

# Addressing child to adult transition in national clinical audit – A guide



“Transition is a vulnerable period for young people and there are enormous risks for them if they disengage with their services or are lost to follow-up in the transition process. All clinicians, whether paediatricians like myself, child and adolescent mental health practitioners, or adult clinicians, must recognise the need for a planned and supported transition process for young people with long term health conditions and complex healthcare needs as they move from child centred to adult delivered services with a consequent change of lifestyle. It is vital that young people remain engaged with their services and are supported to take responsibility for their own health as they move into adulthood. In this way they will get the best health outcomes and develop a responsibility for their long-term condition.

This comprehensive guidance explores the subject of child to adult transition and identifies practical ways to address this topic within national clinical audit. This document should be the first port of call for anyone developing their national clinical audit to understand the significance of transition and the role clinical audit can play to stimulate improvement in the quality and outcomes of care received by children and young people.”

**Jacqueline Cornish, National Clinical Director,**  
Children, Young People and Transition to Adulthood, NHS England

**Authors:**

Shradha Sharma, National Medical Director’s Clinical Fellow 2017/18  
based at HQIP

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## 2.0 Executive Summary

The transition of a young person from child to adult services should be a purposeful and planned person-centred process that starts before the formal transfer of care occurs. The period of transition in healthcare coincides with a critical time of biopsychosocial change for a young person as they mature from a child to an adult. During the process of transition, young people should feel empowered to take responsibility for their health through adequate health education and health promotion. Paediatric and adult services should be co-ordinated to support a process of transition that will establish positive life-long health behaviours for all young people with chronic illnesses and prevent their disengagement from services that can result in detrimental long-term outcomes.

This guide explores the topic of child to adult transition and its relevance to national clinical audits within the national healthcare context. It offers a practical guide on how to address transition through the different stages of audit development for those who commission, design and participate in national clinical audits and includes information on policies, guidelines, standards and healthcare commissioning incentives that align with child to adult transition.

The Healthcare Quality Improvement Partnership (HQIP) is committed to supporting national clinical audit providers and local clinical audit teams to engage with this topic in order to deliver the highest quality transition services that meet the needs of young people and their families. Recommendations are featured in the next section and throughout the body of the text and are numbered for ease of reference, not magnitude of importance. They are intended to be considered by all national clinical audit topics, although HQIP acknowledges that not all will be relevant or possible for each audit. Additional considerations are included at the end of the document to support local teams in delivering improvement initiatives.

Appendices are available online to provide further support in implementing these recommendations.

### **3.0 Recommendations to address child to adult transition in National Clinical Audit**

1. Child to adult healthcare transition should be considered in both paediatric and adult national clinical audits.
2. Consider transition measurement requirements when setting the age range for inclusion in the audit.
3. Consider where and how transition from child to adult services features within the proposed audit topic and whether measures on transition could stimulate and sustain improvement in quality of care.
4. Consider how to include transition when selecting specific improvement aims for the audit.
5. Consider how best to align audit transition measurements with national policies and commissioning priorities.
6. Involve children, young people and their families in the design and development of the audit and encourage them to consider the topic of transition.
7. Include quality of care measures that address the NICE quality standard QS140 for transition in the audit where possible.
8. For established national clinical audits, consider reviewing existing metrics and evaluate their capacity to measure transition services within the scope of the audit.
9. Explore additional condition-specific standards, best practice pathways, financial levers and specialised service specifications when designing clinical outcome and process measures for transition services.
10. Consider proxy measures to reduce data burden for new and commissioned national clinical audits.
11. Identify opportunities to address transition through process, outcome, organisational and/or patient experience measures.
12. Consider a spotlight audit focussed on transition services.

## 4.0 Introduction

### 4.1 Scope and purpose of this guide

The purpose of this guide is to raise awareness of the importance of child and adult services supporting transition. It will assist adult, paediatric and combined paediatric and adult national clinical audits to incorporate the theme of transition into the design, delivery and reporting of their audit. The guide refers to the clinical outcome review programmes (CORP) where they can offer examples of learning on child to adult transition and the guide may be useful as a reference for incorporating the topic of transition into future CORP.

This guide aims to help those developing their national clinical audit to understand the significance of transition and the role national clinical audit can play to stimulate improvement in the quality and outcomes of care received by children and young people during transition. This guide encourages national clinical audits that have already been commissioned to consider including transition into their audit in the future.

This guide will offer recommendations for how to address transition in line with recognised quality standards, guidelines and best practice, including examples where this has been achieved successfully.

