NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Transition from children’s to adults’ services

Date of Quality Standards Advisory Committee post-consultation meeting:
21 September 2016

2 Introduction

The draft quality standard for transition from children’s to adults’ services was made available on the NICE website for a 4-week public consultation period between 25 July and 22 August 2016. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 56 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the quality standards advisory committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the committee as part of the final meeting where the committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendix 1.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

3. Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please submit your example to the NICE local practice collection on the NICE website. Examples of using NICE quality standards can also be submitted.

4. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- QS generally welcomed and the statements address the key areas
- Concerns over the lack of resources available to fund transition care and how statements will be implemented in practice where there is variation in service availability and age of acceptance into services
- Define more clearly the population covered including young people who do not meet the eligibility for adult services and therefore do not transition, young people with long term conditions where improvement may occur, young people with terminal disease and palliative care needs who remain with children’s services, young people seen entirely by primary care, specific population groups e.g. children with autism, oral and dental health; care leavers
- More emphasis needed that transition is a process and not an event.
- Highlight that transition care should be holistic, developmentally appropriate and person centred
- QS seems to have a social care focus
- Include reference to the value of consulting the school or college that the young person is attending as this is a constant relationship.

Consultation comments on data collection

- Clarity needed over what is expected to measure and what is feasible.
- Difficulties with data collection where young people move from a single children’s services to multiple adult services.
- Data systems across services are not compatible to capture all the data.
- Stakeholders reported it is possible to collect the data for small discrete services, for young people with a single disease and in social care.
- Stakeholders proposed the use of a generic transition programme tool or framework in all organisations to aid data collection.

Consultation comments on resource impact

- Resources needed to collect data as the information would need to follow the young person across services.
- Concerns about the pressures faced by local providers and the need to provide additional resources and time to support change and increased workloads.
- Resources needed to provide new services or the level of service that was received in paediatrics.
- Cost savings achieved by improved clinical outcomes from successful transition.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

Young people who will move from children's to adults' services start planning for their transition by year 9, or immediately if they enter the service close to the point of transfer

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- Questioned the appropriateness of the age transition planning starts
  - some young people remain in paediatrics for longer
  - planning could be from age 11-12 or include 'at the latest' in the statement
  - planning should be based on the young person and not a rigid age threshold
  - it is not always known if a young person will need to transition especially in mental health services and an older age may be more appropriate.
- A specific age would be more useful than the term 'year 9'.
- Children's needs and the availability of services will change over time.
- Emphasise the benefits of including adult services early in the transition process
- The statement is measurable but information systems would need improving
- Outcome measures on young people's views of the process and their experience should be added.
- Education and healthcare plans could be a useful data source.
- Definition of 'starting planning for their transition' needed and should include having a plan and reference to the mental capacity act/decision making.
- Reference to GPs is not appropriate as they have a limited role in transition planning.

5.2 Draft statement 2

Young people who will move from children's to adults' services have an annual meeting to review transition planning.

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- Statement not feasible for practical and financial reasons:
  - given the location of services which make it difficult to bring together the relevant professionals
  - difficult to include GPs because of workloads
  - professionals don't have the allocated time for planning and coordinating the meetings.
- It would be helpful to include when the annual meetings start and stop.
- The meeting should be in a transition clinic, held 6-monthly as the young person nears the point of transfer or held more frequently for those young people who join the service close to the point of transfer.
- The meeting should be tailored to the young person especially where there are issues with confidentiality e.g. HIV or where young people do not have annual reviews for medication use.
- More information needed in the definition of the meeting. This could include:
  - who should arrange and chair the meetings, who should attend e.g. key worker, education, GP and how they should input for example written reports
  - reviewing adherence to treatment and consequences of non-adherence, identifying fire risk and current living arrangements
  - link to education and healthcare plans and social care plans where these exist
  - mental capacity act/decision making and its impact
  - whether transition planning is needed especially for mental health services.

5.3 Draft statement 3

Parents and carers of young people who will move from children's to adults' services discuss their expectations of the transition process at the annual meeting.

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- There is a possible overlap with statement 2.
- Alternative focuses of the statement could be:
  - identify parent/carers needs and future support
  - young people's expectations and provision of appropriate information about future changes in their care.
  - describing the care plan under adult services to ensure parents and carers are aware of the changes.
- Young people are currently asked about parental involvement but their wishes are not always carried out and the level of parental involvement may be different for each young person.
- The statement gives the impression the annual meeting is the main time when parents and carers are involved instead of throughout the process, recognising that this would be hard to measure.
- The statement is hard to measure as annual meetings are not in a structured format across organisations
- An outcome measure on the satisfaction of the young person should be added.

5.4 Draft statement 4

Young people who are moving from children's to adults' services have a named worker to coordinate their transition care and support before and after transfer.

Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

- The role requires proper commissioning, identification of how this is commissioned and allocated time and expertise for professionals.
- Further information needed on who the named worker should liaise with and if they are the liaison for parents as well.
- An effective named worker would reduce the need for multiple MDT meetings.
- The tasks of the named worker e.g. coordination are more important than having a named worker.
- A timeframe for when the named workers role starts and stops should be added.
- If the named worker is from paediatrics, they may not be able to continue their role when the young person moves to adults services.

5.5 Draft statement 5

Young people who will move from children’s to adults’ services meet a practitioner from the adults’ service before they transfer.

Consultation comments

Stakeholders made the following comments in relation to draft statement 5:

- The statement is a key part of the transition process and shows that children’s and adults’ services are working together and is measurable.
- There is a possible overlap with statement 2 as the practitioner from the adults’ service may be part of the annual meeting.
- Alternative focuses of the statement could be:
  - ‘offered the chance to see’ taking account of patient choice
  - meeting a practitioner more than once for some groups of young people e.g. those with autism
  - visiting the service
  - including a timeframe for when this meeting should take place.
- Not possible to achieve if young people are transitioning out of children’s services but there are no adults services for example mental health and physiotherapy.
- Practical issues to deliver the statement such as services not always being based near each other, difficulties meeting children in secure settings and the impact on clinicians time.
- ‘Practitioner’ needs to be more clearly defined and should be someone who will have a continued role in the young person’s care. For young people being transferred to several services, this may be more than 1 person.

5.6 Draft statement 6

Young people who have moved from children's to adults' services but do not attend their first meeting or appointment are contacted by adults' services and given other opportunities to engage

Consultation comments

Stakeholders made the following comments in relation to draft statement 6:

- This is a key area as non-engagement leaves young people vulnerable.
- If appropriate preparation is made during planning this statement should not be needed.
- The reported impact on resources varied between stakeholders, some felt it would reduce unplanned healthcare interventions others felt it may need additional resources depending on team structures.
- Alternative focuses of the statement could be:
  - checking attendance at all follow up appointments
  - ongoing engagement rather than attendance for example by phone, email
  - continued support from the named worker until the young person engages in adults services and to follow up if they do not.
- Wording of the population should be 'young people who have transferred' as some may be discharged to primary care.
- Clarity needed on the role of parents and carers in the process.
- Young people should not be discharged from children's services until seen by adults' services.
- Contact with the young person should be made by someone the young person knows, ideally the named worker or someone from children's services or an administrative assistant with support from senior practitioner.
- It may not be appropriate to include the named worker and children's services in the definition of 'opportunities to engage'.
- Support from health and social care organisations would be needed to implement the statement for example offering another appointment may conflict with provider DNA policies, requesting another referral would need CCG support.

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

- Continuity of care, not seeing a different professional at each appointment
- Young person’s self-management of their condition
- Young person’s involvement and expectations of the transition process with agreed timeframes
- GP involvement for example GP contact after unplanned admissions, named GP, medical with GP
- Development of a portable, accessible medical summary
- Young people being placed outside of their home local authority in a residential setting having a practitioner from the home local authority attend the review meeting.

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Statement number	Comments[1]
1	Action on hearing Loss	General	Action on Hearing Loss, formerly RNID, is the UK's largest charity working for people with deafness, hearing loss and tinnitus. Our vision is of a world where deafness, hearing loss and tinnitus do not limit or label people and where people value and look after their hearing. We help people confronting deafness, tinnitus and hearing loss to live the life they choose, enabling them to take control of their lives and removing the barriers in their way. We give people support and care; develop technology and treatments and campaign for equality. Our response will focus on key issues that relate to people with hearing loss. Throughout this response we use the terms 'people with hearing loss' to refer to people with all levels of hearing loss and 'people who are deaf' to refer to people who are profoundly deaf who use British Sign Language (BSL) as their first or preferred language. We are happy for the details of this response to be made public. Action on Hearing Loss supports the aims of the Transition from children's to adults' services quality standard and believes the quality statements broadly reflect the key areas for quality improvement. Hearing loss is a long term health condition that affects a large number of people across the UK. People with hearing loss often find it difficult to communicate with other people and have increased risk of mental health problems such as anxiety and depression. Diagnosing and managing hearing loss and taking hearing loss into account when diagnosing and managing other conditions is crucial for good communication and care. Without a qualified British Sign Language (BSL) interpreter or other communication support, people who are deaf may be at risk of poor health and worse care. Young people who are moving to adult services may face additional barriers to communication during the transition process if hearing loss isn't diagnosed or properly managed. Young people and their parents, guardians or carers who are deaf or have hearing loss may also require additional support to make sure they're fully involved in discussions about care. Background 11 million people with hearing loss across the UK, about one in six of the population[1]. Hearing loss can be caused by the ageing process, regular and prolonged exposure to loud sounds, ototoxic drugs, genetic predisposition or complications from injuries or other conditions. There are also 45,000 children with hearing loss in the UK[2]. Around 40% of children with hearing loss also have additional needs[3]. There are also an estimated 900,000 people in the UK with severe or profound hearing loss. Some people with severe or profound hearing loss may use British Sign Language (BSL) as their main language and may consider

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[1] PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

ID	Stakeholder	Statement number	Comments[1]
			themselves part of the Deaf Community, with a shared history language and culture. Based on the 2011 census, we estimate that there are at least 24,000 people across the UK who use BSL as their main language – although this is likely to be an underestimate. A significant body of evidence shows that hearing loss is a serious condition that can have an adverse impact on a person's health and quality of life[4]. Hearing loss has been shown to have a negative impact on overall health and it needs to be taken into account when managing other conditions. Studies have found that hearing loss is independently associated with increased use of health services, an increased burden of disease amongst adults and an increased risk of mortality[5]. Hearing loss has also been associated with more frequent falls[6], diabetes[7], stroke[8] and sight loss[9]. Evidence suggests that people with learning disabilities are more likely to develop hearing loss earlier compared to the general population and are at greater risk of associated health problems[10]. Research shows that people with hearing loss may find it difficult to communicate with other people and this may lead to feelings of loneliness, emotional distress and withdrawal from social situations[11]. People with hearing loss are more likely to develop paranoia, anxiety and other mental health issues – for example, evidence shows that hearing loss doubles the risk of developing depression[12]. Without additional support people who are deaf may be at risk of worse care and poor health. Research by the charity SignHealth[13] shows that over a third (34%) of people who are deaf were unaware they had high or very high blood pressure and more than half (55%) of those who said they had cardiovascular disease were not receiving appropriate treatment. This suggests that people who are deaf may not be getting the care they need due to problems with communication and understanding. Additional research suggests that people who are deaf may be unable to access preventive services and are at greater risk of cardiovascular disease due to the lack of information available in sign language[14]. Evidence suggests that children who are deaf are more likely to develop mental health problems compared to the general population and adults who are born deaf are at greater risk of mood, anxiety, personality or developmental disorders[15]. Standard tests and mental health measures may be ineffective for people who are deaf if they are unable to communicate well in English[16]. Diagnosis and management Hearing aids are shown to improve quality of life[17] and help people communicate, stay socially active and reduce the risk of loneliness and depression[18]. Since 2006, all parents of new babies have been offered a hearing test soon after birth However, many people who develop hearing loss later in life are waiting too long to get their hearing tested. Research shows that people wait on average ten years before seeking help for their hearing loss[19]. Delays in treatment mean by the time they get help, many people with hearing loss are less likely to benefit from hearing aids. Evidence suggests that hearing aids are most effective when fitted early and people with severe hearing loss may find it more difficult to adapt to hearing aids[20]. There are currently no national screening programmes for adults with hearing loss and more should be done to encourage people to check their hearing and seek help.

ID	Stakeholder	Statement number	Comments[1]
			Diagnosing hearing loss may also be difficult if people face barriers to getting help due to other conditions. Our A World of Silence[21] report shows large numbers of older people in care homes have undiagnosed hearing loss and care staff found it difficult to encourage them to seek help. The report found that care home staff lacked training on hearing loss and basic hearing aid support and were often unaware that hearing loss can lead to major communication difficulties, social isolation and mental health problems. These issues are also common in other residential care services used by young people. Additional research shows that prevalence of hearing loss in people with learning disabilities is higher compared to the general population[22], but this often goes undiagnosed or isn't properly managed due to hearing loss being misdiagnosed as behavioural difficulties[23]. Under the Care Act 2014, community equipment (including household aids and adaptions) up to the value of £1,000 and intermediate care and reablement (provided up to six weeks) must always be provided free of charge if people meet the eligibility criteria. This includes any equipment which is recommended through an assessment as part of a rehabilitation intervention. However, our Life Support[24] research shows that the availability of adult social care services depends to a large extent on where people live. Although the Department of Health and NHS England's Action Plan on Hearing Loss[25] states that hearing loss should be included in Joint Strategic Needs Assessments (JSNAs), only a third of local authorities who responded to our survey in England included hearing loss as a specific issue in their JSNAs, and only a quarter (25%) of respondents in England and one in six respondents in Wales said they have a strategy dedicated to hearing loss. All respondents in England and Wales offered assistive technology for people with hearing loss who met the eligibility criteria and a high proportion also offered social and support work and occupational therapy. However, a quarter (25%) did not offer any advocacy support and more than 10% did not offer crucial interpretative support. Younger people who are deaf who need to access social care for other conditions may need culturally sensitive care and support that takes account of the unique values and culture of the Deaf community. This could include the provision of a qualified BSL interpreter or other qualified communication support, as well as help to attend Deaf clubs or other community groups[26].Evidence suggests that people who are deaf may be at risk of loneliness and loss of cultural identity if they are unable to communicate in a meaningful way with care staff or other people in care homes. Poor communication or ignorance of Deaf culture can lead to ineffective care and deterioration in health and wellbeing[27]. Accessing services People who are deaf or have hearing loss may find it difficult or impossible to use the telephone and may benefit from accessible alternatives such as email, SMS text, text relay, or BSL video relay. For face-to-face contact, some people who are deaf or have hearing loss may need support from a communication professional such as a BSL interpreter or speech-to-text-reporter. People who use hearing aids may benefit from a hearing loop which can help people hear more clearly by reducing background noise. Many people with hearing loss will also benefit from simple behavioural changes and communication techniques such as speaking clearly and ensuring lip movements are clearly visible.

ID	Stakeholder	Statement number	Comments[1]
			Despite legal protection from the Equality Act 2010, our research shows that people with hearing loss often struggle to hear what is being said by GPs and other health and social care professionals due to poor deaf awareness and the lack of communication support in consultation areas, which may lead to confusion over their diagnoses – and ineffective care. Our Access All Areas[28] report shows that one in seven (14%) survey respondents missed an appointment because they didn't hear their name being called in the waiting room. After their appointment, more than a quarter (28%) said they didn't understand their diagnosis and one in five (19%) were unsure about their medication. The situation is even worse for BSL users; around two-thirds (68%) who asked for a BSL interpreter didn't get one. Similarly, in social care, our Life Support[29] report shows people who are deaf or have hearing loss often struggle to get information on social care and support. Almost a quarter (25%) of local authorities in England and three quarters (75%) of local authorities in Wales (75%) did not offer a bespoke telephone or minicom service. In most cases, an under-qualified BSL interpreter was provided during adult social care assessments. Recommendations In general, the quality standard must make reference to the following: Planning and commissioning co-ordinated and person centred services for young people who are deaf or have hearing loss The Department of Health and NHS England's Action Plan on Hearing Loss[30] states that hearing loss is "responsible for an enormous personal, social and economic impact throughout life"[31] and that urgent action is needed to increase the awareness of its impacts and the level of support for people with hearing loss. Tackling the growing prevalence and impact of hearing loss is now a national priority. When commissioning services for young people who are deaf or have hearing loss, commissioners should follow guidance issued by NHS England and other organisations to ensure services meet needs and take into account the views of people who use services. As stated in the "Co-ordinated services" section of this quality standard "a person-centred integrated approach to providing services is fundamental to delivering high-quality care to young people who are moving to adult services". NHS England has recently published a new framework[32] for CCGs commissioning hearing loss services which aims to reduce unwarranted variations in services quality and provision and sets out a clear process to make sure adult audiology services take account of the personal circumstances, needs and wishes of patients. As a member of Think Local Act Personal Making It Real partnership, we have also produced guidance for local authorities on how to deliver personalised care to people with sensory loss, including people who deaf[33]. We recommend adding these references to the "Policy Context" section of this quality standard. More guidance is also urgently needed to ensure local authorities plan to meet the growing level of need and commission high quality adult social care services for people who are deaf or have hearing loss. As stated in the Department of Health and NHS England's Action Plan on Hearing Loss, local authorities should also ensure hearing loss is included in their JSNAs. NHS England's Accessible Information Standard

ID	Stakeholder	Statement number	Comments[1]
			NHS England's Accessible Information Standard provides clear guidance for providers of NHS care and publicly funded adult social care on making their services accessible for people with disabilities and sensory loss (including people who are deaf or have hearing loss). The Standard sets out a clear process to make sure people with disabilities and sensory loss can contact services when they need to, communicate well during appointments and understand the information they're given. This includes the communication and/or information needs of parents, guardians or carers. The Care Act statutory guidance states that local authorities should take account of information standards published by the Information Standards Board under the Health and Social Care Act 2012. It's vital that providers of NHS care and providers of publicly funded adult social care follow the Standard to ensure young people and their parents, guardians or carers are fully involved in discussions about their care. When commissioning services, commissioning organisations must also seek assurance from providers that they are meeting the Standard's requirements. Given the relevance of the Accessible Information Standard for providers and commissioners in meeting the requirements of quality statement 3: Involving parents and carers, we recommend adding the Standard to the "Policy Context" section of this quality standard.
2	ALD Life	General	From our experience of transition for children with complex and multiple needs we have consistently poor feedback from parents and carers on the ease and success of this process. We would like to question how monitoring and evaluation of transition successes and failures will be measured for each local authority and if an explanation of this can be added to the document. Currently there is much confusion as to how parents and carers can challenge and ensure health and social care staff meet transition process requirements in accordance with recommendations for best practice. For example, is there a national or regional department to oversee compliance and adherence to guidelines?
3	Association of School and College Leaders (ASCL)	General	In general ASCL is happy to welcome this quality standard.
4	Barnardo's	General	Barnardo's is responding to the quality statements in respect of children in care and young people leaving care and making the transition to independent adult life. In particular we wish to comment on the arrangements for transition from CAMHS to adult mental health services.
5	CLIC Sargent	General	As indicated in the briefing paper, it is inappropriate to transition cancer patients in the end-of-life phase, as childhood cancer palliative/end-of-life care tends to be relatively short, compared with other long term conditions such as congenital or degenerate disorders. Transitioning children with cancer at end-of-life means the child and the family lose the support of those they are familiar with, peers and familiar environment. Some reference needs to be made to this in the guidance.
6	Department of Health	General	I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.
7	Genetic Alliance UK	General	Genetic Alliance UK is the national charity working to improve the lives of patients and families affected by all types of genetic conditions. We are an alliance of over 180 patient organisations. Our aim is to ensure that high quality services, information and support are provided to all.

