NHS
London

London: Type 1 Diabetes Outpatient Transformation Framework

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This document will continue to be reviewed and re-released to reflect new and emerging evidence. Please email england.diabetes-ldncn@nhs.net to request the most recent version.

This London guide will be updated to align with other national and regional guidance once published.

NHS
London
Clinical Networks

Type 1 Diabetes Outpatient Transformation Framework

A guide for Integrated Care Systems

April 2022

TABLE OF CONTENTS

1. **Background** **3**

2. Why should we transform type 1 diabetes care? **3**

An opportunity to transform service delivery 3
Development and adoption of framework 5

3. Key components of an outcome focussed type 1 diabetes service **8**

4. Proactive engagement of people not accessing specialist care **9**

5. Shared clinical risk registers **11**

6. Workforce **12**

7. Outcomes and Metrics **13**

8. ICS level maturity matrix **14**

9. Appendices: Type 1 care pathways **16**

New diagnosis 16
Children and young people 17
Self-management education 19
Peer support 22
Hypoglycaemia 24
Reproductive health 25
Frailty, dementia and end of life care 26

10. Langauge matters **27**

11. List of contributors **28**

12. Reference List **29**

1. Background

Type 1 diabetes is a potentially devastating diagnosis for individuals and families putting enormous demands on the individual for self-care. Furthermore, as it often occurs at a young age it can cause substantial morbidity and premature mortality, if not optimally supported. At its best, type 1 diabetes care is exceptional and the potential outcomes now for someone diagnosed with type 1 diabetes are transformed from previous generations. The avoidance of complications should be achievable for all.

In 2016, the London Diabetes Clinical Network published **‘**Creating excellent Type 1 diabetes services in London: comprehensive commissioning pack**’**. The document set out to provide a service specification which recommended optimal care pathways, advising both commissioners and providers on how to develop, implement and measure improvement plans.

Unfortunately, while the advances have been tremendous there remains significant variation and inequality in the levels of support available; in access to appropriate education and self-management support, access to specialist input where it is needed and access to life transforming technology. The basis of this document is to build on the principles of excellent diabetes care laid out previously and to suggest specific measures using modern transformation principles to address these variations and inequalities.

2. Why should we transform Type 1 diabetes care?

Variation in care outcomes

Type 1 diabetes typically develops at a much younger age than type 2 diabetes and therefore potentially has an even greater impact on premature morbidity and mortality. Care in type 1 diabetes also seems to be more variable than type 2 diabetes. The National Diabetes Audit (NDA) indicated that on average, 24.4% of Londoners living with type 1 diabetes achieved the three treatment targets with 41.9% receiving all eight care processes in 2019-20. In comparison 42.7% of Londoners living with type 2 diabetes achieve the three treatment targets and 61% received the eight care processes (NDA, 2021). Furthermore, the NDA suggests inequalities in health outcomes for those living with type 1 diabetes on the grounds of ethnicity and deprivation. Between January 2020 and March 2021, there were lower percentages of people in the most deprived quintile achieving the three treatment targets (3TT), compared to the least deprived quintile. Similarly, there was variation across London with 3 out of 5 Integrated Care Systems (ICSs) having a lower percentage of ethnic minority groups achieving the 3TT compared to the white ethnicity group. Ultimately, the NDA shows that while some areas in London have amongst the best national outcomes, there is wide and harmful variation.

Variation in access to technology and self-management support

Access to technology and self-management support is crucial in type 1 diabetes, where the daily self-management and precise adjustment of insulin doses is essential to optimal self-management and quality of life.

Unfortunately, there is substantial variation in access to structured education, specialist support and technology. At a Clinical Commissioning Group (CCG) level, the percentage of Londoners with type 1 diabetes managing their diabetes with an insulin pump ranges from 4.9% to 16.2% with overall average of 9.7% (NDA, 2021). Eleven Primary Care Networks (PCNs) in London have less than 20% uptake of flash glucose monitoring devices for their type 1 population. 10 out of 11 of these PCNs have higher deprivation levels than the national average. All 11 PCNs have a higher percentage of ethnic minority population groups compared to the national average.

Variation in provision of and access to specialist care

Pockets of data across London indicate significant variation in the provision of, and access to, specialist care for type 1 diabetes. In 2017, City and Hackney CGG found 36% of the type 1 population were not under specialist care. In 2016, Brent CCG found 32% of people with type 1 diabetes were not under specialist care. Only 39% of adults living with type 1 diabetes across England and Wales are recorded as registered under the care of an adult specialist service (NDA, 2021). There are 24,055 people living in London with type 1 diabetes (NDA, 2021). If the picture was similar to across all of London, at an assumed 30% rate, there may be over 7,000 people living with type 1 diabetes not receiving specialist care to support optimal self-management. Despite a number of different datasets, there are no shared registers at PCN, ICS or regional level which routinely identify all people living with type 1 diabetes.

The challenge

Our challenge is to question how to design and deliver type 1 diabetes care differently. The variation that currently exists across London must be addressed. Health inequalities relating to deprivation, ethnicity or any other factor must be addressed.

The ambition is to ensure 100% of people living with type 1 diabetes have access to structured education, self-management support, specialist diabetes care and technology in a way that meets their needs and expectations, irrespective of location, ethnicity and deprivation.

This framework document is the first step on this journey; designed as an outcomes-focused guide to ensure specialist care is equitably accessible to all Londoners living with type 1 diabetes, at the right time and in the right setting. Learning from this population will also be of enormous benefit in reducing variation in type 2 diabetes care and outcomes.

An opportunity to transform service delivery

In 2017, the NHS Long Term Plan set out a strategic vision to transform diabetes care. Over £100m has been invested nationally though the treatment and care transformation fund, in over 180 projects to support improvements in care for those living with diabetes. From 2017 to 2021, London has received in excess of £20m to invest across the four treatment and care areas to improve:

- attainment of three treatment targets (HbA1c, blood pressure and cholesterol)
- uptake of structured education
- universal access to diabetes inpatient specialist nurses
- universal access to multi-disciplinary foot teams

COVID-19 has presented an extraordinary challenge to this strategic vision by dramatically impacting on delivery of diabetes care. People with diabetes have been at greater risk of developing COVID-19 and were three times more likely to die from the disease. People living with type 1 diabetes were at particularly high risk of COVID-19 related mortality (The Lancet, 2020). The disruption of care for people with type 1 diabetes increased waiting times for new patients and for those on long term follow up across specialist and non-specialist care, potentially increasing the risk of diabetes related complications.

