also be helpful[11].

Recommendation | Carbohydrate counting

- All patients with a new diagnosis of type 1 diabetes should be taught an awareness of carbohydrate counting and the ability to adjust doses of insulin. The teaching of formal CHO counting can be daunting for some at the very beginning of their diagnosis and also not always suitable during the honeymoon phase. Therefore, the aim will be to initiate CHO counting within the first year where possible / when practical.

- All patients with a new diagnosis of type 1 diabetes should be encouraged to complete a structured education course within a year of diagnosis.

- Each CCG / specialist service should develop a clear strategy around how basic carbohydrate counting and structured education will be delivered to those patients who already are living with diabetes. (Note: DAFNE research clearly demonstrates that there is no difference in benefit from DAFNE based on duration of diabetes.)

- Planning for capacity should include networking with other centres to provide a single point of access for type 1 diabetes structured education across sectors.

- Patients who decline structured education should continue to be offered it, and all professionals should understand that this is the cornerstone of type 1 diabetes care. To increase uptake, providers and commissioners should collaborate to make structured education accessible to all patients. For example, DAFNE can be delivered over five consecutive days or one day for five weeks; not all providers offer both options. By enabling access to alternative delivery at other CCGs we would anticipate that more patients would access structured education.

- Structured education training should be considered mandatory training for those with type 1 diabetes. Clinics should be prepared to provide a rationale that patients can share with their employers regarding any absence from work.

Hospital insulin self-management for adult inpatients with diabetes

There is evidence that people with diabetes who are in hospital, particularly those taking insulin, may suffer harm during their admission as a result of prescribing and management errors by hospital staff.

The National Patient Safety Agency (NPSA) has issued alerts to improve the safety of inpatients with diabetes, and recommends that patients who wish to take responsibility for managing their diabetes and are well enough to do so should be allowed to self-manage.

Suggested hospital self-administration criteria (based on NPSA and used at St George's Hospital):

- Currently has mental capacity to self-administer his/her own insulin.
- Currently self-administers at home.
- Currently has the manual dexterity to self-administer his/her own insulin (with aids if necessary).
- Has the necessary knowledge and skills regarding insulin and diabetes to self-administer.
- Has been given, read and understood a self-administration leaflet and his/her questions answered.
- Has signed the self-administration consent form and the form is filed in the patient's notes.

This is assessed on a daily basis as the person's condition can fluctuate whilst in hospital.

Recommendation | Hospital self management for adult inpatients with diabetes

- It is important that there are protocols in place that enable individuals with type 1 diabetes who are willing and able to self-manage their insulin either via injections or insulin pump, which also include information explaining when it is important for the healthcare professionals to temporarily take over and the criteria for resuming self-administration of insulin.

- For an individual on an insulin pump, it may mean that they will temporarily be commenced on intermittent subcutaneous insulin injections, and sick patients may need their usual insulin replacement to be replaced with monitored intravenous insulin infusion.

Hypoglycaemia pathway

A degree of iatrogenic hypoglycaemia (low blood glucose) is inevitable with type 1 diabetes. On a weekly basis, most adults with well-controlled type 1 diabetes report that they experience 1-2 episodes of mild to moderate hypoglycaemia that they can self-treat. Symptoms can occur at various glucose levels depending on previous hypoglycaemic experience.

All patients with type 1 diabetes should receive education with regard to hypoglycaemia avoidance and treatment, ideally as part of a structured education programme with review of this as part of their routine clinical review. Services for people with type 1 diabetes should implement a screening strategy to identify those at high risk of problematic hypoglycaemia. This should record hypoglycaemia frequency and severity, and awareness of symptoms, using the GOLD score[12].
The GOLD score asks a single question: *Do you know when your hypos are commencing?*

A hypo is unpredictable and potentially dangerous. It exerts psychological effects and is greatly feared by those affected and by their relatives. It 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.

A proportion of adults with type 1 diabetes will develop problematic hypoglycaemia, often as a result of loss of awareness of key symptoms which alert the individual to onset of hypoglycaemia. Such loss of awareness greatly increases the risk of severe hypoglycaemia (which requires the assistance of a third party to treat the episode) which may lead to paramedic call out and hospital admission.

Severe hypoglycaemic episodes can have a huge impact on everyday lives of people with type 1 diabetes, and those around them. Unpleasant symptoms and fear of the consequences of severe hypos can reduce independence and spontaneity, significantly impacting on quality of life. Hypos also put pressure on family, colleagues and friends, to be involved in their prevention and management. An individual who has frequent severe hypos at work may be at risk of losing their job.

Repeated severe hypos, can reduce cognitive function, prevent an individual from driving and impact on employment with certain occupations being debarred completely to people on insulin due to the risk of hypoglycaemia. Changes to licensing have been implemented within the European Union that require strict rules around glucose monitoring before driving, and not driving if blood glucose is below 5mmol/l, and having their license revoked if they have two or more episodes of severe hypoglycaemia in a 12-month period or have complete unawareness of their hypoglycaemia. Following suspension of a driving license, a medical report is required assessing their hypoglycaemia risk and their medical fitness to drive. The DVLA provides specific guidance in relation to driving with diabetes, and healthcare professionals should make sure patients with a current driving license are made aware of the guidelines and that the conversation is documented[13].

All people with type 1 diabetes should receive education around avoidance of hypoglycaemia, (through DAFNE, ideally) with particular emphasis on physical exercise, sport and recreational activities and during travel, including long distance flights. Commissioners working in an integrated whole system way with councils, police, prison services, for example, should also be aware that hypoglycaemia is a risk in the elderly in residential and care homes and a potential risk during short-term police custody and for prison inmates with diabetes[14].

All clinical staff working in services for people with type 1 diabetes, should have the expertise to provide appropriate input to those at high risk of problematic hypoglycaemia:

- **Structured education such as DAFNE or other local equivalent if not already attended** - Such programmes have been shown to reduce hypoglycaemia whilst improving overall glycaemic control. A hypoglycaemia-specific education programme may be considered if available.
- **Use of insulin pump therapy** - This intervention, implemented by a multidisciplinary team competent in its use, has been shown to reduce frequency of severe hypoglycaemia frequency. Services should follow NICE technology appraisal guidance, Continuous subcutaneous insulin infusion for the treatment of diabetes mellitus[15] (TA151).
- **Consideration of use of real time continuous monitoring (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. We urge a joint commissioning policy across London to support select patients who meet the NICE criteria and continue to show an improvement to be funded for CGM through local commissioning agreements as per NICE guidelines.

If these skills are not present within the team, the team should have a pathway in place to refer these patients to an appropriate service:

- **Islet or pancreas transplantation** - For patients where the above interventions are unsuccessful or unsuitable, consideration should be given to refer the person with type 1 diabetes for assessment of suitability for islet or pancreas transplantation. Islet or pancreas transplantation is centrally commissioned and provided for those patients who experience frequent severe hypoglycemia despite best medical treatment. In current circumstances that should include assessment and management at an experienced centre, including a trial of insulin pump therapy and continuous glucose monitoring.

Recommendation | Prevention of hypoglycaemia

- Services for people with type 1 diabetes should implement a screening strategy to identify those at high risk of problematic hypoglycaemia. The record should note: Hypoglycaemia frequency and severity, and awareness of symptoms using the *GOLD score.
- All episodes of severe hypoglycaemia requiring third party assistance, the frequency of glucose levels under 3.5 mmol/mol and awareness of hypoglycaemia using GOLD score, should be recorded in the patients shared record.
- Services for type 1 diabetes should have a pathway in place for patients identified as being at high risk of problematic hypoglycaemia (eg those with a GOLD score greater than 4 and/or severe hypoglycaemia in the preceding 12 months, the lower limit of the recommended glucose target for people with type 1 diabetes[17, 18]).
- Services for people with type 1 diabetes should create links with local ambulance providers, to enable referral of all patients with severe hypoglycaemia to the diabetes MDT.
- Links for psychology and specialist MDT support for all people with type 1 diabetes and recurrent hypoglycaemia should also be shared across all healthcare provider organisations.

Islet / pancreas transplant services in London are available through the Royal Free London NHS Foundation Trust, King's College Hospital NHS Foundation Trust and Imperial College Healthcare NHS Trust. We would recommend initial referral for assessment to the clinical lead for islet / pancreas transplant services, if patients fit into this category. Data from the King's College Hospital centre suggests that up to two-thirds of patients who meet the criteria for islet transplantation do not require transplantation if provided access to a specialist hypoglycaemia unit with access to education, psychology and technology[16].

Pathway to reduce hyperglycaemia

Persistently elevated HbA1c (more than 69 mmol/mol or >8.5 per cent)

Most adults with type 1 diabetes will experience episodes of hyperglycaemia (high blood glucose) each week. However clinical services should place an emphasis on those who have persistently elevated HbA1c greater than their individualised HbA1c target. In line with NICE guidance for CSII, persistent levels above 69 mmol/mol (>8.5%) on at least two occasions over 6 to12 months can be deemed of concern, and support should be in place to enable these individuals to achieve their individualised target HbA1c. Type 1 diabetes is a complex long term condition, which requires the individual to own the condition for the rest of their life and take responsibility for their health and behaviours. It is a condition which affects the individual's way of life, every hour, every day, as glucose profiles and insulin requirements can vary on a daily basis depending on multiple factors.

Diabetes distress, which can be measured by validated scales, is often a critical barrier to diabetes control. The Problem Areas in Diabetes (PAID) scale and the Diabetes Distress Scale (DDS) are both widely used scales to assess for these barriers[19, 20]. The DDS is a preferable measure of diabetes distress related to HbA1c and self-management behaviours[21] and hence we recommend use of the DDS here. Additionally we can explore any mental health reasons for difficulties with self-management[22]. Those with type 1 diabetes, like others with a long term condition, can experience barriers like depression, making self-management more challenging. Once we are able to establish any barriers, we can use these as enablers to convey the benefits of education, enable better self-care and/or treatment intensification as appropriate to their needs (*see next page*).

When assessing an individual with type 1 diabetes who demonstrates persistently elevated HBA1c, we recommend a number of factors that should be taken into consideration:

- Target HbA1c should be discussed and agreed with the patient, taking account of the disease duration, their hypoglycaemia risk and presence or absence of complications. It should also be noted that the rate and reliability of insulin absorption also varies on a daily basis, complicating things further.
- The diagram (*next page*) highlights the checks and balances that must be made in setting personalised glycaemic target.
- Clinicians should ensure that the patient's persistent hyperglycaemia is not the result of frequent hypos, over treatment of hypos, or deliberately running their HbA1c high to prevent hypos.
- Additionally, assessing for disordered eating would be justified in those with very high or persistently raised HbA1c. This is where blinded CGM is useful, as patients may not recognise what is happening themselves.

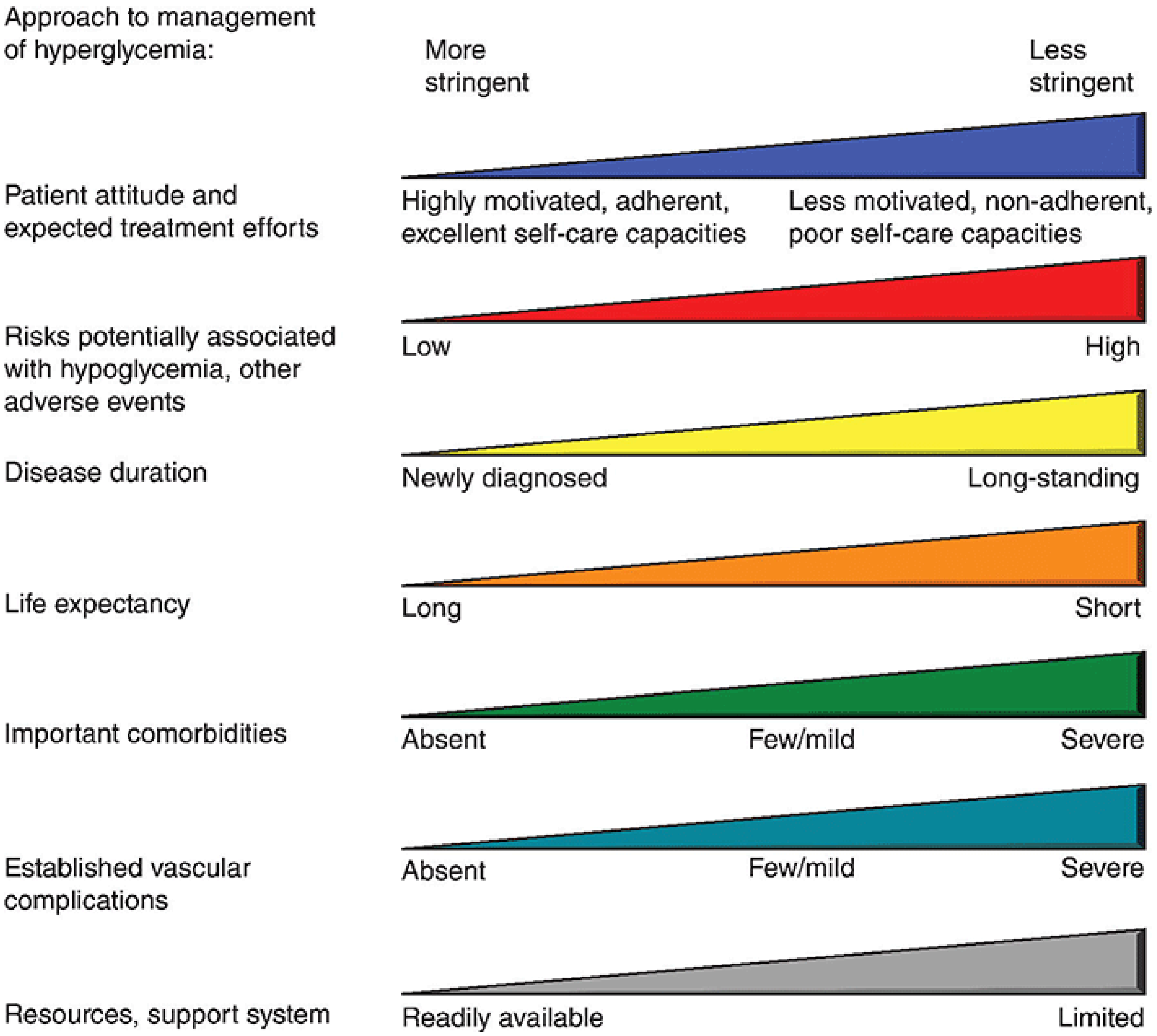
Pathway for persistently elevated HbA1c (more than 108 mmol/mol / > 12%)

In the subgroup of patients with HbA1c levels above 108mmol/mol (>12%) there may be risks of insulin neuritis or progression of microvascular disease, particularly retinopathy, and evidence suggests HbA1c can be lowered safely by 22 mmol/mol (2%)in three months (eg 108 mmol/mol [12%] to 86mmol/mol [10%]) with low risk of treatment-induced neuropathy or retinopathy[23].

The pathway includes:

- **Structured education such as DAFNE or other local equivalent if not already attended, plus refresher courses** - Such programmes have been shown to improve overall glycaemic control.
- **Use of insulin pump therapy** - As per NICE TA151[15], insulin pump therapy should be considered in patients who have elevated levels of HbA1c over 69.5mmol/mol (>8.5%) and who have attended structured education.
- **Peer support** - Use of local and national peer networks including social media.
- **Psychological support**
  - Addressing barriers to self-management behaviours
  - Addressing reasons for diabetes distress
  - Evaluating depression

Whilst developed with reference to type 2 diabetes, this diagram is also relevant to individualising the treatment aims for people with type 1 diabetes.



Source: Inzucchi SE, Bergenstal RM, Buse JB, Diamant M, Ferrannini E, Nauck M, et al. *Management of hyperglycemia in type 2 diabetes, 2015: a patient-centered approach*: update to a position statement of the American Diabetes Association and the European Association for the Study of Diabetes. Diabetes Care. 2015; 38:140-9.

Diabetes and psychological support

Assessing diabetes distress

Diabetes distress is an emotional response to living with and managing diabetes. It has four domains:

- Emotional burden of diabetes
- Treatment burden
- Health professional relationship burden
- Interpersonal burden.

