NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Transition from children’s to adults’ services

Output: Prioritised quality improvement areas for development.

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1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for transition from children's to adults' services. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the Committee in considering potential statements and measures.

1.2 Development source

The key development source referenced in this briefing paper is:

Transition from children's to adults' services for young people using health or social care services. NICE guideline NG43 (2016). No review schedule presented.

2 Overview

2.1 Focus of quality standard

This quality standard will cover all young people (aged up to 25) using children's health and social care services who are due to make the transition to adults' services. It will include young people:

- with mental health problems
- with disabilities
- with long-term, life-limiting or complex needs
- in local authority care.

It will cover the period before, during and after a young person moves from children's to adults' services.

The quality standard will cover all settings in which transitions from children's to adults' health or social care services take place.

2.2 Definition

Transition is defined as a purposeful and planned process of supporting young people to move from children's to adults' services where the young person and their family is at the centre of the process.

2.3 Overview

Transition takes place at a pivotal time in the life of a young person, part of wider cultural and developmental changes that lead them into adulthood. Making this move can be difficult or provoke anxiety in young people and their carers. Young people need appropriate support during this period to ensure they continue to engage with services. Adverse effects can occur if young people disengage and this can be disruptive for young people, particularly during adolescence when they are at a higher risk of psychosocial problems.

There is evidence that good transitional care is often not reflected in practice, and that transition support can be patchy and inconsistent. Poor management of transitions has been reported across all services, including those for young people with a single long-term condition such as diabetes and people with learning disabilities. Particularly vulnerable groups are identified as those with complex health and social care needs, child and adolescent mental health service users, young people leaving residential care and young people with life-limiting conditions. A report by Rare diseases UK[1] highlighted that 16% of the people they surveyed experienced problems in transition to adult services.

A study of young people’s transitions from Children’s and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS) found that two thirds of teenagers are either ‘lost’ from or interrupted in their care during this time[2]. Those that do make a transition can still experience poorer quality of care. For example, research from the SDO TRACK[3] study showed that only 4% of young people experienced their ‘ideal’ transition from CAMHS to AMHS.

2.4 Resource impact assessment

The resource impact report for NG43 did not anticipate any significant costs in implementation. No areas were identified as having a significant resource impact (>£1m in England each year). The guideline may however result in the following benefits and savings:

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[1] Rare diseases UK (2015) The Rare reality – an insight into the patient and family experience of rare disease.

[2] Singh et al. (2010) Process, outcome and experience of transition from child to adult mental healthcare: multiperspective study

[3] Transitions of Care from Child and Adolescent Mental Health Services to Adult Mental Health Services (TRACK Study): A study of protocols in Greater London, Singh et al. (2008)

- Reduced risk of young people falling between services and needing care, or treatment, for crisis that could have been avoided.
- Avoid duplication of costs where young people have multiple needs.
- Improved health and care outcomes for young people from effective transition.

2.5 Legislation

Care Act 2014 – The Act sets out the legal framework for the provision of adult social care in England, makes provisions about care standards, establishes and makes provision about Health Education England and the Health Research Authority.

Children and Families Act 2014 - takes forward a range of Government commitments which are intended to improve services for key groups of vulnerable children (children in the adoption and care systems, those affected by decisions of the family courts and those with special educational needs and disabilities) and to support families in balancing home and work life, particularly when children are very young.

In conjunction with the Children and Families Act (2014), the Care Act places a duty on local authorities to promote better choice and control over care and support for young people and families (rather than requiring them simply to provide services). The Children and Families Act introduces a system of support which extends from birth to 25, while the Care Act deals with adult social care for anyone over the age of 18. Both pieces of legislation ensure that people aged 18–25 will be entitled to support, placing the same emphasis on outcomes, personalisation and the integration of services. The acts are also aligned with a range of other policies and guidance relating to transitional care. The importance of joined-up working, and the integration of services is prioritised so that people do not ‘get lost’ in the system during these critical periods.

2.6 National Outcome Frameworks

Tables 1–2 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 **The Adult Social Care Outcomes Framework 2015–16**

Domain	**Overarching and outcome measures**
1 Enhancing quality of life for people with care and support needs	***Overarching measure*** 1A Social care-related quality of life** ***Outcome measures*** **People manage their own support as much as they wish, so they are in control of what, how and when support is delivered to match their needs** 1B Proportion of people who use services who have control over their daily life
3 Ensuring that people have a positive experience of care and support	***Overarching measure*** **People who use social care and their carers are satisfied with their experience of care and support services** 3A Overall satisfaction of people who use services with their care and support *Placeholder 3E The effectiveness of integrated care* ***Outcome measures*** **Carers feel that they are respected as equal partners throughout the care process** 3C The proportion of carers who report that they have been included or consulted in discussions about the person they care for **People know what choices are available to them locally, what they are entitled to, and who to contact when they need help** 3D The proportion of people who use services and carers who find it easy to find information about support **People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual** This information can be taken from the Adult Social Care Survey and used for analysis at the local level.
Alignment with NHS Outcomes Framework ** Indicator is complementary Indicators in italics in development	

Table 2 **NHS Outcomes Framework 2015–16**

Domain	**Overarching indicators and improvement areas**
2 Enhancing quality of life for people with long-term conditions	***Overarching indicator*** 2 Health-related quality of life for people with long-term conditions** ***Improvement areas*** **Ensuring people feel supported to manage their condition** 2.1 Proportion of people feeling supported to manage their condition **Enhancing quality of life for carers** 2.4 Health-related quality of life for carers** **Enhancing quality of life for people with mental illness** _ii Health-related quality of life for people with mental illness**_
4 Ensuring that people have a positive experience of care	***Overarching indicators*** 4a Patient experience of primary care i GP services 4b Patient experience of hospital care 4c *Friends and family test* *4d Patient experience characterised as poor or worse* *I Primary care* *ii Hospital care* ***Improvement areas*** **Improving experience of healthcare for people with mental illness** *4.7 Patient experience of community mental health services* **Improving people’s experience of integrated care** _4.9 People’s experience of integrated care**_
Alignment with Adult Social Care Outcomes Framework ** Indicator is complementary Indicators in italics in development	

3 Summary of suggestions

3.1 Responses

In total 25 stakeholders responded to the 2-week engagement exercise 21/03/16 – 06/04/16, one of which had no comments to make.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 3 for further consideration by the committee.

Full details of all the suggestions provided are given in appendix 3 for information.

Table 3 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Timing and review • Timing of transition planning • Annual review	HS, FPM, NHSE, NUI, RCN, RCPCH, SCM, TSL
Named worker • Named worker • Named GP	BSG, BTS, Ha, HS, LTH, RCP, RCPCH, SCF, SCM
Building independence • Building independence and information	GA, Ha, HS, RCP, SCM
Involvement • Involving parents and carers	NHSE, RCPCH, TSL
Support before transfer • Introduction to adult services • Personal folder • Expectations	BTS, Ha, HS, LTH, RCP, RCPCH, SCM, TSL
Support after transfer • Non-attendance	CLDF, NUI, SCM
Services • Joint planning • Developmentally appropriate service provision	ABN, BANNAR, BTS, CLDF, GA, ICS, LTH, NHSE, NPRANG, NUI, RCN, RCP, RCPCH, RCPsy, SCM, TSL
Additional areas • Ownership • Data • Scope • Funding • Research • End of life care plans	ABN, BHA, BSG, BTS, CLDF, COT, GA, LCT, NUI, RCP, RCPCH, RCPsy, RCSLT, SCF, SCM, TSL
ABN – Association of British Neurologists BANNAR – Barbara Ansell National Network for Adolescent Rheumatology	

Suggested area for improvement	Stakeholders
BHA – British HIV Association BSG - British Society of Gastroenterology BTS – British Thoracic Society CLDF – Children's Liver Disease Foundation COT – College of Occupational Therapists FPM – Faculty of Pain Medicine GA – Genetic Alliance UK Ha – Haemnet HS – The Haemophilia Society ICS – The Intensive Care Society LCT - Lancashire Care NHS Foundation Trust LTH – Leeds Teaching Hospital NHS Trust NHSE – NHS England NPRANG – National Paediatric Respiratory and Allergy Nurses Group NUI – Newcastle University Institute of Health and Society RCN – Royal College of Nursing RCP – Royal College of Physicians RCPCH – Royal College of Paediatrics and Child Health RCPsy – Royal College of Psychiatrists RCSLT – Royal College of Speech and Language Therapists SCM – Specialist Committee Member SCF – Sheffield Children's NHS Foundation TSL – Together for Short Lives	

3.2 Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 216 papers were identified for transition from children's to adults' services. In addition, 44 papers were suggested by stakeholders at topic engagement and 95 papers internally at project scoping.

Of these papers, 5 have been included in this report and are included in the current practice sections where relevant. Appendix 1 outlines the search process.

4 Suggested improvement areas

4.1 Timing and review

4.1.1 Summary of suggestions

Timing of transition planning

Stakeholders highlighted the importance of an early start to transition planning to ensure a smooth transition to adult services. The timing of transition needs to take into account service requirements and the needs of the young person, for some this is the point of diagnosis. Early planning allows service users to visit and try out services before making any final decisions, and for service users and their families to adjust to future changes.

Stakeholders reported that a sudden movement to adult care with no preparation or support is not unusual. This can be detrimental to care as confidence and trust is lost in healthcare teams and young people often struggled to take responsibility for their care and appointments having had little or no preparation. A more gradual transition can lead to a much smoother and less traumatic experience.

Annual review

Stakeholders suggested periodically updating transition planning documentation through an annual meeting.

4.1.2 Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 4 to help inform the Committee's discussion.

Table 4 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Timing of transition planning	NICE NG43 Recommendations 1.2.1, 1.2.2 and 1.2.3
Annual review	NICE NG43 Recommendation 1.2.4

Timing of transition planning

NICE NG43 – Recommendation 1.2.1

For groups not covered by health, social care and education legislation, practitioners should start planning for adulthood from year 9 (age 13 or 14) at the latest. For young people entering the service close to the point of transfer, planning should start immediately.

NICE NG43 – Recommendation 1.2.2

Start transition planning early for young people in out-of-authority placements.

NICE NG43 – Recommendation 1.2.3

Ensure the transition planning is developmentally appropriate and takes into account each young person's capabilities, needs and hopes for the future. The point of transfer should:

- not be based on a rigid age threshold
- take place at a time of relative stability for the young person.

Annual review

NICE NG43 – Recommendation 1.2.4

Hold an annual meeting to review transition planning, or more frequently if needed. Share the outcome with all those involved in delivering care to the young person. This meeting should:

- involve all practitioners providing support to the young person and their family or carers, including the GP (this could be either in person or via teleconferencing or video)
- involve the young person and their family or carers
- inform a transition plan that is linked to other plans the young person has in respect of their care and support.

4.1.3 Current UK practice

Timing of transition planning

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder’s knowledge and experience.

Annual review

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder’s knowledge and experience.

4.2 Named worker

4.2.1 Summary of suggestions

Named worker

Stakeholders highlighted that many young people find transition a difficult time as it can be a lengthy process and involves numerous professionals. Having one person they know and trust can lead to a smoother transition period and continued engagement following transition.

Suggestions were made about the role the named worker should have including:

- attending joint appointments as the young person moves in adult services
- being able to be contacted in a way that works for the young person e.g. text, email
- coordinating and implementing the transition plan
- aiding communication and engagement
- acting as a patient advocate
- identification and resolution of issues
- helping to manage expectations especially where children’s and adults services are very different
- supporting self-management

Concerns were raised over the resources available to provide a named worker.

Named GP

Stakeholders suggested a named GP could play a role in the overall coordination of care. This would be important especially for those children and young people with multiple complex needs or where there are no parallel adult services in a specialty for example paediatric neurodisability.

4.2.2 Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 5 to help inform the Committee’s discussion.

Table 5 Specific areas for quality improvement

Suggested quality improvement area	**Suggested source guidance recommendations**
Named worker	NICE NG43 Recommendations 1.2.5 and 1.2.6

Named GP	NICE NG43 Recommendations 1.1.8 and 1.1.9

Named worker

NICE NG43 – Recommendation 1.2.5

Help the young person to identify a single practitioner – who should act as a 'named worker' – to coordinate their transition care and support. This person could be supported by an administrator.

NICE NG43 – Recommendation 1.2.6

The named worker:

- could be, depending on the young person's needs:
  - a nurse, youth worker or another health, social care or education practitioner
  - an allied health professional
  - the named GP (see recommendation 1.1.9)
  - an existing keyworker, transition worker or personal adviser
- should be someone with whom the young person has a meaningful relationship.

Named GP

NICE NG43 – Recommendation 1.1.8

Check that the young person is registered with a GP.

NICE NG43 – Recommendation 1.1.9

Consider ensuring the young person has a named GP.

4.2.3 Current UK practice

Named worker

The 2014 Care Quality Commission (CQC) report ‘From the pond into the sea: children’s transition to adult health services’[4] highlights the experience of:

- 58 young people aged 14-25 with complex health needs (53% before transition and 47% after transition)
- 124 family members, parents and carers
- 437 multi-disciplinary teams
- 78 commissioners and managers of services.

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[4] Care Quality Commission (2014) From the pond into the sea: Children’s transition to adult health services.

The report found that there is variation in the perceptions of young people and healthcare professionals around support available pre-transition and post-transition. 50% of young people said there was no lead professional to support them through transition compared to 70% reported by health and care staff. The same difference in perceptions was shown post-transition where 20% of young people reported there was no lead professional compared to 48% reported by health and care staff. Families and health and care professionals said that the parents were the main coordinators of care and services.

Was there a lead professional to support the transition process pre-transition?

	Yes	No	Total
Case notes	27 (37%)	46 (63%)	73
Health and care staff	32 (30%)	75 (70%)	107
Young people/parents/carers	32 (50%)	32 (50%)	64

Is there a named lead professional to support care needs post-transition?

