The development of these best practice pathways has been led within the South East Maternity, Children and Young People Strategic Clinical Network (SE MCYP SCN) by:

- **Dr Ryan Watkins** – Joint Clinical Director for MCYP
- **Dr Maggie Wearmouth** – Clinical Lead for Transition
- **Edwina Wooler** – Clinical Lead for Transition
- **Farhaj (Jan) Pathan** – Quality Improvement Lead
- **Charlotte Clow** – Network Manager
- **Jackie Huddleston** – Joint Interim Associate Director

The SE SCN would like to thank the following stakeholders for their invaluable contribution and support:

- The Transition Clinical Advisory Group
- The Transition Best Practice Pathways Working Groups

We would also like to acknowledge the work and contribution of Adam Cook from the South of England Quality Observatory and Laura Ansboro, Quality Improvement Lead for the MCYP SCN.
The transition from childhood to adulthood means leaving school and entering work or higher education, leaving the family home, becoming more independent. Children and young people with long term conditions (LTCs) frequently have to negotiate many more hurdles and obstacles than their peers when making important future plans and decisions.

For young people with any form of disability, LTC or significant mental health problem, transition is made all the harder when health professionals fail to plan or manage the process of handover from services designed for children to adult oriented systems. All too often, there is an abrupt transfer from one service to another or worse still; no arrangements are made at all. These young people have difficulty in finding an interested and competent service which is able and willing to provide continuity of medical care. The outcome of poor transition from paediatric to adult healthcare services can lead to poor compliance with treatment and less successful self-management. It can also affect the health and wellbeing of family and carers which in return can directly impacts on young people and their resilience.

The South East Maternity, Children and Young People Strategic Clinical Network (SE MCYP SCN) aims to both improve quality of care and reduce unwarranted variation in health outcomes for young people living with long term conditions who are transitioning into adult services. The Transition Clinical Advisory Group (CAG) has developed transition best practice pathways for three long term conditions – asthma, epilepsy and diabetes, with the support of three “Task and Finish” Groups, which were assembled with the specific purpose of achieving this aim. The generic principles identified in this document can be adapted to any long term condition impacting on healthcare for young people. The Transition CAG is clinically led and has membership from a range of stakeholders from across Kent, Surrey and Sussex. Patients, families, carers and the voluntary sector have contributed to the development of this guidance. The recommended pathways are developed by utilising examples of best national and local practice, key national policies and the draft generic Transition Service Specification developed by the NHS England, National Clinical Director for Children and Young People.

This document highlights the need for accurate data collection, something which is very limited at present. The available data indicates that A&E attendances and hospital admissions rise for children and young people (hence forth “young people”) with these conditions, roughly from the age of 15 years upwards. This raises important issues around patient safety, the patient experience and waste of valuable NHS resources. This guidance has used data from the Quality Observatory to demonstrate current non elective admission rates for young people and the estimated cost to the commissioners. A more robust audit is required to develop a business case for investment in transition services. This guidance also recommends each CCG develops a “Transition Co-ordinator” role to help young people, families and healthcare professionals as transition services are developed.

This guidance recommends safe and effective transition systems throughout children’s services which also provide tangible links with adult, social, education and voluntary services. Best practice pathways should ensure that patients and their families can be confident that they are not going to ‘fall through the net’. This guidance has utilised key national drivers and quality indicators to make a business case for change. The generic and condition specific key principles identified by the Task and Finish Group and supported by the Transition CAG are as follows:

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1 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 2006)
Generic Recommendations

A successful transition aims to ensure engagement and empowerment through a coordinated strategic approach. The ultimate goal is that young people have control of their condition and are able to make choices that will enable them to achieve the best possible state of health and psychological wellbeing. Below are the generic recommendations to support young people with long term conditions who are transitioning from paediatric to adult services.

- Transition should be a planned and purposeful process rather than a single paper exercise between clinicians. There should be a clear process for transferring care from young people to adult services, between providers and between primary, secondary and tertiary care and across specialities in the case of young people with complex needs.

- Each Trust should have a named lead for transition who will oversee the provision of services for young people in both paediatric and adult care to ensure they are fit for purpose.

- Each secondary care provider should have a generic transition policy supported by additional disease specific best practice pathways which may be complementary to, for example, the Best Practice Tariff (BPT) for diabetes and epilepsy or national guidelines such as those in place for asthma.

- Each health care provider should be able to demonstrate that they are providing written information and access to psychological support for young people with long term conditions.

- Young people with LTCs should have access to the best clinical care that empowers them to manage their condition on a day-to-day basis. This care should extend beyond hospital settings, reaching places such as education establishments, to ensure young people can lead their daily lives at school and home in a way that is clinically optimal and personally and psychologically right for them.

- Transition clinics should be set up in all Trusts and must include input from paediatric and adult clinicians. Strong consideration should be given to setting these clinics up at times that fit with school or university commitments and are acceptable to young people.

- All health care professionals who work with young people should have additional training in the specific needs of, and communication with, young people.

- Wherever services are delivered to young people, providers should strive to provide an ‘adolescent friendly’ environment. This will include primary and secondary care, outpatient departments and in-patient settings.

- Did not attend (DNA) rates should be tracked and monitored in this age group. The aim should be to minimise disengagement of young people from health services by monitoring attendance rates and offering patient acceptable outreach services where needed. There should be a responsive DNA policy for young people in each provider organisation ensuring good communication between secondary and primary care.
• Young people should feel safe and supported in managing their condition in school or college. Good communication strategies should be in place between the young person and their family, health care professionals and educational establishments.

• The young person’s skills in communication, decision-making, confidence and self-care, self-determination and self-advocacy should be promoted.

• Young people and health care providers should work together to co-produce an individual transition plan. This ensures that there is clarity about where and when services will be delivered and identifies the key professional contacts. This should ideally be in an electronic format. Access should be provided to patients, families or carers as appropriate and within information governance agreements.

• Consideration should be given to the role of multimedia in the management of young people for both the delivery of education and for clinical follow up. This could be the use of telephone triage, Skype consultations and text messaging, appropriately funded by commissioners.

• All written communication should be accessible and available in an easy to read format.

• Young people with Learning Disabilities (LD) with any other long term condition may require reasonable adjustments to the services in line with the public sector duties in the Equalities Act 2010.
Specific Recommendations for Diabetes, Asthma and Epilepsy

Asthma, epilepsy and diabetes are managed well in paediatric, primary and secondary care but there is often a poor link with adult services. The Transition Working Groups have developed best practice pathways for each of these conditions with a specific focus on promoting young people’s knowledge throughout their developmental years. They also give guidance as to how clinicians can support this and thereby avoid unnecessary hospital admissions. The key recommendations specific to each condition are as follows:

Diabetes Recommendations

- All providers should have Transition Clinics from the ages of 14 to 17 years.
- There should be a “young adult” clinic to help transition from the age of 18-24 years – until the 25th birthday.
- There should be a “local tariff” (see Finance section for recommendation) to support the development of “young adult clinics”.
- Providers should make provision to offer advice on smoking cessation, drug and alcohol abuse, contraception, pregnancy and sexual health.
- Transition clinics should be supported through a “coordinator” who can signpost and support young people in non-urgent matters and offer peer-group support.
- Young people and health care providers should work together to co-produce an individual transition plan. This ensures that there is clarity about where and when services will be delivered and identifies the key professional contacts. This should ideally be in an electronic format. Access should be provided to patients, families or carers as appropriate and within information governance agreements.
Asthma Recommendations

- Many young people with asthma will be cared for in primary care. More severe cases will be referred to adult respiratory physicians in secondary care. A clear pathway between secondary and primary care should be in place to ensure that young people receive the best possible care.

- National asthma guidance should be fully adhered to and monitored through the use of a “Personalised Asthma Action Plan” (PAAP) which has been agreed with the patient, ideally in an electronic format, from the ages of 13 to 24 years (until their 25th birthday). The PAAP should be shared between healthcare and education settings, patient, family and carers.

- There should be a special “young person’s” clinic from the age of 18-24 years.

- Transition clinics should be supported through a “coordinator” who can sign-post and support young people in non-urgent matters and offer peer-group support.

- Providers should be ready to offer advice on smoking cessation, drug and alcohol abuse, contraception, pregnancy and sexual health.

Epilepsy Recommendations

- There should be a “young adult” clinic to help transition from the age of 16 to 24 years – until the 25th birthday.

- For young people with learning difficulties (LD), transition services should start at the age of 13 and continue until the patient is at least 19 years of age.

- There should be a transition co-ordinator with the ability to advise young people about all aspects of living, including sign-posting to appropriate agencies/professionals and the offer of peer group support.

- Providers should be ready to offer advice on smoking cessation, drug and alcohol abuse, and sexual health. Female patients should be advised of the risks involved in unplanned pregnancies whilst on anti-epileptic drugs (AED). The transition co-ordinator should be involved in this.

- There should be support and monitoring of seizure control and medication adherence. Young people may be eligible for (or become eligible for) tertiary services such as vagal nerve stimulation or surgery. Professionals involved in their care (both secondary and primary) should understand eligibility requirements and monitor their patients for indications that they qualify and understand the pathways for referrals.

- Young people and health care providers should work together to co-produce an individual transition plan. This ensures that there is clarity about where and when services will be delivered and identifies the key professional contacts. This should ideally be in an electronic format. Access should be provided to patients, families or carers as appropriate and within information governance agreements. The parents/carers of young people with limited mental capacity will require expert support and advice regarding decision making.
Many more children with chronic illnesses are surviving into adulthood and need to be prepared and supported to live healthy and fulfilling lives. Young people who require continuing healthcare into adulthood are generally transferred from paediatric services between 16 -19 years of age, depending on the condition and local healthcare service arrangements. Blum et al (1993) stated that the aim is for transition to be a planned, purposeful movement of the young person from a child-centred to an adult-orientated health care system. It is a process that evolves over a considerable period of time and should not be considered a single event. However, we still find examples of transition which simply involves a letter to the GP or to the adult services requesting them to take over the patient's care, with limited background information provided.