Diabetes distress has been assessed for more than 20 years[24] using the PAID[25] and, more recently, the DDS scales. A screening tool version of the DDS, the DDS2, has been well validated[26] and presents an effective way of identifying diabetes distress and determining if further psychological assessment is required. It is a simple, two question tool that scores with a high degree of sensitivity and specificity people who have diabetes related distress. Due to its concise two question score it was well received in early pilots in south London, and identifies people who may score highly on more detailed psychological screening tools.

Research has found that diabetes distress, as opposed to other more severe psychological morbidities such as depression and anxiety, was found to be at the root of most people's self-care coping struggles with diabetes[27]. The DDS has been found to provide useful sub scales around the four domains so that the areas in which diabetes distress is most elevated can be targeted for additional patient therapeutic support by the diabetes team.

Structured education such as DAFNE has been shown to be an effective tool to reduce diabetes distress, and in a qualitative study, low mood and likely major depressive disorder was a significant contributor to distress in up to a third of patients[28].

It is strongly advised that referral pathways to psychological services such as IAPT are well established before using any tool to assess the psychological demands of diabetes. The flow chart (*next page*) is an example of a pathway for using DDS2 as a screening tool.

In conclusion, a number of psychology services currently exist within diabetes departments that work specifically with individuals presenting with diabetes related distress. Pathways for such services should be made clear to all staff.

When working with specific diabetes related distress the psychologist / therapist often has in-depth knowledge of diabetes and various aspects of self-management. There is also the flexibility to offer one off appointments or monthly follow up appointments in addition to the usual course of therapy. IAPT services may not be set up to do this, as they often having restrictive attendance policies and focus primarily on relieving symptoms of depression and anxiety.

Case study: *Hackney Diabetes Centre*

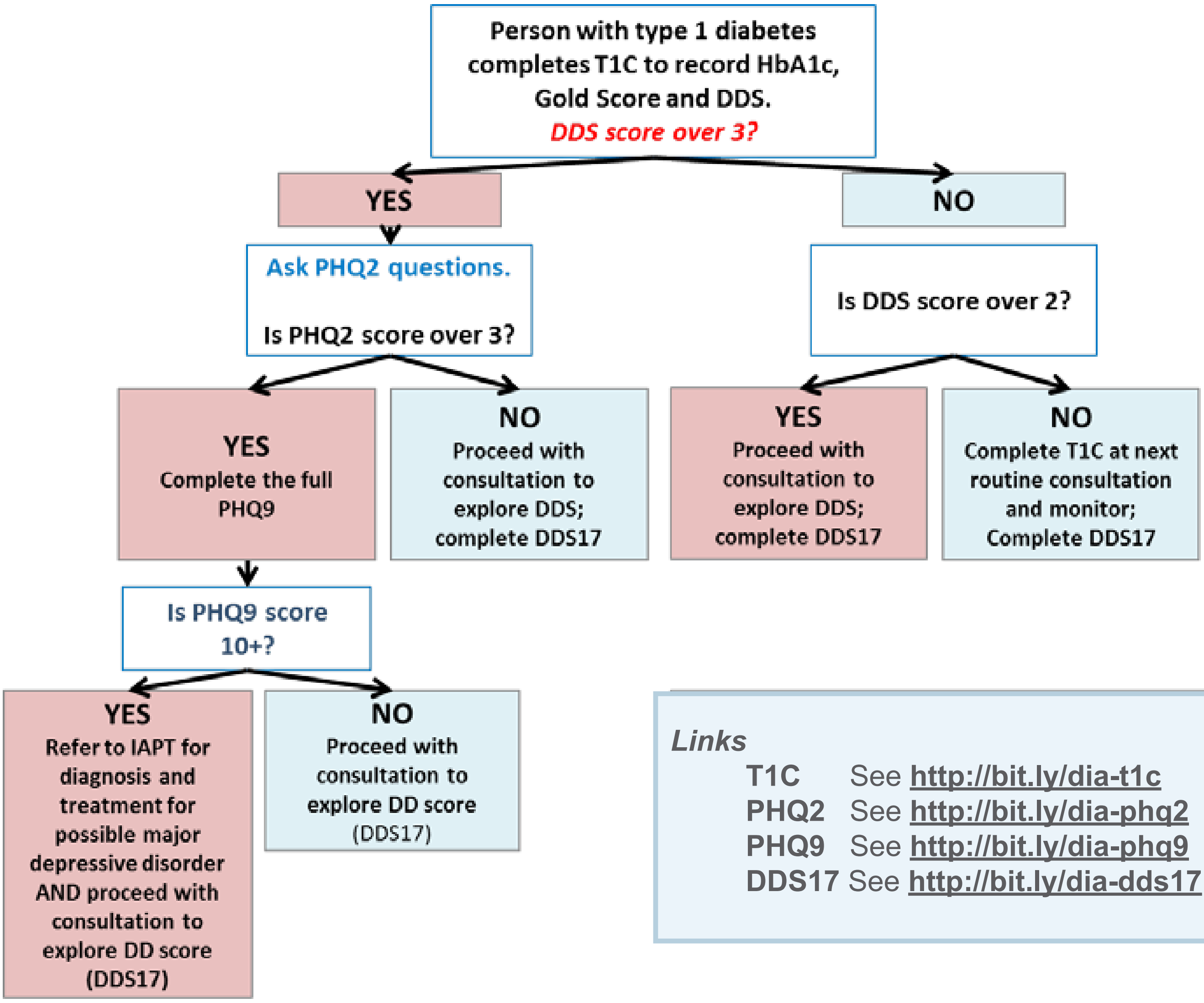
A 2015 focus group held in Hackney for people with type 1 diabetes identified the importance of psychology being embedded within services and having access to psychology following diagnosis.

All patients with type 1 diabetes reporting diabetes related distress are currently seen by the in-house psychology service within the Hackney Diabetes Centre. Patients presenting with non diabetes related distress are signposted to local psychology services (after assessment). Peer groups are another element being addressed in Hackney. In 2015/16, they have been trialling facilitated peer support groups, facilitated by a psychological therapist and DSN/ DSD when required. Feedback is that people with diabetes prefer support from a group including professionals, not just peers.

Case study: *Camden IPU*

A tiered diabetes psychology pathway is in place in Camden as part of their Integrated Practice Unit (IPU), with a consultant clinical and health psychologist leading a team of clinical psychologists at Tier 3, who works as part of a MDT in intermediate care, supported by Tier 2 and Tier 1 IAPT workers trained in diabetes distress.

Suggested flow diagram for diabetes distress; reproduced from the HIN AHSN.



Links

T1C	See **http://bit.ly/dia-t1c**
PHQ2	See **http://bit.ly/dia-phq2**
PHQ9	See **http://bit.ly/dia-phq9**
DDS17	See **http://bit.ly/dia-dds17**

Eating disorders

Eating disorders were thought to affect more than a third of young people with type 1 diabetes[28]. Recent research by the Diabetics with Eating Disorders (DWED) charity indicates this may be as high as 40 per cent of all those with type 1. DWED provides information, advice, support and advocacy, and will provide free training for health professionals to recognise those individuals who regularly omit insulin over concerns about eating and weight ("diabulimia"). Regular weight fluctuations are a key sign of an eating disorder, and are often overlooked as a danger sign as these conditions are often secretive, and believed to be shameful behaviours.

There are tools available to identify these patients[29] People who experience these issues are associated with worse glucose control and a two- to four-fold increase in the risk of complications, such as kidney disease, eye disease and even death. However, these issues are frequently unrecognised and individuals can suffer with these problems for many years. Morbidity and mortality increase dramatically in those with type 1 diabetes and eating disorders or regular insulin omission for body image reasons. The impact on quality of life and indeed life expectancy is paralleled by an increase in healthcare costs dealing with increased rates of hospital admissions and increased costs dealing with the complications of diabetes. These patients frequently surface as recurrent emergency admissions with an HbA1c significantly above target.

In summary, diabulimia, binge eating and aggressive / obsessive dieting will result in poor diabetes management. Multiplying that with diabetes related complications can have life-threatening consequences for a person of any age with type 1 diabetes, requiring urgent specialist treatment and support.

Referral and treatment pathways should be agreed locally to specialist psychological and eating disorder services[30].

The ethos of the diabetes clinic should include:

- Psychological mindedness as a core component of treatment
- Collaborative approach to development of self-management skills
- Develop supportive skills training for families/ carers.

A clinical psychologist as part of the MDT is crucial in ensuring that the whole team are trained in motivational interviewing and are aware of the needs of these vulnerable patients with the complex picture of type 1 diabetes and an eating disorder, to allow earlier identification.

Additionally, if all staff are aware, measures can be put in place to understand the pressures and be able to support a person with type 1 diabetes in order to reduce the risk of the development of these disorders, particularly around the time of diagnosis. Where these behaviours are established there is a need for diabetes teams to be supported in their care of these individuals and families by linking mental health and eating disorder teams with the diabetes team to transfer skills and training and, where necessary, jointly care for these individuals.

At a London Diabetes Clinical Network event[31], it was strongly felt that integrating the approaches (rather than splitting care between diabetes teams and mental health/ED teams) was important, and this was particularly echoed by people with type 1 diabetes.

Skills from the mental health team need to be disseminated with families, carers and staff. These are highly valued as life skills. Interventions to disseminate these skills are delivered through workshops, books, peer support, telephone coaching and online resources.

Recommendation | Diabetes psychology pathway

- All type 1 diabetes services should have access to diabetes trained consultant clinical and health psychologists with a robust referral process to consultant psychiatrists within their structure. We recommend a tiered approach. (See an Integrated career and competency framework for diabetes nursing from TREND-UK.)
- The clinical psychologist, as part of the MDT, is crucial to ensuring that the whole team is trained in motivational interviewing and are aware of the needs of these vulnerable patients with the complex picture of type 1 diabetes and an eating disorder, to allow earlier identification.

Diabetes services should:

- Deliver training for staff alongside families/carers; aim for co-production.
- Recruit and train a small number of staff in higher level mental health / psychological therapy.
- Draft information for patients and families/carers.
- Develop partnerships with third sector organisations and expert patients and carers to deliver peer support through online and print materials.
- Create shared care pathways for people with the most severe and complex co-morbid type 1 diabetes and eating disorders, offering integrated care from both diabetes and eating disorder services.

Proposed model of type 1 diabetes-related distress management integrated within the multidisciplinary diabetes care team

Target area	Specific task	Care setting	Potential barriers
Regular screening for depression and type 1 diabetes related distress	Structured clinical interviews and subjective self report questionnaires	Diabetes clinics or a pre visit setting	Lack of resources or personnel
Type 1 diabetes related emotional and physical burden	Coping strategies module introduced in a diabetes educator-led education class and refresher courses; follow up care by diabetes knowledgeable psychologists; psychological treatments integrated with other diabetes support interventions	Diabetes clinics, mental health professional settings, and diabetes support groups	Time pressures of clinical care, a need for specially educated and trained diabetes care teams, and a lack of psychologists trained in diabetes
Type 1 diabetes related interpersonal and social distress	Promotion of health behaviours and treatment of psychological problems; increasing public awareness of type 1 diabetes	Diabetes clinics, mental health professional settings, public and community settings	Lack of psychologists trained in diabetes, lack of resources or personnel and an unresponsive society
Type 1 diabetes regimen related distress	Self management interventions delivered by diabetes educators, diabetes specialist nurses, dietitians, or diabetologists	Diabetes clinic and diabetes support groups	Unintentional non adherence because of communication failure
Healthcare related type 1 diabetes distress	Provision of good clinical care; increase in clinical awareness and understanding of type 1 diabetes related distress; development of a new model of integrated diabetes care	Primary care and specialist services	Lack of resources or personnel; unwilling, unaware, or unresponsive providers; ill-advised interventions; a fragmented model of diabetes care
All areas of type 1 diabetes related distress	Follow up counselling on the use of coping strategies for type 1 diabetes; increasing public awareness of type 1 diabetes; promotion of healthy behaviours	Over the phone	Lack of resources or personnel; need for specially educated and trained diabetes care teams; non adherence because of communication failure

Eye screening / treatments for retinopathy

Yearly eye screening is recommended for all patients with diabetes (types 1 and 2) over the age of 12. This is currently delivered via the national Diabetic Eye Screening Programme (DESP) across the UK[32] at various community and hospital sites. Although previously diabetic eye screening attracted Quality and Outcomes Framework (QOF) points for GPs, these were no longer included from 2014. This is likely to have a negative impact on GPs engaging with the DESP, making them less likely to support an accurate DESP database or encourage non attenders to attend screening[33]. In the long term this could reduce overall uptake for local programmes, increasing the risk of sight loss.

Evidence from the FLURRI study[34] identified five modifiable factors at the GP practice level to increase screening uptake:

- Communication with screening services
- Contacting patients to make screening appointments
- Integrating screening with other diabetes care
- Ensuring newly diagnosed people were registered quickly with the screening service
- Proactive approach to “hard to reach” patients.

Following the recent re-procurement of services in London there are now five programmes, instead of the original 17, responsible for screening patients in each sector of London and arranging referrals as necessary to hospital eye services (HES). A further change has meant that DESP services are now only responsible for screening and referral of patients and no longer have to ensure that treatment is carried out at the referral centre. It is therefore essential that commissioners ensure pathways are in place for treatment of retinopathy (pan-retinal laser treatment) and maculopathy as appropriate (including laser, anti-VEGF injection treatments and steroid dexamethasone implants) by local ophthalmology HES. Local trusts also have to ensure that adequate failsafe is commissioned to ensure patients don’t get lost through non attendance or rescheduling of appointments by hospitals, as the risk of visual loss in these patients is very high.

Recommendation | Eye screening

It is imperative that all diabetes staff:

- Remain engaged with their local DESP service to ensure that patients don’t fall through the net due to multiple non attendances.
- Ensure that patients are not incorrectly coded or excluded from eye screening.
- Educate patients as to the importance of eye screening as patients can develop advanced levels of retinopathy and still remain asymptomatic. This can then increase the risk of subsequent blindness if untreated.

Diabetic retinopathy is relatively asymptomatic until the late stages and so we cannot rely on patients presenting with symptoms[35]. Those with type 1 diabetes have a higher risk of proliferative disease and visual loss in relation to the duration of their diabetes[36].

Pre-conception, pregnancy and diabetes

Type 1 diabetes is often diagnosed in childhood or early adulthood. For women of childbearing age with type 1 diabetes, pregnancy planning is essential to reduce risks to the mother and baby. Pregnancy planning ensures that risks are identified and minimised to maximise the health of both mother and baby.

Childbearing age is defined as the period in a woman's life between puberty and menopause, so this discussion should begin early, with age appropriate discussions in paediatric diabetes services from around 11 years old.

The rates of serious adverse outcomes (congenital malformation, stillbirth or neonatal death) are 3 to 5 times higher in women with diabetes than in the general population[37].

It has therefore been recommended by NICE that all women of reproductive age with diabetes are offered annual preconception counselling and advised to avoid unplanned pregnancy[38].

It is well documented that diabetes specialist pre-pregnancy care improves glycaemic control and reduces adverse outcomes in women with type 1 diabetes[39], and more recently, there is clear evidence that a regional pre-conception program can improve outcomes in both type 1 and type 2 diabetes[40]. Organised pre-conception care reduced severe adverse outcomes (SAE) such as congenital malformation, stillbirth or neonatal death from 7.8 per cent to 1.3 per cent, which is similar to the non diabetic population.

However, the uptake of pre-conception care is poor. As long ago as 2005, the Confidential Enquiry for Maternal and Child Health (CEMACH)[41] showed that only 17 per cent of maternity units offered pre-conception care, and only 10 per cent of women with diabetes (mostly with type 1) attend. The CEMACH survey reported a stillbirth rate of 26.8 per 1000 births and congenital abnormalities of 41.8 per 1000 live and stillbirths.

The National Pregnancy in Diabetes (NPID) audit[42] in 2013/14 reports stillbirths at 12.8 per 1,000 births and congenital abnormalities at 44.2 per 1,000 live and stillbirths. In comparison, the non diabetic population are reported to have 4.7 stillbirths per 1,000 and 22.7 congenital anomalies per 1,000 live and stillbirths.

Although it is not possible to directly compare CEMACH, NPID and other sources due to methodological differences, it is clear that women with type 1 and type 2 diabetes have worse outcomes than the rest of the population, and that although the rate of stillbirths seems to have improved, rates for congenital anomalies remain high.