### 4.2 Who is this guide for?

The guide is aimed at two key audiences:

1. Commissioners of national clinical audit including NHS England and other funders, the Healthcare Quality Improvement Partnership, professional groups and patient charities.
2. All those involved in the shaping and delivery of a national clinical audit whether they are national clinical directors, clinical leads, programme/project managers, clinicians, patient or parent representatives. Although written primarily with the National Clinical Audit and Clinical Outcome Review Programme (NCAPOP) national clinical audits in mind, the principles of this guidance are intended to be applicable to all national audits.

There is an additional section in this guide to assist teams performing local level audits and other measurement driven quality improvement initiatives that are aimed at improving child to adult transition within their institutions.

Key recommendations for national clinical audits will be highlighted throughout this guidance in the blue boxes.

### 4.3 About HQIP

HQIP is a registered charity that is led by the consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. It aims to promote quality improvement in patient outcomes and to increase the impact that clinical audits, outcome review programmes and registries have on healthcare. HQIP commissions, manages and develops NCAPOP on behalf of NHS England and the Welsh government, and for some individual projects with other devolved nations and Crown Dependencies. HQIP works in partnership with patients and health professionals to enable those who commission, deliver and receive healthcare to measure and improve healthcare services and patient outcomes.

## 5.0 Background

### 5.1 Defining Transition in Child to Adult Healthcare

Transition from child to adult healthcare is defined as the purposeful and planned process of supporting young people with long-term conditions as they move from child-centred to adult-orientated healthcare systems. The process of transition commonly begins during adolescence from the age of 12 and can span into early adulthood until the age of 25.

Adolescence is a critical time of change when young people negotiate physical, psychological and behavioural developmental milestones as they mature from children into adults. Many social transitions are also expected to occur at this time such as: leaving school, leaving the parental home, development of new peer networks, changing relationships with parents or care givers and increasing financial independence. For young people with chronic health conditions, there is the additional responsibility of managing their own health. Research has shown that the adolescent brain continues to develop up to the age of 25 as a process of reorganisation and fine-tuning occurs<sup>1</sup>. Risk-taking behaviours are more likely during adolescence and life-long behaviours including health behaviours become established as the adolescent develops their personal identity. Child and adult services have to be tailored to support a young person as they navigate this period of uncertainty. Poor transition processes can have long-term implications on health and social well-being due to disengagement with health services<sup>2,3</sup>. As an increasing number of children with long-term conditions survive into adulthood<sup>4-6</sup>, recognising the requirement of health services to support the changing biopsychosocial needs of young people becomes increasingly relevant.

In 2010, Sir Ian Kennedy published his report “Getting it right for children and young people” describing the challenges facing services for children and young people (CYP)<sup>7</sup>, which included an analysis of the obstacles surrounding transition. This report spurred a national strategy for addressing the needs of CYP through the establishment of a Children and Young People’s Health Outcomes Forum in 2012<sup>8</sup>. The forum recommended four new outcome indicators to be included within the NHS Outcomes Framework, one of which was “effective transition from children’s to adult services”. In line with these recommendations, national health policy has reflected the importance of developing services that support transition and has promoted the commissioning of these services including the introduction of different best practice tariffs and a mental health CQUIN<sup>9-11</sup>. Transition is one of the six key priorities identified by the National Clinical Director (NCD) for Children, Young People and the Transition to Adulthood.

Despite this, the UK continues to rank poorly for patient experience of healthcare within the 16-24 age groups and has some of the highest mortality rates for long term conditions in CYP compared to other European countries<sup>12-14</sup>. There is evidence of variation in the process of transition across different health conditions, and rates of transition to adult services continue to be lower than expected across England<sup>15</sup>. In 2014, the Care Quality Commission (CQC) published its report on children’s transition to adult services “From the pond into the sea”<sup>16</sup>, which highlighted the continuing inconsistencies in transition processes and how “previous good practice guidance had not always been implemented”.

The “State of Child Health” report<sup>14</sup> published in 2017 by the Royal College of Paediatrics and Child Health (RCPCH), provides a snapshot of young people’s health and wellbeing using 25 measures of child health in the UK. The development of dedicated services for young people and transition programmes to adult care in order to ensure better transitions, remains a key priority and supports the RCPCH’s major policy recommendation of tailoring the health system to “meet the needs of children, young people, their parents and carers”.