ID	Stakeholder	Statement number	Comments[1]
			Rare Disease UK (RDUK) is a campaign initiative run by Genetic Alliance UK. It is the national alliance for people with rare diseases and all who support them. RDUK is a stakeholder coalition brought together to work with Government to develop a UK Strategy for Rare Diseases, which was published by the Department of Health in November 2013. RDUK continues to campaign for the implementation of the Strategy across all four home nations of the UK. SWAN UK (Syndromes Without A Name) is a patient and family support initiative run by Genetic Alliance UK. It is a UK-wide network providing information and support to families of children without a diagnosis. It works to support the development of high quality information and services for families of children affected by undiagnosed genetic conditions and raise public and professional awareness of undiagnosed genetic conditions and the unique challenges faced by affected families.
8	Genetic Alliance UK	General	We are on the whole very happy with the draft quality standard, and are hopeful that the emphasis on communication and planning ahead contained in it will lead to significant improvements in how those with rare, genetic and undiagnosed conditions experience transition from children's to adults' services.
9	Genetic Alliance UK	General	We were pleased to see reference to a report (The Rare Reality, 2015) produced by our Rare Disease UK campaign in the briefing paper published with this quality standard. However, we would request to be cited as "Rare Disease UK" rather than "Rare diseases UK". Thank you.
10	Institute of Health and Society, Newcastle University. On behalf of the NIHR funded Transition Research Programme.	General	We were complimentary about the Draft NICE Guidance on Transition and welcomed the changes that were made for the definitive version. However, we think the Draft Quality Standard document lacks clarity. As will be presented below, we think many of the recommendations about concrete things to measure are not sufficiently precise to know what is expected and therefore whether it would be feasible to capture; and the more general recommendations are so general as to be unmeasurable.
11	NHS England	General	Thank you for the opportunity to comment on the above Quality Standard. I wish to confirm that NHS England has no substantive comments to make regarding this consultation.
12	Pfizer	General	We have no comments to make on the draft Quality Standard
13	Royal College of Nursing	General	Transition for young people who have learning disabilities or mental health needs has been a very longstanding challenge in that they have often fallen between services and not received seamless care that they should. This has been well documented. It is essential to collaborate and communicate with families who often know the young people the best. Transition causes all sorts of issues around funding and this causes untold stress and distress when someone does not get their needs met. This is particularly the case now as services are cut to the bone.
14	Royal College of Paediatrics and Child Health	General	We are concerned that the CGC did not seem to include a representative from RCPCH
15	Royal College of	General	The RCP is grateful for the opportunity to respond to the above consultation. In doing so we would like to endorse the

ID	Stakeholder	Statement number	Comments[1]
	Physicians (RCP)		response submitted by the British Thoracic Society. We have also liaised with our Young Adults and Adolescents Steering Group and would like to make the following comments.
16	Royal College of Physicians (RCP)	General	Our experts believe that this draft quality standard for transition is broadly helpful. However, although most of the standards would be met by specialist medical services where joint paediatric/adult transition clinics or similar arrangements are in place, our experts believe that they lack the necessary detail to meaningfully make changes to services to best meet the needs of young people. Where people may have complex long term conditions that require a joined-up approach across different teams, there is no suggestion of how the medical input to care should be offered. Most children with long term conditions are seen by paediatric services, but there are no adult equivalents. Our experts suggest that providers and commissioners look for adult services that could take on the needs of individuals with complex multi-factorial problems who currently fall between the gaps of condition-specific systems.
17	Tees Esk and Wear Valleys NHS Foundation Trust	General	The quality standard seems quite social care focused. Could more emphasis be placed on transition between healthcare services?
18	The Faculty of Pain Medicine (FPM) of the Royal College of Anaesthetists	General	There may be some logistical confusion. Most paeds services are centralised and the transition might be to a service away from parent hospital based on geographic location. Therefore, one could assume that each paediatric service should develop a system in place for transition?
19	The Faculty of Pain Medicine (FPM) of the Royal College of Anaesthetists	General	a. Problems within pain medicine that would ideally be addressed by the quality standard include: Developmentally appropriate timing. Natural history of problem. Many patients do not end up needing transition but some do. It is rather negative to plan for continuing pain pathway if it is not needed. The quality standard seems to take in to account children’s long term conditions but not conditions where improvement may occur. Psychosocial issues, particularly around family coping strategies (or lack of them) Non streamlining of transition (varied onward routes() variation of service availability and age of acceptance.
20	The Guide Dogs for the Blind Association (Guide Dogs)	General	Our response makes reference to “Habilitation”. By this we mean specialist mobility, orientation and independence skills for children and young people with visual impairment delivered to the national standards.
21	The Guide Dogs for the Blind Association (Guide Dogs)	General	Research that we undertook in 2008 into the functionally ability and needs of children and young people with visual impairment amongst other things revealed that: Blind and partially sighted children and young people do not perform as well as other young people in terms of confidence, independence, initiative, self-esteem, social skills, mobility and social networks. They are less included in sports, play, extra-curricular activities and social networks.

ID	Stakeholder	Statement number	Comments[1]
			There is evidence to suggest this only gets worse with transition from Primary to Secondary school and beyond. They do not all receiving vital habilitation services. There is no key role to coordinate the services they require. Therefore, we welcome the opportunity to comment on this draft NICE standard in the hope that it will help to improve the quality of transition for this group.
22	The Royal College of Anaesthetists (RCoA) and the Association of Paediatric Anaesthetists of Great Britain and Ireland (APAGBI) joint response	General	The development of this Quality Standard is to be welcomed and will help to improve the process of transition in an under-resourced area of healthcare, where current arrangements are somewhat ad-hoc and vary throughout the UK.
23	The Royal College of Anaesthetists (RCoA) and the Association of Paediatric Anaesthetists of Great Britain and Ireland (APAGBI) joint response	General	The definition of terms should be at the beginning of the document.
24	The Royal College of Anaesthetists (RCoA) and the Association of Paediatric Anaesthetists of Great Britain and Ireland (APAGBI) joint response	General	For lay people the references to numerator and denominator numbers should be explained more clearly
25	The Royal College of Anaesthetists (RCoA) and the Association of Paediatric Anaesthetists of Great Britain and Ireland (APAGBI) joint response	General	Measures of improvement should be mentioned and explained.
26	CoramBAAF Adoption	General	This response is being submitted on behalf of the CoramBAAF Health Group, which is also a special interest group of

ID	Stakeholder	Statement number	Comments[1]
	and Fostering Academy		the Royal College of Paediatrics and Child Health (RCPCH). The Health Group was formed to support health professionals working with children in the care system, through training, the provision of practice guidance and lobbying to promote the health of these children. With over 500 members UK-wide, an elected Health Group Advisory Committee with representation from community paediatricians working as medical advisers for looked after children and adoption panels, specialist nurses for looked after children, psychologists and psychiatrists, the Health Group has considerable expertise and a wide sphere of influence. Our area of concern is the particularly vulnerable group comprised of looked after and adopted children and young people.
27	Association of School and College Leaders (ASCL)	Introduction	It would be helpful to have a more explicit reference to the value of consulting the school or college that the young person has been attending, as this is often the most frequent and continuous relationship with a professional organisation.
28	Association of School and College Leaders (ASCL)	Introduction	Likewise, when planning, many vulnerable young people will at 18 just be entering a college environment. It would be helpful to refer to this and, for many, the need to liaise with a suitable college (or other education and training provider) to prepare the way.
29	British Academy of Audiology And British Society of Audiology (Paediatric Audiology Specialist Interest Group)	Introduction	There is an omission in current guidance which is transition from one service to another rather than from child to adult service. For example, going from one service to another (in a region or between regions) happens more frequently and there is huge variation in what is being done. It is suggested that same guidelines apply as from child to adult might apply in service to service change. At this stage it is unclear whether this aspect appears at all or in another NICE standard at a generic level.
30	British Academy of Audiology And British Society of Audiology (Paediatric Audiology Specialist Interest Group)	Introduction	We support the fact that this draft quality standard reflects the key areas for quality improvement; however we are concerned that the document states maximum of up to 25 years old. This may not be appropriate and in some cases in Audiology, particularly patients with complex and other health needs, they may never transfer into routine adult audiology service provision particualary where specialist services for complex adult needs are not locally available). It may therefore be necessary to consider removing the upper limit age range.
31	British Society of Paediatric Dentistry	Introduction	This document refers to GPs and medical issues there no mention of the oral heath which is necessary for general health. Yet again by narrow minded thinking oral health and eye health have been omitted. Between 2012 and 2014 30% of children did not have oral health monitored by a dental surgeon so these children will not benefit at all from a transition process as they are being transitioned from nowhere to nowhere
32	British Society of Paediatric Dentistry	Introduction	There should be a named GP on the NHS Spine that ensures that regular oral health and eye health monitoring is ensured for a young person and that this is checked “after transition”. Better still a dental surgeon on the NHS Spine too.
33	British Society of Paediatric Dentistry	Introduction	In his introduction from the CQC’s supporting document “From the Pond into the Sea” Professor Steve Field, Chief Inspector of Primary Medical Services and Integrated Care states that “I was frustrated and upset when I read this report…….”. From the BSPD’s perspective after reading this report we would regard this as an understatement as

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			far as young people's oral health is concerned, there is no mention at all.
34	CLIC Sargent	Introduction	There appears to be a gap in sources from excellent work undertaken in Children's cancer care. See below. - Benchmarks for transition from child to adult health services. Prof. Faith Gibson et al (2014) www.transitionstudy.co.uk (Faith.Gibson@gosh.nhs.uk) - What to expect in follow-up care. This is based on extensive work in paediatric cancer services about survivorship and follow-up for childhood cancer which includes transition to adult care for long term surveillance and managing late effects. http://www.cclg.org.uk/Aftercure/what-to-expect-in-follow-up-care. - National Cancer Survivorship Initiative. Paediatric follow-up pathway and transitions. www.ncsi.org.uk/wp-content/uploads/Paediatric-Pathway-Z-Card.pdf. There is also some really useful info in the Briefing Paper appendices that doesn't seem to have made it into this document.
35	CoramBAAF Adoption and Fostering Academy	Introduction	It would be helpful if looked after young people and care leavers could be specifically included in the list of vulnerable groups.
36	Darlington Borough Council	Introduction	The suggested Quality Standards measures are contained within NHS Outcomes Framework and Adult Social Care Outcomes Framework provide consistent measures and opportunities to benchmark performance. The suggested indicators are the correct measures to measure the transition from children's to adults' services.
37	Ferring Pharmaceuticals Ltd.	Introduction	It is not clear whether the remit includes young people who are receiving growth hormone treatment and need to make a transition to adult services. Can NICE kindly clarify this, for eg. does the subcategory of young people with long-term, life-limiting or complex needs, include people on treatment with growth hormone?
38	Great Ormond Street Hospital	Introduction	Further clarification of what training, and who needs to be trained. Are Admin staff who book people into clinics to be included? Should reception staff be trained?
39	Haemnet	Introduction	Whilst the introduction identifies transition as a 'purposeful and planned process', the statements do not sufficiently reflect that transition is a process not an event (the point of transfer). The statements cover elements that contribute to ensuring that transition is a seamless process, however greater emphasis could be placed on the whole as well as the parts and this is reinforced by the range of measures. The statements as written could lead to an improvement in delivery of transition as a seamless process of engagement with young people in supporting them to transfer to adult services. Do these statements sufficiently challenge us to adequately reflect what haemophilia care could be delivering that would support individuals in the self management of their condition, which feedback from service users and their families indicates is one element that underpins successful transition?
40	Health Education England	Introduction	The guidance looks at young people moving from a childrens service to an adult worker. Many young people receive a service from childrens service but (due to different eligibility criteria) they do not receive a service from adult services. This young people still have high levels of need and need to be supported through the transition from childrens services to have their needs met/address their needs and access some support perhaps in the community

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			and develop their independence skills, otherwise these needs may escalate.
41	Institute of Health and Society, Newcastle University. On behalf of the NIHR funded Transition Research Programme.	Introduction	The tables taken from the Adult Social Care Outcomes Framework, and the NHS Outcome Framework are poorly expressed and very hard to understand.
42	Institute of Health and Society, Newcastle University. On behalf of the NIHR funded Transition Research Programme.	Introduction	This includes a measure 'Proportion of people who use services who have control over their daily life'. Yet the statement immediately above it says it is about control of the support they receive. So these are clearly different. Further different people want different amounts of control. Some want little as such control creates anxiety. This 'outcome measure' seems to us to be unmeasurable.
43	Institute of Health and Society, Newcastle University. On behalf of the NIHR funded Transition Research Programme.	Introduction	We found this section incomprehensible. What instruments will be used? How often will the assessments be carried out? Who will do it? In how many settings of the ones suggested?
44	National Community Hearing Association	Introduction	In our view there should be a greater focus on enabling individuals to be involved in the management of their own care. This is particularly important as most children in transition will have a long-term condition and co-management is shown to improve outcomes in long-term conditions. Our main concern is that the quality standard does not define complex needs, and sometimes these labels might be applied in the context of health care delivery – i.e. complex care, but the individual in question might be very much like other people of the same age in terms of aspirations – e.g. thinking about GCSEs, A-levels, universities and careers etc. This is why it is important that "complex needs" or "complex services" are not labels that unnecessarily and/or inadvertently limit life chances. Services need to focus on helping children through transition and into the life the child has in mind – i.e. not providing a set of options based on institutional forms and services. For example, more needs to be done to ensure services are flexible and work across organisational forms if that is what is in the best interests of the individual. For example, a child born with hearing loss might grow up under the care of a hospital based audiology department in their own town, this is because they might need complex hearing/communication support. When the child turns 18 they are often able to transition to an adult hearing service – e.g. they might be a very experienced hearing aid user

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			and able to decide for themselves what is right for them. They should also have the same legal rights to choice as other adults aged 18 in their region. The impact (and ethics) of labels are also noted in the screening literature – i.e. how we think about service users, and how we describe them can have an impact on them both directly and indirectly. Put simply, it is important, when working with children during transition not to inadvertently breach the Equality Act 2010 and/or deny them choices based on local descriptors of complex needs/services. Hearing loss is also a relevant example because there are gaps in transition, and many of children with hearing loss also have comorbidities. For example, 30-40% of children with hearing loss have additional health or development needs, with approximately 20% having more than two comorbidities[i]. It is important that during transition each child's care plan includes their communication needs and they, whenever possible, have access to the same choices/options as other people their age.
45	National Deaf Child and Adolescent Mental Health (NDCAMHS)	Introduction	We would encourage further reference to communication needs, specifically in relation to deaf children. We recommend there is a shared understanding of the child's level of deafness and mode of communication. This includes booking qualified British Sign Language interpreters for children who use sign language. This may include the need for Deaf Awareness training if within mainstream mental health services. There are Highly Specialist Deaf Child and Adolescent and Deaf Adult mental health services who could offer advice/consultation.
46	National Deaf Child and Adolescent Mental Health (NDCAMHS)	Introduction	Where the issues of deafness and communication are central then we recommend referral to Specialist Deaf Adult Mental Health services.
47	Royal College of General Practitioners	Introduction	The RCGP finds the introduction ambiguous- it says that the Quality Standard document covers all young people using health and social care services but then goes on to describe specific groups. In fact the standard was never intended to cover either the majority of young people who do not fit into the defined groups but still transition from child to adult use of health services, nor was it intended to cover those with long term conditions who are managed entirely in primary care.
48	Royal College of Nursing	Introduction	In general, the standard should pay special attention to looked after children and those in adoption / care services.
49	Royal College of Paediatrics and Child Health	Introduction	These standards do not reflect the holistic approach to transition which has been reported to be associated with YP and parental satisfaction other than the content of the annual review meeting [Shaw KL, Watanabe A, Rankin E, McDonagh JE. Walking the Talk. Implementation of transitional care guidance in a UK paediatric and a neighbouring adult facility. Child: Care, Health Development 2014 Sep;40(5):663-70]. It is important to emphasise that the care in between should be similarly holistic and developmentally appropriate
50	Royal College of Paediatrics and Child Health	Introduction	With regard to comments received from the Paediatric Educators Special Interest Group , the draft quality standard has no specific effect on the education or training of Paediatric Trainees. In light of the increasing recognition of the importance of transitional planning it is worth highlighting the relatively small focus on transitional care in the RCPCH postgraduate curriculum (Assessment Standard 15). To ensure equal provision of this proposed guidance it is vital that all trainees are confident in arranging and monitoring appropriate

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			transitional care, especially the points raised in this draft standard. Additionally we want to note that this is rarely taught in the undergraduate curriculum and is not mentioned in the recently launched and RCPCH backed national undergraduate curriculum http://www.rcpch.ac.uk/system/files/protected/page/Undergraduate%20Curriculum%20for%20Child%20Health%20Nov.%202015.pdf
51	Royal College of Paediatrics and Child Health	Introduction	There is no reference to primary care
52	Royal College of Paediatrics and Child Health	Introduction	"recommendations in the development source(s) on specific types of training for the topic that exceed standard professional training are considered during quality statement development" Comments: This requires references to justify the above statement.
53	Royal College of Paediatrics and Child Health	Introduction	There is no mention or QS specifically related to Transition to adult services for Children with learning difficulties/early onset dementia/palliative care etc.
54	Royal College of Physicians of Edinburgh	Introduction	The measures listed in Tables 1 and 2 are very generic and may be difficult to measure objectively. For example, 1B 'Proportion of people who use services who have control over their daily life' – this is not binary, many have some but not full control. Also, do these refer only to patients or to carers/parents as well, who are stakeholders in this area? Unless these standards are very clearly defined for this, data will be highly variable and of limited value.
55	Suffolk County Council	Introduction	Key areas identified in the quality standard There should be greater clarity about the breadth of young people covered by the quality statements - meaning there needs to be an unambiguous statement about whom the quality statements refer that can be taken at face value for any reader (avoiding referral to several other places of reference to avoid confusion). There is a wider number of descriptors around eligibility for services and about responsibilities during preparation for adulthood in a local authority setting (making it hard to comment as to what is included and what is excluded).
56	Tees Esk and Wear Valleys NHS Foundation Trust	Introduction	The legislation and policy section is rather limited; there are other key policy documents that reference transitions, for example, Future in Mind.
57	The Howard League for Penal Reform	Introduction	The National Preventive Mechanism is attempting to get data on the number of children transitioning from children's custodial provision to adult custodial provision in each part of the UK. Therefore this information may not be currently available but ought to be made available shortly. It is our view that most children transitioning to the adult secure estate will have at least one health need. In March 2016 there were 615 children aged 15-17 and 4,668 young people aged 18-20 in prison custody[36]. Children detained on long term sentences of a year or more may transition from children to adult health and social

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			care services whilst in custody. Statistics from the Ministry of Justice[37] show that in March 2016, 1,869 boys and young men were serving sentences of one to four years, 1,177 were serving sentences of four years or more and 122 were serving indeterminate sentences. Children and young adults in prison have complex and multiple health and social needs. A Ministry of Justice study on the needs and characteristics of young adults aged 18-20 in prison custody[38] found: Ten per cent reported needing help with a medical problem 15 per cent were assessed as suffering from anxiety and depression A third of young adults were receiving treatment or counselling for a health or medical problem in the 12 months prior to custody 18 per cent of young adult prisoners were disabled A quarter had spent time in local authority care as children. A report by the Youth Justice Board and Her Majesty's Inspectorate of Prisons[39] found 19 per cent of the children surveyed in prison had a disability, a quarter of boys in prison had emotional or mental health problems, one in four said they had health needs which were not being met and over half had been or were in local authority care.
58	VISION 2020 UK	Introduction	We are keen to note that much of what the guidance covers is consistent with the processes (and underlying principles on which they're based) of the special educational needs and disability (SEND) Code of Practice, particularly in relation to YP (young people) with an Education, Health and Care (EHCP) plan. With this in mind we wonder if it would be useful to specifically identify this. This would ensure that transition planning could be securely linked to the shared information and planning required for those children with an EHCP. It should also be noted that there are those YP with Visual Impairments in need of transition planning who do not have an EHCP but are on what is now called Support Plus or School Support. They will not now have the trigger of a Yr 9 Review for planning. Hence the importance of communication between services. There is already some concern that health isn't engaging with the EHCP process as well as it should. This would also ensure that all relevant professionals are engaged. This is particularly important with low incidence groups such as vision impairment (VI) and where health and social care provision may not be well connected with broader/ more generic service provision.
59	National Autistic Society	Introduction	For young autistic people, the transition between child and adult services can prove to be disruptive time. Many parents describe the process as being like 'falling off a cliff', as support falls away. We believe that it is vital that the needs of young autistic people are covered within this Quality Standard.
60	The Royal College of Anaesthetists (RCoA) and the Association of Paediatric Anaesthetists of Great Britain and	Introduction	It is important to state within the introduction that Transition is not appropriate for every child, for example 1. Children with terminal disease whose life expectancy is so short such that transition to a different service would be inappropriate or 2. Children with oncological disease whose treatment is close to completion and who may be approaching a "cure" or 3. Where surgical techniques needed are confined to paediatric rather than adult surgeons in the locality. All these factors will confound data collection and illustrate that there will always be a small number of

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	Ireland (APAGBI) joint response		exceptions where Transition may not be in the best interest in the child or young person. It would be helpful if this were to be raised within the QS process to ensure that commissioning is appropriate and "understands" this concept.
61	British HIV Association	Question 1	Continuity of care with the same team is important-not seeing a different Dr each time Attendance at adult service physical environment within the transition process That the young person has an understanding in advance what's expected of them on transitioning (e.g. -some centres use a written contract which Dr & transitioning patient both sign e.g. outlining how often they will be expected to attend, need to be in charge of picking up meds/ordering more/ that they are aware of who to call out of hours or during hours if they are unwell or they can't attend a booked follow up Appropriate hand over between team who has looked after them pre transition & the new post transition team e.g. a written summary or health passport (The patient to see this summary/ outgoing team go through it with them Agreed timeframe which the young person is involved in. They need to understand why it is happening, when it is happening and agree to it
62	British Society of Paediatric Dentistry	Question 1	The American Academy of Paediatrics, produced a policy statement in 2002 which articulated 6 critical steps to ensure a successful transition to adult-orientated care. They propose that a portable, accessible, medical summary should be developed which would facilitate the smooth collaboration and transfer of care among and between health professionals. Examples of good practice: The Hospital passport and patient held record ; Dorset Yellow Book. These form the basis of a transition document containing valuable information for the adult services. Dorset Healthcare University Foundation Trust have also developed a Transition Information Proforma. This accompanies the patient's notes but is purely related to Dentistry. However, this could be adapted for all clinical specialties. It provides valuable additional information on issues such as access and transport needs, social history, and preferred methods for communication.
63	British Thoracic Society	Question 1	Q1 'The draft quality standard accurately reflects the key areas for quality improvement '(namely a)early planning – year 9, 13-14 yo, b) regular review of progress in transition (annual meeting), c)involvement of parent and carers, d)named key worker and e) young person to meet adult team before transfer)
64	British Thoracic Society	Question 1	Q1 The quality standard does a reasonable job of identifying key areas of improvement from a document which is certainly aspirational but less clear on the specific measures to be enacted.
65	Coeliac UK	Question 1	To facilitate transition of care, a transition document should be created by the paediatric team prior to transfer. This documentation should include details of the diagnosis and information during follow up. In the case of coeliac disease this could include serology, anthropometric data, comorbidities and dietary compliance.
66	Health Education England	Question 1	I think the statements should include some that measure whether the process is person centred and the young

