

Diabetes transition

Assessment of current best practice and development of a future work programme to improve transition processes for young people with diabetes.

Transition in healthcare is only one part of the evolution from dependent child to independent adult (David, 2001).

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Supporting, Improving, Caring



Association of British Clinical Diabetologists

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Executive summary

Transition processes in diabetes healthcare are important. The move from paediatric to adult services needs to be via a smooth process that helps young people feel empowered to self-manage their diabetes for the rest of their lives.

This transition has to be set in context of the wider changes the young adult and their family undergo, from dependent child to an independent adult in all aspects of life. Health service moves are only a small part of this and can either help or hinder the wider process for families.

National policy, guidance and documents (e.g. Transition: Moving on Well, DH, 2008) have identified failings in the effective transition of young adults from all paediatric to adult healthcare services. Some principles have been outlined to improve this (e.g. You're Welcome Standards, DH, 2011). It is clear transition needs to be a process over a period of time and not a one-off transfer or joint appointment. There is, however, no clarity about the perfect model for transition.

This document reports on:

- An NHS Diabetes project to assess best practice and develop a practical work programme to improve the transition process in diabetes and which can be applied nationally.
- Outcomes from a small working group of leading diabetes clinicians including the Association of British Clinical Diabetologists (ABCD), who has developed a set of practical principles that can be used to deliver improvement in transition services.

It is aimed at providers, commissioners and clinicians involved in the delivery of transition services in diabetes and may also be of use to service users to support involvement in service improvement. In particular, the beneficial features of a transition service, case studies and identification of good practice offer a practical way to begin to consider local service delivery.

Summary of key findings:

- Effective transition processes are urgently needed.
- Generally, professionals feel they do not do it well (or well enough).
- There is no clear model for what is most effective.
- If done well, it is recognised this will help prevent complications and improve engagement with adult services and lead to increased attendance at clinics.
- Young adults have repeatedly been surveyed and report they care more about the interaction with the health professional than the model of transition used.
- There are many publications outlining why it is important but more needs to be done with what health services actually need to do to implement a good transition service.

Recommendations:

- All units be asked to sign up to the core values of a quality consultation.
- Agree minimum standards for the contents of a transition policy – based on national guidance and evidence such as “You’re Welcome”².
- Ask people to ensure their policy is in line with the minimum standards - initially through the paediatric diabetes network coordinators and then formally through self-assessment, peer review and ultimately via Best Practice Tariff (BPT).
- Ensure there are paediatric and adult lead diabetologists working in collaboration in each unit and that there is an adult diabetologist on each of the regional paediatric networks.
- Each unit to identify training needs for paediatric and adult teams around young adult communication and consultation skills.
- Develop a health plan prompt sheet. This would include prompt sheets for both the professional and young adult on all aspects of health.
- Develop a transition planning process prompt sheet for professionals to improve their transition process.
- Improve the standard relating to transition in the Best Practice Tariff with requirements possibly taking into account the age group 18 to 30.
- Offer support to Diabetes UK if it chooses to campaign for better transition such as ‘what care to expect’ documentation.

NHS Diabetes is delighted to support further work to implement the findings of this report in 2012/13. The support of local paediatric diabetes networks will be key to this. More information on their work and how they link into the transition work can be obtained from Ruth Gordon (ruth@ruthgordonassociates.co.uk) or Marie Cummins (marie.cummins@diabetes.nhs.uk).

Context

Transition in healthcare is only one part of the evolution from dependent child to independent adult (David, 2001).

For this work the agreed definition for diabetes transition is:

“The period of time during which there is planned, purposeful and supported change in a young adult’s diabetes management from child orientated to adult orientated services, mirroring increasing independence and responsibility in other aspects of their life.”

Transition processes in diabetes healthcare are important. The move from paediatric to adult services can be via a smooth process that helps young people feel empowered to self-manage their diabetes for the rest of their lives. This transition has to be set in context of the wider changes the young adult and their family are undergoing. For them, the wider picture is a move from a dependent child, who has their diabetes looked after by their parents or carers, to an independent adult who manages their own diabetes. This, in turn, is set in the wider context of moving from a dependent child to an independent adult in all aspects of their life. Health service moves are only a small part of this and can either help or hinder this wider process for families. Getting transition right and keeping young adults involved in their healthcare is important as it is also a key principle in the NSF:

“Standard 6, And all young people with diabetes will experience a smooth transition of care from paediatric diabetes services to adult diabetes services, whether hospital or community-based, either directly or via a young people’s clinic. The transition will be organised in partnership with each individual and at an age-appropriate time.”

(pg. 7, DH, 2001)

Good transition means young adults are more empowered to self-manage their diabetes effectively in the long term. This reduces the risk of complications and in turn reduces morbidity and mortality.

“These vulnerable individuals are often lost to the system with no follow-up, and are at greater risk of diabetic complications (retinopathy, nephropathy, neuropathy, heart disease and stroke) due to the duration of the disease and often poor control.”

(pg. 1 Cropper, 2008).

People with diabetes have a higher mortality rate than their peers without diabetes. This is particularly pronounced in young people. A study by The Yorkshire and Humber Public Health Observatory (YHPHO) calculated the hazard ratios of different age groups. These ratios “identify the additional risk of death in one group compared to another” (Holman, 2008). The highest ratios were in 20 to 39 year age group (table 1).

Table 1 Hazard ratios of death with diabetes versus without diabetes.

	20 – 39 years	40 – 59 years	60 – 79 years
Males	2.54	2.17	1.91
Females	3.76	2.54	2.53

The National Diabetes Audit Mortality Analysis 2007-2008 (NHS Information Centre, 2011) also shows a higher risk of mortality for people with diabetes. The Mortality Analysis document demonstrates an increased summary mortality rate (SMR) for all people with both Type 1 and Type 2 diabetes across England (this is for all ages) and also variation by SHA. The table shows the highest SMR for people with Type 1 is in the North of England.

Table 2 Excerpt from “Summary mortality rates by type of diabetes and Strategic Health Authority (pg. 18)” showing SMR for Type 1 for the three SHA regions in the North of England.

SHA Region	SMR
North East	314
North West	283
Yorkshire and Humber	240



Background and rationale

Transition has long been an area of concern not only for young adults and their parents and carers but also for professionals. During transition young adults can be “lost” to the system if they are discouraged by the differences in the way care is delivered in adult services compared to paediatric services.

National policy, guidance and documents (e.g. Transition: Moving on Well, DH, 2008) have identified failings in the effective transition of young adults from all paediatric to adult healthcare services. Some principles have been outlined to improve this (e.g. You’re Welcome Standards, DH, 2011). It is clear transition needs to be a process over a period of time and not a one-off transfer or joint appointment. There is, however, no clarity as to the perfect model for transition. Young adults also express they do not want to have a sudden transfer process;

“Those young people who had been through transition thought the time spent in transition was important. Ideally, they believed a year or more was appropriate for the transition process. This enabled the young person to spend time with the paediatric and adult diabetes teams and, therefore, build up a comfortable rapport.”

(Pg. 15 Kime and Carlin, 2012).

