Implementation guide

NHS

London Clinical Networks

Ensuring excellence in type 1 diabetes provision and commissioning

September 2016

How to use this pack

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

There are three parts to this commissioning pack:

- **Service specification** - Aimed at commissioners, this document details the commissioned care that would be expected for adults with type 1 diabetes, including an overview of diabetes, elements of an excellent service plus commissioning recommendations.
- **Clinical management: Optimal pathway** - Aimed at providers, this document details expected clinical care for type 1 diabetes.
- **Implementation guide *(this document)*** - This document provides the tools and templates for both commissioners and providers to measure and improve 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 planning tool (developed by Health Innovation Network and King's Health Partners).

The London Diabetes Clinical Network, working with the academic health science networks in London, CCGs, Diabetes UK, JDRF (Juvenile Diabetes Research Foundation), Association of British Clinical Diabetologists (ABCD) and other stakeholders to 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.

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COMMISSIONING FOR TYPE 1 DIABETES

Nine commissioning recommendations

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

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

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

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

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

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

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

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

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

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

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

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

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

Commissioning for type 1 diabetes

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

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

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

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

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

Core and enhanced classifications

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

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

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

Clinical and service recommendations

Recommendation 1 | Type 1 service

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

Recommendation 2 | Structured education / self management programme

- All staff caring for patients with type 1 diabetes should be trained in DAFNE (or a NICE compliant alternative).
- All adults with type 1 diabetes should be offered a diabetes structured education programme.
- There should be a coherent CCG strategy to offer and deliver structured education to ALL patients with type 1 diabetes – prioritising in the following way:
  1. All people newly diagnosed with type 1 diabetes within one year of diagnosis.
  2. Those with problematic hypoglycaemia or an HbA1c above target
  3. All women of childbearing age with type 1 diabetes.
  4. All patients with type 1 diabetes on an ongoing basis throughout their lives to ensure motivation is maintained and skills are refreshed and up to date with new developments.

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

Recommendation 3 | Carbohydrate counting

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

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

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

Recommendation 5 | Prevention of hypoglycaemia

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

Recommendation 6 | Diabetes psychology pathway

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

Recommendation 7 | Eye screening

It is imperative that all diabetes staff:

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

Recommendation 8 | Type 1 services for women of childbearing age

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

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

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

Additionally:

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

Recommendation 9 | Transition to adult diabetes services

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

Recommendation 10 | Technology

Patients who require it should have:

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

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

National Diabetes Audit results

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

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

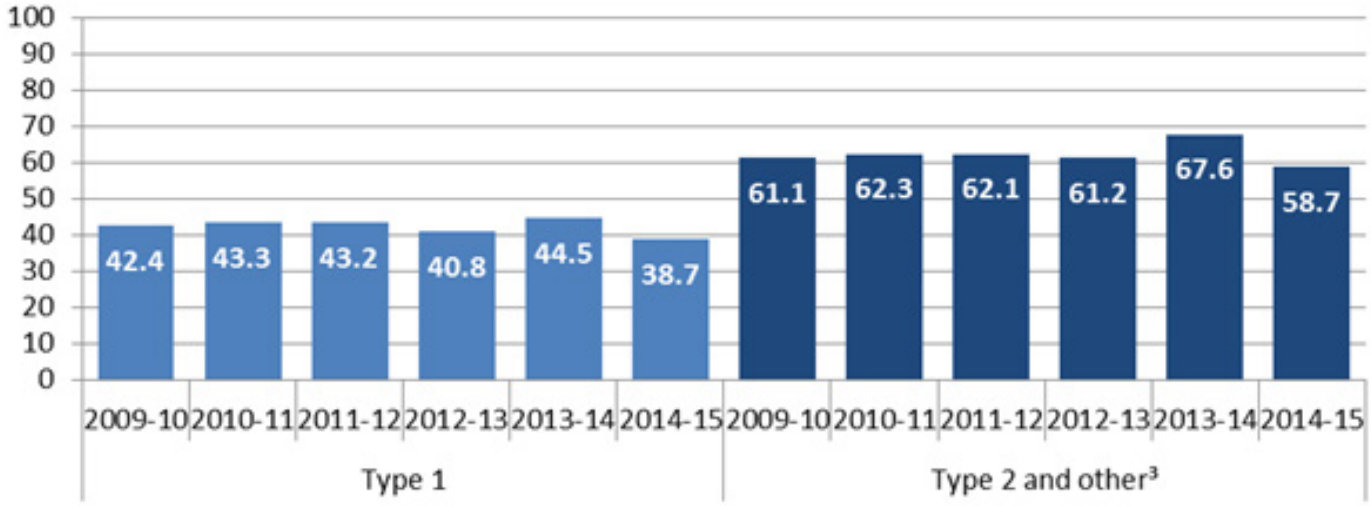


Table 1: Percentage of people with diabetes in England and Wales receiving all eight NICE recommended care processes by diabetes type and audit year

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

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

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

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

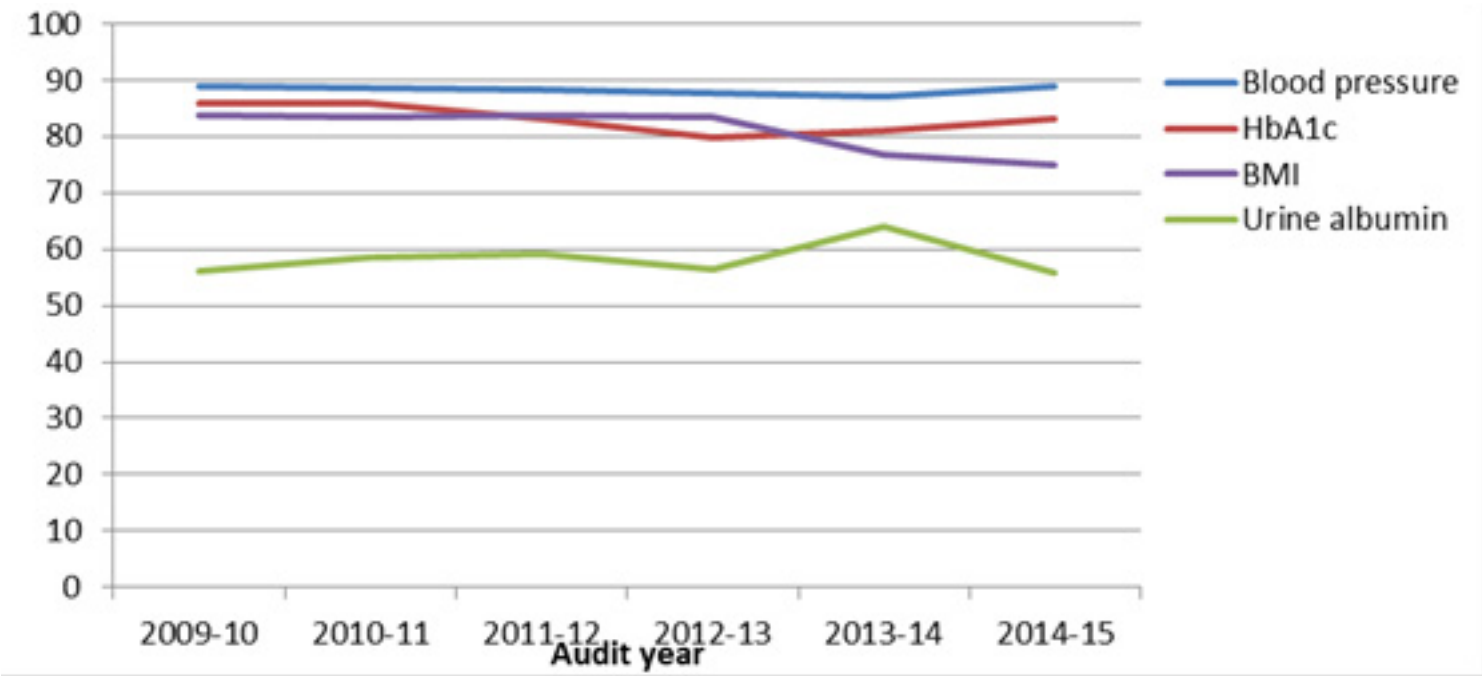


Table 3: Percentage of people with type 1 diabetes in England and Wales receiving certain care processes by audit year
Note: There was a 2013/14 'health warning' regarding the screening test for early kidney disease (urine albumin creatinine ratio, UACR).