	Yes	No	Total
Case notes	42 (57%)	32 (43%)	74
Health and care staff	44 (52%)	40 (48%)	84
Young people/parents/carers	24 (80%)	6 (20%)	30

Named GP

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder’s knowledge and experience.

4.3 Building independence

4.3.1 Summary of suggestions

Stakeholders highlighted the positive contribution that development of knowledge, skills and confidence to self-manage a condition, treatment regime's or daily activity can have in facilitating smoother transition. A gradual programme or an adolescent clinic can help patients to prepare for how to start managing their own condition which should be accessible for everyone regardless of the condition.

As young people take responsibility for their care, they may have questions to help them learn more to ensure they can be actively involved in decisions about their future. Access to both condition specific and general information in a variety of formats was also suggested.

4.3.2 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 6 to help inform the Committee's discussion.

Table 6 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Building independence and information	NICE NG43 Recommendations 1.2.11, 1.2.14 and 1.2.17

NICE NG43 – Recommendation 1.2.11

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

- peer support
- coaching and mentoring
- advocacy
- the use of mobile technology.

NICE NG43 – Recommendation 1.2.14

Include information and signposting to alternative non-statutory services, including condition-specific support services, in transition planning. This may be particularly important for people who do not meet the criteria for statutory adult services.

NICE NG43 – Recommendation 1.2.17

If the young person has long-term conditions, ensure they are helped to manage their own condition as part of the overall package of transition support. This should include an assessment of the young person's ability to manage their condition, self-confidence and readiness to move to adults' services.

4.3.3 Current UK practice

Supporting young people in the context of their family, and parental involvement, can be complex during transition. Research has found that only 54% of young people preparing for transition and their families felt they had been involved as much as they wanted to be[5]. Furthermore, there is evidence that children's services and transition teams do not consistently provide preparation or training for young people and their families for the differences they are likely to face when transferring to adult services, with support plans additionally not reflecting young people's wishes.

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[5] Department for Children, Schools and Families / Department of Health (2007) A transition guide for all services; and, Commissioning Panel for Mental Health (2012) Guidance for commissioners of mental health services for young people making the transition from child to adult mental health services

4.4 Involvement

4.4.1 Summary of suggestions

Stakeholders highlighted two issues on the involvement of parents and carers. They reported that parents want to remain involved in their child's care but do not feel welcome in adult services. It was also highlighted that whilst transition should be focused on the young person, parents and carers are also undergoing their own transition as they come to terms with changes to the way they support and engage with their child's condition. Parents and carers have separate needs that need to be addressed. Stakeholders highlighted that engaging well with and supporting parents and carers can help the young person through the transition process.

4.4.2 Selected recommendations from development source

Table 7 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 7 to help inform the Committee's discussion.

Table 7 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Involving parents and carers	NICE NG43 Recommendation 1.2.19

NICE NG43 – Recommendation 1.2.19

Ask the young person regularly how they would like their parents or carers to be involved throughout their transition, including when they have moved to adults' services.

4.4.3 Current UK practice

The CQC report 'From the pond into the sea: children's transition to adult health services[6] highlighted that parents felt "abandoned" by health and social care services at this most difficult time. The report found there appeared to be a culture of overreliance on partner agencies to recognise and assess the demands on family members as carers, to follow these up appropriately, and to develop strategies to address their needs. Families reported little concern from health professionals as to their roles as carers and a lack of support or explanation of choices and control over the future. The report also found that some community children's nurses have had no training in assessing the needs of carers. Despite widespread recognition of the

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[6] Care Quality Commission (2014) From the pond into the sea: Children's transition to adult health services.

impact of caring for a young person with complex health needs at home, report that they don’t have the resources to address issues highlighted by carers.

4.5 Support before transfer

4.5.1 Summary of suggestions

Introduction to adult services

Stakeholders suggested an introduction to adult services as part of the transition process. This could be as part of a transition clinic where paediatric and adult services meet together to discuss a young person’s care. Stakeholders highlighted that meeting new professionals early can help build confidence in asking for their involvement at a later stage, increasing awareness of the availability of future services and ensuring a smoother transition process.

Personal folder

Stakeholders highlighted that good transfer information, preferably patient held, is important to ensure there is a shared understanding of the needs of the young person between children and adults services. It can also improve communication between young people and professionals who may struggle to repeatedly tell their story and may not realise the professionals do not have all the relevant information about them. Stakeholders reported that young people can arrive in adult clinics where little is known about them beyond their diagnosis (e.g. family background, lifestyle, personal understanding of their condition and management, all of which are important in bleeding disorders).

Expectations

Stakeholders suggested young people and their families should be given appropriate information about what to expect from future services. The importance of information was also highlighted to ensure families and their children’s and adult’s care teams have shared and equal expectations about their future care. Stakeholders for example highlighted physiotherapy services where there are not the corresponding adult services a young person may have used in children’s services and therefore the focus of their care changes.

4.5.2 Selected recommendations from development source

Table 8 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 8 to help inform the Committee’s discussion.

Table 8 Specific areas for quality improvement

Suggested quality improvement area	**Suggested source guidance recommendations**
Introduction to adult services	NICE NG43 Recommendations 1.3.1 and 1.3.5
Personal folder	NICE NG43 Recommendation 1.3.3
Expectations	NICE NG43 Recommendations 1.3.4 and 1.3.8

Introduction to adult services

NICE NG43 – Recommendation 1.3.1

Children's and adults' service managers should ensure that a practitioner from the relevant adult services meets the young person before they transfer from children's services. This could be, for example, by:

- arranging joint appointments
- running joint clinics
- pairing a practitioner from children's services with one from adults' services.

NICE NG43 – Recommendation 1.3.5

Consider finding ways to help the young person become familiar with adults' services. This could be through the use of young adult support teams, joint or overlapping appointments, or visits to the adults' service with someone from children's services.

Personal folder

NICE NG43 – Recommendation 1.3.3

Consider working with the young person to create a personal folder that they share with adults' services. This should be in the young person's preferred format. It should be produced early enough to form part of discussions with the young person about planning their transition (for example 3 months before transfer). It could contain:

- a 1-page profile
- information about their health condition, education and social care needs
- their preferences about parent and carer involvement
- emergency care plans
- history of unplanned admissions
- their strengths, achievements, hopes for the future and goals.

Expectations

NICE NG43 – Recommendation 1.3.4

All children's and adults' services should give young people and their families or carers information about what to expect from services and what support is available to them. This information should be provided early enough to allow young people time to reflect and discuss with parents, carers or practitioners if they want to (for example 3 months before transfer). It should:

- be in an accessible format, depending on the needs and preferences of the young person (this could include, for example, written information, computer based reading programmes, audio or braille formats for disabled young people)
- describe the transition process
- describe what support is available before and after transfer
- describe where they can get advice about benefits and what financial support they are entitled to.

NICE NG43 – Recommendation 1.3.8

If a young person is not eligible for statutory adult care and support services, make sure that they, and their family or carers, are given information about alternative support.

4.5.3 Current UK practice

Introduction to adult services

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder’s knowledge and experience.

Personal folder

The CQC report ‘From the pond into the sea: children’s transition to adult health services’[7] found that health passports were not widely used

Expectations

The CQC report ‘From the pond into the sea: children’s transition to adult health services[8] showed there was inconsistent and often poor information and preparation from children’s services for young people and their parents about the changes they can expect as they move into adult services. This led to a lack of understanding of the process of transition.

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[7] Care Quality Commission (2014) From the pond into the sea: Children’s transition to adult health services.

[8] Care Quality Commission (2014) From the pond into the sea: Children’s transition to adult health services.

4.6 Support after transfer

4.6.1 Summary of suggestions

Non-attendance

Stakeholders highlighted the importance of trying to ensure young people remain engaged in the transition process either by identifying those at risk of disengaging before transition or helping those who have disengaged after transition has taken place. When the latter happens, GPs can have a role in communicating with the young person and referring them back into services. Stakeholders suggested that young people are seen in adult services within 6 months of transfer to ensure they are not disengaged.

4.6.2 Selected recommendations from development source

Table 9 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 9 to help inform the Committee's discussion.

Table 9 Specific areas for quality improvement

Suggested quality improvement area	**Suggested source guidance recommendations**
Non-attendance	NICE NG43 Recommendations 1.4.1, 1.4.2 and 1.4.3

<u>NICE NG43 – Recommendation 1.4.1</u>

If a young person has moved to adults' services and does not attend meetings, appointments or engage with services, adult health and social care, working within safeguarding protocols, should:

- try to contact the young person and their family
- follow up the young person
- involve other relevant professionals, including the GP.

<u>NICE NG43 – Recommendation 1.4.2</u>

If, after assessment, the young person does not engage with health and social care services, the relevant provider should refer back to the named worker with clear guidance on re‑referral (if applicable).

<u>NICE NG43 – Recommendation 1.4.3</u>

If a young person does not engage with adults' services and has been referred back to the named worker, the named worker should review the person‑centred care and support plan with the young person to identify:

- how to help them use the service, or
- an alternative way to meet their support needs.

4.6.3 Current UK practice

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

4.7 Services

4.7.1 Summary of suggestions

Joint planning

Stakeholders highlighted the importance of joint planning, working and sharing which ensures young people receive the services they need and do not become disengaged and that knowledge and experience can be shared between children's and adult's services.

Stakeholders reported poor communication and coordination between different provider's especially young people who are seen by different services that are not working together. This can lead to parents and carers coordinating their own child's care. Stakeholders also reported that where care is not joined up, treatments may be changed because of the practice of the service rather than based on their needs for example hearing aids in audiology.

Stakeholders highlighted that there are groups of young people growing and maturing with conditions that adult services have little experience of. This can result in the high quality care received in children's services not being continued into adult services because of the lack of knowledge. Joint working can ensure the expertise of professionals in children's services are shared with colleagues in adult services.

Further issues were raised including the complexity of funding streams when young people use several services and waiting lists being a barrier to accessing adult services.

Developmentally appropriate service provision

Stakeholders suggested age appropriate services are not always available. Where they are not available young people are reported to not be transitioning to adult services at an appropriate time and in some cases care becomes split across children's and adult's services. The provision of age appropriate services also ensures the professionals who work within these services are trained in young people's care especially around communication skills.

4.7.2 Selected recommendations from development source

Table 10 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 10 to help inform the Committee's discussion.

Table 10 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Joint planning	NICE NG43 Recommendation 1.1.5, 1.5.9 and 1.5.10
Developmentally appropriate service provision	NICE NG43 Recommendation 1.5.11

Joint planning

NICE NG43 – Recommendation 1.1.5

Health and social care service managers in children's and adults' services should work together in an integrated way to ensure a smooth and gradual transition for young people. This work could involve, for example, developing:

- a joint mission statement or vision for transition
- jointly agreed and shared transition protocols, information‑sharing protocols and approaches to practice.

NICE NG43 – Recommendation 1.5.9

Jointly plan services for all young people making a transition from children's to adults' services.

NICE NG43 – Recommendation 1.5.10

Consider joining up services for young people who are involved with multiple medical specialties. This might include a single physician, such as a rehabilitation consultant, taking a coordinating role.

Developmentally appropriate service provision

NICE NG43 – Recommendation 1.5.11

Service managers should ensure there are developmentally appropriate services for children, young people and adults to support transition, for example age-banded clinics.

4.7.3 Current UK practice

Joint planning

The CQC report ‘From the pond into the sea: children’s transition to adult health services[9] reported that a number of adult health professionals lacked experience in supporting young people with complex needs when they first move to adult services, that some services available from children’s community nurses were not available from adult district nurses due to capacity and resources but also different skill and expertise between the two services and some parents had witnessed disagreements in A&E between adult and children’s wards, and even intensive care units, about the best place for care to be provided.

Developmentally appropriate service provision

There is current evidence[10] of service gaps for some young people, in particular those with mental health needs, those leaving specialist residential schools to move back to their original communities, and young people with palliative care needs. Service gaps are caused by a lack of relevant adult services, or because young people do not qualify for adult services. For this reason some young people move from specialist children's services into primary care, often relying on provision by voluntary agencies. There is a reported lack of information about services, and poor integration between services.

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[9] Care Quality Commission (2014) From the pond into the sea: Children’s transition to adult health services.

[10] NICE guideline NG43 (2016) Transition from children’s to adults’ services for young people using health or social care services

4.8 Additional areas

Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or require further discussion by the Committee to establish potential for statement development.

There will be an opportunity for the QSAC to discuss these areas at the end of the session on 18 may 2016.

Ownership

Stakeholders highlighted managerial responsibility and ownership of young people entering transition to ensure improved transition practices are sustainable. The roles could be for example chief executives, senior trust executives or senior managers in health and social care. Their role would be to own the policy on transition and ensure the policy is followed by all areas of their organisations. This does not align with the purpose of quality standards.

Data

Stakeholders proposed additional audit questions for the National Transition Audit in Audiovestibular Medicine to reflect NICE guidance and suggested key outcome measures including patient reported satisfaction, DNA rates, unplanned admissions and time to first appointment. It is not within the remit of the quality standard to propose audit questions and overarching outcomes will be addressed as part of the introduction to the quality standard.

Scope

This quality standard covers health and social care services and is relevant for any young person regardless of their conditions/needs already in children’s services that will be transitioning to adult services. It does not include young people who are referred straight into adult services. Where there are particular requirements needed for specific populations these will be addressed in the equality and diversity considerations sections for each quality statement.

Funding

Stakeholders highlighted the difficulties in funding streams to address transition and propose a transition tariff. Setting national tariffs is outside of the remit of the quality standard.

