



Diabetes Transition Service Specification

January 2016

Diabetes transition and young adult service specification and guidance document

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Description	The purpose of this specification and guidance is to set out a best practice model and to outline the considerations commissioners may want to make in stipulating and providing services for young people with diabetes going through the transition process. The document is presented in two parts - part one provides guidance, and part two is the specification template.
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Contents

Contents	4
Note to commissioners – using this document	5
1 Part One: Guidance on using this specification	7
1.1 Introduction	7
1.2 Wider context of transition and diabetes in young adults	7
1.3 Mental health and diabetes.....	8
1.4 Financial cost of failing to implement appropriate transition	8
1.5 Needs of parents and carers	9
1.6 Structure of service development	9
1.6.1 Paediatric/early preparation	9
1.6.2 Planned transfer	10
1.6.3 Supported integration	10
1.7 Links to other documents and sources of support	11
2 Part Two: Specification.....	12
2.1 Service specification	12

Note to commissioners – using this document

The purpose of this specification is to set out a best practice service provision model and to outline the considerations to be made by commissioners in stipulating and providing services for young people with diabetes going through transition and as young adults. The use of this document should support improvements to existing CYP and adult services to ensure that they take account of the needs of those who are transitioning. In the context of this specification, commissioners should consider the needs of all young people with diabetes up to the age of 25.

This specification is non-mandatory. It has been prepared by an expert reference group supported by NHS England, and led by the National Clinical Director for Children, Young People and Transition to Adulthood and the National Clinical Director for Obesity and Diabetes. It is designed to inform the development of a clear local approach with multi-agency partnerships to include: health, social care, education, local authorities and where appropriate, third sector providers.

This document is presented in two sections: the guidance on using this service specification (part one); and the specification template (part two), which can be put into the NHS Standard Contract. Within the template, local detail should be added below the green headings as indicated. The text that is in **red** is guidance for commissioners and must be deleted before the service specification is included in the NHS Standard Contract. Text in **black** is suitable for inclusion in the NHS Standard Contract but may be varied locally by commissioners. The service specification documents should be read in conjunction with the NHS Standard Contract and the NHS Standard Contract Technical Guidance located on the [NHS England website](#).

Commissioners should set out a clear specification for transition and young adult services based on the local context and information from tools such as the Joint Strategic Needs Assessment (JSNA). The guidance and considerations set out in this document are intended as a framework from which a local transition and young adult service can be shaped.

Although the specification has been developed using an NHS template, its content can be used by other commissioners as appropriate and it aims at all times to acknowledge the multi-agency nature of commissioning and delivery of diabetes services and support. The specification should be appended to the NHS Contract as Schedule 2A.

The specification should be consistent with any Public Health and other Local Authority contracts or specifications relating to diabetes and transition in specialist services and long term conditions. Engagement and consultation with young people and their families has informed the content of this specification, to ensure the resulting care pathway is most representative of young people.

The template should be used as a tool to highlight the responsibilities of the commissioner and provider in delivering transition and young adult services to the standards set out in the NICE guidelines for Diabetes (type 1 and type 2) in children and young people: diagnosis and management and Diabetes in adults (see link below).

Thorough engagement has also taken place with CCGs and other commissioners to ensure that this specification is a useful tool for them to improve the transition process for their local population. Commissioners should include young people and their parents / carers, as well as providers, in adapting this specification to suit local circumstances and needs.

Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010)ⁱ and those who do not share it;
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from, healthcare services and in securing that services are provided in an integrated way where this might reduce health inequalities.
- Commissioners must also assess local equality and inequality needs at a local level when they are commissioning a service by conducting an Equality and Health Inequalities analysis.

This specification contains hyperlinks (underlined sections) to guidance developed by a group of NHS and Local Authority commissioners, providers and young people who worked on this specification together. For this reason, commissioners may find it helpful to work with this document on a computer rather than with a printed copy.

Please note that this sample service specification has been produced at a moment in time and will not be routinely updated.

1 Part One: Guidance on using this specification

1.1 Introduction

Diabetes can have a significant impact on the life of a young person and their family or carers.ⁱⁱ Good management and support through insulin management, education, and psychological services are essential to promote lifelong management of the condition and positive outcomes.ⁱⁱⁱ Engagement with transition and young adult services is crucial to achieve this, and can fall down at times of transition, sometimes with serious and lasting consequences.^{iv}

Transition in this context refers to the time when a young person moves from one diabetes service to another. Often this is from a paediatric service to an adult service, but this specification also refers to moves between different adult services, including to primary care settings, and moves across geographical locations. This is because many people with diabetes between ages 13 and 25 have never seen paediatric services due to being diagnosed after age 18.^v Indeed these may well constitute the majority in this age range, however, they would still benefit from transition services as they move from one type of provision or service to another.

There is evidence to suggest that often young people do not get a good experience of transition and consequently may not have such good management of their diabetes.^{vi} This specification is designed to support commissioners in developing transition and young adult services that provide the best support to young people at this time.

1.2 Wider context of transition and diabetes in young adults

An existing specification is in place to support the generic principles and outcomes for transition for a range of long term conditions and that generic specification applies to all services providing specialist health services for young people detailed within the NHS England Prescribed Specialised Services Manual.^{vii} This specification builds on those common principles and also highlights the diabetes specific issues to be addressed in the development of any diabetes specific transition service.

Many children and young people suffer more than one co morbidity or long term condition, so could be experiencing multiple service transitions simultaneously. Whilst this specification highlights a diabetes specific approach, it could be relevant more widely.

Transition and young adult services should also take into account the broader changes to a young person's life at this time. As well as dealing with diabetes, they may also be experiencing other concurrent life changes such as the end of full-time education, a potential move away from parents and carers, university, starting work, making career choices, and experimenting with alcohol, sex, drugs and as well as the interchange between primary and secondary care.

Services for young people with diabetes aged up to 25 will require engagement with both paediatric and adult diabetes services. The annual incidence of a new diagnosis of diabetes is the same for those aged 16-20 and 20-25^{viii} and inevitably there will be higher numbers aged 19-25 in any locality. Both in-patient and out-patient diabetes

care for those aged 19-25 will most usually take place in adult services,^{ix} most certainly when diabetes first presents at that age.