Despite numerous challenges, as the NHS recovers from COVID-19, **there is a growing opportunity to transform the way outpatient care is delivered to ensure equity of access for all people living with diabetes**; equity of access to specialist care at the right time and in the right setting for them. Throughout COVID-19, diabetes teams in London have adapted to ensure continued provision of services to support people living with diabetes by offering a range of consultation options, including remote telephone and video. As alternatives to face to face appointments become more established, it is becoming a strategic priority for the NHS to work quickly to evaluate new, evolving and established outpatient pathways to ensure service provision is equitable, accessible and effective for all people living with type 1 diabetes.

Diabetes teams are already embracing the use of technology and remote working. Across England, over 50% of diabetes care continued to be delivered remotely between the first and second waves (MedRxiv, 2021). There are a range of opportunities to engage with the type 1 diabetes population to personalise their care via technology, which many specialist and non-specialist teams may already be testing. For example, patient initiated follow up (PIFU), remote monitoring technologies and platforms, digital structured education and virtual group consultations.

It is imperative that increased personalisation of diabetes care, through technology or self-management support, does not unintentionally exacerbate health inequalities. Addressing inequalities for people with type 1 diabetes means working to ensure that ethnicity, age, deprivation, educational attainment, language, and any other protected characteristic are not a barrier to accessing any aspect of care, education or support. A critical component of this is to ensure detailed data collection within ICSs and regionally across London. The London Diabetes Clinical Network will work with ICS type 1 diabetes leadership teams to increase more specific ethnicity reporting, enabling more appropriate interventions to address inequalities arising from ethnicity. Furthermore, ICSs should consider routinely incorporating Equality and Health Inequalities Impact Assessments (EHIAs) or similar assessment tools as a means of actively evaluating the impact of service design and reconfiguration on different population cohorts, with assessments discussed at an ICS type 1 diabetes leadership level.

Development and adoption of the framework

The London Diabetes Clinical Network established the Outpatient Transformation Task and Finish Group in March 2021, tasked with revising the 2016 '*Creating excellent Type 1 diabetes services in London: comprehensive commissioning pack*' into an outcome focussed framework. This new framework builds on regional and national guidelines, collating the experiences of type 1 diabetes specialist teams and experts by experience, with newly established practice and pan-London data to define the future ambition of type 1 diabetes outpatient care in London.

The framework is designed as a tool to **assist ICSs to understand, measure, monitor and subsequently address local variation in care and outcomes across their whole system.** It aims to provide suggestions of measures that may enhance equity of access across all diabetes care pathways for all Londoners living with type 1 diabetes, across specialist and non-specialist care settings. Diabetes care pathways benefit from being designed with inclusivity and personalisation at their core, identifying and subsequently overcoming structural, educational, environmental and psychosocial barriers to accessing care, assistive technologies and education.

The framework asks ICS to consider 5 areas as fundamental to a strategy that aims to improve clinical outcomes and reduce variation and inequality in type 1 diabetes care:

1. **Engage and connect with people with type 1 diabetes in the community, and particularly those not currently under the care of specialist diabetes teams**
2. **Improve equitable implementation of, and access to, technology**

3. Drive improvement in provision of, and access to self-management support, including structured education and peer support
4. Build capacity and type 1 diabetes competency within the workforce across all specialist and non-specialist care sectors
5. Improve data monitoring, reporting and transparency on health outcomes to measure experience of care

The London Diabetes Clinical Network will work with each ICS to develop three-year plans, aligned to the framework metrics. To support delivery of these plans, non-recurrent transformation funding has been agreed by the National Diabetes Programme in 2021. Each ICS has committed to the following:

1. **Adopt a local approach to identify the type 1 population across both specialist and non-specialist care, working towards a shared type 1 population register**
2. **Implement a type 1 diabetes clinical risk register (to inform clinical prioritisation), managed by a clinical risk register coordinator, and with regular multidisciplinary & multiagency review**
3. **Develop 3-year plans for type 1 diabetes care across specialist and non-specialist providers, in line with the type 1 diabetes transformation framework**
4. **Name a senior responsible officer (SRO) accountable for implementation of the type 1 diabetes transformation programme and care at ICS level**
5. **Name a medical and allied health professional/ nursing lead for type 1 diabetes to work with the SRO to implement the type 1 diabetes transformation framework**
6. **Build capacity and competency within the diabetes workforce across specialist and non-specialist care by implementing the Diabetes Specialist Practitioner Framework**

At a regional level, the framework has been approved through the NHS England (London) governance structure. This includes the London Diabetes Clinical Leadership Group and the London Clinical Executive Group. ICS type 1 diabetes leaders will acquire automatic membership to the London Type 1 Diabetes Network and will report on outcomes through the London Diabetes Clinical Network governance structure, including the Clinical Leadership Group and London Diabetes Oversight Group.

3.Key components of an outcome focussed type 1 diabetes service

All people living with diabetes should have access to a range of key components to ensure they can achieve good health outcomes, in line with NICE Guidance recommendations and supported by the London Type 1 Diabetes Network. For the type 1 diabetes population, the components below are common to all care pathways and have been found to positively impact both ability to self-manage and reduce the risk of diabetes related complications.

1. **Annual reviews delivered in any care setting, aligned with the person's preference** which includes:
    a. Delivery of care processes
    b. Monitoring and management of the three treatment targets
    c. Co-ordination of care between specialist and non-specialist care to prevent duplication and risk of becoming 'lost to follow up'. Ideally people with type 1 diabetes should be offered a choice of where their annual review takes place

2. **Regular access to specialist diabetes practitioners** to support Insulin management, dietary needs, self-monitoring and technology support

3. **A discussion with a member of the specialist multidisciplinary team** to include assessment of hypoglycaemia frequency, severity and awareness, diabetes education, pregnancy plans, technology usage and psychosocial wellbeing. This should be delivered in a setting and format consistent with the person's wishes where possible. Referrals to other specialist services should be made, e.g. Type 1 Disordered Eating Service (T1DE) as appropriate

4. **Written information and signposting to diabetes resources**, including online education programmes where appropriate

5. **Personalisation of care delivery** including:

- Co-creation of personalised care plans delivered in a format that the person can use e.g. NHS Year of Care
- Choice of appointment type: face to face, telephone, video, app based, email
- Identify pathways where patient initiated follow up (PIFU) is clinically appropriate
- Choice of structured education course: face to face or digital
- Access to mental health support e.g. Talking Therapies, liaison psychology/psychiatry to support psychosocial aspects of living with type 1 diabetes
- Offer of diabetes technology where clinically appropriate e.g. insulin pumps, continuous glucose monitors and flash glucose meters.
- Signposting or referral to social prescribing e.g. personalised health budgets
- Signposting to local face to face or virtual peer support

4. Proactive engagement of people not accessing specialist care

‘Knowing how many type 1 patients a specialist service has in its catchment area is crucial, in order to plan effective services and build a case for investment and improvement (GIRFT, 2020).