Many paediatric clinical teams have expressed concerns to the Transition Clinical Advisory Group (CAG) that they simply do not have adult clinical teams to transfer care of these young people to. This is a particular concern for young people with learning disabilities and their families who continue to receive care from children's services well into adulthood. Families and patients have expressed similar anxieties and sometimes feel disengaged and frustrated with care providers during transition years.

The National Service Framework for Children, Young People and Maternity Services (2004) set out the need for the standardisation of processes for the transfer of young people from paediatric care into adult services. Government policy emphasises that this is not solely a matter for healthcare professionals, since long-term conditions also have important educational, social and financial implications. Ten years on from this integral document, we are still trying to identify ways to create better links between child and adult healthcare services and with other agencies. There are examples of good practice both locally and nationally where clinicians have created effective transition services, but they are often limited to using single specialities or providers. They often do not reach out beyond their own clinical environment to link up with the voluntary sector, education, social services or wider healthcare services.

The development of this guidance has been led by the South East Maternity Children and Young People Strategic Clinical Network (SE MCYP SCN). Strategic Clinical Networks bring people together to advise commissioners on what good services look like in order to improve health care outcomes for our population now and for future. The Transition CAG, which has developed these recommendations comprises a wide range of stakeholders, including clinicians from all relevant disciplines, commissioners, young people, families, carers and voluntary services. Over 200 stakeholders have been involved in total.

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The purpose of this paper is to provide guidance for commissioners to support and develop services for young people with any of the three long term conditions; asthma, epilepsy and diabetes. It recommends safe and effective transition throughout children’s services alongside tangible links with adult, social, education and voluntary services.

The goal is for all agencies to work together to support young people and their families to receive the best possible healthcare and lead fulfilling lives. Best practice pathways ensure that patients and their families can be confident that they are not going to ‘fall through the net’. The generic key recommendations have been created in such a way that once these principles are understood, they can be applied to any long term condition affecting young people. Performance will be measurable and will demonstrate continuous improvement in health outcomes for young people transferring to adult services.

This document has been agreed by the South East Transition Clinical Advisory Group and the Maternity, Children and Young People Strategic Clinical Network. It aims to create well-executed transition best practice pathways which meet the needs of the local population. The SE Transition CAG and the Transition Best Practice Pathways Groups have agreed transition age as being between 13 and 25 years of age, which aligns with guidance from the NHS England National Clinical Director for Children and Young People.
Physical emotional and psychological changes are normal aspects of adolescence. For those young people with any form of disability, long-term condition (LTC) or significant mental health problem, making a successful transition to adult healthcare services can present special difficulties. Young people will find significant differences in the expectations, style and culture of these services to the ones they are used to, whilst their own care needs will still be evolving (RCN 2013).

Effective transition care depends on collaboration across health care institutions. However, institutions often function in isolation and there is no process for allocating responsibility when problems arise. A literature review regarding transition by Coleman EA, Berenson (2004) found that patients and their caregivers are unprepared for their role in the next care setting, did not understand essential steps in the management of their condition and were unable to contact appropriate health care practitioners for guidance.

Many patients and caregivers were disappointed about a perceived lack of support by health care professionals at a key time of their lives. Most young people’s healthcare services operate in silos, separated from adult services. The lack of coordination between child and adult services creates anxiety and unnecessary distress for children, their families and carers. This often results in poor compliance with treatment, frequent visits to hospital, poor engagement with healthcare services, poor social engagement and mental health issues.

Table 1 shows the current population of young people from the ages of 10 to 29 across the South East.

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4. Lost in Transition - Moving Young People Between Child and Adult Health Services. Royal College of Nursing (2013)
Table 1: Current population of young people from the ages of 10 to 29 across the South East (ONS population projection for 2014 based on mid-year 2011 population).

<table>
<thead>
<tr>
<th>AREA</th>
<th>AGE BAND</th>
<th>POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kent</td>
<td>10-14</td>
<td>102581</td>
</tr>
<tr>
<td></td>
<td>15-19</td>
<td>110954</td>
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<tr>
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</tr>
<tr>
<td></td>
<td>25-29</td>
<td>109699</td>
</tr>
<tr>
<td>Surrey</td>
<td>10-14</td>
<td>66001</td>
</tr>
<tr>
<td></td>
<td>15-19</td>
<td>67151</td>
</tr>
<tr>
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<td>20-24</td>
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</tr>
<tr>
<td></td>
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<td>66696</td>
</tr>
<tr>
<td>Sussex</td>
<td>10-14</td>
<td>57152</td>
</tr>
<tr>
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</tr>
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</tr>
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<td>245406</td>
</tr>
<tr>
<td></td>
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Table 2 provides data for asthma, diabetes and epilepsy across the South East and illustrates that the number of elective and non-elective (A&E) attendances increases in most cases from the age of 15 years onwards. This data indicates that young people rely more on A&E to seek medical help.

*NB* the data is weighted proportionally to show its effect on a population of 10,000.
**Table 2:** Elective and non-elective admissions with Asthma, Epilepsy and Diabetes for the South East: January - December 2014

<table>
<thead>
<tr>
<th>County</th>
<th>Itc</th>
<th>Inpatient type</th>
<th>Age band</th>
<th>Admissions</th>
<th>Projected admissions</th>
<th>Total admissions</th>
<th>Rate per 10,000 population</th>
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<tr>
<td>SEC</td>
<td>Asthma</td>
<td>Elective</td>
<td>10-14</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>0.2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>15-19</td>
<td>12</td>
<td>9</td>
<td>21</td>
<td>0.9</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>20-24</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>0.1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>25-29</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>0.2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Non-Elective</td>
<td>10-14</td>
<td>172</td>
<td>123</td>
<td>295</td>
<td>13.1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1-19</td>
<td>118</td>
<td>84</td>
<td>202</td>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>20-24</td>
<td>159</td>
<td>114</td>
<td>273</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>25-29</td>
<td>132</td>
<td>94</td>
<td>226</td>
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<tr>
<td></td>
<td></td>
<td>Asthma total</td>
<td></td>
<td>600</td>
<td>429</td>
<td>1029</td>
<td>43.2</td>
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<tr>
<td></td>
<td>DM</td>
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<td>7</td>
<td>5</td>
<td>12</td>
<td>0.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>15-19</td>
<td>8</td>
<td>6</td>
<td>14</td>
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<tr>
<td></td>
<td></td>
<td>Non-Elective</td>
<td>10-14</td>
<td>153</td>
<td>109</td>
<td>262</td>
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<td>1-19</td>
<td>209</td>
<td>149</td>
<td>358</td>
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<td>20-24</td>
<td>188</td>
<td>134</td>
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<td></td>
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<td>25-29</td>
<td>107</td>
<td>76</td>
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<tr>
<td></td>
<td></td>
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<td>675</td>
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<td>1157</td>
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<tr>
<td></td>
<td>Epilepsy</td>
<td>Elective</td>
<td>10-14</td>
<td>12</td>
<td>9</td>
<td>21</td>
<td>0.9</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>15-19</td>
<td>24</td>
<td>17</td>
<td>41</td>
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<td>7</td>
<td>17</td>
<td>0.7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Non-Elective</td>
<td>10-14</td>
<td>61</td>
<td>44</td>
<td>105</td>
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<tr>
<td></td>
<td></td>
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<td>1-19</td>
<td>106</td>
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<td></td>
<td></td>
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<td>20-24</td>
<td>113</td>
<td>81</td>
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<td></td>
<td></td>
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<td>25-29</td>
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<td>1726</td>
<td>1233</td>
<td>2959</td>
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</table>
Visits to A&E tend to increase when young people are being transferred to adult services, moving to higher education or work, or moving away from home. Overall, the chances of 15-19 years with epilepsy and diabetes visiting A&E is higher than for those aged 10-14 years of age with similar conditions. Asthma is slightly different as it is the most common long-term medical condition. Roughly 1 in 11 children have asthma (www.asthma.org.uk). This places a huge stress on the healthcare system and leads to poor patient health outcomes and experiences.

It should be noted that exact A&E data is difficult to obtain due to differences in what is recorded at reception and what is noted on the discharge letter. It also appears that the conditions are coded under overall speciality; hence asthma is coded under respiratory, diabetes under endocrinology and epilepsy under neurology.

The SE MYCP SCN Children’s Services Baseline Review has highlighted significant areas of unwarranted variation in young people’s health outcomes across the SE when compared with those in other developed economies such as Sweden and Norway. The Task and Finish Group expressed similar views that they are not effectively meeting the needs of young people with LTCs. They would like commissioners to support them by commissioning services to promote best practice.

The Royal College of Physicians (RCP) outlined a position statement in July 2014 on young adult and adolescent patient care. This affirms a commitment to patient-centred care which is designed and delivered around each patient’s individual needs. The RCP recommends that clinicians adopt developmentally-appropriate approaches to young adult and adolescent patients.

Transition is also high on the national agenda and has been identified as one of the six key priorities identified by the National Clinical Director for Children and Young People. Transition covers all five domains in the NHS Outcome Framework but mostly sits under Domain 2.

The three LTCs – asthma, epilepsy and diabetes (for those under 19 years of age) are key priorities under Domain 2 in the CCG Outcomes Indicator Set 2014/15.

The Department of Health published a national pledge in 2013 to improve health outcomes for young people and to reduce child deaths. The pledge has five elements which are outlined in figure 1.

FIGURE 1

1. Children, young people and their families will be at the heart of decision-making, with the health outcomes that matter most to them taking priority.

2. Services, from pregnancy through to adolescence and beyond, will be high quality, evidence based and safe, delivered at the right time, in the right place, by a properly planned, educated and trained workforce.

3. Good mental and physical health and early interventions, including for children and young people with long term conditions, will be of equal importance to caring for those who become acutely unwell.

4. Services will be integrated and care will be coordinated around the individual, with an optimal experience of transition to adult services for those young people who require ongoing health and care in adult life.

5. There will be clear leadership, accountability and assurance and organisations will work in partnership for the benefit of children and young people.
Pledge 4 emphasises the need for integrated care with a positive experience of transition to adult services. These pledges have wide support from the NHS, non NHS organisations and the voluntary sector.