1.3 Mental health and diabetes

Mental health has shown to be a significant co-morbidity in type 1 diabetes, whereas good emotional and mental well-being and support can promote vital resilience at this time.^x

There is a strong correlation between a high number of psychosocial issues including anxiety and depression, and an increase in of negative outcomes for CYPs including increased HbA1c and a longer gap between young people's appointments. Young people with a chronic condition are also shown to be more likely to engage in risky behaviours such as alcohol and substance misuse.^{xi}

Diabetes has also been linked to increased risk of eating disorders, with some studies suggesting rates as high as 20% in the adolescent population with those young persons who have type 1 and 2 diabetes.^{xii} Disturbed eating behaviours are common where manipulation of insulin or hypoglycaemic agents is used to manage body weight.^{xiii} When commissioning diabetes transition and young adult services, commissioners should be aware of this increased risk and employ screening tools to ensure those at risk can be appropriately supported.

Timely and ongoing access to mental health professionals should be integral to any diabetes transition provision for young people and their families or carers.

1.4 Financial cost of failing to implement appropriate transition

There is a growing evidence base documenting the significant mortality and morbidity risks in relation to young people's acute and long- term health and wellbeing if disengagement and non-concordance with their recommended health care plan occurs during adolescence and young adulthood.^{xiv}

Eighty per cent of NHS spending on diabetes goes on managing complications, much of which could be prevented.^{xv} The point of transfer between services and engagement with a new team and culture in adult health care is recognised as a potential risk escalator, but can also be viewed as a key opportunity to support effective management and engagement.^{xvi}

In addition to the adverse impact on the health, social and educational outcomes for the young person and their carers, if transition is not effected appropriately, there are recognisable impacts on resources in health care and other agencies through repeated non-attendance for planned care, increased use of urgent / out-of-hours care and increased complexity of need through secondary / avoidable complications.^{xvii}

The impact of preventable complications can add a significant burden to already overwhelmed healthcare systems, increase unemployment, reduce job productivity, and increase cost of disability. The presence of diabetic complications increases NHS costs more than five-fold, and increases by five the chance of a person needing hospital admission^{xviii}.

1.5 Needs of parents and carers

Whilst transition is often focused around the needs of the young person, it should be noted that the parents and carers are also often undergoing their own transition as they come to terms with change to the way that they support and engage with the young person's condition.

Parents have separate needs that should be accounted for in the development of any transition and young adult service especially in the way that they are communicated with, the information that they need and how it is provided as well as in support of the parallel transition that parents often make. Advice and support should be offered to parents and carers, about other services and support that they may be entitled to including entitlements specified in the [Care Act 2014](#).

Good outcomes have been achieved where clinics have implemented models in which there is a gradual and well planned move away from joint consultations, where the young person has the opportunity to have independent sessions with clinicians and where there is a specific service to meet the needs of parents. Information should be provided specifically to the parent to address the issues that they are likely to face, in formats or using methods that are familiar and accessible, including the provision of separate consultation sessions.

1.6 Structure of service development

The development of any service should be considered according to three key stages of transition; paediatric preparation; planned transfers and supported integration into adult services and new care settings.

In addition to this, further themes to be considered in the development of good transition services are presented in the specification around the following themes:

- Person centred and responsive
- Access and engagement
- Partnerships and coordination / Integrated services
- Independence and autonomy
- Staged and timely
- Structures and systems
- Psychological support
- Clinical standards
- Continuing care and assessment

1.6.1 Paediatric/early preparation

In order to enable service users and their carers to become and remain active partners in their care, to prepare for transfer(s) and to engage with a new service, engaging, sensitive and developmentally appropriate care planning should start with the young person and their family from the point of diagnosis.

Early preparation and planning for the transition period is essential in managing expectations, promoting understanding and involvement in the wider process, and

ensuring that the service user is well informed and therefore empowered Planning must be based on the young person's physical development, emotional maturity and local circumstances.^{xix}

1.6.2 Planned transfer

It is essential that the young person is not only well prepared prior to transition, but also throughout the actual transfer process. Local protocols should therefore be clearly established with both healthcare teams working jointly to provide assessment and services to young people with diabetes and clarity about who the lead clinician is, to ensure continuity of care

Providers should agree the pathway between the transferring service and receiving services and early as possible to facilitate a smooth and coordinated change. Well planned transfers allow for overlap between the existing and new service; have some consistency, for example a member of the team who moves across the old and new service; and transfer of information; and implementation of the agreed plan and pathway.

'My care plan' (see sources of information section) provides a good template for early initiation of transition planning. Planning for transition should begin early and involve the young person whilst they are still receiving paediatric services to support early preparation and maximise the time the young person has to prepare for the changes.

Young people may be subject to serial and sequential transfers within and across different health care organisations / specialist teams over time. This time also represents great movement and instability for example going to university. Providers should therefore design transition and young adult services with this movement in mind and to engage multi-disciplinary and multi-speciality teams from across the health economy and across geographies.

1.6.3 Supported integration

The transition and young adult service must support integration into adult or new care settings and the design of services must attend to the wider health, psychological, social, educational and vocational outcomes for young people in addition to condition specific outcomes. There should be a focus on enabling optimal health and wellbeing outcomes with young people as they move towards and into adult, specialist services, or primary care services, with close collaboration with GP's and other primary care professionals.

A transition and young adult service should support integration into adult or new services, running both in addition to, and in conjunction with existing child and adult services. Transfers from children's diabetes services, whether to adult diabetes services or to other services, including to and within primary care, are single point events in the entire transition process.

Healthcare teams should work jointly to assess and provide transition and young adult services that are wrapped around and responsive to the needs and preferences of the young person. Diabetes care for those aged 19-25 may be best provided in

dedicated clinics, with the same staff from adult diabetes services that contribute to transitional diabetes clinics.