## 5.2 What Transition Means to Young People

Young people have been sharing their views on transition between children's and adult's services with the &Us Engagement team at RCPCH. Here is what they had to say about their experience of transition in healthcare and their wishes for the future:

*"Having an appointment with my doctors [children's] with the one from the new hospital [adult's] helps and we can go on a visit before". Young person, RCPCH &Us Voice Bank 2018*

*"My wish is that when I am admitted that I have people my own age near me, would have made me feel more comfortable when I was on an adult ward since it was such a large age range. I feel more comfortable in the clinic. My hospital has a young people's ward area which is good but there isn't one at the adult's hospital, so I got freaked out and left". Young person, RCPCH &Us Voice Bank 2018*

*"Waking up after surgery on an adult ward for the first time was nothing short of scary. My parents couldn't stay with me and it felt worlds away from the safe haven of a children's ward. At an already stressful time the addition of moving to and navigating round adult services can feel all too much for many young patients. Often transition happens suddenly with little warning. The paediatrician who knew you so well is replaced by a GP who struggles in the short appointments to grasp the whole complex picture. "From the pond into the sea" accurately describes how many patients feel". Charlotte, RCPCH Annual Conference 2016*

*"Transition hasn't gone well for me. I had one meeting between children's and adults' services that was really quick and didn't do anything other than say here you go. Other people in our group have had better experiences. I thought you could stay with children's if it was right until 25". Young person, RCPCH &Us Voice Bank 2016*

*"The information should change when you get older - at 16 I went with what I was being told. At 18 I understand more and what you do and why. Transition is when you go through all of this (in paediatrics) then you go straight to adults. You need a young adult clinic to go to until you are 25. You feel childish in adult services like you are expected to know everything just coz you are in an adult clinic. It's comfortable here (in children's) and feels homely - they all know you". Young person, RCPCH &Us Voice Bank 2018*

*"The perfect age for the transition process for young people with long-term and complex conditions is at age 14, this allows for young people to go through an adolescent service. This allows us to get used to the differences between children services and adults' services. By graduating to young adult/ adolescent services allows us to have joint meetings with our paediatricians and adult specialists for a few years before moving fully into adult services. Adolescent services would be a perfect interim status for young people to stay until they reach a point in their lives when it's appropriate for them to fully transition before age 25. The age at which transition happens is a difficult enough time without radical changes occurring in our health and social care management.*

*Alongside access to adolescent services, it is imperative for these young people to have a key named worker who is able to support us to access and negotiate the terrain of adolescent and adult services. The thresholds are different, the link-up between services are different, we need someone to help us navigate this minefield. The final two things which would bring together the perfect transition is to have the consistency of transition process across all health and social care transitions in all parts of the country. Secondly, it is imperative that everyone who may be involved in dealing with young people through transition age have access to resources/ central databank which allows for better signposting of services and support".*  
Young adult, RCPCH &Us Voice Bank 2018.

### 5.3 Current Representation of Transition within National Clinical Audit

A scoping review was undertaken in Spring 2018 to identify where transition is represented within national clinical audits. The CORP, which are commissioned by HQIP, were also reviewed as some of the programmes have looked in detail at transition services as part of their case reviews.

The National Diabetes Transition Audit is currently the only national clinical audit (NCA) dedicated to measuring child to adult transition across a service, it published its first report in June 2017. The audit linked patient level data from the National Paediatric Diabetes Audit (NPDA) to the National Adult Diabetes Audit (NDA) and used proxy measures to infer the quality of transition for young people with Type 1 diabetes by assessing whether transition was associated with changes in care processes.

Two NCAs (the Epilepsy 12 Audit and the National Asthma and Chronic Obstructive Pulmonary Disease Audit Programme) have incorporated organisational level metrics within the scope of their audits from 2018 onwards to evaluate the arrangement of transition services across Trusts.

Three CORP have analysed the provision of transition services through case note reviews for their condition topics and will be publishing their findings in 2018. The Child Health CORP for chronic neurodisability identified significant variation in transition planning and found that examples of good practice were the exception<sup>17</sup>.

There may be potential within some of the existing national clinical audits to address transition that do not do so already.

### 5.4 National Policy for Transition

It is evident from the scoping review that there is an overall paucity of national comparative data on the provision and quality of transition services across specialities and Trusts. National level data for transition can provide a comparative assessment (which is currently limited) of how well national policies on child to adult transition are implemented, Appendix I illustrates some of these policies.

