National Institute for Health and Care Excellence
Transition from Children's to Adults Services Scope Consultation Table

Date of consultation 25th March – 24th April 2014

Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
Acorns Children's Hospice Birmingham	1	3.2.2	Provision by 'voluntary agencies' *which are poorly funded to undertake this work or have found themselves undertaking the work by default as no one else is doing it.* Reported lack of information about services – is this a lack of information about services provided by voluntary agencies?	Thank you for your comment. The role of voluntary services in transitions may emerge as a key area by the evidence review but this cannot be assumed at this time.
Association of Directors of Adult Social Services (ADASS)	1	3.2.2	Whilst recognising instances where there are service gaps for individuals are transitioning from Children to Adult Social Care Services, the proposed standards must take account of the difficult decisions having to be made by Councils to ensure equal and fair accessibility of scare resources for all those meeting the eligibility criteria for adult social care services and support. It is noted that it is likely that many young people who emerge from Children's Services and special education have considerable needs but will not meet the proposed national eligibility criteria as set out in the care reforms. This is, therefore, an issue for services for adult's not simply adult social care. Equally it is important that the process of transition is not dependency creating or assuming and needs to be underpinned by principles of personalisation and ambition for independence.	Thank you for your comment. The issue of many young people not meeting the threshold of adult services is duly noted.
Association of Directors of Adult Social Services (ADASS)	2	4.4	ADASS welcomes and fully supports the list of proposed outcomes arising from the introduction of quality standards for transitions from Children to Adult services, namely – self efficacy (independence, choice and	Thank you for your comment.

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			control), transition readiness, quality of life (health and wellbeing), individual outcomes (personalisation), experience and continuity of services. These are all core principles that resonate with those implicit in the care bill.	
Association of Directors of Adult Social Services (ADASS)	3	4.6	ADASS recognises the value of understanding the long term cost effectiveness of interventions and would suggest that such an approach should lead to more mature discussions of how these efficiencies can be attributed and recycled to create a sustainable funding system that rewards and recognises innovation and whole system approaches.	Thank you for your comment.
Association of Directors of Children's Services (ADCS)	1	General	My only comment on re-reading the scope document recently is that it would be wise to consider children who are undergoing treatment services for drug and / or alcohol misuse	Thank you for your comment. All young people undergoing transition from children's (adolescent) to adult services are within scope.
Autism NI	1	3.1.2 4.1.1	This is a very useful draft but should specify somewhere that transition planning may begin at 16. This is specified for example in Clinical Guideline 170 on Autism. Establishment of need may begin as young as 14.	Thank you for your comment. We agree that transition needs to start before the actual transfer. A lower age limit is not set to reflect that transition preparation might start at very different ages depending on the child's maturity and also the nature of and practises within the service.
Bayer Plc	1	4.4	**Main outcomes** Adherence to treatment regimen, including any self-monitoring, is also an important outcome that should be considered when assessing the evidence.	Thank you for your comment. Thank you for your comment. The role of the scope is to lay out the areas for consideration, the guideline will provide recommendations based on the best available evidence.
Beat	1	3.1.3	We completely support this statement but unfortunately we hear from people suffering from an eating disorder that this is not always the case. Often transition is not	Thank you for your comment. We agree that health and social care planning may vary across services and in relation to specific

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			planned, young people and their families and carers are not at the centre and they do not understand the changes.	groups. The scope is a summary document which can't give an exhaustive account of what will be covered. Young people with eating disorders are covered by the guideline as users of CAMHS.
Beat	2	3.1.4	People affected by eating disorders have told us that good transitional care and support is patchy and inconsistent.	Thank you for your comment. All young people who undergo transition from children's/adolescent to adult services are in scope. Due to the brevity of the scope document we could not make specific reference to individual conditions.
Beat	3	3.1.5	The views of our supporters and service users below highlight some of the issues identified in this section – anxiety, insecurity, being punished and a negative impact on their life	Thank you for your comment. We will search for evidence around young people's experiences of transition and have identified important systematic reviews as well as individual studies which are likely to inform the guideline alongside other sources of evidence.
Beat	4	3.2.3	The thoughts of Aimee below highlight this issue. She felt if she had received an introduction or more information about AMHS this would have helped her prepare for the transition.	Thank you for your comment.
Beat	5	4.5	Many of these review questions are addressed by our supporters below in their comments and testimonials.	Thank you for your comment.
Beat	6	General	At Beat we run a Transitions Project funded to support young people in London who are affected by eating disorders during transitions – a time when they are at their most vulnerable. Research shows that young people are particularly prone to relapse during these times and can often struggle to re-engage with healthcare services. Members of Beat's Young People Forum have told us they want more direct support at	Thank you for your comment and for sharing the practice example. The aim of this guideline is to improve service transition for all young people including those receiving CAMHS.

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			these times of transition. With this in mind Beat designed a project funded by City Bridge to directly support young people struggling through transitions. Our overall aim is to reduce the number of young people who relapse following treatment through the sharing of skills and tips from mentors to help successfully navigate difficult transitions and facilitate recovery. This project gives young people the opportunity to talk openly about their difficulties with Recovery Buddies – trained volunteer mentors who have themselves recovered from an eating disorder.	
Beat	7	General	We asked Beat supporters to comment on the scope and three people wished to share their views: Aimee, Kathleen and Naomi. (**Names have been changed**)	Thank you for including young people's comments on this scope, this is particularly important.
Beat	8	General	Aimee Having been under CAMH'S for three years and then adult services for six years I have strong feelings on this issue. I was 15 when I was admitted to CAMHS. I eventually grew to trust my nurse and therapist and relied on them heavily, I got myself into a routine seeing them once a week for three years. I was told two months before turning 18 my nurse would stop seeing me and that I would need to go to adult services. The thought of this petrified me. My therapist agreed not to suddenly stop seeing me when I turned 18 and I managed to see her for a few months after turning 18. During this period it was discussed with my parents and I what would happen to me. I really needed to go to adult services, despite moving forwards over the three years in CAMHS I had not gained much weight and was still very stuck with my anorexic thoughts and traits. I	Thank you for these really insightful illustrations of the lived experiences of young people in the transition. We will consider these in-depth and take the main messages to the Guideline Development Group. We notice that many of the issues raised reflect concerns highlighted by the scope. We hope that this guideline will help improve the situation for young people undergoing service transition.