1.7 Links to other documents and sources of support

- National Institute for Health Care Excellence (NICE) guidelines:
 - o [NICE NG17: Type 1 diabetes in adults – diagnosis and management](#)
 - o [NICE NG28: Type 2 diabetes in adults – management](#)
 - o [NICE NG18 Diabetes \(type 1 and type 2\) in children and young people – diagnosis and management](#)
 - o [NICE Guideline NG3: Diabetes in pregnancy: management from preconception to the post-natal period](#)
- [NHS England Generic Transition Service Specification](#)
- [NHS England Child and Adolescent Mental Health Transition Service Specification](#)
- NHS England [Diabetes Sample Service Specification](#)
- Care Quality Commission (CQC) - [From the Pond into the Sea](#)
- The National Institute for Health Research, [The transition from paediatric to adult diabetes services: what works, for whom and in what circumstances?](#)
- [My Transition Plan, NHS Diabetes](#)
- [Me first, education and training resource](#)
- [NHS Diabetes & Association of British Diabetologists \(ABCD\) Diabetes transition: Assessment of current best practice and development of a future work programme to improve transition processes for young people with diabetes](#)
- [Diabetes UK Recommendations for the provision of services in primary care for people with diabetes](#)
- [Best practice for commissioning diabetes – an integrated care framework](#)
- Department of Health, [Transition: Getting it right for young people](#)
- National Diabetes Audit (NDA) Reports:
 - [Report 1](#)
 - [Report 2](#)
 - [National Paediatric Diabetes Audit](#). Latest published for 2013/14
- [NHS England Equality and Health inequalities guidance for Commissioners](#)
- [VOCAL: Virtual online consultations: advantages and limitations](#)
- [Winocour PH, Care of adolescent and young adults with diabetes – much more than transitional care: a personal view Clinical medicine 2014; 14:274-78](#)

2 Part Two: Specification

2.1 Service specification

Mandatory headings 1 – 4: mandatory but detail for local determination and agreement.

Optional headings 5-7: optional to use, detail for local determination and agreement.

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All subheadings for local determination and agreement.

Service Specification No.	
Service	
Commissioner Lead	
Provider Lead	
Period	
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

The number of young people in need of specialist health care services from paediatric and adult providers is increasing. Improving outcomes in neonatal and paediatric care is resulting in a growing population of young people whose diabetes specific health needs, as they transition from adolescence to young adulthood, require specific and personalised care and support.

The National Paediatric Diabetes Audit (NPDA) measured that there are currently around 27,000 children and young people up to the age of 25 in England with diabetes, around 96% of whom have Type 1 diabetes^{xx}. Although incidence of Type 1 diabetes is particularly high in childhood and adolescence, prevalence will naturally increase in each age band (for example, prevalence 345.1 per 100,000 aged 10-14 years versus 45.2 per 100,000 aged 0-4 years). The prevalence of diabetes therefore remains higher amongst those aged 19-25 than those aged 13-19. The management of diabetes is increasingly an issue with the number of hospital admissions in England among 10 – 19 year olds because of diabetes increasing by 31% between 2002/3 and 2009/10.^{xxi}

The 2012/13 National Diabetes Audit (NDA) showed that people with all types of diabetes were 34.4 per cent more likely to die than their peers in the general population. Among those with Type 1 diabetes, mortality was 131.0% greater than would be expected if they had the same mortality rates as the general population in

1. Population Needs

England and Wales. Overall the annual additional death rates from diabetes continue to fall but there is still a much higher relative risk in younger people and in people with Type 1 diabetes.^{xxii} The relative risk of premature death for young women with diabetes is particularly high.

The NDA also tells us that, in terms of delivery of care processes and achievement of treatment targets, there is a need to address the substantially worse routine care and treatment in younger people with Type 1 and Type 2 diabetes and in people with Type 1 diabetes at all ages. The NDA results have been consistent in highlighting this issue for several years which suggests that the current systems of care that work reasonably well for older people do not deliver the same benefits to younger people with diabetes. Given the inevitable adverse consequences for these younger people of disability and premature mortality in middle life, designing better systems of care for them would yield considerable health benefits.

In those people who avoid complications of diabetes, life expectancy is good, whereas it is severely compromised for those who experience complications, more so in those with diabetic nephropathy. In type 1 diabetes aside from diabetic ketoacidosis (DKA) which is an immediate consequence of treatment failure, the other complications arise only after many years of exposure to high blood glucose, high blood pressure and high cholesterol compounded by age, inactivity, weight gain and smoking, meaning that failure to deliver effective care to diabetic children and young people is likely to store up health problems for later in life.^{xxiii}

Diabetes transition and young adult care has been prioritised by both the Department of Health and NHS England and whilst effort has been made to generate improved outcomes in transition, transition and young adult Services remain varied according to local resources, patient mix and clinical expertise. The Best Practice Tariff, introduced in 2012 to ensure equity of care for young people with diabetes dictates that all paediatric units must now have a clear policy for transition to adult Services.^{xxiv}

Local Context

Local data and narrative to be inserted here. The figures should be adjusted for deprivation or other locally agreed benchmarking formats.

Commissioners should note that this national context is emerging, and that the nature and prevalence of diabetes in the UK is an evolving picture. The incidence of type 2 diabetes in young people is increasing with the prevalence of childhood obesity. Furthermore, the incidence of young onset type 2 diabetes is particularly marked in BME communities. Commissioners should take note of the impact of demographic and social change on the increase of type 2 diabetes, with areas such as Newham responding effectively to notable demographic changes.

Local scoping and the resulting Services should be proportionate to and based on local data and information and delivered in light of existing structures and service

1. Population Needs

provision with the way that transition and young adult Services are provided adapting and evolving to consider local demographic and wider structural changes. The local context for diabetes transition should be developed in response to data from the Joint Strategic Needs Assessment (JSNA) and service outcomes fed back into the JSNA document to inform further commissioning.

The planning and scoping of transition and young adult Services at a local level should also consider the outcomes of robust stakeholder engagement, including with local clinicians, young people and their families and carers.

For data relating to the local context see the [CCG Outcomes Tool](#).

Indicators specific to diabetes care in the [CCG Outcomes Indicator Set](#) include:

- Myocardial infarction, stroke and stage 5 kidney disease in people with diabetes
- People with diabetes who have received the nine care processes
- People with diabetes diagnosed less than 9 months referred to structured education
- Unplanned hospitalisation for diabetes in those under 19 years of age
- Complications associated with diabetes including emergency admissions for diabetic ketoacidosis and lower limb amputation

Please see NHS England's webpage on [Commissioning for Value](#).