A transfer rather than a true transition process in particular can lead to a “lost tribe” of young adults who move services but end up being unknown to, or not attending the adult service; “10 - 69% of young adults with diabetes have no medical follow up after leaving paediatric care” (pg. 7, McDonagh, 2006). There are many reasons for disengagement with services but if this leads to poor control then there is an increased risk of long term complications of diabetes developing in these young adults. It is acknowledged that, “Diabetes services that are not tailored to the needs of adolescents may be rejected by them and cause them not to seek medical help when necessary” (Cropper, 2004).

Different units who are striving to offer good diabetes transition services do this through a variety of delivery models. Some offer teenage clinics and some young adult clinics. In some cases, a young person might start transition into the teenage clinic at 12 and then move into the young adult clinic at about 18; others may just have one transition clinic. However, the research remains unclear which produces the best outcomes (TCADS, 2010) and young adults also rarely exhibit a strong preference for one particular model. Of course, it is not just diabetes services affected by this problem, all long term conditions will have similar or related issues, but diabetes services are in a strong position to lead the way in improving the process.

Aims of the project

There were two aims for the project:

- To undertake an assessment of current best practice.
- To develop a future work programme to improve transition processes in diabetes care.

Objectives

Within the project there were several objectives:

- To gather examples of good practice in effective transition processes.
- To develop a work programme describing:
 - how to share this good practice.
 - how to develop a gold standard process for transition that could be applied across the country.
 - what needs to be in place to deliver this, in particular in relation to Best Practice Tariff (BPT)
 - Commonalities and links with other disease areas that are also addressing transition problems such as kidney care, cardiovascular disease (CVD), and cystic fibrosis (CF).

The outputs from the project are intended to help NHS Diabetes support various groups in a number of ways. These include:

Support commissioners – the work programme will help implement effective transition services and the benefit to commissioners will be in potentially huge savings in the future. Young adults should receive better quality care leading to improved control of their diabetes and in turn a reduction in complications and their associated costs.

Support healthcare professionals – this work will share good practice and help units to develop more efficient ways of working, making best use of clinical time. The long term work programme will describe a process to improve efficiency of transition services. It will also aim to improve the expertise teams have in managing young adults, and the knowledge they have about that group of patients. In this way, the expertise that paediatric teams have about the individual young adults they care for can easily be passed on to adult services, ensuring there is good continuity of care.

Support organisations – there will be a small financial benefit to providers if sharing good practice encourages them to develop a model of care which will allow the Acute Trust to obtain BPT for young adults up to their 19th birthday.

Enhance quality and capacity – the work programme will recommend a more efficient way of working, delivering improved quality of care.

Support people with diabetes – young adults with diabetes and their families will receive a more flexible and patient-centred care process. This will allow young adults to fully develop the competencies they need to manage their diabetes effectively in the long term. This will lead to increased confidence for both young adults and parents in managing diabetes and means they are likely to have better blood glucose control, reduced HbA1c levels and frequency of hypoglycaemia. This not only leads to a better quality of life but reduced complications. It will allow patients to transition psychologically, meaning they remain engaged with their diabetes care providers beyond transitional care.

Timing of the project

There are several reasons why the timing of this project was well placed.

Most crucially, in April 2012 a Best Practice Tariff (BPT) (Department of Health, 2012) for paediatric diabetes care was introduced. This tariff requires that all 13 specified standards are met in order for an Acute Trust to receive full payment for their paediatric diabetes services. The overall aim is to ensure paediatric services are all being delivered to the same high standard of care. Trusts can claim the tariff (BPT) for all patients up to their 19th birthday as long as they meet the standards required; one of which states that each Trust produces a transition plan.

Work has been carried out by the North West Paediatric Network to develop a tool to support writing a transition policy. This work has also been designed to help to support the implementation of the BPT. In the pilot phase of its implementation, use of the tool has shown that processes for transition are far from ideal.

Paediatric diabetes networks have been established with support from NHS Diabetes. A network has been set up in each of the ten former SHA regions across England and each is supported by a network coordinator funded by NHS Diabetes to June 2012. Through the networks all the providers of paediatric diabetes services across England are engaged with a regional network. The paediatric diabetes networks have been a vehicle for sharing good practice. Ahead of this project, they had shared work started by the North West region on how to write an effective transition policy.

Nationally, a group of expert clinicians has been brought together by Dr Rowan Hillson, National Clinical Director of Diabetes. The first output from this group is to develop a joint position statement on the principles of diabetes transition from ABCD and NHS Diabetes. This is attached as Appendix 1.

There is on-going work being led by the Royal College of Paediatrics and Child Health (RCPCH) in their transition workstream that looks at what action needs to be taken to make transition processes more effective in all care areas.

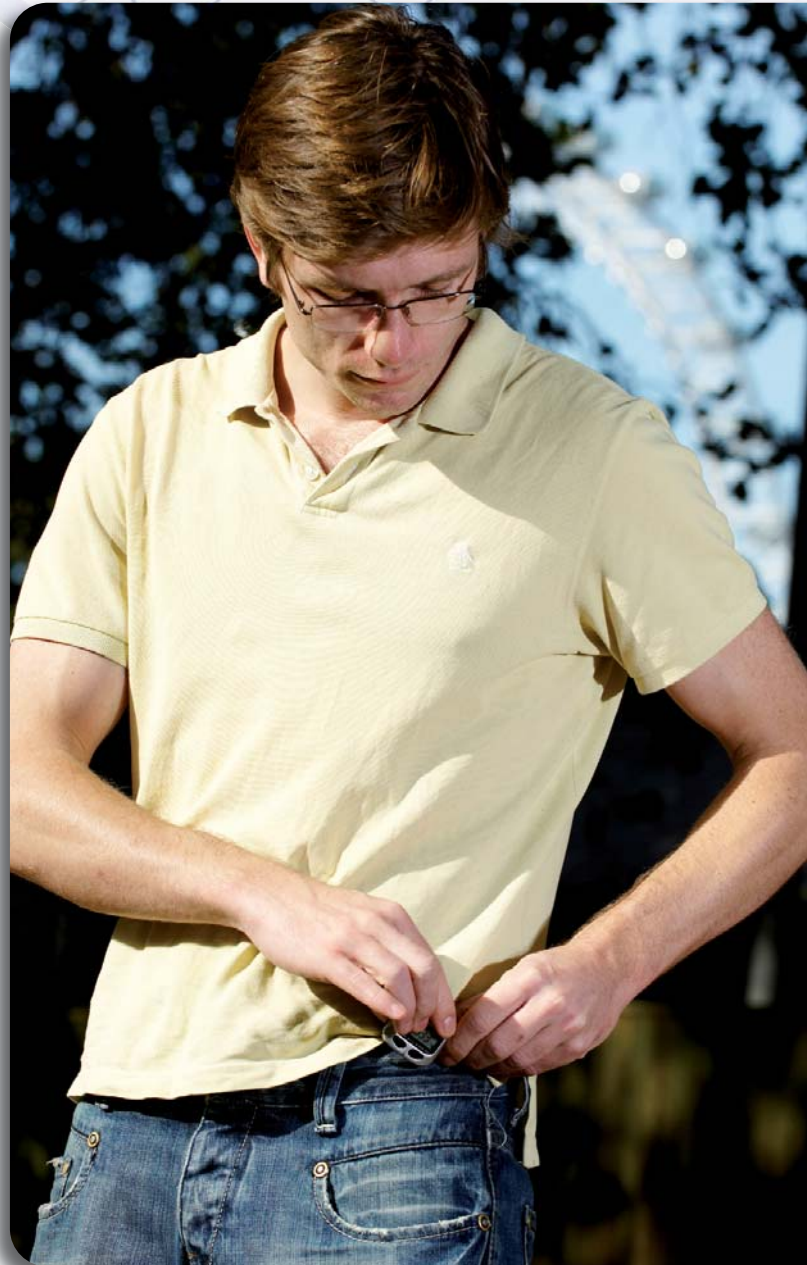
NHS reorganisation, the move to Clinical Commissioning Groups and the overview of Health and Wellbeing Boards present an opportunity to promote the care of diabetes generally and the importance of transition in particular.