The NPID is part of the National Diabetes Audit (NDA) programme, and is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit (NCA) programme. Additionally the Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK (MBRRACE-UK) stillbirth report[43] and the recent Maternity Review both highlight diabetes in pregnancy as high risk[44].

The 2014 NPID report is the second annual report from a continuous audit of the quality of care and outcomes for women with diabetes who become pregnant. Data from the audit came from 150 hospitals and trusts.
The audit looks at three key questions:

- *Were women adequately prepared for pregnancy?*
- *Were adverse maternal outcomes minimised?*
- *Were adverse fetal /infant outcomes minimised?*

Results

- Combined 2013 and 2014 audit data confirm high rates of adverse outcomes: 12.8 stillbirths per 1,000 live and stillbirths, 7.6 neonatal deaths per 1,000 live births and 44.2 anomalies per 1,000 live and stillbirths.
- More than one-third of women (34.3 per cent) had babies that were large for gestational age.
- Two-thirds (66.6 per cent) of babies were able to remain with their mothers and did not need intensive or special neonatal care.
- Less than half of women in the audit (41.9 per cent) were taking folic acid in any dose prior to pregnancy.

- Only 15.4 per cent of women with type 1 diabetes and 35.8 per cent of women with type 2 diabetes had a first trimester HbA1c measurement below 48 mmol /mol (6.5 per cent).
- At the time of conception 6.2 per cent of women were taking potentially harmful medications (statins, ACE inhibitors and ARBs).

Diabetic eye screening in pregnancy

Pregnancy may cause a rapid increase in the progression of diabetic retinopathy, hence the requirement for good diabetic control throughout[45]. In accordance with NICE recommendations[46], diabetic eye screening should be offered to pregnant mothers (with pre-existing diabetes) at the first antenatal appointment and again at 28 weeks gestation. If any abnormalities are detected at the first screen, a further screen is offered at 16-20 weeks (see diagram below). This does not include patients with gestational diabetes as they do not have a risk of retinopathy.

It is recommended that diabetic eye screening is carried out with digital photography through dilated pupils (NICE guidance). Eye drops, typically tropicamide (1%), are safe to use in pregnancy. The screening protocol (*next page*) is taken from the Diabetic Retinopathy website[47].

Laser treatment during pregnancy is effective at slowing diabetic retinopathy and reducing the risk of bleeding from abnormal new vessels on the retina[48]. This treatment is safe in pregnancy and carries no risk to the unborn baby. Any laser treatment required must not be delayed till after the pregnancy as this can increase the risk of visual loss risk and bleeding within the eye.

Some pregnant mothers develop swelling at the back of the eyes, causing mild blurring of vision (maculopathy). This often spontaneously improves after the delivery and does not require treatment. If this persists however, laser treatment can be carried out after the delivery.

A large UK-based study showed that an intensive pre-conception pathway for women with type 1 diabetes involving visits to a multidisciplinary clinic 1-3 times monthly reduced SAE from 10.2 to 2.9 per cent.

Recommendation | Type 1 services for women of childbearing age*

The NICE guideline recommends that women with diabetes who are planning to become pregnant:

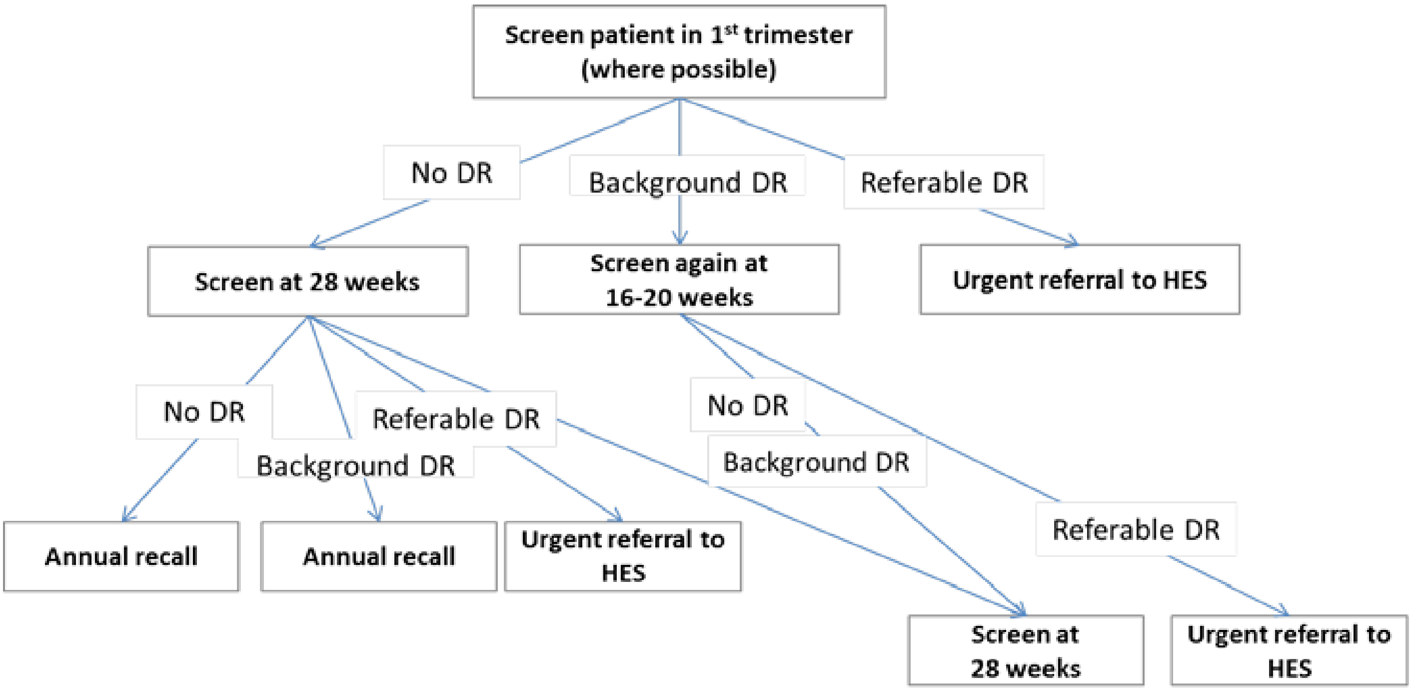
- Take 5mg/day folic acid prior to becoming pregnant and until 12 weeks of gestation to reduce the risk of having a baby with a neural tube defect.
- Aim to maintain HbA1c below 48 mmol / mol (6.5%), without causing problematic hypoglycaemia.
- Reassure women that any reduction in HbA1c level towards the target of 48 mmol/mol (6.5%) is likely to reduce the risk of congenital malformations in the baby.
- Strongly advise women with diabetes whose HbA1c level is above 86 mmol/mol (10%) not to get pregnant because of the associated risks.
- In accordance with NICE recommendations[49], diabetic eye screening should be offered to pregnant mothers (with pre-existing diabetes) at the first antenatal appointment and then again at 28 weeks gestation.

** Childbearing age is defined as the period in a woman's life between puberty and menopause, so this discussion should begin early, with age appropriate discussions in paediatric diabetes services from around 11 years old.*

Additionally:

- Introduce a discussion about pre-conception in the annual diabetes care plan for all women of child bearing age with known pre-existing diabetes.
- All women to consider contraception if not actively trying for pregnancy.
- Refer all women considering pregnancy to the multidisciplinary pre-conception clinic if Hba1c level is equal or higher than 48 mmol/mol (>6.5%).
- Women will be seen in a multidisciplinary secondary care clinic for a new consultation and then seen 2-4 times monthly for follow up visits until they have achieved adequate glycaemic control. Some women will need more frequent clinic/telephone/email appointments
- If women are not pregnant after 12 months, then consider referral for fertility services.

Eye screening pathway in pregnancy



Reproduced from www.diabeticretinopathy.org.uk

Transition from paediatric to adult diabetes services

Diabetes UK and others recognise the importance of a transition clinic[50]. A transition clinic should be commissioned with clinic appointments long enough for the person with diabetes to build up a relationship with the new team as they move from the familiar paediatric clinic to adult services. Commissioners should note that many children and young adults moving into the adult diabetes services will be treated with an insulin pump, and they need to account for this in the diabetes budget, as this will increase year on year.

Additionally, people with diabetes may experience a different emphasis on their care, as they transition to adult services. Depending on their paediatric experience, they may now be expected to be more self-empowered and self-directed. If this transition is successful, it can improve engagement of the young person and subsequent diabetes clinic attendance, management of diabetes and minimise complications.

Specific local protocols should be agreed for transferring young people with diabetes from paediatric to adult services and the decision about the age of transfer to the adult service should be based on the young person's physical development and emotional maturity, and local circumstances. Ideally, that transition from the paediatric service occurs at a time of relative stability in the young person's health and is coordinated with other life transitions (such as school, college, university, or work). It should be clearly explained to young people with type 1 diabetes that some aspects of diabetes care will change at transition.

Transition care should be provided by a multidisciplinary team (MDT) including:

- Paediatric diabetes specialist nurse
- Paediatric diabetes dietitian
- Consultant or associate specialist/speciality doctor with training in paediatric diabetes
- Consultant or associate specialist/speciality doctor with training in adult diabetes
- Adult diabetes specialist nurse
- Access to psychological support

Recommendation | Transition to adult diabetes services

- A transition clinic should be commissioned with clinic appointments long enough for the person with diabetes to build up a relationship with the new team as they move from the familiar paediatric clinic to adult services. This should harness new technologies.

The Best Practice Tariff supports transition care for people with diabetes up to the age of 19 and recommends provision of the following:

- **Structured education programme** -Tailored to the child or young person's and their family's needs, both at the time of initial diagnosis and ongoing updates throughout the child or young person's attendance at the paediatric diabetes clinic
- **Regular appointments** - A minimum of four clinic appointments per year with the multidisciplinary team
- **Dietetics** - One additional appointment per year with a paediatric diabetes dietitian
- **HbA1c testing** - A minimum of four HbA1C measurements per year. All results must be available, discussed and plans recorded at each MDT clinic appointment
- **Complication screening** - Annual retinopathy screening performed by regional screening services in line with the national retinopathy screening programme. Where retinopathy is identified, timely and appropriate referral to ophthalmology must be provided by the regional screening programme.
- **Psychological support** - Annual assessment by the MDT as to whether input to their care by a clinical psychologist is needed, and access to psychological support, which should be integral to the team, as appropriate.
- **Additional contact** - Eight additional contacts per year are recommended as a minimum between the person with diabetes and the diabetes specialist team. They should be available for check-ups, telephone contacts, school visits, troubleshooting, advice, support. In light of NHSmail 2 IT system offering secure email and Skype facilities for patient-clinician communications, these should now be considered as potentially appropriate methods for clinicians to offer additional support to adolescents and young adults.

Adults who may be vulnerable

The vulnerable adult is defined as an individual who is or may be in need of community care services by reason of disability, age or illness; and is or may be unable to take care of /unable to protect him/herself against significant harm or exploitation.

Some groups may be less able to monitor and self-manage their condition and so are at particular risk of both significant hyperglycaemia, or of problematic hypoglycaemia.

This includes adults who are / have:

» Learning disabilities
» Frail elderly
» Dementia
» Severe mental illness
» Living in residential homes
» Homeless, in hostels, in prisons or remand centres
» An eating disorder
» Housebound
» A previous amputation

Challenges with cognition, mobility, dexterity, vision, hearing, depression and chronic pain interferes disproportionately with type 1 diabetes in the elderly. It should be considered that challenges with peer pressure and the cultural drive to be thin can also interfere diabetes management at all stages of life with type 1 diabetes.

Type 1 diabetes services should recognise the needs of such groups of patients and family/carers, and tailor care as appropriate on an individual basis. Liaising with other services involved in the patient's care (such as mental health services, community care staff, social workers and residential care homes) will often be necessary to ensure a holistic approach to the individual's management.

Parents and carers should be aware of the basic principles of sick day rules and local arrangements for seeking help. Continuity of care from the same diabetes professional is important both clinically and for the individual's wellbeing.

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[51] 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[52]. Diabetes technologies support self-management and are effective as an adjunct to ongoing education and support.

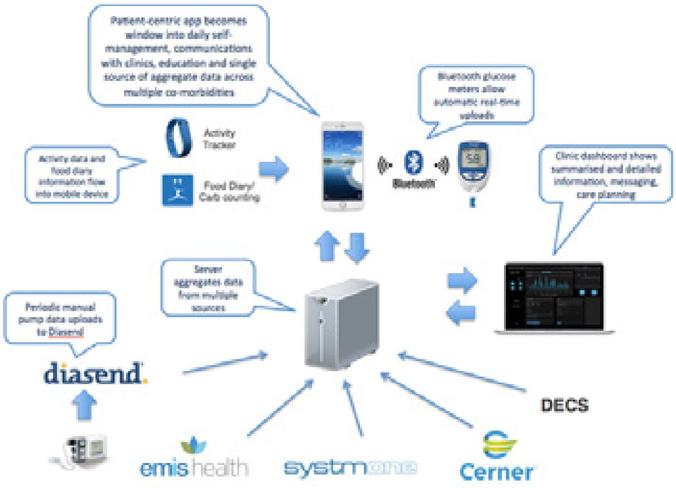
There are many categories of technology that can help people with diabetes, but integration between different areas of care and different technologies, in a way that provides a patient-centric view rather than a condition-centric view, is likely to move towards the goal of person-centred coordinated care as part of the House of Care[53] model. The diagram below shows a sample technology ecosystem.

New technology for diabetes is emerging faster than it can be evaluated in large randomised controlled trials. For many technologies, there is little risk or cost associated, and benefits will be variable from individual to individual based on particular circumstances. For example, bolus advisors cost no extra in terms of glucose checking strips, but offer clear advantages to a group of people who find the calculations required to dose insulin challenging. On the other hand, by the time NICE reviewed two advanced technologies as part of a diagnostic assessment (NICE DG21[54], the Medtronic Paradigm Veo and the Dexcom G4), newer products superseded both.

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.

Capillary blood glucose monitoring

It is crucial that individuals with type 1 diabetes are able to check their blood glucose with a glucometer frequently each day. This may be up to 10 times per day according to life circumstances.



Above: Sample technology ecosystem

The latest NICE guidance recommends that patients with type 1 diabetes should be supported to check their blood glucose frequently, as it is cost effective to do so up to 10 times per day. This is based on large cohort data suggesting that the mean number of checks per day in people who achieve the NICE audit standard of HbA1c under 53 mmol/mol (7 per cent) is eight checks per day. Data from a large cohort of more than 10,000 people in the USA show a clear correlation between number of CBG checks and achieved HbA1c. Checking up to 10 times a day has possible lifetime savings of about £3,500 per person through achieving an HbA1c level of 48 mmol/mol (6.5%) compared with 58.5 mmol/mol (7.5%)[55].NICE indicates an HbA1c of 53 mmol/mol (7%) is reasonable.

There is a clear relationship between self monitoring frequency and achieved HbA1c. This suggests that to achieve target HbA1c under 7 per cent on average people will need to check up to 10 times per day. In the same database, frequency of blood glucose checking was a key factor seen in people with blood glucose results *at target* and those *above target*[56].

Features of glucose meters have evolved requiring a smaller blood volume with a more accurate result. Some meters now incorporate an integrated insulin bolus advisor which can be a very helpful feature. Many CCGs have recommended a range of glucose meters which they will support due to cost of the strips, although most glucose checking strip usage is for type 2 diabetes, as these are in the majority. It is important to consider accuracy and precision standards (eg ISO 15197, 2013) when selecting capillary blood glucose meters, along with convenience, cost and additional features such as download connectivity. A meter with a memory should be used by people with diabetes who drive.

Bolus advisors

At every meal, the person with type 1 diabetes may benefit from complicated mathematics. Each dose of insulin is determined by the formula:
Food insulin + correction insulin - insulin on board
Which can be expressed as
(Carbohydrate intake / insulin : carbohydrate ratio) + ((current glucose – target glucose) / insulin sensitivity factor) - insulin on board

Many people find this difficult to perform day in and day out, often “guesstimating” their requirements. Data suggest that in most cases people underestimate their requirements, leading to a post meal glucose above target. Some modern meters, and smart phone applications can perform these calculations based on current glucose and the estimated carbohydrate intake, with studies showing improved HbA1c using this technology[57]. The smart phone applications are not validated for bolus calculation.

