



East of England Children and Young people's Diabetes Network

Guideline for Transition Care for young people with Diabetes

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TABLE OF CONTENTS

| | |
|-----------------------------|---|
| Definition and keywords | 3 |
| Introduction and background | 3 |
| Scope and objectives | 3 |

| | |
|--|---------|
| Purpose | 4 |
| Annual care processes | 4 |
| - 5 | |
| Key issues | 6 |
| Broad recommendations | 6 |
| Key elements | 7 |
| Timing and review | 7 |
| Keyworker | 7 |
| Involving the young people | 8 |
| Building independence | 8 |
| Involving the parents and carers | 8 |
| Multidisciplinary Team | 9 |
| Inpatient care during transition | 9 |
| Surveys, Patient and Parents Involvement | 9 |
| Access to out of hours | 9 |
| - 10 | |
| References | 10 |
| Appendices | 11 - 13 |

Definition of Transition¹

Transition is “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult orientated health care systems”¹.

Key Words

Paediatric, adolescent, transition, diabetes, chronic disease

Introduction and background of transition care

Transition is the process whereby young people are being prepared for the transfer to adult services. Transition is a multifaceted process, which includes the event of transfer and attends to the medical, psychological and educational/vocational needs of such young people and the needs of their parents. Transition should be conceived as a dynamic process with a beginning, middle and end.

- The beginning phase should start with introducing the idea of transition provided by the paediatric team.
- The middle phase is that of transition readiness when the adolescent, their family and the providers are prepared to begin, continue and finish the process of transition.
- The final or end stage occurs when the adolescent or young adult not only transfers to adult care but is actively participating in adult care activities e.g. of self-management and decision making

It is important that diabetes clinics are able to understand the needs of young people going through the transition process². This guideline aims to improve transitional care for young people with type 1 diabetes.

Scope

This guideline offers guidance for young people with Type 1 Diabetes transitioning from child to adult services. This document should be used by members of the diabetes team to develop a consistent approach to managing the transition and transfer of young people from paediatric to adult services.

Objectives

- To achieve a seamless transition of diabetes care from children's services to adult care that is high quality, uninterrupted, co-ordinated, developmentally appropriate, psychologically sound and comprehensive in the East of England
- To promote skills in communication, decision making, assertiveness and self-care, self-determination and self-advocacy in young people with diabetes
- To enhance the young person's sense of control and independence
- To provide support for the parent(s)/carer(s) of the young person during this process
- To reduce acute and long-term complications of diabetes in this high-risk group
- To reduce loss to follow up
- To optimise in-patient care during the transition period
- To improve patient satisfaction with care during the transition period

Purpose

The purpose of this guideline is to facilitate a smooth movement for young people moving from children's and young people's Diabetes services whilst recognising the particular needs of this age group as identified in the documents referenced in this guideline.

It is widely acknowledged that the self-management of Type 1 diabetes (T1DM) is difficult and complex, particularly so during adolescence, where a marked deterioration in glycaemic control is common in part due to pubertal endocrine changes, but also due to psychosocial changes such as;

- Erratic eating and exercise patterns
- Poor adherence to insulin regimens
- Risk taking behaviours
- Family stressors
- Psychological and self-image problems
- Frequently missed appointments
- Binge drinking
- Smoking
- Eating disorders (in a small minority)

The National Diabetes Transition Audit (NDTA) 2011-2017⁴ highlighted poor care outcomes in young people with T1DM. The NDTA links datasets from the adult and paediatric national diabetes audits. The NDTA has been designed to audit care provision during the period when young people with Type 1 diabetes move from paediatric to adult based clinical care⁷.

Below are some of the key findings from this:

Annual Care Processes from 12 years

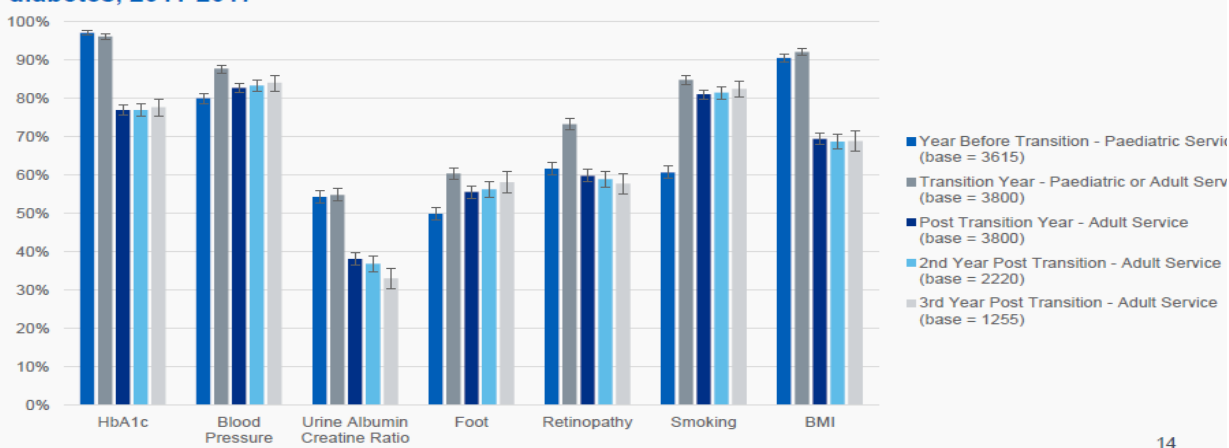
- Annual measurement of HbA1c decreases after transition.
- Annual measurements of blood pressure and cholesterol remain similar, whereas kidney, foot, retinopathy and smoking check completion rates increase after transition
- The least variation in care process completion rates was found where transition occurred between the age of 16 and 19 years. This may be because planned transition usually occurs during this time frame. Planned movement from paediatric to adult care is less likely at younger and older ages.
- The HbA1c target is more likely to be reached pre-transition compared to post-transition.
- For both cholesterol and blood pressure, the percentage of children achieving the targets is higher pre-transition compared to post-transition.
- There are a higher number of DKA admissions post-transition. However, this may be due to the fact that DKA rates increase with increasing duration of diabetes
- Yearly Thyroid screening
- Coeliac Disease screening

Care processes completion pre- and post-transition, 2011-2017 ⁴

Care Processes

- During the year of transition to adult care the completion rate of essential care processes were similar or better than the year before transition.
- Generally there was a 5 to 15 per cent reduction in completion of care processes in the 1st year following transition to adult care which did not improve in the 2nd or 3rd year.

Figure 2: Ratios of care process completion before and after transition to adult care, Type 1 diabetes, 2011-2017



14

Transition to adult diabetes services can be a traumatic period for young people with diabetes, who commonly fall between services. The risk and morbidity associated with this transition are well described and a common clinical experience⁵

Key recommendations from the NDTA report to avoid this risk and morbidity associated with transition are:

Clinical Commissioning Groups and Local Health Boards: -

Must understand that transition from paediatric to adult care is a vulnerable period.

Should specifically contract Paediatric and Adult Multi-disciplinary team's services to deliver appropriate, joined-up services during this period, so essential key healthcare checks are not missed, and DKA admissions do not increase.

Specialist Services: -

Adult and Paediatric Services should have clear transition pathways designed to make the process user-friendly but focussed on sustaining stable HbA1c and minimising DKA.

Paediatric Services should ensure that children and young people with Type 1 diabetes remain in their care until at least 16 years of age before transition.

Adult Services should ensure that young people with diabetes have transitioned into their service by 19 years at the latest.

Key Issues around transition⁵

- For young people - the perception of a lack of appreciation of young people's needs and issues, the worry that they will not receive adequate information, the worry about leaving their familiar health care team for an unknown medical provider, and the desire for autonomy and involvement in decision-making.
- For families – concern about poor communication between families and providers, empowering the young person to gain independence whilst still offering support.
- For clinicians and researchers - a growing concern about inadequate transitional care across a variety of medical subspecialties including large gaps in service provision and knowledge of specific transitional care.
- Loss to and lack of follow up post transfer- in the transition period, young people with diabetes face a high risk of loss of diabetes specialist follow up, with a reported rate of 11-69% and this is associated with poor metabolic control and high risk of hospital admission^{2,4,6}.
- Potential of delayed adolescent development into young adulthood due to poor metabolic control.
- Young people may start living away from family for the first time (university, work, etc.) during the transition period. In the study of patients with diabetes (the Diabetes UK cohort) who died before age 40 years, living alone was identified as a risk factor for deaths from acute events. Flexible appointments should be considered such as appointments during school holidays for university students⁴.
- There is clear evidence that a proper transition of care improves engagement of young people with the diabetes services and thus improves glycaemic control. It has also shown an adherence to appointments post transfer for diabetes.