Research led by Northumbria NHS Trust is looking at how to define the best model of transition for long-term conditions. The results of this five-year project will not be available for some time and it was recognised that some work was needed ahead of the findings from this research, to improve processes in the short to medium term.

Process undertaken for the project

The work reported here is a short-term funded project to collate what is already happening in diabetes transition care and recommend next steps for the short and medium term. A project manager was appointed to coordinate this work who, during the lifetime of the project (three months):

- Reviewed the literature and identified what made good practice.
- Sought out good practice by talking to paediatric diabetes experts and others involved in delivering diabetes care.
- Undertook a piece of snapshot research which asked teams to self-assess their transition processes and identify what would improve them.
- Brought together experts to lead a review and also to help shape suggestions for work to be done.
- Appointed two clinical leads (to review documents, the recommendations and also advise on case studies).
- Linked into work that was being led nationally about transition through both NHS Diabetes and ABCD (the principles document which is part of this work is attached as Appendix 2).
- Started the process of linking into transition work being undertaken in other disease areas, particularly other long-term conditions.



Evidence base and policy background

The importance of good transition

If transition is completed well and young adults remain engaged with their healthcare providers, this leads to better outcomes in the short, medium and long term.

“young people with physical health problems have more health difficulties the less contact they have with healthcare services ... dropping out and failing to attend clinic appointments and lack of concordance with treatment regimens have been extensively documented as a consequence of failing to provide adequate transition support.”

(Christie and Viner, 2009).

Research acknowledges that both the professionals and young adults recognise improvements to transition processes are needed, and that there are differences in the way paediatric and adult services are run. For some, the change from one type of service to another is difficult, “many find the cultural change unacceptable and non-attendance at adult diabetes clinics is often higher in young people and young adults than in older people and children” (pg. 2, Cropper, 2004). Professionals have additional concerns about young adults who did not attend (DNA) paediatric clinics before they started the transition process as they are discharged from one service and not picked up in adults, resulting in them not being known to either service.

However, if done well, the healthcare transition can be supportive of the young adult’s increasing independence and can enhance their quality of life and move to independent living. In order for the transition process to be delivered to a high standard there needs to be specific training on how to address the needs of young adults and how to consult with them effectively:

“Although specific health needs of adolescents clearly have been acknowledged and extensively documented in the United Kingdom, few paediatricians have received specific training in adolescent health.”

(pg. 1, Christie and Viner, 2009).

A gold standard model for transition?

Nationally, work has been carried out on improving standards in transition. This has included the “You’re Welcome standards” (DH, 2011) and also the “Moving on Well” document (DH, 2008). These outline what all transition services need to have in place to meet the needs of young adults to ensure they transition well into adult healthcare services.

There is a variety of models for the transition process in diabetes but none can be clearly identified as “gold standard”. “The importance of getting transition from paediatric to adult services right for young people is increasingly acknowledged but research evidence to inform the design of services is weak” (pg. 1, TCADS, 2010).

From research, and anecdotally, different services have tried offering clinics at different times in an attempt to reduce the number who DNA their clinic appointment. There are some units that run joint clinics with paediatric and adult teams and some that run these clinics in parallel. Other units have tried open-access models and some held clinics at times, such as in the evenings, more conducive to attracting young adults. Some units are creative in terms of using technology to remind young adults

of their appointments. Datta (2003) looked at reasons why young adults failed to attend appointments in various different models of diabetes transition services, including those who offer evening clinics. The reasons why people DNA varied for all services. Often, it was that the young adult forgot or that they had other things on. This reflects the view that healthcare transition is only a small part of the young adult's life.

Standards help define what makes a good transition process. For example, McDonagh's (2006) extensive literature review identifies barriers to transition and also what is needed to provide an effective process. She has recently developed some of these key themes in a book (not yet published) and this "toolkit" ensures all areas that need to be covered when examining a transition process are outlined. There are also Department of Health standards such as those described in You're Welcome (DH, 2011) and Diabetes UK (DUK) has developed top tips for transition on their website (DUK, 2012).

The snapshot research (Appendix 2) shows some of the basic steps needed to support an effective transition process are still not embedded in the process of the units who responded. Not one professional responded saying they provided an excellent transition service.

Quality consultation

The wider body of transition research shows it is the quality of the consultation that really matters to young adults. Some research has shown young adults do not like to attend services where there are mainly older people who have lots of complications, but attend clinics with people who are working age which is more acceptable. Studies "... found that young people prioritised privacy, confidentiality, short waiting times and an informal atmosphere" (pg. 4, Cropper, 2004). However, professionals have reported mixed success in attempts to make clinics a place where young adults can attend and talk to one another with things like refreshments provided. In many cases it seems that young adults do not really like informal chats with one another. They report they like to be in and out of the appointment (Datta, 2003). Even if they are the only young adult attending a clinic full of older people, it is the way that they are spoken to and the quality of the consultation that is key to their satisfaction with the service. Dovey-Pearce (2003) stressed the importance of staff approach for young adults. This has led to the work (detailed in the good practice example below) where training in adolescent communication skills for professionals working with young adults has been developed.



Involvement of young adults and their parents

Research into users' views of transition has been carried out (e.g. Datta, 2003 and Kime and Carlin, 2012). As seen in other areas of transition, the research makes similar points about what young adults want. They are keen to be involved in the service, they want to be talked to directly, and respected. The RCN produced a document "Lost in Transition" (RCN, 2007) which set out standards for transition in all disease areas. These include: "young people are involved in the design of the services" and "teaching young people how to cope with transition is part of the transition process" (pg. 8, RCN, 2007).

In addition, young adults, and often their parents, want to have the concept of transition introduced to them at an early stage. "The general feeling regarding transition from paediatric to adult diabetes services was that young people and parents needed to be better informed of the process. They did not necessarily know what the transition process meant and when they were in transition they were often unaware of what was happening and why. Young people and parents stated too much was assumed by the diabetes teams, particularly the paediatric teams, regarding their knowledge of transition." (pg. 15 Kime and Carlin, 2012).



The role of parents in transition needs to be recognised. However, it is a complex one depending on the young adult's desire and readiness for autonomy and how their parents and carers react. Into this mix, the role of the health professional and how they treat the young adult and their parents can either help or hinder the process, "Professionals need to be aware of the potentially competing aspects of the parenting role during transition i.e. protecting their son/daughter's health while supporting their growing need for independence, privacy and autonomy" (pg. 14 McDonagh, 2006). Added to this complex family dynamic is the mix of normal

adolescent rebellion and risk taking. Risk taking behaviour, however, creates a double jeopardy for young adults with long term conditions. Firstly they take more risks, and then the risks they take have more impact on their health (McDonagh, 2006). This can lead to an increase in parental anxiety and desire to protect the young adult.