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			specifically remember having this fear about adult services and what it would be like, I thought it would be like a hospital and it would be full of "mental people". I said that I would not go to adult services and refused to negotiate. What I wanted deep down was to continue to see my therapist, she was the first person who started to help me on my journey to understand my anorexia. Why did I suddenly need to move to adult services because I was 18? I didn't feel 18 I felt like a child still. My nurse and therapist suggested to my parents I try private therapy, which I agreed to do (anything to avoid the crazy place!) It turned out private therapy did not work for me, I was too entrenched in my anorexia that I could not take the therapists advice and I could not manage on my own. I continue to slip deeper into anorexia and all the work I had done in CAMHS was unravelling rapidly. I spent months trying to get myself better and my parents spent months trying to help me. Eventually my Mum contacted my old therapist from CAMHS (thankfully the therapist had given my Mum her number) and she agreed to see me privately. After spending one hour with her she said to me and my parents I needed to go to Adult services and that there was nothing she could do to help me at this stage and that I need further support from a CPN and psychiatrist. She referred me to adult services. By this stage I knew I needed help and I was prepared to give adult services a go, I was exhausted from trying to get better on my own (I think it was roughly 6-12 months since leaving CAMHS). To this day I believed adult services helped save my life I stayed under their service for six years. I was given the full treatment plan CPNS, therapists, psychiatrists and unfortunately inpatient treatment. Adult services wasn't	

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			what I had imagine it would be at all, there were no "crazy people" it was not like a hospital and the CPN I had was amazing she listened to me, helped me and was one of the nurses over the years I will never forget due to her honestly and her approach with me. Not once was a transition period offered to me from CAMHS it was suggested I needed to go to Adult Services and that was it. If I had been shown around adult services and was given the opportunity to meet the staff and who I would be working with, I believe this would have reassured me and helped me to let go of CAMHS and focus on getting better with the help of adult services. No one told me what to expect therefore someone of 18 is going to build up their own picture and mine was very negative. If the transition period had been smooth and slow I believe I would not have slipped back so far during the time I was receiving private help. What I needed was to have some sessions with CAMHS and adult services in order to feel safe with the new team. How can people expect children to go from children's services to adult services without panicking? Children under this service are vulnerable and obviously all have difficulties therefore how people work with them needs to be thought out well and planned in order to ensure the best outcome. I felt like because I was 18 that was it CAMH's stopped caring and no one else could help me or would be "bothered". More information needs to be given to children leaving children's services, I feel people like me could be used to speak with children leaving children's services in order to educate them on adult services. If I had the opportunity to meet someone from adult services all those years ago maybe they would have been able to	

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			help me take the first step through the doors of adult services.	
Beat	9	General	Kathleen Young people need to be given the right to choose the department that they will receive treatment in - at the moment, young people accessing mental health services cannot choose the hospital/department that they wish to be referred to. It is time that this changed e.g. our daughter was not allowed to attend the department at the service with the best success rates for treating eating disorders. She was told by CAMHS that her only option was to attend a different service. There she was exposed to uncaring, unhelpful and at times destructive approaches to her problem. Once discharged, her father and I followed the approach taught by the Maudsley method and supported her at home. She has now made a full recovery. There needs to be a period of time during which the transition may is made e.g. 16-21 years. This allows time for the transition. It also provides options to young people who are at various points along the axis towards maturity, particularly if mental health issues have been involved.	Thank you.
Beat	10	General	Naomi There is a great lack of communication and inconsistency across the country. Some people are helped a long time before their 18th birthday, some just a few weeks before. We need to prepare and support young people over a period of time to help with the transition. At CAMHS I always saw the same people and developed relationships with them but when I moved to AMHS I had to repeat information all over again.	Thank you.

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			There was a real lack of awareness. A lack of what else was going on in my life as well as the transition from services. AMHS are very fragmented, CAMHS more integrated. AMHS is harder to navigate, I didn't know where to go, who was responsible and they didn't know what to do with me. I didn't get told what was happening and didn't know who to contact. The transition led to a relapse and stay in an adult inpatient unit. Relapse prevention support disappeared at AMHS. There was a lack of coordination. AMHS were open that they couldn't commit to the transition, they had too many people to see. AMHS didn't have suitable therapy for me that had previously worked well at CAMHS. My care coordinator was an OT, had no knowledge of eating disorders, didn't know what to do with me and didn't have the knowledge to help. You start AMHS on a waiting list, it's like starting all over again. Had AMHS support for two years and I have never seen the same psychiatrist twice and not able to build up a relationship. CAMHS were good but AMHS were not. I just felt like another number, no urgency, no set guidelines, making it up as they go along and felt like I was the problem. Had a CAMHS key worker for eight years, she became frustrated, very annoyed, made complaints and went above and beyond to try and help me.	

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			CAMHS was one trust, AMHS a social enterprise which had been contracted out to another trust. They have different policies, different ways of working and not even the same computer system. It's the young person that ends up suffering. If had been better supported I wouldn't have got to that point and felt it was my fault. There needs to be a national transitions policy that is stuck to across the country. You can't put a young person on a waiting list until they are 18, there is no merging period, they are just cut off and then begin again. We need to look at people aged 16-25 to bridge the gap between the two. There needs to be people responsible for making sure both parties are doing their job and young people are getting the help that they need. It often seems to be more about bureaucracy than the person themselves. I haven't heard one positive experience from another person about the transition from child to adult services.	
Birmingham Children's Hospital NHS Foundation Trust	1	4.4	Comprehensive inclusion of outcomes for assessing the evidence. Incorporates important outcomes relating to young people's services.	Thank you for your comment.
Birmingham Children's Hospital NHS Foundation Trust	2	4.5	Comprehensive list of review questions.	Thank you for your comment.

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Birmingham Children's Hospital NHS Foundation Trust	3	4.5.6	Much literature to date has made recommendations about what should be included in transition services but not much evaluation of interventions or programmes to date to assess efficacy and to inform future intervention planning. Good review question to include.	Thank you
British Association for Adoption and Fostering (BAAF)	1	General	This response is being submitted on behalf of the BAAF Health Group, which is also a special interest group of 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.	Thank you for your response. Looked after children are in scope.
British Association for Adoption and Fostering (BAAF)	2	General	The significant financial and resource implications inherent in delivering NICE guidance should be acknowledged and addressed within the guidance if it is to be effective. While local authorities and health services may aspire to meet the recommendations in NICE guidance this may be very difficult to accomplish within existing professional capacities and economic parameters; developing guidance which cannot be delivered is not helpful.	Thank you for your comment. NICE guidelines cannot make funding recommendations.

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British Association for Adoption and Fostering (BAAF)	3	3.1.6	We would see **all** looked after young people, not just those leaving residential care, as particularly vulnerable and at risk of experiencing poor management of transitions.	Thank you for your comment. Looked after children are within the scope of this guideline, we will take into account a variety of transitions which affect this group.
British Association for Adoption and Fostering (BAAF)	4	3.2.2	There have been longstanding concerns about access and adequacy of provision of Child and Adolescent Mental Health Services (CAMHS) for looked after children and young people, namely: There are frequently problems with thresholds for referral and intervention as CAMHS may require a psychiatric diagnosis which is often lacking despite well recognised high levels of need. CAMHS practitioners frequently do not understand the needs of this population and require specialist training. Services need to be flexible, innovative and delivered to address the needs of this population, including accommodation of the frequent need for ongoing or intermittent services throughout the child's developmental stages. CAMHS should be able to offer skilled comprehensive mental health assessments which recognise that most of these children have experienced trauma and loss. Our members express great concern at the difficulties of transition for looked after young people who have been receiving mental health services from CAMHS, as the difficulties above are even more pronounced within adult services. There is frequently an almost total lack of understanding of the experiences and additional vulnerabilities of these young people, and an	Thank you for your comment. The Guideline Development Group will be making recommendations which may well support your point, but this cannot be assumed at this stage.