Many CCGs have a recommended list of blood glucose meters and strips, and we strongly recommend that individuals with type 1 diabetes should be supported to self-monitor as frequently as they require with access to appropriate technology to achieve optimal glucose control including insulin bolus advice technologies.

Recommendation | Bolus

- Patients with type 1 diabetes should be supported to check glucose frequently, with evidence to support this is cost effective up to 10 checks per day.
- Patients with type1 diabetes should have a freedom of choice regarding which blood glucose meter they want to use, including access to specific meters that provide bolus calculation (eg Roche Accu-Chek Expert, Abbott FreeStyle Insulinx, Dario).
- There should be NO restriction of number of strips for those with type 1 diabetes.

Continuous glucose monitoring (CGM)

This is available in two forms, blinded (or diagnostic) and real-time.

Blinded monitoring - This comprises an interstitial glucose sensor used up to one week as a diagnostic tool to explore patterns of glucose control which may be missed by capillary glucose monitoring, including unappreciated hypoglycaemia and hyperglycaemia and response to exercise. It should only be used within a specialist team experienced in type 1 diabetes management. Discussion of the results between the healthcare professional and patient can then be used to inform ongoing management decisions.

Realtime CGM[58] - Uses a sensor that measures interstitial glucose that is then send to a reader and allows the individual with type 1 diabetes to be aware of their glucose level and magnitude and rate of change on a constant basis. These systems (Abbott Navigator, Medtronic Guardian Connect, Dexcom G4 Platinum and G5 Mobile) have alarms that can be set to alert the patient to impending high or low glucose readings.

Sensor-augmented insulin pump therapy - The Medtronic Veo and Medtronic 640G systems can use this data to suspend insulin delivery if the patient fails to respond to a *low glucose* alarm.

This technology has been shown in randomised and observational studies to significantly reduce overnight hypoglycemia and reduce severe hypoglycemia in those experiencing recurrent severe hypoglycemia. The recent NICE DG21[54] recommends the use of the Medtronic Veo in those patients experiencing recurrent severe hypoglycemia.

Commissioning considerations

To use this information effectively[59], advanced education in the interpretation of CGM and subsequent decisions about insulin dosing is key. Recent NICE[60] documents have provided guidance as to the subgroups of type 1 patients who may benefit, particularly those with ongoing problematic hypoglycaemia, despite optimised education and insulin management (which often includes insulin pump therapy). CCG funding for CGM has until now been dependent on individual funding requests, with a great deal of variation between CCGs.

With the robust evidence base and support of NICE, we strongly recommend that CCGs provide funding for use of real time CGM, according to the recommendations in NG17[1], DG21[54] and NG18[68].

Although some of these technologies are costlier to implement than the previous 'standard' management, using technology to achieve optimal glycaemic control can improve self-management to help people with type 1 diabetes to achieve their target HbA1c. This may delay the onset of complications, can prevent hospital admissions for hypoglycaemia, diabetic ketoacidosis (DKA) and other diabetes related complications, resulting in cost savings in the long term. Additionally, appropriate use of technology can improve quality of life for the individual with type 1 diabetes, as well as contributing to the overall economy by reducing the number of sick days.

The Abbott FreeStyle Libre device (called Flash glucose monitoring) is approved in Europe and Australia. The system consists of a sensor that reads interstitial glucose via a reader using near-field technology. The advantage is that patients can read their glucose without having to prick their finger to test capillary blood glucose. The software provides data on the previous eight hours so the patient can determine if the glucose is rising or falling and a trend arrow.

In contrast to CGM, the system only provides data *on-demand*, and does not alarm in response to high or low readings. It costs less than traditional CGM. Importantly, although the interstitial readings are approved to be used to support treatment decisions, the DVLA has not yet provided an opinion if the data can be used to judge if the patient is safe to drive. It should also be noted that the Libre device is not as accurate as capillary blood glucose and does not meet ISO 15197(2013).

Currently many patients are self-funding these systems (at a cost of £100 per month), although the costs are very similar to the cost of the 10 tests per day. A randomised controlled trial showed a reduction in time in hypoglycaemia in adults with well-controlled type 1 diabetes using the Abbott FreeStyle Libre[70].

We suggest that this technology may be considered in people who:

- Are regularly testing up to 10 times per day and achieving target control
- Do not test yet may test if this technology would allow them to do so painlessly and frequently

Our caveat is that it should only receive continued funding for that patient if there is demonstrable benefit in either HbA1c, hypoglycemia or quality of life, in accordance with the way these are measured for benefit from CSII therapy. People using the Libre must continue to test capillary blood in accordance with DVLA driving guidelines.

Glucometer/mobile device integration: Tracking and charting applications

These are mobile applications, which help track and chart blood sugar, insulin, carbohydrates and record notes. They can help people with type 1 diabetes to look for patterns and trends as well as providing a useful record for later review but do not have an evidence base for clinical or quality of life outcomes. Details on available apps for iPhone and Android can be found online. One example is on the Healthline website. Other examples include mumoActive, MySugr, Glooko and Diabeto.

Continuous subcutaneous insulin infusion (CSII) – Insulin pump therapy

Continuous subcutaneous insulin infusion (CSII) or insulin pump therapy is a routine clinical option for insulin treatment in type 1 diabetes. Insulin pumps are a NICE appraised technology (TA151), and have been recommended for the management of type 1 diabetes since 2008[61] but access remains variable across London. Using a pump should be seen as a routine clinical option for insulin treatment in some people with type 1 diabetes.

In 2013, the UK Insulin Pump Audit reported that only 6 per cent of adults with type 1 diabetes were accessing insulin pump therapy[62], despite 2006 evidence[63] which found that the use of insulin pump therapy in adults with type 1 diabetes should be between 15 and 20 per cent.

A 2015 audit by the Health Innovation Network (HIN) demonstrated that across south London the uptake of insulin pumps in adults with type 1 diabetes is 10.9 per cent. However, due to the variability of recording diabetes by type within local electronic patient records and within QOF data, any figures relating to pumps are difficult to quantify.

The lack of classification between type 1 and type 2 diabetes, within QOF and Hospital Episode Statistics (HES) data, hinders accurate commissioning decisions that relate solely to people with type 1 diabetes (eg the use of insulin pumps and continuous glucose monitoring).

There are five pumps currently available in the UK, with a number of new products geared for launch in the next few years. All have small differences that may be of particular relevance to certain patient sub groups. For example:

» Ability to bolus remotely (Accu-Chek Insight system)
» Ability to link with CGM (Animas and Medtronic systems)
» Small length of tubing (Cellnovo / Kaleido or Omnipod patch pump)

When units are undergoing procurement exercises, it is important to consider a variety of pumps that are available to allow a degree of patient and physician choice.

CSII is constantly evolving and the integration of CSII with CGM has now been available for some time. This means that insulin pumps are now available that can suspend insulin delivery when the glucose level falls to, or is predicted to reach, a specified low level.

This is a valuable feature for patients with problematic hypoglycaemia and particularly those with hypoglycaemia unawareness. Recent NICE diagnostics guidance[64] recommends integrated sensor-augmented pump therapy systems for managing blood glucose levels in type 1 diabetes (MiniMed Paradigm Veo system).

Funding and procurement for diabetes technologies

Currently, NICE TA 151 recommends insulin pump therapy (CSII) for people with type 1 diabetes who fulfill the following criteria:

1. Attempts to achieve target HbA1c levels with multiple daily injections result in the person experiencing disabling hypoglycaemia

OR

2. HbA1c levels have remained high (that is, at 69 mmol/mol [8.5%] or above) on MDI therapy (including, if appropriate, the use of long acting insulin analogues) despite a high level of care.

Therefore, patients should be assessed for eligibility for CSII therapy by clinicians experienced in type 1 diabetes care delivery in an MDT setting. After CSII initiation, patients should be reassessed at 6 and 12 months by the MDT, specifically noting the impact of CSII on HbA1c, frequency of hypoglycaemia episodes (mild and severe), hypoglycaemia awareness and quality of life (PAID). These data should be recorded in the patient's case notes and forwarded to the funding body. The funding body for adults over 19 years will be their local CCG (Payment by Results exclusion, or PBRe, applies) or NHS England, for children/adults up to the age of 19.

Thereafter, it is the responsibility of the MDT to continuously reassess the patient's eligibility for insulin pump therapy at least annually, via clinic visits. Appropriate targets should be set individually by the patient's clinical team. The MDT should confirm the patient's continuing eligibility based on meeting targets for the local/national funding body.

Applications for CSII funding can be very stressful and unnecessarily distressing for patients. Both the funding body and the clinical team should ensure that they try to minimise this by clear, timely communication and transparent decision making.

The choice of CSII device should be made by the patient and the clinical team. However, the funding body can refuse to fund CSII technologies that are significantly more expensive than their competitors unless specific additional clinical benefit can be demonstrated. Clinical teams should be able to negotiate local procurement strategies so as to lead to reduced costs and greater choice for patients.

Continuous glucose monitoring (CGM)

Similarly, NICE guidelines NG17 (*Type 1 diabetes in adults: diagnosis and management*[1]), DG21 (Integrated sensor-augmented pump therapy systems for managing blood glucose levels in type 1 diabetes[54]) and MIB51 (*MiniMed 640G system*[65]) have recommended continuous glucose monitoring to support insulin therapy by injections or pump if patients fulfill certain criteria.

Consider real-time continuous glucose monitoring for adults with type 1 diabetes who are willing to commit to using it at least 70 per cent of the time and to calibrate it as needed, and who have any of the following despite optimised use of insulin therapy and conventional blood glucose monitoring:

- More than one episode per year of severe hypoglycaemia with no obviously preventable, precipitating cause
- Complete loss of awareness of hypoglycaemia
- Frequent (more than two episodes per week) asymptomatic hypoglycaemia that is causing problems with daily activities
- Extreme fear of hypoglycaemia
- Hyperglycaemia (HbA1c level of 75 mmol/mol [9%] or higher) that persists despite checking blood glucose at least 10 times a day (see recommendations 1.6.11 and 1.6.12)
- Continue real-time continuous glucose monitoring only if HbA1c can be sustained at or below 53 mmol/mol (7%) and/or there has been a fall in HbA1c of 27 mmol/mol (2.5%) or more

Funding for CGM for adult patients aged 19 or above fulfilling the above criteria should be arranged with the patient's local CCG. It is preferable that this is arranged as a cohort business case negotiated with the local CCG, if more than two or three new applications a year are expected.

Similar to CSII above, the patients should be assessed at six and 12 months to confirm ongoing suitability for CGM, and these data relayed to the funding body. Thereafter, clinical teams should continue to assess this on an individual basis, at least annually, and relay this information to the CCG on a 2-yearly basis.

Recommendations for the commissioning process

At present throughout London there is no single agreed funding process for patients being considered for CSII. Many insulin pump services report that they are required to obtain individual funding authorisation for each patient. Some areas are also subject to arbitrary quotas on the number of pump starts which will be approved per year.

The London Diabetes Clinical Leadership Group (CLG) recommends that commissioners:

- Ensure sufficient suitable structured education (eg DAFNE) is available and delivered in collaboration with the specialist services for the type 1 population.
- Should not require individual patient authorisation before pump therapy can be commenced, unless the treatment is being requested for a patient who does not meet the NICE criteria or involves continuous glucose monitoring or a patch pump. Such requirements for NICE approved technology place an unnecessary administrative burden on insulin pump services and CCGs which can delay access to pump treatment.
- Ensure that patients are offered CSII when this is assessed by the MDT as clinically appropriate. Quotas of maximum number of pump starts per year are clinically inappropriate and are not recommended.
- Ensure pump therapy is available locally across London, delivered as part of a comprehensive service for patients with type 1 diabetes. Patients should be able to access specialists and the MDT as part of the service. Patients should have choice as to which service to access and funding should reflect this.

Expectations of type 1 pump services

Whilst it is recommended that commissioners should not require individual funding application for each patient considered suitable for CSII, commissioners need to be confident that services are delivering this treatment appropriately.

The London Diabetes CLG recommends that clinical services ensure that:

- Patients have received appropriate education in diabetes self-management before CSII is recommended. For the majority of patients this will be in the form of a structured education programmed (eg DAFNE). Patients unable or not willing to participate in group education should receive equivalent individual education.
- All patients have their psychological and emotional needs considered and addressed as these can be a barrier to enabling patients to optimise their self-management.
- Patients transitioning from paediatric to adult services may not have attended DAFNE and therefore should be offered appropriate structured education.
- At pump initiation, a common form should be used across London specifying indications for CSII (main and secondary indications) and propose targets for one and four years post initiation. It is not expected that this should be submitted to CCGs at pump start, but should be used as part of the overall process of quality assurance.
- Yearly clinical reviews are held against targets specified above. Where improvement is not as expected this will enable a specific plan to be agreed between the patient and clinical team.

Artificial pancreas

A further significant step in this process is the development of the *artificial pancreas*, a closed-loop system that controls insulin delivery based on the glucose level, using sophisticated algorithms. Clinical trials of such systems are now at an advanced stage and have been shown to reduce the time spent in both hyper- and hypoglycaemia. Such systems will become more widely available over the next few years and will represent a step stage in treatment of type 1 diabetes. It is important that commissioners are aware of such developments to enable future service planning[66].

Pump and meter download tools

Periodic downloading of pump and glucometer data provides valuable insights to clinicians and patients. However, it should be noted that while downloading of data may be useful for review by clinicians, the current financial investment presents a barrier for its use by clinicians and patients (precluding uptake).
Examples: Diasend, Medtronic Carelink

Case study: *Diabeter clinic*

One of the pioneer centres in the world in using technology to innovate and optimise care for type 1 diabetes is the Diabeter clinic in Rotterdam, set up by two pediatricians, and recently purchased by Medtronic. This unit has one of the lowest mean HbA1c levels in the Netherlands, with less than half the proportion of patients with HbA1c over 9 per cent. Additionally, it has half the admissions for DKA and severe hypoglycemia than the national average, achieved with double the patient to healthcare professional (HCP) ratio.

Key principles that contribute to these outstanding results are:

- The environment of the clinic is friendly and office like, rather than hospital like
- Regular upload of glucose data from patients at home, to monitor and track patients who may not be at target
- Frequent contact through email / Skype or other technologies to provide support to patients.

Activity tracking

Activity tracking is available by default in most mobile devices and systems, such as Apple Health and Google Fit. These platforms enable sharing of fitness and activity data between different products. However, although the capability to overlay diabetes and activity data is not yet commonplace, they provide benefit to both patients and clinicians by helping to refine diabetes management strategies during exercise.
Examples: iOS and Android devices, Fitbit, Jawbone UP, Strava, Runkeeper

Integration with primary care

Being able to order prescriptions, book GP appointments and retrieve test results electronically via mobile devices all help to reduce the overhead in managing type 1 diabetes. All GPs should offer their patients online access to summary information of their GP records.
Examples: EMIS Patient Access, mumoActive (expected 2016)

Care planning tools

Providing a structure for care planning helps deliver points two (Engaged, informed individuals and carers) and four (Health and care professionals working in partnership) of the House of Care model[53]. By providing a more holistic picture of the patient's health (including GOLD hypoglycaemia and DDS2 diabetes distress scores), issues which may be preventing optimal glycaemic control can be identified and addressed.
Examples: mumoActive, in collaboration with Health Innovation Network (expected 2016)

Education

Educational material, presented at the most appropriate time to the patient and made accessible through mobile devices may supplement in-person training.
Examples: PocketMedic by eHealthDigital, BERTIE type 1 diabetes education programme

Carbohydrate counting applications

Mobile applications to help count carbohydrates offer greater convenience to the patient than paper-based solutions. Some allow barcodes on food packaging to be scanned with the mobile device and carbohydrate content to be automatically looked up. Applications which also provide crowdsourced content tend to cover a greater range of foods.
Examples: Carbs & Cals, MyFitnessPal

Patient access to EHR data

My Diabetes My Way is the NHS Scotland interactive diabetes website to help support people who have diabetes and their family and friends. It has leaflets, videos, educational tools and games containing information about diabetes. Patients can now also use this website to view their own up-to-date diabetes clinic results, to help manage their condition more effectively.