Staff involved in transition

The BPT (Department of Health, 2012) highlights those professionals that are required in paediatric care as part of the MDT. The principles document (Appendix 2) also comments on the staffing required and their need to have appropriate competencies. The expert group, which has helped to develop this report, has reflected on the need for a smooth process for patients to move from the known paediatric team to the unknown adult team. Ensuring that members of both teams are not only available in clinic but that the same range of professional groups are available in the adult service. The minimum requirements for the paediatric team are; doctor, nurse and dietitian, with access to psychology. This minimum should

be reflected in the adult service that the patient is transferring to. The importance of the involvement of other team members has also been noted by the expert panel and the impact of podiatry is reported in one of the good practice case studies shown below.

Complexity in the process

From the snapshot research carried out in the North of England, paediatric units can clearly describe their process for Type 1 diabetes transition. The process is managed well, even in cases where there is a transfer rather than a transition. Professionals have anecdotally expressed concerns that for young adults with additional complications or care considerations, such as having CF, a pump (particularly if there is not a large pump service in the adult service) and pregnancy, can knock the normal process off course. For pump users and some other groups there may be a need to be seen in more than one clinic e.g. a pump clinic and a transition clinic, increasing the complexity of the transition process.

Additionally, if diagnosis happens when the young adult is over 16 years of age then hospital admitting policies often state they must be admitted directly to an adult ward. The young adult is then unlikely to receive any subsequent out-patient care in the paediatric service and move straight into adult services, thus bypassing the transition stage altogether.

Other disease areas

Research studies into other disease areas attempting to resolve their own transition issues, such as kidney care, CVD, and CF, have identified many issues in common with diabetes transition.

Diabetes is often ahead of other services in its transition planning and delivery. This is most notable where children have previously not survived into adulthood and so transition services are in their infancy or do not yet exist. The Study by Watson et al (2011, p 786), highlighted that no transition services were identified for young adults with autism spectrum disorder, Furthermore Viner et al (1999, p. 274) noted that "Transition programmes are poorest where no adult services exist, for example in metabolic diseases" (pg. 274).

Even in transition services for diseases where this is an established process, differences arise due to differing needs of other disease areas. For example, a study of transition into a 'care consultation service' conducted by Meek and Nourle (2011), had patients referred to this service who were cared for by several paediatric sub specialties. In diabetes this is less common as usually there is one main medical lead for each young adult.

The size of the young adult population in any disease influences the ability to devote resource to it. A study for British Association of Paediatric Nephrology (2009), recognised the case load for young adults versus the adult case load, "adolescent and young adult patients form a small part of the patients load in any adult service" (pg. 5). However, the study recognised that for nephrology, "specialised adolescent medical services are unlikely to be developed in the majority of adult hospitals in the foreseeable future" British Association of Paediatric Nephrology, 2009 pg.5-6), which may well be due to the relative population size. For diabetes, although young adults make up a small percentage of the adult case load, there are still large numbers and an increasing desire to develop a service specifically for people up to the age of 25 or even 30.

Generally, there are more similarities than differences to diabetes transition in the issues and challenges of the transition processes than other disease areas.



The importance of transition timing and early preparation is also identified in other disease areas. This has resulted in increased complications and poor outcomes. (McDonagh, 2006) and (Zelikovsky et al, 2008). Meek and Nourle (2011), report that “families have had little preparation for the differences between pediatric and adult health care delivery”. Fredricks et al (2010) highlights a model describing three, stages of transition: early, mid and late. This approach has also been used in the work on the individual transition plan prepared by the North West Paediatric Diabetes network.

The report prepared for the British Association of Paediatric Nephrology (2009), identifies areas of concern overlapping those reported in this work on diabetes transition. These include: adolescent and young adult patients forming only a small part of the case load in adult services (pg. 5), that transition and transfer are different things (pg. 3) and the way the workforce should be arranged needs consideration e.g. the importance of a dedicated transition team (pg. 6).

Research into other disease areas also recognises this stage of life as a challenging time for young adults and that services have to be flexible in their work with young adults; “Adolescents endorsed several reasons that contribute to the non-adherence. It makes sense that “just forgot” was the most common obstacle as teenagers are focused on spending time with their friends ...” (pg. 305, Zelikovsky et al, 2008).

The interaction of parents and adolescents was explored by Zelikovsky et al (2008), showing that adherence was better if the parent had responsibility for adherence (in this case adherence to medication regimes). However, as in diabetes care, involving the family and the role of parents in increasing independence is an important consideration. A recent study commissioned by NHS Kidney Care “Supporting Young Adults with Kidney Disease” (Beecham, 2011) to review the evidence base on models of young adult kidney care services, Juvenile Arthritis (JA) & Cystic Fibrosis (CF) services to inform & underpin the evaluation design and outcome measures in the evaluation” (presentation at DUK, Spring 2012). The conclusion of the study recognises that, “There is a wealth of evidence suggesting that being a young adult with kidney disease is a problematic time for these patients” (ibid). The same conclusion has been drawn for diabetes. The study found that critical components of a model of care

for young adults with Kidney Disease, CF and JA that chime with those needed for diabetes care. Many of the same components are reflected in the core principles work (Appendix 1) developed for diabetes. The components were described as:

- Holistic approach
- Involving the family
- Self-management skills
- Key worker role
- Trained professionals
- Educational and vocational planning
- Written care plans
- Peer support
- Development and education in adherence to medication
- Planned, coordinated and early start to transition

Finally, the NHS Kidney Care study recognises the problems for patients they describe as 'crashlanders' who arrive straight into adult services. In diabetes this is often at diagnosis on an adult ward. This is reflected in research into other disease areas "Within many services like ... rheumatology, there will be people diagnosed in late adolescence and young adulthood who have never experienced paediatric care, further highlighting the importance of ensuring the provision of age and developmentally appropriate care beyond the event of transfer in adult services" (pg. 10, McDonagh, 2006).

The research from diabetes and other disease areas reflects the issue of transition is an important one that does not have one easy quick-fix solution.

Results from the snapshot research

The process

A simple tool was created and teams were asked to complete it at the North West and the Yorkshire and Humber network meetings and also via newsletter to the whole of the North of England. Members of the North Mersey network group, mainly adult diabetologists, and parent and carer representatives on the North West and Yorkshire and Humber Paediatric Diabetes Networks were asked the same questions.

The tool was a short questionnaire that asked teams to rate 11 different aspects of their service on scale of poor to excellent.

Results

In total, 27 responses were received. The full set of results is shown in Appendix 2. Some responses were from teams and some from individuals. Not every respondent completed every section.

Overall the research shows that very few aspects of any services are rated as excellent. The combined number of ratings in each of the 11 different aspects of service is shown below.

poor	satisfactory	good	excellent
59	99	84	12

The largest area of need has been identified as “support for psychological wellbeing”. This is shown by not only being the area most frequently rated as 'poor', but also as the most common factor identified as the “thing that would improve transition”.

After psychological support the most pressing need identified was for a transition policy. Through the work on BPT this should be significantly improved during the financial year 2012-13 as having a transition policy is one of the standards that have to be met in order to claim BPT.

The area in which units believed they had most excellence was “Communication with patients and their families and carers”. No parents rated this aspect of care as excellent or good, although it should be noted the number of responses was small. All parents believed “Care planning and coordination” was the one thing that would improve transition.