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			expectation that they should be able to 'fit within' the confines of existing adult services. We would advocate for the delivery of innovative services and provision of specialised training for adult mental health practitioners, which would enhance ability to engage with these vulnerable young people, which is fundamental to addressing their difficulties.	
British Association for Adoption and Fostering (BAAF)	5	3.2.3	Our members often report that it is very difficult to engage adult services in planning transition for looked after young people, and this is probably in part a reflection of the lack of understanding by adult commissioners and providers of the backgrounds and needs of this group.	Thank you for your comment and for taking the time to reflect on the draft scope. Adult services are now explicitly covered by the scope in section 4.3.1.
British Association for Adoption and Fostering (BAAF)	6	4.1.1	We welcome the recognition that the guidance will be particularly relevant to looked after young people, who frequently are over- represented in the other groups identified: with mental health problems, with disabilities and complex health needs.	Thank you for your comment.
British Association for Adoption and Fostering (BAAF)	7	4.1.1	The guidance should also explicitly address unaccompanied asylum-seeking young people and those young people who have experienced sexual exploitation and trafficking, who may have additional and specific needs related to these experiences.	Thank you for your comment. This is an important point which will be raised with the Guideline Development Group.
British Association for Adoption and Fostering (BAAF)	8	4.1.1	The guidance should also explicitly address privately fostered children. There is a 'hidden' or less visible group of privately fostered children and young people who may be children in need, and those who are trafficked or "runaways", whose status and well-being may be at risk. They may be 'excluded' from accessing	Thank you for your comment. The focus of this guideline will be service transitions, meaning that all young people undergoing transition from children's to adult services are in scope.

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			the support services they and their carers may need. They may have basic as well as additional health needs, including mental wellbeing supports. These children will not be privately fostered once they reach the age of 16 or 18 if disabled. For some their immigration status may remain unresolved. Unlike looked after children, this group will not benefit from the government's 'staying put' proposals and their transition to independence will place them at risk. Adult Services will need to identify the particular needs of these privately fostered young people and to consider how best they can be supported, given that they are on the 'edge of care'.	
British Association for Adoption and Fostering (BAAF)	9	4.1.1	Young people who have been adopted should be specifically included in those listed here, as they frequently have needs similar to looked after young people. They should be specifically addressed in the guidance, as they are likely to be overlooked by commissioners, providers and practitioners. Our members report on the difficulties for adopted young people and their adoptive parents, a number of whom may be managing disabilities, behavioural issues, mental ill health etc., who can feel quite abandoned when the young person reaches 18. Clearly the issues relating to their pre-birth and childhood experiences have a significant impact but support services in children's social care stops at 18 as there is no equivalent for adopted children of the 'Staying Put' / leaving care provisions in place for looked after young people.	Thank you for your comment. This is an important group and all young people using health and social care services will be included. Note that this guideline will only focus on service transitions. Due to the very broad remit in terms of populations there is a need to focus the guideline. It would be a considerable expansion to consider the evidence on how to meet the developmental transitional needs of all groups included in the scope.
British Association for Adoption and	10	4.3.1.d	We agree that preparation of parents and carers for transition is also important, and the guidance should	Thank you for your comment. The populations you mention are covered by the scope and were

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Fostering (BAAF)			also address the impact of transition for those young people who may lack a committed adult advocate, for example those in residential care, asylum-seekers, trafficked young people or those with unstable foster placements.	identified in the Equality Impact Assessment.
British Association for Adoption and Fostering (BAAF)	11	4.3.1.e	It is essential that the guidance effectively address organisational frameworks for transition. Some service users interact with multiple professionals and services, at different times and the scope therefore needs to look at different approaches to management and leadership of the process.	Thank you for your comment. As stated in 4.3.1 the guideline will include evidence on different organisations frameworks and interventions to improve continuity of care.
British Association for Adoption and Fostering (BAAF)	12	4.3.1.f	For the guidance to be effective, it is essential to address the considerable training needs of staff working with young people in transition, in children's and adult services. Our members frequently comment on the lack of understanding of the health and social care needs of the population of looked after young people in general, and in particular, those in the very vulnerable groups noted earlier.	Thank you for your comment. Training of professionals is in scope.
British Association for Adoption and Fostering (BAAF)	13	4.3.1.g.	Multidisciplinary working is one of the most important principles in delivering effective health services for looked after children and young people, yet our members report that this is frequently a problematic area for services of all types. Recommendations in the guidance should be based on good practice examples which can be replicated by others.	Thank you for your comment. NICE guidelines are informed by the best available evidence, examples and expertise from practice and the deliberations of the Guideline Development Group.
British Association for Behavioural & Cognitive Psychotherapies	1	general	We welcome the proposal to produce a NICE guideline.	Thank you for your comment.

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British Association for Behavioural & Cognitive Psychotherapies	2	general	The guideline could include looking at the use of Personal Health Budgets/ Personal Budgets and how these can work better together to support young people in transition across the range of child – adult services	Thank you for your comment. Personal health budgets will be included if researched in relation to transition support and planning.
British Association for Behavioural & Cognitive Psychotherapies	3	3.2.1	This statement is not entirely accurate. Young people also transfer to "young people's" services who provide support to those over 18 e.g. up to 21 or 25 years. Professionals often choose these services because they are more used to working with young people and therefore have greater confidence and skill in working with young people, e.g. more able to engage them, work with families and carers where appropriate, and adapt their approach to meet their developmental needs.	Thank you for your comment The guideline development process will engage with evidence from a range of contexts, particularly services specific to young people's transitions. The scope has been changed (3.2.1) so that adolescent services are clearly included.
British Association for Behavioural & Cognitive Psychotherapies	4	3.2.2	Other gaps are for people with mild learning disability and/or autistic spectrum disorders who do not have a learning disability but do need support beyond 18. There is also a particular gap for young people whose mental health difficulties, e.g. anxiety and depression, mean they struggle to attend clinic-based appointments, but are otherwise not judged as being an immediate "high risk" to themselves or others by adult services.	Thank you for your comment. The scope is just a brief summary of the topic area.
British Association for Behavioural & Cognitive Psychotherapies	5	4.3.2	We wonder why the transition of young offenders is excluded from this scoping document bearing in mind research showing the high number of offenders with mental health concerns.	Thank you for your comment. Young offenders' transition from adolescent to adult mental health services is in scope. All young people receiving or using social care and/or health services are in scope. The guideline will not provide recommendations for transitions of young offenders to adult prisons or back to the community.
British Association for Sexual Health	1	General	We recommend that the scope includes a specific comment addressing the sexual health needs of a	Thank you for your comment. The guideline will only focus on service transitions. Due to the very broad