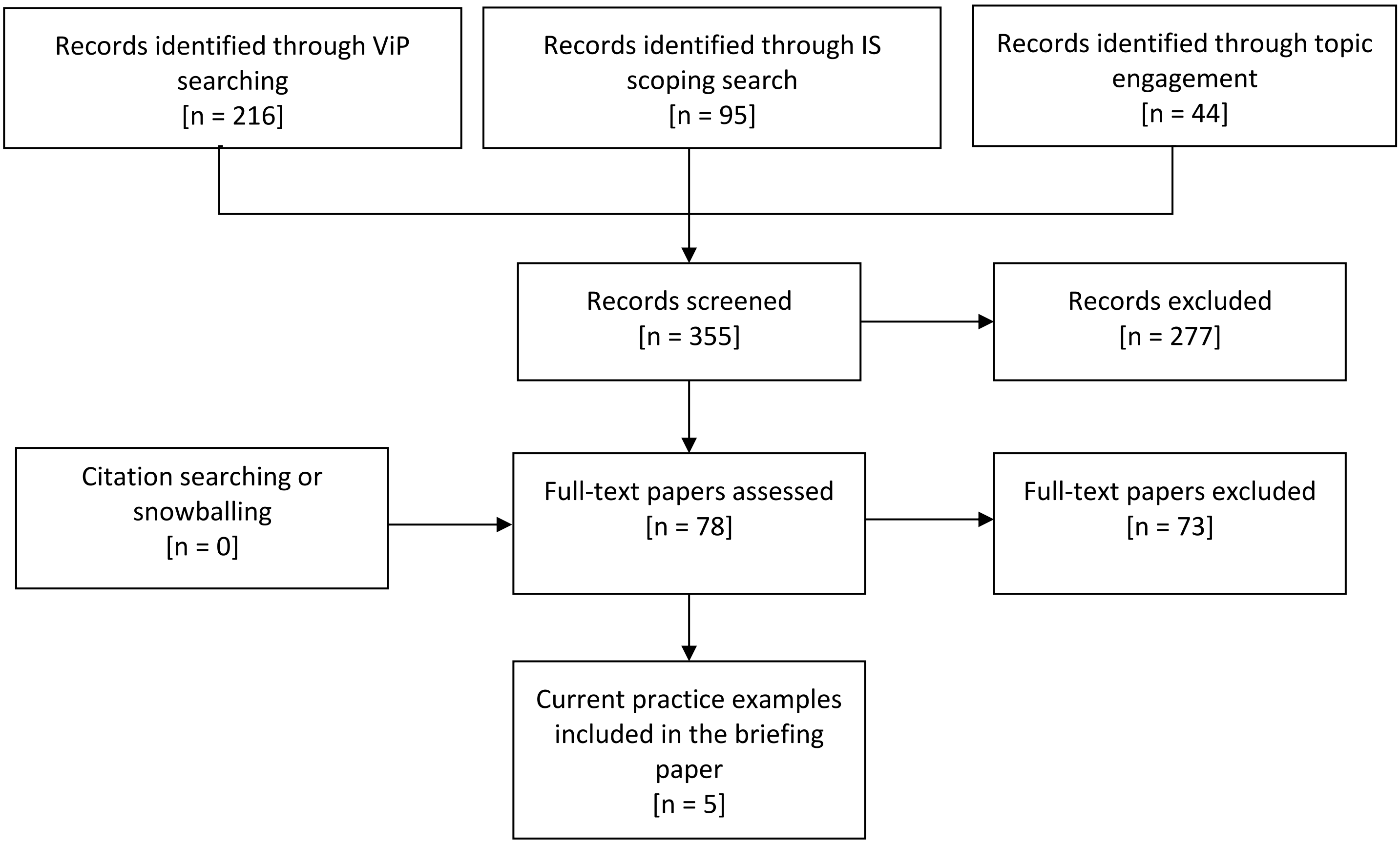
Research

Stakeholders highlighted the importance of research in young people going through the transition process. Quality standards do not address areas for research.

End of Life Care Plans

Stakeholders suggested every young person with a life-shortening condition should have an end of life plan which is developed in parallel to planning for ongoing care and support in adult services. This is outside the remit of this quality standard.

Appendix 1: Review flowchart



Appendix 2: Glossary

Developmentally appropriate is an approach to supporting young people that recognises them as a distinct group, subject to constantly changing circumstances. Developmentally appropriate care and support considers the young person as a whole, addressing their biological, psychological and social development in the broadest terms. This approach will need joined-up service provision, and for the young person to be informed about, and supported to play an active role in, their care and support (Farre et al. Developmentally appropriate healthcare for young people: a scoping study 2015).

Named worker is a role rather than a job title. This should be one of the people from among the group of workers providing care and support to the young person, who has been designated to take a coordinating role. It could be, for example, a nurse, youth worker, an allied health professional or another health and social care practitioner. It could also be someone who already has the title keyworker, transition worker or personal adviser.

Person-centred means seeing the person using care and support as an individual and an equal partner who can make choices about their own care and support. The recommendations in this guideline seek to ensure that all of a young person's needs are supported, including those related to their wider context (for example, education and employment, community inclusion, health and wellbeing including emotional health, and independent living and housing options).

Transfer is the actual point at which the responsibility for providing care and support to a person moves from a children's to an adults' provider.

Appendix 3: Suggestions from stakeholder engagement exercise – registered stakeholders

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
Timing and review – timing of transition planning					
1	Faculty of Pain Medicine	Key area for quality improvement 1 Transition arrangements, both timing and support, should be developmentally appropriate to the young person	Increasingly, early exposure to transition is recommended, particularly in services such as Diabetes and Asthma. There are often, however, individuals within services for whom a blanket approach is not suitable and causes distress to families.	I am not aware of high quality evidence to support this proposed quality improvement area. However, it is firmly embedded in NICE Guideline 43. Working in Paediatric Pain Management Services, often with young people with multiple Co-morbidities, I am aware of: i. Young people for whom transition has been broached too early by services with firm age guidelines. ii. Having to consider transition arrangements of other specialties when organising transition of Pain Management.	NICE Guideline 43 Transition from children's to adults' services for young people using health or social care services Sections 1.1.2 and 1.2.3
2	Newcastle University Institute of Health and Society	Key area for quality improvement 4 The need for services to be Developmentally Appropriate should be set out in the Commissioning Contract and the Transition Policy of provider organisations.	This is specifically mentioned in the NICE Guidance: 1.1.2 Ensure transition support is developmentally appropriate, taking into account the person's:……	We have published two articles to date on this which are: Farre A, Wood V, McDonagh JE, Parr JR, Reape D, Rapley T; Transition Collaborative Group. Health professionals' and managers' definitions of developmentally appropriate healthcare for young people: conceptual dimensions and embedded controversies. Arch Dis Child. 2016 Mar 4. doi: 10.1136/archdischild-2015-309473. [Epub ahead of print]. Farre A, Wood V, Rapley T, Parr JR, Reape D, McDonagh JE. Developmentally appropriate	Some but definitely not all the important elements of Developmentally Appropriate Healthcare are included in the You're Welcome Criteria. Every Provider should have to show that training in Developmentally Appropriate Health and Social Care is part of its Transition policy.

				healthcare for young people: a scoping study. Arch Dis Child. 2015;100:144-51	
3	NHS England	Key area for quality improvement 3 The importance of well planned, timely and coordinated services	In order to enable service users and their carers to become and remain active partners in their care, to prepare for transfer(s) and to engage with a new service, engaging, sensitive and developmentally appropriate care planning should start with the young person and their family from the point of diagnosis. Planning for transfer should begin early and involve the young person whilst they are still receiving paediatric services to support early preparation and maximise the time the young person has to prepare for the changes. A pathway should be agreed between the transferring service and receiving services and early as possible to facilitate a smooth and coordinated change. Once the transfer to the receiving service has taken place, services must support integration into adult or new care settings and the design of services must attend to the wider health, psychological, social, educational and vocational outcomes for young people in addition to condition specific outcomes. There should be a focus on enabling optimal health and	Early preparation and planning for the transition period is essential in managing expectations, promoting understanding and involvement in the wider process, and ensuring that the service user is well informed and therefore empowered. My Care Plan provides a successfully implemented good template for early initiation of transition planning. Examples of good care planning have incorporated the young person’s physical development, emotional maturity and local circumstances. Coordination between professionals at all three stages in essential to ensure that the overall transition is consistent and to avoid variation, particularly where a young person moves to a different geographical location.	The NHS England Diabetes Transition Service Specification (see above) further evidence can be found in the ‘links to other documents and sources of support’ section of the service specification. The CAMHS service specification (see above) My Care Plan provides a successfully implemented good template for early initiation of transition planning.

			wellbeing outcomes with young people as they move towards and into adult, specialist services, or primary care services, with close collaboration with GP's and other primary care professionals.		
4	Royal College of Nursing	Key area for quality improvement 1 Transition planning should include physical and learning disability with the involvement of the young person and their family.	There is good evidence that supports the need to begin transition arrangements early and to have a transition plan which should be put together with the involvement of the young person and family. This is particularly important for children and young people with physical and learning disability.	Whilst the importance of early transition arrangement is generally recognised, what is often not mentioned is the provision for young people with a physical disability but not a learning disability. These young people may have a lot of support with physiotherapy, occupational therapy etc. as children but there is very little provision once they transfer to adult services. Where once there was previously excellent specific support for young disabled adults from a multidisciplinary team (including physiotherapy, occupational therapy, dietitian, sexual health advice). There is variation in how this service is provided. We aware that some units have incorporated this service into their generic neurology service and work mostly with older adults with strokes, Parkinson's disease etc. The young people are therefore not given the support they need to prevent contractures and allow them to go to university, find employment etc. Any mention of disability in lots of service documents is related to learning disability, whilst physical disability is much more common and many people with a physical disability do not also have a learning disability.	Transition from children's to adults' services for young people using health or social care services. http://nice.org.uk/guidance/ng43 Diabetes transition and young adult service specification and guidance document – NHS England Medical Directorate; 21 January 2016

5	Royal College of Paediatrics and Child Health	Key area for quality improvement 4 Mental Health Services	Traditionally, children have been seen in transition clinics between the ages of 14 and 18 yrs in order to prepare them for adult services, but this is rare in Mental Health	Child and Adult Psychiatrists may see young people up to the age of 25 yrs, but other staff such as Educational Psychologists and Community Paediatricians would only be involved until school leaving age (19 if special needs)	Lack of consistency in the transition arrangements between services makes the coordination of care difficult. Families often feel abandoned by one service eg respite care, before an alternative adult service has been identified.
6	SCM1	Key area for quality improvement 1 Timing of transition planning	NICE guidance recommends adequate and person centred transition planning, which takes into account service requirements, as well as the needs of the young person. NICE guidance highlights the need for considering cognitive understanding, how stable the young person is at that time, and the possibility of planning for returning home from out of city placements.	Cut-off dates in terms of chronological age are too often the benchmark for transition, which do not account for individualised approaches or encourage time spent to work in a multi-disciplinary way at an early stage. Variable commissioning arrangements, different referral/ access criteria. Adult and child services are often very different physical environments, and working practices, as well as new personnel and the possibility of access to different treatment/ support.	NICE research highlighted transition as a key point of disengagement.
7	SCM3	Key area for quality improvement 3 1.2.1 Transition planning should start early on in year 9 (or as appropriate)	NICE guidelines – 1.2.1 – For groups not covered by health, social care and education legislation, practitioners should start planning for adulthood from year 9 (age 13 or 14) at the latest. For young people entering the service close to the point of transfer planning should start immediately. (For those with EHC plans this must happen from year 9 as per Children and Families Act 2014 or from 15 ½ for those leaving care).	As a carer I continually asked for information so that I could visit services and find out if I thought they were suitable. The earlier planning starts the more time there is to enable families to go out, visit and try out services before finally making a decision. This needs to be done over time, especially to allow parents to go to work or attend meetings or appointments with their disabled child. Parents frequently have to work part-time and earn less money as they	

				have to fit in with the timing of services which are often shorter than normal. Both parents and young people need to have both quality and time. For some families decisions on some services like supported living needs to be done with plenty of notice. This will enable families to visit services and make decisions. Decisions cannot always be made at short notice or without visiting the services to get a feel for them, as is sometimes the case. I had to ask at several of our annual reviews while with children's services about supported living as I heard of a case in Cheshire, but no-one in children's services was aware of any local supported living. It was only once the adult social worker came along when my son was 18, stating there were plenty of examples in my borough which surprised me! Adult and children services need to share this information. Enough time and sufficient knowledge of this service if required. It also takes time to come to terms with letting go of your child. My husband knows even less about supported living so it is even more difficult for him to let go. It also shows the need for children's	

				and adult services to work together!	
8	The Haemophilia Society	Age at which transition preparation begins.	An early start to self-management is essential in preparing for a smooth transition to adult care, this should be a journey, not an event. Speaking to members who have recently moved from children's to adult care, this was highlighted as a key issue. They suggested transition should begin with understanding and managing your own care as early as possible. Probably from age 6-8. This could be self-treating (thinking about haemophilia and bleeding disorders where frequent intravenous injections are required), involvement in decisions about your care, meeting with healthcare professionals without your parents etc.	No formal evidence has been published, but The Haemophilia Society and Haemnet are working on gathering evidence from young people and their parents on this issue. Feedback from many members suggests that a sudden move to adult care is not unusual with no preparation or support. They felt this was detrimental to their care as they lost confidence and trust in their healthcare team and often struggled to take responsibility for their care and appointments having had little or no preparation. Members who had a more gradual transition reported a much smoother and less traumatic experience.	
9	Together for short lives	Early support	Every young person from age 14 should be supported to be at the centre of preparing for adulthood and for the move on to adult services. Their families should be supported to prepare for their changing role.	Stepping Up, Together for Short Lives, 2015 states that transition planning takes at least two years for young people with complex needs. It is vital that this planning begins as early as possible – ideally during Year 9 (age 14) so that they are fully involved in and prepared for their transition. Stepping Up measures this standard using five service goals: 1. Person-centred planning 2. Parallel planning 3. Conversations take place at a time and place that suits young person and their family 4. Follow-up meetings with young	