Engaging and connecting with people living with type 1 diabetes who are not currently under the care of specialist diabetes teams represents a real challenge. Attempts to identify the total type 1 population at a borough or ICS level have proved time consuming and difficult to maintain. However, proactive case finding is vital if, as estimated, 30% of people living with type 1 do not receive regular specialist diabetes care. This would equate to over 7,000 people with type 1 diabetes in London potentially not receiving specialist support. Factors such as the nature and quality of care currently received is unknown, as are the potential barriers that are hindering access to specialist services.

ICS type 1 diabetes teams will therefore need to:

1. **implement a strategy to identify people not routinely accessing specialist diabetes recorded**
2. **identify people not accessing specialist care, and explore why. If they were previously, but decided to discontinue that care, establish what led to that decision and address issues that have led to a service failing to meet the needs of that person**
3. **work to deliver specialist type 1 diabetes care for those identified as not accessing specialist care**
4. **ensure equitable access to structured education for people not routinely accessing specialist care**

We must find robust approaches to identify, search, code and engage the type 1 diabetes population, measuring access points of current service provision and considering health inequalities and barriers to access across each element of the care pathway, including where new interventions are created. It is acknowledged that coding and uncertainty of diabetes phenotypes may limit identification of some people. ICS type 1 diabetes teams must support unified coding across specialist and non-specialist IT infrastructures and work towards reductions in dual coding and in no type of diabetes recorded.

A data-driven approach to quality improvement will allow ICSs to build a case to re-design existing services and/or develop new services that offer more accessible specialist care to all, in a range of settings, if appropriate. An example case study of one such service is found below:

Delivering specialist clinics in non-specialist settings

The King's College University Health Centre is an NHS General Practice surgery with a patient list made up from King's College students and staff. The clinic is situated in the campus and is readily accessible by all patients. Recognising the challenges for students to travel to specialist centres around London, and the relatively high prevalence of type 1 diabetes in the practice diabetes register (reflecting the young age group), a monthly MDT specialist clinic was established.

Importantly for continuity the clinic is led by the GP and is attended by a specialist consultant and type 1 diabetes educator. Support, advice, prescribing and personalised care plans are provided in a one-stop clinic model, including flash glucose monitoring initiation.

Each clinical interaction is an opportunity to discuss specialist care availability and accessibility. The universal touch point for people with type 1 diabetes is their pharmacist and engaging community pharmacists to be part of the type 1 diabetes MDT, delivering information, support and signposting may be an effective strategy.

Similarly, at each non-specialist encounter, recording specialist MDT access and the person's preference for access (especially location and format) enables personalisation.

Following a hospital admission, especially for an acute diabetes complication must include organising specialist MDT follow up in a location and format agreed with the person living with type 1 diabetes, as well as written contact details and ICS-specific peer support signposting.

From user surveys, 78% were satisfied or extremely satisfied with the one-stop-shop provision and well as the Joint MDT clinic held monthly during term time and most would recommend the service to a friend or family. One respondent commented that "I believe the diabetes clinic at Kings College Health Centre is exceptional. the best organised and executed service I have experienced in the UK"

5. Shared clinical risk registers:

Identification and management of clinical risk and complications

Good diabetes management can significantly reduce the risk of acute or chronic complications like hypoglycaemia, diabetic ketoacidosis, blindness, kidney failure and vascular diseases. Between 1 January and 30 June 2018, 1503 people with type 1 diabetes were attended to by London Ambulance Service with an episode of hypoglycaemia (Uduku et al. 2021). This represents in excess of 8 call outs per day, more than a third of which are recurrent, and more than a third of whom are conveyed to hospital. Severe hypoglycaemia is associated with significant mortality. London saw a year-on-year increase in admissions for diabetic ketoacidosis by 10% between 2016 – 2019. Length of stay increased from an average of 3 days to 4 days between 2016-2020.

Addressing morbidity and mortality for people with type 1 diabetes at highest risk requires a specialist multidisciplinary team with multiagency support. It also requires ICSs to be able to identify their type 1 population, stratify and deploy targeted interventions at particular high-risk groups. ICSs will therefore need to implement shared risk registers of those at highest risk and will co-ordinate regular multi-agency meetings.

Highest risk people with type 1 diabetes include, but are not limited to:

- **People with more than one episode of severe hypoglycaemia in any 12-month period**
- **People with more than one episode of DKA in any 12-month period**
- **Homelessness**
- **Severe mental illness**
- **People with eating disorders**
- **People with type 1 diabetes in care homes**
- **People with type 1 diabetes in prisons**
- **Children or young adults with type 1 diabetes in foster care, or those with active safeguarding**

Day-to-day management of those at high risk is the responsibility of the provider or providers where there are shared care provisions in place. Oversight and update of the shared clinical risk register at ICS level is the responsibility of ICS type 1 diabetes clinical leadership.