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(BASHH)			transitioning population. This very vulnerable population require access to sexual health advice, screening for sexually transmitted infections and contraception services. The wider issues of developing sexuality in those with chronic illnesses / disabilities also need to be considered (for example, sexual health needs in those with learning disabilities, questions around reproduction for those with genetic conditions, fertility post childhood chemotherapy, issues surrounding growing up with a sexually transmitted infection for those with vertically acquired HIV).	remit in terms of populations there is a need to focus the guideline. It would be a considerable expansion to consider the evidence on how to meet the developmental transitional needs of all groups included in the scope.
British Association for Sexual Health (BASHH)	2	3.1	Adolescents with chronic physical and mental health conditions have higher rates of sexual intercourse and unsafe sexual practices than their healthy counterparts. Those with learning disabilities, living in residential care or in chaotic or dysfunctional circumstances are also at higher risk of sexual exploitation (Health Working Group Report on Child Sexual Exploitation (CSE), January 2014). Sexual health needs should be considered in all young people undergoing transition and all health and social care providers should be alert to the risk of CSE.	Thank you for your comment The remit of the guideline is to cover health and social care needs, and young people with a sexual health service need undergoing transition into adult services will therefore be in scope. However, the scope document is a summary which cannot give an exhaustive account of all that will be covered.
British Association for Sexual Health (BASHH)	3	4.2	The scope should include access to services for sexual health advice, treatment, prevention, and HIV services, including services for individuals diagnosed with HIV infection in their teenage years.	Thank you for your comment. This guideline is about the transition from children's to adult services, in health and social care, and not about particular topics which are important to young people's new life phases. Of course, these information needs might be covered in literature on support models and interventions.
British Association for Sexual Health (BASHH)	4	4.2	Young people with chronic health conditions frequently have co-existing psychological needs and complex social circumstances. The scope should include	Thank you for your comment. The scope now emphasises the importance of considering the needs of young people who access a range of

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			psychology services providing support for individuals with chronic conditions. Concerns have been raised that these services currently are frequently only available until an 18th birthday.	different services in health and social care.
British Association for Sexual Health (BASHH)	5	4.3.1	Caregivers from all disciplines need to be aware and alert to the issues highlighted in comments 1and 2. Training should include how to approach sensitive issues such as risk taking behaviour, sexual history taking, and recognising vulnerabilities and safeguarding / child protection concerns. In April 2014 BASHH and Brook launched a new proforma, Spotting the Signs, which provides a framework to support conversations with young people around CSE linked to latest research and evidence bases and has been designed to help health professionals identify young people who may be at risk of or experiencing sexual exploitation. This may provide a useful reference.	Thank you for your comment. The role of the scope is to lay out the areas for consideration, the guideline will provide recommendations based on the best available evidence.
British Association for Sexual Health (BASHH)	6	4.4	Outcomes could include quality standards for services e.g. You're Welcome accreditation of services, completion of staff safeguarding training, performance outcomes e.g. DNA rates & lost to follow up rates	Thank you for your comment. Performance outcomes are often used in studies to assess the impact of a transition support service. We would not want to add these as main outcomes but they might be included if used in high quality UK-based evaluations.
British Association for Sexual Health (BASHH)	7	General	BASHH members have expressed concerns with regards to cutting back of support services for young people undergoing transition, for example withdrawal of social services and independent / voluntarily sector support once individuals reach their 18th birthday. Although we are aware that NICE guidelines do not describe how services are funded, there is an urgent	Thank you for your comment and for taking the time to consider the scope. NICE guidelines cannot make funding recommendations.

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			need for clarity of commissioning support and intent. These guidelines need to be carefully supported to ensure adequate staffing for implementation of the desired transitions of care and to ensure a co-ordinated approach across all health and social care settings, including the voluntary sector.	
British HIV Association (BHIVA)	1	General	BHIVA welcomes this piece of work. Young people with vertically transmitted HIV have complex needs and transition is a time when they can become lost to care and/or have deterioration in their control.	Thank you for your comment. Young people using sexual health services as you describe are in scope.
British HIV Association (BHIVA)	2	General	Some young people under 18 years may be accessing an "adult" HIV service for various reasons, although it is effectively an adolescent service. With changes to commissioning the flexibility that has allowed these young people to be given effectively a transitional care service may be lost. Therefore, the scope should include those accessing adolescent services (even if labelled as adult) such as Genitourinary Medicine Clinics and Infectious Disease clinics, so they continue to get the extra input, support and expertise until the age of 25 years.	Thank you for your comment. This is an important issue and one which may well emerge in the finding of the Guideline Development Group, although it cannot be assumed at this time. The final guideline may be relevant to commissioning.
British HIV Association (BHIVA)	3	General	Young people with chronic disease or disability may not be able to access services for HIV testing and other infections that may be sexually transmitted, or for advice on prevention. The scope should include access to services for HIV and sexual health advice, treatment and prevention.	Thank you for your comment and for highlighting this point.
British HIV Association (BHIVA)	4	General	Related to comment 2, young people with HIV under 18 years, particularly where sexual transmission including sex between males is the route, are likely to present to	The guideline development process is committed to upholding equality and diversity values, and these issues are also covered by the Equality Impact

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			Genitourinary Medicine (GUM) (Sexual Health) services, or Infectious Disease (ID)-delivered HIV services. If these young people are not covered within this scope, this could be discrimination on the basis of sexuality because of the disproportionate effect it would have young males who have sex with males. Additionally, vertically infected young people may first present to a GUM or ID service and in the current scope would not meet the criteria for being included in transition; and this group is predominantly from the Black and Minority Ethnic community.	Assessment.
British Orthopaedic Association	1	General	We support the BSCOS (British Society for Children's Orthopaedic Surgery) comments for all sections.	Thank you for your comment.
British Pain Society	1	4.1.1	Considerable difficulties can arise in transition in multidisciplinary environments and when more than one specialty is involved. For example: a) In some areas paediatric pain clinics see adolescents up to the age of 18 years; however the paediatric psychology service can only see children up to 18 years of age if they are in full-time education. If the adolescent is 16 years and working they have to be referred to adult psychology services, not attached to the clinic, which is often totally inappropriate. b) The age at which adult services accept adolescents varies between specialties. So, for example, an adolescent of 17 years with severe pain and arthritis might wish and be able to transition to adult rheumatology services, but not to adult pain services because that service does not accept patients less	Thank you for your comment and for taking the time to consider the scope. The guideline will cover the question of referrals and service access for young people entering at the time when existing service users are in transition. A new point has been added to 4.1.1 to reflect this particular group.