				person and family take place 5. Multi-agency team meeting takes place	
Timing and review – annual review					
10	Newcastle University Institute of Health and Society	Key area for quality improvement 5 Documented evidence of transition planning which is periodically updated and which the young person holds a copy of.	NICE Guidance states: 1.2.4 Hold an annual meeting which should …….and inform a transition plan that is linked to other plans the young person has in respect of their care and support.		The plan should be first drawn up at least two years before Transfer and should continue for at least one year after transfer. If appropriate, this could be combined with an Education, Health and Social Care Plan (EHSP).
Named worker – named worker					
11	British Society of Gastroenterology	Key area for quality improvement 3 Improving the transitional process for young people that are under the care of several different specialities	Enabling services to have access to a named transition health care professional or youth worker who can help co-ordinate transition care and support young people and their families that need complex multi speciality transition.	As before	
12	British Thoracic Society	Key area for quality improvement 5	Transition Link in Social care	Paediatric social care and adult are different world. Services that have been set up that have kept patient stable. A key contact person should help navigate the transition process for the young adult and his/her carer/parents ‘Young adults with chronic medical conditions requiring on-going specialist care should have a named key worker to provide continuity of care during the transition from child-centred to adult-orientated care’ Paediatric social care and adult are different world. Services that have been set up that have kept patient	

				stable.	
13	Haemnet	Key area for quality improvement 4: Empower nurses to lead transition services for people with haemophilia (all severities) and other inherited bleeding disorders	NICE guidance states that the co-ordinator of transition care and support should be someone with whom the young person has a meaningful relationship. Haemophilia clinical nurse specialists (CNS) frequently develop an effective and supportive working relationship with people with bleeding disorders and their families during their childhood and adolescence.	Haemophilia clinical nurse specialists are in a prime place to enable this aspect of the guidance to become practice.	Clinical nurse specialists (CNS) are well placed to work with service users to support them in transitioning from children to adult services. There is some evidence showing that the one-to-one relationship with the CNS was considered by service users to be the most valued part of the CNS role. (McArthur L, Flynn A. Evaluating the clinical nurse specialist role in child health. Nursing Times; 2008.) In our centre based research it was reported that where nurses had led the multi-disciplinary transition clinics process attendance levels were increased. We are continuing to investigate this.
14	Leeds Teaching Hospitals NHS Trust	Implementation of a Named Worker for each young person	To coordinate and implement the Transition Plan Single point of contact Aids communication and engagement Patient advocate Identification and resolution of issues Helps to manage expectations re: transfer to adult services Enable and support self-management	Research indicates that poor adherence and non-attendance can be evidenced when a named worker is not in post. Thus leading to poorer outcomes.	Coulter et al. 2013 Delivering better services for people with long term conditions. The King's Fund. SEND Guidance https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf Coulter et al. 2013 Delivering better services for people with long term conditions. The King's Fund. Crowley, R., et al. "Improving the transition between paediatric and adult healthcare: a systematic review." Archives of disease in childhood (2011): archdischild202473.
15	Royal College of	Additional developmental	Many chronic diseases have their		

	Paediatrics and Child Health	areas of emergent practice	own guidance and include aspects of transition so this should be included, e.g. cystic fibrosis, epilepsy, diabetes etc. One overarching principle we feel has to be emphasised is that any recommendations has to be realistic within the confines of the current restricted budgets and suggesting named key workers and clinics with 2 consultants is becoming more unlikely in job plans etc.		
16	Royal College of Physicians	Key area for quality improvement 3 Continuity	Our experts note the value of having a key worker secured in the receiving room. Our experts suggest the use of formal 'transition clinics' and 'keyworkers' for the major medical specialties. eg young adults with chronic medical conditions requiring on going specialist care should attend a transition clinic at which adult and paediatric teams are present; and should have a key worker during transition.		
17	SCM1	Key area for quality improvement 2 A named worker	The need for a named worker to coordinate the transition process was highlighted during NICE guideline development. In order to have a smooth transition, there should be a trusted accountable person for the young person to contact.	The possibility of a large number of adult and child professionals, plus family/ carers to be involved with the transition of a young person. The transition cut-off points for different services may vary considerably from 16 -25 years, which can be useful to stagger change, but also leads to a lengthy period of instability. It is key that one person can hold information and liaise with the family, so	

				communication is swift and accurate. The named worker could ensure information was shared in an appropriate way, for a holistic approach to supporting the young person.	
18	SCM3	Key area for quality improvement 4 Everyone should have a named worker or keyworker.	NICE guidelines – 1.2.5 – Help the young person to identify a single practitioner – who should act as a ‘named worker’ – to co-ordinate their transition care and support. This person could be supported by an administrator. 1.2.9 – The named worker should ensure that the young person is offered support with the following aspects of transition, if relevant for them (which may include directing them to other services). – education and employment, community inclusion, health and wellbeing including emotional health, independent living and housing options.	A named worker of some sort should be available to support families, even if not always used, families should know they can turn to someone when needed. Families are all different and some may need help more than others, even those not currently requiring help should still have access to a named worker for when they do need them. I am more knowledgeable than many parents but I don’t know everything and at times I also need help to work out what service is appropriate. My life at times is complicated with all the different services my son has to access and it can be overwhelming at times. Support from a named worker can ease the stress for many families. Families should be able to access better outcomes through a named worker whether the named worker is fully trained themselves to advise around everything or whether they use their own skills to signpost families to other relevant services. Young people need to know what is available to them without it being limited by assumptions about their	

				abilities. A named worker can ensure that the information is made available to the young person.	
19	Sheffield Children NHS Foundation	Key area for quality improvement 3 Improving the transitional process for young people that are under the care of several different specialities	Enabling services to have access to a named transition health care professional or youth worker who can help co-ordinate transition care and support young people and their families that need complex multi speciality transition.	As before	
20	The Haemophilia Society	Having a key worker or named person that is your main contact	Having a key worker or named person that is your main contact that you know and trust has been identified by our younger members as an essential element of transition. It could be any member of the MDT, probably a nurse, but possibly a physio, (not a doctor, who is often currently the decision maker). This person should be a support through the transition period and start building relationships over a long period.	We were told by our members that when you do eventually begin to move into adult care, this person should be able to be with you for some joint appointments to smooth the transition over time. You should be able to contact them in a way that works for you i.e. text or email etc. and not be expected to conform to what works for them. Many young people find this a difficult time and having one person you know and trust can make all the difference, however they want to be able to pick who this is from their healthcare team. Many felt the decision of when to move was led by the doctor, not by the person themselves and this felt very wrong. A key worker could help with this decision making.	
Named worker – named GP					
21	British Society of Gastroenterology	Key area for quality improvement 2 Improving the transitional process for paediatric specialities that lack a parallel adult service	Lack of parallel adult services in specialities such as paediatric neurodisability result in difficulties in ensuring effective and smooth transition for such young people. Enabling primary care to have greater involvement in transition	As before	

			planning and care should help with supporting these young people and families		
22	British Thoracic Society	Key area for quality improvement 2	Named GP who has met patient and carers	Coordinate care in adult services and be a replacement for School Health services, community paediatricians where there are no equivalents in adult services	
23	Royal College of Paediatrics and Child Health	Key area for quality improvement 1	It is often difficult to find appropriate Adult Physicians to care for young people with multisystem disorders with or without learning disabilities. Examples of good transition arrangements do exist in some specialities e.g. Rheumatology and CF but provision is patchy.	Adult services are too much organised around one system i.e. gastroenterology or respiratory medicine. The concept of a general physician has been lost, except in care of the elderly. Therefore, sometimes the most appropriate physician to take over care of a young person is paradoxically an elderly care doctor.	General Practitioners could also be more involved, but continuity of care is essential, therefore the concept of a named GP for each young person needs to be required before good or excellent care could be achieved solely in the community. Most GP's do not feel that they have the expertise to care for e.g. a person with a syndrome, or complex multisystem disorder. However they could have a larger role in the coordination of care.
24	Sheffield Children NHS Foundation	Key area for quality improvement 2 Improving the transitional process for paediatric specialities that lack a parallel adult service	Lack of parallel adult services in specialities such as paediatric neurodisability result in difficulties in ensuring effective and smooth transition for such young people. Enabling primary care to have greater involvement in transition planning and care should help with supporting these young people and families	As before	
Building independence – Building independence and information					
25	Genetic Alliance UK	Medical professionals receive insufficient training in adolescent care and medicine	Young people have differing needs to those of children and adults. Some conditions only develop during adolescence whilst other conditions present themselves in a clinically distinct manner during	Many patients told us how the atmosphere of their consultations changed when they transitioned from child services to adult services and said that clinicians began addressing them rather than their parents. This is	See above.

			adolescence, yet the NHS does not make provision for adolescent medicine. As a result, there is a lack of specialists who are able to meet the needs of young people, which is especially acute for young people affected by rare conditions.	one example of a significant shift in how an individual's healthcare is provided that can be difficult to get used to and can, at first, be disconcerting and challenging. Active engagement with patients rather than their parents encourages young people to become independent and gain the necessary knowledge, skills and confidence required to manage their own condition. Having a gradual programme or an adolescent clinic can help patients to prepare for how to start managing their own condition.	
26	Haemnet	Key area for quality improvement 1: Developing knowledge and skills for effective self-management	Building independence and transition planning are recommended in the NICE guidelines. For people with severe haemophilia there is growing understanding of the positive contribution that development of the skills to self-manage their treatment regime and also their condition have in facilitating smoother transition from children's to adult services Training in prophylaxis offers an opportunity to develop skills to self manage treatment regime from an early age	There are variations in practice with respect to teaching self-management skills across the country. There is a need for an agreed (developmentally appropriate) age range for development of skills such as these that will enable individuals to manage their treatment and subsequent transition. Developing self-management skills improves the chances of delivering a person-centred approach as the focus is on empowering the individual to take ownership of their condition and to see NHS and other practitioners as equal partners in their care.	We conducted a literature review of transition among people with long term conditions that identified education, training and development as a key theme. Young people and parents/carers should be provided with knowledge about their condition and armed with the skills and support to best manage their own care. In haemophilia, this means teaching self-infusion skills and and building independence (Chaplin S. Transition from adolescent to adult services in haemophilia. J Haem Pract 2016; 3(1):71-93. doi: doi:10.17225/jhp00059. Available at http://www.haemjournal.com/external/articles/doi/doi:10.17225/jhp00059) Our ongoing research on transition in haemophilia and bleeding disorders (funded by the Burdett Trust for Nursing) is showing: • Innovations in the development of

					the skills to self manage as well as variations in practice among the centres providing haemophilia care. • That for people with long term conditions, such as haemophilia, they experience a number of transitions throughout their life, of which the transfer from NHS children's services to adult services is one. Our interview programme with young people who have been through transition and parents indicates that those with severe haemophilia who were trained to self manage their treatment experienced smoother transition in adolescence. We are continuing to investigate this. We are investigating optimal age ranges for development of self-management skills, both treatment regime and condition more generally.
27	Haemnet	Key area for quality improvement 2: Improve the transition process for people with non severe haemophilia and other bleeding disorders	Building independence and transition planning are recommended in the NICE guidelines. There are potential health consequences for individuals with non severe haemophilia and bleeding disorders as their engagement with service is more variable. Equality of provision is important	There is greater variability of engagement with health services among people with non severe haemophilia and bleeding disorders. They are less likely to have access to the same opportunities to develop the knowledge and skills to manage their conditions as a result of their patterns of contact with treatment services. The principal focus of services is on those individuals with severe haemophilia. The reduced access to training in the skills to manage their	In our research we heard examples of effective transition practice from individuals but also: • People with non severe haemophilia who were still requiring episodic treatment in adulthood • Young women with Von Willebrand Disease (VWD) who received no training or transition planning • Young people who had started university having no introductions to and contact with new centres • People with non severe who expressed a lack of confidence in managing their treatment regime

				condition can result in less co-ordinated transition planning and potentially more acute presentations to health services later on.	
28	Royal College of Physicians	Key area for quality improvement 4 Empowerment	Our experts believe that services should prioritise engagement of young person's involvement in their care. Our audiology experts also note the following as what is needed in order to support this patient groups to attend appointments: • Flexibility of appointment times and durations in both settings, according to patient need • Deaf awareness of reception staff and specialist training of the adult audiology staff • Follow through after the DNA (the re-referral to the key worker in the NICE guideline) • Access to BSL interpreter or sign support		
29	SCM3	Key area for quality improvement 1 1.1.3: Transition support identifies the support available to the young person.	NICE guidelines 1.1.3 - Ensure transition support identifies the support available to the young person, which includes but is not limited to their family or carers 1.1.4 – Use person-centred approaches to ensure that transition support: addresses all relevant outcomes, including those related to education and employment, community inclusion, health & wellbeing including emotional health, independent	These are my experiences of transition for my severely disabled son and other parents in my borough. I apologise for the personal approach which may not necessarily be easily evidenced. In my experience as a carer I have found that available options have sometimes been excluded for my child and this is at times based on a professional's assumptions that the disabled child – (1) will not be able to work so only day services are offered (a group of	

			living and housing options 1.1.6 – Service managers in both adults and children's service, across health, social care and education, should proactively identify and plan for young people in their locality with transition support needs. 1.2.14 – Include information and signposting to alternative non-statutory services, including condition –specific support services, in transition planning. This may be particularly important for people who do not meet the criteria for statutory adult services.	17 parents on facebook had not been told of the education option for those with lower levels of learning) (2) it is too expensive so it isn't offered, (I hear social workers telling parents this) (3) it doesn't exist in borough (but does exist out of borough and is available but is not offered so families are not aware), (4) protocols set by government are not pointed out to the family so it is up to the parents or young person to find out provided they are able to or know where to look, and (5) parents together with supportive professionals still have to argue every reason for accessing a particular service especially for post 18 education. (6) some professionals continue to argue that a service is either not available or not suitable despite the opposite being true. Every disabled young person should be valued. Every disabled young person should have a reasonable offer of some kind of service. They deserve some quality time with a good service provider. If it is not possible then an alternative solution should be found either using that option (eg less hours, or spread over 5 days rather than just 2, or looking at other services that are very similar).	