Broad recommendations

- Every young person with diabetes should have a proper transition of care.
- Transition should be a clear process over a defined period (e.g., between 12-19 yrs of age) and not just “one off transfer of care” from children to adult services
- The transition process should start at an earlier age (12-14 yrs of age)
- Timing of actual transfer into adult services should be tailored to individual patient's needs depending upon their emotional maturity and cognitive and physical development but would usually be recommended no later than their 19th birthday.
- A clear management plan is recommended for inpatient care during the transition period (please see page 9)

- A named **key worker** who offers support around the transition should be identified for each individual. The key worker can be any member of the multi-disciplinary team (MDT).
- Young people should be given the opportunity of being seen on their own during part of the consultation. This can be offered at an appropriate time depending upon the emotional maturity.
- Local trusts should adhere to their local safeguarding of young people policy.
- For seamless transition, a formal multidisciplinary meeting between paediatric and adult teams is encouraged. MDTs are valuable for ensuring arrangements for joint clinic visits, unifying common management pathway, discussing difficult issues around transition.
- There may be a need to consider early transition to adult services in certain situations such as pregnancy, or developing complications like nephropathy or retinopathy.

KEY ELEMENTS

Timing and review⁵

Practitioners should; start planning for movement into the transition clinic at age **13 or 14yrs of age** at the latest, ensure the transition planning is developmentally appropriate and considers each young person's capabilities, needs and hopes for the future.

Active planning for transfer into adult services should begin at **age 17-19yrs of age**

The point of transfer should:

- Not be based on a rigid age threshold
- Take place at a time of relative stability for the young person.
- At each multi-disciplinary team meeting appropriate transition planning should be discussed.
- The outcome of these discussions should be shared with the young person and their parent/carer.
- Communications should involve all diabetes practitioners providing support to the young person and their family or carers, including the GP.
- Involve the young person and their family or carers
- Inform a transition plan that is linked to other plans the young person has in respect of their care and support an example of this can be found in Appendix 1
- Transition/Transfer plan to accompany the young person as the transfer to adult services, as per local arrangement. See Appendix 2 as an example of 'Handover of Care' template.
- Ensure the young person is helped to manage their own Diabetes as part of the overall package of transition support. This should include an assessment of the young person's ability to manage their condition, self-confidence and readiness to move to adults' services. see appendix 2 for an example of this.

Key Worker⁵

The Diabetes team should identify a key worker who will help the young person to identify a single practitioner who will coordinate the young person's transition and support.

The Key worker:

- Should be a diabetes specialist e.g. PDSN, Diabetes Dietitian.
- Should be someone with whom the young person has the opportunity to develop a therapeutic relationship.

The Key worker should:

- Oversee, coordinate or deliver transition support, depending on the nature of their role.
- Be the link between the young person and the various practitioners involved in their support, including the named GP.
- Help the young person navigate services, bearing in mind that many may be using a complex mix of care and support.
- Support the young person's family, if appropriate.
- Ensure that young people who are also carers can access support
- Act as a representative for the young person, if needed (that is to say, someone who can provide support or advocate for them).
- Direct the young person to other sources of support and advice, for example peer advocacy support groups provided by voluntary and community sector services.
- Think about ways to help the young person to get to appointments, if needed.
- Provide advice and information.

Involving Young People⁵

Offer young people help to become involved in their transition planning. This may be through:

- Peer support.
- Advocacy.
- In clinic appointments
- Home visits
- School/college visits
- Additional contact between appointments (text message/email)

Building Independence⁵

Include information and signposting to alternative non-statutory services, including condition specific support services, in transition planning.

- Put young people in touch with peer support groups if they want such contacts. This type of support:
 - May be provided by voluntary- and community-sector organisations, such as specific support groups or charities.

- Should be provided in a way that ensures the safety and wellbeing of the young people involved.

Consider providing opportunities for young people to have individual peer support and mentoring during transition from children to adults' services.

Involving the Parents and Carers⁵

Ask the young person regularly how they would like their parents or carers to be involved throughout their transition.

With the consent of the young person and where appropriate, discuss the transition with the young person's parents or carers to understand their expectations about transition. This should include:

- Recognising that the young person's preferences about their parents' involvement may be different and should be respected.
- Considering the young person's capacity, following the principles of the Mental Capacity Act and other relevant legislation, as necessary.

Help young people develop confidence in working with adult services by giving them the chance to raise any concerns and queries separately from their parents or carers.