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			than 18 years of age.	
British Society for Children's Orthopaedic Surgery	1	3.2.2	1-Scarcity of knowledge re resource for neuromuscular rehabilitation is a real issue in the adult sector, especially in contrast to the resources readily available in the paediatric sector 2- certain paediatric orthopaedic musculoskeletal problems are best treated in centres where there is already a seamless transition	Thank you for your comment Neuromuscular conditions are within scope and so these examples are highly relevant.
British Society for Children's Orthopaedic Surgery	2	3.2.3	There is good interlinking (MDT-concept) between services/specialties in the paeds sector which is particularly notable by its absence in the adult sector. This and the importance of investment in it to be able to maintain a high standard of care (e.g. allowing space in a given job plan for the same and modifying clinic rules and providing equipment (e.g. hoist) and appropriately trained nursing staff) should be emphasised to the adult Trusts. This includes the necessary provision of physiotherapy and rehab facilities such as hydrotherapy in the adult sector.	Thank you for your comment. The Guideline Development Group will be making recommendations which may well support your point, but cannot be assumed at this stage.
British Society for Children's Orthopaedic Surgery	3	3.3	"disabled young people may face more challenges than most in the critical transition to adulthood. The Government will provide £19m over the CSR period for a Transition Support Programme to help disabled young people and their families benefit from intensive, coordinated support and person centred planning." is lifted from the 2007 DfES report "Aiming high for disabled children – better support for families". This also includes information regarding "short breaks" for patients and families which should be within the scope of the costings in transition. The load of the	Thank you for your comment. We agree that this is a good example of the need for services to work in partnership, and this will be covered in the guideline.

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			physically more demanding young adult (heavier, stronger) on families and carers in conjunction with the invariably reduced resource base having left children's services means a significant fatigue factor for those caring for them. This is where funding for 'short breaks' is particularly welcomed.	
British Society for Children's Orthopaedic Surgery	4	4.3.1	This is reasonably inclusive but facilities and equipment should be present.	Thank you for your comment. The guideline does not cover treatment or support for particular conditions (which we recognise may involve equipment or facilities), but will, instead focus specifically on the support for young people to make a transition.
British Society for Children's Orthopaedic Surgery	5	4.6	It is important to use appropriate outcome measures in patients with neuromuscular conditions and those in whom mobility aids are needed.	Thank you for your comment, we note your point about neuromuscular conditions. Most outcomes relevant to this guideline will be about service use and continuity of care due to the generic nature of the guideline.
British Society for Children's Orthopaedic Surgery	6	General	a wide reaching generic approach although transition of certain paediatric musculoskeletal and especially neuromuscular problems at present very poor and detrimental to ongoing care of these patients.	Thank you for your comment.
British Society for Children's Orthopaedic Surgery	7	4.5.7	Barriers include inappropriate referrals to adult services	Thank you for your comment. The role of the scope is to lay out the areas for consideration; the guideline will provide recommendations based on the best available evidence.
British Transplant Society	1	3.1.5	It should include the impact poor transition and disengagement also impacts on relationships with family and friends. We have done some interviews with young adults and friendships both sexual and not can be	Thank you for your comment. The guideline development process will involve young people and record their experiences of transitions and the effects of poor transitions. There

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			affected by poor transition and chronic health problems, though these often go undiscussed.	will be specific focus on what 'works' for young people.
British Transplant Society	2	general	More emphasis needs to be made about involvement of parents and guardians in the process of transition. It is important for the young adults to have their support, but also the freedom to start becoming independent. Parents and guardians often find transition very stressful themselves and in the renal community there is a very helpful programme for guiding transition called 'ready steady go hello' with a parental/guardian component to help parents during this time. It allows parents and guardians opportunity to express their fears and anxieties so that these can be addressed. It is important that concordance is stressed as a major concern in this group of young adults, both medically in terms of medication and treatment, but also more generally in societal terms.	Thank you for your comment. Involving carers will be a key concern. They are represented on the Guideline Development Group and literature on their experiences of transition will be assessed.
Buckinghamshire County Council	1	General	This guidance document does not seem to consider the possible impact of the Children and Families Act. This Act will bring about a change in how the transition process takes place for disabled young people. These changes to the process will include the introduction of Education, Health and Care Plans, which for some young people could continue until they are 25. As part of this scoping exercise, it would be useful to see what the impact of these changes will be especially as the thresholds and the amount of service provision varies across the country.	Thank you for your comments, the Children and Families Act 2014 will inform this work.

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Buckinghamshire County Council	2	4.5.9	The question should also include what improvements should be made to Children's Services.	Thank you for your comment. Children's services are included in the question about improving transition. The question about adult services is there to emphasise that the transition doesn't just start in good time before the transfer, it also continues on after transfer.
Buckinghamshire County Council	3	General	A focus on the young person's social care as well as their mental health would also be useful to explore. The Social Care element can be overlooked when transition from Children's mental health services to adults. This has been highlighted for instance, where the primary need is Autism. Due to this lack of clarity, the young person and their families often face barriers in being able to access the right type of service provision.	Thank you for your comment. This guideline will cover both health and social care, including mental health, and the co-operation between services.
Buckinghamshire County Council	4	General	The key area this scoping exercise needs to consider regarding equality of opportunity is mental health needs, which are often not, addressed when there is dual diagnosis.	Thank you for your comment. The scope identifies the mental health needs of young people as an area where there are service gaps. We agree that there is particular need to consider the transition process for young people with multiple long-term conditions.
Buckinghamshire County Council	5	General	There seems to be very little on Joint Commissioning	Thank you for your comment. NICE guidelines can support commissioning, but not direct it.
Buckinghamshire County Council	6	General	Further information regarding the evidence base being used would be useful.	Thank you for your comment. The guideline will be based on the best available evidence of effectiveness and cost effectiveness. NICE will publish the literature search strategies as well as a list of evidence with the guideline.

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Carers Trust	1	3.1.6	Young Carers are a particularly vulnerable group at transition and need to be included in the scope of this guidance. Who are they? Young carers are children and young people under 18 years old who provide unpaid care to a family member who is physically or mentally ill, disabled or misuses substances. The 2011 Census identified 237,240 young carers aged 18 – 24 years old in England. These figures are likely to be significantly under representative as many young carers remain hidden. Legal Context Children and Families Bill: The new provisions amend Part 3 of the Children Act 1989 section 17 •Extension of the right to an assessment of needs for support to all young carers under the age of 18 regardless of who they care for, what type of care they provide or how often they provide it •A clearer duty to assess young carer's needs based on the appearance of need (or request) to assess a young carer's needs for support – young carers will no longer have to request an assessment or be undertaking a 'regular and substantial' amount of care •Appropriate links between children's and adults' legislation to enable local authorities to align the assessment of a young carer with an assessment of an adult or child they care for Local authorities must meet needs for support by:	Thank you for your comment. A key area to be covered is support for carers of young people in transition, including young carers. Young carers will be within scope if they care for another young person in transition or if they themselves are experiencing transition into adult services. Your comments will be passed to the Guideline Development Group.