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

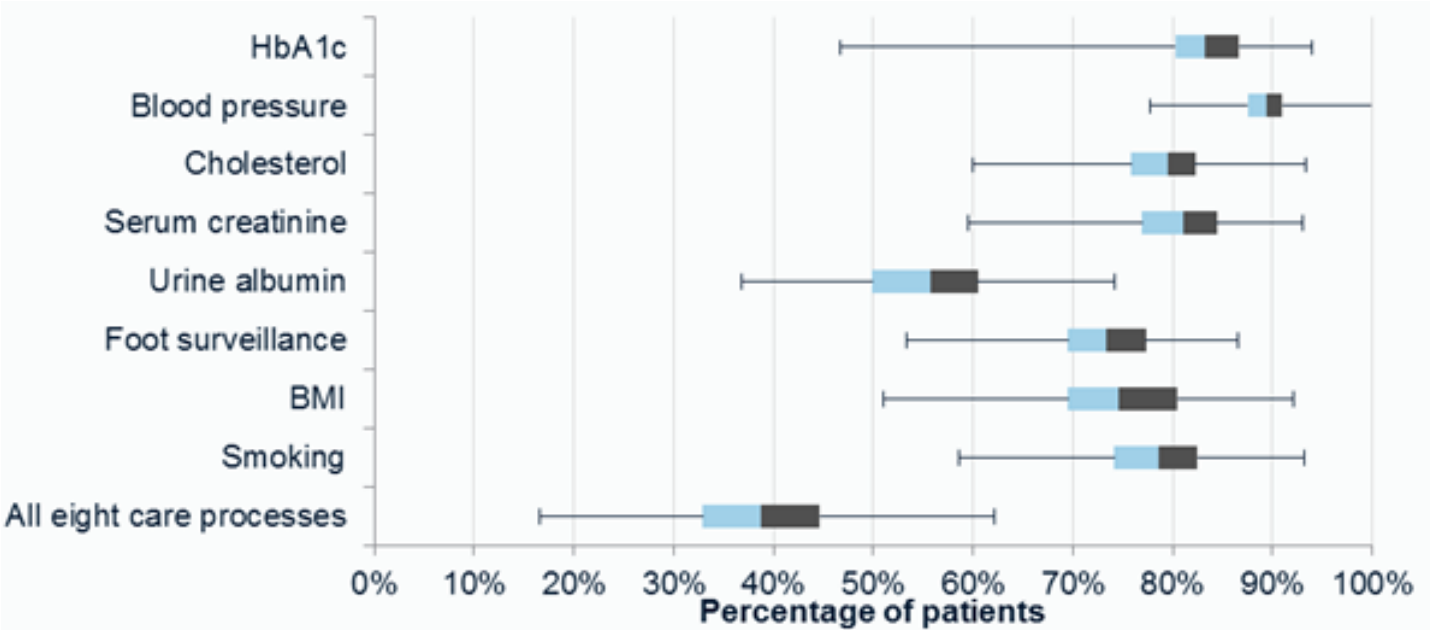
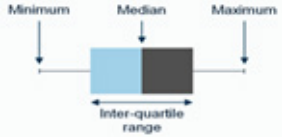


Table 4: The range of CCG/LHB care process completion for people with type 1 diabetes in England and Wales, 2014/15