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			person/carer is involved e.g. the young person and their carers understand the transition process the views of the young person/carers are gained and feed into the transition planning young people have the opportunity to/attend the annual review/transition meetings.
67	Institute of Health and Society, Newcastle University. On behalf of the NIHR funded Transition Research Programme.	Question 1	Are the standards an accurate reflection of key areas for quality improvement? It would be interesting to know why these particular quality standards were chosen. Given that the evidence of benefit for the changes/interventions required by the standards is limited, other quality indicators could equally well have been chosen such as: Having a written Transition Plan Evidence of a holistic approach - that the wider needs and aspirations of the young person were being considered and taken account of by health services, not just the health care. Having a coordinator of Transition across an NHS Trust (or health and social care providers), rather than a named worker for each individual.
68	Kidney Research UK	Question 1	Kidney Research UK welcomes this quality standard as transition in renal services is a critical issue. In particular young people face significant risks of losing transplants when transitioning because of the disruption to their relationships and circumstance. The quality standard correctly identifies some of the key areas where quality improvement is needed in transitional care. It is good to see the acknowledgement of the difficulties and disruption of transition and the risk that without proper support young people can disengage from services with possible adverse effects to their care. The experiences of our patient contacts has been variable and inconsistent. A person-centred, integrated approach to services is key. Although a concern raised is that it could come across as very process-driven and that a key factor needs to be the attitudes and behaviours of staff. A focus should be on caring and continuity for the transitionees. The processes therefore need to be flexible in order to incorporate this.
69	National Association of Independent and Non-Maintained Special Schools (NASS)	Question 1	The evidence in the introduction makes explicit reference to the additional challenges faced by young people leaving out of authority residential schools, and trying to make a successful transfer to adult services (Beresford and Cavet, Transitions to adult services by disabled young people leaving out of authority residential schools, 2009). The experience of our members (independent special schools, non-maintained special schools, special academies and special free schools) backs up these findings 100 per cent. There are particular challenges for young people who are placed some distance from home. Our member schools tell us that for these young people, it can be incredibly hard to engage their home local authority and the adult services local to their home in their transition planning. The result of this is that there is often no contact whatsoever with the home local authority or local services prior to the young person leaving the school. This obviously has an impact on the success of the transition to adult services for the young person. Due to the well-evidenced additional challenges for young people placed in residential schools outside of their home local authority, we strongly suggest an additional standard is added to improve the quality of transitions and outcomes for these young people. Our suggesting wording would be:

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			QS 7 ‘Young people who will move from children’s to adults’ services and are placed outside of their home local authority in a residential setting will have a practitioner from their home local authority attend their annual transition review meeting from Year 9 onwards’.
70	Royal College of General Practitioners	Question 1	The RCGP welcomes this document but recommends to include the following: 1) GPs ought to make contact after unplanned admissions during and after transition. 2) A comprehensive letter ought to be sent to the GP at the time of transition to include a summary of the records, a care plan and a list of medium to long term squeal of treatment and things for the GP to monitor. Especially important where young people are discharged to primary care- e.g. those who have had cancer. 3) Each young person going through transition ought to have a named GP. 4) Each young person going through transition ought to have a medical with their GP- it could be one GP within the practice as often happens with patients with Learning Difficulties or their usual GP. At this appointment, their general health and mental health would be assessed, confidentiality would be explained, they would be seen for at least part of the consultation by themselves. This would have resource implications. 5) When a young person is deemed to be going through transition the paediatrician ought to see them by themselves for part of every appointment. 6) Every child going through transition ought to have confidentiality explained to them - this could be included in 5. It would be ideal to collect a series of case studies and develop a literature of good practice.
71	Royal College of General Practitioners	Question 1	This page sets the tone of the document yet there is no mention either of the health needs of the young person unconnected with their condition and which have been managed in secondary care or new health needs such as contraception, new mental health problems (young people with long term conditions and young people leaving care are at high risk of developing mental health problems). The document talks about continuity yet there is no mention of the GP who can provide the bridge between children's and adult services
72	Royal College of Paediatrics and Child Health	Question 1	There is no reference to the transfer of information between hospitals – highlighted as important from a medical perspective by multiple authors in the research literature
73	Royal College of Physicians (RCP)	Question 1	Does this draft quality standard accurately reflect the key areas for quality improvement? Our experts believe that the draft quality standard does accurately reflect the key areas for quality improvement. It would be feasible to collect the data but it might be necessary to develop local systems in order to collect it. Where transition services have not yet been developed some funding from commissioners may be needed to help establish joint paediatric and adult transition services. Cost savings are likely to be achieved by improved clinical outcomes from successful transition.
74	Tees Esk and Wear Valleys NHS Foundation Trust	Question 1	The quality standard does not reflect transition of care of young people from secondary to primary care. A significant number of young people take this route.

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75	The Faculty of Pain Medicine (FPM) of the Royal College of Anaesthetists	Question 1	Question 1: Does this draft quality standard accurately reflect the key areas for quality improvement? Yes, as easily measurable objectives. Overall the idea is clearly motivated well but for Pain Management Services it does not reflect current realities (provisions, CCG funding etc.)
76	British Academy of Audiology And British Society of Audiology (Paediatric Audiology Specialist Interest Group)	Question 2	In audiology most services use some patient management system. In these cases it should be possible to collect the data required. This will depend upon achieving agreed outcome criteria and methods of measurement. Many audiologcial staff in the main work with adults and do not always routinely support paediatric service users. The general population of an adult audiology clinic tends to be on average 55 + years of age. Paediatrics present with many different audiology issues to those of the older population such as different prescriptions for hearing aid fittings right through to situations which they will encounter, school, work, university etc. We therefore recommend it is not practical for children of 13 or 14 years of age to enter the routine adult service. In addition, majority of audiology service commissioning now differentiates adult and paediatric services, with an age cut-off at 18 + years of age. Routine adult services tend to more often than not be commissioned with multiple NHS providers (public and private), whereas more specialist adult services remain with one main provider. Paediatric services tend to be commissioned from one local NHS provider (either in acute or community). Hence at transition one paediatric provider could be in the situation of transitioning to numerous different routine adults providers. We strongly advise that clear guidance is given to ensure that adult service providers have the necessary skills, expertise and facilities to deal with individuals' needs and specifically to safeguard against delayed care that complex cases are appropriately referred to non-routine adult service providers.
77	British Thoracic Society	Question 2	It will be necessary to develop local systems to collect data for the proposed quality measures given the nature of services, however clarity of what is to be measured is essential, eg . How do you genuinely 'measure' if the parents/carers have discussed their expectations?
78	CoramBAAF Adoption and Fostering Academy	Question 2	Presumably social care would be responsible for data collection and some members report that required systems and structures are largely in place. Social care takes the lead on organising the annual meeting as part of the LAC review and having a named worker for all care leavers.
79	Institute of Health and Society, Newcastle University. On behalf of the NIHR funded Transition Research Programme.	Question 2	How feasible would it be to collect the necessary data? It depends at what scale it should be collected. It should be feasible for a smallish, discrete service or single disorder to capture the necessary data – eg congenital heart disease. But many young people with long term health conditions will have multiple needs and problems so that the monitoring of health and social care transfer will be complex, with young people transferred from a single children's secondary care to a mixture of many adult secondary care providers and General Practice. This would be even more difficult to collate at NHS Trust level for all long term health conditions; or at Commissioner level across a number of provider NHS Trusts.
80	Royal College of	Question 2	Recording of quality may be a challenge for some organisations as digital systems remain sub-optimal to deal with

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	Physicians of Edinburgh		the transition of data and collect the data that is necessary to ensure “quality”. It may be worth considering investing in staff in departments to universally record the necessary metrics for measurement of quality and delivery. All these quality standards require resource to flag and track patients. This can be difficult with paper based systems but will work better with the move to electronic records. A clear issue is that in most parts of the country electronic systems in hospital, general practice, social care etc. are not compatible. Where would data capture be held and shared?
81	Suffolk County Council	Question 2	Not presently. The extent and complexity of reporting may result in diverting resources into tracking and recording (away from delivering support) which is a worry. One alternative might be reporting by exception (co-ordinate reporting around numbers of cases requiring unmet support and the speed of response). There are plans for a single record for each Suffolk citizen in the near future, but the practicalities of fully utilising these are in development.
82	The Faculty of Pain Medicine (FPM) of the Royal College of Anaesthetists	Question 2	No, without clearer guidance on what is actually meant by some of the proposed quality measures, it wouldn't be feasible.
83	The Royal College of Anaesthetists (RCoA) and the Association of Paediatric Anaesthetists of Great Britain and Ireland (APAGBI) joint response	Question 2	We are not convinced that there are any local systems and structures in place to collect data for these quality standards nor that whatever systems are available collect a universally applicable or comparable dataset. Commissioning in this area will need to be very proscriptive to ensure that meaningful data is accrued. Each QS requires local data collection, that is a big ask!
84	The Royal College of Speech and Language Therapists	Question 2	We believe that local systems and structures are in place, but this is not a big issue in terms of local speech and language therapy services.
85	Suffolk County Council	Question 3	Suffolk has made a decision to have a 0-25 team starting with our most complex cases from 1 September 2016 (who are managed by a smaller cross-section of professionals). We are modelling many of the themes posed in the quality statements, and we will be able to anticipate and reflect on some of the challenges of applying this approach and meeting the quality statements for other cases beyond that initial group. Reflections on the complexity around managing a broader range of cases is included in other comments. Suffolk Signs of Safety and Well-Being sets out the principles behind practice in Children’s Services in Suffolk which can be found here Suffolk Supporting Lives Connecting Communities sets out the principles behind practice in Adult’s Services in Suffolk which can be found here Early help teams (Suffolk Prevention and Early Help Strategy 2014-2016) facilitate the family to find solutions to own

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			problems PATH is one planning tool of choice across Suffolk found here and referenced here and is delivered by a range of professionals and settings (including West Suffolk College Foundation education)
86	The Faculty of Pain Medicine (FPM) of the Royal College of Anaesthetists	Question 3	We need this transition as currently the patients are with paeds till 18 and then suddenly emerge in adult clinic. This will be ideal in better equipped bigger services. In Leeds, there is currently such a system, where patients (including parents) are seen with both adult and paed pain consultants and a transition planned. They are clearly debriefed about the lack of pampering that they are used to in the paeds service and a proper follow up management is organised.
87	The Royal College of Speech and Language Therapists	Question 3	No comment
88	British Thoracic Society	Question 4	The NICE Guideline 'Transition from Children's to adults' services for young people using health or social care services' is a broad general guideline covering all medical conditions, mental health and social services. For Respiratory Medicine it may be particularly relevant to areas such as Cystic Fibrosis, bronchiectasis (e.g. primary ciliary dyskinesia), complex asthma and neuromuscular disease (muscular dystrophies). The NICE Guideline and Quality Standards were developed with in-put from the RCP Young Adult and Adolescent Steering Group, chaired by Dr Helena Gleeson. For several well established services that are already commissioned as in the cystic fibrosis year of care the quality standards would be met by transition clinics held jointly between paediatric and adult services, or similar arrangements. However in the absence of such established funding mechanisms, many adult services have difficulty in providing the support and infrastructure that children / young adults have received previously. Some form of "transition funding" is needed to bridge this gap in both real and expected availability in support. This may be especially so wehre medical equipment is involved, such as in the use of assisted breathing kit, eg cough assist machines, suction machines and ventilators. If such services don't exist , and they will not for many conditions then they should be encouraged to develop with funding from commissioners. NICE acknowledges that 100% compliance with a standard may not be appropriate taking account of safety, choice and professional judgement.
89	British Thoracic Society	Question 4	'Where transition services have not yet been developed some funding from commissioners may be needed to help establish joint paediatric and adult transition services'. For some services, eg ventilator support this may be more of an issue than say asthma, where there is a need for medical equipment as well as support from clinical staff Cost savings are likely to be achieved by improved clinical outcomes from successful transition.
90	Institute of Health and Society, Newcastle University. On behalf of the NIHR funded	Question 4	Are the statements achievable? As mentioned in our comment above (No 7), we think annual meetings for all young people would not be feasible for practical and financial reasons. As mentioned in our comment above (No 11), we do not think having a named worker for all young people across

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	Transition Research Programme.		transition is feasible. We think the other statements are achievable and would not require many additional resources. They are about existing services and staff working in a different and more collaborative way. However, we think there would need to be considerable resources to actually collect the data. So there is a paradox. The changes needed are clear and achievable. But it would be expensive to routinely monitor changes.
91	Royal College of Paediatrics and Child Health	Question 4	On the whole we are happy with this document. The quality standards are appropriately accompanied by requirement to the Commissioners to commission a service that has capacity to provide these needs. It would be sensible to strengthen these statements. There is currently unprovided capacity in many of the receiving adult services. For example, there is currently no defined Adult Osteogenesis Imperfecta Service to lead on from the commissioned national service with 4 centres for Children's OI. Appropriate investment in these services will be essential for children with this as one example of many paediatric conditions which will require improved provision in adult services to adequately ensure seamless transition.
92	Suffolk County Council	Question 4	If funds were available (so resource dependent) increasing capacity to take on a wider range of cases within an Integrated Early Help Team setting for example would address significant capacity issues around those eligible for limited (or no) services A return to Year 9 reviews across schools for a wider range of vulnerable young people (where professionals are invited when they have been involved in planning for the young person) would place the school and education at the centre of planning for all those needing support with preparing for adulthood rather than just those eligible for an Education, Health and Care Plan
93	The Faculty of Pain Medicine (FPM) of the Royal College of Anaesthetists	Question 4	Question 4 Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? No. For Pain Services the statements do not reflect the nature of the problem or its management. They would incur costs as Adult and Paediatric professionals would need to be engaged in significant time actions to implement. It would require reorganisation of pain management services across regions to provide equity and continuity. More resources would be required to facilitate named workers and appropriate follow up in adult services There are fundamental differences in the provision of Pain services and the adult reflection of child services with psychology support is still geared to brief education and discharge. We have the following examples provided by a Pain Medicine Consultant that illustrate the lack of resources available generally: "Not sure where we would find time to see young people with our paediatric colleagues or be lenient to accommodate DNAs. We need all the clinic time we have to see patients already waiting 18+ weeks. Paediatric input involves little or no intervention, is psychology and OT heavy with a lot of one-to-one support and

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			liaising with school and other services. Patients are seen in an MDT clinic over an hour. Because GPs are uncomfortable with medication paediatric services often prescribe all medications and review frequently. There is also support for parents. In contrast, we see adult patients as little as possible for as shorter time as possible, as individuals (not MDT). There is a drive to pass as much care as possible back to the GP and MSK. Self-management is the central theme. Interventions are our primary specialist input. There is minimal support for the patient and no support for their family. One to one psychology is a limited resource with a long waiting list. If a patient doesn't engage we do not chase them because to be frank, it's one less patient on the list. I am not suggesting this is an ideal model but one that reflects the resources of the modern NHS. The withdrawal of financial penalties for breaches of RTT and A&E wait is acknowledgement that there are no resources to meet the current rudimentary models of care and that trusts have no money. My Medical Directors suggested that the CQC are soon to be told to reframe from recommending change that is resources dependent and that trust will be encouraged to ignore recommendations from colleges that also require increased resources." The above examples highlight the need for consideration of how children's long-term pain should be treated outside of specialised hospitals and the need for better integration between adults and adolescent pain management services. What happens if there is absolutely no children's pain service? Does the acute paed pain team get involved? If no children's pain service, does there need to be a liaison person between adult and children pain services for the few children that may have chronic pain? There is concern that patients may have inappropriate medication prescribed by well-meaning paeds professionals or even an acute pain team.
94	The Royal College of Anaesthetists (RCoA) and the Association of Paediatric Anaesthetists of Great Britain and Ireland (APAGBI) joint response	Question 4	The Quality Standards might well be achievable provided there is investment in systems for data collection. However resources will need to be appropriately redirected to "follow the patient" and to include the formalised process described in QS 1-6. It is not envisaged that cost savings are achievable here; however investment should not need to be significant provided resources are appropriately directed.
95	The Royal College of Speech and Language Therapists	Question 4	We welcome the draft quality standard and its focus on communication. The standard is much needed and does reflect the key areas for quality improvement in relation to transitions from children's to adults' services. However, we are concerned that it does not provide sufficient detail to support changes in practice at a local level. In many ways the quality standard is aspirational, it reinforces what best practice should look like in terms of the transition process and what staff on the ground should be sighted on and committed to at present, but it does not

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			include new ideas. Regrettably the document also does not acknowledge pressures faced by local providers and the need to provide additional resources to support change. Local health and social care services are already struggling to deal with their current caseloads and coordinating the transition of support for children with severe disabilities and complex communication needs from children's to adults' service requires a large amount of work. Adding additional responsibilities to practitioners' roles without extending resource is unrealistic and without a mandatory element it is unlikely that a generalised NICE quality standard will be prioritised and implemented at a local level.
96	The Royal College of Speech and Language Therapists	Question 4	We are concerned that the resource impact report for the standard says there is no resource impact for this quality standard, which does not reflect or acknowledge the work at a ground level with young people and the complexities of the systems around them. As noted above, adding additional responsibilities to the role of professionals working with children and young people will require extra time and therefore additional commissioned resource. The quality standard does not reflect the complexity of the transition process or the diverse and complex needs of children and young people. The document uses an example of the transition of a child with diabetes from children's to adults' service. However, the transition of children with complex communication needs and severe disabilities is multifaceted and is very hard to deliver and navigate. Supporting the transition of children with profound multiple needs to adults' services would require the involvement of a range of professionals including local respite services, a range of specialist primary and secondary health care services, social care and education services, all of which have different structures and models existing between child and adult provision. We believe that the quality standard can be improved by acknowledging the complexities of the transition process and the challenges faced by local health and social care practitioners noted below. In particular, there is a need to acknowledge the extra capacity needed to support young people with complex communication needs and the importance of building in the named transition officer role into local commissioning processes and all health and social care contracts. Current commissioning arrangements: The document implies that lifelong commissioning arrangements are in place or shortly to be in place at a local level; however, this does not reflect the current commissioning arrangements for child and adults services. In many local areas, children and adults' health and services are not integrated and a child's support worker will often have to navigate an adult system that they have no knowledge of. We are disappointed that the document does not acknowledge that in many instances young people may not meet the eligibility criteria for adult services. RCSLT members have highlighted that there is a 'cliff-edge' at age 18 where some young people move from continued care to almost no support. For example, 43% of respondents to the RCSLT's recent SEND survey (publication forthcoming) reflected that SLT support was not being commissioned for young people aged 18-25 in their local area, following the implementation of the SEND reforms. Partnership working:

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			The document references GP involvement in the transition process, but in practice it is often extremely difficult to engage them in the transition planning process. Levels of partnership working varies greatly between different localities and despite guidance outlined in the Children and Families Act and the Special Educational Needs and Disabilities Code of Practice in many areas education, health and care service do not work together in a coordinated way. For example, only 18% of respondents to the RCSLT SEND survey said that they worked effectively with adult social care colleagues. Possible solutions and areas for improvement of the quality standard include: The inclusion of quality indicators: the document does not make reference to specific quality indicators which can help to measure progress towards implementation of the standards. We recommend that as the standard is developed it could include indicators that measure outcomes that reflect the delivery of quality care for young people, for example, using a self-assessment tool. The development of infrastructure and systems to support children's needs: It is important to recognise that the additional time and resources needed to effectively support young people with complex communication needs. We welcome the standard's reference to non-engagement by children and families, as it is important to allow time for follow-up with young people with communication needs as they may experience challenges with attending meetings. For example, young people with Specific Learning Difficulties (including problems with spoken language) can also experience difficulty with sequencing, organisation and time management. Page 19 of the standard states that a named worker should support a young person after transfers and until a time agreed with the young person and their family. However, we recommend that in order to prevent a backlog, there is a need to agree a set time by which the named worker will no longer be involved, as young people (and understandably families) may wish to continue contact with their named worker as preference, but this may not be possible in terms of resource. We agree that there is a need to begin transition planning at year nine, but there is a need to be pragmatic and acknowledge that a child or young person's needs are likely to change over a four year period, as are the services and eligibility around them. It would be helpful if the reference to this issue within the quality standard document is revised to reflect this. In addition, we recommend that the list of issues reviewed as part of the annual meeting process on page fourteen of the standard should be revised to include the mental capacity act/ decision making and the impact this has for the young person and their families.
97	CoramBAAF Adoption and Fostering Academy	Questions 1 and 4	Although the standard appears to cover some key areas it is overly simplistic in suggesting that starting early and having an annual planning meeting are the main requirements. Considering transition planning from the perspective of the health of a looked after young person, the young person needs to understand their health history, learn to manage any health conditions, engage with health promotion and gradually assume more responsibility for their own health. This is an ongoing process which requires engagement and ongoing support, usually from the specialist nurse for LAC/care leavers and may involve various appointments, discussions, and availability of support by phone and

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			text. This is a resource intensive role and our members report that commissioning arrangements are often insufficient. Resource implications for the full scope of activities involved in high quality transition planning should be addressed in the QS.
98	Barnardo's	Statement 1	Barnardo's is responding to the quality statements in respect of children in care and young people leaving care and making the transition to independent adult life. In particular we wish to comment on the arrangements for transition from CAMHS to adult mental health services. In Barnardo's experience the sooner arrangements are made for the support of care leavers in respect of their health needs, including mental health, the better. Barnardo's believes that the timing and planning for transition as appropriate should be incorporated in to each care leaver's Pathway Plan when this is drawn up. However earlier consideration of transition needs would be to the benefit of the looked after child when planning for their transition to adult life more broadly.
99	British Academy of Audiology And British Society of Audiology (Paediatric Audiology Specialist Interest Group)	Statement 1	Children with severe learning difficulties (and other comorbidities) will often remain with paediatric services for longer, so transition should start later.
100	British Association of Paediatric Nephrology (BAPN)	Statement 1	This statement may be hard to measure in all organisations due to available resources or infrastructure. Many organisations can measure this if they use one of the available generic transition programme tools or frameworks. (For example the Ready Steady Go programme (www.uhs.nhs.uk/readysteadygo)) Using a generic multi-disciplinary tool or framework provokes discussion of issues with the young person, ensures documentation of aims, planning and progress can be reviewed. This also allows benchmarking across the UK. The introduction of electronic databases across Trusts will allow this to be measured.
101	British Association of Paediatric Nephrology (BAPN)	Statement 1	If already in a service young people (YP) can start planning for transition by the end of year 6, beginning of year 7 at the age of 11 years. Studies show that starting transition at around 11–12 years of age leads to better knowledge and skills, resulting in improved long-term outcomes. Starting around 11 years of age or soon after ensures the YP and carer has more time to prepare for adult services and can move through the process at their own pace. For many YP, this is also a time of change as they are moving from junior to secondary school, are taking on more responsibility and 'feeling like big boys and girls'.
102	British Society of Paediatric Dentistry	Statement 1	Page 9: We support the aim of planning the transition as early as possible. This should be easily measurable
103	CLIC Sargent	Statement 1	We completely agree that a more gradual transition can lead to a much smoother and less traumatic experience.
104	CLIC Sargent	Statement 1	Transitional care and joint clinics should be mentioned in commissioning contracts, especially where an adult hospital trust is fed by a Children's hospital. Such transitions can be even more traumatic where families are moving to a completely new hospital, not just a different service within the same location.