Transition and young adult health care planning will require increased engagement with local primary and secondary health services and in some cases with the youth voluntary sector. In addition to health service providers, it will also require integration with social care and educational planning processes as set out by the proposals within the [Children and Families Act 2014](#) (for example the Birth – 25 Education, Health and Care Plan), [Children \(Leaving Care\) Act 2000](#) and the [Children and Young Person's Act 2008](#)). See guidance for document links.

This specification should be linked to other service specifications and local strategic plans, including those published around;

- Public Health
- Workforce planning
- Adult Diabetes services (including those prescribed services directly commissioned by NHS England)
- Community Child Health
- Sexual Health services
- School Nursing services
- Community Adult Health services

1. Population Needs

- Maternity services
- Acute adult services
- Acute Paediatrics
- Perinatal services
- Learning Disabilities services
- Continuing care services
- Children and Young People's mental health
- Adult Mental Health

Commissioner to add to list as appropriate

Commissioners should also consider:

- Local guidance which may have an impact, for example, local approaches to paediatric and adult diabetes services, Looked After children guidance, work with troubled families and safeguarding
- Linking with local partnership arrangements and Directors of Children's Services and Adult Services to ensure duty of cooperation (across both commissioners and services including schools as commissioners, referrers and users)
- Health and Wellbeing board priorities

Local commissioning arrangements should be framed by the following principles:

- The mental and physical health of young people in transition should not decline during the process of transition.
- Young people should be assisted to maximise their health and life opportunities.
- Young people should be treated as far as possible within their own community and close to home.
- Appropriate plans should be in place for young people in crisis, not attending or showing signs of disengagement.
- Transition and young adult services should work together in integrated and coordinated ways in the best interests of children and young people including across sectors and disciplines, and geographical areas.
- It is essential that young people and families are involved in commissioning and service design, as well as providing feedback to transition and young adult Services. Young Service Users and their families, as well as those who do not yet have access to transition and young adult Services can help commissioners prioritise and identify any gaps and blocks to access, and assist providers in improving transition and young adult Services and evaluating change.
- Commissioners should consider the diversity of the populations that they are responsible for, not only in terms of cultural and ethnic diversity, but all of the

1. Population Needs

factors that might influence take up and engagement with diabetes transition and young adult Services.

2. Outcomes

2.1 NHS Outcomes framework

1. Preventing people from dying prematurely	1a) Potential years lost (PYLL) from causes considered amenable to healthcare
2. Enhancing quality of life for people with long-term conditions	2. Health related Quality of life for people with long term conditions Reducing time spent in hospital by people with long-term conditions 2.3 Reducing time spent in hospital by people with long-term conditions ii Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s 2.7 Health-related quality of life for people with three or more long-term conditions
3. Helping people to recover from episodes of ill-health or following injury	3a Emergency admissions for acute conditions that should not usually require hospital admission 3b Emergency readmissions within 30 days of discharge from hospital
4. Ensuring people have a positive experience of care	4a Patient experience of primary care Improving people's experience of outpatient care 4b patient experience of hospital care 4.8 Improving children and young people's experience of healthcare 4.9 Improving people's experience of integrated care
5. Treating and caring for people in a safe environment and protecting them from avoidable harm	

In addition to this framework, the [National Paediatric Diabetes Audit \(NPDA\)](#) and [National Diabetes Audit \(NDA\)](#) are used as powerful tools for measuring performance

2. Outcomes

and shaping outcomes. These standards allow commissioners to measure progress and identify gaps in provision, and can be used as a benchmarking tool for young people and their families or carers.

Public Health Outcomes Framework 2013-2016;

Domain 1	Improving the wider determinants of health
Domain 2	Health improvement
Domain 3	Health protection
Domain 4	Healthcare, public health and preventing premature mortality

Adult Social Care Outcomes Framework 2014/15;

1	Enhancing quality of life for people with care and support needs
2	Delaying and reducing need for care and support
3	Ensuring that people have a positive experience of care and support
4	Safeguarding adults whose circumstances make them vulnerable and protecting them from avoidable harm

2.2 Locally defined outcomes

Commissioners should ensure that the Local Area strategic outcomes link to national policy and make best use of underpinning evidence, whilst at the same time reflecting evidence based local priorities as identified in the JSNA and other planning tools.

Local Authorities may wish to consider guidance and support material from the [Local Government Association](#).

Outcomes could also be measured using available data or indicators such as the CCG Outcomes Indicator Set (CCGIOS); HSCIC Indicator portal, the National Paediatric Diabetes Audit (NPDA) and other national surveys.

Providers should be encouraged to use the tools that best facilitate continuous quality improvement in their clinical practice to ensure quality requirements are meaningful both in tracking progress in and for day-to-day clinical work and collaborative practice.

2.3 Local outcomes and measures

Locally specific outcomes and performance measures are to be agreed and defined by the commissioner based on existing local performance and baseline data. Suggested outcomes and measures might include;

2. Outcomes	
Service Description	Indicator
Structures and processes	
Staff working with young people have access to training relevant to caring for this population	% staff involved in transition completing training module including in paediatrics, diabetes and transition specific issues as well as cultural competencies, and knowledge of risk taking behaviours.
Provision of joint care plan, agreed and developed between individual and carers prior to transfer	% of young people with a joint care plan
Prior to transfer individuals should be seen in joint clinic between both the original and future Service	% of young people transitioning that have attended or had the opportunity to attend a joint clinic
Local network should provide a platform from which to engage and review and agree priorities and improvement programmes across paediatric and adult services	Young people provided with an open and engaging opportunity to engage with local networks
Each consultation should be held for a minimum of 30 minutes	It is suggested that clinicians base clinic templates on appointment times of around 30mins, from which local capacity requirements can be calculated.
Individual care; application of all quality standards and audit targets stated in NICE T1DM docs	
Each individual should have agreed individualised goals which are reviewed and updated regularly within the planning process	Goals identified through jointly agreed care plan and recorded consultations to assess progress
Young person remains engaged in Services to support effective self-management of condition	% of young people at the specified age of transition engaging in Services during and after engagement with the transition and young adult Service
Young person attending scheduled visits in adult care	No missed consultations unless previously cancelled and rescheduled
DNA / attendance rates at clinics	Reduction in individuals DNA rates from the baseline
Young person's first visit to adult care no later than three months after transition	Ongoing after 1 st visit and then 4-6 monthly Non clinic contacts from named DSN
Preventing complications	Rate of associated complication is minimised or reduced from established baseline Young people with type 1 diabetes offered measurement of their HbA1c level 4 times a year (more frequent testing may be appropriate if there is concern about