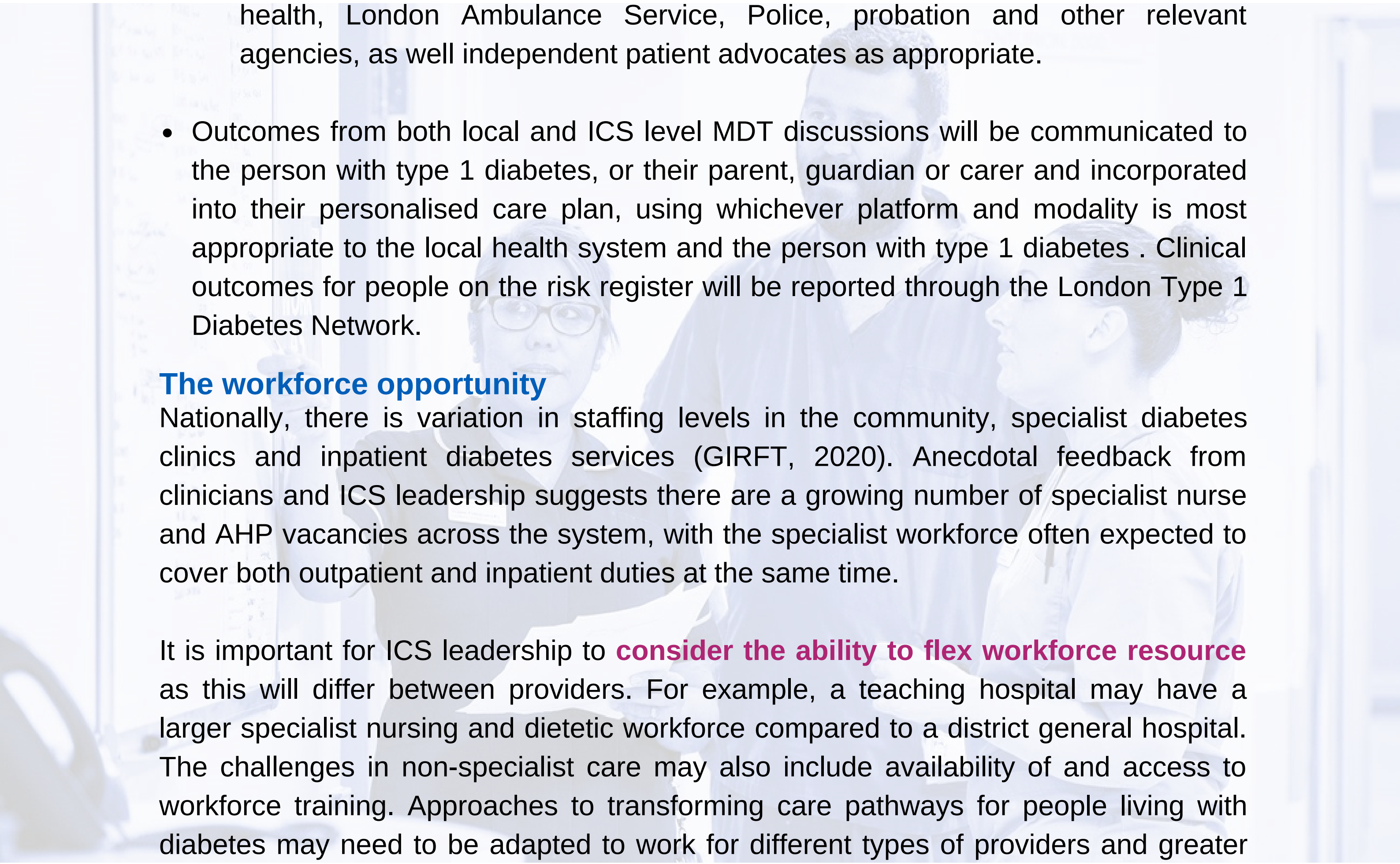
Shared risk registers should also reflect the demographics of the type 1 population as a whole. COVID has shone a renewed light on disparities in health outcomes for people from minority ethnic communities, in areas of high deprivation and others with protected characteristics. Lower socio-economic status and higher levels of deprivation are associated with a higher risk of experiencing diabetic ketoacidosis in people with type 1 diabetes (Lindner et al. 2018).

6. Workforce

- Specialist teams should comprise a broad workforce of roles including physicians, nurses, podiatrists, dietitians, clinical psychologists and pharmacists (Diabetes UK).

- Each specialist provider should hold a regular specialist type 1 diabetes multidisciplinary team (MDT) meeting, ideally with input from local non-specialist teams who care for people with type 1 diabetes.

- Like Cancer MDTs, **it is recommended each ICS establishes an ICS level specialist diabetes MDT meeting, hosted by a nominated provider**.
    - Core membership includes ICS clinical leadership, specialist and non-specialist teams.
    - Extended membership may include social services, youth services, mental health, London Ambulance Service, Police, probation and other relevant agencies, as well independent patient advocates as appropriate.



- Outcomes from both local and ICS level MDT discussions will be communicated to the person with type 1 diabetes, or their parent, guardian or carer and incorporated into their personalised care plan, using whichever platform and modality is most appropriate to the local health system and the person with type 1 diabetes . Clinical outcomes for people on the risk register will be reported through the London Type 1 Diabetes Network.

The workforce opportunity

Nationally, there is variation in staffing levels in the community, specialist diabetes clinics and inpatient diabetes services (GIRFT, 2020). Anecdotal feedback from clinicians and ICS leadership suggests there are a growing number of specialist nurse and AHP vacancies across the system, with the specialist workforce often expected to cover both outpatient and inpatient duties at the same time.

It is important for ICS leadership to **consider the ability to flex workforce resource** as this will differ between providers. For example, a teaching hospital may have a larger specialist nursing and dietetic workforce compared to a district general hospital. The challenges in non-specialist care may also include availability of and access to workforce training. Approaches to transforming care pathways for people living with diabetes may need to be adapted to work for different types of providers and greater collaboration and support across providers in an ICS will be essential.

One opportunity to future-proof the specialist diabetes workforce, opening recruitment up to expanded roles is the implementation of **Diabetes Specialist Practitioner guidelines.** The London Diabetes Clinical Network produced this guideline to provide a framework for competency-based rotational training at band 6 level, suitable for nurses, dietitians, pharmacists, and midwives.

7. Outcomes and metrics to implement and measure

Aims

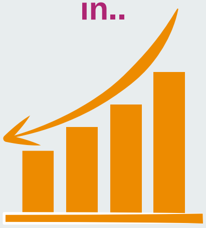
Reducing the risk of acute and long-term diabetes related complications like hypoglycaemia, diabetic ketoacidosis, blindness, kidney failure and vascular diseases

All people living with type 1 diabetes :

- have access to routine specialist diabetes care in a setting suitable for them
- are offered a choice of appointment type - face to face, telephone or video
- have access to peer support
- have access to structured education suitable for them
- receive the care processes annually
- achieve the three treatment targets annually
- have equitable access to remote monitoring technologies (i.e. insulin pump, continuous glucose monitoring (CGM), flash), in line with national and local guidance
- All pregnant women living with type 1 diabetes are offered a CGM device

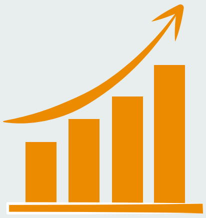
Outcome metrics

% decrease in..