The value of national clinical audits aligned with national policy initiatives has been evidenced in a recent publication by Kossarova et al.<sup>18</sup> Their data suggested that a reduction in unplanned A&E admissions for children with diabetes aged 0-14 between 2005 and 2016 coincided with the introduction of the National Paediatric Diabetes Audit and the best practice tariff, and similarly a reduction in unplanned admissions for epilepsy coincided with the Epilepsy 12 national paediatric epilepsy audit and the national epilepsy best practice tariff. Conversely for young adults in the 20-24 age group, there has been an increase in emergency diabetes admissions over this same period which corresponds with when the young person transitions into adult services. Increasing attention on transition through national clinical audits aligned with national policies could help to counter these widening inequalities.

## 5.5 Feedback from NCAPOP Programmes

The Project managers and/or clinical leads for the NCAPOP programmes that currently measure transition services were asked to consider what has prompted the assessment of transition services and what messages have stood out after evaluating transition. Typical reflections included:

“Currently there is a dearth of what good transition looks like.”

“Transition as a term has different meanings for different people. Often is thought of as the interface between child and adult services but we should look at it longitudinally as the phase through adolescence to young adults – so that it encapsulates the broader scope of young people and young adults.”

“The language is important. We need to change the language in health and recognise young people as an independent patient group.”

“Engagement of children and young people and their families is important.”

“It would be useful to produce common clinical outcome measures or process measures that could be measured in child and adult services that are pragmatic and achievable.”

“To understand transition, one needs both the ‘take-off’ and ‘landing’ phase...what happens to these children once they’ve entered adult care – the real success of the process and true outcomes can only be judged when the patient has ‘landed’ in adult services.”

“Transition planning to adulthood and adult services needs to be started early at age 14, be well led and appropriate to the needs of each young person. There is currently significant variation and examples of good practice were the exception.”

“Four key considerations for child to adult transition from the NCD for Children, Young People and the Transition to Adulthood:

- a) Is there a transition plan?
- b) Has the child/young person been central to that transition guide?
- c) Does the GP have a full history of the child/young person transition plan and medical history?
- d) Has a key worker been appointed? “

“Spread good practice and learn by example.”

**Jacqueline Cornish, National Clinical Director  
Children, Young People and Transition to Adulthood, NHS England**

## 5.6 Standards for Measuring the Quality of Transition

The National Institute for Health and Care Excellence (NICE) Quality Standard for transition services (QS140) was developed in 2016 to cover the aspects of a successful transition process.<sup>19</sup> In line with the HQIP commissioning guidance it is recommended that NCAs should attempt to benchmark against NICE quality standards.

The NICE quality standard for transition (QS140) contains 5 quality statements:

**Statement 1:** Young people who will move from children's to adult's services to start planning their transition with health and social care practitioners by school year 9 (aged 13 – 14 years), or immediately if they enter children's services after school year 9.

**Statement 2:** Young people who will move from children's to adult's services to have an annual meeting to review transition planning

**Statement 3:** Young people who are moving from children's to adult's services to have a named worker to coordinate care and support before, during and after transfer

**Statement 4:** Young people who will move from children's to adult's services meet a practitioner from each adult's service before they transfer

**Statement 5:** Young people who have moved services but do not attend their first meeting or appointment are contacted by adult services and given further opportunity to engage

A mapping exercise was performed in January 2018 to analyse what information is collected through NCAPOP to measure the provision of transition services against the NICE quality standard for transition (QS140). The results of this can be seen in Tables 1 and 2 below and provides practical examples of questions or metrics that have been used by national clinical audits to measure transition against the NICE quality statements.

**Table 1: Metrics collected by NCAPOP National Clinical Audits measured against NICE quality standard for transition (QS140)**