“Integrated working with adult services” was highlighted as “good” by 12 respondents yet was also the area that many teams identified as in need of improvement (five respondents). All those who thought this would improve services rated their present service in this area as poor or satisfactory at present. This suggests that where there is good engagement between adult and childrens services, the sharing of good practice could support service improvement for other units.

Good practice

Good practice criteria

Criteria for an assessment of good practice within the context of this project were developed. In order to be recorded here, a piece of work or document needed to meet at least five of the following six criteria. That the work:

- Is patient (and parent and carer) centred.
- Has a locally relevant configuration.
- Has been tried in practice.
- Is flexible for the patient and can be used or adapted for implementation in different levels of care.
- Is innovative.
- Promotes the values underpinning the results of the key findings.



Examples of good practice

North West transition policy work

One of the work streams for the North West Paediatric Diabetes network was on improving transition. A small sub group met to draw together examples of policies that had been written locally and nationally.

From the collection of policies the “best of the best” were selected by the clinical members of the team and a suite of tools was developed. The tools have been designed to help units and Trusts develop a transition policy if they do not already have one.

The “suite of tools” has been developed to help units assess transition processes, write their policy and develop a plan to work with young adults. It is made up of four documents. These are:

- How to use the tools and worked examples.
- A checklist for transition.
- A draft transition policy.
- A transition plan.

The documents have been distributed as stand-alone tools for units to use and adapt. Pilot sites have used the transition documents to write a transition policy if they do not have one or adapt an existing one.

Improving transition at Alder Hey

Jane Edmunds, PDSN from Alder Hey in Liverpool, was part of the team who wrote the documents and one of the first to try them in practice. Alder Hey is a specialist children’s trust and young people from the paediatric diabetes team can move to one of five different adult services. Because of the Trust’s children’s status this currently has to take place at age 16 years.

The suite of tools has been written in such a way that they can be developed and adapted to fit the local service. Jane reported that by adapting the policy, significant time was saved compared to starting with a blank sheet of paper. However, she noted the process had still taken time but had helped to shape the way the team would like to work. At Alder Hey, the individual transition plan is being piloted to use as a patient-held record from the age of 11 years through to adult services, and the young people are being encouraged to bring the document to each clinic visit. It is hoped the document will continue to be used within the adult service by the adult teams who can carry on the transition process through to independence.

The team now introduces transition to young people and their families at an earlier age. Each year Alder Hey run a “summer day” for children moving from primary to secondary school and the team will begin to introduce the concept of transition at this point.

Transition in Bury

The transition process delivered in diabetes has evolved over time and, although historically it had no clear remit from commissioners, the process has been changing rapidly. The transition service in diabetes is delivered by two main providers (Pennine Acute Hospitals Trust and Pennine Care FT). Some of the progress to improve the service has been slower due to staff shortages, competing priorities and because there has been little clarity around how the business side of things works, despite services being intrinsically linked.

The service has developed a strong ethos based on:

- A process, not a one-off event (transition not transfer).
- Process is bespoke to patient and family – no one size fits all.
- Flexible (one visit – multiple visits).
- Multi disciplinary – paediatric ± adult DSN, paediatric/adult consultant, dietitian.

The evolution of the transition service has been guided by clinical need and “doing the right thing” for the patients, as well as a national focus for 2013 on the transition phase for people with diabetes. This, along with clinical enthusiasm and ensuring the current service “on the ground” is in keeping with “best practice”, has led to a flexible service that supports the move of young people from paediatric to adult services. The way this is done is described in the flow diagram shown below.



As always there is scope for improvement and there is also an ongoing challenge to get clarification of the various components of the service and its development.

Young people's healthcare: core skills

A one-day training programme being run for staff within Northumbria Healthcare NHS Foundation Trust.

This is a full-day course for staff within the Trust who have some contact with young people in their work. It is aimed at all staff at all grades and covers those who have periodic contact with young people and those with the age-group as their focus. It is aimed at those with acute contact with young people and those who have to build longer-term working relationships. The aim is to consolidate core skills across the organisation, so that a young person receives an age-appropriate service, wherever and whenever they access Trust services.

Typical agenda for the full day course is shown below:

- Introduction
- Adolescent development and epidemiology
- Young people's experience of healthcare
- Signposting: advocacy and health promotion
- Communication skills and top tips
- Consent and confidentiality
- Mini projects: what might you like to take forward in your service area?
- Meet the experts! Young service users
- Taking things forward: Applying today's learning

The day is supported by a poster and flyer display of local young person support services with displays and information about national groups, other agencies and voluntary groups.

Podiatry involvement in diabetes clinics

A podiatrist has joined the transition clinics at Pennine Acute Trust (PAT). This is to ensure that the podiatry team are able to provide education that equips young adults with information they need to take ownership and have active involvement in monitoring and caring for their feet.

This aspect of the clinic has been very popular with young people. Initially, the focus was on discussion about issues such as dry skin and footwear. In this way the professionals were able to help young adults understand how diabetes relates to their feet. As young adults have become more used to having that service at the transition clinic they now come to clinic ask how to avoid the foot complications they have heard about.

By providing this information to equip young adults for the future these clinics are helping to empower the next generation of patients with diabetes to help them look after their feet properly from the early stages of their condition.

Transition planning in Leeds

Leeds Teaching Hospitals Trust holds the transition clinic at the same time as the young adult clinic, so that all young people can attend at the same time. Thirty-minute appointments allow time for young people to discuss issues relevant to them, and the team are trained in motivational interviewing. There is an opportunity for part of the consultation to be without parents from the age of 13 to 14 years old. Monthly appointments and more frequent contact with their named nurse are offered when diabetes control is poor or there are other problems affecting diabetes management. A retinal screening clinic is also available, set up for the young people, but there are often older people with complications who are put into this clinic in order to reduce waiting time and they use the waiting area near reception, which is less than ideal. There is a robust system in place to ensure young people are not lost to follow up, with phone calls, texts and emails following non-attendance at clinic.

The young people are introduced to the adult staff before handover and particular issues are discussed. The paediatric multidisciplinary team members with special remit for transition have joint meetings with their colleagues in the adult team every six to eight weeks. The adults' side of the work is led by a diabetologist with a special interest in young people, who is in regular contact by email with those patients that prefer this method of communication. This evaluated highly in the transition from Child to Adult Diabetes Services (TCADS) study. There are two nominated adult DSNs but they have a less than ideal amount of resource required to meet all the needs of young people. Young adults who have transferred attend the young adult clinic, but also have to go to the specialist pump clinic for any CSII therapy specific problems. Additionally, at the time of renewal of the pump, there is only one type of pump available to them in the young adult service.

The team continue to work tirelessly to evaluate the service and make improvements, based on young people's views (focus groups and questionnaires), consensus, evidence and best practice. Julie Cropper has adapted the North West transition toolkit and checklist for use in Leeds. These are going to be put onto the electronic Diabetes Management System, with prompts at different stages of the Transition process from the age of 12, and future plans look promising. The paediatric team has identified the need for a Transition Consultant and Nurse lead and a specific transition team, with an out-of-hours advice service to fulfil the requirements of Best Practice Tariff (BPT). The money from BPT will be used, in part, to appoint two transition DSNs and a 0.5 WTE diabetes dietitian, specifically for 16 to 19 year olds.