2. Outcomes	
	<p>suboptimal blood glucose control)</p> <p>Measurement of HbA1c levels every 3 - 6 months in children and young people with type 2 diabetes</p> <p>Diabetes transition and young adult Services should document the proportion of children and young people in a service who achieve;</p> <ul style="list-style-type: none"> - an HbA1c level of 48 mmol/mol or lower (NICE NG18 recommendation) - an HbA1c level of less than 58 mmol/mol (audited annually as part of the National Paediatric Diabetes Audit) - an HbA1c level of greater than 80 mmol/mol (audited annually as part of the National Paediatric Diabetes Audit)
Population level processes; application of all quality standards and audit targets stated in NICE T1DM docs	
Reduced reported complications associated with diabetes including admissions for diabetic ketoacidosis	Reduction from agreed baseline
Increase in the number of users reporting positive experiences of transition care	Quantitative increase from the baseline
Reduced unplanned hospital admissions amongst young people 13- to19 and 19 to 25 years	Reduction from agreed baseline
Young people's service experience measured and acted upon	Mechanisms in place to measure and monitor take up, satisfaction and access to transition and young adult Services for the young person and their parents or carers.
Young Person's families satisfaction with care received and transition and young adult Service measured and acted upon	PREM data
DNA / attendance rates at clinics	Reduction in DNA rates from the baseline

2. Outcomes	
<p>Screening for complications</p>	<p>Enhanced monitoring and measurement of complications according to NICE standards – completion rates for all nine care processes</p> <p>Support for emergency admissions with hypoglycaemia and DKA inc psychological team support IP and after discharge</p> <p>Young people offered screening for:</p> <ul style="list-style-type: none"> • thyroid disease at diagnosis and annually thereafter until transfer to adult services • diabetic retinopathy annually from 12 years • moderately increased albuminuria (albumin:creatinine ratio [ACR] 3–30 mg/mmol; 'microalbuminuria') to detect diabetic kidney disease, annually from 12 years • hypertension annually from 12 years. • anxiety and depression to children and young people who have persistently suboptimal blood glucose control
<p>Patient reported experience measures (PREMS) and experience of the transition and transfer process of their associated MDTs. The results should have been presented and discussed at a CYPD MDT meeting, and actions implemented as appropriate</p>	<p>Patient experience and engagement has improved (from baseline). Specific examples of improvement to transition and young adult Services as a result of feedback via PREMs are discussed and evidenced.</p>
<p>Robust population monitoring and measurement through providers submission to NPDA and NDA</p>	<p>Details of children and young people with diabetes on a population-based, practice-based or clinic-based diabetes register recorded</p>

3. Scope
<p>3.1 Aims and objectives of service</p>

3. Scope

The Provider must;

- Deliver a planned, structured, cohesive and Service User centred transition and young adult Service led by a dedicated multi professional team to support Service Users in a way that is acceptable to them and their lifestyles.
- Make transition and young adult services available to all Service Users without regard to gender, sexuality, religion, ethnicity or social or cultural determinants. However, where it is deemed clinically appropriate, alternative services may be established that meet the specific needs of one or more groups within a community. Such services will enhance rather than detract from the existing provision.
- Provide physical and mental health care/interventions that will reduce diabetes related complications and unnecessary admission to inpatient beds and promote safe discharge and recovery.
- Provide transition and young adult Services that support the confidence and competence amongst Service Users and their Carers in the take up of adult diabetes services.
- Provide an opportunity for Service Users to develop positive, longitudinal relationships with HCP's.
- Encourage Service Users to take increased responsibility for their own health and exercise autonomy, whilst encouraging freedom and honesty in lifestyle choices.
- Support and empower Carers through specific guidance and support to assist the transition.
- Empower Service Users to improve confidence and responsibility for their condition.
- Encourage Service Users to self-manage and take up adult provision.
- Reduce admissions secondary to diabetic ketoacidosis, especially those due to non-compliance or non-engagement.
- Engage Service Users through the creation of flexible and appropriate transition and young adult Services for and with Service Users.
- Support Service Users increasing in maturity through person led consultations.
- Reduce organ damage such as retinopathy and nephropathy.

3.2 Service description/care pathway

Local protocol for assessment and early initiation and planning to be inserted here

Transition and young adult services should be commissioned that include and encompass paediatric/early preparation, planned transfers and supported integration into adult services and new care settings as well as enabling young adult care for those who present with diabetes between 19-25 years of age.

3. Scope

The Provider will deliver transition and young adult Services that address the following standards and requirements;

3.2.1 Person centred and responsive services

The Provider must;

- Ensure that Service Users and their Carers/families are treated with compassion, respect and dignity, without stigma or judgment.
- Co-produce a joint plan and provide written information to the Service User and, if appropriate, Carer about the plan, how to access the transition and young adult Services routinely and in relation to specific issues or complications.
- Co-produce and provide information at all stages of the pathway about interventions or treatment options to enable Service Users and/or Carers/families to make informed decisions about their care appropriate to their competence and capacity as well as to their personal preference and expertise.
- Agree the aim and goal of the transition and young adult Service with the Service User and, where appropriate, their Carer.
- Provide structured and relevant education to the Service User to maximise their understanding and management of their condition, including a range of optional modules.
- Allow the Service User to 'flow' through the transition period at their own pace according to their personal development and confidence.

3.2.2 Access and engagement

The Provider must deliver the transition and young adult Services in a flexible, welcoming and appropriate environment with a variety of methods available for Service Users to interact with based on their personal needs and preferences.

