

*Clinical management:
Optimal pathway*



London Clinical Networks

How to deliver type 1 diabetes services



September 2016

HOW TO USE THIS PACK

The London Diabetes Clinical Network has developed this comprehensive commissioning pack to ensure we deliver excellent type 1 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** - 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 (this document)** - Aimed at providers, this document details the expected clinical care for type 1 diabetes.
- » **Implementation guide** - This document provides the tools for both commissioners and providers to measure, analyse and develop improvement plans for their local diabetes service. It includes a summary of expectations and self assessments for commissioners and providers, performance targets and a sample patient reported outcome measures (PROM) form to collate patient feedback. It also highlights the [type 1 care consultation tool](#) (developed by [Health Innovation Network](#) and [King's Health Partners](#)), which can be used in the management of people with type 1 diabetes.



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

The London Diabetes Clinical Network, working with the academic health science networks in London, CCGs, [Diabetes UK](#), [JDRC](#) (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.

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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, and specifically the great efforts by Lis Warren and Melissa Holloway; 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

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

SUMMARY | CLINICAL AND SERVICE RECOMMENDATIONS

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 diabetes¹ 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/m²
- » 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/m² 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:

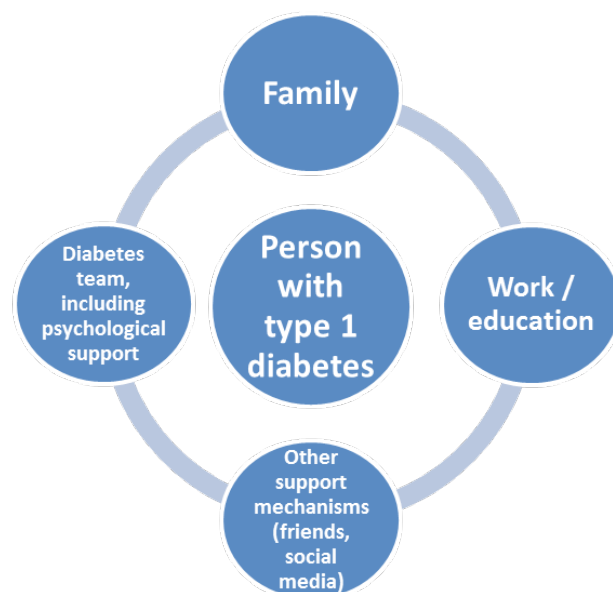
- » Type 1 diabetes is suspected but the clinical presentation includes some atypical features (for example, aged 50 years or above, BMI of 25 kg/m² or above, slow evolution of hyperglycaemia or long prodrome); **or**
- » Type 1 diabetes has been diagnosed and treatment started but there is a clinical 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.



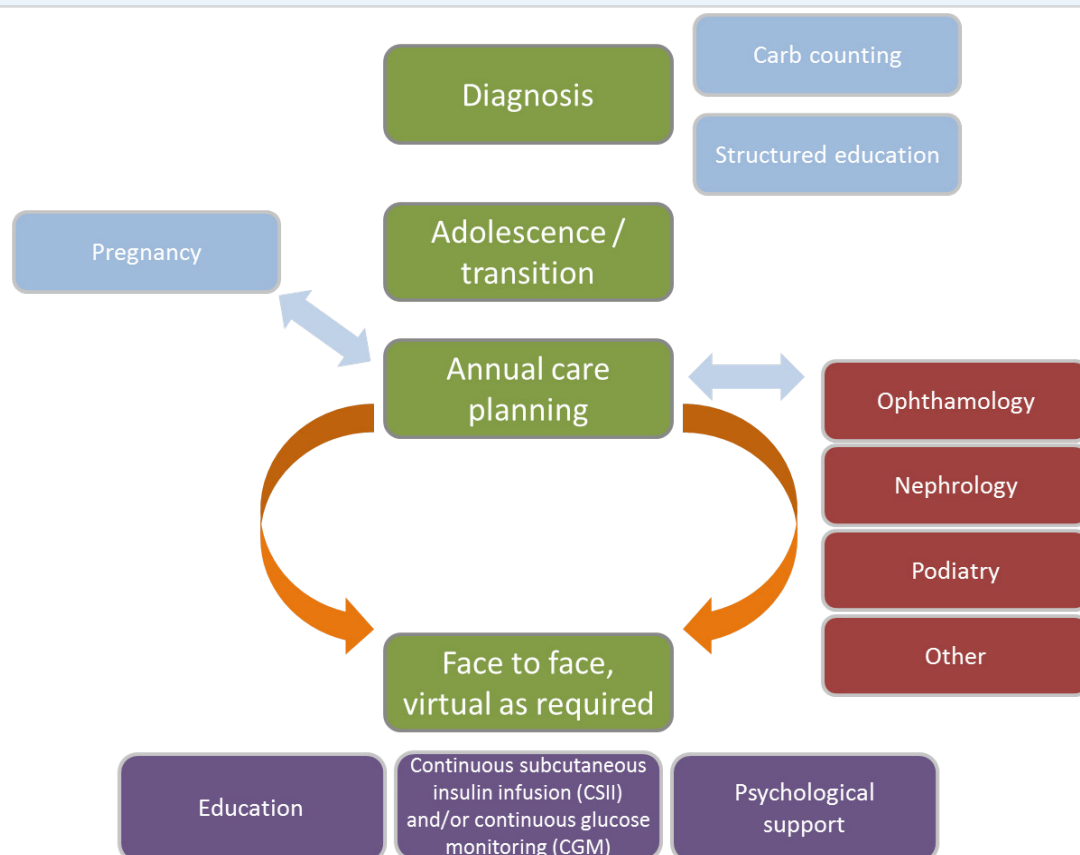
Everything surrounding a person with type 1 diabetes.