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105	CLIC Sargent	Statement 1	We think that some reference should be made to NICE NG43 – Recommendation 1.2.3 - that the point of transfer should not be based on a rigid age threshold or take place at a time of relative stability for the young person, as referenced in the Briefing Paper.
106	CLIC Sargent	Statement 1	We agree that, 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.
107	CoramBAAF Adoption and Fostering Academy	Statement 1	Specialist nurses for looked after young people have a key role to play with all aspects of health care and transition planning for care leavers and much good work is carried out, including early planning for transition. However, our members advise that in practice most paediatric health services including those for looked after children are only commissioned until the age of 18, which makes it impossible to provide effective services and follow up beyond that age. Many LAC health services report that adult health services, particularly CAMHS, have a poor understanding of the health and social care needs of LAC, and that it can be difficult to engage with adult health services for transition planning. Furthermore these young people often fail to meet thresholds to receive adult mental health services despite well recognised complex needs, and this must be addressed if transition planning is to succeed.
108	CoramBAAF Adoption and Fostering Academy	Statement 1	Although the QS does specifically mention children in LA care no reference is made to the fact that this group of YP will be subject to the LA pathway planning which is to prepare for transition to leaving care; the QS should link with that guidance.
109	Darlington Borough Council	Statement 1	This statement provides a clear directive to ensure that all young people have effective planning for their future needs and aspirations. All young people have a transition review in Y9. Participation in the Local Government Association Learning Disability Project highlighted the strengths of a service which operates from ‘cradle to grave’ with two teams covering Children 0-25 and Adults aged 26+. An innovative Housing Needs Matrix gathers information from age 14 of young people known to the service to gather information for their aspirations/needs for housing, employment and independence in the future. This assists with the wider development agenda for colleagues in housing services.
110	Derbyshire County Council and North Derbyshire CCG	Statement 1	Early planning is essential but timing must be flexible and in accordance with young person’s needs. It may not be known at year 9 whether the young person will be eligible for adult support; needs, thresholds and services are subject to change. Young person’s view of the process and of their experience of adult support would be useful measures to capture. Also Parental views should be obtained. Who should arrange and chair meetings if the young peron is not subject to a statutory review (they may not have an EHC plan)
111	Durham County Council	Statement 1	It is extremely important that health/education/social care services agree local systems and structures to work in a coordinated way with families so that planning for adulthood is meaningful and purposeful to the young person. Health/education/social care services and commissioning need to find ways of reducing the number of transitions a young person must experience. For example: we need to develop a better and balanced understanding of the holistic needs of the young person, i.e. social opportunities, identity and the importance of family rather than focusing heavily on educational needs. As much as possible young people should have the opportunity to remain living or near to family and should be able to access in-county education and health and social care services.

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112	Genetic Alliance UK	Statement 1	We welcome the emphasis placed on early preparation and gradual transition contained in this statement. However, we feel that the quality standard should include mention of the importance that transition should be developmentally appropriate, and not based on a rigid age threshold, contained within the guideline. We feel that the quality standard should mention the importance of ensuring that the point of transfer occurs at a time that is suitable for the specific needs of the young person and their family, in order to lead to significant improvements in how those with rare, genetic and undiagnosed conditions experience transition from children's to adult's services. 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 have repeatedly 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.
113	Great Ormond Street Hospital	Statement 1	The wording 'by year 9' is confusing in healthcare settings. Are we to measure those at the beginning of year 9 or the end? Far better to have a specific age
114	Great Ormond Street Hospital	Statement 1	As a tertiary centre we have YP who will be transferred to adolescent services at another hospital at 16. We also have YP transferring to adult care at 16 depending on local paediatric/adult service provision.
115	Great Ormond Street Hospital	Statement 1	As a tertiary Paediatric centre we have a large number of YP who are referred for one episode of treatment, investigations or 2nd opinion. It is often challenging to differentiate between these and YP who will receive ongoing care at the tertiary centre.
116	Great Ormond Street Hospital	Statement 1	We have a cohort of YP who are unlikely to survive into adulthood and it is not always appropriate to start transition
117	Haemnet	Statement 1	In haemophilia the key areas for quality improvement are development of the skills to self manage in preparation for transition planning and this happens well before year 9. If the statement were to include 'at the latest' this would add weight to the statement
118	Institute of Health and Society, Newcastle University. On behalf of the NIHR funded Transition Research Programme.	Statement 1	'The proportion of young people who will………who have started their planning for transition'? What is the definition and operationalisation of this? Is the measure to be collected by a NHS Trust for all the young people who will transfer across chronic illness, complex physical impairment, mental health, learning disability, palliative care? It would be difficult to establish the denominator, let alone the numerator.
119	Kidney Research UK	Statement 1	Our patient contacts felt that although this seemed early to start transitional care, their experiences of having had 10 year long plus relationships with consultants meant that building bonds with those in adult care and getting used to changes needed to start early. Those who had to cut ties with their consultants suddenly after knowing them for so long found this very hard.
120	National Association of	Statement 1	The experience of our members is that local authorities (LAs) currently do not develop transition plans with the young

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	Independent and Non-Maintained Special Schools (NASS)		disabled people in their schools much before they are due to leave the school, and rarely, if ever, in Year 9. We know that quality transition support should start by Year 9 at the latest, and therefore suggest statement 1 is strengthened to read 'Young people who will move from children's to adults' services have an initial transition plan in place by year 9, or immediately if they enter the service close to the point of transfer. The legal duty on LAs to ensure effective transition planning from Year 9 onwards for young people with Education, Health and Care Plans (ECHPs) is clear in the Children and Families Act 2014 and related Code of Practice. This could helpfully be highlighted in the QS.
121	National Association of Independent and Non-Maintained Special Schools (NASS)	Statement 1	EHCPs are statutory documents that the LA has legal responsibility for. There is a requirement that from Year 9 onwards the annual review of the EHCP includes a focus on 'preparing for adulthood'. EHCPs may provide a valuable data source for monitoring the delivery of this quality standard.
122	National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Statement 1	This statement may be hard to measure in all organisations due to available resources or infrastructure. Many organisations can measure this if they use one of the available generic transition programme tools or frameworks. (For example the Ready Steady Go programme) Using a generic multi-disciplinary tool or framework provokes discussion of issues with the young person, ensures documentation of aims, planning and progress can be reviewed.
123	National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Statement 1	If already in a service young people can start planning for transition by the end of year 6, beginning of year 7 at the age of 11 years. This coincides with their natural progression / transition to secondary school. Commencing transition planning at a younger age allows gradual preparation with small steps and targets to promote independent care, increase knowledge and / or self management of own condition or need.
124	Real Life Options	Statement 1	We would want to emphasise the benefits of bringing the expertise and opportunities of adult services into the picture at an early stage and not leave to a later tender process.
125	Real Life Options	Statement 1	It is vital that local authorities make available data about future needs available in their market position statements and work with providers to ensure that there is a range of suitable support available.
126	Royal College of General Practitioners	Statement 1	This is obviously an easy to measure standard but does not fit in with the evidence that we should enable a developmentally appropriate transition process not one governed by the calendar e.g. Brain development continues up to the age of 25 and some parts of the country are now transitioning from Child and Adolescent Mental Health Services to adult services between the age of 20 and 25.
127	Royal College of General Practitioners	Statement 1	As this guideline is to do with young people transitioning in secondary care, it is going to be difficult for GPs to start planning this.
128	Royal College of Nursing	Statement 1	It may be inappropriate to commence transition planning of a new referral during an acute treatment plan despite the child's age at presentation; For example a 15-year-old male with typical presentation of Acute Lymphoblastic Leukaemia - Transition planning would commence after completion of the acute treatment phase at 17 years of age.
129	Royal College of	Statement 1	Information systems will need to be improved to ensure all such young people are identified particularly in large

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	Paediatrics and Child Health		services.
130	Royal College of Paediatrics and Child Health	Statement 1	Timing of transition from Yr 9 may mean several years of transition from 13 yrs old at least until 18 yrs and there is no recommended quality standard for adult care and responsibility which may extend several yrs beyond 18. In practice age of transition varies according to care responsibilities and localities as well as resources. This standard should indicate age (13-14yrs) rather than school year (9) which vary in different schools, and some children may be home educated or not attend school at all.
131	Royal College of Paediatrics and Child Health	Statement 1	Statement 1. Young people who will move from children’s to adults’ services start planning for their transition by year 9, or immediately if they enter the service close to the point of transfer. Nb: Year 9, is defined as ages 13 or 14 years in the document. Comments: The above definition of Year 9, relies on children going through education without gaps/delays and attaining normal academic achievements. It would be more appropriate to specify that planning for Transition starts by age 13 to 14 years. The Second part of the statement “or immediately if they enter the service close to point of transfer” is unclear and even not required. By defining a specific age, this would include all children who require Transition to adult services.
132	Royal College of Paediatrics and Child Health	Statement 1	“Health and social care practitioners (such as GPs, hospital consultants, nurses, social workers and mental health workers) ensure that they start transition planning for young people who will move from children’s to adults’ services by year 9, or immediately if they enter the service close to the point of transfer.” Comments: Does this QS recommend GPs to be involved in Transition, as this is not the case for patients with inherited metabolic disorders transitioning from a Tertiary childrens hospital to a tertiary adult hospital
133	Royal College of Paediatrics and Child Health	Statement 1	Question 1 – Yes. A maximum age target provides sufficient guidance to standardise national care policy whilst allowing the flexibility needed to be developmentally appropriate (as stated by NICE guideline NG43 recommendation 1.2.3). A flaw could arise in conditions that have a very unpredictable or fluctuating course (eg mental health), where predicting future service use is difficult. Question 2 – Uncertain. Presumably the onus will remain with clinicians for identifying the need for transitional planning to start. To ensure high consistency clinicians will need the change in guidance highlighting in training. Auditing 283process ‘a)’ could prove challenging. The numerator calculation should be theoretically simple as long as local systems have simple records of transitional planning starting. An accurate denominator calculation may be more challenging as it relies on a prediction of who will require transition into adult services. Question 4 – Yes. The resource impact of implementing this guidance should be negligible.
134	Royal College of Physicians (RCP)	Statement 1	Young people who will move from children’s to adults’ services start planning for their transition by year 9, or immediately if they enter the service close to the point of transfer. Our experts suggest making this statement more precise by stating:

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			'Young People and their parents/carers should be introduced to the concept of transition at age 11-12 and have entered a formal programme of transition planning by year 9, or immediately if they enter the service close to the point of transfer.'
135	Royal College of Physicians of Edinburgh	Statement 1	Starting transition by age 13-14 seems reasonable as a starting point, as it acknowledges it as a gradual process. However it may be inappropriate to assign an age group– transition should only commence when the child is ready and it is appropriate. A specific age may not work for all so flexibility and the judgement of Paediatricians is required in deciding when young people are suitable for transition. Therefore, a quality measure with a specific age could push patients inappropriately into the transition process. There are also current financial inducements within some care pathways which are likely to result in children remaining in paediatric services. This is because of the use of enhanced service payments for Paediatric clinics achieving high level service measures.
136	Suffolk County Council	Statement 1	This is the process for young people who are eligible for Education Health and Care Plans in Suffolk, however not all schools follow the process and there are many more young people for whom such a meeting to commence planning would be helpful.
137	Sussex Partnership NHS Foundation Trust	Statement 1	- This statement would be hard to plan, implement and measure in relation to transition in Child and Adolescent Mental Health Services (CAMHS) for the following reasons - Not all children and young people at that age will be expected to remain with CAMHS consistently until they reach adulthood and very few would have symptoms that meet the criteria for adult mental health services. Given that children and young people are expected to attend and access education at age 13-14, it would be important to emphasise the role of educational staff (tutors, SENCo (Special Educational Needs Coordinator), or other appropriate staff at school or educational department if being home schooled) in planning and supporting young people through their transition. If the young person is in care, then the allocated social worker will have a central role in coordinating and liaising with all relevant agencies in planning and supporting transition care plan across education/vocation, health (physical and mental health), social services and any other services. Most community CAMH (Child and Adolescent Mental Health) teams are under resourced and struggle to meet the clinical demand of increasing and complex referrals. The clinical teams usually have a waiting list even to deliver timely therapeutic interventions to children and young people to address mental health difficulties and starting transition plans at age 14 without additional investment in services to employ transition workers are likely to further divert existing resources to other areas resulting in longer clinic waiting lists Currently most CAMH teams plan transition at 17.5yrs of age which is too short period to even plan transfer to adult mental health services and gives little time to develop a comprehensive transition plan. Hence, our CAMHS (Child and Adolescent Mental Health Service) in Hampshire has planned to start the transition process when a young person is 17yrs old with an expectation of joint review and joint working between CAMHS and Adult Mental Health

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			Services (AMHS) and Learning Disability Services up to 6 months before and after 18. Discussions in relation to transition could be started earlier if appropriate. Hampshire CAMHS has set up a multi-agency mental health transition steering group that includes representation from service users, providers and commissioners from adult and children's services including primary care, acute, community services, learning disability services, education, social care and voluntary sector who have jointly developed a comprehensive transition care protocol to establish principles and expectation of different services in supporting young people and their carers during transition from CAMHS to adult services in the community that includes adult mental health services.
138	Tees Esk and Wear Valleys NHS Foundation Trust	Statement 1	Agree with planning transition early (from year 9). However, our service is working towards a model of recovery and it is not always clear if young people will require transition to adult services. There will be young people who clearly will be transitioning to adult services and others who will only be with us for short-term interventions; there is also a 'middle group' for whom we would not automatically start planning transition at year 9.
139	The Association for Family Therapy and Systemic Practice in the UK	Statement 1	Coming from a background in CAMHS, I have concerns about the appropriateness of identifying young people who may need to transition to adult services as early as Year 9. That may work well for young people with chronic conditions but at that age mental health issues are not fixed and predictable. It could be positively unhelpful and counter-productive to introduce the idea that a mental health problem is going to persist for five years and beyond. Possibly instead there could be a standard requiring written recording that consideration had been given to the question Having said that, I agree totally with the principle of good transition planning. In practice I would say that for mental health services Year 12 is the time to start thinking and planning.
140	The Faculty of Pain Medicine (FPM) of the Royal College of Anaesthetists	Statement 1	Should be qualified by "if developmentally appropriate". We would suggest that age 13-14 may be too early to begin a transition. We would hope that many adolescents with pain do improve and do not need transition.
141	The Guide Dogs for the Blind Association (Guide Dogs)	Statement 1	Our concern with this standard is not so much with the process (transition planning by year 9 makes sense) but in relation to what actually happens for many blind and partially sighted young people. In our experience, many young people are still not equipped with the pre-requisite skills that they need for the next stage of the education and personal development. By way of an example, it is often the case that a Habilitation Specialist will be approaced two or three weeks prior to a young person beginning a work placement with a request to offer some guidance and training to prepare a student for journeying to, and navigating their way around, the placement. In some cases, they have not even mastered the basics of orientation and mobility let alone be in a position to acquire and be able to use the skills they need with any degree of confidence in the time available. Children with visual impairment do have discrete needs that generic systems and processes do not adequately address. We are not arguing for specific reference to habilitation needs within the statement, but did want to flag up our concern about its effectiveness in

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			addressing a longstanding issue about poor transition planning for children and young people with visual impairment.
142	The Howard League for Penal Reform	Statement 1	Founded in 1866, the Howard League for Penal Reform is the oldest penal reform charity in the world and is the leading non-governmental organisation dealing with penal reform in the United Kingdom. It was awarded special consultative status with the United Nations in 1947. The Howard League provides an expert legal service to children and young adults (under 21) in prison. We are an independent charity which accepts no grant funding from the UK government. The Howard League is a member of the Transition to Adulthood Alliance (T2A). The Howard League has represented young people in prison who have transitioned from children's services to adult services during their time in custody and our response draws on this experience. The distinct health and social needs of children and young adults who begin the process of transition from children to adult services while in secure settings (including prison settings, secure children's homes and training centres and mental health settings) must be recognised and planned for by health and social care providers and facilitated by the Ministry of Justice and the prison service. Children and young people in secure settings must be given opportunities to engage in health and social care planning at an early stage. Health and social care services must ensure that custody does not act as a barrier to prevent engagement. Health and care services must ensure secure settings facilitate discussion and annual planning meetings, involve parents and carers and support young people in making choices about their care. The early planning suggested here is to be commended but so far from the current reality of children in secure settings. Their next physical location as adults is unlikely to be known even six months before they turn 18 and transition to adult services. Special safeguards need to be in place for this group.
143	The Royal College of Anaesthetists (RCoA) and the Association of Paediatric Anaesthetists of Great Britain and Ireland (APAGBI) joint response	Statement 1	The term "year 9" is used in this statement, firstly on p7 and then throughout the document but it is not defined until page 11. School year, i.e. "year 9" is not a universally understood term.
144	The Royal College of Anaesthetists (RCoA) and the Association of Paediatric Anaesthetists of Great Britain and Ireland (APAGBI) joint response	Statement 1	The Quality Standards would be simpler and more accessible if the easier reference term of "age" rather than school year was used throughout.

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145	The Royal College of Anaesthetists (RCoA) and the Association of Paediatric Anaesthetists of Great Britain and Ireland (APAGBI) joint response	Statement 1	There is an assumption within this Standard that there is always a parallel service to move to in adult health which is not infrequently false e.g. Multidisciplinary teams for neuro-disability in paediatrics but often no equivalent services to move to. There are also notable examples of deficiencies in services where there is an absence of a service for YP until they reach e.g. 18 years of age." Paediatric" services may well be reluctant or even refuse care to 16/17 year olds particularly if they newly present but some adult services will not take on YP until they reach 18 years e.g. Chronic Pain Services where typically training by psychologists does not encompass the 16/17 year old. This gap is not acknowledged either by the NICE guidance or associated Standards and is an important missed opportunity. There are groups of young people requiring active health interventions in whom the need for Transition to Adult services is indefinite at Year 9/age 14 e.g. following a complex set of surgical procedures for congenital abnormality. In this situation there may be a reluctance to plan an annual meeting with adult care as there is an expectation that it will not be needed. Again this is not noted or addressed by the Guideline or Standards.
146	Transitions Service, Leeds Camhs	Statement 1	Year 9 would be far too young to start planning for transitions in mental health services. We wouldn't know this early if adult mental health services were required. In Leeds, we start planning for transitions at 17.5 which seems about right. Sometimes it might be appropriate to start the planning just after 17 if they are particularly complex but this is still a long time til 18 and needs can change drastically during this time period. We don't know the outcome of any therapy or treatment at such early stages. Many young people who require a mental health service at 13/14 do not by 18.
147	VISION 2020 UK	Statement 1	We support the aim to begin planning for transition at this time (for 13 to 14 year olds). We agree that specific reference to YP entering the service close to the point of transfer as there are eye conditions that emerge and begin to have significant on function around these ages.
148	Barnardo's	Statement 2	An annual meeting with relevant health professionals for children in care should be included in the child in care six monthly review and chaired by an Independent Reviewing Officer in accordance with the CYP Act of 2008
149	Barnardo's	Statement 2	In the case of children in care parents and/or carers will be present at six monthly reviews and the overall care of the child and future plans for their health care including mental health care should be incorporated in a meeting chaired by and IRO as above
150	Birmingham Children's Hospital Rare Disease Team	Statement 2	This type of annual meeting requires resources, lots of planning and coordination to achieve all stakeholders attend. Most health care practioners do not have allocated time for transition so it is essential that the role of a named worker is actually a person with dedicated time to enable all the objectives to be met rather than wishing and hoping that this will happen. Therefore, commissioners needs to fund the transition post and also the time required for lead practioners such a consultants to have this in their job plan rather than being something additional that certain individuals do but not all
151	British Academy of Audiology And British	Statement 2	An annual MDT for several years for every child transitioning to adult's services would have a very high cost implication across all of primary care, secondary care, education and social care. For example, a child with a

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	Society of Audiology (Paediatric Audiology Specialist Interest Group)		moderate hearing loss but no other comorbidities this would involve: paediatric audiology, adult audiology, teacher of the hearing impaired, GP, SENCO, possibly an ENT consultant, possibly a speech and language therapist, and the family. There would need to be strong evidence that several such a meetings would add significant value to the individual child to justify this.
152	British Academy of Childhood Disability (BACD)	Statement 2	There is a request for the lead clinician to attend annual transition planning meetings. This will not be possible as there are insufficient resources at this time in the paediatric workforce across England to allow this to happen. Hopefully these transition planning meetings will be part of planned education led annual review of EHC plan meetings, as an additional raft of meetings will not be welcome by families or professionals. The guidance should make this clearer. It may be more achievable to say that lead clinicians should be asked for their most up to date report to inform the meeting, rather than asking them to attend in person. The guidance states the annual meeting should include also the GP. This is completely unrealistic and will really get GPs backs up, at this time when they are so very overstretched that they are struggling to deliver basic services. It is really important that NICE recognise this and do not make statements that are completely unachievable. Again, it would be more realistic to state that the GP should be asked for a contribution if they would like to make one, should be invited to attend if possible (recognising that this is unlikely) and should be included in minutes of the meeting, as well as the paediatrician / lead clinician (this would be a very positive step as doesn't always happen at the moment). It would be a disaster if NICE were to raise families expectations that lead clinicians, paediatricians and GPs should be attending these transition meetings, as this will not help relationships between these hard-pressed clinicians and the families who they are doing their very best to serve.
153	British Association of Paediatric Nephrology (BAPN)	Statement 2	Whilst it would be ideal to have an annual meeting regarding transition planning this would be hard to implement due to the differences in provision of local systems across all organisations. The young person may be transitioning to a service some distance away or transitioning to primary care therefore professionals whose attendance would be valuable, are not able to attend annual meetings due to work commitments. Many children's health services have established young person's / adolescent clinics several times a year often permitting joint reviews between children's and adult's services. The young person may be under the care of several professionals at different locations creating limitations for an annual meeting. Use of a generic transition programme tool or framework provides a progressive approach that different professionals can utilise regarding their own specialty. This allows documentation of planning for the young person each time they see professionals, rather than rushing to address issues in the final year or months close to transition or transfer to adult services. Using a generic transition tool with a structured framework and monitoring progress of the YP and carer through the programme would formalise the measurement of progress through the programme - as in Ready Steady Go
154	British HIV Association	Statement 2	The annual meeting needs to be individualised to the needs of the young person. Those young people (and the carers of them) with HIV are concerned about confidentiality and the school and other services apart from General Practitioner may not be aware of their status. They may have no other health issues or social care needs. The