The Patients Know Best (PKB) patient portal is the most integrated patient portal and health information exchange. PKB is live in more than 200 sites across eight countries and 17 languages. PKB is designed to empower patients to manage their care, whilst enabling clinicians to share information and engage with patients in new and powerful ways.

mumoActive is building next generation diabetes management tools for tracking and real-time sharing of key diabetes information. It is making diabetes management more like text messaging and less like a visit to the doctor. mumoActive aims to change what it feels like for patients to manage their diabetes by building the best tools available.

Case study: *DAWN*

A pilot scheme in Newham, which uses Skype appointments and was originally started to help young people keep on top of their diabetes care, has been rolled out to all patients as part of a successful four year trial[67].

Since its launch in 2011, the Diabetes Appointments via Webcam in Newham (DAWN) scheme, web-based follow up is used routinely for young people aged 16 to 25. DAWN has carried out 480 webcam appointments, reducing *did not attends* (DNAs) from 30 to 50 per cent to just 16 per cent. The service is thought to increase productivity and patient throughput by 22 to 28 per cent, saving approximately £27 per consultant appointment in clinician time.

Recommendation 10 | Technology

Patients who require it should have:

- Access to a variety of CBG meters, including those with built-in bolus calculators
- Access to adequate CBG strips (10 per day or more if needed where cost effective) to support them to achieve NICE recommended HbA1c targets.
- Access to insulin pumps as per NICE TA151 in patients who have disabling hypoglyacemia or HbA1c above 8.5 per cent, despite structured education
- Access to a choice of insulin pumps as per individual needs

A policy should be in place for access to emerging technologies, such as continuous glucose monitoring, which may be valuable in individual settings.

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

REFERENCES

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

2. NICE, NG3 *Diabetes in pregnancy: management from preconception to the postnatal perio*d (2015)
www.nice.org.uk/guidance/ng3

3. King's Health Partners, *Learning hub* website, "Depression in Diabetes"
http://learninghub.kingshealthpartners.org/course/depression-diabetes

4. Veena Mazarello Paes, et al, *Protocol for systematic review of evidence on the determinants and influence of early glycaemic control in childhood-onset type 1 diabetes,* Pediatr Diabetes. (2014) Aug;15(5):372-83; Edge et al; Diabetic medicine 2010 Nov;27(11):1284-8

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

6. Kruger J, Brennan A, Thokala P, Basarir H, Jacques R, Elliott J, Heller S, Speight J. *The cost effectiveness of the Dose Adjustment for Normal Eating (DAFNE) structured education programme: an update using the Sheffield Type 1 Diabetes Policy Model*. Diabet Med. 2013;30:1236-44.

7. Speight J, Amiel SA, Bradley C, Heller S, Oliver L, Roberts S, Rogers H, Taylor C, Thompson G. *Long-term biomedical and psychosocial outcomes following DAFNE (Dose Adjustment For Normal Eating) structured education to promote intensive insulin therapy in adults with sub-optimally controlled type 1 diabetes*. Diabetes Res Clin Pract. 2010;89:22-9.

8. Hopkins D, Lawrence I, Mansell P, Thompson G, Amiel S, Campbell M, Heller S. *Improved biomedical and psychological outcomes 1 year after structured education in flexible insulin therapy for people with type 1 diabetes: the U.K. DAFNE experience*. Diabetes Care. 2012;35:1638-42.

9. NICE, *Quality and productivity cost savings tool* webpage
www.nice.org.uk/about/what-we-do/into-practice/local-practice-case-studies/quality-and-productivity-cost-savings-tool

10. Diabetes Spectrum June 20, 2009

11. Diabetes UK, *#Type1uncut* webpage
www.diabetes.org.uk/Guide-to-diabetes/Type-1-Uncut-for-young-adults/

12. GOLD - Gold AE, MacLeod KM, Frier BM. Frequency of severe hypoglycemia in patients with type 1 diabetes with impaired awareness of hypoglycemia. Diabetes Care 1994;17(4):697-703.

13. Gov.uk, *Diabetes and driving* webpage (www.gov.uk/diabetes-driving) with links to DVLA, *When to inform the DVLA about your diabetes* video (https://youtu.be/Is96Cwpxtpk)

14. Brian M. Frier MD, FRCP(Edin), FRCP(Glas), Simon R. Heller DM, FRCP and Rory J. McCrimmon MD, FRCP(Edin) *Living with hypoglycaemia*, (2013)
http://dx.doi.org/10.1002/9781118695432.ch18

REFERENCES

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

16. Choudhary P et al; *CSII and CGM,* Horm Metab Res. 2015 Jan;47(1):9-15.

17. Yeoh E, Choudhary P, Nwokolo M, Ayis S, Amiel SA. *Interventions that restore awareness of hypoglycemia in adults with type 1 diabetes: A systematic review and meta-analysis,* Diabetes Care. (2015) Aug;38(8):1592-609.

18. Choudhary P, Rickels MR, Senior PA, Vantyghem MC, Maffi P, Kay TW, Keymeulen B, Inagaki N, Saudek F, Lehmann R, Hering BJ. *Evidence-informed clinical practice recommendations for treatment of type 1 diabetes complicated by problematic hypoglycemia*. Diabetes Care. 2015 Jun;38(6):1016-29.

19. Sturt J, Dennick K, Hessler D, Hunter BM, Oliver J, Fisher L. E*ffective interventions for reducing diabetes distress: systematic review and meta-analysis*. International Diabetes Nursing. 2015b Aug 1;12(2):40-55.

20. Sturt J, Dennick K, Due-Christensen M, McCarthy K. *The detection and management of diabetes distress in people with type 1 diabetes*. Current diabetes reports. 2015c Nov 1;15(11):1-4.

21. Schmitt A, Reimer A, Kulzer B, Haak T, Ehrmann D, Hermanns N. *How to assess diabetes distress: comparison of the Problem Areas in Diabetes Scale (PAID) and the Diabetes Distress Scale (DDS)*. Diabetic Medicine. 2015 Sep 1.

22. Sturt J, McCarthy K, Dennick K, Narasimha M, Sankar S, Kumar S. *What characterises diabetes distress and its resolution? A documentary analysis*. International Diabetes Nursing. 2015a Aug 1;12(2):56-62.

23. Brain (2015) 138 (1): 2-3 *Treatment-induced neuropathy of diabetes: an energy crisis?* (2015)

24. Polonsky, W.H., Fisher, L., Earles, J., Dudl, R.J., Lees, J., Mullan, J. and Jackson, R.A., 2005. *Assessing psychosocial distress in diabetes development of the diabetes distress scal*e. Diabetes care, 28(3), pp.626-631.

25. Welch, G.W., Jacobson, A.M. and Polonsky, W.H., 1997. *The Problem Areas in Diabetes Scale: an evaluation of its clinical utility*. Diabetes care, 20(5), pp.760-766.

26. Fisher L, Glasgow RE, Mullan JT, Skaff MM, Polonsky WH. *Development of a brief diabetes distress screening instrument*. The Annals of Family Medicine. 2008 May 1;6(3):246-52.

27. Sturt, J., Dennick, K., Hessler, D., Hunter, B.M., Oliver, J. and Fisher, L., 2015. *Effective interventions for reducing diabetes distress: systematic review and meta-analysi*s. International Diabetes Nursing, 12(2), pp.40-55.

28. Sturt J, McCarthy K, Dennick K, Narasimha M, Sankar S, Kumar S. *What characterises diabetes distress and its resolution? A documentary analysis*. International Diabetes Nursing. 2015a Aug 1;12(2):56-62.

29. d’Emden H, et al *Choosing a screening tool to assess disordered eating in adolescents with type 1 diabetes mellitus*. - PubMed - NCBI. J Diabetes Complications. 2015 Jan-Feb.

References

30. *Symptoms of eating disorders and depression in emerging adults with early-onset, long-duration type 1 diabetes and their association with metabolic control*
www.ncbi.nlm.nih.gov/m/pubmed/26121155/

31. London Clinical Networks *Sugar and spice: Type 1 diabetes and eating disorders (event summary)*
www.londonscn.nhs.uk/publication/sugar-and-spice-type-1-diabetes-and-eating-disorders-event-summary/

32. Gov.uk, *Diabetic eye screening: programme overview* webpage (2014)
www.gov.uk/guidance/diabetic-eye-screening-programme-overview

33. NICE, *QOF indicator development programme consultation report*
https://www.nice.org.uk/Media/Default/standards-and-indicators/qof%20indicator%20key%20documents/NM74DiabetesConsultationReport.pdf

34. Lindenmeyer A, Sturt JA, Hipwell A, Stratton IM, Al-Athamneh N, Gadsby R, O'Hare JP, Scanlon PH. *Influence of primary care practices on patients' uptake of diabetic retinopathy screening: a qualitative case study*. Br J Gen Pract. 2014 Aug 1;64(625):e484-92.

35. National Eye Institute (NEI), *Facts about diabetic eye disease* webpage
https://nei.nih.gov/health/diabetic/retinopathy

36. Ronald Klein, MD; Barbara E. K. Klein, MD; Scot E. Moss, MA; Matthew D. Davis, MD; David L. DeMets, PhD Arch Ophthalmol. *The Wisconsin epidemiologic study of diabetic retinopathy* 1984;102(4):520-526
http://archopht.jamanetwork.com/article.aspx?articleid=635006

37 Estimated life expectancy in a Scottish cohort with type 1 diabetes.
http://jama.jamanetwork.com/article.aspx?articleid=2088852

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

39. The Health and Social Care Information Centre. (2013) *National Diabetes Audit 2011–2012 Report 1: care processes and treatment targets*.
`
https://catalogue.ic.nhs.uk/publications/clinical/diabetes/nati-diab-audi-11-12/ nati-diab-audi-11-12-care-proc-rep.pdf

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

41. CEMACH / HSC Public Health Agency, Diabetes in pregnancy: Are we providing the best care? (2007)
http://www.publichealth.hscni.net/publications/diabetes-pregnancy-are-we-providing-best-care

42. NHS Digital, *National Pregnancy in Diabetes Audit Report – 2014* (2015)
www.hscic.gov.uk/catalogue/PUB19042

43. MBRRACE-UK, P*erinatal mortality surveillance report for 2014 births*, (2016)
www.npeu.ox.ac.uk/mbrrace-uk/reports

REFERENCES

44. NHS England, *Maternity review documents* (2016)
www.england.nhs.uk/tag/maternity-review/

45. Best and Chakravarthy, *Diabetic retinopathy in pregnancy* BJO 1997;81:249-251)
http://bjo.bmj.com/content/81/3/249.full

46. NICE, *Diabetes in pregnancy: management from preconception to the postnatal period*
www.nice.org.uk/guidance/ng3/chapter/Key-priorities-for-implementation

47. *Diabetic retinopathy* website, edited by David Kinshuck, Heart of England NHS Foundation Trust.
www.diabeticretinopathy.org.uk/

48. Hercules BL, Wozencroft M, Gayed II et al *Peripheral retinal ablation in the treatment of proliferative diabetic retinopathy during pregnancy* (1980) BJO: 64:87-93.

49. NICE, D*iabetes in pregnancy: management from preconception to the postnatal period* (2015)
www.nice.org.uk/guidance/ng3/chapter/Key-priorities-for-implementation

50. Diabetes UK, *Transition to adult clinics* webpage
www.diabetes.org.uk/Guide-to-diabetes/Teens/Me-and-my-diabetes/Transition-to-adult-clinics/

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

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

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

54. 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

55. 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

56. 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

57. 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

58. 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

REFERENCES

59. 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

60. 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

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

62. 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

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

64. 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

65. 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

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

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

68. NICE, NG18 *Diabetes (type 1 and type 2) in children and young people: diagnosis and management* (2015)
https://www.nice.org.uk/guidance/ng18?unlid=93837120920162252941

69. Elliott J, Jacques RM, Kruger J, et al. *Educational and psychological issues Substantial reductions in the number of diabetic ketoacidosis and severe hypoglycaemia episodes requiring emergency treatment lead to reduced costs after structured education in adults with type 1 diabetes*. Diabetic Medicine. 2014;31(7):847-853. doi:10.1111/dme.12441.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4264891/

70. Bolinder J, Antuna R, Geelhoed-Duijvestijn P, Kröger J, Weitgasser R, *Novel glucose-sensing technology and hypoglycaemia in type 1 diabetes: a multicentre, non-masked, randomised controlled trial* Lacnet (2016)
http://www.sciencedirect.com/science/article/pii/S0140673616315355

Part 3 | *Implementation guide*

London Clinical Networks

Ensuring excellence in type 1 diabetes provision and commissioning

TABLE OF CONTENTS

Nine commissioning recommendations

People with diabetes require nine regular checks to ensure their continued good health. 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) or value based commissioning (VBC).

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).

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 partners.

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. Progress reports should be published locally for sharing with service users.

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 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 (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 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.

Consideration should be give to the 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 conditions set out in 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 plus access to all other specialities (*see note at 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.

Recommendation 1 | Type 1 service

- All people with type 1 diabetes should have a patient-focused care plan. This should be shared with the patient and all staff caring for them.
- Services for adults with type 1 diabetes should have sufficient capacity to enable early frequent review of the newly diagnosed person with diabetes. Initial individual education by one or more appropriately trained members of the diabetes MDT should be provided in the following areas, taking account of the individual's home and work environment:
  - *What is diabetes?*
  - *Education on insulin regimen and injections*
  - *Self-monitoring and appropriate blood glucose targets*
  - *Recognition and management of hypoglycaemia*
  - *Initial dietary advice, introduction of carbohydrate counting*
  - *Pre-conception planning*
  - *Everyday challenges (eg exercise)*
  - *Information about driving regulations*
  - *Complications of diabetes (and avoidance) and the importance of regular screening.*

Recommendation 2 | Structured education / self management programme

- All staff caring for patients with type 1 diabetes should be trained in DAFNE (or a NICE compliant alternative).
- All adults with type 1 diabetes should be offered a diabetes structured education programme.
- 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 people newly diagnosed with type 1 diabetes within one year of diagnosis.
  2. 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.

Across London we will need to understand the demand for education based on local populations with type 1 diabetes and develop strategies, which may include co-commissioning or using hub and spoke models to deliver capacity for structured education.

Recommendation 3 | Carbohydrate counting

- All patients with a new diagnosis of type 1 diabetes should be taught carbohydrate counting and how to adjust their insulin dose. The teaching of formal CHO counting can be daunting for some at the very beginning of their diagnosis and may not be appropriate during the honeymoon phase. Therefore, the aim will be to initiate CHO counting within the first year where possible / when practical.
- All patients with a new diagnosis of type 1 diabetes should be encouraged to complete a structured education course within a year of diagnosis. Each CCG / specialist service should develop a clear strategy around how basic carbohydrate counting and structured education will be delivered to those patients who are already living with diabetes. (Note: DAFNE research clearly demonstrates that there is no difference in benefit from DAFNE based on duration of diabetes.)
- Planning for capacity should include networking with other centres to provide a single point of access for type 1 diabetes structured education across sectors.
- Patients who decline structured education should continue to be offered it, and all professionals should understand that this is the cornerstone of type 1 diabetes care. To increase uptake, providers and commissioners should collaborate to make structured education accessible to all patients. For example, DAFNE can be delivered over five consecutive days or one day for five weeks; not all providers offer both options. By enabling access to alternative delivery at other CCGs we would anticipate that more patients would access structured education.
- Structured education training should be considered mandatory training for those with type 1 diabetes.

Recommendation 4 | Hospital insulin self management for adult inpatients with diabetes

- It is important that there are protocols in place that enable individuals with type 1 diabetes who are willing and able to self-manage their insulin either via injections or insulin pump, which also include information explaining when it is important for the healthcare professionals to temporarily take over.
- For an individual on an insulin pump, it may mean that they will temporarily be commenced on intermittent subcutaneous insulin injections, and sick patients may need their usual insulin regime to be replaced with monitored intravenous insulin infusion.