The transition team also has plans to consult with the young people, by questionnaire and face-to-face discussion, about plans to move the transition clinic into the paediatric diabetes centre when the younger children are not there, and also to identify other improvements they might like.

Plans for the future

The Trust hopes to recruit additional psychology and social work hours for all children and young people, including those in transition. There are also plans for an information leaflet and additional support specifically for parents of young people during this very often difficult period of "letting go".

Soon there will be an on-call service and out-of-hours emergency advice line (24 hours) available in Leeds for 16 to 19 year olds as there is for the children currently, with easier contact by mobile phone texts and by email. At present, adult DSNs do not have mobile phones and this is a development the transition team would like to see to further improve communication with young adults using this medium.

Those diagnosed between 16 and 19 will have to be admitted to adult wards but will be visited by the transition nurses and discharged as quickly as is appropriate with follow up for education sessions in the children's diabetes education centre. The diabetes team hopes to be able to expand this service to 19 to 25 year olds in the future.

NIHR Research - how can health services contribute most effectively to facilitating successful transition of young people with complex health needs from childhood to adulthood?

This programme will investigate how transition services in the NHS can be improved. The overall aim of the programme is to promote the quality of life and health of young people (YP) with complex health needs (CHN) by generating evidence to enable NHS commissioners and Trusts to facilitate successful transition of YP from child to adult healthcare, thereby improving health and social outcomes.

Objectives are to:

- Work with young people with complex health needs to determine what successful transition means to them
- Identify the features of transitional care that yield better outcomes
- Determine how transitional care should be provided and commissioned

The programme will:

- Involve the reference group of young people with complex health needs in all aspects of the programme
- Interview young people about what 'successful' transition means to them. An economic study will determine the relative importance of different components of success
- Undertake a longitudinal study of 450 young people with diabetes, cerebral palsy and autism. This will identify service features which improve the outcomes of quality of life, satisfaction with care and disease status.
- Work with commissioners to determine what and how to commission

The programme will deliver an evidence-based plan for NHS Trusts and commissioners to use to provide optimal transition services, leading to the best health and social outcomes for young people.

Future case studies

The clinical leads for this transition project, along with the project manager, have identified possible areas for case studies for NHS Diabetes to follow up. These are:

- Work on transition in Portsmouth.
- Work on learning through change in Northumbria.
- Work with pump patients in Leeds.
- The Grimsby transition process.

Review of key findings

The processes carried out in this project have led to the production of these key findings about the current state of play in diabetes transition processes across the North of England¹.

Summary of key findings:

- Effective transition processes are urgently needed.
- Generally, professionals feel they do not do it well (or well enough).
- There is no clear model for what is most effective.
- If done well it is recognised this will help to prevent complications and improve engagement with adult services with increased attendance at clinics.
- Young adults have repeatedly been surveyed and report they care more about the interaction with the health professional than the model of transition used.
- There are many publications about why it is important but more needs to be done on what health services actually need to do to implement a good transition service.

Next steps

Some things are already in place due to the timing of the project. These are:

- Results of the research carried out in Northumbria NHS Trust to describe an effective model for transition.
- BPT implementation will ensure that each Trust has completed a transition policy. This is a key opportunity to encourage local units to either set up good practices or check that existing processes are effective.
- A principles statement has been developed (Appendix 1) and is now being disseminated.
- The North West Paediatric Diabetes network will continue to develop the “fill in the blanks” transition suite of tools.
- All paediatric networks are to be asked to have an adult diabetologist to join their meetings and be part of the network.
- All paediatric diabetes networks need to consider transition as part of their work plan for 2012/13.
- Improvement in the way clinicians “keep track” of patients to ensure they are having their diabetes care looked after by at least one service. There may be a clear role for primary care under the auspices of CCGs in this and possibly a requirement to nominate a lead for transition for each CCG.
- Work on BPT for the coming years to look at how the age group 18 to 30 could be included.

Work programme recommendations from the expert panel

There are several suggested steps, shown below, that can be developed into a national comprehensive work programme to support local areas to improve the transition process.

The aim is to develop services that are developmentally appropriate and support the young adult’s increasing independence as they move through paediatric health care to adult health care. This needs to be in a planned and co-ordinated manner regardless of their age and is separate to the transfer process of moving the patient from one service to another.

¹ This work was based in the North of England as some transition work had been initiated in the North West.

Project recommendations

The following recommendations have been drawn up by drawing together the combined elements of this project.

- All units asked to sign up to the core values of a quality consultation.
- Agree minimum standards for the contents of a transition policy – based on national guidance and evidence such as “You’re Welcome”².
- Ask people to ensure that their policy is in line with the minimum standards initially through the paediatric diabetes network coordinators and then formally through self-assessment, peer review and ultimately via BPT.
- Ensure there is an adult representative on each paediatric diabetes network. This person is to be supported by a wider body of adult diabetologists.
- Each unit to identify training needs for paediatric and adult teams around young adult communication and consultation skills.
- Develop a health plan prompt sheet. Included in this would be prompt sheets for both the professional and the young adult on all aspects of health³.
- Develop a transition planning process prompt sheet for professionals to improve their transition process⁴.
- Improving the standard relating to transition in the Best Practice Tariff requirements. Possibly taking into account the age group 18 to 30.
- Develop active integrated working with Diabetes UK

This work could be undertaken by utilising the role of the paediatric diabetes network co-ordinators.

² “You’re Welcome”; Transition: getting it right for young people. Improving the transition of young people with long term conditions from children’s to adult health services (DH)

³ This could be developed from the North West transition policy work and also work on transition at Southampton and would include work on the information that would be sent out ahead of the consultation and a checklist for professionals on areas to cover.

⁴ Included in this would be all the steps they need to undertake to ensure that their transition process is robust and incorporates the core values of a quality consultation.

Core values, competencies and skills needed to deliver a quality consultation

The following were developed by the expert panel using their experience of working with young adults. These key principles are fundamental to improving the consultation from the young person's point of view.

- Age appropriate communication – including talking to the young adult as well as the parent/carer.
- Provide the opportunity for the young adult to see the HCP without parent/carer for, at least, a short part of the consultation.
- Understand health issues in the context of everything else that is happening for the young adult at that time.
- Needs to be a non-judgemental and empowering experience for the young adult. The appointment should aim to develop mutually-agreed goals, identifying the young adult's strengths and building upon their existing capabilities.
- Aim for consistency of contact – not necessarily through one person but a small team to allow relationship to develop (needs to be supported by effective succession planning and identification and delivery of training needs).
- A balance of paediatric and adult healthcare professionals to see the young adult. All professionals need to be appropriately trained and specifically interested in the needs of young adults living with a long term condition.
- Include a statement on privacy and confidentiality up front (also needs to be in the Trust policy and backed up by training including training on safeguarding and understanding the legislation of competency to consent and CRB checks).