				Young people deserve and can have an improved quality of life and should not have to live at home full time or part of the time because of no alternative offer. When services are in place then parents can gain their own quality of life including education, training or work without having to sit at home looking after their disabled children. I have 4 days of day service and one at home – there should be alternatives as it is exhausting looking after someone with complex needs. Young people who do not meet the criteria can still have quality of life and also self esteem when offered other services that are available to them. I had to insist on my son having two separate day services out of term time (as well as an out of borough residential college in term time) otherwise I would be looking after my son at home. The out of borough residential college was on the Approved List on the .Gov.uk website that the Local Authorities listed are allowed to consider. Young people should not be left without any services.	
30	SCM4	Key area for quality improvement 4 Encouraging independence in health	Proactively encouraging independence of the young person. Addressing parents concerns so that they feel confident in supporting young people to see	In studies lone consulting has been associated with increased transition readiness, improved QoL and more likely to attend appointments in adult services. It also allows safeguarding	Predictor of improvement in HRQoL during transition at 6 months McDonagh JE et al 2007 Determinant of Transition Readiness: Perceived self-efficacy in skills for

		care working with young people and parents	health care professionals by themselves.	and important aspects of health screening.	independent hospital visits Van Staa A et al 2011 Determinant of attendance at 1 adult clinic appointment Reid GJ et al 2004
31	The Haemophilia Society	A resource of all the common questions	There are often lots of questions young people have as they begin to take responsibility for their care and learn more about joint decision making in adult care. They often want answers quickly and don't want to cause problems by asking their health care team. Our members felt an easy to access resource with disease specific information with localised information could be key to a positive transition and wasn't something they had access to.	Our members tell us they would have liked information on what you can expect from an appointment, how to access help if you need it and people to contact. This could also include 'your rights'. This would probably be online and localised to your centre, but with some national standards	
32	The Haemophilia Society	Making the most of a teachable moment	We know that many young people have a great deal of support and direction in their daily lives and this can change when you become an adult and particularly when you have a long term health condition. At this point in someone's life it could be very beneficial to look at self-management of daily activity levels and movement abilities equally. This is particularly relevant to people with a disorder that impacts mobility, but relevant to all. As long term users of healthcare, being fit, mobile and physically active will be beneficial to their general health and using this moment of becoming independent could be a key point to teach more about this.		

Involvement – involving parents and carers					
33	NHS England	Key area for quality improvement 2 The importance of delivering a transition service that also takes into account the needs of parents and carers.	Whilst transition is often focused around the needs of the young person, it should be noted that the parents and carers are also often undergoing their own transition as they come to terms with change to the way that they support and engage with the young person's condition. Parents have separate needs that should be accounted for in the development of any transition and young adult service especially in the way that they are communicated with, the information that they need and how it is provided as well as in support of the parallel transition that parents often make. Engaging well with and supporting parents and carers at this time can help to assist the young person through the transition process and add value to the service that is being provided.	Advice and support should be offered to parents and carers, about other services and support that they may be entitled to including entitlements specified in the Care Act 2014. Good outcomes have been achieved where clinics have implemented models in which there is a gradual and well planned move away from joint consultations, where the young person has the opportunity to have independent sessions with clinicians and where there is a specific service to meet. Parents and carers have been successfully engaged where information is provided specifically to the parent to address the issues that they are likely to face, in formats or using methods that are familiar and accessible, including the provision of separate consultation sessions. The NHS Five Year Forward View made a commitment to better supporting carers and recognised the crucial role that carers can play in supporting those with long term conditions, as well as the importance of good engagement, information to and involvement of families and carers. The findings of engagement undertaken jointly by NHS England and diabetes UK in 2015 with young	The Care Act 2014. Care Quality Commission (CQC) - From the Pond into the Sea NHS Five Year Forward View The great divide: Transition care from child to adult mental health NHS England Diabetes Transition Service Specification

				people supported the need for good engagement with in information provision to, parents and carers. Advice and support should be offered to parents and carers, about other services and support that they may be entitled to including entitlements specified in the Care Act 2014.	
34	Royal College of Paediatrics and Child Health	Key area for quality improvement 3 Involvement of Parents and Carers	Parents tend to want to remain involved in their child’s care beyond adolescence, but are often not welcomed into the Adult services.	Some transition clinics allow parents to be present as well as allowing young people to have time on their own with the professionals.	Ready Steady Go enables parents to express their wishes before and during the transition process, but better coordination of the care is needed, with a key worker ensuring that their wishes are taken on board by the clinic staff.
35	Together for short lives	Planning for the future	Every young person should be supported to plan proactively for their future. They should be involved in ongoing assessments and developing a comprehensive holistic plan that reflects their wishes for the future.	Stepping Up, Together for Short Lives, 2015 states that regular multi-agency assessments and a multi-agency transition plan are vital to ensuring that a young person experiences a smooth transition to adult services. During this change of focus from family-centred care to a young person-centred approach, professionals should also work with families to support them to ‘let go’ and support young people to build their confidence and ability to make decisions. Stepping Up measures this standard using four service goals: 1. Young person and their family are helped with transition from family centred to young person-centred care 2. Young person has a key worker to facilitate continuity of care and transition to adult services	

				3. Young person is supported to consider future plans, supported by ongoing multi-agency assessment 4. Young person supported top identify adult servicers which can meet their needs	
Support before transfer – introduction to adult services					
36	British Thoracic Society	Key area for quality improvement 1	MDTs / Age at which transition starts and how it is introduced/key worker	Adult and children's Multidisciplinary teams (MDTs) for complex areas such as assisted ventilation. Care should be staggered and gradual with progress monitored via joint MDTS. For patients moving to different hospitals / regions care needs to be coordinated, with adult physicians meeting early to discuss care needs before transition occurs, eg via bi-annual MDTs This would allow planning for when and how transition occurs. There is a need to encourage transition clinics for young adults with chronic medical conditions: 'Young adults with chronic medical conditions requiring on-going specialist care should attend a transition clinic at which adult and paediatric teams are present'	
37	The Haemophilia Society	An introduction to the MDT team you may benefit from meeting should be part of the transition process (such as a gynaecologist for women with a bleeding disorder).	This is often a point where new members of a clinical team become involved as people move into adulthood. Meeting people at the point of transition can help with confidence in asking for their involvement at a later date.	Members tell us they didn't know there may be other people who could help them and they didn't have access as a child, despite having problems. For women with bleeding disorders this is particularly related to the menstrual cycle and reproduction. An introduction and early referral could be key to positive health and education attendance.	

Support before transfer – personal folder					
38	Haemnet	Key area for quality improvement 3: Improve transfer support that facilitates building of service users' relationships with their adult clinical team	Support before and after transfer is recommended in NICE guidelines. Lack of development of an effective relationship with adult clinicians can result in not engaging with services appropriately. This may result in adverse health outcomes	Good transfer information, preferably patient held, can help to reduce variations in practice. Shared understanding is needed of information that will facilitate the transfer process; between service users and the clinical team.	Our research has shown some examples of effective transfer practice but also identified instances in which: • Individuals arrive in adult clinics where little was known about them beyond their diagnosis (eg family background, lifestyle, personal understanding of their condition and management, all of which are important in bleeding disorders) • Transfer letters appear typically to be passed from doctor to doctor, whilst the clinician to have had most frequent contact with the person is their clinical nurse specialist. • The sharing of notes between paediatric and adult services continues to be affected by the known barriers of information transfer between hospitals. One of our research team members is part of the European Patient Forum Youth Group, which hosted a Roundtable on Transition to Adult Care on 21 March in Brussels. Roundtable attendees included representatives of patient organisations, healthcare professionals, health organisations, family carers, parents' organisations, youth organisations, MEPs, and representatives of Member States. The aim is to develop concrete recommendations that will lead to increased cooperation and

					understanding between young patients and healthcare professionals. The outputs of this work could be an interesting source of information for your team
39	Leeds Teaching Hospitals NHS Trust	Implementation of a Transition Plan for each young person which is linked to all other plans	Evidence indicates that a plan improves patient experience and outcomes Communication tool for all other professionals involved in their care - multidisciplinary teams. Young people jointly develop the plan which also acts as support tool for parents/carers.	Without a Transition Plan there is a potential for many key issues to not be addressed/missed completely Care may become disjointed and young people may become lost in the system Enables the Holistic Approach to care; all professionals aware of what the young person knows and how any issues are being addressed	Coulter et al. 2013 Delivering better services for people with long term conditions. The King's Fund. Shaw et al. 2013. Walking the talk - implementation of Transitional Care Guidance in a UK Paediatric and a neighbouring adult facility. Child Health and Development
40	SCM2	Key area for quality improvement 3 Consideration of a 'health passport' document that young people can carry with them	Young people can struggle to tell their story repeatedly, and may not realise that professionals do not have relevant information about them. Young people of 18 and 19 are highly mobile	Many older adolescents will be leaving home either to live with partners, study or because of family breakdown. Key information about their healthcare needs can be lost. An electronic document which could be stored on a smartphone and carried by the young person would allow them to decide who can access this information.	
Support before transfer - expectations					
41	Royal College of Physicians	Key area for quality improvement 2 Expectations	Our experts note the importance of all three parties, patient/family, discharging team, and receiving team, having shared and equal expectations of care.		
42	Royal College of Paediatrics and Child Health	Reduction in apparent gap between what is provided in adult and paediatric services	Using physiotherapy as an example, young people with cerebral palsy are seen regularly during school years and therapy is	From being well- supported, the young person may new feel abandoned as do parents. This is a poor start to their experience of adult	See care commission report

			built into school timetable. When the young person moves on to college, university, work experience, or community based day- care, this cannot be continued because of lack of resources, facilities and staff. The focus is now on self-directed therapy or left to parents/carers.	services and will affect relationship with and engagement with adult services. Transition should involve a slow change of emphasis if adult services truly do not have the resources to continue the same level of support or if there is quality evidence that this high level of support is not beneficial.	
43	SCM3	Key area for quality improvement 5 Information about services and what is available (to be updated and) given to families.	NICE guidelines – 1.3.4 – All children's and adults services should give young people and their families or carers information about what to expect from services and what support is available to them.	My experience has been that information may currently be either lacking or inconsistent or not up-to-date. Commissioners, managers and services need to be encouraged to produce information, preferably at least in leaflet form that can be accessed by families and professionals working with the families so that everyone has access to some information. Services need to be encouraged to keep their information updated rather than not providing it at all or purely by word of mouth! Families can then be reassured that they have up to date, current information, about services they can access (rather than nothing at all as sometimes has been my case). Professionals also need to be encouraged to follow standard business practice for example if making a decision they then send a letter to the family and a copy to the service to confirm what has been	

				decided.	
44	Together for short lives	Multi-agency support	Every young person should be supported in adult services with a multi-agency team fully engaged in facilitating care and support. The young person and their family have been equipped with realistic expectations and knowledge to ensure confidence in their care going forward.	It is commonplace for there to be multiple healthcare, education and social care professionals involved in supporting a young person with a life-shortening condition. Within adult healthcare, there are likely to be a number of professionals from a range of different specialties with no equivalent of the holistic care provided by a paediatrician. Together for Short Lives' Transition Taskforce found that co-ordinating this number of professionals can be burdensome for the young person and/or their family. We support the inclusion of the 'named worker' in the new guidelines and believe that the inclusion of a named worker in a young person's transition plan, from both children's and adults' services is an important indicator in evaluating whether adequate transition support is being offered. Stepping Up measures this standard using eight service goals: 1. Key worker provided for each young person 2. Age and developmentally appropriate services are available that address full range of young person's needs 3. Palliative care services provide single clinical overview for young person and link with other specialists 4. Frequent review and	

				communication across services about care plans and end of life decisions 5. Primary health care services, including GPs, develop relationship with young person and their family 6. Adult services in secondary care make sure there is appropriate lead clinician to take responsibility for young adults 7. Short breaks are considered and are provided in an appropriate setting 8. Parents included as appropriate	
Support after transfer – non-attendance					
45	Children's Liver Disease Foundation	Identifying young people at risk of non-adherence pre transition/during transition	One of the main aims of a successful transition is maintaining the adherence of a young person to their treatment regime. Medical outcomes can be heavily influenced by this. There needs to be identification of those at risk of becoming disengaged prior to transition to ensure this doesn't happen.	The experience of CLDF has led to the inclusion of this area for improvement. It is clear from those who access our support services that for a number of individuals support is not available for the young person at the right time which can lead to disengagement and a lack of adherence.	Links have been proven between poor transition and graft outcomes in liver transplantation: Annunziato RA, et al (2007) Adherence and medical outcomes in pediatric liver transplant recipients who transition to adult services. Pediatr Transplant 11(6):608–614 Similar studies are available regarding other organ grafts.
46	Newcastle University Institute of Health and Society	Key area for quality improvement 3 Patient not lost to follow-up. Children who need to transfer to adult services should be seen in the adult service within 6 months of transfer	In a recent Delphi exercise, 91% of respondents said this was an essential indicator. Other indicators only had 30% to 60 % agreement. Suris JC, Akre C. Key elements for, and indicators of, a successful transition: an international Delphi study. J Adolesc Health. 2015; 56:612-8.	One attraction of this standard is that it should encourage change to the current prevalent practice in adult health services that if you do not attend outpatients, you are discharged. This is not appropriate for individuals with long term conditions in this age group. This could be an important role for the 'Named Worker'.	
47	SCM1	Key area for quality improvement 5	The NICE GDG identified that when a young person disengaged or did	GPs often have community opportunities to re-engage young	Advocacy – The Care Act 2014