The Providers must;

- Deliver active and accessible opportunities for engagement that are relevant to Service Users, including (depending on local structures) the involvement of youth commissioners, and peer to peer support and networking opportunities and involvement with youth workers. Build the capacity of these groups or Service Users to best support peers and improve outcomes.
- Provide virtual clinics or clinics in education settings to minimise time to promote take up of transitions and young adult Services and attendance rates, reduce time away from school, disruption to other areas of life, and to overcome barriers.
- Provide information that is clear, jargon free (with any technical terms defined) and in plain English

3. Scope

- Provide information that takes into account the health literacy of the intended audience
- Provide information that allows for the physical and sensory needs of the Service User and their carer, including the needs of those with difficulties speaking or reading English.
- Provide transition and young adult Services that use technologies such as social media, email, texts, apps and Skype to reduce disengagement and promote uptake of Services.
- Take into account the transient lifestyles of Service Users at this age, when using written communication. For example Service Users could move from university accommodation, across geographies, moving away from home or too and from university in and out of term time.
- Offer flexible appointment times in safe accessible and appropriate locations to best meet the lifestyles of Service Users, and reduce the likelihood of DNA's or disengagement. For example drop in Services or clinic locations in primary care rather than acute settings, online consultations or clinics in educational or recreational settings such as community centres.
- Create open and flexible pathways through which Service Users can move and progress at their own pace, regardless of chronological age, and according to their level of maturity, comfort and confidence.
- Work to engage Service Users more effectively through links to education colleagues. Service Users value the expertise of school nurses for example in the support, understanding and consistent guidance that they offer.
- **The following documents can support effective engagement;**
 - [Department of Health \(2011\) Quality Criteria for young people friendly health services \('You're Welcome'\) sets out principles to help commissioners and service providers to improve the suitability of NHS and non-NHS health services for young people.](#)
 - [National Youth Agency \(2006\) Hear by Right. Standards for young people's participation](#)

Disengagement

The Provider must;

Deliver transition and young adult Services to best engage Service Users and should take into account the needs of those at risk of disengagement or who are already not attending or have become disengaged. A clear 'safety net' or plan will be in place within the standard Service provision to account for DNA's. This will include;

- Work alongside GP's and pharmacists to emphasise the importance of their role in monitoring attendance and signposting to other services

3. Scope

- Peer to peer mentoring.
- Clear identification of groups who are particularly at risk of becoming disengaged will be in place, through establishment of a clear threshold for recognising disengaged Service Users or those at risk, additional mechanisms can be implemented e.g. specific peer group support/facebook/other social media tools to assist in reengaging these Service Users.
- Providers will monitor attendance rates to ensure that Service Users who are identified as starting to disengage can receive more specialised support and putting in place a clearly defined threshold for identifying where support is needed, for example a number of missed appointments.
- Clear policy should be in place by the Provider to identify early signs of disengagement and to trigger further interest and support.

3.2.3 Partnerships and coordination/integrated services

The Provider must;

- Deliver transition and young adult Services with links to schools, universities, other educational settings and employers to support the wraparound of care and holistic approach.
- Consider the role of educational establishments or school nurses and their role in supporting transition between educational establishments over time, for example the school could alleviate some of the added stress on a Service User moving on to college, by preparing the college, passing on information, care plans etc.
- Foster strong links and clear pathways between acute, primary and tertiary care as part of the integrated care model.
- Recognise a Service User's employer as a partner or stakeholder in the transition process. Not all Service Users go to university and for those that move into employment in the transition period understanding and cooperation from employers can be crucial.
- Integrate working with local authorities and other providers to ensure that all developmental trajectories and support needs are recognised and responded to.
- Provide transition and young adult Services that encompass the differing support needs of Carers who require different information, communication and types of engagement throughout the process.
- Work with school nurses to maximise the opportunity that they have to support Service Users and provide transition and young adult Services that take into account the wider issues that a Service User may be facing in their lives.
- Include referrals to other local clinics and services relevant to Service Users health and wellbeing.

3. Scope

3.2.4 *Independence and autonomy*

The Provider will;

- Focus on choice and fostering independence and supporting the active decision making and autonomy of the Service User.
- Encourage ownership of decisions about care and personal responsibility for the management of a Service User's condition and complications.
- Value the expertise and insight of the Service User in their own care and condition, encouraging young people to be more active and involved.
- Support a sensitive and gradual move away from both paediatric care, and the support and influence of parents or Carers.

3.2.5 *Staged and timely*

The Provider will deliver Services that ensure;

- Transition is managed longitudinally over time, with clear markers, monitoring of progress and next steps.
- Put good progress management structures in place, which can be managed and are meaningful to the Service User to support progression.
- Developmentally appropriate support is in place to allow the Service User to access support that the Service User is comfortable with and at a pace that suits the individual and their level of comfort and maturity, rather than prescribed by age.
- Transition and young adult services are developed to consider the staged and gradual move away from parent centred or supported care towards independence.
- The timely introduction of transition should be initiated in paediatric care to prepare the Service User for changes and new care models as early as possible.

3.2.6 *Structures and systems*

The Provider will;

- Support the development of co-ordinated, documented and integrated support plans for Service Users and their parents/Carers from all health services involved in their care and in partnership with any other multi agency providers (e.g. education and social care) that constitute the changing team around the Service User at this time.
- Ensure that Service Users who require Services during and post transition are seen in a timely manner.
- Ensure that Service Users leaving the transition and young adult Service have

3. Scope

a written and agreed plan that supports self-management where possible and explains how to access help if this becomes necessary.

- Ensure that where a Service User is moving to a new service, the sending service will agree with the Service User what information will be provided to receiving service to minimise the need for the Service User to repeat information and to ensure that the most effective and informed care can be provided by the new service.
- Ensure that there will be at least one joint meeting between the Provider and the new service that includes the Service User and/or Carer, and the receiving service will provide at least one follow up contact with the Service User and if appropriate the parent/Carer after 6 months to check that the transition has proceeded smoothly. The outcome of the 6 month contact and transition will be recorded in the Service User's clinical records.
- Develop a risk management plan in collaboration with the Service User and their family/Carer, where appropriate.
- Ensure that a specific named clinician should be in place to support the care of the Service User throughout the process of transition, someone who understands the Service User and their situation and who can provide assurance and continuity.
- Ensure that any cross charging arrangements for cross-boundary Service Users are detailed. Service Users (LAC) should not be denied a Service because they originate from another LA/CCG area.