- the type 1 diabetes population requiring unscheduled hospital presentations
- variation between the most and least deprived quintile of the type 1 population achieving the three treatment targets
- variation between the most and least deprived quintile of the type 1 population receiving the care processes
- variation between the most and least deprived quintile of the type 1 population attending structured education
- variation between white and ethnic minority type 1 population achieving the three treatment targets
- variation between white and ethnic minority type 1 population receiving the care processes
- variation between white and ethnic minority type 1 population attending structured education

% increase in..



- the type 1 diabetes population under non-specialist care achieving the three treatment targets
- the type 1 diabetes population under specialist care achieving the three treatment targets
- the type 1 diabetes population under non-specialist care receiving the care processes
- the type 1 diabetes population under specialist care receiving the care processes
- the type 1 diabetes population not under specialist care attending structured education
- the type 1 diabetes population under specialist care attending structured education
- number of people with type 1 diabetes are offered a personalised care plan including:
    - choice of face to face, telephone, and video consultations
    - access to remote monitoring technologies
    - choice of patient initiated follow up (PIFU)
- type 1 diabetes population offered CGM or Flash

Evidence of collation of and signposting to peer support for people with type 1 diabetes which will need to be regularly updated.

8. ICS maturity matrix

A maturity matrix has been designed by the London Diabetes Clinical Network to assist ICSs to begin to self-determine their current infrastructure for type 1 diabetes care and aid future self- assessment of progress of their transformation programme.

	Leadership & governance	Working in partnership with type 1 diabetes population	Use of population health management data	Design and delivery of type 1 care
Level 1 (Baseline)	ICS level leadership for diabetes exists Established governance structure for diabetes programme across the ICS Clinical engagement across diabetes programme, may or may not have formal clinical leadership Awareness of principles for managing type 1 diabetes but few or no formal workstreams are in place	Awareness of available local community spaces e.g faith groups, that can support improvements in type 1 diabetes population health Awareness of diabetes specific peer support groups e.g. Diabetes UK, JDRF, practice-based groups Is engaging directly with some of their population and are beginning to develop trusted relationships with wider community groups	Regular review and analysis of NDA data for type 1 diabetes population for three treatment target attainment and delivery of eight care processes. Able to utilise local and ICS level population health management data to produce high level analysis on variation in outcomes and service provision for some type 1 population cohorts Ability to extract high level data on health inequalities e.g. ethnicity, deprivation, gender, age, impacting local type 1 diabetes population	Awareness of current service level provision and some of the challenges faced by each provider
Level 2 (Develop)	A Senior Responsible Officer(SRO) and Clinical Leads for type 1 diabetes have been appointed ICS level leadership team is able to create a safe space for specialist and non-specialist providers to have transparent conversations about care provision, data and performance	Beginning to work in partnership with known community groups, to hear first-hand how unmet population need could be addressed Has developed a strategy to identify people not currently accessing specialist care and unknown community groups. Strategy describes how they will obtain understanding of barriers to care, education or support Insight from PLW type 1 in the community and in the voluntary sector is beginning to be utilised to inform service planning and decision making	Accesses data from specialist and non-specialist providers to identify where the type 1 diabetes population has been receiving eight care process and three treatment targets Understands gaps in provider data and creates solutions to consolidate data sources Ability to test different solutions to creating an ICS level shared register for total type 1 diabetes population	Ability to undertake an equality impact assessment for each care pathway to highlight inequity and barriers to access for all population groups Ability to utilise insights from partnership with type 1 community, population health management data and equality impact assessments to critically evaluate access to existing care pathways, self-management education and technologies for all population cohorts

	Leadership & governance	Working in partnership with type 1 diabetes population	Use of population health management data	Design and delivery of type 1 care
Level 2 (Develop)		Has undertaken an initial assessment of available non-clinical community spaces e.g faith groups, that can support improvements in type 1 diabetes population health	Working with local analyst and BI colleagues to run regular reports on type 1 population across clinical health outcomes and health inequalities	
Level 3 QI	ICS type 1 diabetes teams, led by the nominated clinical leads and SRO, implement locally appropriate and sensitive strategies to deliver specialist services, including to people with type 1 diabetes who were not previously reached ICS type 1 leadership teams are able to routinely employ diabetes specialists practitioners to deliver type 1 diabetes services ICS leadership teams able to establish regular high risk MDT meetings, monitoring clinical outcomes.	Has developed established relationships with all local community groups, including people who historically have not accessed specialist care People living with type 1 diabetes are an integral part of planning and decision making, and leaders value their input and insight to inform and co-design service provision Has developed a strategy to support communities to develop self-management resources e.g. facilitate establishing of local peer support groups, where a recognised need is identified	Data analysis is easily accessible, is well coded and routinely reported on across ICS, consistently measuring all outcome metrics and wider determinants of health System utilises data driven approach to evaluate current service provision and develop targeted interventions to address unmet need and health inequalities. Data on the availability and uptake of diabetes technology is routinely measured, reported and evaluated for inequity in access Data is able to measure the impact of personalised care and support its continued development. Shared clinical risk and population registers are fully mobilised and capture total type 1 diabetes population across all specialist and non-specialist providers Full usage and interoperability of shared care registers is in place and is able to monitor at risk groups	Ability to take findings from critical evaluation of existing care pathways and design and implement targeted interventions to address unwarranted variation Has developed a strategy to commission new services, where applicable, that reflect population need, and incorporates deprivation, ethnicity, language, literacy, mental health and learning disability status A cyclical quality improvement approach to review equitable service provision and outcomes for all population groups, underpinned by evidence-based data, is routinely undertaken

9. Appendices: Type 1 care pathways

The Outpatient Transformation Task and Finish Group reviewed each of the care pathways within type 1 service provision. For each pathway, a list of key components, considerations and recommendations are provided, along with some examples of where some initiatives have been implemented

New diagnosis

The diagnosis and management of type 1 diabetes in adults from new diagnosis to 6 months