Adults' services should consider the individual needs and wishes of the young person when involving parents or carers in assessment, planning and support.

Multidisciplinary team meetings (MDT) and cross boundary working

- The MDT is defined as Adult Consultant, CYP Consultant, Adult Diabetes Specialist Nurse, CYP Diabetes Specialist Nurse, CYP Dietician. Where possible, Adult Psychologist and CYP Psychologist, and Adult Dietician
- For seamless transition, a formal multidisciplinary meeting between paediatric and adult teams should take place monthly. MDTs are valuable for ensuring arrangements for joint clinic visits, unifying common management pathways, discussing difficult issues around transition and even challenges of individual cases.
- A dietician should be present in all clinics and patients should be offered a dietetic consultation at least annually.
- A psychological assessment should take place annually.

In-patient care during transition

There should be a clear arrangement between adult and children's services for inpatient care during transition period. Patients should be looked after by the team, which has previously looked after them at the outpatient setting wherever possible.

ADD LOCAL TEAM/TRUST ARRANGEMENTS

Surveys, Patients and parent's involvement

As a network we aim to consult with the user group (patients and parents) regarding this guideline. We carry out an annual survey of satisfaction of young people with the diabetes transition experience.

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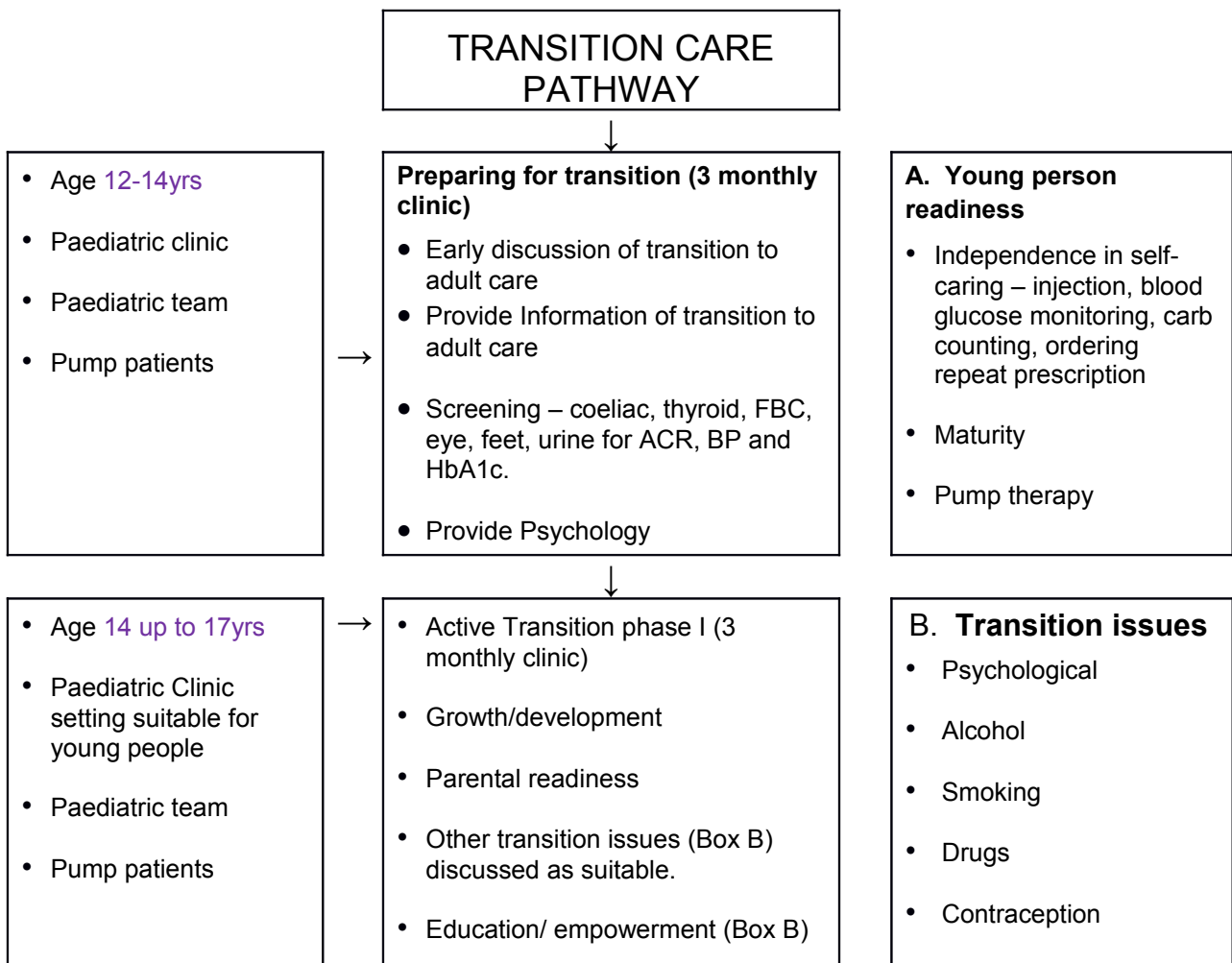
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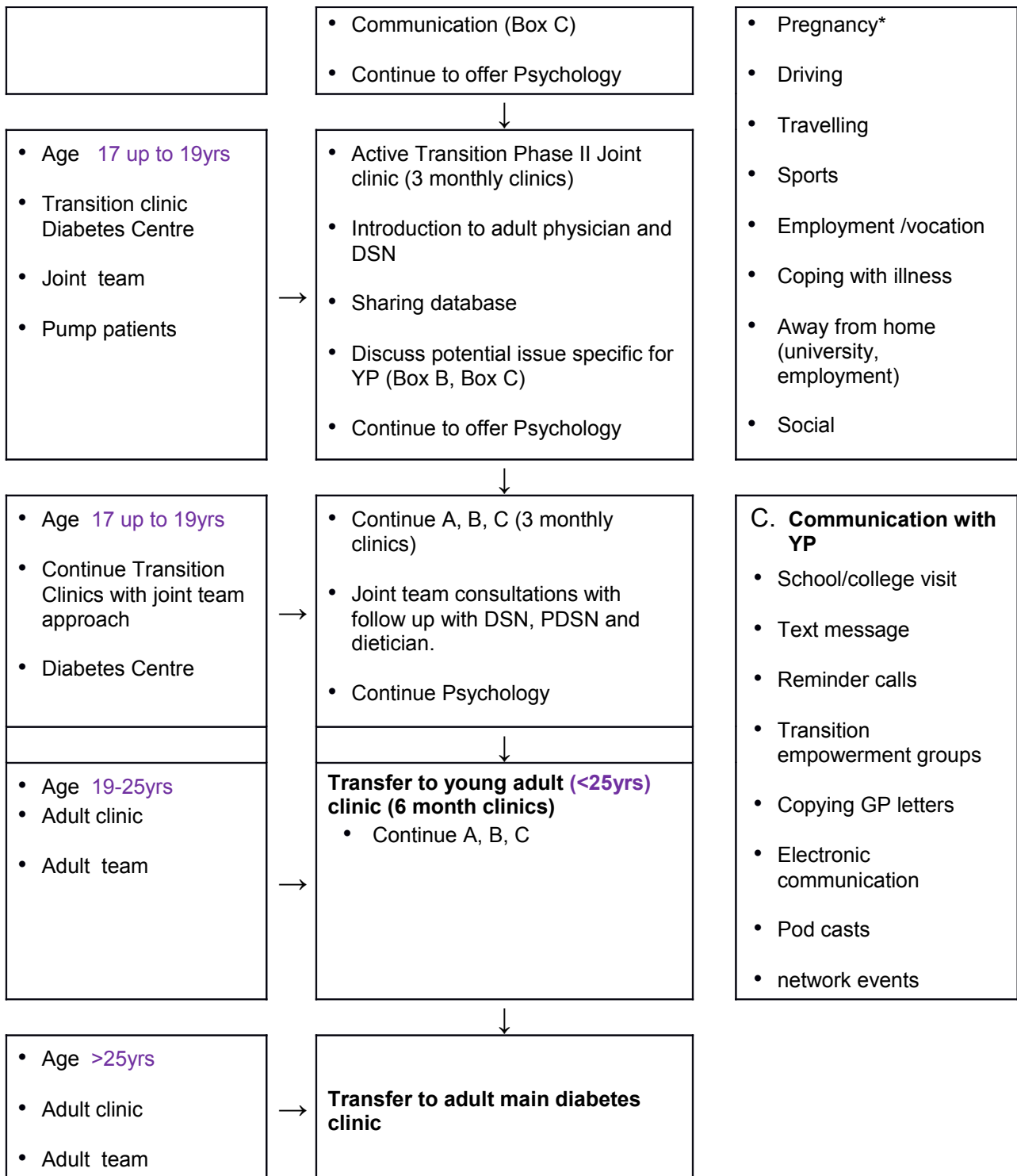
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APPENDIX 1 PATHWAY

CARE PATHWAY FOR TRANSITION CARE IN DIABETES





MANAGING TRANSITION – Paediatrics to Transition
 (Insert unit specific transition checklist/process here if not using this checklist)

Before transfer to adult services the YP will be supported and assessed on their diabetes knowledge, self-management skills and ability to participate actively in health care decisions.