3.2.7 Psychological support

The Provider will;

- Deliver diabetes transition and young adult Services that incorporate mental health services as part of an integrated approach to diabetes management.
- Incorporate education for Service Users, Carers and staff around eating disorders, and their coincidence with diabetes, and how to identify indications that a Service User is taking risks in this respect.
- Support mitigations of the impact of wider risk taking behaviours, through open, non-judgemental and engaging staff who are skilled and able to support Service Users more broadly than in relation to their specific condition.
- Ensure Service Users' emotional and behavioural needs are assessed by the multi-disciplinary teams to avoid co-morbidity from depression, eating disorders or drug taking.
- Annual screening should take place to identify those needing expert psychological assessment.
- Link the transition being made around diabetes, to other transitions effecting the Service User and any associated transition specifications, such as CAMHS transition specification. Promote integrated models of care, seeing 'the person and not the condition'.

3. Scope

- Monitor the 9 key care processes including weight, over time to monitor indications of an eating disorder or misuse of insulin and have a clear pathway in place to support the Service User where issues arise.

3.2.8 Clinical standards

The Provider will;

- Explain the benefits of safely achieving and maintaining the lowest attainable HbA1c to Service Users, their family members or Carers (as appropriate).
- Explain to Service Users and their family members or Carers (as appropriate) that an HbA1c target level of 48 mmol/mol (6.5%) or lower is ideal to minimise the risk of long-term complications.
- Explain to Service Users who have an HbA1c level above the ideal target of 48 mmol/mol (6.5%) and their family members or Carers (as appropriate) that any reduction in HbA1c level reduces the risk of long-term complications.
- Agree an individualised lowest achievable HbA1c target with each Service User and their family members or Carers (as appropriate), taking into account factors such as daily activities, individual life goals, complications, comorbidities and the risk of hypoglycaemia.

3.2.9 Legal and regulatory framework

The transition and young adult Service will operate according to legislation and guidance with particular reference to:

- The [Children's and Families Act 2014](#) including specific duties in relation to children and young people with [SEND](#).
- The [Equality Act 2010](#)
- The [Medicines Act 1968](#)
- [Safeguarding procedures](#) (e.g. Working Together to Safeguard Children & Safeguarding policy: vulnerable adults)
- The findings from serious case reviews, in particular the requirements to share information in a timely manner. See [Working Together to Safeguard Children 2013 and Safeguarding policy: vulnerable adults](#) for further guidance
- [Public Services \(Social Value\) Act 2012](#).
- [Personal Health Budgets](#) may be a good way of arranging transition and young adult Services for some patients.
- [NHS Choice of Provider initiative](#)
- [The Health and Social Care Act 2012](#)
- [Care Act 2014](#)
- [Children \(Leaving Care\) Act 2000](#)
- [Children and Young Person's Act 2008](#)

3. Scope

3.2.10 Continuing care assessment

The Provider will maintain the on-going support and maintenance of transition and young adult Services to a Service User through;

- Ensuring that the transition and young adult care plans are in place for Service Users receiving support. These plans may include more than one professional or agency group delivering care and should be developed in collaboration with Service Users and Carers. A copy should be given to the Service User or Carer (if appropriate) and GP.
- Ensuring that the transition and young adult care plan includes risk management and 'safety net' planning.
- Reviewing the transition and young adult care plan with the Service User, including the goals of treatment, and revise the care plan at agreed intervals of no more than 6 months.
- Selecting treatment options in consideration of NICE guidelines and NICE Quality standards, as follows:
 - Age-appropriate best practice/evidence based psychological intervention.
 - Environmental and occupational/educational interventions or provision.
 - Ensure that clear discharge systems are in place to coordinate effectively with other services when Service Users are in treatment, when they move between other services both for their physical and mental health, and that there are processes in place to plan the ending of treatment or services.
- The needs of vulnerable Service Users should be taken into account specifically in transition and young adult Service development, including;
 - Looked after children.
 - Care leavers – moving to independent living.
 - Young people entering or leaving inpatient care.
 - Young people entering or leaving prison.
 - Young offenders.
 - Children and young people with learning disabilities.
 - Children with ADHD, and ASD or Asperger's syndrome.
 - Any planning for children and young people with severe educational needs should take account of and be part of the child or young person's statement.
 - Unaccompanied asylum-seeking minors.
 - Children and young people with caring responsibilities.
 - Pre-pregnancy planning, pregnancy and antenatal care for those aged 13-25.
 - Substance abuse.

Any planning for Service Users with severe educational needs should take account of and be part of the Service User's statement or Education Health plan.

The locally agreed transition pathway(s) is/are here: [Commissioner to insert link to](#)

3. Scope

care pathway diagram or flow chart of local service

3.3 Population covered

In this specification the term transition is used to describe Service Users between the ages of 13 – 25 as a minimum expectation for application, however transition and young adult Services should be delivered that are developmentally appropriate so flexibility should be employed, for example where a Service User begins the transition process at the upper end of this age range, and the transition might go beyond their 25th birthday.

3.4 Any acceptance and exclusion criteria and thresholds

The Provider will have clear acceptance criteria that are transparent and made clear to referrers, Service Users, their families/Carers and other agencies/services.

Commissioners should also consider;

- What happens to cases that are not eligible?
 - Collection of data regarding cases declined.
 - Sign posting on/ information packs/technology.
- Ensure they provide locally available, age and developmentally appropriate, co-produced information for Service Users, Carers and referrers about the transition process, transition and young adult Services provided and how they are accessed.
- Support and ensure interagency working.
- If the transition and young adult Service concludes that the needs of Service Users or Carers are better met by other agencies it will **insert protocol here**.

3.5 Interdependence with other services/providers

Commissioners should refer to other local structures, relevant strategic plans, transition and young adult Services and Service Users Services to inform the local context and approach.