Key components

- Confirmation of diagnosis of type 1 diabetes is crucial, given that misdiagnosis or delayed diagnosis can occur
- Initial treatment targets may differ from population targets to enable a period of adaptation and to accommodate type 1 diabetes partial remission (‘Honeymooning’)
- Recognition of the psychological impact of a new diagnosis and the need to present a realistic management of expectations to support good health outcomes
- Supportive person-centred language, early identification of distress association with diagnosis

Considerations

- How to prevent those newly diagnosed from becoming lost to follow up in specialist care
- Designing processes that add proactive support to prevent distress aid the person to come to terms with their diagnosis, rather than waiting to identify people in distress
- The first-choice insulin regimen at diagnosis is multiple dose injections with basal insulin in line with NICE Guidance but there may be scenarios, especially in very young children, where it is appropriate to consider immediate insulin pump therapy.
- It may be appropriate to immediately commence flash or real-time CGM but the person may require more time to adjust or room to develop skills, ability and confidence. Specialist MDTs should consider contingency for device failure and ensure newly diagnosed are able to self-manage safely with capillary blood glucose testing
- While frequent specialist MDT contact is required immediately after diagnosis, a transition to a patient-initiated follow-up model may be appropriate for people self-managing safely and effectively
- Where someone who is newly diagnosed does not want to engage with specialist care or is unable to come into hospital for a variety of reasons, consider potential alternatives as means of support eg. PCN social prescribing or personal health budgets for those on lower incomes

Recommendations

1. Rapid specialist clinic access for people with suspected type 1 diabetes to avoid admission
2. Delivery of eight care processes in specialist or non-specialist care
3. Monitoring of three treatment targets
4. Referral for structured education to be delivered after 12 months
5. Ensure those newly diagnosed are signposted to peer support services in their area
6. Co-ordination of follow up care across specialist and non-specialist providers
7. Robust and consistent coding of outcomes and of the type 1 diagnosis
8. Regular review of shared register at local or ICS level MDT
9. Review and consider what technology is appropriate to a newly diagnosed person

Supporting examples

- Rapid access clinics at Guy's and St Thomas's Rapid access diagnostic clinic
- Rapid access clinics at Imperial College Healthcare with same day or next day review by specialist MDT

Children and young people

The diagnosis and management of type 1 diabetes in children and young people under 18 years of age.

Key components

- Children and young people (CYP) should be seen in specialist care on the same day of suspected diagnosis and should receive confirmation of diagnosis and treatment initiation that same day by trained paediatric diabetes professionals
- Supportive child-centred messaging at diagnosis and throughout to stave off disengagement with their diabetes. Families, children and young people with diabetes benefit from a good start to diabetes care with confident, positive support and advice (NICE, 2015)
- All eligible CYP can have access to a suitable insulin pump and CGM, if they satisfy NICE criteria, including children below 2 years of age. Early education and training on device data and uploading encourages self-management ownership

Considerations

- Children and their carers' ability to use technology needs to be considered, when deciding upon insulin regime to optimise glycaemic control, with adjustments made for those with learning disability, visual impairment and/or hearing impairment. The involvement of play therapists, learning disability nurses, family support workers and youth workers can all play a role in supporting assistive technology use. Very young children (<2 years) and their carers would need more intensive support and they should have access to appropriate technologies to maintain normoglycaemia
- Remote, virtual consultations and occasional home visits undertaken by Paediatric DSNs and/or dietician could be considered as alternatives for those who have difficulty in attending hospital clinics, particularly in the initial phases of diabetes management
- School based clinics can improve attendance of secondary school children and their parents/carers, whilst also minimising disruption to school learning. Consider establishment of nurse led clinic facilities in sixth form colleges – often the most difficult age group to engage
- Transition services for young adults are often under resourced and sometimes unavailable and therefore risk a cliff edge descent into poorer health outcomes. It is more likely that an effective and well attended transition service will be one that is co-designed with young people around their needs and preferences and co-located with the paediatric service (GIRFT, 2020)
- Pathways should include specific advice and support to aid type 1 diabetes management during teenage pregnancy

Recommendations

1. Delivery of eight care processes in specialist or non-specialist care settings
2. Monitoring of three treatment targets
3. All newly diagnosed CYP with type 1 diabetes to achieve a HbA1c <53 mmol/mol by 1 year post diagnosis
4. Co-ordination of follow up care across specialist and non-specialist providers
5. Robust and consistent coding of outcomes and of the type 1 diagnosis
6. Regular review of shared register at local MDT with ICS level oversight MDT
7. Ensure CYP and their families are signposted to peer support services in their area
8. Provision of psychological input to all children and young people who need it, offering emotional support, online or telephone counselling or referrals for specialist support
9. All providers to have a dedicated transition service with a clear pathway between paediatric and young adult services, in line with GIRFT recommendations, given the variation of service provision that currently exists across London

Supporting examples

- Guys & St Thomas' Foundation Trust -Youth empowerment skills (YES) transition programme
- Hillingdon Hospitals NHS Foundation Trust – School clinic for children with diabetes
- Paediatric diabetes - Barts Health NHS Trust

Self management education

Background

The NHS Long Term Plan set out to improve access and uptake of structured education for all people living with diabetes. Diabetes self-management education allows people to make the daily self-care decisions required to effectively manage their diabetes. This has been shown to reduce severe hypoglycaemia by 67% and ketoacidosis by 61% (Diabetes UK) and to improve psychological well-being.

Despite significant transformation funding investment into structured education across England between 2017-2021, structured education provision for type 1 diabetes is still limited to a small number of accredited courses. It is estimated that only between 15-30% of people newly diagnosed with diabetes attend structured education despite high referral rates by GPs (NHS Long Term Plan). NICE NG17 recommends adults with type 1 diabetes are offered a structured education programme 6 to 12 months after diagnosis (NICE, 2015)

An individual's diabetes knowledge and ability to self-manage their condition should be regularly reviewed as their needs may change over time. Self-management education should not be limited to structured courses 6-12 months post diagnosis and should be offered ad hoc at key touch points, for example:

During COVID-19, face to face provision of structured education was paused. Some ICS in London were able to develop virtual and digital offers while others utilised the nationally commissioned offers. ICS continue to increase the number of digitally commissioned places as face to face provision recovers.