National Clinical Audit	Questions collected on Child to Adult Transition	NICE Quality Statement that could be measured through collected questions
<p><b>Epilepsy 12</b></p>	<p><b>Annual organisational data collection:</b></p> <ol style="list-style-type: none"> <li>1. Does your trust have a specific outpatient clinic specifically for young people with epilepsies?</li> <li>2. From what age does this young people's clinic typically accept young people?</li> <li>3a. Does your trust have an outpatient service for epilepsy where there is a presence of both adult and paediatric professionals?</li> <li>3b. Is this usually a single appointment, a series of several joint appointments, a flexible approach including mixture of joint or individual reviews, other.</li> <li>4. As an estimate, what percentage of young people transferred to adult services are transitioned through this joint professional process?</li> <li>5. Which adult professionals are routinely involved in transition or transfer to adult services?</li> <li>6. Does your transition use structured resources to support transition?</li> </ol>	<p>1, 2, 3, 4</p>
<p><b>National Asthma and Chronic Obstructive Pulmonary Disease Audit Programme – ASTHMA Questions</b></p>	<p><b>Organisational data collection:</b></p> <p><b>Adult:</b></p> <ol style="list-style-type: none"> <li>1. Do your processes for transitioning young people from paediatric to adult services include ensuring that: <ul style="list-style-type: none"> <li>- the young person has a full record of their condition</li> <li>- the GP is sent the same record.</li> <li>- the young person has a transition plan and they have worked on this with both paediatric and adult clinicians.</li> <li>- the young person has a named case worker to assist in signposting for them and their family.</li> <li>- there are no formal transition arrangements.</li> </ul> </li> </ol> <p><b>Paediatric:</b></p> <ol style="list-style-type: none"> <li>1. Do your processes for transitioning young people from paediatric to adult services include ensuring that: <ul style="list-style-type: none"> <li>- the young person has a full record of their condition</li> <li>- the GP is sent the same record.</li> <li>- the young person has a transition plan and they have worked on this with both paediatric and adult clinicians.</li> <li>- the young person has a named case worker to assist in signposting for them and their family.</li> <li>- there are no formal transition arrangements.</li> </ul> </li> </ol>	<p>1,3,4,</p>

**Table 2: Metrics collected by NCAPOP CORP measured against NICE quality standard for transition (QS140)**

Clinical Outcome Review Programme	Questions collected on Child to Adult Transition	NICE Quality Statement that could be measured through collected questions
<p><b>Child Health CORP*</b></p> <p><b>*The questionnaires with the cited sections can be found via these links to access the specific questions:</b></p> <p><b>MH</b>  <a href="http://www.ncepod.org.uk/amh.html">http://www.ncepod.org.uk/amh.html</a></p> <p><b>CND</b> <a href="http://www.ncepod.org.uk/cn.html">http://www.ncepod.org.uk/cn.html</a></p>	<p><b>Mental health (MH):</b>            Services in general hospital clinical questionnaire (section H).            Community mental health services clinical questionnaire (section I).            Organisational questionnaire young people (sections E,F,D).            Organisational questionnaire young adults (sections F,G).</p> <p><b>Chronic neurodisability (CND):</b>            Paediatric inpatient organisational survey (sections I,J).            Paediatric outpatient (section L).            Community paediatrics (section K).            Adult inpatient (section I).            Adult outpatient (section K).            Allied health professionals paediatrics inpatient care (section G).            Allied health professionals paediatric outpatient care (section G).            Allied health professionals, young adult outpatient care (section F).            Allied health professionals, young adult inpatient care (section G).</p>	<p>MH: 1, 2, 3, 4.</p> <p>CND: 1, 3, 4</p>
<p><b>Mental Health CORP (NCISH)</b></p>	<p>Had there been a transition from CAMHS to adult services in the previous year?</p>	<p>1</p>
<p><b>Cancer in children, teens and young adults (medical and surgical care CORP) up to 25 years old</b></p>	<p><b>Organisational questionnaire:</b>            Does this hospital have a policy covering the transition of care from children to adult oncology services?            What is the age that transition should occur according to the policy?            Is the implementation of this policy audited - what is the compliance?            Where would patients be routinely referred to when they are transitioned?</p> <p><b>Clinical questionnaire:</b>            Has this patient recently been transitioned between services?            - was this paediatric to adolescent or paediatric to adult.            In your opinion were there any problems associated with the transition of care?</p>	<p>1, 3</p>

Other general and condition-specific transition standards and guidelines have been identified that could be incorporated into a NCA. These additional standards can also be useful for benchmarking in local improvement projects that are focussed on a particular service or aspect of the commissioning pathway. For example, “You’re Welcome”<sup>20</sup> is a set of quality criteria for developing young people friendly services as part of a project supported by Public Health England, NHS England and the Department of Health and led by the British Youth Council, the Association for Young People’s Health and Youth Focus North West. It provides a “systematic framework for commissioners and service providers to improve the suitability, accessibility, quality and safety of health services for young people” and become “You’re Welcome” accredited.

Appendix II contains a non-exhaustive list of available standards/guidelines and examples of where to resource standards/guidelines that maybe relevant to a national or local clinical audit.

## 6.0 Recommendations

The following sections provide recommendations on where and how to address child to adult transition within your national clinical audit at different stages along the commissioning and development process<sup>18</sup>.