4. Applicable service standards

4.1 Applicable national standards (e.g. NICE)

NICE Quality Standard: Diabetes in adults (QS6)

NICE Guideline NG18: Diabetes (type 1 and 2) in children and young people: diagnosis and management

NICE Guideline NG17: Type 1 diabetes in adults: diagnosis and management

NICE Guideline NG3: Diabetes in pregnancy: management from preconception to the post-natal period.

4. Applicable service standards

NICE Guideline NG28: Type 2 diabetes in adults: management

4.2 Applicable standards set out in guidance and/or issued by a competent body (e.g. Royal Colleges)

4.3 Applicable local standards

The care processes already specified in this document highlight some of the objectives that must be achieved to deliver robust, exemplar care pathway for Service Users with diabetes who are in the transition phase. The indicators below provide a mechanism for assessing and measuring performance towards these outcomes.

Commissioners should establish a clear baseline against which improvement can be measured over a specified period of time.

5. Applicable quality requirements and CQUIN goals

5.1 Applicable quality requirements (See Schedule 4A-D)

NICE Quality Standard: Diabetes in adults (QS6) see above section 4.1

Quality requirements and CQUIN goals

Quality Standard 1

The Provider has a documented transition to adulthood and adult health services, and a young adult 19-25, policy developed and reviewed with key stakeholders.

Quality Standard 2

All Services provided for Service Users (13-19 and 19-25) routinely evaluate and improve the quality of their Service based on annual You're Welcome assessments and Patient Surveys, and patient reported outcome measures (PROMS).

Quality standard 3

The paediatric and adult services will work together with local primary and secondary care and other multi-agency services to enable holistic and integrated person centred care planning and delivery. Working together processes are built into the transition policy at service and provider level.

Quality standard 4

All Service Users identified in paediatric services are likely to need the continuing assessment, review and intervention of adult health services as a result of a long term condition / complex health needs has a person centred plan which covers:

- Developmentally attuned preparation for increased autonomy and self-management.

5. Applicable quality requirements and CQUIN goals

- Co-ordinated and supported transfer planning in partnership with the Service User and their support system led by a named health professional.
- Developmentally attuned integration into adult receiving services with proactive support to maintain engagement with Services.
- All people aged 19-25 identified in adult services need specific care planning as offered to those in transition diabetes Services.

Quality standard 5

All staff working with Service Users (13-16, 16-19 and 19-25) have received training on understanding the developmental needs and working in partnership with this age group. This may be as part of their core competencies in professional training or post qualification additional training.

Quality standard 6

A range of multi-media information and resources on transition to adulthood and adult health services and young adult clinics, within the context of their specialist health needs, will be available and accessible to Service Users and their Carers.

5.2 Applicable CQUIN goals (See Schedule 4E)

6. Location of provider premises

The Provider's Premises are located at:

7. Individual service user placement

¹ Equality Act 2010 (c. 15) UK: The Stationery Office Limited

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- ⁱⁱ National Institute for Health and Care Excellence. 2015. *Diabetes (type 1 and type 2) in children and young people: diagnosis and management*. (Cm. NG18) London: National Institute for Health and Care Excellence.
- ⁱⁱⁱ Ibid.
- ^{iv} Association of British Clinical Diabetologists. 2012. *Diabetes transition: Assessment of current best practice and development of a future work programme to improve transition processes for young people with diabetes*. Leicester: Prontaprint.
- ^v Winocour, P.H. 2014. Care of adolescents and young adults with diabetes – much more than transitional care: a personal view. *Clinical Medicine*. [Online] **14**(3), 274-8. [Accessed 22 October 2015] Available from: <http://www.clinmed.rcpjournals.org/content/14/3/274.abstract>
- ^{vi} Diabetes UK. 2015. *Why it matters: The importance of a good transfer to an adult clinic*. [Online] [Accessed 22 October 2015] Available from: <https://www.diabetes.org.uk/Guide-to-diabetes/Teens/Me-and-my-diabetes/Transition-to-adult-clinics/Why-it-matters/>
- ^{vii} NHS Commissioning Board. 2012. *Manual for prescribed specialised services*. Leeds: NHS Commissioning Board.
- ^{viii} aa
- ^{ix} Ibid, n. 5.
- ^x aa
- ^{xi} Garvey, K.C., Wolpert, H.A., Finkelstein, J.A. 2013. Health Care Transition In Young Adults With Type 1 Diabetes: Barriers To Timely Establishment Of Adult Diabetes Care. *Endocr Pract*. [Online] **19**(6), 946-952. [Accessed 22 October 2015] Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4034180/>
- ^{xii} Philpot, U. 2013. Eating disorders in young people: development, diagnosis and management. *Journal of Diabetes Nursing*. [Online] **17**(6), 228-32. [Accessed 22 October 2015] Available from: <http://www.thejournalofdiabetesnursing.co.uk/journal-content/view/eating-disorders-in-young-people-with-diabetes>
- ^{xiii} Ibid.
- ^{xiv} NHS England. 2015. *Model Specification for Transitions from Child and Adolescent Mental Health Services*. Leeds: NHS England
- ^{xv} NHS England. 2014. *Action for Diabetes*. Leeds: NHS England.
- ^{xvi} Diabetes.co.uk. 2015. *Cost of diabetes*. [Online] [Accessed 22 October 2015] Available from: <http://www.diabetes.co.uk/cost-of-diabetes.html>
- ^{xvii}
- ^{xviii} Diabetes UK – [Diabetes in the UK](#)
- ^{xix} NICE Guidelines
- ^{xx} [National Paediatric Diabetes Audit. 2013/14](#)
- ^{xxi} AYPH research paper 2012
- ^{xxii} [National Diabetes Audit Report 2, 2012/13](#)
- ^{xxiii} [National Diabetes Audit Report 2, 2012-13](#)
- ^{xxiv} Diabetes UK – [Paediatric Diabetes Best Practice Tariff Criteria](#)

[Winocour PH, Care of a adolescent and young adults with diabetes – much more than transitional care: a personal view
Clinical medicine 2014; 14:274-78](#)