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			presence of their GP may or may not be required but liaison with the GP about transition care must occur but this can be done via letter in non-complex cases. If the child/parent wishes the GP to be involved this should be facilitated, although there is a resource issue of GP availability. The measure needs to reflect how long young people should be supported for and take into account if they have moved to another centre e.g. moving city because of university/work. Who then is responsible for ensuring engagement? This is often when young people maybe lost to care. Will a transfer letter mean that obligation has been met? What are the obligations of the new provider?
155	British Society for Children's Orthopaedic Surgery	Statement 2	This is not achievable within the resources currently available. The group of children looked after by BSCOS members and for whom transitional care is of most relevance is those with cerebral palsy and myelomeningocoele. These children commonly receive simultaneous care from several subspecialties. For meaningful preparatory meetings this would ideally require the attendance of all such subspecialties. Not all BSCOS members work in units where such multidisciplinary team meetings (MDTMs) exist anyway and therefore consideration would need to be given to the resource implications of not only setting aside time for such meetings in units with existing MDTMs but also in those where these do not exist as yet. Further, standalone Children's Units would have to accommodate the additional practical (location) and organisational aspects of involving the adult and children's subspecialty clinicians and allied health professionals although for some BSCOS members they undertake care in both children's and adult sectors. BSCOS supports preparation for transition and recognises timely input. It would ask NICE to recognise that the resources for this are not available as things stand if the coexistent ongoing work of their members is to be maintained at its present level. A further consideration is the anticipated extension of the paediatric age group to the end of the 18th year of age. If this is so then would the transition planning not be better delayed until 16/17 tears of age?
156	British Society for Children's Orthopaedic Surgery	Statement 2	As for the response to statement 1 BSCOS supports preparation and review in planning for entry into adult services. Those children that some of our members care for that will transfer into ongoing adult care are a significant number overall and BSCOS would again raise the issue of resource implications. There would have to be additional funding to manage the existing caseload that would be displaced by such meetings if there was to be no effect on the service provision in terms of time frames (eg 18-week waits for surgeries and clinic appointments). That would be in terms of additional manpower at consultant level in the simplest terms and may mean relocation/centralisation of the care of children with these pathologies.
157	British Society of Paediatric Dentistry	Statement 2	Page 12: We support the concept of an annual meeting but would propose that there is input from the child's dentist at this point so that Oral care and preventive programmes are included, as appropriate for each individual child. Page 14: Clinical needs should include oral care.
158	British Thoracic Society	Statement 2	Quality Statement 2 refers to an annual meeting 'which should involve the GP, representatives from both children's and adults' services, the young person and their parents or carers'. In many specialist respiratory conditions (e.g.

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			cystic fibrosis) this will usually be achieved by a joint paediatric and adult transition clinic with the young person and parent present. In practice it would be difficult to expect a GP to attend; and it would be more appropriate that '..the GP is kept informed of the transition process; rather than necessarily attend a meeting..
159	CLIC Sargent	Statement 2	We agree and support the approach that transition planning documentation be periodically updated through an annual meeting.
160	CLIC Sargent	Statement 2	We think that it is a great idea to involve all practitioners providing support to the young person and their family or carers, including the GP, at the annual meeting. According to NICE NG43 – Recommendation 1.2.4 (in the briefing notes) this could be either in person or via teleconferencing or video. However, we wonder if this is workable? How can we ensure that GPs commit time to this?
161	Coeliac UK	Statement 2	During the transition process, the importance of adherence to the treatment, and consequences of non-adherence should be discussed. This is of importance as the responsibility for adherence starts to transfer from the parent/carer to the adolescent.
162	Darlington Borough Council	Statement 2	All young people have an annual review meeting which addresses all of the transition issues for the young person and their family/carers. In Darlington the Life Stages Service supports children and young people from birth with two teams - Children 0-25 and Adults 26+. This aspect is key to ensuring robust and effective transition planning for young people and their families.
163	Derbyshire County Council and North Derbyshire CCG	Statement 2	A six monthly meeting as the young person nears the point of transition may be preferable to annual meetings, however – who is responsible for arranging, chairing, follow up etc?. Young person may have an annual review if they are the subject of an EHC plan but this tends to focus on education planning, often health are not represented at the meetings. GPs do not attend these meetings. Clarity needed on responsibility for arranging and chairing the meetings particularly if the young person does not have an EHC plan and may not have a formal statutory review.
164	Durham County Council	Statement 2	Consideration needs to be given around the complexity of the young person's needs and any additional needs of parents/carers to inform appropriate time of reviews. Many young people with complex needs and severe disabilities will require a minimum of a 12 month review. Unless they have complex needs which require 6 monthly reviews.
165	Haemnet	Statement 2	Haemophilia services will need to have increased capacity (greater local resources) to engage with service users who may not have needed to attend clinics with any degree of regularity (for example, those with less severe phenotypes)
166	Institute of Health and Society, Newcastle University. On behalf of the NIHR funded Transition Research Programme.	Statement 2	Annual Meeting. It is totally unrealistic to involve all practitioners who provide support, GP, representatives of both adult and child health and social care (including education) services. It is often the case that the GP cannot attend even for Safeguarding Conferences or EHCP meetings for children with disabilities. So the idea that such a large group could form every year for all young people with ongoing and/or chronic illnesses such as diabetes, neurodevelopmental disorders, mental health problems or those with cerebral palsy only under an orthopaedic surgeon is unrealistic.
167	Institute of Health and	Statement 2	Under definition of terms it currently reads 'The annual meeting should also involve the young person and

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	Society, Newcastle University. On behalf of the NIHR funded Transition Research Programme.		parents/carers'. Surely this 'should' ought to be 'must' involve.
168	Kidney Research UK	Statement 2	Annual meetings for transitional care did not seem enough. The ideal was felt by our patient contacts to have young people attend a transitional care clinic in order to find support and access to services. If transitional clinics were not an option, one meeting a year for transitional planning was not felt to be sufficient.
169	London fire and emergency planning authority	Statement 2	LFB welcomes the opportunity to comment on this draft quality standard and note that it 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 adult's services, including young people with mental health problems, disabilities, long-term, life-limiting or complex needs or in local authority care. LFB has a particular interest in this area as our published evidence1 shows that such individuals are at increased risk from fire due to an impaired ability to recognise risk, respond appropriately or escape if a fire happens. Our data also showed that many of the people with physical or mental health problems that died in a fire were in contact with local health and social care agencies in relation to support for their condition but few were known to LFB before the fire happened. Because of this, we would ask that assessment of fire risk forms part of the transition planning process for young people moving to adult services, ideally as part of the annual meeting referenced in Quality Statement 2 where the young person's needs are reviewed. Fire Safety of People in receipt of Domiciliary Care – FEP 1952 http://moderngov.london-fire.gov.uk/mgconvert2pdf.aspx?id=920 Fire Safety for people with Mental Health issues – FEP 2303 http://moderngov.london-fire.gov.uk/mgconvert2pdf.aspx?id=3292 Review Of Accidental Dwelling Fires and Fatalities – FEP 2484 http://moderngov.london-fire.gov.uk/mgconvert2pdf.aspx?id=4384
170	National Association of Independent and Non-Maintained Special Schools (NASS)	Statement 2	To strengthen this standard we suggest it is amended to be more specific: 'Young people who will move from children's to adults' services have an annual meeting to review transition planning *from Year 9 onwards*.'
171	National Autistic Society	Statement 2	The QS proposes that the annual meeting 'should inform a transition plan that is linked to other plans the young person has in respect of their care'. We believe that the QS should make explicit reference to the fact that a young person may have an education, health and care (EHC) plan. If they have an EHC plan, their transition plan should be coordinated with this, with both documents setting out clearly how the transition process will work and what support

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			will be provided to the young person, when, and by whom.
172	National Autistic Society	Statement 2	The annual meeting should also be coordinated with a young person's social care needs assessment, which the Care Act 2014 requires local authorities to carry out for every young person who is likely to have care and support needs after they turn 18. The statutory guidance on implementing the adult autism strategy further highlights that the Care Act duties 'apply to all young people with autism, not just those with an EHC Plan (p24). It also highlights that 'young people with autism are identified by the Care and Support statutory guidance as a group whose members may not have received support as a child but who may have care and support needs as an adult'. The new Quality Standard offers an opportunity to ensure that all a young person's health and care needs are fully considered in time for necessary services to be planned and put in place.
173	National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Statement 2	Whilst it would be ideal to have an annual meeting regarding transition planning this would be hard to implement due to the differences in provision of local systems across all organisations. The young person may be transitioning to a service some distance away or transitioning to primary care therefore professionals whose attendance would be valuable, are not able to attend annual meetings due to work commitments. Many children's health services have established young person's / adolescent clinics several times a year often permitting joint reviews between children's and adult's services. The young person may be under the care of several professionals at different locations creating limitations for an annual meeting. Use of a generic transition programme tool or framework provides a progressive approach that different professionals can utilise regarding their own specialty. This allows documentation of planning for the young person each time they see professionals, rather than rushing to address issues in the final year or months close to transition or transfer to adult services.
174	Roald Dahl's Marvellous Children's Charity	Statement 2	The definition of the 'annual meeting' should state that the young person's named worker must be present at these meetings.
175	Roald Dahl's Marvellous Children's Charity	Statement 2	This type of annual meeting requires resources, lots of planning and coordination to achieve attendance from all stakeholders. Most healthcare practitioners do not have time allocated for transition, so it is essential that the role of a named worker has the time dedicated to ensure all objectives are met. Therefore, commissioners need to fund transition posts, while at the same time ensure that lead practitioners, such as consultants, have the time to manage transition factored in their job plans, rather than being additional responsibilities for certain individuals, but not all.
176	Royal College of General Practitioners	Statement 2	Are these meetings going to cease as soon as the young person has moved? Often it is after transition that problems occur and support is needed. It may be worth it to review this quality standard again and clarify for how long these meetings are going to take place.
177	Royal College of General Practitioners	Statement 2	See Definition. Although this guideline is about children moving from paediatric services to adult services, the only practitioner who is prescribed to attend these meetings is the GP. The GP is not necessarily the best placed person to talk about the young person clinical needs and has often had little involvement with more complex patients.
178	Royal College of Nursing	Statement 2	Annual meetings to review transition planning may not be practical for those patients that do not routinely require annual review of their medical management.

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			This will have an implication for healthcare professional's caseloads and out-patient department capacity.
179	Royal College of Nursing	Statement 2	The coordination of the annual review to include parent/carer, young person, all practitioners, GP and representatives from both children's and adult services may be an unrealistic expectation. GP – capacity to attend meetings may be a challenge Adult service provider - may be out of region for patients attending supra regional specialist children's services providing a challenge
180	Royal College of Paediatrics and Child Health	Statement 2	Recognition will be required that transition planning requires longer clinic appointments within the NHS to both address transition in addition to all the other medical issues as well as ensure annual review meetings as well as to enable separate appointments with young person as well as with the parent.
181	Royal College of Paediatrics and Child Health	Statement 2	Will this be a formal meeting outside their clinic appointment or can it mean that transition planning will be reviewed with the YP and their family on an annual basis within routine clinics?
182	Royal College of Paediatrics and Child Health	Statement 2	Having annual meetings involving the GP and adult services is not realistic for specialties with relatively large numbers of such young people and large geographical catchment areas eg paediatric rheumatology. Primary care representatives should comment on this as I personally have found it difficult even to engage them on the phone to discuss transition never mind get them to attend a meeting 30 miles away!
183	Royal College of Paediatrics and Child Health	Statement 2	Annual review recommends involvement of a large number of professionals, - possibly for several yrs. There will be limitation of resources and co-ordination of working time between various practitioners to achieve this standard. The involvement of practitioners themselves will change over time, as they change posts or retire – and there are ongoing reconfiguration of services
184	Royal College of Paediatrics and Child Health	Statement 2	Question 1 – Yes. It is clear that the annual meeting should contain a thorough current 'needs' assessment and that this should inform a transitional plan. This will contribute considerably to all the key areas for improvement described. Question 2 – Yes. The binary nature of the process measurement ensures that auditing this guidance should be simple. Question 4 – No. A coordinated meeting of GP's, adult and child's health representatives and parents/carers and child is a significant logistical and resource challenge, especially in children who require multiple specialist input. This service would require large resource investment to be sustainable in most NHS trusts. Perhaps the increasing use of video conferencing in healthcare could increase the efficiency of these consultations. Alternatively and expansion of the named worker role (as recommended in statement 4) could be to provide a link between clinical staff and the patient/parents/carers to avoid the need for everyone involved to physically meet annually.
185	Royal College of Paediatrics and Child Health	Statement 2	Statement 2. Young people who will move from children's to adults' services have an annual meeting to review transition planning. Comments: Suggest: …move from children's to adults services have at least an annual meeting to review transition planning. This may have to be more frequent depending on the complexity and other needs and hence suggest this is

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			mentioned in the QS.
186	Royal College of Paediatrics and Child Health	Statement 2	“Annual meeting” The annual meeting should involve all practitioners providing support to the young person and their parents or carers. It should include the GP and representatives from both children’s and adults’ services. It should also involve the young person and their parents or carers.” Comments: As above
187	Royal College of Paediatrics and Child Health	Statement 2	There is a request for the lead clinician to attend annual transition planning meetings. This will not be possible as there are insufficient resources at this time in the paediatric workforce across England to allow this to happen. Hopefully these transition planning meetings will be part of planned education led annual review of EHC plan meetings, as an additional raft of meetings will not be welcome by families or professionals. The guidance should make this clearer. It may be more achievable to say that lead clinicians should be asked for their most up to date report to inform the meeting, rather than asking them to attend in person. The guidance states the annual meeting should include also the GP. This is completely unrealistic and will really get GPs backs up, at this time when they are so very overstretched that they are struggling to deliver basic services. It is really important that NICE recognise this and do not make statements that are completely unachievable. Again, it would be more realistic to state that the GP should be asked for a contribution if they would like to make one, should be invited to attend if possible (recognising that this is unlikely) and should be included in minutes of the meeting, as well as the paediatrician / lead clinician (this would be a very positive step as doesn’t always happen at the moment). It would be a disaster if NICE were to raise families expectations that lead clinicians, paediatricians and GPs should be attending these transition meetings, as this will not help relationships between these hard-pressed clinicians and the families who they are doing their very best to serve.
188	Royal College of Physicians (RCP)	Statement 2	Young people who will move from children’s to adults’ services have an annual meeting to review transition planning. In many specialist medical conditions this will usually be achieved by a joint paediatric and adult transition clinic with the young person and parent present. In practice it would be difficult to expect a GP to attend; and it would be more appropriate that the GP is kept informed of the transition process; rather than necessarily attend a meeting. Our experts believe that this statement is out of order and should come after statement 4, and probably also after statement 3. The statement also might be interpreted that the whole transition process could be managed through a single annual meeting. Our experts suggest: ‘Transition of young people from children’s to adult services should be a continuous process and integral part of that young person’s healthcare from year 9. Each Young person’s progress towards transition should be assessed at an annual meeting in both children’s and adult services, together with their parent/carer and their key worker.
189	Royal College of Physicians of Edinburgh	Statement 2	We would question whether an annual meeting for all is the best approach. What may be more helpful are on-going discussions at regular clinics as part of the routine care of children and young people approaching transition. This

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			needs to be approached on an individual basis rather than to a formula or designated age. For those with a complex, chronic condition, such as Cystic Fibrosis, more frequent planning discussions are required as transition approaches. The quality statement could instead read "should meet, at least annually". It may also be useful to have a template of best practice for this meeting. All specialists who may be required to follow up patients with long term conditions in secondary care and support services – such as physiotherapy, psychological medicine, substance abuse services, specialist nurses, crisis teams may find it difficult to deliver this statement. An annual meeting needs to have focus and there should be a detailed plan of who should form this group. One key issue is delivering care as close to home as possible. The infrastructure to set up joint clinics may be labour intensive for adult services. The numbers of patients and time allotted between paediatric and adult are vastly different. This will vary between each specialist service and becomes more complex for those in need of multiple specialist services due to the nature of their condition. In addition, one of the challenges is a dedicated adult team. For example, a paediatric patient with a kidney transplant will transfer from the main transplanting centre to a peripheral hospital with a renal service and then to the local hospital which is covered for renal services by the main hospital – hence the transition process can be somewhat complex and will not meet the standards in the current document. It is also likely that many children will have a number of specialist conditions and needs and transition into more than one adult service/clinic. There may therefore need to be parallel planning processes eg for adult renal and diabetic services. Ideally these would be combined but the NHS works in silos and this may not be practically possible. In addition the key MDT members can be diverse and numerous. There may need to be some virtual communication from some members of the team – getting all together will not be easy. For instance having a planning meeting with hospital consultants and GPs together is normally impractical.
190	Sheffield Teaching Hospitals NHSFT	Statement 2	Many of our patients have multiple specialties involved, expecting them all to attend an annual meeting together with the GP and community workers whilst laudable is not a realistic prospect that can be achieved. There will be resource implications for annual meetings as longer appointments will be required for a meaningful consultation to take place.
191	Suffolk County Council	Statement 2	This is the process for young people who are eligible for Education Health and Care Plans in Suffolk, however not all schools follow the process and there are many more young people for whom an annual meeting would be helpful.
192	Sussex Partnership NHS Foundation Trust	Statement 2	This may be relevant in young people with chronic medical conditions, potentially young people who are in long term medication follow up clinics in CAMHS (e.g. Attention Deficit Hyperactivity Disorder (ADHD) clinics) and young people with complex health and care needs that include mental health difficulties (would need clarity on who is the lead professional in such cases to organise annual transition planning and review meetings). It may be in the young person's best interests for educational staff (secondary school staff) to have a central role to plan transition for those young people from Year 9 onwards and involve the relevant health and social care services as appropriate during their annual review meetings.

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193	The Association for Family Therapy and Systemic Practice in the UK	Statement 2	The list of areas that the meeting should review could helpfully include * a review of the likelihood of the need for transition planning (this may be particularly relevant in mental health)
194	The Faculty of Pain Medicine (FPM) of the Royal College of Anaesthetists	Statement 2	Who would the annual meeting be with? This needs qualifying before agreement.
195	The Guide Dogs for the Blind Association (Guide Dogs)	Statement 2	We welcome the sensible focus on ensuring that a review meeting takes place “at least annually”. The quality statement itself though does not make any reference to 12 months as being the minimum frequency and we can envisage some young people benefitting from a review on a shorter timeframe. Of course, the regularity of a review does not necessarily mean that the review itself will be effective and we feel that the nature of the review is as important. In terms of children and young people with visual impairment, having a suitably qualified specialist involved in that review is vital, and that aspect is not reflected in this statement. Effective habilitation skills are essential in achieving life outcomes, and all too often young people in this group are failing to achieve their potential. A poor quality review, no matter how regularly conducted, will fail to identify needs that are not being met.
196	The Royal College of Anaesthetists (RCoA) and the Association of Paediatric Anaesthetists of Great Britain and Ireland (APAGBI) joint response	Statement 2	The standard is impractical. The concept of a separate annual meeting to plan Transition with all practitioners present including a GP may not be a practical or achievable one in the current health financial climate. Even if achieved is it a good use of time for a young person/family who may already have multiple appointments to have a completely separate annual meeting? Could this be done at the same time other annual reviews and be noted in the Standard?
197	Together for Short Lives	Statement 2	Should this state that there is *at least* an annual review meeting - as some young people with complex and fluctuating needs will need more frequent reviews.
198	Together for Short Lives	Statement 2	Young people and their families, shouldn’t just be involved in the annual review, they should be central to it wherever possible.
199	Together for Short Lives	Statement 2	The list of issues to address during the annual review should include living arrangements and short breaks.
200	Transitions Service, Leeds Camhs	Statement 2	This may work for those transitions that begin much earlier such as at year 9, however if we are starting a transitional period 6 months before 18, then an annual review would not be regular enough. We need to review the transitions plan more regularly in a shorter timescale.
201	VISION 2020 UK	Statement 2	We welcome the need to identify a regular review meeting but feel there needs to be specific acknowledgement of the need to review more frequently if required. In addition it would be helpful to ensure that there is a clear statement of outcome – that is the result of the review meeting being the creation/ modification of a transition plan.