Recommendation 5 | Prevention of hypoglycaemia

- Services for people with type 1 diabetes should implement a screening strategy to identify those at high risk of problematic hypoglycaemia. The record should note: Hypoglycaemia frequency and severity, and awareness of symptoms using the *GOLD score.
- All episodes of severe hypoglycaemia requiring third party assistance, the frequency of glucose levels under 3.5mmol/l and awareness of hypoglycaemia using GOLD score, should be recorded in the patient's shared record.
- Services for type 1 diabetes should have a pathway in place for patients identified as being at high risk of problematic hypoglycaemia (eg those with a GOLD score greater than 4 and/or severe hypoglycaemia in the preceding 12 months, the lower limit of the recommended glucose target for people with type 1 diabetes).
- Services for people with type 1 diabetes should create links with local ambulance providers, to enable referral of all patients with severe hypoglycaemia to the diabetes MDT.
- Links for psychology and specialist MDT support for all people with type 1 diabetes and recurrent hypoglycaemia should also be shared across all healthcare provider organisations.

Recommendation 6 | Diabetes psychology pathway

- All type 1 diabetes services should have access to diabetes trained consultant clinical and health psychologists with a robust referral process to consultant psychiatrists within their structure. We recommend a tiered approach.
- The clinical psychologist, as part of the MDT, is crucial to ensuring that the whole team is trained in motivational interviewing and is aware of the needs of any vulnerable patients with the complex picture of type 1 diabetes and an eating disorder, to allow early identification.

Recommendation 7 | Eye screening

It is imperative that all diabetes staff:

- Remain engaged with their local DESP service to ensure that patients don't fall through the net due to multiple non attendances.
- Ensure that patients are not incorrectly coded or excluded from eye screening.
- Educate patients about the importance of eye screening as patients can develop advanced levels of retinopathy and still remain asymptomatic. This can then increase the risk of subsequent blindness if untreated.

Recommendation 8 | Type 1 services for women of childbearing age

The NICE guideline recommends that women with diabetes who are planning to become pregnant:

- Take 5mg/day folic acid prior to becoming pregnant and until 12 weeks of gestation to reduce the risk of having a baby with a neural tube defect.
- Aim to maintain HbA1c below 48 mmol /mol (6.5%), without causing problematic hypoglycaemia.
- Reassure women that any reduction in HbA1c level towards the target of 48 mmol/mol (6.5%) is likely to reduce the risk of congenital malformations in the baby.
- Strongly advise women with diabetes whose HbA1c level is above 86 mmol/mol (10%) not to get pregnant because of the associated risks.
- In accordance with NICE recommendations, diabetic eye screening should be offered to pregnant mothers (with pre-existing diabetes) at the first antenatal appointment and then again at 28 weeks gestation.

A large UK-based study showed that an intensive pre-conception pathway for women with type 1 diabetes involving visits to a multidisciplinary clinic 1-3 times monthly reduced SAE from 10.2 to 2.9 per cent.

Additionally:

- Introduce a discussion about pre-conception in the annual diabetes care plan for all women of child bearing age with known pre-existing diabetes.
- All women to consider contraception if not actively trying for pregnancy.
- Refer all women considering pregnancy to the multidisciplinary pre-conception clinic if Hba1c level is equal or higher than 48 mmol/mol (>6.5%).
- Women will be seen in a multidisciplinary secondary care clinic for a new consultation and then seen 2-4 times monthly for follow up visits until they have achieved adequate glycaemic control. Some women will need more frequent clinic/telephone/email appointments.
- If women are not pregnant after 12 months, then consider referral for fertility services.

Recommendation 9 | Transition to adult diabetes services

- A transition clinic should be commissioned with clinic appointments long enough for the person with diabetes to build up a relationship with the new team as they move from the familiar paediatric clinic to adult services. This should harness new technologies.

Recommendation 10 | Technology

Patients who require it should have:

- Access to a variety of CBG meters, including those with built-in bolus calculators.
- Access to adequate CBG strips (10 per day or more if needed where cost effective) to support them to achieve NICE recommended HbA1c targets.
- Access to insulin pumps as set out in TA151 in patients who have disabling hypoglycaemia or HbA1c above 8.5 per cent, despite structured education.
- Access to a choice of insulin pumps as that meet individual needs.

A policy should be in place for access to emerging technologies, such as continuous glucose monitoring, which may be valuable in individual settings.

NATIONAL DIABETES AUDIT RESULTS

The results from by the National Diabetes Audit (NDA) demonstrate that type 1 diabetes requires a particular emphasis if we are to increase numbers of those receiving all NICE recommended care processes. These processes, and diabetic retinopathy screening, are foundational to type 1 diabetes care. In recent years (2013/14 and 2014/15), the NDA showed that people with type 1 diabetes were less likely than those with type 2 to have their eight care processes recorded, reiterating the need to focus on increasing completion rates for all care processes.

People with type 1 diabetes are less likely than people with type 2 diabetes to receive all of the eight care processes.

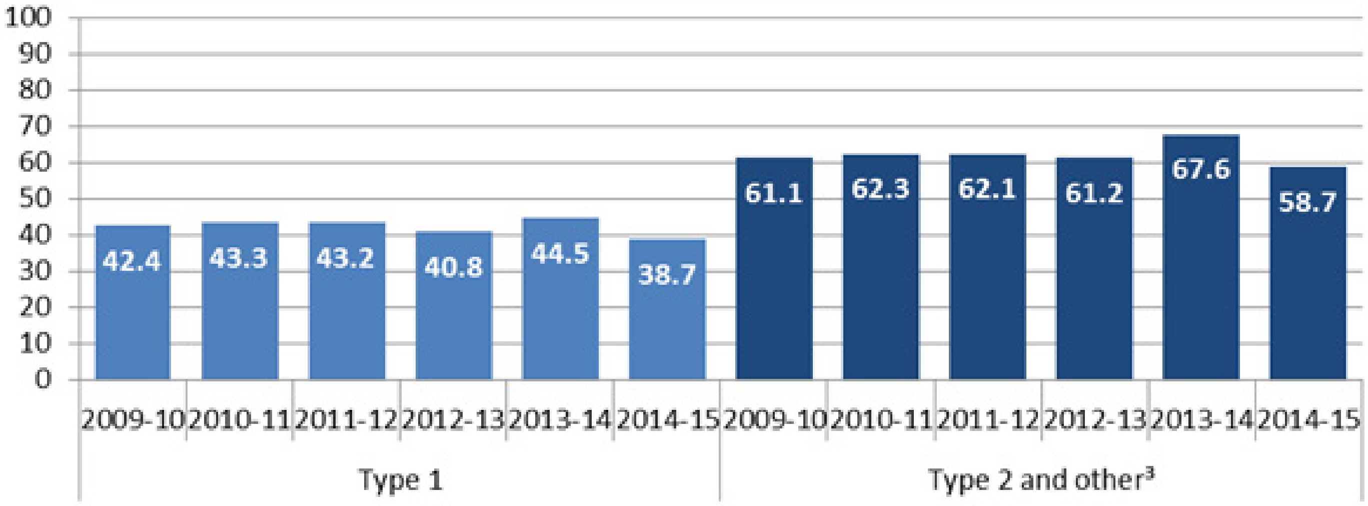


Table 1: Percentage of people with diabetes in England and Wales receiving all eight NICE recommended care processes by diabetes type and audit year

Blood tests (HbA1c, serum creatinine, cholesterol) and blood pressure are more reliably performed than other care processes.

	Type 1					
	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15
HbA1c	85.7	86.0	83.0	79.8	80.9	83.2
Blood pressure	88.9	88.7	88.4	87.7	87.0	89.0
Cholesterol	79.1	78.8	77.8	77.3	77.4	78.7
Serum creatinine	81.0	81.2	81.1	80.3	78.8	80.5
Urine albumin*	56.2	58.4	59.2	56.5	63.9	55.9
Foot surveillance	71.7	71.5	72.8	71.5	70.7	72.4
BMI	83.6	83.4	83.7	83.3	76.8	74.9
Smoking	80.8	78.6	79.0	79.2	77.4	77.9
Eight care processes 4	42.4	43.3	43.2	40.8	44.5	38.7

Table 2: Percentage of people with type 1 diabetes in England and Wales receiving NICE recommended care processes by care process and audit year

Care process completion for blood pressure and HbA1c are stable. BMI measurement was stable but has declined. Urine albumin declined between 2013/14 and 2014/15.

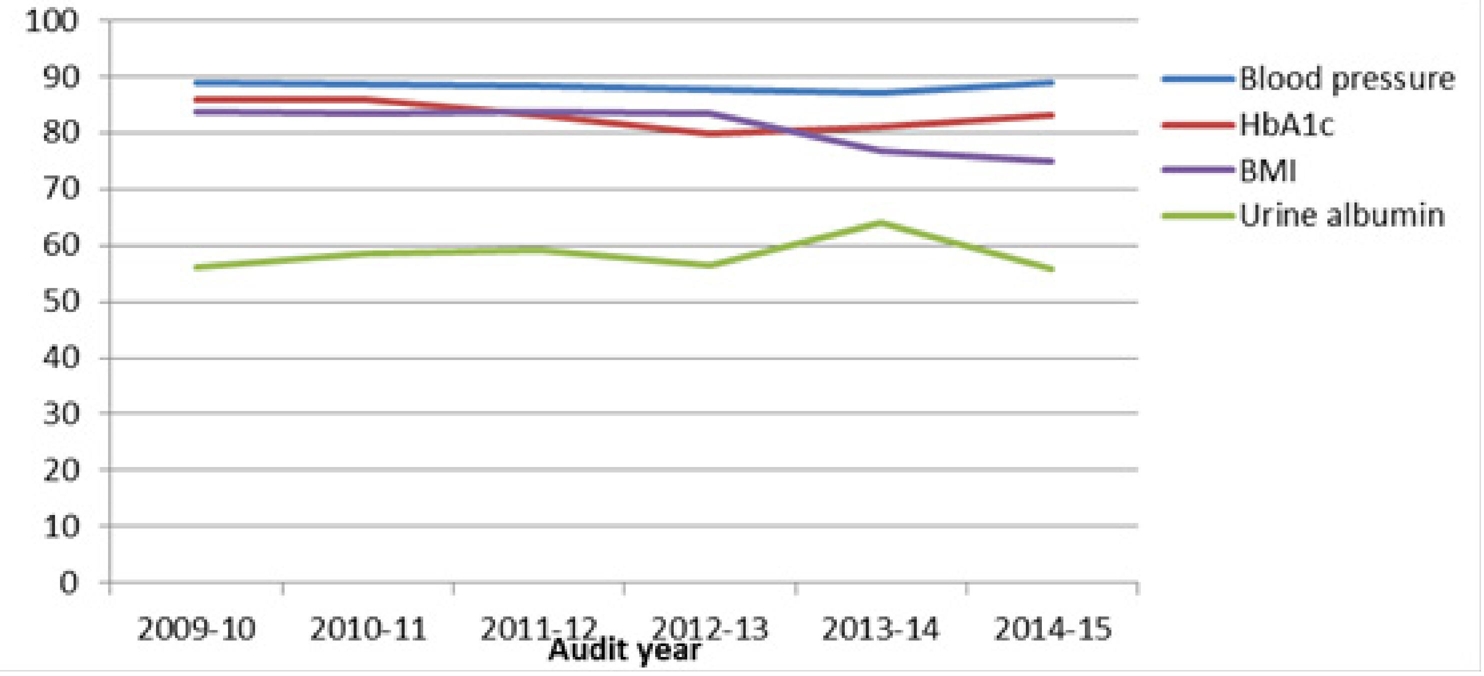


Table 3: Percentage of people with type 1 diabetes in England and Wales receiving certain care processes by audit year Note: There was a 2013/14 'health warning' regarding the screening test for early kidney disease (urine albumin creatinine ratio, UACR).

For people with type 1 diabetes there is a large variation in care process completion performance between CCGs or local health boards (LHBs).

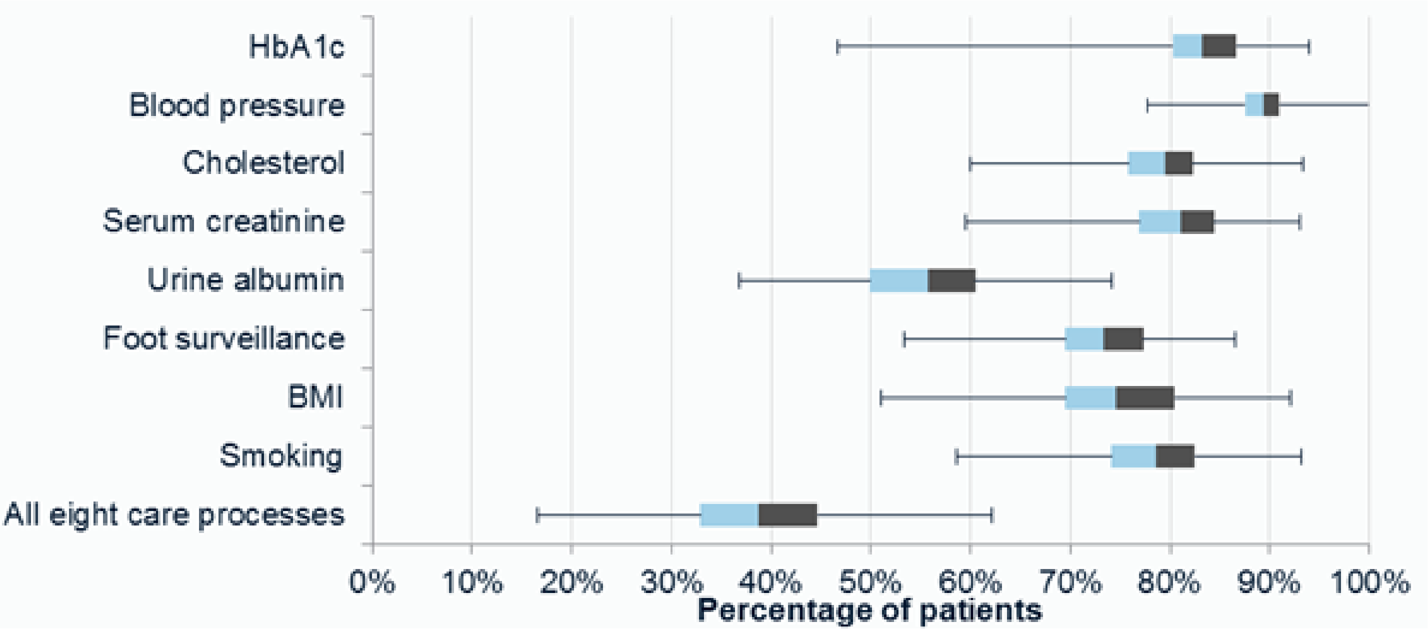
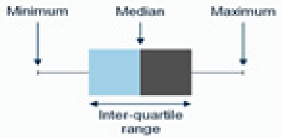


Table 4: The range of CCG/LHB care process completion for people with type 1 diabetes in England and Wales, 2014/15



People with type 1 and type 2 diabetes aged under 40 are less likely to receive all their annual care processes.