A report by the Care Quality Commission (CQC) in June 2014 found that young people who have physical disabilities or illnesses do not always receive the care and support they need when they move on to adult care services. As part of the CQC’s new approach to inspection, the CQC will investigate transition arrangements when it visits primary and community healthcare services.

The four priorities for transition outlined by the CQC are.

1. Commissioners and providers must listen to, involve and learn from young people and their families and understand what they want from their care.

2. Existing national guidance must be followed so that young people are appropriately supported through their transition.

3. GPs should be more involved at an earlier stage in planning for transition.

4. Services must be tailored to meet the needs of young people transferring from children’s health services and include extra training for health care staff in caring for young people.

Their findings will be reflected in the overall rating (Outstanding, Good, Requires Improvement or Inadequate) that they award to services. Commissioners should be aware that their decisions will therefore potentially have a direct impact on a provider’s CQC rating.

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1 Transition arrangements for young people with complex health needs from children’s to adult services (2014).
**Legal Requirements**

Below is a summary of the key legal requirements for commissioners to consider when commissioning services for young people.

The Health and Social Care Act 2012: The Act places greater emphasis on accountability by putting commissioners in charge of shaping local services, with a goal of enabling NHS funding to be spent more effectively. For transition the key points are:

- Improving quality of care
- Tackling inequalities in healthcare
- Promoting better integration of health and care services

The Equality Act (2010): Sir David Nicholson (2013) said “Recognising that every patient has different needs and circumstances, we can best meet those needs and improve outcomes by delivering a personal form of care, using and supporting the diverse talents and experiences of our workforce.” As such, equal access to good quality care for young people with any long term condition is essential and must meet their healthcare needs. The Equality Act gives people legal protection from discrimination in the workplace and in wider society.

The law requires all NHS organisations to ensure health and social care services are fair and meet the needs of everyone, whatever their background or circumstances. As such, transition needs to be an integral part of care planning and commissioning.

The Mental Capacity Act (2005): The Mental Capacity Act (MCA) is designed to protect and empower individuals who lack the mental capacity to make their own decisions about their care and treatment. It is a law that applies to individuals aged 16 and over. The MCA also allows people to express their preferences for care and treatments in cases where they lack capacity to make these decisions. It also allows them to appoint a trusted person to make a decision on their behalf should they lack capacity in the future.

Young people with learning disabilities (LD) have the same rights to treatment and access as everyone else. The MCA is very specific, stating: “Treatment and care provided to someone who lacks capacity should be the least restrictive of their basic rights and freedoms possible, while still providing the required treatment and care.”

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8 [The Equality Act (2010)]
9 [The Equality Act (2010)]
10 [Mental capacity act]
Standards
Table 3 provides a guide for commissioners which will enable them to commission services against national standards. The key national standards are highlighted on the left.

Table 3: Commissioning against the national standards

<table>
<thead>
<tr>
<th>STANDARDS</th>
<th>FOR COMMISSIONERS TO CONSIDER</th>
<th>COMMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS Outcome Framework Domains</td>
<td>NHS Outcomes Framework.</td>
<td>Friends and Family Test in progress. To be rolled out to all services.</td>
</tr>
<tr>
<td></td>
<td>NHS 2.3.ii - Unplanned hospitalisation for asthma, diabetes and epilepsy (under 19s).</td>
<td></td>
</tr>
<tr>
<td></td>
<td>NHS 4 - Improving children and young people’s experience of healthcare.</td>
<td></td>
</tr>
<tr>
<td>CCG Outcome Indicator Set</td>
<td>C 2.7- Unplanned hospitalisation for asthma, diabetes and epilepsy (under 19s).</td>
<td>CCGs to also consider re-admission rate after discharge from hospital for young people with LTCs</td>
</tr>
<tr>
<td>Public Health Outcomes Framework</td>
<td>Domain 1: Improving the wider determinants of health sickness absence rate (indicated here in relation to acute or chronic health/mental health issues).</td>
<td></td>
</tr>
<tr>
<td>NHS England Business Areas</td>
<td>1. Prevention and early diagnosis</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4. Patient experience</td>
<td></td>
</tr>
<tr>
<td></td>
<td>8. Equality and health inequalities</td>
<td></td>
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<tr>
<td></td>
<td>19. Citizen participation and empowerment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>20. Wider primary care provided at scale</td>
<td></td>
</tr>
<tr>
<td></td>
<td>21. A modern model of integrated care</td>
<td></td>
</tr>
<tr>
<td>DH - Better outcomes for children and young people:</td>
<td>Pledge 4 emphasises the need for integrated care with a positive experience of transition to adult services.</td>
<td></td>
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<tr>
<td>our pledge (2013)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NICE Guidance to help tackle transition from</td>
<td>Due in late 2015.</td>
<td>NICE is developing guidance to help address the gaps in health care sometimes experienced by young people as they move from children’s to adult services. This guidance is in early stages of consultation with the anticipated date of publication in late 2015.</td>
</tr>
<tr>
<td>children’s to adult services</td>
<td></td>
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</tbody>
</table>
| **Diabetes Best Practice Tariff** | • Each patient should have an annual assessment by their multi-disciplinary team as to whether input to their care by a clinical psychologist is needed, and access to psychological support as appropriate. Current Diabetes BPT is £3189.  
• Each provider must participate in the annual Paediatric National Diabetes Audit.  
• Each provider unit must have a clear policy for transition to adult services. | Commissioners to monitor providers to submit evidence of MDT, psychological support and effective transition policy.  
More details on all criteria can be downloaded from the [Diabetes UK website](#). |
<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>Epilepsy Best Practice Tariff</strong></td>
<td>As set out on pages 100-102 of the 2013/14 PbR Guidance, BPT is payable for all follow up appointments that meet the defined characteristics of best practice. Where BPT criteria are met, a tariff of £173 is payable under the new paediatric epilepsy Treatment Function Code (TFC) 223. When the characteristics of best practice are not met, a tariff of £125 applies if single professional, or £162 if multi-professional.</td>
<td>It is understood that many providers do not invest in services to claim best practice due to low financial incentives and high associated costs. Commissioners to consider locally agreed tariff to improve epilepsy services for ages 13-25 and create a framework for a more holistic package.</td>
</tr>
<tr>
<td><strong>National Generic Specification for Transition</strong></td>
<td>Generic specialist services specifications for transition – developed by National Clinical Director.</td>
<td>This document is currently in draft format and being reviewed by Clinical Reference Groups. This service insert is intended to be applied in conjunction with the generic paediatric specification E03 and the individual paediatric and adult service specifications where transition planning and support is an identified requirement.</td>
</tr>
<tr>
<td><strong>British Guidelines on the Management of Asthma (2014)</strong></td>
<td>A comprehensive guide and recommendation on asthma management from childhood to adult life. Designing and Commissioning Services for Children and Young People with Asthma.</td>
<td>Download document</td>
</tr>
<tr>
<td><strong>NHS Five Year Forward View (Oct 2014)</strong></td>
<td>Supports services which are focused on disease prevention, new and flexible models of service delivery tailored to local populations and needs, integration between services, and consistent leadership across the health and care system as well as prevention, patient engagement and variance in service provisions.</td>
<td>Download</td>
</tr>
</tbody>
</table>
Engagement with Young People, Families/Carers and Voluntary Services

The Transition CAG has used Patient Public Engagement (PPE) to engage directly and indirectly with over 50 young people, families, carers and many voluntary organisations in order to develop this guidance. The feedback from this engagement has been incorporated into the development of the best practice pathways and highlighted throughout this document. A PowerPoint document was prepared separately, focusing on young people. This was shared with young people via other agencies and by members of the CAG. Here are some anonymised comments that were received.

“‘H’ and I looked at this (document) last night. It was quite an emotional matter to talk about in this context as we both feel if there had been this kind of model available 10 years ago and onwards she may well have coped far better, and her life would not look like it does now. She agrees with all the points raised in the slides especially those relating to becoming independent in her illness. A clear action plan document that can be referred to when needed would have been very useful. ‘H’ would have loved to speak to someone non-clinical (to discuss non-clinical topics). To have a trusted adult to talk to in this context would have been amazing for us both.” (Mother of “H” who has diabetes)

Comments received via West Sussex County Council.

“This document is covers most of the significant issues with transition.”

“J” – a young person with diabetes

“It’s good that people are thinking about us as teenagers. I’ve had asthma for years but I didn’t know the doctors would change when I turned 18. Hopefully it’s not too different. I don’t mind coming out of school for a clinic.”

Comment received via The Trust for Developing Communities (Brighton and Hove) via Facebook.

It has been a useful exercise to use PPE throughout this process. It provided valuable insight into young people’s experiences. It is recommended that providers engage with young people, families and carers when designing transition services, to ensure that they meet the needs of the local population.
Effective approaches to transition will require major cultural and philosophical shifts from healthcare teams. Service providers must acknowledge that there are wide variations in the effectiveness of planning and delivery of healthcare. Frequently services do not meet the expectations of young people.

Given that improving A&E services has been a national priority for successive governments, this presents an opportunity to make positive change. The Transition CAG is proposing the following generic recommendations for any young people with long term conditions. These will help commissioners and providers to meet national standards for improving services.

- Transition should be a planned and purposeful process rather than a single paper exercise between clinicians. There should be clear processes for transferring care from children’s to adult services, between providers, between primary, secondary and tertiary care and across specialities in the case of young people with complex needs.
- Each Trust should have a named lead for transition who will oversee the provision of services for young people in both paediatric and adult care to ensure they are fit for purpose.
- Each secondary care provider should have a generic transition policy supported by additional disease specific best practice pathways which may be complementary to, for example, the Best Practice Tariff (BPT) for diabetes and epilepsy or national guidelines such as those in place for asthma.
- Each health care provider should be able to demonstrate provision of accessible written information and access to psychological support for young people with long term conditions.
- Young people with LTCs should have access to the best clinical care that empowers them to manage their condition on a day-to-day basis. This care should extend beyond hospital settings to places such as education establishments, to ensure young people can lead their daily lives at school and home in a way that is clinically optimal and personally and psychologically right for them.
- Transition clinics should be set up in all Trusts and must include input from paediatric and adult clinicians. Strong consideration should be given to setting these clinics up at times that fit with school or university commitments and which are acceptable to young people.
- All health care professionals who work with young people should have additional training in the specific needs of young people and in how to communicate with young people.
- Wherever services are delivered to young people, providers should strive to provide an ‘adolescent friendly’ environment. This will include primary and secondary care, outpatient departments and in patient settings.
- Did not attend (DNA) rates should be tracked and monitored in this age group. The aim should be to minimise disengagement of young people from health services by monitoring attendance rates and offering patient acceptable outreach services where needed. There should be a responsive DNA policy for young people in each provider organisation ensuring good communication between secondary and primary care.
- Young people should feel safe and supported in managing their condition in school or college. Good communication strategies should be in place between the young person and their family, health care professionals and educational establishments.
• The child or young person’s skills in communication, decision-making, confidence and self-care, self-determination and self-advocacy should be promoted.