### 6.1 Considerations for those Commissioning National Clinical Audits

#### Commissioning and Specification Development:

*“Currently there is a dearth of what good transition looks like”* and so the commissioning and specification development phase offers the opportunity to evaluate how child to adult transition services may be featured within the subject topic being covered and how measurement of these services could be incorporated as part of the aims and objectives of the audit.

For topics being recommissioned or at the point of extension, the commissioners should review the capacity to assess transition services. Can the metrics that are collected in the audit be used to measure relevant outcomes for transition either directly or as a proxy measure? If no relevant metrics are currently collected, can new metrics be included with minimal increase in data burden whilst remaining within the scope of commissioning?

Commissioners of NCAs should consider the following when developing or reviewing their audit:

- Are young people subject to the disease/pathway of the topic proposed?
- What does child to adult transition mean within the condition topic?
- Is there a transition element for this topic and has this been considered at the outset?
- Have deficiencies in transition services been previously identified in the proposed topic? What are the important outcomes and outputs that should be considered in the context of the topic to address these problems?
- How does incorporation of transition into this audit topic align with national policies and commissioning priorities? (Appendix I).
- What are the barriers to effective transition within your speciality and what could be incorporated into a clinical audit that addresses or explores these barriers.
- The benefits versus limitations of picking up a small number of transitioning patients within the audit. For example, data referring to a small cohort of patients could be beneficial in triggering local units to review their services and measuring in detail how transition services are organised and delivered locally but small numbers may hamper meaningful benchmarking.

**Recommendation:** Consider where and how transition from child to adult service features within the proposed audit topic and whether measures on transition could stimulate and sustain improvement in quality of care.

**Recommendation:** Consider how to include transition when selecting specific improvement aims for the audit.

**Recommendation:** Consider how best to align audit transition measurements within national policies and commissioning priorities.

**Recommendation:** For established national clinical audits, consider reviewing existing metrics and evaluate their capacity to measure transition services within the scope of the audit.

## **Involving Stakeholders:**

Involvement of professionals with experience in planning transition services and those with a specialist interest in adolescent medicine can be useful in designing the audit. This could include clinicians, commissioners, national clinical audit providers, researchers, Royal Colleges, specialist societies and charities.

Patient and public involvement is a key component in all of the audits that are commissioned through HQIP and is reflected in all its work<sup>21</sup>. ***“Engagement of children and young people and their families is important”*** for developing the audit. Engaging with CYP advocates, for example the “& Us<sup>®</sup> Engagement Team” at RCPCH (Appendix I), which works closely with CYP and their families so that their voices are represented alongside that of the professional may be helpful. The & Us<sup>®</sup> Engagement Team can help to embed the engagement process into the audit design so that it represents the issues around transition that are important to patients and their families. Methods include deep dive focus groups and capsule challenge models to help form recommendations, and gap analysis of results by CYP to identify areas for future prioritisation for the audit as part of its ongoing development.

Within the Epilepsy12 Audit programme for England and Wales, the RCPCH &Us Engagement Team has worked with the programme board to develop an engagement programme. Children, young people and families have their own project to support the audit and help develop new solutions that will give real time changes for families. Over 140 children, young people and families took part in clinic chats across England between April-June 2018, sharing experiences on contacting services, family mental health, school support, services working together and support for when you move to adult’s services. Young people from the Epilepsy12 Youth Advocates project then reviewed all the results from the clinic chats and identified key themes, which they presented to clinicians at the Epilepsy12 annual conference, giving them ideas for their future quality improvement work. Themes identified included improving contact and access to services, providing more support for schools, having someone identified to talk to about worries and anxieties, increasing access to face to face support (specialist nurses) and support groups and having practical help on living with the condition including going to university, sleep, employment, driving and more.

**Recommendation:** Involve children, young people and their families in the design and development of the audit and encourage them to consider the topic of transition.

## 6.2 Considerations for those designing the audit

### Population and time period:

Transition should be considered in both paediatric and adult orientated audits so that they capture both *“the ‘take-off’ and the ‘landing’ phase”* for young people.

Paediatric audits can evaluate the processes for preparing young people to transition to adult services. Adult audits can assess patients who have transitioned from paediatric services and whether or not these young people remain in health care and are able to manage their health effectively. If the audit can encompass both paediatric and adult patients, then this offers an opportunity to measure the care of patients throughout adolescence and into early adulthood. Patient record-level linkage may provide the opportunity to pick-up patients who have been lost to services due to poor transitioning practices.