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			•Considering whether a young carer's needs for support can be met through services which may be provided under section 17 (to the young carer and/or any member of their family) and; •Whether a young carer's needs can be met by providing support to the person who is being cared for by the young carer Care Bill •Entitlement for assessment for young carers at transition •Preventing needs for support including provision of services and support to adults and families so that children are protected from undertaking inappropriate caring roles •A whole family approach to assessing and supporting adults (provided for in forthcoming Care Bill regulations) so that young carer's needs are identified when undertaking an adult or adult carer's needs assessment. Why are they particularly vulnerable at transition? Transitions into adulthood are a particularly crucial time for young carers when expectations upon them increase and they are at risk of being relied on to undertake increasing caring responsibilities, rather than reducing their caring role. This is often to the detriment of their own outcomes and opportunities. Young Carers should have the opportunity to fulfil their own potential. The negative impact of caring can be significant and	

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			long term on a young person's physical and emotional health, socialisation and life opportunities. Health: The recent 2011 Census showed that young carers providing 50+ hours of care a week were up to five times more likely to report their general health as 'Not good'. 38% of young adult carers reported mental health issues in recent research of 77 school aged carers. Education: At GCSE level young carers perform the equivalent to nine grades lower i.e. the difference between nine C's and nine D's. Young carers aged between 16 and 18 years are twice as likely as their peers to be NEET. Employment: When in work at age 20/21 young adult carers are more likely to be in lower skilled occupations and many young adult carers will consider flexibility and proximity to home.	
Carers Trust	2	4.1.1	As above	Thank you.
Carers Trust	3	4.3.1. d	Transitions need to take account of the impact on any other children in the family. Why: Whole family approaches to transition should take into account the impact of the transitioning adults needs on any other children in the family to prevent inappropriate caring roles developing.	Thank you for your comment. As stated at the end of 4.4 outcomes will be considered for young people and their families and carers.

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Central and North West London NHS Foundation Trust	1	General	The scope looks excellent. The only thing I thought of is if HIV could be included as an example of a long-term condition when other examples are given e.g. I noticed diabetes is mentioned in it several times. http://www.hypnet.org.uk/files/APC-08-0153-Foster.pdf is a Hypnet related reference. And I know CHIVA have a standards document about to go to press which has a whole Standard on transitioning (Standard 6), whilst the equivalent adult standards document is: http://www.bps.org.uk/standards-psychological-support-adults-living-hiv where it's mentioned (admittedly very!) briefly in 7.1.2 Pathways of Care	Thank you for your comment. The reference provided has been added to our reference list. Young people with HIV are clearly in scope and the examples are simply due to the amount of literature and selected references.
Centre for Child and Adolescent Health	1	General	'It is particularly aimed at professionals and managers in health and social care services, in both children's and adult services.' Versions of the guideline should be available for young people and families. Considering the evidence reviewed, it would be helpful to include an exploration of the availability of information on transition that is accessible to young people. The parents / carers version should enable parents and carers to fully understand what best practice should look like so that they can advocate for their young people. It is relevant to young people who use services, their families and carers, communities, care providers (including independent and voluntary sector providers), health and social care practitioners and commissioners (including people who purchase their own care). Could be amended to 'are entitled to use'. One of the	Thank you for your comment. We will pass this information on to NICE and to our implementation team.

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			issues is that not everyone knows how to how to access the services to which they are entitled.	
Centre for Child and Adolescent Health	2	3.1.2	Transitions between care settings and services are significant points at which people are particularly vulnerable to losing continuity in the care they receive**.** In addition to the risk of losing continuity of care, there is also the risk that the collective and organisational memory of this child's needs circumstances and the most appropriate / supportive way to enable care delivery, may be lost at times of transition.	Thank you for your comment. Continuity of care and integrated working have indeed emerged as keys issues for this topic.
Centre for Child and Adolescent Health	3	4.1.1	All young people using children's health or social care services at the time when they are due to make a transition into adult health or social care services, including young people: The scope is broad and thereby inclusive, but perhaps needs to specify those at increased risk e.g. those who cannot attend school because of their health needs, and those for whom transition may mean movement out of the area where they have received services as a child.	Thank you for your comment. The scope is a summary of a very comprehensive area. We agree that the group you mention is at particular risk of poor transitions.
Centre for Child and Adolescent Health	4	4.4	Transition readiness as defined by scales may be inadequate if considered in isolation-the use of other ways to determine transition readiness (e.g. person centered /relationship based approaches to decision making with young people) should be reported where possible and appropriate	Thank you for your comment. Transition readiness will be complemented by evidence of young people's (and their carers') experience of care.
Centre for Child and Adolescent Health	5	4.5	**'**Some possible review questions are'**.** An additional question might be 'What are the broader impacts of transition on family life and the extended family?'	Thank you for your comment. The guideline will focus specifically at service transitions and so the questions will reflect this.

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			Questions relating to funding of transition could be clarified. The best option for the child and family may not be one that the Local Authority can afford. Exploration of the impact of funding on optimal outcomes would be valuable.	
Centre for Child and Adolescent Health	6	4.6	'However, calculations may also be made adopting a societal perspective in order to test the sensitivity of the results to the inclusion of other relevant outcomes (including those relevant to families and carers).' The societal perspective (impact of outcomes on families and carers) is very important. This wording could be changed to "calculations will be made adopting a societal perspective in order to test the sensitivity of the results to the inclusion of other relevant outcomes (including those relevant to families and carers) where evidence is available to do so"	Thank you for your comment, which chimes with our intentions for the economic work. We will consider your suggestion carefully.
Centre for Child and Adolescent Health	7	4.6	Subgroup analysis might be used in situations where the effectiveness or cost effectiveness of interventions is likely to vary between particular groups of young people. Subgroups could include: young people with learning disabilities; those with complex needs; those who have conduct disorders; looked-after young people and teenage or young parents. Costs, outcomes and experiences are likely to vary for different groups of young people. Therefore subgroup analysis should be reported where data and evidence are available.	Thank you for your comment. All the groups you mention are in scope. It is not possible to comment in detail on the economic work at this present moment in time when the searches have not yet been conducted.
Centre for Child and Adolescent Health	8	General	Young people need to have an understanding of the consequences of the choices that they make at transition. It is not clear whether this is intended to be	Thank you for your comment. The review of the evidence will include all types of transition support and there might be good evidence to consider your

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			included in the review.	point, but we cannot say so at this stage.
Children's Cancer and Leukaemia Group (CCLG)	1	1 4.1.1	The choice of identifying young people "using" health care services as those for whom the guidance will apply rather than young people "eligible for" or "under the care of" health care services, has the potential to miss a group of young people who have become disengaged with paediatric services. Children treated for childhood cancer may have complex and on-going health needs as a consequence of their cancer or its treatment. Many of these young people fail to engage with health care as they approach adulthood and the wording of the scope would imply that they will not be targeted for transition services. Transition should be seen as a process which may re-engage disaffected young people and every effort made to involve not only those using health and social care but also those who "ought to be using it" too.	Thank you for your comment The guideline covers a wide population and a decision has been made to therefore focus particularly on transition practice.
Children's Cancer and Leukaemia Group (CCLG)	2	3.1.2	Choice of the word "complicates" gives a very negative association of the impact of the health condition on their transition to adulthood. Although health and social needs can add additional challenges we should move away from these negative implications	Thank you for your comment. The collaborating centre aims to produce a guideline which improves outcomes for young people using health and social care services. The wording of the documents aims to highlight the challenges young people may face during transition.
Children's Cancer and Leukaemia Group (CCLG)	3	3.1.4	Consider adding a reference to childhood cancer follow up which is inconsistent and lacks equality across the UK. Pediatr Blood Cancer. 2004 Feb;42(2):161-8. Long-term follow-up of survivors of childhood cancer in the UK. Taylor A[1], Hawkins M, Griffiths A, Davies H, Douglas C, Jenney M, Wallace WH, Levitt G.	Thank you for your comment. Cancer is within scope; the scope is a brief summary of the topic area and does not reference specific conditions, but all young people undergoing transition from children's/adolescent to adult services are in scope. Thank you for this additional material, which we have added to our reference list.