• Young people and health care providers should work together to co-produce an individual transition plan. This ensures that there is clarity about where and when services will be delivered and identifies the key professional contacts. This should ideally be in an electronic format. Access should be provided to patients, families or carers as appropriate and within information governance agreements.

• Consideration should be given to the role of multimedia in the management of young people for both the delivery of education and for clinical follow up. This could be the use of telephone triage, Skype consultations and text messaging, appropriately funded by commissioners.

• All written communication should be accessible and available in an easy to read format.

• Young people with LD with any other long term condition may require ‘reasonable adjustments’ to the services in line with the public sector duties defined in the Equalities Act 2010.
The Role of the Care Co-ordinator

The role of coordinator is well established in some specialties. For example, cancer services often provide a non-clinical support team to ensure that patients are moving along treatment pathways successfully. Others specialties may fulfil this role through specialist nurses. It is recommended that commissioners should enable the recruitment of care coordinators across the SE to support young people with long term conditions. They can be any professionals (health or non-health) involved in the care or support of young people and their wider families. They must have the confidence and approval of the young people and family/carers as well as good networking, communication and advocacy skills. They will be part of the healthcare team, supporting transition services and acting as a “contact point” in care for non-urgent healthcare needs. The care co-ordinator may be actively involved in any or all stages of the pathway, but does not have to be.

The Queen Elizabeth (QE) Hospital, Birmingham is running a new youth connector project which has been based in the A & E and CDU departments of the QE Hospital since March 2014. Early indications show a reduction of 33% in A&E attendances (30 unplanned admissions) for repeat users of services from March to April 2014. Though the demographics of Birmingham are different to many smaller towns and cities across the SE, new models of care are still needed to reduce the burden on hospitals and improve the quality of care for young people with LTCs. Details of this initiative are in Appendix 2.

Care coordinators could provide the following core functions and be developed further according to local needs:

- To act as a liaison between healthcare, patients, families/carers and other agencies.
- To guide young people/families/carers in non-urgent matters and help them to receive the best possible care, sign-posting services as required.
- To carry out monitoring of the service in the field to ensure that it meets quality standards, that the contractual requirements are understood and that stakeholders are kept informed of the relevant issues and progress.
- To develop or signpost a network of young people with similar conditions to provide peer support.
- To support providers to complete data such as the national paediatric diabetes peer review data, respiratory data or epilepsy 12 data, or as required nationally or locally, in a timely manner.
The importance of environments and timing of clinics is another issue raised by young people and their families/carers. Young people do not feel comfortable in wards or outpatient clinics where they are surrounded by small children or elderly adults. Ideally, an adolescent in-patient ward should be provided but this will not always be possible. Not all consultants have admission rights to inpatient beds and the number of young people with LTCs is small when compared to other age groups.

Flexible approaches, such as designating some beds/bays for young people should be considered. Similarly, outpatient clinics should be decorated in a style appropriate to this age-group. These requirements should be incorporated in any future planning when setting up transition clinics. Another alternative is to consider holding outpatient clinics in non-clinical environments – or even using technology such as “Skype” type services. Timing and location should be adjusted to meet the needs of young people who may be in continuing education or getting ready for their first jobs. The package needs to be holistic and think beyond the traditional “Monday to Friday, 9-5” approach. Commissioners must not penalise providers with a reduced tariff if providers make changes that are appreciated by young people, even if these are perceived to cut costs. The focus should be on quality and better clinical outcomes for patients.

Training

Health Education Kent, Surrey and Sussex (HEKSS) is a Local Education and Training Board and part of Health Education England. It has been established to ensure the effective planning, education and training of the NHS workforce within the region and has supported this piece of work. Online training modules are available through www.rcph.ac.uk and about adolescent health through e-learning for health.
The Royal College of Paediatrics and Child Health (RCPCH), commissioned by the Department of Health, published a survey ‘Growing up with Diabetes’ in 2009 which established that there were 22,783 young people between 0-17 years with diabetes in England on 1st January 2009. The number of young people with diabetes by age group is below:

Table 4: Type of Diabetes by Age in England on 1st January 2009

<table>
<thead>
<tr>
<th>AGE</th>
<th>TYPE 1</th>
<th>% OF TYPE 1</th>
<th>TYPE 2</th>
<th>% OF TYPE 2</th>
<th>OTHER</th>
<th>% OF OTHER TYPES</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4</td>
<td>827</td>
<td>4.0</td>
<td>0</td>
<td>0.0</td>
<td>31</td>
<td>9.7</td>
<td>858</td>
</tr>
<tr>
<td>5-9</td>
<td>3920</td>
<td>19.1</td>
<td>6</td>
<td>1.8</td>
<td>34</td>
<td>10.6</td>
<td>3960</td>
</tr>
<tr>
<td>10-14</td>
<td>8715</td>
<td>42.5</td>
<td>128</td>
<td>39.1</td>
<td>114</td>
<td>35.6</td>
<td>8957</td>
</tr>
<tr>
<td>15</td>
<td>2327</td>
<td>11.4</td>
<td>72</td>
<td>22.0</td>
<td>45</td>
<td>14.1</td>
<td>2444</td>
</tr>
<tr>
<td>16</td>
<td>2498</td>
<td>12.2</td>
<td>71</td>
<td>21.7</td>
<td>51</td>
<td>15.9</td>
<td>2620</td>
</tr>
<tr>
<td>17</td>
<td>2201</td>
<td>10.7</td>
<td>51</td>
<td>15.6</td>
<td>45</td>
<td>14.1</td>
<td>2297</td>
</tr>
<tr>
<td>Total</td>
<td>20488</td>
<td>328</td>
<td>320</td>
<td>15.6</td>
<td>45</td>
<td>14.1</td>
<td>21136</td>
</tr>
</tbody>
</table>
The survey illustrated the distribution of cases of diabetes. It also revealed that the North East and South East Strategic Health Authorities (SHA) areas have a higher number of cases than would be predicted, whereas numbers in East Midlands and London SHA’s are lower than expected.11

It is difficult to obtain information on the number of young people with diabetes who are either on an insulin pump or continuous glucose monitoring (CGM), as these are commissioned through Specialised Commissioning. Dr Alok Gupta (SEC and London Paediatric Diabetes Network) indicated that some units are more proactive in prescribing insulin pumps and/or CGM, with perhaps as much as 50% of their young people patient group on either or both. Dr Ben Field, at Surrey & Sussex Healthcare NHS Trust (SaSH) runs four full transitional adolescent diabetes clinics each quarter, where 43% of the diabetic patients are now on insulin pumps (see Appendix 3 for more details).

This has significant cost implications for commissioners in adult services where services are agreed through the standard contract. There is an urgent need for updated data to ensure continuity of the highest quality care and to enable commissioners to forward plan effectively.

Diabetes UK has published various research reports on transition. Some of the key findings are:

- Only one in five young adults get all the health processes recommended by the National Institute for Health and Clinical Excellence (NICE), including eye examinations and foot checks (March 2008).12
- Teenagers with type 1 diabetes are at greater risk of diabetic complications during their transition from paediatric care to adult care.
- Poor clinic attendance is linked to inappropriate transition, with between 10 – 69% of young people receiving no medical follow up after transfer to adult services. Those lost to follow up have poorer diabetes control. Medical crises could be averted if individuals received regular follow up and education.13
- Up to 40% of diabetics develop serious kidney disease in their lifetime, and around one in five patients starting dialysis have diabetes. Many will also have on going health concerns such as retinopathy (eye problems), arterial problems (heart disease, strokes), or neuropathy (damage to the nerves).

A study in the USA found that without support, young type 1 diabetics were considerably more likely to have chronically high blood glucose levels when transitioning from paediatric to adult care, putting them at higher risk of eye disease, heart problems and kidney disease in later life.14 This study concluded that that transition programmes improve health outcomes and quality of life and that inadequate transition has been associated with poorer health outcomes. Services for young people with diabetes are supported through the Best Practice Tariff of £3,189. This has allowed the development of diabetes services across the South East, as outlined in the following example.

12 Only a fifth of young adults with diabetes get all the health checks they need
13 Care Recommendation - Transition from paediatric to adult services (July 2008)
14 Diabetes Care Peters A (2011)
“Dartford and Gravesham NHS hospital provides care to young people with diabetes. We run a quarterly Transitional Care Clinic, on the first Thursday of March, June, September and December from 16.00-18.00 hours. The patients are put forward to transitional clinics once they have agreed and their conditions are stable or as their condition dictates. Once they have attended the transition clinic successfully then they are followed up in a young adult clinic until the age of 25 by a dedicated young adult team which is comprised of a named clinician, two named DSN and a named dietician.”

Dr Alok Gupta - Dartford and Gravesham Hospital Comments received via West Sussex County Council.

The Diabetes Task and Finish group has provided information (Figure 2) about diabetes services across the South East. The main issues outlined were:

- Paediatric diabetes services are supported through the Best Practice Tariff (BPT) but there is no such arrangement when these young people are transferred to adult services.
- In general diabetes services in young people are good but links with adult services are poor.
- There are examples of good practices for diabetes transition, but there is also wide variation in service provision.
- Young people and families would like to see improvements in diabetes care for young people transitioning into adult services.
- There is a lack of information for young people and their families/carers when young people move away from their homes.