Patient addressograph

| Patient | Plan to start | Needs practice | Independent | comments |
|---|---------------|----------------|-------------|----------|
| Describes their condition | | | | |
| Feels confident asking questions in clinic | | | | |
| Has knowledge of insulins and ratios/doses | | | | |
| Has knowledge of insulin adjustments for meals and correction | | | | |
| Independently inject/cannula insertion | | | | |
| Understands the need for rotating injection sites | | | | |
| Checks BG and is able to interpret result | | | | |
| Recognises hypos and treats appropriately | | | | |
| Recognises hyperglycaemia, when to check BK and treats appropriately | | | | |
| Has written sick day rules | | | | |
| Understands the effect of exercise/parties/events and plans appropriately | | | | |
| Can count carbs with confidence in all situations | | | | |
| Knows how to plan for holiday and travel | | | | |
| Knows how to plan for driving | | | | |
| Requests all prescriptions independently | | | | |
| Knows how to book own medical and other appointments | | | | |
| Understands the importance of screening for complications | | | | |
| Understands the implications of their diabetes on daily life (e.g. smoking, drug and alcohol use, college, work etc.) | | | | |
| Knows how to access contraception +/-, pregnancy planning information | | | | |
| Knows how to contact diabetes team to seek medical advice including emergencies and out of hours | | | | |
| Has transition information leaflet | | | | |

APPENDIX 2: TRANSFER OF CYP TO ADULT DIABETES SERVICE
HANDOVER OF CARE INFORMATION (to be completed with the young person before transfer of care)

| | | | |
|---|---------------------------------|---|---------------------|
| Demographic details: | | GDPR compliant: YES <input type="checkbox"/> NO <input type="checkbox"/> | |
| | | Preferred | |
| | | Mobile tel: <input type="checkbox"/> | |
| | | Home tel: <input type="checkbox"/> | |
| | | Email: <input type="checkbox"/> | |
| Type 1 <input type="checkbox"/> | Type 2 <input type="checkbox"/> | Date of diagnosis: | Age at diagnosis: |
| Relevant family and social history: | | | |
| Psychology input: | | | |
| Any other Professionals/Services involved in care? If so what is their role & contact details? | | | |
| Employment or Studies: | | | |
| Current insulin regimen: MDI <input type="checkbox"/> CSII <input type="checkbox"/> BD <input type="checkbox"/> | | Other <input type="checkbox"/> | |
| If on CSII, make and model of pump: date: (please attach latest pump settings) | | Warranty expiry | |
| Reason for pump initiation: | | | |
| PUMP DETAILS (if on CSII) | | GLUCOSE MONITORING | |
| Make & model: | | Meter type: | |
| Warranty expiry date: | | CGM/Flash monitor: funded <input type="checkbox"/> self-funded <input type="checkbox"/> | |
| When pump therapy started: | | Make & model: | |
| Insulin: | | Oral Diabetes Medications: | |
| Date of last clinic attendance: | | Last HbA1c: | Date of last HbA1c: |
| Pregnancy planning discussion: YES <input type="checkbox"/> NO <input type="checkbox"/> | | Retinal screening: YES <input type="checkbox"/> | |
| <input type="checkbox"/> | | NO <input type="checkbox"/> | |
| On contraception: YES <input type="checkbox"/> | | Date: | |
| NO <input type="checkbox"/> | | | |
| Driving: YES <input type="checkbox"/> | | Adult services contact details: YES <input type="checkbox"/> | |
| NO <input type="checkbox"/> | | NO <input type="checkbox"/> | |

| | |
|--|---|
| Hypo unaware? YES <input type="checkbox"/> NO <input type="checkbox"/> UNKNOWN <input type="checkbox"/> | History of DKA? YES <input type="checkbox"/> NO <input type="checkbox"/> |
| Last hospital admission & reason for? | |
| What else would you like the Adult Team to be aware of? | |