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Children's Cancer and Leukaemia Group (CCLG)	4	4.1.1	Young people surviving childhood cancer should be included in those with "long-term life limiting and chronic conditions". It may be helpful to specify groups which fall into this category to facilitate the guideline preparation and ensure groups are not overlooked.	Thank you for your comment. We have not mentioned specific conditions so as not to exclude any by not listing them, this is particularly important since rare conditions might not be listed, but we do want to include them.
Children's Cancer and Leukaemia Group (CCLG)	5	4.4	Educational outcomes should be added to the main outcome measures	Thank you for your comment. The focus of this guideline is service transitions and the outcomes reflect this.
Children's Cancer and Leukaemia Group (CCLG)	6	4.4	Would it be possible to consider measuring "inequality of access / availability of services" across the UK. Provision of childhood cancer transition services is inconsistent and this is not likely to be restricted to cancer alone	Thank you for your comment. Inequality of access is an important issue to consider, but we would suggest this is not an outcome measure. Outcomes are measured in terms of what happens after someone receives a service (treatment) or not. Inequality of access might result in certain outcomes, but is about service configuration rather than service outcomes.
Children's Cancer and Leukaemia Group (CCLG)	7	5.1	QS55 Quality standard for Children and Young people with Cancer is now published (Feb 2014)	Thank you for your comment. This has been added to the scope.
Children's Cancer and Leukaemia Group (CCLG)	8	5.1	It would be helpful to include a link to the National Cancer Survivorship Initiative which contains evidence and best practices guidelines for childhood cancer long term follow up including transition (available through the NICE website).	Thank you for your comment, this has been added to our reference list.
Children's HIV Association (CHIVA), including the CHIVA Youth Committee	1	4.2.1	4.2.1 Settings that will be covered All settings in which a transition from children's to adult health or social care services takes place including primary, community, residential, secondary care and secure settings. CHIVA suggests that tertiary and higher levels of care, i.e. specialised and highly specialised	Thank you for your comment. Specialist children's services are in scope.

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			children's services should also be included.	
Children's HIV Association (CHIVA), including the CHIVA Youth Committee	2	General	Comments from the CHIVA Youth Committee (CYC): The CYC welcomes this guideline and specifically one young person says: "*I see transition as a make or break point within the services. I do feel the person going through the transition should be made to feel as comfortable and as welcomed as possible by their new team of practitioners. These guidelines I feel will work and young people will become more involved within the service."* The CYC would also like to draw attention to the document below which was recently circulated to the Stakeholders of several relevant CRGs and is highly recommended by the CYC: 'Proposed Transition specification insert for children and young people transitioning to adult services' E03 Paediatric medicine – Generic Transition for children and young people to adult services.	Thank you for both your comment and for that expressed by the young person. We have also made a note of the document mentioned.
College of Occupational Therapists	1	General	The College of Occupational Therapists welcomes this draft scope focusing on the transition between children's and adult services. Guidance in this area is essential in order to help facilitate a coordinated and integrated approach across children's and adult services. Enhancing communication through a shared framework and responsibilities is particularly important.	Thank you for your comment and for taking the time to consider the draft scope.
College of Occupational Therapists	2	3.2.2	There is concern that the scope appears to consider that the problem with gaps in service provision is focused on adult services. From the experience of occupational therapists who work across different sectors, there are gaps in provision in children's services as well. This is	Thank you for your comment. This scope covers both provisions for transition in children's and adult services, as well as the actual transfer. The problem of some young people not meeting the threshold of adult services is recognised and will be covered in

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			due to remits and priorities for services having been developed in isolation, without consideration of the young person's entire pathway. Often children's services have not been available for a young person due to resource limitations and waiting times for services so they are not identified as having health or social care needs. The young person may only be eligible to be referred to adult services following a crisis, which was anticipated and could have been prevented if their needs had been identified at an earlier age. For example, a 16 year old with mild learning disabilities who is struggling with independent community living skills may not be offered occupational therapy by children's services and would not be eligible for adult services until 18. Adult and children services remits and priorities need to be focused on supporting young people to meet their needs at the timescale that is appropriate for them. In addition, gaps in services also exist for young people in secure mental health settings who may be ready to move to less restrictive settings but are unable to do so due to the lack of appropriate adult social care settings (such as supported living) and flexibility in referral age. Thus for some young people, they are referred to one setting only to be transferred a short time later once they turn 18.	the guideline.
College of Occupational Therapists	3	4.1.1	As young people may have needs relating to transition due to their social situation, opportunities or multiple difficulties which do not clearly meet an established diagnostic criteria. Thus provision should also be made to include those young people who are 'at risk'.	Thank you for your comment. Our guideline will focus on service transition, and therefore includes all young people receiving or using social or health care.

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College of Occupational Therapists	4	4.1.2	Within many children's services, occupational therapists are encouraged to offer discrete episodes of care and then discharge children, acknowledging that it is likely that children will need to access services again during periods of transition. This is also the case when resources are scarce, as services may be provided to younger children only. Thus if the young person has been managing successfully with the supports offered within highly structured educational or residential environments or have not been able to access children's services, then they may not be 'actively' on a caseload. However, when they transition to a new life phase such as leaving school, into work, independent living he/she may need support to travel to a new place, manage in a less structured setting and learning independent living skills etc., their needs change and they are more likely to require services. By excluding this group of young people from the guidance, there is the potential for creating a vulnerable group of adults who will only be eligible for services once they are in crisis. The adult learning disability occupational therapy services can offer development opportunities for young people in transition to enhance their life skills (including work skills) to prevent issues escalating and requiring more intensive services. In addition, there have also been examples where young people have been referred to children's services at 17 and have been refused a service as they are likely to be too old for the service due to the waiting time to be seen. It is hoped that this guidance will be able to resolve some of these difficulties so that transition to adult services can be planned and does not rely on the person having to be actively open to a health or social care	Thank you for your comment. The focus of this guideline is on young people's transition from one set of services (children's) to another (adult's). The guideline will cover the question of referrals and service access for young people entering at the time when existing service users are in transition, and an additional bullet has been added to reflect this under 4.1.1.