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

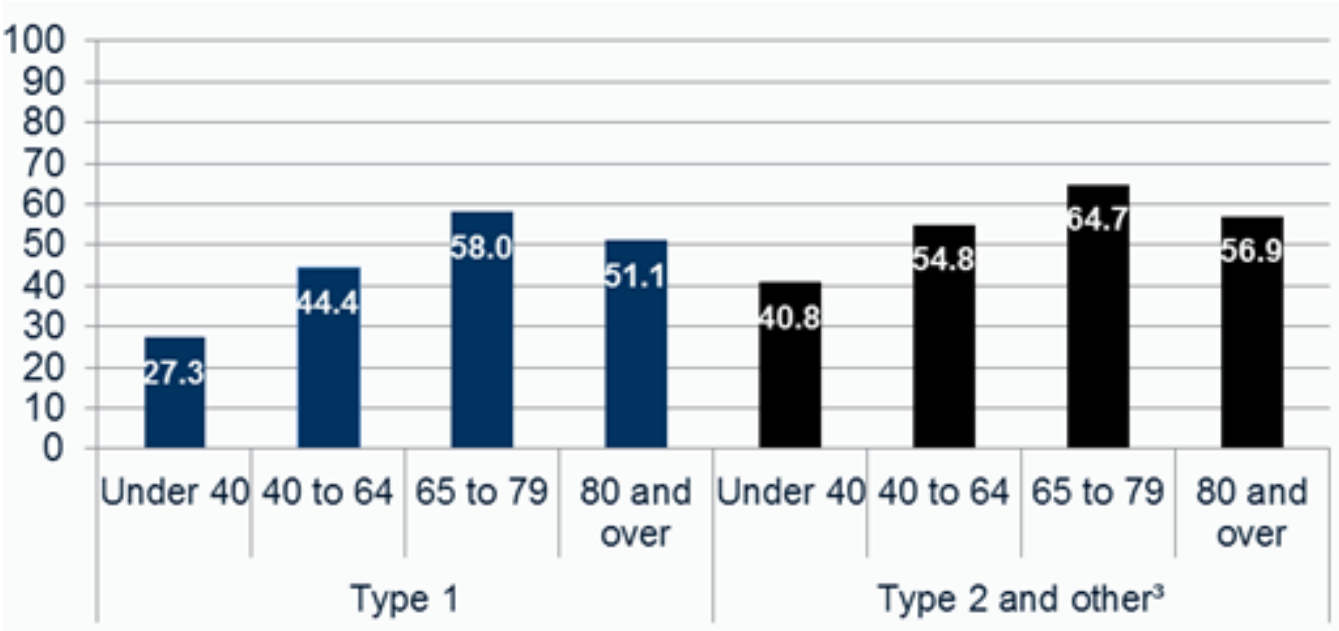


Table 5: Percentage of all people with diabetes in England and Wales receiving all eight NICE recommended care processes4 by age and diabetes type, in 2014/15

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

Image source: Medtronic

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

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

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

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

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

Type 1 performance targets / outcomes

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

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

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

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

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

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

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

» Measure the impact and outcomes for the service.

» Improve quality across the patient pathway.

» Take steps to provide innovative and continually developing services.

Type 1 performance targets / outcomes

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

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

Type 1 performance targets / outcomes

Outcome measures for type 1 diabetes service

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

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

Type 1 performance targets / outcomes

Outcome measures for type 1 diabetes service

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

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

Type 1 performance targets / outcomes

Outcome measures for type 1 diabetes service

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

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

TYPE 1 PERFORMANCE TARGETS / OUTCOMES

Outcome measures for type 1 diabetes service

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

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

Type 1 performance targets / outcomes

Outcome measures for type 1 diabetes service

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

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

Sample PROM form

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

Patient reported outcomes measure feedback questionnaire

Part of IPU (service name)_____

Date: _____

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

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

Name (optional):_____

Email (optional): _____

Mobile (optional): _____

Section A

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

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

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

☐ **YES** ☐ **NO**

If no, please tell us why:

_____

_____

_____

_____

SAMPLE PROM FORM

SECTION B

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

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

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
				

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

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
				

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

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
				

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

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
				

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

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
				

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

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
				

Sample PROM form

Section C

Please circle YES or NO as appropriate:

9. Do you feel that your care is coordinated?

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

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

12. Do you feel involved in planning your care?

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

Thank you for taking the time to complete this questionnaire.

Type 1 diabetes consultation tool

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

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

Download the toolkit via the HIN website:

[Explanation sheet]

[Consultation tool]

[Diabetes distress score worksheet]

[Consultation tool (large text)]