ID	Stakeholder	Statement number	Comments[1]
			Returning to our concerns about engagement around the EHCP process we note that the data collection focuses only recording evidence of meetings. In order to ensure there needs to be some measure of the involvement of the required professionals and the production of an appropriate plan.
202	British Academy of Audiology And British Society of Audiology (Paediatric Audiology Specialist Interest Group)	Statement 3	This statement implies that young adults should transition across all their services at the same time; however in cases with multiple complex health and social needs, this may prove overly complex and detrimental for some individuals and as such we would advise graduated process.
203	British Association of Paediatric Nephrology (BAPN)	Statement 3	This statement may be hard to measure as annual meetings are not available in a structured format in all organisations. Using a transition tool with a structured framework and monitoring progress of the YP and carer through the programme would ensure both the YP and carer are progressing through the programme and any issues are highlighted and addressed- as in Ready Steady Go. Using a generic PREM for YP and carer at the different stages of Ready Steady Go – would allow this to occur. Or use of any structured transition programme- this would allow bench-marking.
204	British Society for Children's Orthopaedic Surgery	Statement 3	BSCOS would support a full and open discussion with relevant AHPs regarding what the realistic expectations should be for transition.
205	Carers UK	Statement 3	This statement says that parents and carers of young people who will move from children's to adults' services discuss their expectation of the transition process at the annual meeting. There is no mention of any associated carer's assessment to coincide with the transition process. As a young person transitions from children's to adults' services, the amount of caring responsibilities that their carer has may change as a result. The parent/carer also needs support through this process. Evidence from Carers UK's State of Caring survey 2016 of over 6,000 carers suggests that carers who look after a disabled child under 18 are much less likely to receive an assessment (only 19% of carers compared to 31% overall). This group of parent carers are also much more likely to have asked for their assessment (22%) rather than have been offered one (13%). Of those parent carers who have had an assessment: 29% said their ability and willingness to provide care was not properly considered in their assessment or the support they received. 44% said that the support they need to look after their own mental and physical health alongside caring was not properly considered; only 22% said that this was thoroughly considered and reflected in the support they received compared to 35% of carers overall. 40% said the support their need to provide care for others (such as another non-disabled child) was not properly considered in their assessment or the support they receive.

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			It is vital that the annual meeting is used to ensure that carers are also receiving the necessary support they need to care properly for the person they look after. The annual meeting is an opportunity to ensure that parents/carers have had an assessment and see what the outcomes have been There are also no standards or guidance on what the expectations of the transition process should be or what the transition process will mean for parents/carers.
206	CLIC Sargent	Statement 3	With regards to asking the young person regularly how they would like their parents or carers to be involved, during a recent CLIC Sargent consultation exercise with young people aged 16-24, most of the young people reported that they were asked about their wishes in regard to parental involvement - however, almost all then also said that despite being asked, their wishes were not taken into account in practice. Examples such as being asked about contraception use in front of parents, or being asked in front of parents if the young person had any questions, the young people said they did have questions that they couldn't ask in front of their parents. Yet at the same time they mostly said they still wanted their parents around and included when they wanted them to be. Young people must be given some time alone without parents for at least a part of the transition meetings.
207	CLIC Sargent	Statement 3	We agree with the following statement from the briefing notes; that ‘young people and their families should be given appropriate information about what to expect from future services’. Our young people with cancer report changes in the way they are monitored in adult services. Eg in paediatrics they may have had regular scans or blood tests as part of ongoing monitoring either for cancer signs or for managing existing late effects or risks of late effects. When they move to adult care monitoring is often perceived to decline in frequency but they do not get an explanation why and worry that they have been missed in the system.
208	CLIC Sargent	Statement 3	We also think it’s important to add describe the care / treatment plan that they will have under adult services (ensuring they are aware of changes, e.g. less frequent scans, limited community physio resources etc.)
209	Coeliac UK	Statement 3	We agree that parents and carers should be involved in the transition process, however during the transition it is important that the responsibility of medical care is gradually transferred to the adolescent to prepare them to have full responsibility for managing their condition.
210	Darlington Borough Council	Statement 3	All young people have an annual review meeting which addresses all of the transition issues for the young person and their family/carers. This provides the family/carers and the young person with the opportunity to raise concerns and discuss with key workers and other professionals. The voice of the child is supported by this quality statement.
211	Derbyshire County Council and North Derbyshire CCG	Statement 3	It is not enough for parents/carers to discuss their expectations; they should be provided with clear information and may need additional support. Additional support for parents/carers would require additional investment.
212	Durham County Council	Statement 3	Involving parents and carers and planning for adulthood should be an on-going process. Early planning and regular reviews from a multi-disciplinary perspective will help ensure young people and their families have realistic expectations of adult services. This also requires transparency of health and social care budgets/funding and care

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			packages and awareness of eligibility criteria.
213	Haemnet	Statement 3	As for statement 2 - Haemophilia services will need to have increased capacity (greater local resources) to engage with service users who may not have needed to attend clinics with any degree of regularity (for example, those with less severe phenotypes) Haemophilia is a condition that affects various members of the family and there maybe more than one person in the family on the transition pathway at the same time, therefore care will be needed in terms of time requirement for service users and their families.
214	Institute of Health and Society, Newcastle University. On behalf of the NIHR funded Transition Research Programme.	Statement 3	'Parents and carers of young people who will move from children's to adults' services discuss their expectations of the transition process at the annual meeting.' We think this gives the impression that the annual meeting is the main time when parents should be involved. It might be interpreted as a minimum standard and this would be unacceptable. Parents need to be appropriately involved throughout. Young people will often still be living at home and asking parents for advice and help around co-ordination of care. Also given our response above (No 7) about Statement 2 that an annual meeting will not be possible for all young people in transition, parents must be involved during consultations, not just at a potential annual meeting.
215	Institute of Health and Society, Newcastle University. On behalf of the NIHR funded Transition Research Programme.	Statement 3	Proportion of meetings at which expectations of transition are discussed. We see this as redundant. Surely that is one of the main purpose of the meetings and therefore covered under Statement 2 process – proportion of young people having an annual meeting. However as statement 3 is about parents, it might be preferable to emphasise (as in the Guidance) the important role that parents should be encouraged to take, in line with the young person's wishes as well.
216	National Association of Independent and Non-Maintained Special Schools (NASS)	Statement 3	Our members tell us that participating as fully as possible in the transition planning process is critical for young people, in terms of their learning, development and progress towards independence, as well as in terms of the plan being based on their preferences. We therefore suggest amending QS 3 to: 'Young people who will move from children's to adults' services, and their parents and carers, discuss their expectations of the transition process at the annual meeting.
217	National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Statement 3	This statement may be hard to measure as annual meetings are not available in a structured format in all organisations.
218	Real Life Options	Statement 3	Providers need to work with local authorities so that quality information about future options is shared in a meaningful way with parents and carers.
219	Royal College of General Practitioners	Statement 3	The default position in paediatrics is that the voice of the parent/carer is heard. It would be recommended to put a quality standard that ensured that the voice of the young person is heard. Part of the meeting, part of each consultation should be without parent /carer in the room.

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220	Royal College of Nursing	Statement 3	Annual meetings to review transition planning may not be practical for those patients that do not routinely require annual review of their medical management. This will have an implication for healthcare professionals' caseloads and out-patient department capacity.
221	Royal College of Paediatrics and Child Health	Statement 3	It will be important to stress the importance of both perspectives and not just that of the parent as the latter may differ from that of the young person!
222	Royal College of Paediatrics and Child Health	Statement 3	What about the satisfaction of the Young person?
223	Royal College of Paediatrics and Child Health	Statement 3	How will satisfaction be measured across services? This will require additional resource as not routinely done
224	Royal College of Paediatrics and Child Health	Statement 3	Question 1 – Yes. This statement directly relates to improving the experience of transition for child, parents and carers but will also influences the other stated outcomes. There is however no mention in the guidance of how the expectations of the child/parents/carers should be managed. Some form of transitional impact assessment would facilitate a clear prediction of how the transition is likely to personally affect a particular patient and could therefore be used to balance expectations. Question 2 – Uncertain. The process measure described would be easy to audit however the impact of this statement lies in the quality of the content of the meeting and not the actual event occurring. Question 4 – Yes. The resource implications of this statement should be minimal.
225	Royal College of Paediatrics and Child Health	Statement 3	Statement 3. Parents and carers of young people who will move from children's to adults' services discuss their expectations of the transition process at the annual meeting. Comments: As above: Parents and carers could discuss their expectations during a Transition meeting or at any time with their child's doctor or named worker.
226	Royal College of Physicians (RCP)	Statement 3	Parents and carers of young people who will move from children's to adults' services discuss their expectations of the transition process at the annual meeting. This statement is also misleading, and could be interpreted as indicating that the transition process only needs to involve and support the parents/carers' needs once a year. Our experts suggest: 'Parents and carers of young people who will move from children's to adults' services must be fully involved and supported throughout their child's transition process/pathway. Their needs and expectations must be formally reviewed, discussed and documented at the annual meeting.'
227	Royal College of Physicians of Edinburgh	Statement 3	It is essential to involve parents and carers at all stages of transition. However in many adolescent services it would be anticipated that carers and parents would gradually become less directly involved (for example a young person

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			with diabetes) with this approach encouraging a sense of individual responsibility. A measure that ticks the box to say the expectations were discussed is of no value unless it can be confirmed that these will be delivered, and if not, what the options are for carers and patients. This comes back to the available resources for centres and within centres.
228	Suffolk County Council	Statement 3	Parent views are important at all stages. Measuring this would be difficult and would need to reflect a balance with the wishes of the young person themselves (for example determining correct action when a parent's voice is different to that of the young person's voice or wishes).
229	Sussex Partnership NHS Foundation Trust	Statement 3	Parents and carers should be made aware of the consent, capacity and right to confidentiality of the young person to make independent decisions of their own care and the important role of carers to support such a transition and change. They would also need to be aware that the young person where they have capacity has a choice around whom they would like to involve during transition meetings.
230	Tees Esk and Wear Valleys NHS Foundation Trust	Statement 3	Parents and carers have a key role in supporting young people but there may be others who have a more significant role who they may wish to engage e.g. advocate, youth worker, tutor.
231	The Faculty of Pain Medicine (FPM) of the Royal College of Anaesthetists	Statement 3	It is not just the patient and parent expectations but also to understand the nature of a different service, which may be difficult discussions. The standard needs to recognise the fundamental difference and how to accept and engage with it – the emphasis on patients and parents is misplaced.
232	The Guide Dogs for the Blind Association (Guide Dogs)	Statement 3	We support this statement as it stands.
233	The Howard League for Penal Reform	Statement 3	Parents and carers are sometimes excluded or prevented from having any meaningful input into decisions and planning regarding their child's welfare or health needs whilst they are in secure custody. Parents can attend planning meetings for children sentenced to custody. However, there is a sharp difference in approach when young people transfer to adult secure settings at the age of 18. For example, children in secure settings have regular planning meetings within the establishment which include discussions about health and mental health. Yet, once they transfer to adult settings, parents are more often than not excluded from such meetings. In the case of young people severe physical and mental health needs, this can have a very adverse impact on their health and well-being. Health and social care services must make sure that they have made every effort to engage and consult with parents and carers and to involve them in the planning process for transition whilst their child is in prison and, with consent, when young person reaches 18. There are some examples of effective practice in secure mental health settings, for example where parents are permitted to attend Care Programme Approach meetings. This ought to be replicated in penal secure settings.

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234	The Royal College of Anaesthetists (RCoA) and the Association of Paediatric Anaesthetists of Great Britain and Ireland (APAGBI) joint response	Statement 3	"Parents and carers of young people discuss expectations…." This statement should explicitly include "young people" and their expectations as well. It is important that the statement is not perceived as third parties talking about the patient to the exclusion of the child/young person themselves. This should be an inclusive statement and include the child/young person within it. So "Children, young people their parents and carers should discuss expectations etc. etc." would be better.
235	The Royal College of Anaesthetists (RCoA) and the Association of Paediatric Anaesthetists of Great Britain and Ireland (APAGBI) joint response	Statement 3	There is an emphasis in the standard about involvement of parents and carers. However there is no equivalent standard which specifically addresses the need to improve involvement and participation of Young people. This is an important omission. Such a standard could include presence of methods of improving all modes of communication with young people, as well as making sure that clinic/hospital attendance is improved by provision of specific facilities for Young people, and flexibility in timing of appointments to suit needs etc. It might also explore the need to offer the Young People a choice of practitioner to lead their care in the future.
236	VISION 2020 UK	Statement 3	We fully support the involvement of parents and carers as outlined
237	British Association of Paediatric Nephrology (BAPN)	Statement 3	Professionals should recognise that parents and carers, questions, opinions and expectations of the transition process must be valued to enhance the therapeutic relationship between them and the key professionals involved in their child's / adolescent's care. These discussions can take place at any opportunity rather than waiting for an annual meeting. Not all young people will transition to identified adult services e.g. in a hospital setting, but will need to be equipped with the knowledge and skills necessary to manage their condition / situation when they are an adult, therefore gradual preparation will be vital. The use of a transition programme framework or tool (such as Ready Steady Go) for the young person should include addressing and supporting the parents and carers concerns, questions and expectations. Addressing these issues in a gradual process from age 11 years and over supports the parents and carers whilst they are supported to slowly hand over responsibility to the young person and / or increase the young person's confidence whilst still being involved in their care. Documentation of aims and progress in a transition programme tool or framework informs everyone of the additional support the parents and carers may need to manage their expectations and address their concerns.
238	Kidney Research UK	Statement 3	Parents and carers can be significant in a young person's care however this should be reviewed on a case by case basis as it can depend on the relationship the child has with their parent(s).
239	National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Statement 3	Professionals should recognise that parents and carers, questions, opinions and expectations of the transition process must be valued to enhance the therapeutic relationship between them and the key professionals involved in their child's / adolescent's care. These discussions can take place at any opportunity rather than waiting for an annual meeting. Not all young people will transition to identified adult services e.g. in a hospital setting, but will need to be equipped with the knowledge and skills necessary to manage their condition / situation when they are an adult,

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			therefore gradual preparation will be vital. The use of a transition programme framework or tool for the young person should include addressing and supporting the parents and carers concerns, questions and expectations. Addressing these issues in a gradual process from age 11 years and over supports the parents and carers whilst they slowly hand over responsibility to the young person and / or increase the young person's confidence whilst still being involved in their care. Documentation of aims and progress in a transition programme tool or framework informs everyone of the additional support the parents and carers may need to manage their expectations and address their concerns.
240	Transitions Service, Leeds Camhs	Statement 3	It is important to get the views and hopes of parents and carers about what the young person might need from adult mental health services and about what carers support might be available to them. A transition plan would need to manage the parent's expectations when young people are making the transitions to adult mental health services. Less emphasis is placed on the role of parents and carers in adult mental health, and more on the individual and whilst they still play an important role, the adult service will be reliant on the motivation of the individual to attend appointments and engage in the work. The implications of sharing information with parents/carers would also need to be clear.
241	Association of Paediatric Chartered Physiotherapists (APCP)	Statement 4	This is an important principle, however due to current commissioning arrangements this is difficult to achieve as children and adult services are commissioned separately with little scope for overlap and so unless commissioning is changed to facilitate a key worker from children's services to continue to support a child after discharge from paediatric services, or a key worker from adult services to support a child prior to their transition this will be difficult to achieve. A key worker is likely to be someone, like a paediatric physiotherapist, who has already developed a good relationship with the child and so someone who is already giving a high level of input to the child and family. The role of keyworker will add to the workload of an individual and will be difficult to manage unless additional resources are made available (i.e. caseloads reduced). It might be better to have specific posts / services created for key workers to focus on supporting children through transition and to act as intermediaries between children's and adult services.
242	Barnardo's	Statement 4	A named worker is welcome and Barnardo's recommends that that worker should liaise closely with local authority social workers and the IRO in the case of children in care, or personal advisers in the case of a care leaver
243	Birmingham Children's Hospital Rare Disease Team	Statement 4	The practitioner chosen by the young person as their named worker should be a transition worker or coordinator rather than adding on to other professional's role. This role requires resources in terms of time and also in terms of their job description. Currently this gets added on to people's already workload which is heavy and therefore gets done as an extra based on the individual health care professionals goodwill
244	Birmingham Children's Hospital Rare Disease Team	Statement 4	This type of annual meeting requires resources, lots of planning and coordination to achieve all stakeholders attend. Most health care practioners do not have allocated time for transition so it is essential that the role of a named worker is actually a person with dedicated time to enable all the objectives to be met rather than wishing and hoping that this

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			will happen. Therefore, commissioners needs to fund the transition post and also the time required for lead practioners such a consultants to have this in their job plan rather than being something additional that certain individuals do but not all
245	British Academy of Audiology And British Society of Audiology (Paediatric Audiology Specialist Interest Group)	Statement 4	An effective named worker would reduce the requirement for multiple multi-disciplinary meetings.
246	British Academy of Childhood Disability (BACD)	Statement 4	Having a named worker as a single point of contact through the transition process is a good idea. Stressing that this needs to be properly commissioned is very important as this role cannot simply be 'bolted on' to professionals day jobs. In Sunderland the learning disability transition nurse specialists fulfil this role for young people with confirmed learning disabilities. The concept of this worker being identified by the young person and therefore may be of variable background/ profession and may have differing levels of skills/attributes. There need to be a clear definition of the role, skills required, training and level of competencies to fulfil this role and the worker needs to have adequate resource/time available in their post and supervision/peer support.
247	British Association of Paediatric Nephrology (BAPN)	Statement 4	This could be problematic to implement or measure in some areas / organisations due to differing resources. Some areas may not have key professionals involved with the young person who possess the skills to link with other practitioners or services. In the health care setting nurse specialists frequently take up this role for the sub specialty that they work in but there are General Paediatrician's who do not have nurse specialist support and therefore need to address and coordinate transition themselves. If areas use a generic framework or tool to document aims, actions and progress this would provide evidence of the process that could be measured. This also provides information for any professional taking over the key named worker role which might be necessary with staff leaving / changing roles during the young person's care within children's services. Due to limited resources and workload pressures, some areas may have difficulty maintaining the key named worker role for a prolonged period after eventual transfer of care to adult services. Ultimately it is the responsibility of the YP's lead paediatric consultant to ensure this happens and ensures that links are made with the appropriate adult team and not left to the GP. Their lead paediatric consultant should be the link person post transfer of care if there are any issues to be addressed.
248	British Society for Children's Orthopaedic Surgery	Statement 4	BSCOS would support this in principle. There are significant resource implications including support workers with sufficient experience and expertise for the complexities of the issues surrounding the care of children with neuromuscular conditions.
249	British Society of Paediatric Dentistry	Statement 4	Page 17: We support the proposal for a single point of contact who will co-ordinate the transition in care both before and after the transfer. Page 18: This includes arranging appointments, which would be of great benefit.

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			Page 19:"this is a role, rather than a job title" - "directing to other services…." It is therefore important that this person is fully aware of all the relevant services available i.e. Paediatric and Special Care Dentistry Services within the area and they will need to have a knowledge of the referral pathways. One example/scenario where this can create difficulties: Child with complex medical condition and a learning disability is seen regularly for dental care by a Paediatric Specialist until the age of 18. They then move to a residential facility in a neighbouring county. The Registered GP changes and although they still come home in holidays, their oral care must be transferred to a Special Care Dentist within the new county. The suggestion in page 20 about meeting the new practitioner before transfer, is excellent and this author has been involved in one such case. However, theoretically this is ideal but may be more difficult to put into practice. Who are the practitioners which will be measured? Does this refer only to the GP? There are so many other elements of care which are critical for a smooth transfer. Parents and carers can be quite overwhelmed and currently, have minimal information available. Early discussions should include the child, parent and carer to enable them to contribute to the transfer plan.
250	Carers UK	Statement 4	Named worker – clarification is needed as to whether this is also the main point of contact for the parent/carer in case of anything arising. If not, there should be a relevant named person that the carer can turn to for support or questions around the transition process.
251	CLIC Sargent	Statement 4	We share the concern, expressed in the briefing notes, over the resources available to provide a named worker. We assume the child's treating consultant could be the named worker & therefore it would be important that the Consultant (or Staff Grade) does the transition meetings and not delegate to registrars rotating through the service on training.
252	CLIC Sargent	Statement 4	With regards to the named worker, we are surprised that Specialist Consultant is not in the list. In cancer the consultant is often heavily involved in transition planning and many conduct shared transition clinics with the adult long term follow-up services.
253	Coeliac UK	Statement 4	As described in the rationale for Quality Statement 4, various professionals are involved in the transfer to adult services. This reflects the importance of having involvement of the multi-disciplinary team during the transfer.
254	CoramBAAF Adoption and Fostering Academy	Statement 4	The specialist nurse for looked after young people may be in an ideal position to support the YP during the transition if this function is included in their remit at the time of commissioning, however this is rarely done in the current climate of stretched health resources.
255	Darlington Borough Council	Statement 4	This is achieved best through a joined-up approach that supports children from birth throughout their lives with seamless transition into adulthood.
256	Derbyshire County Council and North Derbyshire CCG	Statement 4	Is there a recommendation as to who acts as the coordinator for the annual review and where the responsibility for this sits? I.e. within health services. There needs to be capacity for some central coordination of monitoring this process. Each area could agree where this function sits best (e.g. health, social care, education), but there would need to be some admin/coordination function around this process, which was able to work across the different public

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			services.
257	Durham County Council	Statement 4	We agree that a named worker and a single point of contact is important, however young people require good links with advocacy. In many cases there will be a number of professionals involved with the young person's care and transitions cut-off points for different services often vary considerably across the transition period of 14-25. Therefore it is important that one person holds information and liaises with the young person and their family.
258	Genetic Alliance UK	Statement 4	We are very enthusiastic about the inclusion of a single named worker to coordinate transition care and support as one of the key quality standards. This may be the change that if implemented is most likely to improve the experience of transition for the patients we support. 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. Genetic Alliance UK considers a named care coordinator and clear care plan to be essential for all rare disease patients, but this is even more the case at times of transition.
259	Great Ormond Street Hospital	Statement 4	If the named worker is to support the YP after they have transferred this will preclude someone from the paediatric service being in this role unless resourcing is provided.
260	Haemnet	Statement 4	Are the systems in place for the 'named worker' to access both children's and adult services? We believe there are contractual barriers that will get in the way of this happening and will need to be addressed. The role of key worker in transition needs to be reflected in clinical competence frameworks. In haemophilia this is included in the current nurse competence framework, which is to be updated in 2017, and will need greater support from other clinical leads to empower them to take this lead role. Resources across multi-disciplinary team will be needed to engage with people who are infrequent attenders and don't have a relationship with the clinical team, especially as in haemophilia and other bleeding disorders patients often live significant distances from their centres.
261	Haemnet	Statement 4	It is likely to be deliverable for people with haemophilia and other bleeding disorders who frequently attend clinic and have a relationship with members of the clinical team but will be more challenging to deliver for individuals for whom engagement is infrequent because they haven't needed clinical input and yet are likely to have greater need of a named worker.
262	Institute of Health and Society, Newcastle University. On behalf of the NIHR funded	Statement 4	The named worker role is defined as coordinating transition care (e.g. arranging appointments) and providing support to young person and family. Given limited resources in health and social care, it will be very difficult for more than a few young people to have someone with time to take on such a role (consider the difficulties in putting into operation the 'key worker' model for children with disabilities, recommended in multiple documents since the 1976 Court Report

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	Transition Research Programme.		'Fit for the Future'). We heard Swaran Singh say at a meeting that it is the tasks of the named worker that are important, rather than that there should be a single person appointed as the 'Named Worker' to do them all. This is more realistic as a number of people could then deliver the relevant tasks, depending on the complexity for an individual and the service specification. For instance if a service had a manager/coordinator for transition, they could ensure appointments are arranged but might not even know the young person.
263	Institute of Health and Society, Newcastle University. On behalf of the NIHR funded Transition Research Programme.	Statement 4	The expectation is that a 'named person' acts throughout transition. As we stated in our feedback to the Draft Guidance, Transition may take up to 5 years (from 13-14 to 18-19 years of age), and given staff turnover it is highly unlikely a single named worker could operate throughout transition.
264	Institute of Health and Society, Newcastle University. On behalf of the NIHR funded Transition Research Programme.	Statement 4	Given we think it is neither practical nor affordable for every young person in transition having a single named worker, we think it is unwise to calculate a proportion for a target which most services will not even try to achieve.
265	London fire and emergency planning authority	Statement 4	We note that the named worker coordinator role, as set out in Quality Statement 4, is to act as a link and single point of contact with practitioners and service providers where there is need to signpost the young person to other services and sources of support. We would therefore ask that this includes contacting their local fire service to arrange a home fire risk assessment for advice on reducing fire risk specific to the young person's needs particularly where the young person may be leaving local authority care to move to a home of their own.
266	National Association of Independent and Non-Maintained Special Schools (NASS)	Statement 4	To strengthen this standard we suggest it is amended to be more specific: 'Young people who are moving from children's to adults' services have a named worker *from Year 9 onwards* to coordinate their transition care and support before and after transfer'.
267	Roald Dahl's Marvellous Children's Charity	Statement 4	The practitioner chosen by the young person as their named worker must have had, or must undergo, training in transition.
268	Roald Dahl's Marvellous Children's Charity	Statement 4	This type of annual meeting requires resources, lots of planning and coordination to achieve attendance from all stakeholders. Most healthcare practitioners do not have time allocated for transition, so it is essential that the role of a named worker has the time dedicated to ensure all objectives are met. Therefore, commissioners need to fund transition posts, while at the same time ensure that lead practitioners, such as consultants, have the time to manage transition factored in their job plans, rather than being additional responsibilities for certain individuals, but not all.