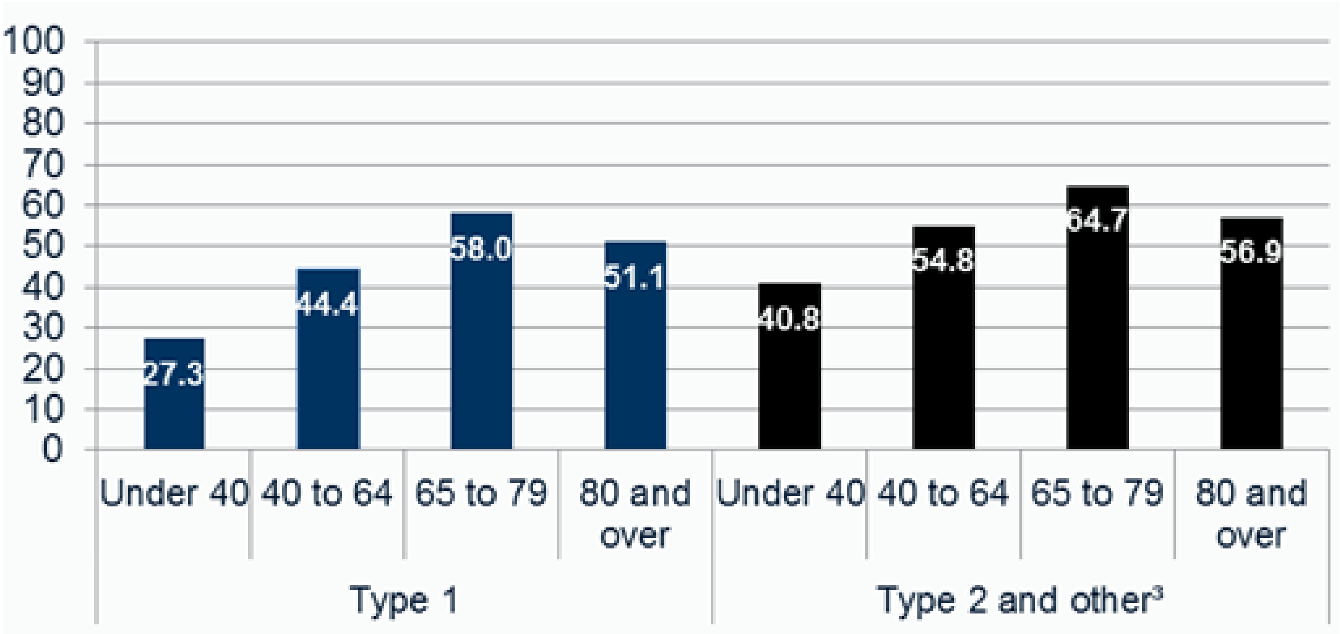


Table 5: Percentage of all people with diabetes in England and Wales receiving all eight NICE recommended care processes4 by age and diabetes type, in 2014/15

Insulin pump coverage varies greatly in London.
More collaborative working is required to ensure that patients in core type 1 diabetes services have the same opportunities as those in an enhanced service.

Image source: Medtronic

Self assessment | For commissioners of type 1 diabetes services in London

No.	Objective	RAG		
1	Establish prevalence and incidence of type 1 diabetes population	🟥	🟨	🟩
2	Look at commissioning for value for type 1 diabetes, using innovative commissioning models such as capitated outcomes-based incentivised commissioning (COBIC) / value based commissioning (VBC)	🟥	🟨	🟩
3	Commissioners to identify a core team (Commission Lead for type 1 diabetes, a Strategic Clinical Lead, and System Leader for type 1 diabetes) with dedicated time to redesign type 1 diabetes services; reporting to type 1 diabetes group	🟥	🟨	🟩
4	Report quarterly on type 1 NICE diabetes care processes	🟥	🟨	🟩
5	Commission all type1 diabetes services to be redesigned to collect all NICE diabetes care processes, acted upon, and develop strong engagement with primary care with a shared record. Links to diabetes eye screening visit, to reduce patient appointments and cost. A transition clinic should be commissioned with clinic appointments long enough for the person with diabetes to build up a relationship with the new team as they move from the familiar paediatric clinic to adult services. This should harness new technologies.	🟥	🟨	🟩
6	Commission that all people with type 1 diabetes who meet the criteria, are offered continuous subcutaneous insulin infusion (CSII) with support from a trained specialist team	🟥	🟨	🟩
7	Structured education is mandatory training for those with type 1 diabetes. Commissioners should ensure that all people with type 1 diabetes are offered structured education (eg DAFNE). Across London this may include co-commissioning or using hub and spoke models to deliver capacity for structured education for type 1. Prioritise as follows: 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	Commission services to ensure that all people with type 1 diabetes have access to technology: » Access to a variety of CBG meters, including those with built in bolus calculators » Access to adequate CBG strips (up to 10/day or more) to support them to achieve NICE recommended HBA1c targets is cost effective » Access to insulin pumps as per TA151 in patients who have problematic hypoglycaemia or HbA1c > 8.5% despite structured education » Access to a choice of insulin pumps as per individual needs » A policy for access to emerging technology such as continuous glucose monitoring that may be valuable in individual settings	🟥	🟨	🟩
9	Identify if you have commissioned a ***core*** or ***enhanced*** type 1 service | 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.	🟥	🟨	🟩

SELF ASSESSMENT | FOR PROVIDERS OF TYPE 1 DIABETES SERVICES IN LONDON

No.	Objective	RAG		
1	1a) All people with type 1 diabetes should have a patient-focused care plan, shared with them and all staff caring for them.	🟥	🟨	🟩
	1b) Early frequent review of the newly diagnosed person with diabetes.	🟥	🟨	🟩
2	2a) All staff who care for patients with type 1 diabetes should be trained in DAFNE or NICE compliant alternative.	🟥	🟨	🟩
	2b) All adults with type 1 diabetes be offered a diabetes structured education programme.	🟥	🟨	🟩
	2c) Deliver structured education to ALL patients with type 1 diabetes over four priority stages as commissioned.	🟥	🟨	🟩
3	3a) Structured education is mandatory training for those with type 1 diabetes. All patients with a new diagnosis of type 1 diabetes should be taught an awareness of carbohydrate counting and the ability to adjust doses of insulin.	🟥	🟨	🟩
	3b) Develop a clear strategy around how basic carbohydrate counting and structured education will be delivered to those patients who already are living with diabetes.	🟥	🟨	🟩
	3c) Network with other centres to provide a single point of access for type 1 diabetes structured education across your CCG/ sector.	🟥	🟨	🟩
	3d) Collate a database of those who decline structured education; and continually offer it, as cornerstone of Type 1 diabetes care.	🟥	🟨	🟩
4	Hospital protocols in place that enable individuals with type 1 diabetes who are willing and able to self-manage their insulin either via injections or insulin pump, which also include information explaining when it is important for the healthcare professionals to temporarily take over.	🟥	🟨	🟩
5	5a) Implement a screening strategy to identify those at high risk of problematic hypoglycaemia. This to record hypoglycaemia frequency and severity, and awareness of symptoms, using the *GOLD score.	🟥	🟨	🟩
	5b) All episodes of severe hypoglycaemia requiring third party assistance, the frequency of glucose levels < 3.5 mmol/l and awareness of hypoglycaemia using GOLD score, should be recorded in the patients shared record.	🟥	🟨	🟩
	5c) Services for type 1 diabetes should have a pathway in place for patients identified as being at high risk of problematic hypoglycaemia (ie those with a GOLD score >4 +/- severe hypoglycaemia in the preceding 12 months [the lower limit of the recommended glucose target for people with type 1 diabetes]).	🟥	🟨	🟩
	5d) Services for people with type 1 diabetes should create links with local ambulance providers, to enable referral of all patients with severe hypoglycaemia to the diabetes MDT.	🟥	🟨	🟩
	5e) Develop integrated service (psychology and specialist MDT support) for all people with type 1 diabetes and recurrent hypoglycaemia.	🟥	🟨	🟩

No.	Objective	RAG		
6	6a) Implement a tiered approach to psychological services: MDT with diabetes trained consultant clinical and health psychologists with a robust referral process to consultant psychiatrists within their structure.	🟥	🟨	🟩
	6b) Using this approach ensure the whole team are trained in motivational interviewing and are aware of the needs of these vulnerable patients with the complex picture of type 1 diabetes and an eating disorder, to allow earlier identification.	🟥	🟨	🟩
7	7a) Remain engaged with your local DESP service to ensure that patients don't fall through the net due to multiple non attendances.	🟥	🟨	🟩
	7b) Ensure that patients are not incorrectly coded or excluded from eye screening.	🟥	🟨	🟩
	7c) Educate patients as to the importance of eye screening as patients can develop advanced levels of retinopathy and still remain asymptomatic. This can then increase the risk of subsequent blindness if untreated.	🟥	🟨	🟩
8	8a) Implement preconception service and encourage attendance – report on this quarterly.	🟥	🟨	🟩
	8b) Implement diabetes and pregnancy clinic as per this specification.	🟥	🟨	🟩
9	A transition clinic should be implemented with clinic appointments long enough for the person with diabetes to build up a relationship and this should harness new technologies.	🟥	🟨	🟩
10	Patients who require it should have access to: » A variety of CBG meters, including those with built-in bolus calculators. » Adequate CBG strips (10 per day or more if needed, where cost effective) to support them to achieve NICE recommended HbA1c targets. » Insulin pumps as per TA151 in patients who have disabling hypoglycaemia or HbA1c above 8.5 per cent, despite structured education. » A choice of insulin pumps as per individual needs. A policy should be in place for access to emerging technologies, such as continuous glucose monitoring, which may be valuable in individual settings.	🟥	🟨	🟩

TYPE 1 PERFORMANCE TARGETS / OUTCOMES

This specification takes into account the guidance published by NICE in August 2015 , Type 1 diabetes: diagnosis and management of type 1 diabetes in adults (NG17), and details the following components of a clinical service for adults with type 1 diabetes.

The service specification (part 1) and optimal pathway (part 2) should:

» Support adults with type 1 diabetes to aim to achieve and maintain a target HbA1c level of 48 mmol/mol (6.5%) or lower, to minimise the risk of long term vascular complications. This will be individualised according to circumstances though, and we urge those caring for elderly or frail people with type 1 diabetes to be cautious with tight control, to minimise risk of falling and fractures.

» Be a full multidisciplinary team, including a consultant clinical psychologist and full inpatient diabetes team (minimum one diabetes specialist nurse per 300 beds), as required to deliver care for people of all levels of risk and with competencies to deliver appropriate care.

» Have available regular structured type 1 diabetes patient education programmes, such as DAFNE (Dose Adjustment for Normal Eating). CCGs should commission a link with neighbouring CCGs to ensure these can be delivered regularly.

» Current clinical services should be self assessed against the optimal pathway.

» Deliver changes to services to ensure the key performance indicators are met.

» Measure the impact and outcomes for the service.

» Improve quality across the patient pathway.

» Take steps to provide innovative and continually developing services.

TYPE 1 PERFORMANCE TARGETS / OUTCOMES

Performance targets per area | Type 1 diabetes (2017-2022)

Indicator		Apr 2017 Baseline	Apr 2018	Apr 2019	Apr 2020	Apr 2021	Apr 2022
1. Type 1 register	Each area to collate an accurate type 1 register to establish prevalence	100%	100%	100%	100%	100%	100%
2. Place of care	Register to include (for each patient) – the team responsible for general review and those for annual review	100%	100%	100%	100%	100%	100%
3. NICE Care processes	Collect all NICE care processes for each patient (quality of care indicator)	Establish baseline	70%	80%	90%	100%	100%
	Evidence that care results have been acted upon	Establish baseline	70%	80%	90%	100%	100%
4. Reduce unscheduled admissions	Severe hypoglycaemic attacks	Establish baseline	Reduce by 10%	Reduce by 15%	Reduce by 20%	Reduce by 25%	Reduce by 30%
	CVD related conditions	Establish baseline	Reduce by 10%	Reduce by 15%	Reduce by 20%	Reduce by 25%	Reduce by 30%
5. KPI for service provision	» Access to an MDT including a consultant psychiatrist supported by consultant clinical psychologist with IAPT team supporting » Access to technology » Access to structured education (link with neighbouring CCGs, if required) » Core team with all competencies (structured education / DAFNE trained) » Pathway in place for hypoglycaemia » Pathway for hyperglycaemia - persistent elevated HbA1c » Evidence of links to MDT / hub for insulin pumps / CGM / transplantation, if skills not in place locally						
	KPIs for pregnancy National Pregnancy in Diabetes Audit (NPID): » Number of women with pre-existing diabetes on folic acid at booking » Number of women on harmful medications at booking (statins/ACE) » Number of women on potentially harmful diabetes medications at booking » Number of women with HbA1c < 48 mmol/mol (6.5%) at booking » Number of women with serious adverse outcomes – stillbirth, neonatal death and major congenital anomalies (cardiac and neurological); evidence of regular HbA1c and failsafe process to ensure this happens						

TYPE 1 PERFORMANCE TARGETS / OUTCOMES

Outcome measures for type 1 diabetes service

NICE states that *"people with type 1 diabetes should be offered the most appropriate insulin preparations (rapid-acting insulin analogues, short-acting insulins, intermediate-acting insulins, long-acting insulin analogues or biphasic insulins) according to their individual needs and the instructions in the patient information leaflet supplied with the product, with the aim of obtaining an HbA1c level of less than 58mmol/mol (7.5%) without frequent disabling hypoglycaemia and maximising quality of life"*.

Outcome measures for people with type 1 diabetes in London (differences made to the patient's life)		
Outcome	**Subjective measure**	**Objective measure**
Health status achieved or retained		
1. Mortality Rate for those with Type 1		1.Mortality rate (Public Health)
2. Age at death	Establishing premature death	2.Mortality rate (Public Health)
3. Measures of Quality of Life	Extent I am able to do the things I want to do	3.EQ-5D, DQOL, DHP-18
4. Measures of symptom control (eg hypoglycaemia, lethargy)		
4a. Symptom-free	Extent I am free of symptoms of high/low blood sugar	4a. Attendances at A&E with primary diagnosis of hypoglycaemia/ hyperglycaemia in a year
4b. Symptom recognition	Extent I am able to recognise symptoms of high/low blood sugar	4.b.1.Number of ambulance call outs per year for hypoglycaemia/ hyperglycaemia in a year
		4.b.2 Number of patients admitted in DKA, as a measure of unscheduled admissions
		4.b.3 Attendances/contacts with care service with diabetes related symptoms in a year (GOLD score > 4)
5. Patient identified measures		
5a. Control	Extent I feel in control of my condition	5a.Diabetes Empowerment Scale or local PROM or DMSES 15
5b. Confidence	Extent I feel confident in managing my condition	5b.Diabetes Empowerment Scale or local PROM or DMSES 15
5c. Support	Extent I feel supported in managing my health	5c.Diabetes Empowerment Scale or local PROM or DMSES 15

Outcome measures for type 1 diabetes service

NICE states that *“people with type 1 diabetes should be offered the most appropriate insulin preparations (rapid-acting insulin analogues, short-acting insulins, intermediate-acting insulins, long-acting insulin analogues or biphasic insulins) according to their individual needs and the instructions in the patient information leaflet supplied with the product, with the aim of obtaining an HbA1c level of less than 58mmol/mol (7.5%) without frequent disabling hypoglycaemia and maximising quality of life”*.

Outcome measures for people with type 1 diabetes in London (differences made to the patient’s life)		
Outcome	**Subjective measure**	**Objective measure**
Health status achieved or retained		
5. Patient identified measures (cont’d)		
5d. Diabetes distress	Extent I feel free from distress related to my diabetes	5d.Measure of distress e.g. GAD 7
5e. Happiness / mood / anxiety	Extent I feel happy	5e. Measure of depression e.g. PHQ-9, PAID scale
5f. Self-management: Education	Extent I feel I have been offered structured support for my diabetes	5f.Attendance at structured education (eg DAFNE)
5g. Self-management: Monitoring	Extent I feel I am able to monitor my diabetes	5g.1 Assessment of frequency of monitoring and HbA1c 5g.2 Patient reported access to blood glucose monitoring equipment commensurate with need to monitor diabetes.
5h. Self-management: Understanding	Extent I feel I understand how to manage my diabetes	5h.Patient Reported Outcome Measure
5i. Self-management: Managing	Extent I feel I am able to manage my own diabetes care	5i. Patient Reported Outcome Measure
6. Measures of clinical outcomes / complications		
6a. Amputation/PVD	Extent to which I am foot complication free	6a.1 Number of admissions for minor amputation of leg, foot or toe (primary procedure) with an additional co-morbidity of diabetes in given time period (data source: SUS) 6a.2 Number of admissions for major amputation of leg, foot or toe (primary procedure) with an additional co-morbidity of diabetes in given time period (data source: SUS) 6a.3.Number of people with diabetes with active foot ulceration

TYPE 1 PERFORMANCE TARGETS / OUTCOMES

Outcome measures for type 1 diabetes service

NICE states that *“people with type 1 diabetes should be offered the most appropriate insulin preparations (rapid-acting insulin analogues, short-acting insulins, intermediate-acting insulins, long-acting insulin analogues or biphasic insulins) according to their individual needs and the instructions in the patient information leaflet supplied with the product, with the aim of obtaining an HbA1c level of less than 58mmol/mol (7.5%) without frequent disabling hypoglycaemia and maximising quality of life”.*

Outcome measures for people with type 1 diabetes in London (differences made to the patient’s life)		
Outcome	**Subjective measure**	**Objective measure**
Health status achieved or retained		
6. Measures of clinical outcomes / complications		
6a. Amputation/PVD	Extent to which I am foot complication free	6a.1 Number of admissions for minor amputation of leg, foot or toe (primary procedure) with an additional co-morbidity of diabetes in given time period (data source: SUS) 6a.2 Number of admissions for major amputation of leg, foot or toe (primary procedure) with an additional co-morbidity of diabetes in given time period (data source: SUS) 6a.3.Number of people with diabetes with active foot ulceration
6b. Preventable blindness	Extent to which I am eye complication free	6b.1 Number of people with diabetes newly registered as blind each year (data source: DECS, SUS) eg. Prevalence of diabetic retinopathy (data source: Public Health) 6b.2 Number of people with diabetes requiring treatment for diabetic retinopathy (data source: DECS, SUS)
6c. Renal disease	Extent to which I am renal complication free	6c.Number of admissions for renal failure (primary diagnosis) with an additional co-morbidity of diabetes in given time period.(data source: SUS)
6d. Stroke (CVA)	Extent to which I am stroke complication free	6d. Number of admissions for stroke (primary diagnosis) with an additional co-morbidity of diabetes in given time period (data source: SUS)

Outcome measures for type 1 diabetes service

NICE states that *"people with type 1 diabetes should be offered the most appropriate insulin preparations (rapid-acting insulin analogues, short-acting insulins, intermediate-acting insulins, long-acting insulin analogues or biphasic insulins) according to their individual needs and the instructions in the patient information leaflet supplied with the product, with the aim of obtaining an HbA1c level of less than 58mmol/mol (7.5%) without frequent disabling hypoglycaemia and maximising quality of life"*.