References

- Beecham, 2011, "Supporting Young Adults with Kidney Disease", NHS Kidney Care.
- British Association of Paediatric Nephrology, 2009, Helping Adolescents and Young Adults with End Stage Renal Failure.
- Cropper J, Working with Young People, 2004, Leeds Teaching Hospitals Trust.
- Cropper. J., Development of Transition Service for Young People with Diabetes in Leeds, Leeds Teaching Hospitals Trust, 2008.
- Datta, J., Moving up with Diabetes, NCB, 2003.
- David T, 2001, Transition from the Paediatric Clinic to the Adult Service, Journal of Royal Society of Medicine, 94, 8, 373–4.
- Department of Health, 2001, National Service Framework for Diabetes: Standards.
- Department of Health, 2008, Transition: Moving on Well - A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability.
- Department of Health, 2011, You're Welcome - Quality criteria for young people friendly health services.
- Department of Health, 2012, PbR Guidance, available at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132654.
- Dovey-Pearce, G., Initial findings from a user-involvement study using the framework approach to inform diabetes care for people aged 16-25, Birmingham Diabetes UK Psychosocial conference, 2003.
- DUK, 2012, Top tips for transition available at http://www.diabetes.org.uk/How_we_help/Magazines/Balance/Past-issues/Archived-issues-and-articles/2009/SeptemberOctober-2009/When-one-size-doesnt-fit-all/Top-transition-tips-for-young-people/.
- Gosden, C., Edge, J., Holt, R. et al, The fifth UK paediatric diabetes services survey: meeting guidelines and recommendations?, Arch Dis Child published online July 2010
doi: 10.1136/adc.2009.176925
- Holman, N., Diabetes Attributable Deaths: Estimating the excess deaths among people with diabetes, May 2008, YPHO.
- Kime, N., and Carlin, E., Join us on Our Journey Developing a New Model of Care of Children and Young People with Type 1 Diabetes, final report, NHS Diabetes, March 2012.

Fredricks, E. M., Dore-Stites, D., Well, A., Magee, J. C., Freed, G. L., Shieck, V., and Lopez, M. J., Assessment of transition readiness skills and adherence in pediatric liver transplant, *Pediatric Transplantation*, 2010, 14, 944 – 953.

Meek, R. S., and Nourle, C. E., *Transition of Care Consultation for Young Adults with Special Health Care Needs*, 2011.

NHS Information Centre, 2011, *National Diabetes Audit Mortality Analysis 2007-2008*, available at www.ic.nhs.uk/nda.

Royal College of Nursing, 2007, *Lost in Transition, Moving Young People between Child and Adult Health Services*.

TCADS, *The Transition from Paediatric to Adult Diabetes Services: What Works, for Whom and in What Circumstances? (TCADS)*, November 2010 available at <http://www.netscc.ac.uk/hsdr/projdetails.php?ref=08-1504-107>.

Viner, R., *Transition from paediatric to adult care. Bridging the gaps or passing the buck?*, *Arch Dis Child*, 1999, 81: 271 – 275.

Watson, R., Parr, J. R., Joyce, C., May, C., and Le Couteur, A. S., *Models of transitional care for young people with complex health needs: a scoping review*, *Child: Care, Health and Development*, 18th June 2011.

Zelikovsky, N., Schast, A. P., Palmer, J., and Meyers, K., *Perceived barriers to adherence among adolescent renal transplant candidates*, *Pediatric Transplantation*, 2008, 12, 300 - 308.

Appendix 1 – Principles for diabetes transition

Definition

Our agreed definition for diabetes transition is:

“The period of time during which there is planned, purposeful and supported change in a young adult’s diabetes management from child orientated to adult orientated services, mirroring increasing independence and responsibility in other aspects of their life.”

Beneficial features

these are highlighted in the table on page 31 and core measures are summarised below.

Core measures

It was agreed the following measures should be considered as part of service evaluation:

- Process
 - An identified lead for transition in each paediatric and adult diabetes service.
 - A joint paediatric/adult transition policy.
 - Evidence of consultation and user involvement in the policy development.
 - That the transition period last at least 12 months with input from paediatric and adult teams over that period with at least one combined appointment⁵.
 - Experience of care audit⁶.
 - Evidence of use of a shared care planning template e.g. the North West Individual Transition Plan.
- Outcome
 - DNA rates monitored and followed up over the course of the transition period.
 - Reduction in admissions for emergency DKA/hypoglycaemia.
 - HbA1c levels less than 58 mmol/mol.
 - Outcomes from a care audit to be undertaken by units.

All standards relating to the implementation of Best Practice Tariff for Paediatric Diabetes need to be met by all paediatric units.

⁵ This is defined as someone from each team (paediatric and adult) in the consultation but it may be any clinicians e.g. paediatric consultant but adult DSN.

⁶ Implementation of a standard patient experience questionnaire e.g. the one under development in the NPDA programme board at RCPCH.

Beneficial features	What it means to services	Core measures
<p>Person</p> <p>The young adult should be at the centre of their care and there should be opportunities to be involved in the on-going development of services. Information for the young adult should be available in a timely manner. The young adult needs to feel empowered to self-manage their own diabetes and exhibit competence to talk about their own diabetes.</p>	<p>There should be an opportunity for young people to shape the transition process and there should be active engagement and listening to ascertain their views.</p> <p>A move to independence of diabetes management needs to be led by the provider for services giving empowerment of young people.</p>	<p>A joint paediatric/adult transition policy.</p> <p>Experience of care audit.</p> <p>Competency measure such as assessment through individual transition plan.</p>
<p>Parent</p> <p>During transition, parents, in almost all cases, are learning to give up their role as carer for the young adult as the transition process happens - not just in diabetes but in all aspects of life. Their views and previous support needs to be taken into account in planning the process.</p>	<p>There should be an opportunity for parents and carers to shape the transition process and there should be active engagement and listening to ascertain their views.</p> <p>This may need to be balanced against conflicting wishes of the young adult.</p>	<p>A joint paediatric/adult transition policy (that explicitly talks about the role of parents and carers).</p>
<p>Partnership</p> <p>Transition should be a partnership between the young adult, their families, friends and other people involved in their lives, the paediatric diabetes service and adult diabetes service.</p>	<p>A 'transition lead', key worker or link person should be in place to bridge the gap between services.</p> <p>Lead clinical responsibility lies with specialist teams working in close partnership with the patient's GP and other organisations.</p> <p>There should be an opportunity for young people to provide peer support to each other in an organised way.</p> <p>Primary care should know about and be engaged in the transition process and plans that are in place.</p>	<p>An identified lead for transition in each paediatric and adult diabetes service.</p> <p>A joint paediatric/adult transition policy.</p> <p>Evidence of consultation and user involvement in the policy development.</p> <p>Experience of care audit.</p> <p>Evidence of use of a shared care planning template.</p>
<p>Participation</p> <p>Effective participation of young adults will not only engage individuals in the services but make the service more appealing to others.</p>	<p>Service users need to be involved at all levels of developing a service.</p>	<p>A joint paediatric/adult transition policy.</p> <p>Evidence of consultation and user involvement in the policy development.</p>