CLINICAL MANAGEMENT | CLINICAL PATHWAY

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 details¹.”

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 Hub³ 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 diagnosis⁴.

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 TA60⁵ 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 adults¹ (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 effective⁶ through improving diabetes control, reducing acute complications and also risk of long term complications and improving mental health⁷ and quality of life⁸. 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 database⁹ 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 example⁶⁹.

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 elsewhere¹⁰.

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 helpful¹¹.

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 score¹².

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 documented¹³.

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 diabetes¹⁴.

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 hypoglycaemia 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 technology¹⁶.

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 to 12 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 behaviours²¹ and hence we recommend use of the DDS here. Additionally we can explore any mental health reasons for difficulties with self-management²². 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 108 mmol/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 86 mmol/mol [10%]) with low risk of treatment-induced neuropathy or retinopathy²³.

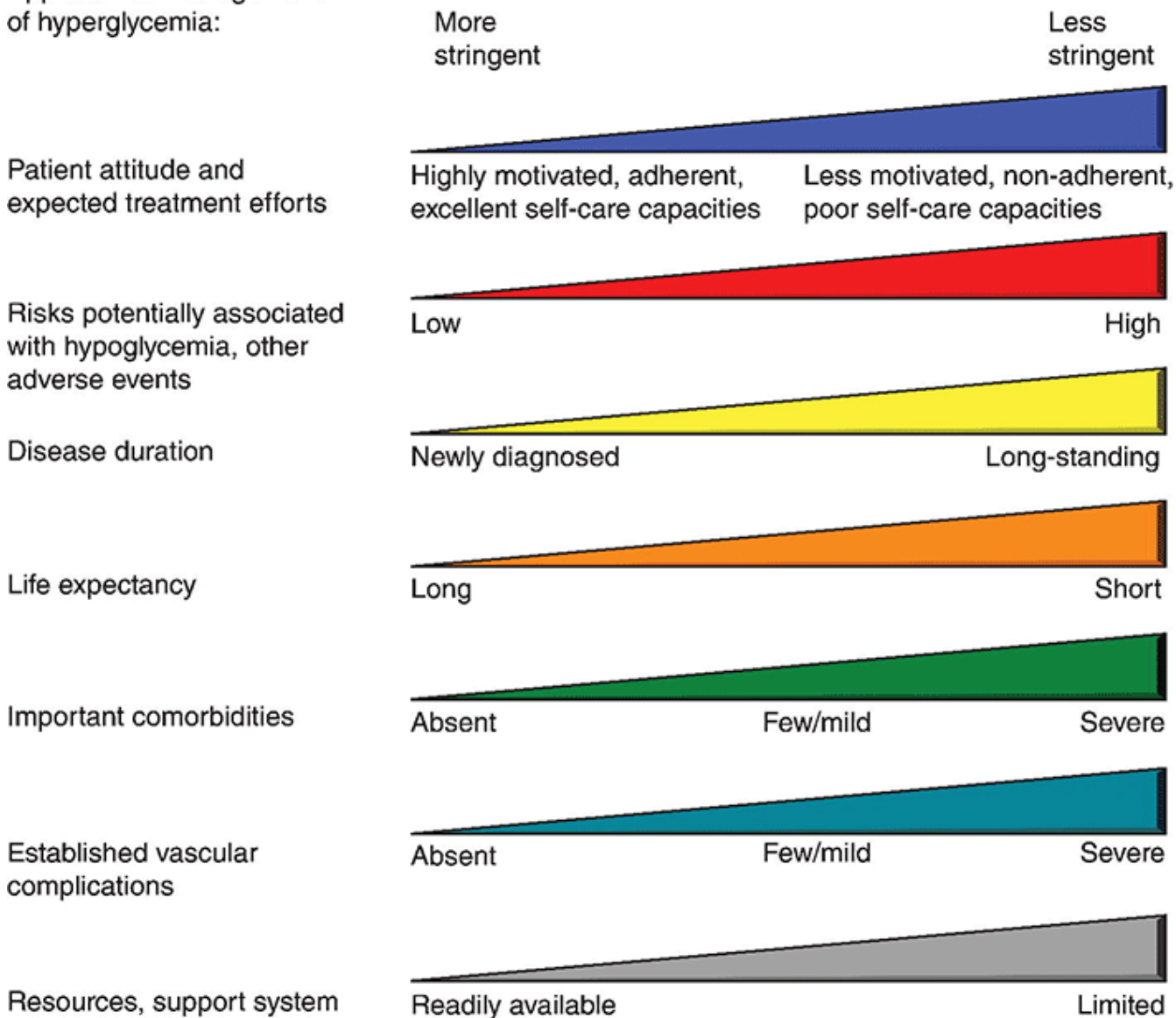
The pathway includes:

- » **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 69.5 mmol/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

CLINICAL MANAGEMENT | CLINICAL PATHWAY

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

Approach to management of hyperglycemia:



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 years²⁴ using the PAID²⁵ and, more recently, the DDS scales. A screening tool version of the DDS, the DDS2, has been well validated²⁶ 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 diabetes²⁷. 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 patients²⁸.

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.