The Transition CAG has engaged directly with two young people with diabetes and a number of adult patients/families with diabetes and parents/carers of children with diabetes. The feedback has been incorporated into the generic recommendations, as well as the specific recommendations for the three long term conditions. Here is a representative sample of what they had to say:

“DNA policy and subsequent follow-up appointments in an adult setting need to be managed differently for the young people to avoid them “falling through the net.”

“Healthcare staff need more education on communication skills with young people and about the latest devices/technology available to help diabetic patients.”

“Young people need peer group support outside the clinical environment.”

“Leaflets and social media should be young people focused.”

“Use peer group support through young people networks, use simple and easy to understand language.”

“Typical clinic appointment timings are not suitable for young people who are busy in schools or universities.”
**Figure 2: Current Issues/Gaps/Good Practices for CYP Transitioning to Adult Services with Diabetes**

**CYP Diabetes**
- Access to GP
- A&E or GP presentation
- Time to make initial diagnosis
- Good CYP diabetes service supported by best practice tariff

**Assessment and Care Planning**
- Variable
- Some examples of good practice
- Lack of coordination of care between providers
- Some units are more proactive with insulin pumps prescription
- Often good family support through Diabetes CNS

**Management**
- Workforce issues
- Treatment options available
- Management of DNA is better than adult services
- Some Transition clinics but generally patients are transferred to adult services with very little preparation offered to young people
- Age at which care is transferred to adult services is also variable between 16-18 years
- Lack of family engagement after transfer of care to adult services
- No transition lead across the SE
- Restrictions by CCGs on access to specialist diabetes care after the age of 18 years
- Some CCGs restrict and new to follow up ratio.

**Admitted Patients**
- Young people admitted to in-appropriate wards
- Depending on the age, care is often provided by CYP or adult services
- Lack of coordination between adult and paediatric services
- Work force issues in adult services to support Young People
- Treatment options in adult setting is limited- pumps or manual injections

**Moderate to Severe Condition**
- Provided at secondary care providers
- Often away from home
- Issues when young people move from one area to another and become lost in the system

**Measuring Outcomes**
- Provider submit data to claim BPT
- Data is retrospective and submitted nationally
- CCG unaware how many patients are on insulin pumps- funding issues when these young people will move to adult services
- There is best practice guidance but the measures are not clear.
Recommendations for Diabetes

Young people with diabetes should have access to the best clinical care. This should empower them to manage their condition on a day-to-day basis. This care should extend beyond hospital settings, to ensure young people with diabetes can lead their daily lives at school and home in a way that is clinically optimal and personally and psychologically right for them.

The focus of the pathway is to develop the skills of young people and their families so they can move from dependence on the healthcare system to more self-care, while creating a process which is seamless from young people to adult services and other agencies. Transition services for diabetes should be standardised across all diabetes services in the SE. The Transition CAG has developed this diabetes transition guidance for commissioners. The guidance recommends:

- Providers should have a transition policy to support young people moving to adult services.
- The age at which transition starts should be tailored to a child’s needs but should start no later than the age of 13.
- There should be ongoing education for young people and their families on self-care and about transition services.
- All providers should have transition clinics for young people from the age of 14-17 years.
- There should be a “young adult” clinic to help transition from the age of 18-24 years – until the 25th birthday, in an age appropriate environment and at times that are suitable for young people’s needs.
- There should be a “local tariff” (see Finance section for current estimated non elective admissions and recommendations) to support the development of “young adult clinics”.
- There should be a responsive DNA policy in place in each provider organisation ensuring good communication between secondary and primary care. Systems should be in place to ensure no one “falls through the net”.
- Health education should be provided in an appropriate format (printed or electronic) that is easy to understand and designed with the support of young people.
- Providers should make provisions to offer advice on smoking cessation, drug and alcohol abuse, contraception, pregnancy and sexual health.
- Transition clinics should be supported through a “coordinator” who can signpost and support young people in non-urgent matters and offer peer-group support.
- Young people and health care providers should work together to co-produce an individual transition plan. This ensures that there is clarity about where and when services will be delivered and identifies the key professional contacts. This should ideally be in an electronic format. Access should be provided to patients, families or carers as appropriate and within information governance agreements.
- Consideration should be given to using tele health devices to promote positive health behaviours such as appropriate BM monitoring, good compliance with medication, motivational advice with regards to exercise, healthy eating etc. The benefit is that patients are not tied to a machine at home or visits to surgery or hospital. They take readings at their convenience whether at home with family, or on holiday, and link up with the healthcare professionals, releasing valuable clinical time. Such services should be funded by commissioners to encourage uptake.

Further details are outlined within the following Transition Best Practice Pathway for Diabetes (Figure 3).
**FIGURE 3: TRANSITION BEST PRACTICE PATHWAYS (DIABETES)**

**Paediatric diabetes clinic (below 14 years of age)**
- Patients accompanied by family/carer to the clinic
- Introduce concept of transition clinic
- Promote knowledge and self help skills

**Patient skills and knowledge**
- Aware of name of diagnosis/long term condition
- Names/doses of medication
- Names of professionals involved
- Aware of lifestyle issues affecting LTC including puberty
- Aware of sources of information and support in secondary and primary care

**Adolescent/Transition diabetes clinic (age 14-15 years)**
- Patient choice to attend clinic alone or supported by the family
- Introduce transition ‘coordinator’
- Agree written Transition Plan
- Appropriate clinic timings and settings

**Patient skills and knowledge**
- Aware of short and longer implementations of LTC
- Able to recognise symptoms requiring medical input or dose adjustment
- Aware of consent/confidentiality issues
- Aware of implication of lifestyle issues eg alcohol, smoking, diet, exercise and driving
- Able to access support resources including external organisations, psychological support, peer group etc
- Able to access support at school, secondary and primary care
- Awareness/involvement in support groups and resources using a wider range of media eg apps, telemedicine, online resources

**Adolescent/Transition diabetes clinic (age 16-17 years)**
- Patient choice to attend clinic alone or supported by family
- Supported by ‘coordinator’
- Update written Transition Plan
- Appropriate clinic timings and settings

**Joint clinic with paediatric and adult diabetes team**
- Patient choice to attend clinic alone or supported by family
- Supported by ‘coordinator’
- Agree written Transition Plan
- Appropriate clinic timings and settings

**Young adult diabetes clinic (age 18-24 years)**
- Patient choice to attend clinic alone or supported by the family
- Appropriate clinic timings and settings

**Paediatric diabetes team**
- Patient choice to attend clinic alone or supported by family
- Introduce transition ‘coordinator’
- Agree written Transition Plan
- Appropriate clinic timings and settings

**Patient skills and knowledge**
- Able to arrange and attend healthcare appointments independently inc. failed/missed appointments and repeat prescriptions
- Aware of impact of LTC on education (current and future) and career options
- Enhanced awareness of issues relating to relationships/sexuality eg contraception, eligibility to drive
- Able to access/transfer to different health services if leaving home
- Able to take charge of health related documents/records inc Transition Plan
- Aware of eligibility for Benefits and how to apply using support networks if necessary
- Awareness/involvement in support groups and resources using a wider range of media eg apps, telemedicine and online resources

**Adolescent diabetes team**
- Patient choice to attend clinic alone or supported by family
- Introduce transition ‘coordinator’
- Agree written Transition Plan
- Appropriate clinic timings and settings

**Adult diabetes team**
- Ability to contact professionals in non-routine circumstances eg re-referrals into secondary care, problems with planning, inter-professional communications
- Longer term implications of LTC inc effects on pregnancy, fertility, genetic issues and longer term condition.
Asthma Best Practice Pathway

National and Local context

Asthma is one of the highest causes of hospital admissions in England for all ages, including young people. An estimated 75% of hospital admissions for asthma are avoidable. Every 10 seconds someone in the UK has a potentially life threatening asthma attack (Asthma UK).

The following table (Table 6) shows asthma admission rates across the UK split by age group.

**TABLE 6 - NUMBER OF HOSPITAL ADMISSIONS FOR ASTHMA IN THE UK (2011–12)**

<table>
<thead>
<tr>
<th></th>
<th>ALL AGES</th>
<th>0–14 YEARS</th>
<th>15+ YEARS</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK</td>
<td>65,316</td>
<td>25,073</td>
<td>40,243</td>
</tr>
<tr>
<td>England</td>
<td>54,789</td>
<td>21,319</td>
<td>33,470</td>
</tr>
<tr>
<td>Wales</td>
<td>3349</td>
<td>1231</td>
<td>2118</td>
</tr>
<tr>
<td>Scotland</td>
<td>5694</td>
<td>1886</td>
<td>3808</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>1484</td>
<td>637</td>
<td>847</td>
</tr>
</tbody>
</table>

(Source: Why Asthma Still Kills - The National Review of Asthma Deaths (NRAD)\textsuperscript{15})
The following comments highlight the concerns of a mother of a young person with asthma, whose child receives treatment through primary care.

“There have always been concerned about the lack of awareness and understanding of asthma by school teachers and other leaders, particularly when B is away overnight on school trips, scout camps, etc. When he leaves home at 18, I have a number of additional concerns:

• The expense of prescriptions (on a student budget!).
• Will he register with a new doctor and will they prescribe different inhalers?
• Will he get the same level of attention and care from asthma nurses when he is an adult?
• What will be the effect of college/university life on his asthma?
• Who will take him to A&E if he needs to go?
• Will he keep us informed?”

Comments from a mother of a young person with asthma

There is work in progress to benchmark quality standards at GP practices, such as the “PACE setter” award which signposts practices with a specialist interest in managing certain long term conditions such as asthma. This should help alleviate concerns such as those raised above.

The Asthma Task and Finish group has provided the following information (figure 4) about the delivery of asthma services locally and identifies areas where there is provision for some transition services. A summary of its conclusions are as follows:

• There is currently no best practice tariff to support asthma services.

• Services are fragmented – for example most adult respiratory physicians are focused on more complex respiratory illnesses such as COPD.

• Personal asthma action plans (PAAPs), whilst acknowledged to improve asthma care, are known to have a poor up-take.

• Most asthma patients are transferred back to primary care services when they reach the age of 16-18, depending on the provider.