<p>Professional</p> <p>Organisational processes in place that facilitate the transition e.g. training should be available for professionals</p>	<p>There should be emphasis on the development of skills to allow self-care.</p> <p>Staff should have the appropriate competencies for working with young adults. Below the age of 16 this requires specific paediatric training.</p>	<p>An identified lead for transition in each paediatric and adult diabetes service.</p> <p>A joint paediatric/adult transition policy (that details how a record of training including appropriate CRB checks and safeguarding training is kept up to date).</p>
<p>Preparation</p> <p>The young adult, family and healthcare professional should be prepared for the process in advance of it starting.</p>	<p>Both the young adult and professionals should have the appropriate knowledge and skills to navigate the process successfully.</p> <p>Care should be developmentally appropriate and young adults should be involved in their care planning.</p>	<p>A joint paediatric/adult transition policy.</p> <p>Experience of care audit.</p>
<p>Planned</p> <p>Transition should be planned and there should be clear, consistent communication about the process for young people, parents and professionals. This should be written and verbal as well as making use of any other appropriate media.</p>	<p>Timing of the process should be appropriate for the young adult.</p>	<p>A joint paediatric/adult transition policy (outlining when transition is introduced and takes place; and patient choice within this).</p> <p>Experience of care audit.</p> <p>Evidence of use of a shared care planning template.</p>
<p>Place</p> <p>There should be flexibility in where the services are provided based on the stage of the process and location of the young adult e.g. a young adult in higher education should be able to choose to continue to receive care whilst on holiday at home.</p>	<p>The young adult should be able to agree their site of care to meet their needs during the transition process. This needs to be appropriate for young adults but there will be some restrictions due to the requirements of the consultation.</p>	<p>A joint paediatric/adult transition policy.</p> <p>Experience of care audit.</p>
<p>Process</p> <p>Transition should be part of a process or journey, not a one-off event.</p>	<p>The process should take as long as is necessary but should be a minimum of one year with at least one joint consultation with paediatric and adult services.</p>	<p>A joint paediatric/adult transition policy.</p> <p>Experience of care audit.</p>
<p>Pumps , pregnancy and pre-existing conditions</p> <p>Particular attention needs to be paid to ensuring that young adults who have pumps, need ante-natal services or have other co-morbidities such as CF are still able to effectively access transition services.</p>	<p>Lead clinical responsibility lies with specialist teams working in close partnership with the patient's GP and other organisations. Other aspects of the young adults care needs to be considered.</p>	<p>A joint paediatric/adult transition policy (to include how complexities such as these issues are dealt with during transition).</p>

Appendix 2

Results of the snapshot research work

The questionnaire was sent to all people who receive the North of England newsletter. 27 responses were received. Some were from teams and some from individuals – not every respondent completed every section and some people ticked more than one thing they wanted to change. In addition to responses from paediatric diabetes units, parents and adult services were asked to respond and few did. The numbers are too small to show here separately.

Self – assessment of where you are now

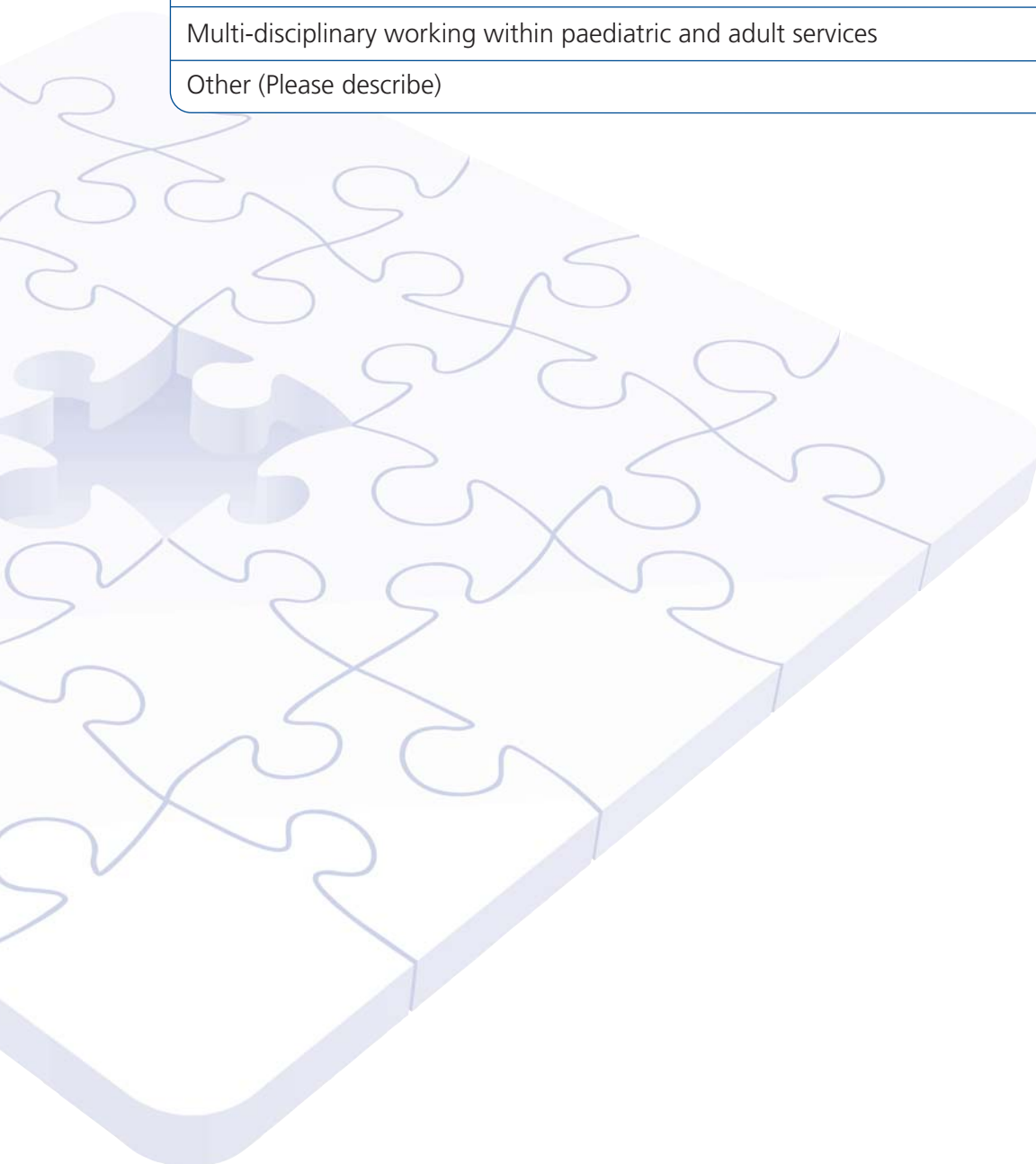
	poor	satisfactory	good	excellent	comments
Transition policy	11	5	8	2	
Assessment at the start of transition	4	16	4	0	
Planning – including a long enough preparation time for families	4	16	7	0	
Education for the patient including the promotion of a healthy lifestyle	3	12	12	1	
Support for psychological well being	17	5	5	0	
Care planning and coordination e.g. having a key worker	7	9	9	1	
Communication with other services	1	11	10	3	
Communication with patients and their families and carers	1	8	14	3	
Integrated working with adult services	6	9	12	0	
Multi-disciplinary working within paediatric and adult services	7	6	11	2	
Other	0	0	0	0	

Estimate of the number of “transition” appointments the young person will be offered (and type of clinic if relevant).

Estimated number of transition appointments	Time period
4	2 years
4	12 months
3	12 months

If one thing was to change to improve transition what it would be?

	Please tick
Transition policy	6
Assessment at the start of transition	1
Planning processes	4
Education for the patient	1
Support for psychological well being	7
Care planning and coordination e.g. having a key worker	3
Communication with other services	0
Communication with patients and their families and carers	0
Integrated working with adult services	5
Multi-disciplinary working within paediatric and adult services	2
Other (Please describe)	0



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