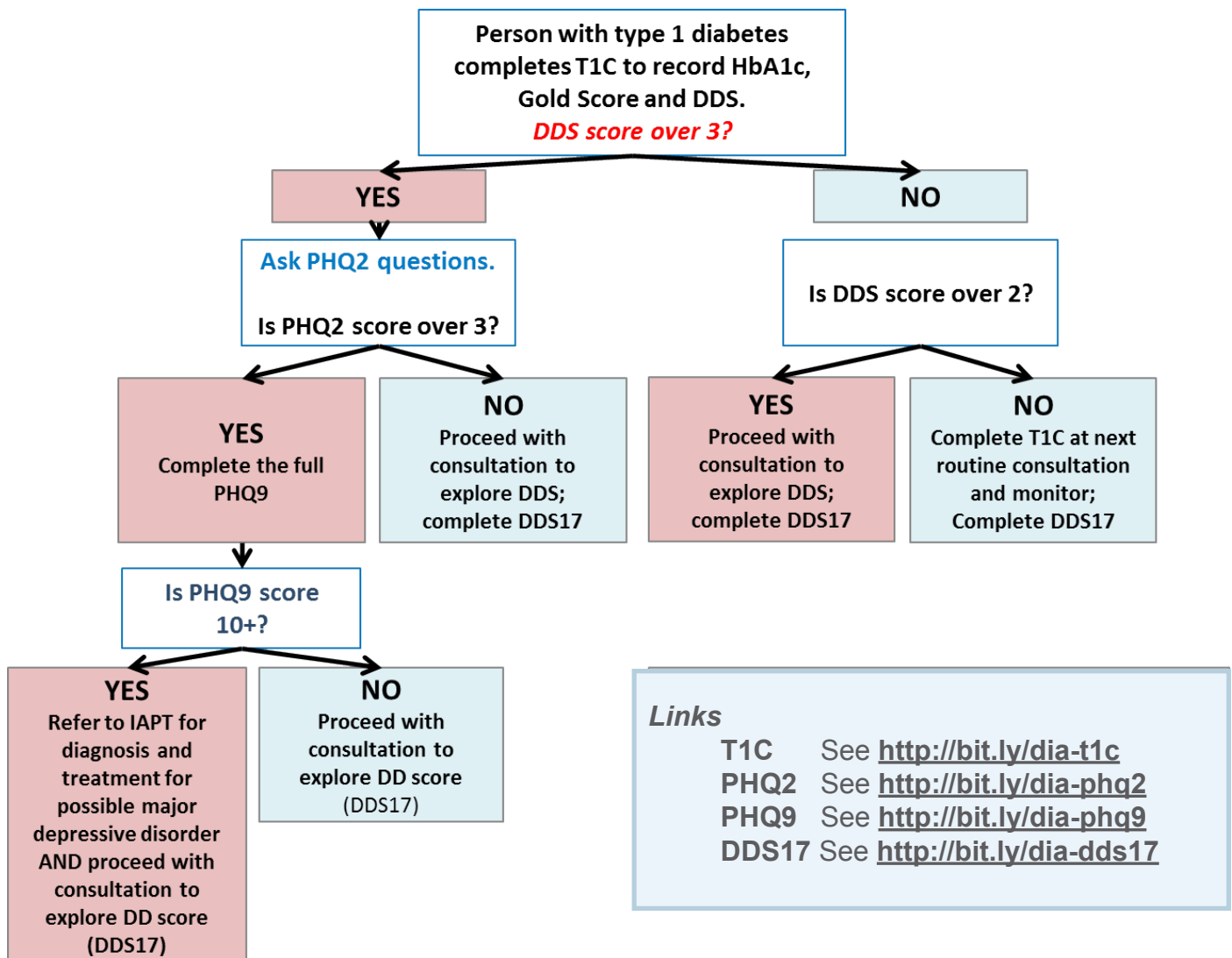
All patients with type 1 diabetes reporting diabetes related distress are currently seen by the in-house psychology service within the Hackney Diabetes Centre. Patients presenting with non diabetes related distress are signposted to local psychology services (after assessment). Peer groups are another 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.

CLINICAL MANAGEMENT | CLINICAL PATHWAY

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 diabetes²⁸. 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 patients²⁹. 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 services³⁰.

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 event³¹, 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 UK³² 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 screening³³. In the long term this could reduce overall uptake for local programmes, increasing the risk of sight loss.

Evidence from the FLURRI study³⁴ 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 symptoms³⁵. Those with type 1 diabetes have a higher risk of proliferative disease and visual loss in relation to the duration of their diabetes³⁶.

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 population³⁷.

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 pregnancy³⁸.

It is well documented that diabetes specialist pre-pregnancy care improves glycaemic control and reduces adverse outcomes in women with type 1 diabetes³⁹, and more recently, there is clear evidence that a regional pre-conception program can improve outcomes in both type 1 and type 2 diabetes⁴⁰. 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) audit⁴² 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 report⁴³ and the recent Maternity Review both highlight diabetes in pregnancy as high risk⁴⁴.

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 throughout⁴⁵. In accordance with NICE recommendations⁴⁶, 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 retina⁴⁸. 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 recommendations⁴⁹, 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.