Consider:

- Does the topic covered by the audit include patients who will transition/could have transitioned between child and adult services particularly the 14-25 age group?
- Will the patient cohort transition between child and adult services during the sampling time period of the audit?
- Could the audit encompass both paediatric and adult patients?

**Recommendation:** Child to adult healthcare transition should be considered in both paediatric and adult national clinical audits.

**Recommendation:** Consider transition measurement requirements when setting the age range for inclusion in the audit.

## Quality of Care Measures and Data Collection Strategy:

*“It would be useful to produce common clinical outcome measures or process measures that could be measured in child and adult services that are pragmatic and achievable”.* The role of any NCA is to support improvement in the quality and outcomes of patient care. Below are some suggestions on how this can be achieved:

- Explore the data that exists or could be collected for the condition topic that gives information on transition.
- Consider how the NICE quality standard for transition services (QS140) could be measured (Appendix II).
- Consider additional standards that could be addressed within the audit and the metrics that could be used to measure these standards (Appendix II).
- Are there additional financial levers such as a Best Practice Tariff (BPT) or CQUIN to optimise care (Appendix II)?
- Are there other best practice pathways of care specific to the disease/topic that have been defined by clinicians/professional bodies e.g. Royal Colleges/patient groups?
- Consider how quality of care measures align with specialised service specifications pertinent to the condition topic, if relevant.
- Refer to existing national audits for examples of common metrics used to measure transition or to guide the design of new metrics.
- What are the features of successful transition?

**Contact your Project Manager or Associate Director at HQIP to discuss up-to-date quality of care measures that are being used across the programme.**

**Recommendation:** Include quality of care measures that address the NICE quality standard QS140 for transition where possible.

**Recommendation:** Explore additional condition specific standards, best practice pathways, financial levers and specialised service specifications when designing clinical outcome and process measures for transition services.

Consider the data collection strategies that could best inform outcome and process measures in a robust and meaningful way.

Possible strategies include:

- Audit of patients in adult and/or paediatric services to capture the transition pathway.
- Data linkage between a paediatric and adult cohort across relevant audits e.g. the National Diabetes Transition Audit has linked patients across a paediatric and adult audit.
- PROMS/PREMS/Patient surveys may give insight into CYP experience of the transition process and where quality improvement strategies could be targeted.
- Organisational surveys to measure the configuration, provision and priorities of transition services. Are transition services commissioned for both paediatric and adult services?
- Utilising proxy measures e.g. care process outcomes or service utilisation (Table 4).
- Consider accessing data across primary, secondary and allied healthcare services.
- Spotlight audit focussed on transition services within the context of the main audit topic.

**Recommendation:** Identify opportunities to address transition through process, outcome, organisational and/or patient experience measures.

**Recommendation:** Consider a spotlight audit focussed on transition services.

## Proxy Measures:

Proxy measures can be used as an indirect measure of the desired outcome when direct measures of the outcome are not routinely collected. They can be used when there is a strong link between an activity and the outcome you are trying to achieve.

The following example of proxy measures is taken from the 2016 HQIP guide 'Social care audit in practice'<sup>22</sup>

Outcome that is desired	Proxy Measure
Substance user achieves stability in using alternatives to street drugs	Substance user is receiving and maintaining a methadone prescription
Person has control over their eating and has established stable eating patterns	Person is eating three balanced meals every day

The National Diabetes Transition Audit used 6 NICE recommended annual clinical care processes for diabetes that are collected across the NPDA and NDA as proxy measures to infer the quality and variation of diabetes transition services. For the purpose of the audit, transition was defined as the last audit year a young person appeared in the NPDA and the following year they had a record in the NDA and this was used as a proxy for the age of transition.

**Table 4: Proxy measures collected by the National Diabetes Transition Audit**

National Clinical Audit	Aims of the audit	Proxy measures
<p><b>The National Diabetes Transition Audit (Linkage of NPDA and NDA)</b></p> <p>The last audit year a young person appeared in the NPDA and the following year they had a record in the NDA, this was used as a proxy for the age of transition.</p>	<ol style="list-style-type: none"> <li>1. Is the transition from paediatric to adult care associated with changes in NICE recommended care process completion rates?</li> <li>2. Is the transition from paediatric to adult care associated with a change in treatment target achievements?</li> <li>3. Is the transition from paediatric to adult care associated with changes in episodes of diabetic ketoacidosis?</li> </ol>	<p>Rate of completion for the care processes below pre and post transition:</p> <ul style="list-style-type: none"> <li>- HBA1c for glucose control</li> <li>- Blood pressure and serum cholesterol for cardiovascular risk</li> <li>- Urine albumin/creatinine ratio for kidney function</li> <li>- Foot risk surveillance</li> <li>- Digital retinal screening for retinopathy</li> </ul> <p>2a. Proportion of patients meeting NICE treatment targets for HBA1c pre and post transition.</p> <p>2b. Achievement of pre-defined targets for blood pressure, cholesterol and kidney function pre and post transition.</p> <p>3. Number of hospital admissions for diabetic ketoacidosis (DKA) pre and post transition.</p>