• There are examples of good practice for asthma transition but there is variation in service provision.

• Many patients and families do not know how to access specialist asthma services or GP services when young people move away from their homes.

• Consideration should be given to possible difficulties in paying prescription charges for regular preventative therapy. This may be one factor in increased rates of emergency/unplanned hospital attendances in young adults with asthma.

13 Number of Hospital Admissions - Why asthma Still Kills - The National Review of Asthma Deaths (NRAD)
**Figure 4: Issues/Gaps/Good Practices for CYP Transitioning to Adult Services with Asthma**

**ASSESSMENT AND CARE PLANNING**
- Patient presented to A&E or primary care
- Access to GP (wait times)
- Potential delays to make initial diagnosis
- Good CYP asthma service supported by hospital/GP asthma services

**In development**
- PACE setter award for LTC (asthma, epilepsy and diabetes) – reviews, communication and care planning
- Guidance on the use of emergency salbutamol inhalers in schools’ DH, October 2014 released

**CYP ASTHMA**
- Some units are more proactive and supported by adequate staffing (primary and secondary care)
- Often good family support through asthma CNS
- Variable staff training
- Some examples of good practice

**ADMITTED PATIENTS**
- Variable staff training
- Some GP practices hold patient data even when patients move away from home

**MANAGEMENT**
- Adult A&E policy for some children (under 6) and younger people over 13+
- Treatment and support options variable when transferred to adult services
- Adult respiratory services often focus on more complex respiratory problems
- Workforce issues in adult services to support young people

**MEASUREMENT OF OUTCOMES**
- Provider data previously available through respiratory network (over 18)
- GP QOF data for some asthma indicator available
- Adherence to treatment plan (prescription refill frequency)
- Monitoring lung function (peak flow)
- Other support networks include pharmacy, smoking cessation, education establishments (SECAMB, mental health (T2), education establishments)

**CONDITION**
- Provided by secondary care providers
- Young people (YP) access to care variable from home, often discharged to primary care

**MODERATE TO SEVERE CONDITION**
- Some GP practices hold patient data even when patients move away from home
- Variable staff training

**CYP SUPPORT NETWORK**
- Lack of uptake of PAAP
- Consideration for other appropriate services such as paediatric allergy

**ADMITTED PATIENTS**
- Age at which care is transferred variable
- YP at which care is transferred is variable between 16-18 birthday

**OTHER SUPPORT NETWORKS**
- Lack of coordination of care between providers
- Workforce issues in adult services to support young people

**MEASUREMENT OF OUTCOMES**
- Provider data previously available through respiratory network (over 18)
- GP QOF data for some asthma indicator available
- Adherence to treatment plan (prescription refill frequency)
- Monitoring lung function (peak flow)
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- Provider data previously available through respiratory network (over 18)
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- Monitoring lung function (peak flow)
- Other support networks include pharmacy, smoking cessation, education establishments (SECAMB, mental health (T2), education establishments)
**Recommendations for the Asthma Pathway**

Children and young people with asthma should have access to the best clinical care that empowers them to manage their condition on a day-to-day basis. This care should extend beyond hospital settings, such as school and primary care, in a way that is clinically optimal and personally and psychologically right for them.

The Transition CAG has developed this asthma transition guidance for commissioners. The following key points and details are in the Transition Best Practice Pathways for asthma in figure 5 below.

- Transition services for asthma should be standardised across the SE, with services developed to meet the needs of the local population.

- Many young people with asthma will be cared for in primary care. Some more severe cases will be referred to adult respiratory physicians in secondary care, where a clear pathway between secondary and primary care should be in place to ensure that young people receive the best possible care.

- National asthma guidance should be fully adhered to and monitored through the use of a “Personalised Asthma Action Plan” (PAAP) ideally in an electronic format, agreed with the patient, from the ages of 13 to 24 years (until their 25th birthday). The PAAP should be shared between healthcare and education settings, patient, family and carers.

- Providers should have a transition policy to support young people with long term conditions moving to adult services.

- The age at which transition starts should be tailored to a child’s needs but should start no later than the age of 13.

- There should be a responsive DNA policy in place in each provider organisation ensuring good communication between secondary and primary care.

- Health education should be provided in an appropriate format (printed or electronic) that is easy to understand and designed with the support of young people.

- A “coordinator” should be assigned to help young people access peer group support and assistance from voluntary organisations and to signpost services as needed.

- All providers should have dedicated transition clinics for young people from the age 14-17 years.

- There should be “young adult” clinics to help transition from the age of 18-24 years – until the 25th birthday, in an age appropriate environment and at time that is suitable for young people’s needs.

- There should be input from respiratory physicians from adult services with an interest in asthma for young people between 16 and 17 years old.

- Providers should be ready to offer advice on smoking cessation, drug and alcohol abuse, contraception, pregnancy and sexual health.

- Wider training for members of the adult services workforce is needed to support young people with asthma.

- Utilisation of the GP Quality Outcome Frameworks (QOF – already in place for children 8 years of age and above\(^{16}\)) for asthma, as a driver for change in the primary care setting. Consideration should be given to agreeing a “local tariff” similar to BPT to raise standards of care in asthma transition services.

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\(^{16}\) Quality Outcome Framework from HSCIC QoF 2013-14.
FIGURE 5: TRANSITION BEST PRACTICE PATHWAYS (ASTHMA)

Paediatric asthma clinic (below 14 years of age)

Paediatric asthma team
- Patients accompanied by family/carer to the clinic
- Introduce concept of transition clinic at GP/secondary care
- Promote knowledge and self-help skills

Patient skills and knowledge
- Aware of name of diagnosis/long-term condition
- Names/doses of medication
- Names of professionals involved
- Aware of lifestyle issues affecting LTC including puberty
- Aware of sources of information and support

Adolescent/Transition asthma clinic (age 14-15 years)

Adolescent/Transition asthma team
- Patient choice to be seen in the clinic alone or accompanied by parent/carer
- Introduce transition ‘coordinator’
- Agree written Transition Plan
- Appropriate clinic timings and settings

Patient skills and knowledge
- Aware of short and longer implementations of LTC
- Able to recognise symptoms requiring medical input or dose adjustment
- Aware of consent/confidentiality issues
- Aware of implication of lifestyle issues eg. alcohol, smoking, diet, exercise and driving
- Able to access support resources including external organisations, psychological support, peer group etc
- Able to access support at school through primary care
- Awareness/involvement in support groups and resources using a wider range of media eg apps, telemedicine, online resources

Adult respiratory team
- Patient choice to attend clinic alone or supported by the family
- Appropriate clinic timings and settings including in patient wards
- Offer smoking cessation, communication skills appropriate to young people

Young adult asthma clinic (age 18-24 years)

Joint clinic with paediatric and adult asthma team
- Patient choice to attend clinic alone or accompanied by family
- Supported by the ‘coordinator’
- Update written Transition Plan
- Appropriate clinic timings and settings

Patient skills and knowledge
- Able to arrange and attend healthcare appointments independently inc. failed/misssed appointments and repeat prescriptions
- Aware of impact of LTC on education (current and future) and career options
- Enhanced awareness of issues relating to relationships/sexuality eg. contraception
- Able to access/transfer to different health services if leaving home
- Aware of eligibility for Benefits and how to apply using support networks if necessary
- Awareness/involvement in support groups and resources using a wider range of media eg apps, telemedicine and online resources

Child Adolescent Adult

FAMILY SUPPORT... ...INCREASING INDEPENDENCE

36
Epilepsy Best Practice Pathway

National and Local Context

The Epilepsy Task and Finish Group raised some important issues for care provided to young people with epilepsy. There are variations in care provision and often clinicians find it difficult to discharge patients to primary care due to lack of expertise. This is of particular concern for families of young people with learning difficulties (LD). Many services caring for young people with LDs hold on to the patients as there are no suitable adult services available locally. Many epilepsy sufferers will require ongoing access to an adult, paediatric or learning disability Epilepsy Specialist Nurse (ESN).

The “Epilepsy Action” website outlines some key statistics:

- Approximately 600,000 people in the UK have epilepsy, which is equates to around 1 in 103 people.
- The proportion of children aged 4 years and under with epilepsy is approximately 1 in 509.
- The proportion of young people aged 18 years and under with epilepsy is close to 1 in 220.
- The total number of young people who are 25 years and under with epilepsy is around 112,000.
- More than one in five people with epilepsy have learning or intellectual disabilities.
- In 2009 there were 1150 deaths related to epilepsy in England and Wales.
- In England and Wales 10% and 11% respectively of those who died from Epilepsy were young adults or children under the age of 25.

In summary:

- There are small financial provisions for Best Practice Tariffs (BPTs) to support epilepsy services for young people.
- Some providers do not claim BPT payments due to the time and resources that are required to meet the criteria.
- Epilepsy services in young people are good, but links with adult services are frequently poor or non-existent.
- There are examples of good practice for epilepsy transition but there is also a wide variation in service provision. Many providers struggle to recruit qualified ESNs.
- Services are fragmented, with most adult neurologists focused on more complex neurological conditions. Therefore many epilepsy patients are treated in primary care after the age of 16 or 18 years. Even those with life-long epileptic syndromes such as juvenile myoclonic epilepsy are likely to be seen only once by an adult neurologist, after which they are discharged back to primary care with written management plans.
- There are currently no standard care plans to care for patients with epilepsy.
- Many young people with LD and their families do not know how to access adult specialist services or GP services as the children grow older. It is thus vital that any young person with epilepsy under primary care alone is able to identify changes in their epilepsy that could necessitate a new referral to secondary care and how to communicate this to their GP.

17 Number of Hospital Admissions - Why asthma Still Kills - The National Review of Asthma Deaths (NRAD)
• There is general workforce shortage of ESNs across the SE.

• People with LDs often have difficulty in recognising illness and communicating their needs. People aged 18 and over who have been assessed as having moderate, severe or profound learning disabilities or people with a mild learning disability who have other complex health needs are entitled to a free annual health check which includes epilepsy. This programme could be used to incorporate transition.

The comments box below, show the thoughts of a mother whose daughter had a poor experience of neurology services.