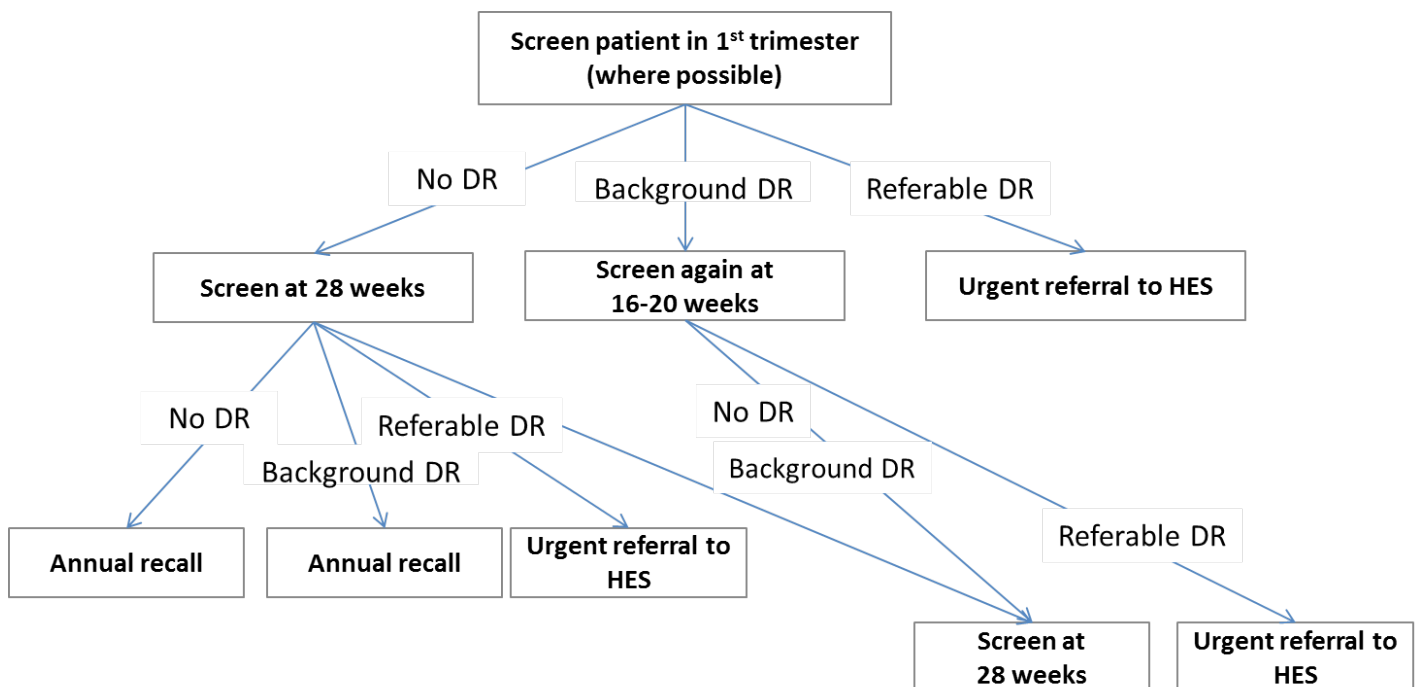
* *Childbearing age is defined as the period in a woman's life between puberty and menopause, so this discussion should begin early, with age appropriate discussions in paediatric diabetes services from around 11 years old.*

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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



Transition from paediatric to adult diabetes services

Diabetes UK and others recognise the importance of a transition clinic⁵⁰. 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 2⁵¹ 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 days⁵². Diabetes technologies support self-management and are effective as an adjunct to ongoing education and support.

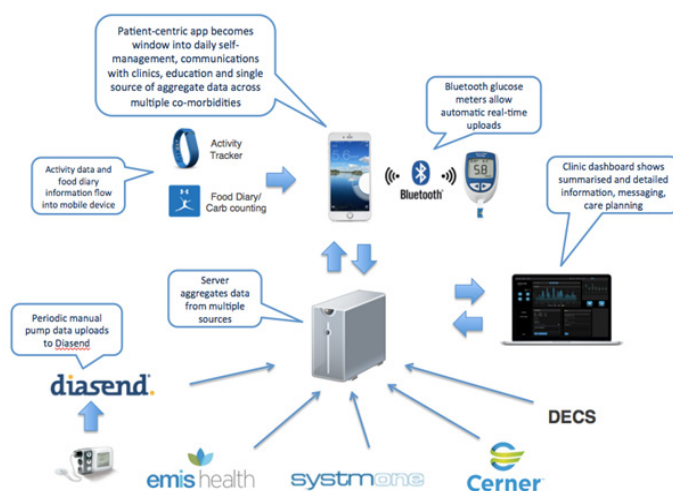
There are many categories of technology that can help people with diabetes, but integration between different areas of care and different technologies, in a way that provides a patient-centric view rather than a condition-centric view, is likely to move towards the goal of person-centred coordinated 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
 $(\text{Carbohydrate intake} / \text{insulin : carbohydrate ratio}) + ((\text{current glucose} - \text{target glucose}) / \text{insulin sensitivity factor}) - \text{insulin on board}$

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 technology⁵⁷. 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 type 1 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 CGM⁵⁸ - 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 effectively⁵⁹, advanced education in the interpretation of CGM and subsequent decisions about insulin dosing is key. Recent NICE⁶⁰ 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 NG17¹, DG21⁵⁴ and NG18⁶⁸.