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269	Royal College of General Practitioners	Statement 4	This is a fundamental part of the guideline- it must be more than a box ticking exercise and the young person must have a voice in choosing the named worker.
270	Royal College of Nursing	Statement 4	The extension of the role of the named worker to coordinate transition including the provision of support after transfer to adult services and the coordination of out–patient appointments may have an implication for the capacity and workload of the named worker(s) making this an unrealistic expectation with current resources. This role may be better supported by a team approach.
271	Royal College of Nursing	Statement 4	The named worker continuing to support the '*young person and their family after transfer has been completed until a time agreed with the young person and their family'* may prove to be an unrealistic expectation due to caseloads depending on the young person and their parents' coping mechanisms and co-dependence. A guide to support an acceptable timeframe may assist this aspect.
272	Royal College of Paediatrics and Child Health	Statement 4	It will be important for such professionals to have this recognised in their job descriptions particularly in view of the workload that such coordination can result in.
273	Royal College of Paediatrics and Child Health	Statement 4	Comments apply as for Statement 2. A named key worker may change over several yrs, and there should be commissioned recognition of extra time that this role may involve.
274	Royal College of Paediatrics and Child Health	Statement 4	Question 1 – Yes. A nominated keyworker would provide a foundation for improvements in all quality outcomes stated. Question 2 – Uncertain. Again accurate calculation of the number of children expected to transition into adult care could be challenging. Question 4 – Uncertain. The resource impact of this statement is heavily dependent on the definition of the key worker role and the stress that exists on services prior to implementation. It would also appear critical that the key workers role is defined to the child/parent/carer as if this is not done appropriately it could lead to large fluctuations in the workload dependent on the child/parent/carers circumstance. In addition the input required from a keyworker is likely to vary significantly dependent on the child's point within transition and personal healthcare needs. Some recognition of this is needed prior to allocation of keyworker to ensure the service can be provided to the defined level. Ensuring equality of this provision would also require some standardised training to take place. The training required would be further influenced by the previous experiences of the personnel adopting this role.
275	Royal College of Paediatrics and Child Health	Statement 4	Statement 4. Young people who are moving from children's to adults' services have a named worker to coordinate their transition care and support before and after transfer. Comments: Please consider moving QS 4 before QS 2. Define Named Worker in the QS – i.e. Clinician/Nurse specialist/other health professional
276	Royal College of Paediatrics and Child	Statement 4	Named worker The named worker is a role rather than a job title. This should be one of the people from among the group of workers

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	Health		providing care and support to the young person, who has been designated to take a coordinating role. The young person should help decide who this person should be. It could be, for example, support planner, 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. A named worker should oversee, coordinate and deliver transition support. They should be the main link with other practitioners, arranging appointments for the young person, acting as their representative, directing them to other services and sources of support, and supporting the young person's family if appropriate. The named worker should be involved throughout transition, supporting the young person before and after transfer until a time agreed with the young person and their family. They should ensure they hand over responsibilities to a practitioner in adults' services (if they are based in children's services). Comments: Does a role as described above actually exist? Discussions around Transition in a Tertiary or hospital based setting is usually led by the clinical team of the Child and not a youth worker or social care practitioner. If this document is generic and includes all children in primary, secondary and tertiary care, the QS will have to take into account differences in service provision in these sectors.
277	Royal College of Paediatrics and Child Health	Statement 4	Having a named worker as a single point of contact through the transition process is a good idea. Stressing that this needs to be properly commissioned is very important as this role cannot simply be 'bolted on' to professionals day jobs. In Sunderland the learning disability transition nurse specialists fulfil this role for young people with confirmed learning disabilities. The concept of this worker being identified by the young person and therefore may be of variable background/ profession and may have differing levels of skills/attributes. There need to be a clear definition of the role, skills required, training and level of competencies to fulfil this role and the worker needs to have adequate resource/time available in their post and supervision/peer support.
278	Royal College of Physicians (RCP)	Statement 4	Young people who are moving from children's to adults' services have a named worker to coordinate their transition care and support before and after transfer. Our experts note the importance of retaining the phrase 'support before and after transfer.'
279	Royal College of Physicians of Edinburgh	Statement 4	In reality the structure of services dictates that the named worker will have to be either a member of paediatric services or of adult services, and usually cannot be both. As they are involved from an early age, and need to be a trusted individual known to the patient, this likely means a member of the paediatric team in practice. Requiring this paediatric team member to arrange the late stages of transition and post transition care may be logistically challenging, especially in cases of geographically dislocated transition. A process of gradual handover from a paediatric named worker to an adult team named worker could be built in. This could be more labour intensive in some areas of medicine than others. The logistics and resource required for standards 2-4 will depend on the size of the patient cohort. For some specialties such as renal, the small number of patients will be relatively easily absorbed into present structures. For

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			others there will need to be new processes and structures in place and resource will need to be explicitly identified. Regional models could be in place where appropriate to reduce duplication at local sites. The risk is that the resource allocated cannot be identified and already stretched services have to adopt a new system without obvious funding.
280	Sheffield Teaching Hospitals NHSFT	Statement 4	Named worker- there is emphasis on this role for part of the time when transferring to adult services but not as much emphasis on the 16 to 25 age group as the year 9 stage of the transition process. To develop practice in adult services there should be emphasis on managing care, services and expectations of young adults up to the age of 25.
281	The Faculty of Pain Medicine (FPM) of the Royal College of Anaesthetists	Statement 4	We would strongly support having a named worker, although clarity is needed as to what the skills and position of this individual are.
282	The Guide Dogs for the Blind Association (Guide Dogs)	Statement 4	A named worker is vital but in the case of children and young people with sight loss, we feel it is vital that the person concerned has a decent understanding of their needs. Whilst we would not want to be prescriptive in terms of arguing that it should be a particular professional, we do think there is a case for emphasising that in the case of children and young people with low incidence disabilities, that the named worker should ideally have a recognised qualification (if one exists) but certainly be suitably knowledgeable about, and experienced in the likely needs of, children and young people in that category.
283	The Howard League for Penal Reform	Statement 4	We welcome the statement which ensures that all children and young adults transitioning must have a named worker. This must apply to children and young people in custody and leaving custody. It is vitally important in terms of providing a degree of continuity for young people who can be moved around the prison estate during their sentence. We have been made aware of some good practice that is rare but possible in this area. For example, where a child transitions from a secure mental health setting to an adult prison setting, the Responsible Clinician may convene a s117 meeting under the Mental Health Act 1983 prior to the transfer to which professionals from the adult receiving service can be invited. In addition, the Responsible Clinician may attend follow up and attend Care Programme Approach meetings within the adult prison setting. Similar approaches should be taken whenever a child with health needs is transferred to an adult setting.
284	The Royal College of Anaesthetists (RCoA) and the Association of Paediatric Anaesthetists of Great Britain and Ireland (APAGBI) joint response	Statement 4	The named person overseeing the transition is weak in that given the start of transition planning is ideally year 9, staff are likely to have moved on so there needs to be something about continuity if this situation arises
285	The Royal College of Anaesthetists (RCoA) and	Statement 4	The statement seems to assume that patients will transition to an adult service in the same geographical location and so will have existing relationships with the clinical teams. This may not be applicable in some specialist services e.g. if

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	the Association of Paediatric Anaesthetists of Great Britain and Ireland (APAGBI) joint response		a service for young patients is provided on a regional basis, because of the small numbers involved .However there may be more local services available once the transition to adult services is made. This may be more convenient for the patient in terms of travel, especially if they have started work, but they will not have established relationships to utilise. In which case, it would be useful for either the regional centre to have an outreach worker to liaise with the local service.
286	The Royal College of Anaesthetists (RCoA) and the Association of Paediatric Anaesthetists of Great Britain and Ireland (APAGBI) joint response	Statement 4	Named worker Whilst clinical leadership of Transition is important the “named worker” role is insufficiently well defined in terms of the resources which will be required to fulfil this responsibility. This role already exists in some mainly secondary care speciality areas e.g. Paediatric oncology, Diabetes but these individuals may be responsible for a very large caseload and is not well acknowledged in job planning. There is also a need for leads to have a level of seniority/authority to perform the expected management of Transition for the young person fully, and this is not acknowledged and should be in the Standards.
287	Together for Short Lives	Statement 4	There should also be a named worker to support the young person on an ongoing basis in adult services. This might be a designated worker in adult services who links with and takes over from the paediatric named worker.
288	VISION 2020 UK	Statement 4	We support the concept of a named worker – assuming that that individual has specific expertise in eye care/ vision impairment. However we believe that this may be a challenge at a local level. This is particularly relevant to YP with VI because while they are at school, their mobility/habilitation support will probably have been provided via the education VI service. Once individuals leave school, it is much more likely that the social care will take over these functions In addition for those YP attending eye departments for ongoing treatment who are not known or not supported by education/ social care we are not certain there are clear mechanisms for identifying a named worker. This would apply for example to children and young people using specialist contact lens services for vision correction.
289	British Association of Paediatric Nephrology (BAPN)	Statement 4	We agree that a named worker should be identified to coordinate the young person’s transition to adult services in a structured approach.
290	Kidney Research UK	Statement 4	Having a named worker to coordinate care was a very welcome idea among our patient contacts as it was a clear aim to provide continuity in care even after the transition. There were however concerns as to how realistic this was and whether the person would have the necessary training and time to carry out the role effectively.
291	National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Statement 4	We agree that a named worker should be identified to coordinate the young person’s transition to adult services in a structured approach.
292	National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Statement 4	This could be problematic to implement or measure in some areas / organisations due to differing resources. Some areas may not have key professionals involved with the young person who possess the skills to link with other practitioners or services. In the health care setting nurse specialists frequently take up this role for the sub specialty

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			that they work in but there are General Paediatrician's who do not have nurse specialist support and therefore need to address and coordinate transition themselves. If areas use a generic framework or tool to document aims, actions and progress this would provide evidence of the process that could be measured. This also provides information for any professional taking over the key named worker role which might be necessary with staff leaving / changing roles during the young person's care within children's services. Due to limited resources and workload pressures, some areas may have difficulty maintaining the key named worker role for a prolonged period after eventual transfer of care to adult services.
293	Transitions Service, Leeds Camhs	Statement 4	In Leeds Camhs there is a dedicated transitions service who manages all young people transitioning in to adult mental health services. They would automatically have a named worker responsible for this. This would be easy to measure on the electronic record system.
294	Suffolk County Council	Statement 4	· Named worker The length of the list of potential types of 'Named Workers' across a range of professions presents a unrealistic training requirement - to provide all with a sufficient overview (rather than all-round expertise) of every aspect of transition is impractical The principle of providing continuity for young people and families through having nominated named workers could create as many (or more) problems as it might solve for example: A named worker is expected to increase dependence on that role (when services are increasingly configured around each professional providing time-limited and targeted support designed to address emerging and known/planned needs in a way that builds community and family resilience) A named worker could result in other practitioners regarding this allocation as disempowering, (or resulting in duplication of effort) It seemed that the quality standards had been conceived around delivering health services interventions, and over simplified in respect of recognising and planning around the diverse range of non-medical practitioners who support young people and their families, especially with social care interventions. It was thought that this was reflected in the number of people in the working group with a medical background and the medical care nature of the stakeholders consulted in the briefing paper for this consultation. This statement has been added here, as the impact of the working group composition appears most pertinent to Statement 4.
295	Association of Paediatric Chartered Physiotherapists (APCP)	Statement 5	In many areas there are not appropriate physiotherapy services for young people with long term conditions to transition to and so input following discharge from children's services will only be provided for acute interventions. In these areas this statement will be difficult to achieve. Should commissioning and organisation of services be re-designed in line with SEND reforms so that some young people are supported within children's services until 25 years?
296	Barnardo's	Statement 5	In the context of mental health provision this statement is applicable only to young people who are likely to make a straightforward transition from CAMHS to AMHS because they have a 'severe and enduring mental illness'.

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			SDQ data from the DfE indicates that 36.7 per cent of looked after children have emotional and behavioural health which shows cause for concern plus 12. 8 per cent who are borderline[34]. This compares with a disorder prevalence of 9.4 percent (https://researchonline.lshtm.ac.uk/1845810/1/sa2012Goodman_SDQfostercare.pdf) in the general population. Children in care and young people leaving care therefore have a very high prevalence of emotional and behavioural disorder which is not necessarily a diagnosed mental illness reaching the thresholds for AMHS. These young people continue to require support with their emotional wellbeing and yet most drop off a ‘cliff edge’ at aged 18 when CAMHS can no longer cater to their needs. The important difference between CAMHS and AMHS lies in the diversity of services offered by CAMHS which can be geared to work with conduct disorders and emotional difficulties arising from the poor attachment typical to care leavers. Many CAMHS also offer a dedicated service to looked-after children. There is no equivalent service for care leavers in the adults’ system, because, whilst children taken into care have suffered trauma due to their previous experiences and having been in care can have a negative impact on mental and emotional wellbeing, on its own, that experience of trauma and distress may not count as an illness in any sense that a specialist secondary health service can work with. The 2010 TRACK[35] survey found that those with neurodevelopmental disorders, emotional/neurotic disorders, or an emerging personality disorder were most likely to fall through the net at age 18. These disorders are typical of the attachment related issues experienced by the care leavers Barnardo’s works with. They continue to need support with these issues even though they do not have a severe and enduring mental illness as defined by many AMHS. Barnardo’s would like to see supportive emotional and behavioural services continued for vulnerable care leavers up to the age of 25 even where direct transition to AMHS is not appropriate.
297	Birmingham Children’s Hospital Rare Disease Team	Statement 5	Adult consultants must have allocated time in their job plan to enable this to happen and commissioners must be prepared to fund this
298	British Academy of Childhood Disability (BACD)	Statement 5	Introduction to adult services is essential and transition can only be transition by definition if there is something to “transition to.” Examples of conditions where this can work well is for renal disease, diabetes, cystic fibrosis. There are many conditions in neurodisability where this is not the case. For example - at present there is almost no adult service that truly provides the comprehensive, holistic care required for children with severe cerebral palsy; who may have difficult epilepsy, dystonia, feeding and nutrition issues, orthopaedic issues, respiratory morbidity alongside health needs as for the general population. The GP may not feel competent in all these areas; and may not have resource to manage them; referral to different adult specialities for adult care can fragment overarching care and result in a significant burden of appointments. NICE guidance needs to recommend development with adequate commissioning for young adult services in neurodisability.
299	British Society for Children’s Orthopaedic	Statement 5	BSCOS would consider this as a most sensible requirement.

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	Surgery		
300	British Thoracic Society	Statement 5	Statements 5 (and 6) are a bit more concrete, and while we endorse the aims of the document, it is not clear that this will provide a useful framework against which to conduct audit.
301	CLIC Sargent	Statement 5	There are some good examples of involving parents and carers in cancer care and where the clinic is held in the adult setting so that young people get used to the new environment.
302	Darlington Borough Council	Statement 5	This must be completed as part of the annual reviews in Y9 that enable forward planning and transition arrangements to be well planned.
303	Durham County Council	Statement 5	As young people may feel unsure about moving service it is important that the young person has an agreed and established care plan and pathway into adult services. Rather than just meeting a practitioner from adult services there should be an agreed period of transfer of joint working to ensure young person is engaged with adult services. Many authorities have joint services between adult and children services to avoid the interface issues between and children and this will require consideration within the standards if they are joint workers.
304	Great Ormond Street Hospital	Statement 5	Since we can't force them to see the adult service this should be reworded as 'offered the chance to see'
305	Haemnet	Statement 5	Agree that this should be part of transition. There may be institutional barriers where teams are based on different sites with the need for additional local resource to ensure that the time is available to enable these meetings to take place. Haemophilia services are increasingly running transition clinics to facilitate the building of the relationships and to ensure that the time and costs for service users and their families is kept to a minimum. The adult service practitioner referred to in this statement needs to be someone that the young person will encounter when they transfer to the adult service who will be engaged in the provision of their care.
306	Health Education England	Statement 5	The Quality statement states: the young people who move from children to adult services meet a practitioner from the adult service before they transfer – I feel this should be more specific and state how long before they transfer should the young person meet the adult professional – 1 week/1month or 1 year?
307	Institute of Health and Society, Newcastle University. On behalf of the NIHR funded Transition Research Programme.	Statement 5	We think this a well thought out statement. The aim of such a meeting is clear. The process measure is important, not just for the meeting, but also because it will almost certainly indicate that child and adult services are talking with each other as part of their shared responsibility for transition for all young people in transition.
308	National Association of Independent and Non-Maintained Special Schools (NASS)	Statement 5	For many of the disabled young people and those with SEN our members support, their confidence in an adult practitioner and their service could not be built up in one meeting. For learners with autism in particular who may struggle with changes to staff and environment, a transition plan setting out a process of meetings, visits and a managed move to a new setting will be critical to the young person's success in the adult placement. We therefore suggest QS 5 is amended to read: 'Young people who will move from children's to adults' services have

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			a detailed transition plan in place 6 months prior to the transfer, setting out how and when they will meet staff from, and visit the adults' service before they transfer.'
309	Real Life Options	Statement 5	We are fully welcome this statement
310	Roald Dahl's Marvellous Children's Charity	Statement 5	It is not clear where this statement differentiates from statement 2, as the practitioner from adults' services will meet with the young person in the annual meetings.
311	Roald Dahl's Marvellous Children's Charity	Statement 5	Adult consultants and other healthcare professionals must have time allocated in their job plans to enable children's introduction to adult health services, and commissioners must be prepared to fund this.
312	Royal College of General Practitioners	Statement 5	This should be a given- surely someone from the adult team ought to be involved in the annual meetings? Couldn't this be part of that standard (Standard 2)? It is vital to maintain confidence of the young people and their parents/carers that adult services are involved throughout transition.
313	Royal College of Nursing	Statement 5	*Introduction to adult services*: The practitioner needs to be more clearly identified. A young person/family requiring specialist healthcare would feel appropriately received if the practitioner is of a senior/specialist level, so this needs to be specified, e.g. diabetes CNS, Cystic Fibrosis CNS, senior Mental Health nurse/CPN (Children Adolescent Mental Health Service) and also for social care, if similar expertise exists in social work.
314	Royal College of Nursing	Statement 5	Young people attending supra regional/international specialist children's services, travelling out of region for paediatric healthcare, may not be able to meet the adult services practitioner as part of a joint clinic/consultation with children's services due to the logistical challenges and availability of the adult practitioner to travel to the children's service provider. This action may also have an additional impact on the adult service provider's workload and capacity.
315	Royal College of Paediatrics and Child Health	Statement 5	This will not be realistic for all young people due to geography – e.g. in a single paediatric rheumatology service there may transfer to >30 different adult rheumatologists so joint clinics are not feasible with all of these. A compromise in such situations is that they have a first appointment in adult care and then return to the paediatric service for a final visit. In such situations, clarity as to who is making the decisions and who the YP should call in an emergency and/or which hospital they will be admitted in an emergency etc. needs to be clarified
316	Royal College of Paediatrics and Child Health	Statement 5	Statement 5. Young people who will move from children's to adults' services meet a practitioner from the adults' service before they transfer. Comments: Suggest mentioning that the child and family/carers meeting a practitioner from the adults service at least once before they transfer. Facilitating the opportunity for the young person and family/carers to visit the adult service before transfer in our experience has been very valuable and should be considered in this QS.
317	Royal College of Paediatrics and Child Health	Statement 5	Young people who will move from children's to adults' services meet someone from the adults' service team before they transfer to help them feel more confident about moving to adults' services. Comments: The word "someone" could be better defined in this sentence as it must reflect the clinical team who will be involved in the young person's care.