“My daughter, now an adult, had very traumatic experience during transition. Local services were inadequate to meet the needs of epileptics with complex needs. My daughter had to endure long journeys to London hospitals to receive care. The services do not talk to each and there was no process to follow. My daughter is now and adult and much more settled with the help from current services. She has also acquired a Seizure Alert Dog which has been a life saver. I would urge clinicians to think about young people with epilepsy especially in transition years.”

Comment from a Mother
Patient presented to A&E or primary care
Possible delays in diagnostics due to atypical presentation
Good CYP epilepsy service supported by hospital/GP epilepsy team/secondary care and primary care and education
Other support network includes social services, mental health, education, voluntary sector.

Some units are more proactive and supported by adequate staffing (primary and secondary care)
Often good family/carer and CYP support through epilepsy CNS
Variable staff training
Some examples of good practice:
Lack of coordination of care when the patient changes address.

Recent SEND guidelines introduced for schools placing a legal requirement on schools in England to support children with medical conditions
Workforce issues in adult setting
Treatment and support options between adult and CYP DNA policies
Age at which care is transferred to adult services
Variables between providers when the patient is transferred to adult services
Differences between adult and CYP DNA policies

Higher admission rate for children (under 6) and young people over 15+ age
Issues around young people moving away from home when moving away from children’s hospital to adult hospital
YP access to care variable from age 16-
Access to care available

Epilepsy 12 data and best practice tariff
A&E data not specific to epilepsy
QOF outcome epilepsy 5-9: seizure free in the last 12 months (over 18) and 5-9: seizure free in the last 3 months (under 18)

For clinicians:
Adherence to treatment plan
Monitoring of seizure frequency
Two or more seizures (over 18) and one GP to be epilepsy link
Patient presented to adult A&E or primary care
Possible delays in diagnostics due to atypical presentation
Good adult epilepsy service supported by adult hospital/GP epilepsy team/secondary care and adult primary care and education
Other support network includes social services, mental health, education, voluntary sector.

Some units are more proactive and supported by adequate staffing (adult care)
Often good family/carer and CYP adult support through adult epilepsy CNS
Variable staff training
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Higher admission rate for children (under 6) and young people over 15+ age
Issues around young people admitted to adult wards under general adult physician
Local workforce issues in adult services to support young people with medical conditions
Most adult services support options for schools placing a legal requirement on schools in England to support children with medical conditions
Schools in England support options for schools placing a legal requirement on schools in England to support children with medical conditions
More support by secondary care
Some units are

Patient presented to adult A&E or primary care
Possible delays in diagnostics due to atypical presentation
Good adult epilepsy service supported by adult hospital/GP epilepsy team/secondary care and adult primary care and education
Other support network includes social services, mental health, education, voluntary sector.

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Recent SEND guidelines introduced for schools placing a legal requirement on schools in England to support children with medical conditions
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Schools in England support options for schools placing a legal requirement on schools in England to support children with medical conditions
More support by secondary care
Some units are
FIGURE 7: CURRENT ISSUES/GAPS/GOOD PRACTICES FOR CYP IN TRANSITIONING TO ADULT SERVICES WITH EPILEPSY—CYP WITH COMPLEX NEEDS

- High prevalence of epilepsy in CYP with LD
- LD patients may be under acute and community paediatrician care
- Good CYP epilepsy service supported by secondary and community epilepsy team and education
- Other support networks include social services, mental health, education, voluntary sector

- Some units are more proactive and supported by adequate staffing (primary and secondary care)
- Often good family/carer and CYP support through epilepsy CNS
- Variable staff training, e.g., buccal midazolam

- Care plans supported in respite care settings
- Learning difficulties patients may have additional support from the case support worker, transport provided, learning disability (LD) team, and additional support may be funded respite or independent living units

- Workforce issues in adult setting—LD psychiatrist and adult epilepsy CNS
- Treatment and support options variable when a patient is transferred to adult services
- Age at which care is transferred to adult services is variable between 16-19 years of age, with a trend to earlier transition to adult services

- Inpatient facilities not always appropriate for young people with LD, e.g., autism and challenging behaviour, communication difficulties
- Long-distance travel to access local services, knowledge of such services, and access to specialists
- Lack of appropriate accommodation for families/friends and carers
- Family carers may not be allowed to stay with the patient

- Some families find it difficult to move locations
- Securing/retaining contact details to transfer care

- Seizure control and secondary care admissions
- Annual health check diary for 18 years, QOF (LD01, 02)
- Learning disability register
- Discharge and transition to adult services
- Age discrimination difficulties

- Measure outcomes

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- Annual health check diary for 18 years, QOF (LD01, 02)
- Learning disability register
- Discharge and transition to adult services
- Age discrimination difficulties

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- Annual health check diary for 18 years, QOF (LD01, 02)
- Learning disability register
- Discharge and transition to adult services
- Age discrimination difficulties

- Some families find it difficult to move locations
- Securing/retaining contact details to transfer care
This guidance was developed with support from the Task and Finish Groups over the last few months and has the support of commissioners. The following key points and details are in the transition Best Practice Pathways for Epilepsy in Figures 8 and 9.

- Transition services for epilepsy should be standardised across the SE, with services developed to meet the needs of the local population, including young people with LDs.

- Providers should have a transition policy to support young people moving to adult services with LTCs.

- The age at which transition starts should be tailored to a child's needs but should start no later than the age of 13. For young people with LDs this should be agreed in collaboration with family/carers.

- There should be ongoing education for young people and their families on self-care, about transition services and early advice (no later than at age 15 years) about the impact of epilepsy control, antiepileptic drugs (AEDs) on driving at the age of 17 years and specific career counselling (e.g. employers such as the armed forces do not accept epileptics).

- All providers must have transition clinics for young people from the age 13-19 years.

- There should be “young adult” clinics to help transition from the age of 16-24 years – until the 25th birthday, and clear signposting for suitable adult services. It should be age appropriate and at times that suits the needs of young people.

- There should be input from adult Neurologists with an interest in epilepsy for young people between 16-17 years old.

- There should be a Transition Co-ordinator with the ability to advise young people about all aspects of living, including sign-posting to appropriate agencies/professionals and the offer of peer group support. Genetic services should be made available if there is an inherited aspect to the epilepsy.

- Advice and support about all aspects of contraception, pre-pregnancy counselling and antenatal care should be available, with discussions commencing early in the transition period. In particular the choice of AEDs for female young people should be considered to be of high priority.

- Sudden unexpected death in epilepsy (SUDEP) should be discussed with both young people and their family/carers early in the transition period.

- ESNs should be available to help young people manage their risks of and improve safety at work, at home and in leisure activities such as swimming in open water and driving.

- Wider training for members of the adult services workforce is needed to support young people with epilepsy.

- Mental health support for young people and their families/ carers should be provided where necessary.

- Information literature should be child friendly and suitable for young people with LDs and complex needs.

- GPs with specialist expertise in epilepsy should be signposted using ROCKY (a quality benchmark initiative under development by Coastal and West Sussex CCG), GPwSie (a GP initiative specialising in epilepsy) or “PACE setter” (a CYP quality kite mark for primary care) where possible.

- There should be a responsive DNA policy in place in each provider organisation ensuring good communication between secondary and primary care.

- Health education should be provided in an appropriate format (printed or electronic) that is easy to understand and designed with the support of young people. There should be support and
monitoring of seizure control and medication adherence. Young people may be eligible for (or become eligible for) tertiary services such as vagal nerve stimulation or surgery. Professionals involved in their care (both secondary and primary) should understand eligibility requirements and monitor their patients for indications that they qualify, and understand the pathways for referrals.

- Young people and health care providers should work together to co-produce an individual transition plan. This ensures that there is clarity about where and when services will be delivered and identifies the key professional contacts. This should ideally be in an electronic format. Access should be provided to patients, families or carers as appropriate and within information governance agreements. The parents/carers of young people with limited mental capacity will require expert support and advice regarding decision making.

The best practice pathways recommendations for young people with epilepsy and normal cognition are outlined within Figure 8 and for young people with LDs/Complex within Figure 9.
FIGURE 9: TRANSITION BEST PRACTICE PATHWAYS (EPILEPSY)

**CYP COMPLEX NEEDS DISABILITIES**

**Paediatric epilepsy clinic** (below 14 years of age)
- Patient/family/carer skills and knowledge
  - Aware of name of diagnosis/long-term condition
  - Names/doses of medication
  - Names of professionals involved
  - Aware of lifestyle issues affecting LTC including puberty
  - Aware of sources of information and support
  - Knowledge of primary and social care and voluntary sector support
  - Family to maintain epilepsy seizure display
  - Awareness of mental capacity assessment

**Adolescent/Transition epilepsy clinic** (age 14-15 years)
- Patient/family/carer skills and knowledge
  - Aware of short and longer implementations of LTC
  - Able to recognise symptoms requiring medical input or dose adjustment
  - Aware of consent/confidentiality issues
  - Aware of implication of lifestyle issues eg. alcohol, smoking, diet, exercise and driving
  - Able to access support resources including external organisations, psychological support, peer group etc
  - Able to access support at school
  - Knowledge of local primary care awareness/involvement support groups and resources using a wide range of media eg. apps, telemedicine and online resources.