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).

COMMISSIONING DIFFERENTLY | HARNESSING TECHNOLOGY

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 Libre⁷⁰.

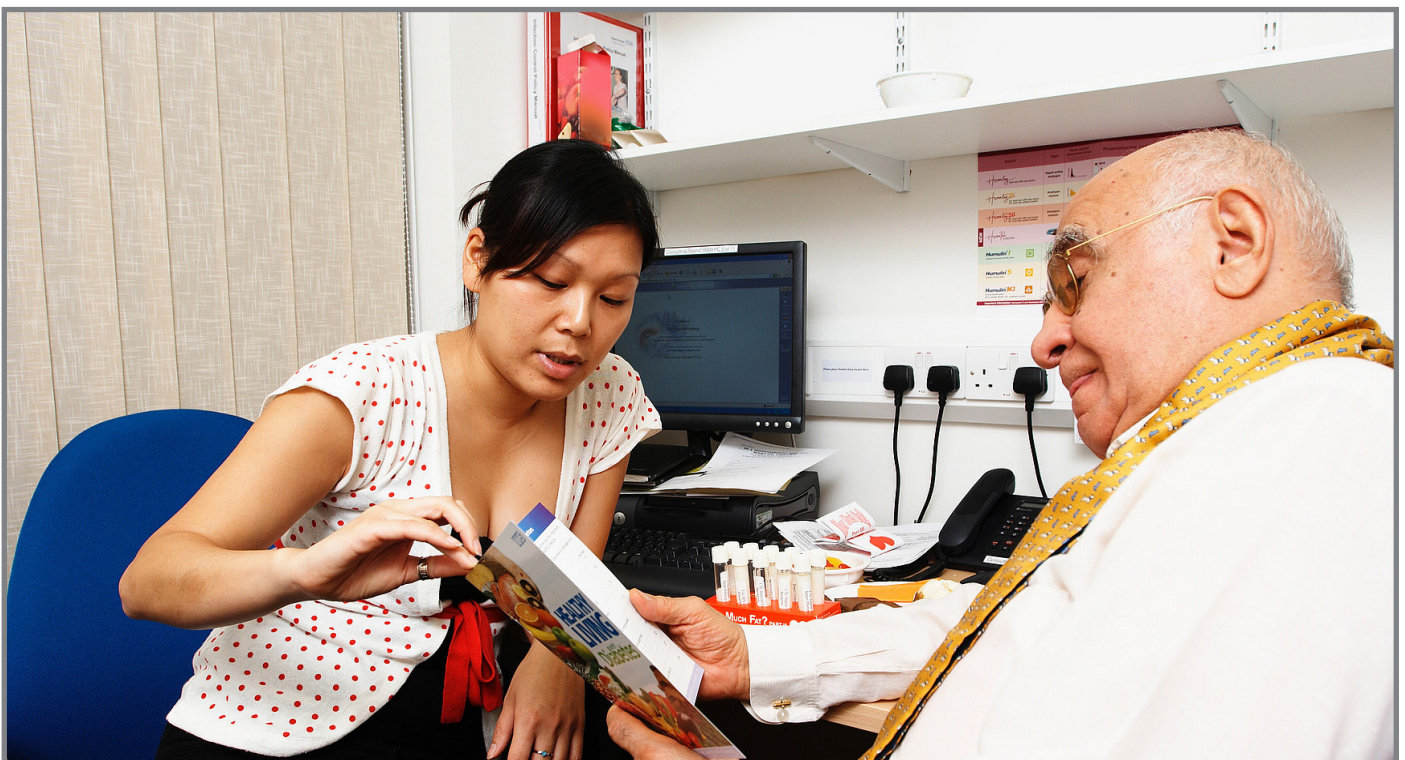
We suggest that this technology may be considered in people who:

- » 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 2008⁶¹ 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 therapy⁶², despite 2006 evidence⁶³ 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 guidance⁶⁴ 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 PBR_e, 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 planning⁶⁶.

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 trial⁶⁷.

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 hypoglycaemia 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



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GLOSSARY OF TERMS

| | |
|-------|---|
| 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.