Outcome measures for people with type 1 diabetes in London (differences made to the patient's life)		
Outcome	**Subjective measure**	**Objective measure**
Health status achieved or retained		
6. Measures of clinical outcomes / complications		
6e. Myocardial infarction (MI)	Extent to which I am heart complication free	6e.Number of admissions for MI (primary diagnosis) with an additional co-morbidity of diabetes in given time period (data source: SUS)
6f. Sexual dysfunction	The proportion of people with sexual dysfunction who feel well supported to manage their condition	6f. Number of people with diabetes who have sexual dysfunction (eg prevalence or incidence TBC) – male and female
Process of treatment		
7. Amount of time out of normal routine		
7a. Disruption	Extent my life is disrupted by care	7a. Days off work because of diabetes-related conditions in given time period
8. Experience of care / treatment process		
8a. Care coordination	Extent I feel my care is coordinated	8a. Patient Reported Outcome Measure
8b. Timely and organised access to services	Extent I feel I can get access to care services when I need them	8b. Patient Reported Outcome Measure
8c. Right person, right time	Extent I feel I have access to the right person/service at the right time	8c. Patient Reported Outcome Measure
8d. Planned care	Extent I feel involved in planning my care	8d. Patient Reported Outcome Measure

TYPE 1 PERFORMANCE TARGETS / OUTCOMES

Outcome measures for type 1 diabetes service

NICE states that *“people with type 1 diabetes should be offered the most appropriate insulin preparations (rapid-acting insulin analogues, short-acting insulins, intermediate-acting insulins, long-acting insulin analogues or biphasic insulins) according to their individual needs and the instructions in the patient information leaflet supplied with the product, with the aim of obtaining an HbA1c level of less than 58mmol/mol (7.5%) without frequent disabling hypoglycaemia and maximising quality of life”*.

Outcome measures for people with type 1 diabetes in London (differences made to the patient’s life)

Outcome	Subjective measure	Objective measure
Sustainability of health / long term consequences of therapy		
9. Measure of clinical outcomes / complications over time		
9a. Amputation	9a. Average age at time of first amputation of foot, leg or toe when additional co-morbidity of diabetes is present	
9b. Preventable blindness	9b. Average age at time of diagnosis of blindness when additional co-morbidity of diabetes is present	
9c. Stroke (CVA)	9c. Average age at time of first CVA when additional co-morbidity of diabetes is present	
9d. Renal failure	9d. Average age at time of onset of renal failure	
9e. MI	9e. Average age at time of first MI when additional co-morbidity of diabetes is present	
Transition population		
10. Ensuring patients are not lost to follow-up	Extent to which I am supported by my diabetes team	10.Using register of type 1 patients, set up a monitoring process to ensure all patients are regularly reviewed
11. Patient identified measures of the quality of transition services	Extent to which I am supported during my transition from child to adult services	11.Patient Reported Outcome Measure of Transition
Obstetric type 1 diabetes population		
12. Marker of control and complications during pregnancy	HbA1c each trimester, if not more often as clinical condition dictates	12. Evidence of regular HbA1c and failsafe process to ensure this happens
13. Measure of a healthy baby	All type 1 women who give birth to a healthy baby	13.Number of healthy babies born to type 1 women who become pregnant (percentage healthy live births)

Type 1 performance targets / outcomes

Outcome measures for type 1 diabetes service

NICE states that *"people with type 1 diabetes should be offered the most appropriate insulin preparations (rapid-acting insulin analogues, short-acting insulins, intermediate-acting insulins, long-acting insulin analogues or biphasic insulins) according to their individual needs and the instructions in the patient information leaflet supplied with the product, with the aim of obtaining an HbA1c level of less than 58mmol/mol (7.5%) without frequent disabling hypoglycaemia and maximising quality of life"*.

Outcome measures for people with type 1 diabetes in London (differences made to the patient's life)

Outcome	Subjective measure	Objective measure
Sustainability of health / long term consequences of therapy		
9. Measure of clinical outcomes / complications over time		
9a. Amputation	9a. Average age at time of first amputation of foot, leg or toe when additional co-morbidity of diabetes is present	
9b. Preventable blindness	9b. Average age at time of diagnosis of blindness when additional co-morbidity of diabetes is present	
9c. Stroke (CVA)	9c. Average age at time of first CVA when additional co-morbidity of diabetes is present	
9d. Renal failure	9d. Average age at time of onset of renal failure	
9e. MI	9e. Average age at time of first MI when additional co-morbidity of diabetes is present	
Transition population		
10. Ensuring patients are not lost to follow-up	Extent to which I am supported by my diabetes team	10.Using register of type 1 patients, set up a monitoring process to ensure all patients are regularly reviewed
11. Patient identified measures of the quality of transition services	Extent to which I am supported during my transition from child to adult services	11.Patient Reported Outcome Measure of Transition
Obstetric type 1 diabetes population		
12. Marker of control and complications during pregnancy	HbA1c each trimester, if not more often as clinical condition dictates	12. Evidence of regular HbA1c and failsafe process to ensure this happens
13. Measure of a healthy baby	All type 1 women who give birth to a healthy baby	13.Number of healthy babies born to type 1 women who become pregnant (percentage healthy live births)

SAMPLE PROM FORM

The below is a sample patient reported outcome measure (PROM) from Camden diabetes IPU.

Patient reported outcomes measure feedback questionnaire

Part of IPU (service name)______________________________

Date: ______________________________

Please complete this to tell us about the treatment you received at diabetes clinic today.

We would like your views so that we can improve the diabetes service. Once complete, please hand it back to the reception staff. All feedback is anonymous, but if you want us to make contact, please add your details here:

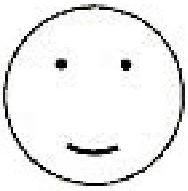
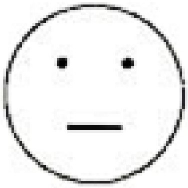
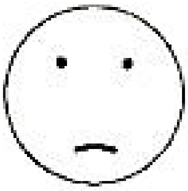
Name (optional):______________________________

Email (optional): ______________________________

Mobile (optional): ______________________________

SECTION A

1. How satisfied are you with the treatment that you received today?

Very satisfied	**Satisfied**	**Neither satisfied or dissatisfied**	**Unsatisfied**	**Not at all satisfied**
				

2. Would you recommend the treatment you receive at this clinic to another person with diabetes?

☐ **YES** ☐ **NO**

If no, please tell us why:

____

____

____

____

SECTION B

These questions are about how you felt about the clinician that treated you today and the treatment that you received. Please circle the answer that is relevant for you.

3. I feel that the clinician provided me with choices about how to manage my diabetes.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

4. I felt understood by the clinician who treated me today.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

5. The clinician encouraged me to ask questions about my diabetes.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

6. The clinicians listened to what I thought about my diabetes.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

7. The clinician tried to understand my view before suggesting changes to my treatment.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

8. The clinician worked with me to develop a plan for how to manage my diabetes.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

SECTION C

Please circle YES or NO as appropriate:

9. Do you feel that your care is coordinated?

10. Do you feel you can get access to care services when you need them?

11. Do you feel you have access to the right person/service at the right time?

12. Do you feel involved in planning your care?

If you would like to make any other comments about the treatment you received today, then please write them here:

Thank you for taking the time to complete this questionnaire.

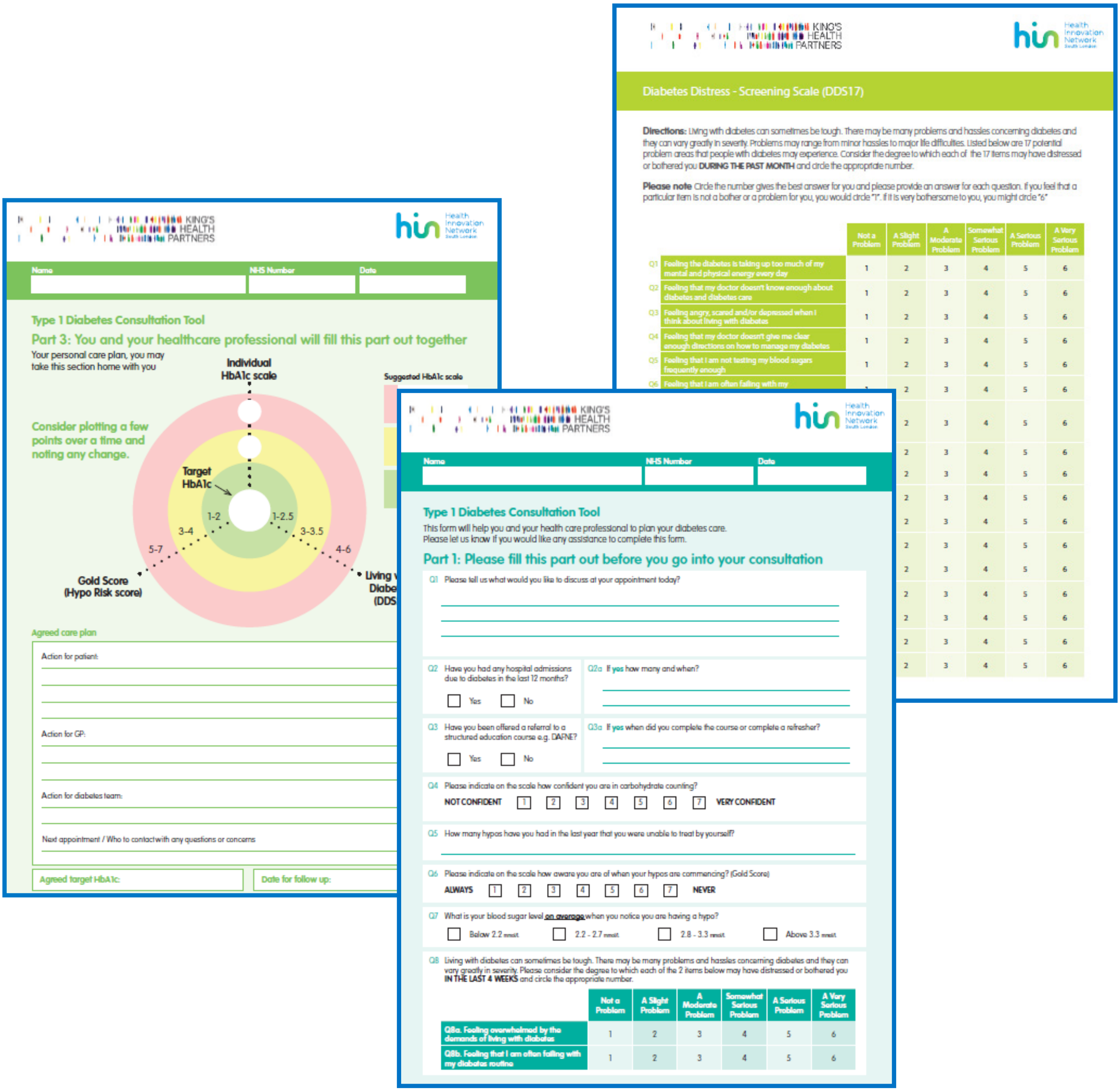
TYPE 1 DIABETES CONSULTATION TOOL

Health Innovation Network and King’s Health Partners have developed a type 1 diabetes consultation tool, which can help people with type 1 diabetes and their healthcare professionals to plan their care.

The form is designed to cover all aspects of care, and will help to create a jointly agreed personal care plan. It consists of three parts to be filled out. The first should be completed by the person with diabetes before they go into their consultation, and the other two parts should be completed by the person with diabetes together with their healthcare professional.

Download the toolkit via the HIN website:

www.hin-southlondon.org/resources/Type1Consultationtool(T1C)-userguide



KING'S HEALTH PARTNERS

Health Innovation Network South London

Diabetes Distress - Screening Scale (DDS17)

Directions: Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 17 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 17 items may have distressed or bothered you **DURING THE PAST MONTH** and circle the appropriate number.

Please note Circle the number gives the best answer for you and please provide an answer for each question. If you feel that a particular item is not a bother or a problem for you, you would circle "1". If it is very bothersome to you, you might circle "6"

		Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
Q1	Feeling the diabetes is taking up too much of my mental and physical energy every day	1	2	3	4	5	6
Q2	Feeling that my doctor doesn't know enough about diabetes and diabetes care	1	2	3	4	5	6
Q3	Feeling angry, scared and/or depressed when I think about living with diabetes	1	2	3	4	5	6
Q4	Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes	1	2	3	4	5	6
Q5	Feeling that I am not testing my blood sugars frequently enough	1	2	3	4	5	6
Q6	Feeling that I am often failing with my	1	2	3	4	5	6

KING'S HEALTH PARTNERS

Health Innovation Network South London

Name
NHS Number
Date

Type 1 Diabetes Consultation Tool

Part 3: You and your healthcare professional will fill this part out together

Your personal care plan, you may take this section home with you

Consider plotting a few points over a time and noting any change.

Agreed care plan

Action for patient:

Action for GP:

Action for diabetes team:

Next appointment / Who to contactwith any questions or concerns

Agreed target HbA1c:
Date for follow up:

KING'S HEALTH PARTNERS

Health Innovation Network South London

Name
NHS Number
Date

Type 1 Diabetes Consultation Tool

This form will help you and your health care professional to plan your diabetes care.
Please let us know if you would like any assistance to complete this form.

Part 1: Please fill this part out before you go into your consultation

Q1 Please tell us what would you like to discuss at your appointment today?

Q2 Have you had any hospital admissions due to diabetes in the last 12 months?

☐ Yes ☐ No

Q2a If **yes** how many and when?

Q3 Have you been offered a referral to a structured education course e.g. DAFNE?

☐ Yes ☐ No

Q3a If **yes** when did you complete the course or complete a refresher?

Q4 Please indicate on the scale how confident you are in carbohydrate counting?

NOT CONFIDENT ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 **VERY CONFIDENT**

Q5 How many hypos have you had in the last year that you were unable to treat by yourself?

Q6 Please indicate on the scale how aware you are of when your hypos are commencing? (Gold Score)

ALWAYS ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 **NEVER**

Q7 What is your blood sugar level **on average** when you notice you are having a hypo?

☐ Below 2.2 mmol/l ☐ 2.2 - 2.7 mmol/l ☐ 2.8 - 3.3 mmol/l ☐ Above 3.3 mmol/l

Q8 Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Please consider the degree to which each of the 2 items below may have distressed or bothered you **IN THE LAST 4 WEEKS** and circle the appropriate number.

	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
Q8a. Feeling overwhelmed by the demands of living with diabetes	1	2	3	4	5	6
Q8b. Feeling that I am often failing with my diabetes routine	1	2	3	4	5	6

GLOSSARY

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 | @NHSLondonSCN