**Young adult epilepsy clinic** (age 16-17 years)
- Patient/family/carer skills and knowledge
  - Able to arrange and attend healthcare appointments independently inc. failed/missed appointments and repeat prescriptions
  - Aware of impact of LTC on education (current and future) and career options
  - Enhanced awareness of issues relating to relationships/sexuality, pregnancy eg. contraception, medications
  - Able to access/transfer to different health services if leaving home
  - Able to take charge of health related documents/records inc Transition Plan
  - Awareness/involvement in support groups and resources using a wide range of media eg apps, telemedicine and online resources

**Adolescent/Transition epilepsy clinic** (age 16-17 years)
- Patient/family/carer skills and knowledge
  - Ability to contact professionals in non-routine circumstances eg re-referrals into secondary care, problems with planning, inter-professional communications
  - Longer term implications of LTC inc issues on pregnancy, preconception advice and alcohol consumption
  - Family/care/close friends able to record on epilepsy seizure diary

**Joint clinic with paediatric and adult epilepsy/neuro team**
- Patient choice to attend clinic alone or supported by family
- Supported by the ‘coordinator’
- Update written Transition Plan
- Appropriate clinic timings and settings
- Discuss risk of SUDEP and other risks

**Paediatric epilepsy team**
- Patients accompanied by family/carer to the clinic
- Introduce concept of transition clinic at GP/secondary care
- Promote knowledge and self help

**Adult neuro/epilepsy team/primary care**
- Patient choice to attend clinic alone or supported by the family
- Appropriate clinic timings and settings inc in patient wards
- Offer advise on lifestyle communication skills appropriate to young people

**Family Support**
- Increasing Independence
- Primary or secondary care
- Paediatric epilepsy clinic (age 12-24 years)
- Young adult epilepsy clinic (age 16-17 years)
- Adolescent/Transition epilepsy clinic (age 14-15 years)
- Adolescent/Transition epilepsy clinic (age 16-17 years)
- Adult neuro/epilepsy team

**Support**
- Family Support
- Increasing Independence
- Primary or secondary care
- Paediatric epilepsy clinic (age 12-24 years)
- Young adult epilepsy clinic (age 16-17 years)
- Adolescent/Transition epilepsy clinic (age 14-15 years)
- Adolescent/Transition epilepsy clinic (age 16-17 years)
- Adult neuro/epilepsy team
This document provides an assessment of the context of care for young people with long term conditions. There are plenty of examples both locally and nationally of how some units have utilised limited resources highly effectively to develop transition services. There is still work to be done to reduce variation in service delivery and quality and to raise the standards of care.

This section below examines current spending on both A&E and inpatient services. There may be scope for savings which could be re-invested back into developing transition services.

Figure 10 illustrates the number of elective and non-elective admissions from January – July 2014 and shows projected trends through until December 2014. The data has been weighted for a representative sample population of 10,000 drawn from across the SE. It is clear that young people with both epilepsy and diabetes use A&E services more frequently after the age of 15 years than in their younger years.

The trend for A&E use amongst those with asthma is more stable after the age of 15, although occurrences are still worryingly frequent. The data for those aged between 25 and 29 is also included to show that even beyond the transition years, non-elective admissions for those with LTCs remains stubbornly high.

Figure 11 illustrates the cost of elective and non-elective admissions from January – July 2014, and shows projected trends through until December 2014. The data has been weighted for a representative sample population of 10,000 drawn from across the SE. A&E admissions for those with LTCs are often an avoidable cost. Investment in prevention through better transition services will save valuable bed days at a time of financial constraint.

Table 7 highlights the financial case for investing in transition services. It is currently estimated to cost around £200K each year for elective admissions for those with diabetes, epilepsy and asthma across the SE. Meanwhile non-elective admissions for the same group are estimated to cost £2.6 million. The table is split by age and includes data from figures 10 and 11.
Figure 10: Elective and Non-Elective Admissions Age 10-29 years Children and young people rate per 10,000 admissions within age band to secondary care for all South East CCGs by primary diagnosis January-July 2014 (projected to December 2014)

Source: SUS Extract Mart, HSCIC
### Children and young people PbR value of admissions to secondary care for all South East Coast CCGs by primary diagnosis January-July 2014 (projected to December 2014)

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<tr>
<th>Diagnosis</th>
<th>Elective</th>
<th>Non-Elective</th>
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<td>£50,000</td>
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<td>£350,000</td>
<td>£400,000</td>
</tr>
<tr>
<td>Diabetes (ICD 10 Code: E10-E14)</td>
<td>£0</td>
<td>£50,000</td>
</tr>
<tr>
<td></td>
<td>£50,000</td>
<td>£100,000</td>
</tr>
<tr>
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<td>£300,000</td>
</tr>
<tr>
<td></td>
<td>£350,000</td>
<td>£400,000</td>
</tr>
</tbody>
</table>

**Figure 11**: Cost of Elective and Non-Elective Admissions from age 10-29 years

Source: SUS Extract Mart, HSCIC
<table>
<thead>
<tr>
<th>Age band</th>
<th>Elective Total</th>
<th>Non-Elective Total</th>
<th>SE Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>10-14</td>
<td>81</td>
<td>78</td>
<td>159</td>
</tr>
<tr>
<td>15-19</td>
<td>138</td>
<td>136</td>
<td>274</td>
</tr>
<tr>
<td>20-24</td>
<td>228</td>
<td>226</td>
<td>454</td>
</tr>
<tr>
<td>25-29</td>
<td>107</td>
<td>105</td>
<td>212</td>
</tr>
</tbody>
</table>

Table 7: Cost and number of elective and non-elective admissions across the SE for these LTCs
Data Collection

Accident and Emergency data is difficult to capture as initial diagnosis may be different to discharge diagnosis. Most of the data available is for ‘admitted patients’ only using the NHS coding profiles of ICD10. The SE dashboard for epilepsy, asthma and diabetes only captures data for people under 19 years of age.

Other costs which may be commissioned separately, such as dialysis, ophthalmology and social services are not included in this document as they fall under either specialised commissioning or the responsibility of local authorities (LA’s). We recommend that commissioners enter into dialogue with local providers to obtain accurate, reliable clinical information. This will inform local decisions on the health economy with regard to the potential for future cost saving by reducing avoidable hospital visits.

This work will require paediatrics and adult A&E services to work together to create accurate information on avoidable hospital admissions. Such a prospective audit would enable CCGs to develop an effective business case for funding transition services. Commissioners have indicated they wish to achieve a cost neutral position if they are to invest in transition services. It is understood that Brighton and Hove CCG is in the process of collecting data for young people admitted to A&E. It has also developed a local CQUIN to reduce avoidable admissions which could be used as a template for other CCGs to develop similar schemes.
Examples of Other Transition Initiatives

The South West Strategic Clinical Network is developing a dashboard to measure delivery of transition services.

The key measures identified are as follows:

- Provision of young people friendly services and transition focused services.
- Population and transition focused care data sets and performance trackers utilised.
- Young people’s service experience measured and acted upon (for example using recognised evaluation tools such as PREM of RCPCH).
- Staffs working with young people have access to training relevant to caring for this population.
- Implementing transition pathway and operational guidelines, which have been jointly developed by paediatric and adult services alongside service users.
- Care plans to include transition support.
- The appointment of a nominated health care transition co-ordinator, who will become known to young service users.
- Access to multi-media transition support resources.
- Access to peer group support.
Conclusion

Adolescence is an exciting time of life but full of emotional and practical challenges for young people. Those young people with long term conditions face extra challenges in this transitional period and deserve the very best help and support in their journey. This should be in the form of partnership working between the young people and their families and all other agencies involved in their care.

Throughout the development of our transition best practice pathways guidance, engagement with patients, families/carers and other agencies has been vital. There is evidence to support the idea that involving patients has contributed to positive changes in the provision of services across a range of different settings. As such, it is important that young people and their families are engaged in all care planning and have access to information which is easy to read and that they are part of developing local transition services. Our best practice pathways have been developed utilising the national service specifications. They have received considerable support from clinicians across the SE. They also support the vision outlined in the NHS Five Year Forward View which articulates why change is needed and focuses on the following areas:

- Disease prevention
- New, flexible models of service delivery tailored to local populations and needs
- Integration between services and consistent leadership across the health and care system
- Patient engagement
- Reducing variation in service provision

This guidance has highlighted a need to develop a new role to support transition in the form of care coordinators. They will become a familiar point of contact for patients and carers, easing access to health and social care services, as well as those from the voluntary sector. They will work closely with primary care services to support patients, their families and carers to better manage living with long term illnesses.

Data collection has been a challenge. It is recommended that commissioners should support a prospective audit to collect accurate data for all conditions. This would be based on the collection of information about young people during their transition years and would support the development of a financial case for transition services.

This guidance has highlighted key standards, legal responsibilities and NHS outcome framework ambitions to support the development of effective transition services. It is hoped that commissioners will utilise this guidance to work with their local population and providers.

The goal should be to develop an effective care package for young people transitioning into adult service with any long term condition. Our hope is that this guidance will help all young people with Long Term Conditions to have a positive experience of transition to adult services; one where they are able to remain engaged with healthcare services, learn to self-manage their condition and achieve their life ambitions.

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19 NHS Five Year Forward View.
Appendices

Appendix 1: Further details of the Transition CAG and its Terms of Reference are available via the SCN website.

Appendix 2: Queen Elizabeth Hospital, Birmingham Youth Connector Project

Appendix 3: Surrey and Sussex NHS Trust Transition Clinics

“Surrey and Sussex NHS Trust (SASH) currently operates four full transitional adolescent diabetes clinic lists each quarter and are likely to increase the capacity with further lists in the near future. Preparation for transition, in the form of discussion in clinic, and provision of written information, starts at age ten to eleven years. Adolescents are then seen quarterly in transition clinic, on each occasion by a paediatric diabetes specialist nurse and both paediatric and adult diabetes consultants, from the sixteenth to the nineteenth birthday, after which they attend adult clinic with the same diabetes consultant. SASH aims to schedule as many of the transition clinics as possible around university and school holidays. They offer additional scheduled and unscheduled paediatric diabetes specialist nurse contact, including domiciliary and school visits; diabetes specialist dietician and clinical psychology visits; direct telephone access for patients 24 hours a day to paediatric consultants and to paediatric diabetes specialist nurses, and telephone, text message and email contact as appropriate. The team includes dedicated dieticians, a clinical psychologist and an administrator who keeps data collection and BPT reporting up to date. It is led by one of the paediatric diabetes consultants, who chairs the monthly multidisciplinary team meetings, at which service developments and patients in difficulty, including those admitted to hospital, are discussed. The service underwent a successful peer review process in April this year. 43% of its patients are insulin pump users; patients are offered their own choice of the full range of available pumps, and the paediatric department is actively recruiting to the SCIPI clinical trial (randomising newly diagnosed patients to pump or multiple daily dose insulin).”

Dr Ben Field - Consultant Endocrinologist & RCP Tutor, Surrey & Sussex Healthcare NHS Trust