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318	Royal College of Paediatrics and Child Health	Statement 5	Introduction to adult services is essential and transition can only be transition by definition if there is something to "transition to." Examples of conditions where this can work well is for renal disease, diabetes, cystic fibrosis. There are many conditions in neurodisability where this is not the case. For example - at present there is almost no adult service that truly provides the comprehensive, holistic care required for children with severe cerebral palsy; who may have difficult epilepsy, dystonia, feeding and nutrition issues, orthopaedic issues, respiratory morbidity alongside health needs as for the general population. The GP may not feel competent in all these areas; and may not have resource to manage them; referral to different adult specialities for adult care can fragment overarching care and result in a significant burden of appointments. NICE guidance needs to recommend development with adequate commissioning for young adult services in neurodisability.
319	Royal College of Physicians (RCP)	Statement 5	Young people who will move from children's to adults' services meet a practitioner from the adults' service before they transfer. Our experts believe that statement 5 is too vague. If a transfer to adult does not take place something more concrete should be stated .In addition there may be a single attendance at adult and then subsequent non engagement nonattendance. Therefore, the QS should state for a full year of regular engagement with the adult team. Young People like to know who is actually responsible for their care. Hence the term 'practitioner' is too vague. It also needs to be made clear that their key worker must be at that meeting to bridge the gap between services. Our experts suggest: 'Before they transfer, the young person who will moved to adult services, together with their parent or carer, must meet and be introduced to the consultant who will be responsible for their care in adult services, by their key worker. Following this introduction there should be full year of regular engagement with the adult team'
320	Royal College of Physicians of Edinburgh	Statement 5	Good practice would be for this to be the same person each time and following an initial joint meeting young people would remain under the paediatric service until they attend an adult clinic. This draft standard does not address the specific challenges of transition for remote and rural patients, or those moving to adult services in a different city or region. The challenge here in chronic illness is often movement from a paediatric District General Hospital service to a distant adult specialist centre, often with a single far-flung patient making the move. This normally precludes the model of visits by the adult team to meet the patient at the paediatric centre and deserves special mention. I.T. can sometimes help, with telemedicine consultations and web-based information on the receiving adult centre to help inform the distant patient, but the process remains much more difficult in this group, and deserves mention.
321	Suffolk County Council	Statement 5	This is the process for young people who are eligible for Adult Services in Suffolk
322	Sussex Partnership NHS Foundation Trust	Statement 5	Every attempt should be made to have joint meetings with the adult service staff to help introduce the service to the young person (and their carers) and clarify any concerns or questions that they may have around access and support in the adult service.
323	The Association for	Statement 5	It is suggested that meeting a practitioner from the adults' services can help build a young person's confidence,

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	Family Therapy and Systemic Practice in the UK		reduce their concerns about moving to adults' services, and increase their willingness to ask the practitioner to be involved in their care. This latter comment implies that there is / needs to be a commitment from adults' services that the practitioner the young person meets is available to be involved in their care. It may be helpful to make this explicit in the quality standard.
324	The Faculty of Pain Medicine (FPM) of the Royal College of Anaesthetists	Statement 5	Agreed
325	The Guide Dogs for the Blind Association (Guide Dogs)	Statement 5	As per our comments about a named worker, we do not think for children and young people with quite specialist needs that it is enough to simply say that they should meet a practitioner from the adults' service before they transfer. We are aware that generic adult practitioners often have a very poor grasp of the incidence or impact of sensory impairment and whilst the needs of a young person with sight loss will hopefully have been identified and flagged up by someone involved in their current arrangements, we believe that the person to whom the individual concerned is being "handed over" should also have relevant knowledge and experience.
326	The Howard League for Penal Reform	Statement 5	Children and young people in secure custody are often isolated from community healthcare services and from their parents and carers. They have very limited control over their daily lives. Health and social services have to go to them as they are not free to visit services or make choices or decisions regarding the provision of services. This standard is commendable. Careful thought will need to be given as to how to ensure health practitioners from adult settings can meet children in secure settings in advance of the transfer.
327	The Royal College of Anaesthetists (RCoA) and the Association of Paediatric Anaesthetists of Great Britain and Ireland (APAGBI) joint response	Statement 5	Meeting with adult Practitioner "Practitioner" is a vague title and one would expect the YP to meet someone in the adult service who will in future be taking on a lead management role in their care. As noted there are some services where there is no equivalent adult team or one person to whom co-ordination of care is entrusted. If the YP has multiple problems e.g. secondary to neuro-disability will they need to see multiple practitioners? Is one meeting sufficient to establish a relationship and confidence in the adult service?
328	Together for Short Lives	Statement 5	This should state that the young person will need to meet with practitioners from the range of adult services that they will transfer to. As written it implies that young people will just be using one service and having one meeting.
329	VISION 2020 UK	Statement 5	Linked to the previous point about the transfer between support from education VI services and social care is the recognition of the serious under staffing in social care as well as the lack of and mechanisms in place to manage this transfer. As regards resources we would suggest that VI enablement services in the form of adult habilitation (usually falling within the remit of adult rehabilitation services) are under resourced. In addition as regards eye health (medical ophthalmology services) the ongoing assessment, treatment and support for children and young people by orthoptists with a specific interest in children's eye health means there are unique

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			issues about the transfer of care in eye departments. This is because there may not be a corresponding role/ professional in adult services. In particular unless there are specialist professionals in place (Low vision specialist or Eye clinic liaison officer for example) there may not be anyone who has particular links with VI education services or with social care.
330	British Association of Paediatric Nephrology (BAPN)	Statement 5	This statement has too narrow a focus. We agree that it is ideal for young people to meet a practitioner from the adult service prior to their transfer but it is also important to highlight any on-going issues that will need to be met in adult services such as any psycho-social concerns/support. The earlier these issues/concerns are highlighted the greater the likelihood of a solution being found in adult services. Starting transition early and engaging adult services early is the ideal. Using a structured generic, holistic framework – such as Ready Steady Go, for all would ensure that this is occurring and that the needs of the YP and carer will be met in adult services-. i.e ensure that adult services have the resources and tools in place to meet the YP's needs. It may often be necessary for there to be more than one joint review by children's and adult services therefore preparation must commence early. There can be logistical and practical issues that may cause limitations with the intended adult service not being local to the current children's service. Recognition should be given to differing resources in some areas and organisations which can impact on this process e.g. some specialist adult services are at capacity and therefore young people need to be transitioned / transferred to alternative services further away from their preferred / intended pre planned adult service. It will be possible to measure these- with a generic survey/PREM
331	Kidney Research UK	Statement 5	This is a vital step in transitional care and the young person should be able to see the same person for a few visits. It has been previously stated that this should be for the first two visits but this seems a rather low target and it is not specified that this is the same person as they saw during their transition. The quality statement does not specify how many times the young person needs to meet a practitioner form adult care but more than once seems necessary.
332	National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Statement 5	We agree that it is ideal for young people to meet a practitioner from the adult service prior to their transfer. It may often be necessary for there to be more than one joint review by children's and adult services therefore preparation must commence early. There can be logistical and practical issues that may cause limitations with the intended adult service not being local to the current children's service. Recognition should be given to differing resources in some areas and organisations which can impact on this process e.g. some specialist adult services are at capacity and therefore young people need to be transitioned / transferred to alternative services further away from their preferred / intended pre planned adult service.
333	Royal College of Paediatrics and Child Health	Statement 5	Question 1 – Yes. This would be an easy way to reduce anxiety surrounding transition for both child and parent/carer and to improve recognition of needs by the adult services. Question 2 – Yes. This should be a simple process to audit. Question 4 –Yes. There will be an impact on clinician time, especially in areas where this wasn't already implemented. However this would be acceptable considering the hope of improving concordance with adult services.
334	Barnardo's	Statement 6	Care leavers making the transition to an independent adult life may experience some disruption in the process given

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			that they may be just 17 or 18 years of age and do not have parental support. This means that making and meeting appointments is challenging to them. Too often they may self harm and attend A&E to precipitate care in a crisis-- a sadly common response to their negative emotions at a time of upheaval. Repeated opportunities should be taken by services to engage them appropriately. The situation which Barnardo's hears about too often where young people are taken off waiting lists because they have missed three appointments is disappointing and dangerous. Contact must use methods that the young person can engage with such as SMS and encrypted messaging systems such as WhatsApp. Young people in unstable housing situations, in unsuitable accommodation, or in foyers or hostels may not receive mail sent in the post.
335	Birmingham Children's Hospital Rare Disease Team	Statement 6	The young person must not be discharged from paediatric services until seen and engaged with adult services as this is a clear safety issue and it should be the named worker or transition coordinator that needs to be ensuring ongoing follow up. These are often the most vulnerable young people who need extra support. Again resources must be allocated.
336	British Academy of Childhood Disability (BACD)	Statement 6	This is really, really important as non engagement with adult services at the point of transition leaves disabled young people very, very vulnerable.
337	British HIV Association	Statement 6	We recommend that follow up of non-attenders must be proactive and ongoing, not a one-off event with the need for re-referral subsequently. This occurs for transitioning children with HIV. There must be flexibility in the system up to the age of 25ys. For example options are phone, text, letter, home visit, emails. A young person may engage with ongoing care through these communication methods. Measurement. Not attending their first appointment is a poor indicator in the HIV field. A better indicator would be those who are receiving ongoing support/contact with the HIV centre. An indicator based solely on if they attend their first appointment could deter clinics from then continuing to engage with the young person as they would already be measured as having failed. The sign of good quality HIV care is continuing engagement with an adult service.
338	British Society for Children's Orthopaedic Surgery	Statement 6	BSCOS would not see this as a likely event had there been the preparation beforehand that this proposal defines. However it fully supports providing further engagement opportunities given the requirements such children have. It is worth mentioning at this point that there is a real 'cliiff face' effect that many patients and carers and clinicians observe when a child with neuromuscular pathology moves out of the children's services. Falling off this cliff is experienced in orthotics, wheelchairs and seating, in physiotherapy, in schooling/education and in orthopaedic services etc. That is, across a spectrum of areas which have previously been addressed and covered for the child in the paediatric sector. There are significant resource implications across these areas and BSCOS draws these considerations to the attention of NICE in these quality standards.
339	Carers UK	Statement 6	Quality statement 6: "Young people who have moved from children's to adults' services but do not attend their first meeting or appointment are contact by adults' services and given other opportunities to engage." There is no mention of carers/parents and how they will be involved in this process or how they will be supported at this time. This should

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			be clarified.
340	CLIC Sargent	Statement 6	Regarding non-attendance after transition, it's important to also check that they have a follow-up appointment and have not slipped out of the system.
341	CoramBAAF Adoption and Fostering Academy	Statement 6	We welcome the recognition that engagement with adult services can be difficult for young people and this can be particularly the case for care leavers. Adult services need to acquire understanding of additional needs of particular groups such as care leavers and this may require both specialist training and development of services for these groups.
342	Darlington Borough Council	Statement 6	This statement ensures that young people do not slip through the net during transition. Joined up transition planning and annual reviews that are focused
343	Great Ormond Street Hospital	Statement 6	This would be the responsibility of the adult service
344	Haemnet	Statement 6	Contact needs to be made by someone with whom the service user has an existing relationship, this maybe the named worker if this relationship has been established and is more likely to be someone working in the children's service. Preferable if adult and paediatric service determine who is best to make contact rather than just being the adult service as there are multiple reasons why service users may not have engaged.
345	Institute of Health and Society, Newcastle University. On behalf of the NIHR funded Transition Research Programme.	Statement 6	In several places the phrase 'young people who have moved from children's to adults' services' is used. This does not allow for the likelihood of discharge to general practice and primary care. 'Been transferred' would be nearer to the process.
346	Institute of Health and Society, Newcastle University. On behalf of the NIHR funded Transition Research Programme.	Statement 6	We agree with this Statement.
347	Roald Dahl's Marvellous Children's Charity	Statement 6	Given that the purpose of the named worker is to be an individual selected by the young person as someone they know and trust, it would seem most appropriate that the named worker is accountable for making first contact with a young person after a missed first meeting or appointment. The young person must not be discharged from paediatric services until seen and engaged with adult services as this is a clear safety issue.
348	Royal College of General Practitioners	Statement 6	It is important to highlight that DNAs ought to be followed up for longer than the first appointment, perhaps for the first two years. It is fundamental that the GP is informed and that someone from the practice follows this up. GPs ought to make contact after unplanned admissions during and after transition.

ID	Stakeholder	Statement number	Comments[1]
349	Royal College of Nursing	Statement 6	The follow up of 1st DNA to the adult services is essential but may need additional resources dependent on team structures and capacity and GP capacity. We are aware that at Birmingham Children's Hospital for example, within some specialties a model of promoting communication between specialist nurses across both services, adult and children's, allows for effective communication and follow up of young people who fail to attend 1st Out of Patient Appointment (OPA).
350	Royal College of Nursing	Statement 6	*Missed first appointments:* This role should be delegated to an administrative assistant with senior practitioner overseeing that this has been done.
351	Royal College of Paediatrics and Child Health	Statement 6	If the family doesn't attend the paediatric service, it would be preferable for the paediatric service to contact as they will know the YP and family better. However this depends on the adult service informing the paediatric service of those who don't attend i.e. a tracking mechanism.
352	Royal College of Paediatrics and Child Health	Statement 6	Non-attendance at subsequent visits is probably a better quality standard i.e. reflects engagement ion the adult system better than just attendance at the first appointment. The significant admin workload is underestimated in transitional care services [Chanchlani N, McGee M, McDonagh JE. Informational continuity is integral for successful transition of adolescents. J Rheumatol 2015;42;901-902]
353	Royal College of Paediatrics and Child Health	Statement 6	Patients who do not attend appointments with adult services should be offered another appointment, but in practice this recommendation may conflict with provider DNA policies, and the provider should have a guideline to overrule the DNA policy with discretion. The guideline should include guidance on links with paediatric and adult safeguarding teams for patients who repeatedly miss appointments.
354	Royal College of Paediatrics and Child Health	Statement 6	Question 1 – Yes. This statement is likely to improve engagement with adult services and reduce the amount of unplanned care needed in adult services Question 2 – Yes. This should be a simple process to audit using most clinic booking systems. Question 4 – Yes. This should have minimal resource impact and should serve to reduce resource heavy unplanned healthcare intervention and the implications of losing contact with vulnerable individuals.
355	Royal College of Paediatrics and Child Health	Statement 6	Statement 6. Young people who have moved from children's to adults' services but do not attend their first meeting or appointment are contacted by adults' services and given other opportunities to engage. Comments: This statement is vague and addresses an issue post transfer and should be audited but it is unclear as to how this is a Quality Statement.
356	Royal College of Paediatrics and Child Health	Statement 6	Opportunities to engage If a young person does not attend meetings and appointments in adults' services the adults' service should try to contact them and their family, then involve other relevant professionals (including children's services and their GP) if need be. If there is still no contact then the relevant provider should refer back to the named worker with clear guidance on re-referral, if applicable. If the young person does not want to engage in services they should offered alternative ways to meet their support needs Comments: The named worker in page 19 is defined as a role rather than a job title. Referring back to the named

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			worker with guidance on re-referral does not seem to make much sense. It would also not be appropriate to refer back to Children's Services. Please clarify and revise the above.
357	Royal College of Paediatrics and Child Health	Statement 6	This is really, really important as non-engagement with adult services at the point of transition leaves disabled young people very, very vulnerable.
358	Royal College of Physicians (RCP)	Statement 6	Young people who have moved from children's to adults' services but do not attend their first meeting or appointment are contacted by adults' services and given other opportunities to engage. Our experts believe that disengagement will only happen if the other statements are not met, and if they have disengaged then a contact by adult service alone may be ignored. Our experts suggest rewriting this statement, while retaining its essential meaning: 'The young person's transition key worker remains responsible for their successful transition at least until they have attended their first adult clinic appointment, and the transition key worker should be responsible for contacting their patient should they fail to engage with adult services.'
359	Royal College of Physicians of Edinburgh	Statement 6	It is important to provide reminders for appointments, including by email/text, in addition to by post. A structured letter and information would be useful to send to patients to ensure they do not feel intimidated. Experience suggests that on occasion some patients are not ready to transfer but pressures come from the paediatric service to transfer.
360	Suffolk County Council	Statement 6	This would be expected best practice but is not mandated or measured at present.
361	The Faculty of Pain Medicine (FPM) of the Royal College of Anaesthetists	Statement 6	Patients and GPs are informed of failures to attend and can request another referral. This would need CCG support to change the process.
362	The Royal College of Anaesthetists (RCoA) and the Association of Paediatric Anaesthetists of Great Britain and Ireland (APAGBI) joint response	Statement 6	The data source outlined (evidence of having sent a further appointment if the first is not attended) is insufficient – direct contact needs to be made with the YP to establish that they have received it and explore the best alternatives for them. Flexibility is important here as is using a preferred form of communication which the YP recognises as convenient and with the appropriate level of confidentiality. Similarly being contacted by their GP may not be a suitable alternative – many young people will not have a GP who they know and see regularly and will find this intrusive and their wishes need to be established and respected pre-transition by someone within the service that they know and Trust. However the concept of the named GP noted in the full guidance is something that could and should be built upon in Standards e.g. " In YP with long term health needs GP practices must allocate a named GP according to the preference of the YP "
363	Transitions Service, Leeds Camhs	Statement 6	In Leeds camhs, where young people are going through transitions services, they are likely to get a further chance to attend if they dna the first time. They also get supported by their transitions worker to attend to minimise the chances of this happening. However, this may be more difficult for primary mental health care in adult mental health services (in the cases where the transitions worker is not involved) to put into practice if they young person dna's and does

ID	Stakeholder	Statement number	Comments[1]
			not contact. This would involve a change in working practices for them and there may be implications for their capacity and demand.
364	VISION 2020 UK	Statement 6	We welcome attempts to ensure that there is some mechanism to identify YP lost at transfer. However once again we note the issues as regards the impact on YP of a change in habilitation provision moving from VI education to social care and eye health care moving away from orthoptic support.
365	British Association of Paediatric Nephrology (BAPN)	Statement 6	We agree that professionals in adult services should contact young people who have not attended their first meeting or appointment. Failure to attend the appointment should also be highlighted to the paediatric team –who should also contact the young person to ensure they attend. Responsibility of the young person should not be handed over to adult services until that first appointment in adult services has been attended. This is vital to ensure engagement with the service and ensure the best long term outcome for their health or social well being. Adult services in the health setting can offer another appointment or reschedule another appointment whilst also notifying the GP or named worker in children's services so that they can encourage the young person to engage or discuss issues / concerns.
366	Kidney Research UK	Statement 6	This is a key area where young people can be lost from services. It is very important to engage with them. Our patient contacts felt that the named person from quality statement 4 should be involved in this and be finding ways to engage with the individual in order to maintain their contact with adult services.
367	National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Statement 6	We agree that professionals in adult services should contact young people who have not attended their first meeting or appointment. This is vital to ensure engagement with the service and ensure the best long term outcome for their health or social well being. Adult services in the health setting can offer another appointment or reschedule another appointment whilst also notifying the GP or named worker in children's services so that they can encourage the young person to engage or discuss issues / concerns.

Registered stakeholders who submitted comments at consultation

- Action on hearing loss
- ALD life
- Association of Paediatric Chartered Physiotherapists (APCP)
- Association of School and College Leaders (ASCL)
- Barnado's
- Birmingham Children's Hospital Rare Disease Team

- British Academy of Audiology And British Society of Audiology (Paediatric Audiology Specialist Interest Group)
- British Academy of Childhood Disability (BACD)
- British Association of Paediatric Nephrology (BAPN)
- British HIV Association
- British Society for Children’s Orthopaedic Surgery
- British Society of Paediatric Dentistry
- British Thoracic Society
- Carers UK
- CLIC Sargent
- Coeliac UK
- CoramBAAF Adoption and Fostering Academy
- Darlington Borough Council
- Department of Health
- Derbyshire County Council and North Derbyshire CCG
- Durham County Council
- Ferring Pharmaceuticals Ltd.
- Genetic Alliance UK
- Great Ormond Street Hospital
- Haemnet
- Health Education England
- Institute of Health and Society, Newcastle University. On behalf of the NIHR funded Transition Research Programme.

- Kidney Research UK
- London Fire and Emergency Planning Authority
- National Association of Independent and Non-Maintained Special Schools (NASS)
- National Autistic Society
- National Community Hearing Association
- National Deaf Child and Adolescent Mental Health (NDCAMHS)
- National Paediatric Respiratory and Allergy Nurses Group (NPRANG)
- NHS England
- Pfizer
- Real Life Options
- Roald Dahl’s Marvellous Children’s Charity
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Paediatrics and Child Health
- Royal College of Physicians (RCP)
- Royal College of Physicians of Edinburgh
- Sheffield Teaching Hospitals NHSFT
- Suffolk County Council
- Sussex Partnership NHS Foundation Trust
- Tees Esk and Wear Valleys NHS Foundation Trust
- The Association for Family Therapy and Systemic Practice in the UK

- The Faculty of Pain Medicine (FPM) of the Royal College of Anaesthetists
- The Guide Dogs for the Blind Association (Guide Dogs)
- The Howard League for Penal Reform
- The Royal College of Anaesthetists (RCoA) and the Association of Paediatric Anaesthetists of Great Britain and Ireland (APAGBI) joint response
- The Royal College of Speech and Language Therapists
- Together for Short Lives
- Transition Service, Leeds, CAMHS
- VISION 2020 UK