		Communication	not meet threshold for adult services the GP may be their only contact. Communication is essential for this to be an effective gateway to re-referral. Young people may communicate in a variety of styles, and have varied understanding.	people, or monitor health/ support needs. For a transition process to be person-centred, communication must take place in the young persons preferred style of language, and account for their level of cognitive understanding. This will impact on the time scale of the process as well as the structure of meetings.	
Services – joint planning					
48	Association of British Neurologists	Key area for quality improvement 2 Improvement of transitional care for patients with epilepsy and mental health problems	A significant proportion of young patients with epilepsy have mental health problems	Better coordination of care and communication between CAMHS and AMHS and epilepsy services – currently disjointed and not communicating effectively/ based in separate structures of care. Psychiatric comorbidities are a recognised risk factor for premature death in epilepsy	Transitions in mental health care- Young Minds Premature mortality in epilepsy and the role of psychiatric comorbidity: a total population study Fazel S, Achim W, LångströmN et al. Lancet 2013; 382: 1646–54 https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf
49	Association of British Neurologists	Key area for quality improvement 3 Improvement of transitional care of epilepsy patients who may benefit from epilepsy surgery assessment	There is good evidence that epilepsy surgery performed early in appropriately selected cases of medically refractory epilepsy results in better educational, occupational and psychosocial outcomes and prevents chronic disability. Patients reaching transitional age should be seamlessly transitioned from Paediatric to Adult Epilepsy Surgery Programme so that their presurgical assessment and postoperative care are not delayed.	There is a good chance of achieving excellent seizure and quality of life outcomes in this group of patients. Due to the variation in waiting lists (often long) for epilepsy surgery assessment it is important that accredited Paediatric Epilepsy Surgery Centres have robust transitional links with the Adult Programs to transition patients between the Teams – transitional adult epilepsy surgery neurologist and epilepsy surgery nurse would facilitate this	“Epilepsy surgery in children and adults” Ryvlin P, Cross H, Rheims S. Lancet Neurology 2014. https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=3&cad=rja&uact=8&ved=0ahUKEwjI3se7kvrLAhXCYQ8KHZgKC3sQFgg4MAI&url=http%3A%2F%2Fwww.thelancet.com%2Fjournals%2Flaneur%2Farticle%2FPIIS1474-4422(14)70156-5%2Fabstract&usg=AFQjCNF8xd4qmFqPbYIyIlQ47QIo48sq7Q https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=17&cad=rja&uact=8&ved=0ahUKEwjWn5GrlPrLAhVDcA8KHfTLAuo4ChAW

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50	Genetic Alliance UK	Poor communication and coordination between different healthcare providers	People affected by rare conditions often have to see many different specialists who can be located across different departments and treatment centres.	Patients and carers told us that communication between different healthcare providers is not always consistent. This is a known barrier to receiving high-quality care for many patients with rare conditions but is further exacerbated during periods of transition, especially from paediatric to adult services. As a result, parents and carers often have to shoulder the responsibility of coordinating their child or loved one's care during transition. Knowing that the hospital, clinician and specialist team that you have been working effectively with is soon to change can be unsettling for the patient as well as their parents, family and carers. This may be the case particularly if you have been receiving care from the same team over many years or have finally got used to a team after a long period of time feeling lost in the healthcare system. As a result many of the parents and families we spoke to told us that they had felt anxious and worried about their child's transition.	Advances in science and medicine have led to better health outcomes for patients living with a rare condition. Patients who previously would not have survived childhood are now living on into adulthood, a fact which should be celebrated. Better treatments mean that patients affected by rare diseases will be requiring a transition plan for the first time and the challenge now will be for healthcare systems in the four nations to develop age appropriate services for these patients. The UK Strategy for Rare Diseases committed to the development of seamless pathways for transition. It suggests that arranging coordinated transition from children's to adults' services should be a minimum standard for specialist centres. In light of this, during summer 2014 we undertook a study to gain a better understanding of the issues faced by patients transitioning from child to adult care. The report based on this work, "Patient experiences of transition between care providers" was published in November 2014, and can be found at: http://raredisease.org.uk/documents/Website%20Documents%20/patient-

					experiences-of-transition-between-care-providers.pdf Unfortunately our work in this area suggests that standard in this area have not greatly improved in the 18 months since the report was published (see eg. Our report "The Rare Reality – an insight into the patient and family experience of rare disease", published January 2016 and available at: http://raredisease.org.uk/documents/patient-experiences-2015.pdf). We are happy to discuss these findings in further detail.
51	Leeds Teaching Hospitals NHS Trust	Improve service provision for young people with complex needs, transitioning through multiple services and organisations	There is evidence that tells us that, due to the complex care provision for this group young people may get lost in the system. Funding does not follow them through the various systems, causing disparities in care. Risk of duplication of work - or missed work	The most challenging part of transition services to get right. Multiple funding streams (i.e education, social care) add to the complexity.	SEND Guidance https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf
52	Newcastle University Institute of Health and Society	Key area for quality improvement 1 Transition should be commissioned. Further, adult and children's commissioners should collaborate around commissioning for Transition and introduce it in contracts for child and adult services.	Poorly managed transition is associated with poor outcomes. Transition is important because there is NICE Guidance about it: 1.1.5 Health and social care service managers in children's and adults' services should work together in an integrated way to ensure a smooth and gradual transition for young people. This work could involve, for example,….. jointly agreed and shared transition protocols, information-sharing protocols and	Transition is rarely formally mentioned in contracts. Although we have not yet published it, our research with commissioners confirms that they usually do not mention it specifically in contracts and often do not regard Transition as a priority.	

			approaches to practice.		
53	Newcastle University Institute of Health and Society	Additional developmental areas of emergent practice 1 Additional rehabilitation physicians should be appointed with sufficient time to receive from children's services young people with complex conditions such as cerebral palsy and to subsequently coordinate their care.	This is specifically mentioned in the NICE Guidance: 1.5.10 Consider joining up services for young people who are involved with multiple medical specialties. This might include a single physician, such as a rehabilitation consultant, taking a coordinating role.		
54	NHS England	Key area for quality improvement 1 There is evidence to demonstrate the importance of recognising mental health as a key issue to be addressed in transition and that it is something which should transcend all approaches to supporting transition.	Mental health has shown to be a significant co-morbidity in conditions such as type 1 diabetes, and at the same time, good emotional and mental well-being and support at this time, provided through quality transition services, can promote vital resilience. Timely and ongoing access to mental health professionals should be integral to any diabetes transition provision for young people and their families or carers. Many children and young people suffer more than one co morbidity or long term condition, so could be experiencing multiple service transitions simultaneously. Good quality transition services should therefore work with the individual to develop a transition pathway that is integrated, responsive, and build around the specific needs of the	The importance of mental health and transition is mentioned specifically in Future in Mind and mental health is also featured in the Five Year forward view. A sample specification for contracts and transfer protocol has been published and is currently being updated to encourage commissioners to deliver best practice in this area. Studies on type 1 diabetes have shown a strong correlation between mental and physical health with a high number of psychosocial issues including anxiety and depression, and an increase in of negative outcomes for CYPs including increased HbA1c and a longer gap between young people's appointments. Young people with a chronic	NHS future in mind report - NHS England Diabetes Transition Service Specification - NHS Five Year Forward View for Mental Heath - Transition from CAMHS to Adult Mental Health Services (TRACK): A Study of Service Organisation, Policies, Process and User and Carer Perspectives - SCIE programme materials: http://www.scie.org.uk/publications/introductionto/adultmentalhealthservices/legalandpolicycontexts.asp - Better mental health outcomes for children and young people, a resource pack for commissioners - National Mental Health Development Unit programme materials accessible here - Garvey, K.C., Wolpert, H.A., Finkelstein, J.A. 2013. Health Care

			individual.	condition are also shown to be more likely to engage in risky behaviours such as alcohol and substance misuse.	Transition In Young Adults With Type 1 Diabetes: Barriers To Timely Establishment Of Adult Diabetes Care. Endocr Pract. [Online] 19(6), 946-952. [Accessed 22 October 2015] Available from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4034180/ - Philpot, U. 2013. Eating disorders in young people: development, diagnosis and management. Journal of Diabetes Nursing. [Online] 17(6), 228-32. [Accessed 22 October 2015] Available from: http://www.thejournalofdiabetesnursing.co.uk/journal-content/view/eating-disorders-in-young-people-with-diabetes
55	NHS England	Key area for quality improvement 3 The importance of well planned, timely and coordinated services	In order to enable service users and their carers to become and remain active partners in their care, to prepare for transfer(s) and to engage with a new service, engaging, sensitive and developmentally appropriate care planning should start with the young person and their family from the point of diagnosis. Planning for transfer should begin early and involve the young person whilst they are still receiving paediatric services to support early preparation and maximise the time the young person has to prepare for the changes. A pathway should be agreed between the transferring service	Early preparation and planning for the transition period is essential in managing expectations, promoting understanding and involvement in the wider process, and ensuring that the service user is well informed and therefore empowered. My Care Plan provides a successfully implemented good template for early initiation of transition planning. Examples of good care planning have incorporated the young person's physical development, emotional maturity and local circumstances. Coordination between professionals at all three stages in essential to ensure that the overall transition is	The NHS England Diabetes Transition Service Specification (see above) further evidence can be found in the 'links to other documents and sources of support' section of the service specification. The CAMHS service specification (see above) My Care Plan provides a successfully implemented good template for early initiation of transition planning.

			and receiving services and early as possible to facilitate a smooth and coordinated change. Once the transfer to the receiving service has taken place, services must support integration into adult or new care settings and the design of services must attend to the wider health, psychological, social, educational and vocational outcomes for young people in addition to condition specific outcomes. There should be a focus on enabling optimal health and wellbeing outcomes with young people as they move towards and into adult, specialist services, or primary care services, with close collaboration with GP's and other primary care professionals.	consistent and to avoid variation, particularly where a young person moves to a different geographical location.	
56	Royal College of Physicians	Key area for quality improvement 1 Commissioned MDT service enabling transfer of care for long term conditions from paediatric to adult services	Our experts believe there are major adverse outcomes of vulnerable cohort lost at point of transfer to adult services	This can be utilised for range of LTC areas and can be directly assessed by commissioners	NHS England document on commissioning transitional diabetes services https://www.england.nhs.uk/wp-content/uploads/2016/01/diabetes-transition-service-specification.pdf
57	Royal College of Physicians	Key area for quality improvement 3 Continuity	Our audiology experts note that there are some areas where young people have to change to a different make or model of hearing aid when transferring to the adult service, which is very difficult for them (often at a time when they are also going to university or away from home). There have been cases where these patients persist with an old hearing aid until it stops		

			working and so are left with one that may be outdated or broken. This is due to lack of collaboration between services, funding, training, and technical support. Our experts believe that the NICE guideline re 'joint protocols/pathways', 'gap analysis' and 'pooled budgets' can improve this situation, but that it will take time.		
58	Royal College of Paediatrics and Child Health	Joint working between clinicians and therapists in children and adult services	There are groups of young people growing and maturing with conditions that adult health services have little experience of. This is a result of the high quality care that children have received resulting in longer survival with hopefully a reasonable quality of life. This benefit is due to respiratory care and support, and nutritional support in particular.	It is unrealistic to expect adult services to develop the skills and expertise overnight. These skills are present in paediatric services and there should be the opportunity for paediatric staff to follow the young person into their adult years. It perhaps requires a new branch of adolescent and young adult medicine in the are of chronic neuro-developmental disorders, metabolic disorders etc.	Similar services already exist in oncology, diabetes etc
59	Royal College of Psychiatrists	Young people's participation in planning transition services	Experience from CYP-IAPT shows that young people's involvement in service planning is a key driver in quality improvement.	Surveys of Local Transformation Plans (Health Watch England and NHS-E) show that the extent to which young people participated in the development of LTPs was very variable. LTPs will be key drivers in improving transition arrangements in England	
60	SCM1	Key area for quality improvement 3 Joint commissioning	In a time of austerity, alongside legislative change about 0-25 services, NICE guidance states that effective commissioning must be financially and practically fit for purpose, to address the needs particular to individuals in transition.	Service contracts vary across areas, and disciplines, leading to challenges to smooth transition. Waiting times may be a challenge, as are referral criteria in children / adult services. Developmental appropriateness may be an issue, particularly around staff training and involving family/carers/advocates. Gap	The Care Act 2014

				analysis and anecdotal knowledge will identify gaps in support and treatment options. This may be due to low levels of need, but will still leave some individuals without a support network	
61	SCM2	Key area for quality improvement 1	Treatment for children, young people and adults with ADHD is recommended by NICE. However waiting lists for adult ADHD treatment can be as long as two years	ADHD is associated with high levels of comorbidity e.g. increased rates of depression and anxiety and substance use. It is also linked to higher rates of offending and early morbidity. Untreated ADHD in young adults impacts on the individual, their families and society	Nobody Made the Connection https://www.childrenscommissioner.gov.uk/sites/default/files/publications/Nobody%20made%20the%20connection.pdf
62	SCM2	Key area for quality improvement 2 Development of transition services working with people between 16 - 25	Young people develop at different rates, health problems can impact on young people's development of adult skills.	Thus sometimes the most vulnerable 18 year olds can find themselves trying to navigate adult services.	NICE - Transition from children's to adults' services
63	SCM3	Key area for quality improvement 2 1.1.5 Working together in an integrated way.	NICE guidelines – 1.1.5 – health and social care service manager in children's and adults' services should work together in an integrated way to ensure a smooth and gradual transition for young people.	As a carer I have found that services do not always join up and share, resulting in gaps, some young people do not get services or the young people are not identified on any lists and seemingly disappear of the radar until another service (like Learning Disability Team) somehow identify the young people needing a service. Parents and young people have a lack of information about services, or else are given a widely varying mix of information. There seems to be an apparent lack of services (but which at times is only perception or a reluctance by some professionals to promote those	Children and Families Act 2014 National trends. Local trends. ?Office for National Statistics?