Examples of online resources

BERTIE Online : a free modular e-learning resource

T1 resources : a free website curating and quality assuring existing web content for T1 diabetes

Diabetes UK Learning Zone tailored online education for type 1 & type 2 diabetes

My Type 1 Diabetes : Nationally commissioned free online learning modules and resources

Ideas for low literacy/numeracy

Resources to help people with low health literacy and numeracy to upskill or work around some of the complicated calculations needed to manage type 1 diabetes include:

- **Skills for Health** : government backed programme to reduce health inequalities by improving language, literacy and numeracy skills
- **National Numeracy Challenge** : website to check and improve numerical ability
- Some diabetes educators use scoops/cups/finger sizes to measure carbohydrate content of meals

Considerations

- Commitment to support local innovation to become accredited and financially viable
- Strategies in place to identify and overcome psychosocial barriers to attending structured education
- Working with providers to ensure course places are available to those not under specialist care
- Provision of structure education in a range of languages and using peer support when this is not available
- Factoring in retention and training of educators into commissioning processes
- Forecasting future need including oversight of workforce required to meet this
- Questions and considerations during the commissioning process include:

Commissioner	Provider
Where are the courses delivered?	• Venue – non-clinical building, ease of parking, ease of travel, disability access, hearing loops.
When are the courses delivered?	• Weekend, evenings, full day and smaller ‘chunks’ options.
What is the delivery method?	• Group with peer support element, one to one, remote learning, digital app based or mixed method
What are the ongoing infrastructure costs?	• Number of educators trained and re-validated per year • Administrative support • Running and export of reports • Cost of accreditation and revalidation
How is data captured and reported?	• Systems are in place to capture referrals, attendance, completion, ethnicity, deprivation, gender? • Outcomes are SNOMED coded?
What are the strategies in place to overcome local barriers?	• Supporting low literacy and low numeracy skills • Accepting referrals for patients not under specialist care • Supporting those without usual access to virtual or digital education • Reasonable adjustments to courses for different needs, skillsets and languages • Signposting to local resources or peer support groups • Easy access to commissioned mental health support such as IAPT services & Good Thinking app • Access to social prescribing and personalised care offers e.g. personal health budgets
Is the course NICE or QiSMET accredited?	• If not, is the provider working towards this?
How are the courses promoted?	• Easy for specialists and non-specialists to refer in • Information available for referrers to discuss options with patients

Recommendations

- Commissioning of face to face and digital course provision, should reflect the needs of local population in terms of deprivation, ethnicity, language spoken, mental health and learning disability status (NICE, 2015)
- Promote nationally commissioned offers where there are local gaps
- Work with structured education providers and primary care networks to improve outcome SNOMED coding in primary care records
- Set key performance indicators with each provider, in line with outcomes in this framework
- Regular data reporting at ICS, regional and national level on referrals, uptake, completion and how provision in the ICS is addressing local health inequalities

Peer support

What is peer support?

We define peer support as practical support or advice provided by people living with a condition about what it is like to live with condition

Why is peer support important?

- Peer support can deliver practical assistance, and emotional and social support to manage long term conditions.
- The combined years of lived experience within a peer support group is a unique and powerful resource. Peer support can provide emotional support to reduce isolation, allowing people to discuss how their diabetes makes them feel, within a safe environment, with others living with the same condition
- On average people living with diabetes spend up to three hours a year with a healthcare professional, managing their diabetes by themselves for the remainder of the year. Inevitably, there will be queries about management where easy access to their healthcare team may not be possible
- Peer support can be delivered in a range of face to face or online formats providing convenience and flexibility

Examples

While not for everyone, peer support can provide safe spaces to share experiences and practical tips about living with diabetes and to troubleshoot technology issues. It can empower members to speak about issues and offer emotional support to each other.

WhatsApp messenger groups

face to face groups e.g. Diabetes UK group finder

social media groups through Facebook & Twitter e.g.
Diabetes Lounge
UK Diabetes Online Community

virtual group meetings e.g. Zoom, MS Teams, FaceTime

Key components

- **Safe space** - Provides a fun, safe and open environment where members feel they can give and receive support
- **Facilitation** - Run by skilled, energetic facilitators with lived experience who encourage members to have choice and control in how they are involved in their peer support
- **Ground rules** - Sets agreed ground rules on how it will operate and recognises that its purpose is to provide practical and emotional support, rather than clinical advice
- **Inclusive** - Considers the mode of delivery for peer support. Online platforms may benefit more those with children and caring responsibilities
- **Consistent** - Meetings are held regularly and provide variety in how they are delivered; a blend of discussion and activities

Considerations

- ·Access to peer support is patchy and not universally offered to all people with type 1 diabetes
- Consider supporting a local community organisation to set up a peer support group where there is a particular need. Group design should be such that the facilitator does not act as a diabetes expert. The group, as a collective, are the experts and each member will have something to offer through their lived experience. If starting a group initially led by health professionals, training should include how to make sure the group is not dependent on them and identifies the right time to step away, to allow growth into a peer-led group
- Consider how peer support could promote health literacy and reduce health inequalities. There are opportunities to encourage all communities to engage with the benefits of peer support and to feel informed about their health. Be mindful of the impact digital exclusion and digital health literacy could have, on access to and uptake of online peer support forums, within particular demographics. Access to and confidence with smartphones, laptops and broadband should not be assumed. Select venues for face to face groups that are accessible for those with disabilities

Recommendations

1. **Encourage peer support access for all**: Every person with type 1 diabetes should be signposted to available peer support in their area, include face to face and virtual/online options, and any other resources of note (e.g. online resources, leaflets eg 'Your life, your way guide to Type 1 diabetes' .

2. Establish a peer support database for your area:

- Carry out an engagement exercise to be aware of existing local peer support services for people living with type 1 diabetes
- Ask individuals if and where they are accessing peer support, as this is likely to generate groups not discoverable through Google searches
- Utilise online diabetes peer support group finders such as Diabetes UK
- Categorise support groups into face to face and online options
- Share list widely across the Trust department
- For those hospital services with a wide patient population, remember to reach out more widely than just the immediate vicinity of the hospital
- Review resources at agreed intervals (e.g. annually) to ensure the information is still up to date

3. Provide training for peer support facilitators, and raise awareness among staff of the value of peer support

- Diabetes UK can provide volunteer training for facilitators to lead groups
- Some Trusts have supported the development of facilitator training for peer-led support groups in their local community
- Promote staff awareness of local peer support groups and provide information on governance and responsibilities

Hypoglycaemia

This section relates to the initiation of pathway after an episode of severe hypoglycaemia (requiring the assistance of a third party for active treatment), in anyone with hypoglycaemia unawareness (Gold Score 7), or where the type 1 diabetes specialist MDT agree there is exceptional risk of severe hypoglycaemia.