**Recommendation:** Consider using proxy measures to reduce data burden for new and commissioned national clinical audits

## 6.3 Considerations for Local Audit Teams

Local audits can play an important role in improving transition services. Local teams can plan targeted improvement projects and implement sustainable solutions relevant for their patient cohort and the local commissioning environment. They have the opportunity to ***“spread good practice and learn by example”***.

Appendix III provides examples of good practice within local transition services established across different NHS providers that may be a useful benchmark when considering how to improve your own services.

When embarking on a local audit of child to adult transition services review the preceding sections of this document and in addition consider the following:

- How are services supporting transition commissioned in your local area/for your speciality, are they commissioned across paediatric and adult services?
- Is transition a Trust level priority? How can your audit or improvement project influence this? Are there financial consequences of delivering best practice care e.g. best practice tariff?
- How best to align your audit with your Trust’s clinical audit programme?
- How do the services supporting transition that you provide align with national policies/best practice pathways and professional standards? What can you do to improve this from your baseline?
- What guidelines and standards are available and pertinent to measure your service against?

Refer to Appendix II for guidance on the resources that can be explored to find guidelines/standards that may be suitable to measure your local service against.

- How can you involve children, young people and their families to develop local pathways, protocols and services?

The HQIP documents “Patient and public involvement in quality improvement”<sup>23</sup> and “Developing a patient and public involvement panel for quality improvement”<sup>24</sup> and the RCPCH guide “How to write a children and young people’s engagement plan”<sup>25</sup> provide guidance on how to involve patients and public locally in quality improvement initiatives.

Every borough in England has a Children in Care Council as a statutory duty delivered by the local authority and the majority of councils across the UK should have a youth forum or a Special Educational Needs or Disabilities (SEND) forum for young people and a SEND parent/carer forum that could be approached for involvement when developing local services. Also find out if your local Healthwatch has a Youthwatch group that could be involved. Other devolved nations may have a different equivalent arrangement.

- How to audit transition across both your paediatric and adult services to fully assess the efficacy of services supporting transition? Local teams may be in a position to do this more directly than national audits.
- Is there a relevant national clinical audit to inform the development of your local audit or which can provide ongoing outcomes?

## 7.0 Conclusions

This guidance has been created to promote the subject of child to adult transition within national clinical audits by offering practical assistance on how transition can be incorporated into both paediatric and adult audits in alignment with quality standards and national policies. Improving transition services has the potential to improve the long-term health outcomes for children and young people with long term health conditions. Regular analysis of patient outcomes, experiences and the organisation of transition services through national and local clinical audits, as well as other forms of measurement driven quality improvement initiatives, provides an opportunity to highlight and then to reduce any unwarranted variation in service provision and make good practice the norm rather than the exception.

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<https://www.rcpch.ac.uk/resources/rcpch-us-how-write-children-young-peoples-engagement-plan>

## 10.0) Glossary

A&E:	Accident and Emergency
BPT:	Best Practice Tariff
CORP:	Clinical Outcome Review Programmes
CQC:	Care Quality Commission
CQUIN:	Commissioning for Quality and Innovation
CYP:	Children and Young People
DKA:	Diabetic ketoacidosis – an acute metabolic complication of diabetes characterised by a biochemical triad of hyperglycaemia, ketonaemia and acidaemia.
HQIP:	Healthcare Quality Improvement Partnership
NCA:	National Clinical Audit
NCAPOP:	National Clinical Audit and Patient Outcomes Programme
NCD:	National Clinical Director
NHS:	National Health Service
NICE:	National Institute for Health and Care Excellence
NIHR:	National Institute for Health Research
NTI:	Newcastle Transition Implications
PREMS:	Patient Reported Experience Measures
PROMS:	Patient Reported Outcome Measures
Transfer:	The formal event when the responsibility for the healthcare of a young person moves from children’s services to adults’ services.
Transition:	The purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with long term conditions as they move from child-centred to adult-orientated healthcare systems.