				services). Working together could help in identifying knowledge gaps and missing services and provide training to all involved. Sometimes information is not released because it is not seen as being "perfect" so it is not released, or sometimes is never released, especially when professionals then move on to another role or another post the gap remains. In my experience health services think they are working in a joined up way but often miss off disabled young people. In adult services health is split into individual departments each of whom aim to discharge everyone unlike in children's service where one person, usually the consultant paediatrician acts almost as a named person or keyworker or co-ordinator dealing with health issues themselves or else signposts to other relevant health services. In children's services children with complex needs are not discharged after each appointment in the different departments but only at approximately age 18 when moving to adult services. Adult services needs to work in the same way to support complex needs and ensure good health outcomes. National trends show that young	

				people with disabilities and/or with learning disabilities already die younger than the national average of those without disabilities; and in some boroughs (like Sandwell) those with disabilities/learning disabilities die even younger than the national average for disabilities. Because of this it is even more important that the health services are properly co-ordinated and work together with social care and do not miss any young people through their aim of discharging everyone every time they are seen.	
64	The Intensive Care Society	The ICS urges early, consistent and open dialogue between paediatric and adult critical care services about children who may require adult critical care after transition. This may be conducted at unit level but the involvement of relevant operational delivery networks is also recommended. This is important because of the cultural differences between child and adult critical care services and because of the large resource considerations."			
65	Together for short lives	Joint working	Children’s and adult services should actively work together to enable a smooth transition.	For the past two years, Together for Short Lives has run a series of workshops on the implementation of the SEND reforms. During these sessions, commissioners from CCGs	

				and local authorities, as well as service providers and service users, have regularly reported disparities in how well children's and adult services work together to support transition. Whereas in some areas commissioners reported strong relationships between children's and adult services, many others reported that communication barriers remain and that some commissioners in adult services to not realise that transitions for young people falls within their remit. Stepping Up measures this standard using three service goals: 1. Child and adult services work together so there is overlap of care planning and provision 2. Services within all agencies engage in planning for specific needs of young person 3. Ongoing reviews (at least annually) take place with young person	
Services – developmentally appropriate service provision					
66	Barbara Ansell National Network for Adolescent Rheumatology	Key area for quality improvement 1 Provision of age and developmentally appropriate adolescent and young adult appropriate care immediately post transfer and into young adulthood	The guidelines as they stand are biased to transition as focused around transfer. They are therefore biased to the needs of those in early-mid adolescence (10-17 year olds). They ignore or do not explicitly address the important needs for older adolescents/young adults (18-24 year olds) where current adult models of care are more often than not inappropriate. It also therefore does not address the	Adolescence is a unique developmental period dominated in early/mid adolescence by puberty but in later adolescence/young adulthood by neurocognitive development in the frontal lobe of the brain with regard to adult 'executive' functions such as long term planning, abstract thought and impulse control. It is therefore a time where patterns of health service usage and non-communicable disease/prevention are set. Failure to	The Royal College of Physiscians has recently made extensive study of the issue of young adult care and is excellent reference tool https://www.rcplondon.ac.uk/guidelines-policy/acute-care-toolkit-13-acute-care-adolescents-and-young-adults

			needs of newly presenting 16 year olds in adult services. Recent evidence confirms; Compared with older adults, adolescents and young adults report: • being less satisfied with their care • being less likely to feel involved in their care • having less confidence and trust in their doctor • being less likely to feel that they are treated with respect and dignity	continue age and developmentally appropriate services in the longer term, post-transfer period risks disengagement of young adults and consequent morbidity. The quality improvements must be explicit about continuing age and developmentally appropriate care well into young adulthood and not just the immediate post transfer period. For example 1.4.4 Ensure that the young person sees the same healthcare practitioner in adults' services for the first 2 attended appointments after transfer. This is a very short term immediate post-transfer focus and should be extended to a commitment to longer term continuity of care and therefore support to young adults	
67	Barbara Ansell National Network for Adolescent Rheumatology	Key area for quality improvement 2 Staff training in age and appropriate care of adolescents and young adults	In order to tailor pre, inter and post transfer transition care all health care practitioners need training in the unique aspects of the adolescent and young adult developmental stage. This is sadly lacking in healthcare professional training and reflected in experiences of adolescents and young adults in their care	Easily available training packages are accessible and staff training is both a ‘quick win’ but also a solution to the cultural challenges of transition and adolescent/young adult care as per the recent CQC report ‘ from pond to sea’ https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report_Summary_lores.pdf	This is an excellent, easily accessible generic training package freely available to healthcare practitioners http://www.e-lfh.org.uk/programmes/adolescent-health/
68	British Thoracic Society	Key area for quality improvement 3	Young adult hospices	Number of Children’s hospices provides support for children and carers and enables a community approach and respite for carers in a safe environment. Adult hospices are not suitable in view of disease profile and facilities available.	
69	Children’s Liver	Equity of transition	When asking young people of their	This suggestion is again based on	The NHS constitution states that

	Disease Foundation	provision needs to be achieved and maintained	experiences of transition CLDF has received a wide variety of responses from those who had received a full transition programme including joint clinics with children's and adult centres and transition information days to those who underwent no activities to support the transition process. This leads to a lack of equity in care and provision.	CLDF experience of supporting young people undergoing transition and the answers of a recent questionnaire regarding transition have been utilised.	"NHS staff must contribute towards providing fair and equitable services for …..helping to reduce inequalities in experience, access or outcomes between differing groups or sections of society requiring health care".
70	Genetic Alliance UK	A patient's individual circumstances are not always considered during transition	Most clinical transitions happen during teenage years when there are a lot of other important events taking place in an individual patient's life, including taking exams and moving schools, or starting college or university. Patients told us that undergoing transition between health services at a different time makes it easier for them to manage. Many of the patients and families we spoke to wanted to see the specific circumstances of their family given more consideration in the planning of transition. Care doesn't start and stop with hospital appointments and trips to consultants. Many patients also require support from social care providers. As their healthcare needs change during transition so too will their social care needs. As a result, it is critical that the transition of both social care and health care take place at the same time.	It was felt by many patients and carers that the transition between paediatric and adult services can occur too suddenly and sometimes even without warning. There was agreement that programmes or facilities that aid a more gradual process of transition would be preferred by patients and their families, with some patients having the benefit of being able to speak from personal experience. For those whose experience of transition had been abrupt, they felt that a more staged approach would have avoided what otherwise felt like a disconcerting step-change in their healthcare provision that was difficult for themselves and their family to adapt to. 80% of rare diseases have a genetic component and because of this, it is not uncommon for more than one family member to be affected by the same condition. This can mean that there might be multiple members of the same family who will need to transition from one healthcare	See above.

				provider to another at some stage. In some cases parents and families felt there can be merit in waiting so members of the same family can transition together.	
71	Genetic Alliance UK	Age-appropriate services are not always available	In some cases, the lack of an appropriate service for adolescents means that patients are being forced to transition into adult services earlier than they should be. Patients and their families were particularly concerned that necessity is often the trigger for transition rather that it being what was best for the patient.	Patients told us that clinical consultations often focus on the clinical and physical needs of the patient, which doesn't give them the chance to voice their concerns and put in place a plan for transition that takes into account other issues of importance to them. For example, in the report mentioned above we discussed the experiences of Debra's daughter, who has haemophilia. A lack of appropriate services for managing adolescents with this condition means that her daughter has had to transition prematurely to adult services for some of her care, while still being treated as a child in a different hospital.	See above.
72	National Paediatric Respiratory & Allergy Nurses Group	Key area for quality improvement 1 Improved resources in adult services for continued assessment and monitoring of long term respiratory conditions such as asthma, beyond transition to adult services (including General Practice)	Ongoing support, education, & assessment reviews are vital for self management and symptom control.	Secondary/Tertiary care is provided for children & young people with long term conditions (e.g. asthma) at a level that does not meet the criteria for Secondary / Tertiary care in Adult Services. Patients are often transitioned to the care of their General Practice and the frequency of follow up reviews varies considerably between children's and adults' services. Children's health services follow a 'Was Not Brought' policy for non attendance of appointments but patients can disengage with adult services after	Please refer to the Royal College of Physicians National Review of Asthma Deaths 2014

				missing an appointment. The National Review of Asthma Deaths highlighted that 57% of people who died of asthma were not receiving specialist supervision for the previous 12 months.	
73	National Paediatric Respiratory & Allergy Nurses Group	Key area for quality improvement 2 Improved inpatient and outpatient services for young adults	Young people with difficult asthma remain under paediatrician/paediatric services until 19 years old because of complex needs.	If the young person needs to be admitted to hospital due to an exacerbation of asthma, they are admitted to an adult ward-under the care of adult physicians who are not yet known to the young person. This issue needs to be addressed as it is equally inappropriate for young people over 16 to be nursed on paediatric wards. There are not enough adolescent units in secondary care settings to address this need.	Colver AF et al, Study Protocol: Longitudinal Study of the transition of young people with complex health needs from child to adult services. BMC Public Health 2013: 13:675
74	NHS England	Key area for quality improvement 4 The importance of effective engagement and developmentally appropriate services	Valuing the expertise of the young person in their own health and wellbeing is crucial at this time, when young people can be very susceptible to disengagement from traditional services. Transition and young adult Services should be provided in a flexible, welcoming and appropriate environment with a variety of methods available for Service Users to interact with based on their personal needs and preferences. Good services should provide active and accessible opportunities for engagement that are relevant to Service Users lifestyles and level of		

			development.		
75	Royal College of Nursing	Key area for quality improvement 2 Provision for young people on adult wards after the age of 16 years	Provision for young people on adult wards after the age of 16 years is a key area of concern. Adult wards are often unsuitable and frightening places for children and young people (e.g. there might be people with dementia or alcohol/drug abuse in the adult wards) and staff are not familiar with the specific needs of young people.		Transition from children's to adults' services for young people using health or social care services. http://nice.org.uk/guidance/ng43
76	Royal College of Physicians	Key area for quality improvement 5 Training	Our experts note that receiving team doctors should have training in young people's care including communication skills.		
77	Royal College of Paediatrics and Child Health	Key area for quality improvement 2 Involvement of Young people themselves.	There are examples of good practice, e.g. Ready Steady Go in Southampton, but services often do not have the capacity to devote sufficient time to the transition process, and do not have the right environment either.	There are few hospitals which have specific designated clinic areas for adolescents, let alone young adults. Therefore, young people have to choose between Paediatric clinics which cater mainly for toddlers and young children, and Adult clinic areas, which are dominated by the elderly.	Some adolescent units are provided in large trusts eg Queen Elizabeth hospital in Birmingham, but only for certain specialities such as haematology/oncology. The average DGH would only have 6-10 young people as inpatients at any one time, under the care of many different specialities, therefore very difficult to provide designated inpatient or outpatient facilities.
78	SCM4	Key area for quality improvement 3 Clear evidence of trusts and services meeting the needs of young people in children's and adult services	Developmentally appropriate health care is called for by young people, defined by You're Welcome and described in the NICE guidance and would be an important quality standard. This includes staff training.	Much talked about but rarely delivered. The fact that we focus too much on the process of transition means that we fail to provide quality care. If we provide quality care transition would probably be less of an issue. Clear evidence of this would prevent young people being invisible among younger children or older adults.	Farre A, Wood V, McDonagh JE, Parr JR, Reape D, Rapley T; Transition Collaborative Group. Health professionals' and managers' definitions of developmentally appropriate healthcare for young people: conceptual dimensions and embedded controversies. Arch Dis Child. 2016 Mar 4. doi: 10.1136/archdischild-2015-309473. [Epub ahead of print]. Farre A, Wood V, Rapley T, Parr JR,

					Reape D, McDonagh JE. Developmentally appropriate healthcare for young people: a scoping study.Arch Dis Child. 2015;100:144-51
Additional areas - Ownership					
79	Newcastle University Institute of Health and Society	Key area for quality improvement 2 Chief Executives and senior managers in health and social care organisations should own the policy on Transition and ensure the policy is followed by all business units within their organisations.	This is specifically mentioned in the NICE Guidance: 1.5.1 Each health and social care organisation, in both children's and adults' services supporting young people in transition, should nominate: one senior executive to be accountable for developing and publishing transition strategies and policies; one senior manager to be accountable for implementing transition strategies and policies.	Few NHS Trusts have across Trust ownership of a Transition policy. Most developments have been introduced in certain specialties by committed individuals, rather than as a result of a Trust wide expectation. Improved Transition practice will never be sustainable if only delivered in the short term by enthusiastic clinicians and field workers.	
80	Royal College of Physicians	General	Our audiology experts believe the involvement of senior trust executives is key to driving the changes required (and inclusion in CQC inspections)		ADD IN PICTURES
81	SCM1	Key area for quality improvement 4 Equality of service responsibility	Managerial responsibility and ownership of young people entering a transition stage, to support the day to day needs of a personalised approach. Recognised as a challenge by NICE guideline.	Shared vision, protocols, policies are needed. Accountability for non-attendance at 'new' adult services should be shared by children and adults teams.	SEN code of practice 2014
Additional areas – data					
82	British Society of Gastroenterology	Key area for quality improvement 1 IT systems within services should be able to easily identify the young people that need annual transition plans	In order to effectively plan and deliver transition it is imperative that the population that needs this can be identified easily and this may not be a simple task for all specialities across the board	As before	