Key components

- An integrated pathway with 111, emergency services, local diabetes teams, primary care and pharmacy
- An established high-risk multidisciplinary team (MDT)
- Psychological support to manage fear of hypoglycaemia or fear of high blood glucose values

Considerations

- This pathway provides an opportunity to listen and engage with people not previously known to a specialist MDT service. When agreeing treatment plans, consideration should be given to language, culture, deprivation, psychosocial status and personal preference to address any barriers to obtaining improved and consistent hypoglycaemia awareness
- Evidence-based technologies to reduce the frequency and severity of hypoglycaemia are real-time continuous glucose monitoring with alerts and alarms, and insulin pump therapy. NICE Guidance and London commissioning guidance ensures access to both modalities for people with severe hypoglycaemia or hypoglycaemia unawareness
- When considering remote monitoring, PIFU and technologies, numeracy, literacy and access to internet and data services are primary considerations
- Each ICS must have an identified referral pathway for whole pancreas and pancreatic islet cell transplantation programmes, where technologies are not effective or not appropriate
- While frequent specialist MDT contact may be required initially after an episode of severe hypoglycaemia, a transition to a patient-initiated follow-up model may be appropriate where risk has been reduced

Recommendations

1. Implement pathway to identify people with type 1 diabetes utilising emergency medical services in partnership with London Ambulance Service and ICS Accident and Emergency Departments
2. Ensure urgent specialist MDT access (eg ‘two-week wait’) for people meeting pathway access criteria

3. Provide fast-track access to evidence-based interventions to prevent recurrent and life-threatening severe hypoglycaemia (including structured education, psychological interventions, continuous glucose monitoring, and insulin pump therapy)
4. People unable to travel to specialist MDTs should have care delivered in an appropriate environment (eg in care homes). Care can also be offered virtually in order to maximise choice
5. Regular reporting of SUS data to monitor the number of admissions for hypoglycaemia and ketoacidosis every 12 months

Supporting examples

- **Lambeth London Ambulance Service collaboration** – pathway implementation to identify Lambeth residents with severe hypoglycaemia attended by emergency medical services
- **Imperial College Healthcare NHS Trust severe hypoglycaemia pathway–** a specialist MDT pathway
- **HARPdoc** programme at King's College Hospital– hypoglycaemia restoration awareness programme using talking therapies

Reproductive health

For women with type 1 diabetes, to support optimal self-management before, during and after pregnancy, and around the menopause.

Key components

- A diabetes specialist midwife and obstetric team
- Establishment of a pre-conception counselling pathway

Considerations

- Women with type 1 diabetes not regularly able to access specialist MDT care are at high risk of adverse maternofetal outcomes. Careplans for contraception and pre-conception care for these women should be shared across all ICS providers and proactive care provided, taking in to account location, deprivation, cultural and psychosocial needs
- Technology - CGM access must be provided for all pregnant women with type 1 diabetes. CGM has been associated with a reduction in rates of pre-eclampsia, and a reduction in adverse neonatal outcomes (large for gestational age, neonatal hypoglycaemia and neonatal intensive care admission) for their babies (Feig et al, 2017)
- Frequent face-to-face antenatal MDT contact is often required during pregnancy, but remote monitoring may support interim virtual consultations. For glucose challenges during the menstrual cycle or menopause a PIFU model may be established to address challenges when they arise in a changeable scenario

Recommendations

1. Offer pre-conception counselling to all women with type 1 diabetes of childbearing age at each clinical encounter
2. Discuss contraception with all women with type 1 diabetes of childbearing age at each clinical encounter
3. Discuss potential impact on glycaemia of menstrual cycle and the loss of the menstrual cycle at menopause
4. Women with extreme glycaemic variability associated with their menstrual cycle should have access to a reproductive endocrinology service
5. Offer continuous glucose management (CGM) to all pregnant women with type 1 diabetes

Supporting examples

Health Innovation Network (HIN) Tackling Diabetes in Pregnancy through a Community of practice: A London Experience

Frailty, dementia and end of life care

People living with type 1 diabetes may have other conditions that contribute to multimorbidity (irrespective of their age), and older people with diabetes may be frail elderly, or live with cognitive impairment. End of life care for people with type 1 diabetes may be managed at home, in hospice care, or in hospital and may require specialist input. This pathway aims to ensure multidisciplinary input for multimorbid, frail, elderly, cognitively impaired and dying people with type 1 diabetes.

Key components

- ICS level type 1 diabetes links to elderly care services, community support for frailty, care homes, palliative care services and memory clinics to identify people at risk and plan care

Considerations

- People with type 1 diabetes living with multimorbidity, frailty, dementia, or in end of life care, may not benefit from intensive glucose management
- Balance avoidance of extremes of glucose with potential long-term benefits of aiming for target glucose

- Changes to treatment priorities may need to be communicated to multiple agencies
- Face to face care may not be possible
- De-intensification of glucose management may be distressing to the person with type 1 diabetes and dependency on others for management may be challenging

Recommendations

1. Agree personalised treatment targets, ensure careful documentation and disseminate across the multiple agencies involved in care
2. Where possible, discuss the transfer of management with the person living with type 1 diabetes before it is required so it can occur, if safe and feasible, in line with their prior wishes
3. Discuss any advanced directives with the person with type 1 diabetes
4. Prioritise avoidance of symptomatic hyperglycaemia and hypoglycaemia for people in end of life

Supporting examples

Diabetes UK End of Life Care Position Statement

10. Language matters

Healthcare professionals are in a position to influence people with diabetes positively or negatively through language. The impact of our choice of language, whether verbal, written or non-verbal can affect the thoughts, feelings and behaviours of a person living with diabetes.

Language Matters: Language and diabetes sets out the principles for interactions between healthcare professionals and people living with diabetes and offers practical examples of research-based language that can encourage positive interactions and subsequently positive outcomes.

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