83	Royal College of Physicians	General	Our experts propose some additional audit questions for the next cycle of our national transition audit in Audiovestibular Medicine (BAAP) to reflect the NICE guideline. These are included under supporting information to show how this might be included in a quality standard. (The previously covered questions were adapted from the NDCS and NHS Scotland Paediatric Audiology Transition guidelines).		
84	SCM4	Key area for quality improvement 1 Tracking of patients undergoing transition and transfer up the age of 25	Need to improve transition is linked to studies demonstrating lost to follow up and increased morbidity and mortality. Unless we start measuring quantitatively young people passing through transition and getting to their destination of adult services and engaging there will be no drivers for change for services and trusts. I am thinking a similar model to the A&E or cancer targets. This could include DNA rates, unplanned admissions and time to first appointment in adult services etc. Some specialties could track markers of disease control as well	This will ensure that this is discussed at every level of the organisation and services will be supported to improve the process. Also useful for commissioning. In the absence of evidence as to the ideal model this ensures that quality improvement is ongoing.	Recommended in the NICE guidance Information on other targets etc Paper on measuring transition Prior et al. Pediatrics December 2014
85	SCM4	Key area for quality improvement 2 Real time patient reported experience of the process of transition and transfer at key time points	Need to improve transition is linked to reports of dissatisfaction e.g. the CQC report from the pond to the sea. Patient reported experience at four time points are key – early, mid and late adolescence and young adulthood – would ensure that each stage is addressed – this could reflect the aspirations of the NICE	Similar to friends and family this will enable trusts and services to monitor and benchmark their progress. In the absence of evidence as to the ideal model this ensures that quality improvement is ongoing.	

			guidance – who is your named worker etc?		
86	Sheffield Children NHS Foundation	Key area for quality improvement 1 IT systems within services should be able to easily identify the young people that need annual transition plans	In order to effectively plan and deliver transition it is imperative that the population that needs this can be identified easily and this may not be a simple task for all specialities across the board	As before	
Additional area - scope					
87	Association of British Neurologists	Key area for quality improvement 1 Improvement of transitional care for patients with epilepsy and intellectual disabilities	Patients in this group often have complex problems including: - refractory epilepsy, - communication and behavioural problems - neurological deficits They often require a complex package of multidisciplinary / multiagency care. The risk of SUDEP in patients with epilepsy and intellectual disability is increased across all ages. Ensuring seamless transition of specialist care and support is essential to reducing this risk. They often are a neglected group and setting up standards to ensure access and equality of care is essential We wish to support the efforts of International League Against Epilepsy Task Force on Intellectual Disabilities and the International Bureau for Epilepsy to increase awareness and improve standards of care in this area.	Appropriate transition of patients sets the scene for years of adult care to come. Failure to do this properly and engage with young patients and their families: - increases risk of poorly controlled epilepsy - Increases risk of seizure-related morbidity and SUDEP - adversely affects psychosocial and educational outcomes - risks inefficient use of resources and poor coordination of care / poorly defined lines of responsibility for care. The providers of care for young patients reaching transitional age (Pedaitricians; Paediatric Neurologists) and transitional arrangements vary across the country.	“Listening for a change. Medical and social needs of people with epilepsy and intellectual disability: A joint report of the International League Against Epilepsy Task Force on Intellectual Disabilities and the International Bureau for Epilepsy” . Kerr M, Thompson R, Linehan Ch, et al on behalf of ILAE Task Force. 2013. “Delivery of epilepsy care to adults with intellectual and developmental disabilities” . Devinsky O, Asato M, Camfield P et al. Neurology 2015; 85: 1-10. “A White Paper on the medical and social needs of people with epilepsy and intellectual disability: The Task Force on Intellectual Disabilities and Epilepsy of the International League Against Epilepsy”. Kerr M, Linehan Ch, Thompson R et al. Epilepsia. 2014: 55:1902-1906. “Does intellectual disability increase sudden unexpected death in epilepsy (SUDEP) risk?” Young Ch, Shankar

					R, Palmer J et al. Seizure 2015; 25; 112–116. https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf
88	Association of British Neurologists	Key area for quality improvement 4 Ensuring ongoing discussion of key topics that affect seizure control and risks	The topics that should be systematically discussed during transitional period include: -adherence to antiepileptic medication -risks of seizure related injuries and SUDEP -driving -occupational safety -life style factors affecting epilepsy - contraception - awareness of teratogenic effects of antiepileptic drugs particularly review of indications for. valproate	The relevance of this topics increases as the young person matures and takes control of their epilepsy Many of these topics have not been introduced before transition to adult epilepsy clinic Information should be offered more than once to ensure its understanding and retention	“TAKING OVER EPILEPSY FROM THE PAEDIATRIC NEUROLOGIST” Philip E M Smith, Sheila J Wallace* J Neurol Neurosurg Psychiatry 2003;74:i37-i4 doi:10.1136/jnnp.74.suppl_1.i37 ILAE document regarding valproate in women and girls https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&cad=rja&uact=8&ved=0ahUKEwjqssrHlvrLAhWDZg8KHVx6D08QFgghMAE&url=https%3A%2F%2Fwww.epilepsy.org.uk%2Fnews%2Fnews%2Fmhra-new-guidance-women-valproate-and-pregnancy-64438&usg=AFQjCNGE4iQ4-kUH-274J1t14p1RQp6HjA MHRA document re: valproate in women and girls https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&cad=rja&uact=8&ved=0ahUKEwjqssrHlvrLAhWDZg8KHVx6D08QFgghMAE&url=https%3A%2F%2Fwww.epilepsy.org.uk%2Fnews%2Fnews%2Fmhra-new-guidance-women-valproate-and-pregnancy-64438&usg=AFQjCNGE4iQ4-kUH-274J1t14p1RQp6HjA “Transition From Pediatric to Adult Epilepsy Care:

					A Difficult Process Marked by Medical and Social Crisis" Camfield P, Camfield C, Pohlmann-Eden B. Epilepsy Currents, Vol. 12, No. 4 Supplement 2012 pp. 13–21
89	British HIV Association	General comments	BHIVA welcomes this quality standard and would like to be sure that HIV infected young people will be included.		
90	Children's Liver Disease Foundation	Transition/additional support for young people who move straight into adult services is essential	There is a subset of young people who bypass the transition stage as they are referred straight to adult services between the ages of 16-18. They haven't been diagnosed with a liver condition until this age. Young people who have undergone this have described issues such as a lack of support, poor communication skills and a lack of understanding of young people. Guidance on how to support this subset of young people is essential.	Feedback obtained by CLDF when consulting with young people and their families has highlighted this as a particular issue.	
91	College of Occupational Therapists	Unique group of transition for people with Learning disabilities.	This is a group that has particular needs that should be addressed. And these should be a focus in their own right.		Transition – Foundation for people with learning disabilities. http://www.learningdisabilities.org.uk/help-information/learning-disability-a-z/t/transition/
92	College of Occupational Therapists	Inclusion of children in a secure setting making transition to adult services.	A child within a secure setting with a past of offending, may have a variety of complex needs. Good transition is important to help prevent further offending behaviour, and / or support move from child to adult's settings.		Section 7 - Transfer and Continuity of Care. http://www.rcpch.ac.uk/system/files/protected/page/Healthcare%20standards%20A4%20report%20pages%20english%20compressed%20FINAL.pdf
93	Lancashire care NHSFT	We have some general comments that do not seem to fit the comments form, mainly that the guideline of the same			

		topic covers a wide range of diverse services and health topics, so the focus may need to be narrowed on the QS to be meaningful; and that I'm not convinced QS14 and QS16 are truly related quality standards as they are for adult age and healthcare settings.			
94	Royal College of Paediatrics and Child Health	Key area for quality improvement 5 Education	Transition meetings may be held in both mainstream and special schools, but frequently representatives of the child's healthcare provider are neither present, nor informed of the outcome of the meetings.	School nurses might be able to bridge the gap by acting as a conduit of information between Social Services, Education and Health, but they are also frequently unable to attend the meetings, and many children requiring transition will attend a mainstream school rather than a special school.	There is a large amount of duplication of information between services, and current forms being used tend to be very cumbersome to complete, both for the parents and for the professionals concerned. Face to face meetings are helpful, but difficult to organise because everyone is very busy and professional caseloads are large.
95	Royal College of Psychiatrists	Key area for quality improvement 3		It may be sensible to differentiate neurodevelopmental disorders (ADHD and ASD) from mental illness on section 3.1 on page 4 by adding a bullet point called: neurodevelopmental disorders.	
96	Royal College of Psychiatrists	Linking implementation of CG43 with local Special Educational Needs and Disability Reforms	Collaboration between multiple agencies is crucial to effective transition. Education services are key players in supporting young people who transition from children's to adult services	The National Development Team for Inclusion's recent survey showed poor linkage between Local Transformation Plans and SEND plans	
97	Royal College of Speech and Language Therapists	Co-ordination of the transition of young people from children's to adult services as part of the Special Educational	The Children and Families Act 2014 introduced substantive reforms to SEND policy in England. The SEND reforms aim to improve the delivery of support to children and	Comments that RCSLT members have shared with us to date include: Commissioning gap/ services for 19-25 year olds (of particular concern	

		Needs and Disability (SEND) reforms.	young people with SEND (including speech, language and communication needs). However, RCSLT members have reported that there is a commissioning gap and poor co-ordination of the transition of young people from children’s to adults’ services as part of the SEND reforms.	are those who do not fit the severe learning disability profile, for example those with autism, specific language impairment or physical disabilities such as cerebral palsy): o Therapists are being asked to write advice for education, health and care (EHC) plans regarding what support these young people might require in Further Education (FE) or apprenticeships – often this will be in relation to upskilling others in the young person’s new environment. However, adult services are often not commissioned to do this – they are generally commissioned to provide acute care or to provide rehabilitation services (rather than habilitation), and have little experience of working within educational settings. o From a healthcare perspective, many of the young people will be discharged back to their GP, who will have variable knowledge and skills in supporting them, and may not understand the role that therapies can provide. o Despite the clear guidance in the Code of Practice, there is still an issue of engaging health commissioners in the process, and confusion over whether speech and language therapy should be considered a health or education need, and therefore who is responsible for commissioning. This is particularly true for adult commissioners who will be less familiar with the Children and	

				Families Act.	
98	Royal College of Speech and Language Therapists			o Given that young people over 16 were not previously covered by the legislation, there is a query regarding the readiness of the FE sector to support EHC plans, and they may also not understand the role that therapies can provide.	
99	Royal College of Speech and Language Therapists			This combination of factors means there is a risk that young people aged 19-25 may not receive the appropriate support, and therefore struggle to be included at FE level, potentially resulting in them becoming NEET, involvement in the criminal justice system or having mental health difficulties, ultimately impacting on their educational attainment and employment.	
100	Royal College of Speech and Language Therapists	Additional developmental areas of emergent practice	RCSLT members have also highlighted a need to align the work of adult and child learning disability practitioners to support the delivery of the SEND reforms and the Transforming Care agenda.		
Additional area - funding					
101	British Thoracic Society	Key area for quality improvement 4	Funding streams	The tariff for childrens care, is at least double and with specialty paeds top up, that will like occur in patients who are going to be transitioned, young adults and their parents expect the same standards of care but these cannot be provided by adult services where there is a large drop in income. This leads to unrealistic demands on adult services and probably poor care. This is occurring at a time where demands (of young adult) are likely to be greater.	

				Plans need to be in place for a transition tariff for say 2 years where the paeds tariff is paid to the adult services to allow the transition to occur, especially at the time where community infrastructure has gone eg community paeds.	
102	British Thoracic Society	Additional developmental areas of emergent practice	Transition link in CCG's	This should enable the smooth transition in funding complex care packages.	
Additional area - research					
103	Genetic Alliance UK	Research studies are not compatible with the transition process	Many rare diseases are severe and life-limiting. For individuals or families affected by most rare diseases, the day-to-day challenges of managing a severe condition are made worse by the absence of an effective treatment or cure. These patients look to research as the source of new therapies to address their unmet health need. For this reason, the vast majority of rare disease patients are eager to participate in research studies.	Adolescence is a time of significant change in terms of physical, emotional and educational development, yet it is in this age group that the least amount of medical research is performed. Clinical trials have often overlooked teenagers and as a result, treatments for young people are based on research carried out on adults and children. Research is vital for understanding how and why diseases develop and progress. This has the potential to lead to the discovery of new or better medicines and treatments, tests that will improve our understanding of a condition as well as methods to prevent complications. Patients with rare conditions are particularly eager to take part in research studies but this is currently incompatible with how transition between services is managed.	See above.
Additional area – end of life care plans					
104	Together for	Parallel end of life	Every young person with a life-	Stepping Up, Together for Short	

	short lives	planning	shortening condition should have an end of life plan which is developed in parallel to planning for ongoing care and support in adult services.	Lives, 2015 highlights that for children with life-shortening conditions, death can occur at any point during their transition. For young people who are experiencing a deterioration of their health and might seem to be approaching end of life, service providers may put on hold their arrangements for transition. This means that placements and other opportunities for that young person can be lost and they can lose a sense of purpose for the future. Parallel planning enables young people to plan for their ongoing future in adult services, whilst making plans for their end of life care. Stepping Up measures this standard using ten service goals: 1. Transition planning takes place even in times of uncertainty 2. Young person has end of life plan running alongside plan for their future life 3. Young person’s pain and other symptoms are dealt with effectively 4. Every effort made to make sure that young person’s death takes place according to their wishes 5. Family members and carers are supported & involved 6. Young person has best quality of life and care to the end 7. Parents retain parenting role after death of young person 8. Siblings supported and included in decisions 9. Professionals/agencies informed	

				of the death, with the parents' consent 10. Family members supported for as long as they need it	
105	SCM4	Additional evidence sources for consideration	https://www.england.nhs.uk/wp-content/uploads/2016/01/diabetes-transition-service-specification.pdf		
106	Pfizer	Thank you for the opportunity to participate in the topic engagement exercise. I can confirm that Pfizer have no further comments to submit.			