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			professional at the time of transition.	
College of Occupational Therapists	5	4.2.1	Involvement in productive occupations such as work, education and training is a vital part of a young person's transition into adulthood and supports their health and wellbeing. Extending the scope of the settings to include services such as colleges, universities and workplaces would assist in this seamless transition.	Thank you for your comment. We agree that transitions outside health and social care are important but the guideline will only focus on service transitions. Due to the very broad remit in terms of populations there is a need to focus the guideline. It would be a considerable expansion to consider in-depth the evidence for how to meet the developmental transitional needs of all groups included in the scope.
College of Occupational Therapists	6	4.3.1 (c)	Occupational therapists have a key role in supporting young people in their life transitions. To state support will be provided by 'transition workers, peer support groups and transition clinics', limits the specialist provision often required in many services. This could be extended to 'and specialist input such as occupational therapy'.	Thank you for your comment. We will not limit the review to only covering transition-specific roles. Research which has evaluated occupational therapists' role in the planning or support of young people transitioning from children's to adult services is within scope.
College of Occupational Therapists	7	4.3.2	Issues which will not be covered include 'community projects which do not provide health and social care-related transition support'; however occupational therapists work with these projects when establishing a young person's engagement and routine in their local community and is a vital part of supporting transition. There should be a caveat with this point, as per the first point in this section, to say 'this type of support is not covered by this guideline, unless it forms part of a support package for transition from children's to adult services'.	Thank you for your comment. If a study of the kind of support you describe is found this would be assessed for inclusion, since it does support young people's transition from children's to adult services.
Contact a Family	1	3.4	Children & Families Bill now passed - so refer to as Children & Families Act 2014. You will want to refer to the Children & Families Act 2014	Thank you for your comment; we recognise the importance of the Children and Families Act 2014 to this work.

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			revised code of practice, chapter 8 - preparing for adulthood - NB code of practice currently out to consultation - likely to be published June 2014.	
Contact a Family	2	4.1.1	It would be useful to include section on managing transition when the young person lacks mental capacity to make decisions for themselves regarding medical care.	Thank you for your comment. This is an important point which we will raise with the Guideline Development Group.
Contact a Family	3	4.2.1	This needs to also include tertiary settings and specialised services. It will also need to consider how transition is coordinated for young people who are being seen in more than one health settings/service. Also a young person might stay in the same specialised service, if it sees children and young people. However there still needs to be a transition so the young person takes responsibility for their self-care, and decisions about medical treatment instead of their parents.	Thank you for your comment. Specialist children's services are in scope. The co-ordination of multiple providers is an important point and will be put to the Guideline Development Group.
Contact a Family	4	4.3.1	There appears to be lots of emphasis of on young people IN transition. We would also welcome a little more about preparing young people before transition on topics such as. • knowledge of their medical condition • impact of medical on their lifestyle e.g. having a family, drugs, alcohol • taking more responsibility for managing appointments • becoming gradually involved in decisions about their care from an early age where possible Good example see Ready Steady Go, University Hospital Southampton.	Thank you for your comments. We hope that by emphasising the long-term and preparatory (as well as continuing) nature of transition we have shown that the scope includes the period before actual transfer. The activities you list here would be included in 4.3.1 a) which relates to the involvement of young people and their carers in preparing for transition. We agree that education can have a key role to play.

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			4.3.1a - needs to include involvement of parents - as well as young people - in planning how services are delivered. Parents of disabled children often describe transition as akin to falling off a cliff - where all the support they previously had disappears. (health, education and social care). 4.3.1 g - education should always be involved - even when they are not leading the transition planning .Transition needs to be provided in a holistic way which takes into account what is taking place in the young person life and their aspirations for the future. If a YP wants to go to university it might make sense to plan the transition to adult health service to take place at the same time as they go to university, to avoid having transition at 16 - and then again at 18.. Also young people might need additional support for their health needs to help them in reaching their aspirations re further education.	
Contact a Family	5	4.3.1	Approach needs to encompass person centred planning with the young person at the heart of the process, see http://www.learningdisabilities.org.uk/help-information/information-for-teachers/transition-to-adulthood/using-person-centred-planning/ and http://www.helensandersonassociates.co.uk/reading-room/how/person-centred-reviews.aspx for more material on this	Thank you for your comment. Thank you for this reference which we will consider.
CSV (Community Service Volunteers)	1	4.3.1	CSV's experience supporting the transition of young disabled people and looked after children through peer and community mentor support overwhelmingly demonstrates that this type of impartial, non-professional support is a key factor in a smooth and personalised	Thank you for your comment. The role of the scope is to lay out the areas for consideration; the guideline will provide recommendations based on the best available evidence.

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			Transition. Therefore, we would welcome the introduction of a recommendation to develop, where possible and appropriate, strong links with the VCS in order to facilitate this as part of the Transition process.	
CSV (Community Service Volunteers)	2	4.1.1	CSV would welcome the acknowledgement of some key groups within this for whom the Transition process could prove additionally complex and therefore strong support and guidance is key – young people with multiple complex needs; young people from BME communities, including young people from migrant groups; young people leaving care. It is also important to consider the potential challenges being faced by young people from the LGBT community who additionally have social and health care needs.	Thank you for your comment. The groups you mention are covered by the Equality Impacts Assessment.
CSV (Community Service Volunteers)	3	4.2.2	Clearly, housing is a key factor in a positive Transition. One of the major gaps in service is the transition into independent living; CSV has experience of poor outcomes during Transition for young people leaving care when housing was not appropriate to their wishes or needs. Young people are often placed in hostel accommodation which is sometimes characterised by less support around independent living skills; again peer supporters would be helpful in this area.	Thank you for your comment. We agree that housing is relevant to transition; however, this guideline is focused specifically on how the transition is managed for young people who need health or social care services. Transition models which support transition by including a housing component are included.
CSV (Community Service Volunteers)	4	4.4	It is crucial that the Transition process is person centred, and as such it would seem appropriate to include an outcome which highlights the importance of a personalised Transition which works towards the individual's self-directed outcomes.	Thank you for your comment. Personalised transition will be covered by the types of activities listed in 4.3.
CSV (Community Service	5	General	The value of volunteering based peer support in facilitating effective transitions should be explicitly	Thank you for your comment. The guideline will consider different models and support for

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Volunteers)			acknowledged in guidance to commissioners and others.	transitional care and volunteering might be part of that but this will depend on the evidence available.
CSV (Community Service Volunteers)	6	General	A young people's advisory board to support the development and implementation of the guidance is essential.	Thank you for your comments. As part of the process of guideline development, we are consulting with a group of young people. Young people can also apply to sit on the Guideline Development Group and 4 places there are secured for young people and/or carers.
Diabetes UK	1	4.1.1	Diabetes UK strongly supports the intention that the guideline will cover all young people in transition – aged up to 25. It is very important that this guides the provision of all services for people in this age range, including inpatient care. Currently, whilst young people over 16 may still be under the care of the outpatient paediatric diabetes team if they are admitted as an inpatient they will often be admitted to an adult ward. This lack of consistency can be damaging to the transition process for that young person. This is particularly true when they are under the care of a paediatric team at a children's hospital and the adult inpatient care is at a different site. It would be helpful to provide clarity on how the scope would consider a chronic condition as distinct from a long term condition.	Thank you for your comment. Your example illustrates well the need for guidance in this area. Section 4.1.1 has been changed so the scope refers to long-term conditions only, and we will see chronic conditions as included in that.
Diabetes UK	2	4.3.1	We suggest that point 'd' be expanded. In addition to providing support to parents it would be helpful if the guidance covered the need for parents to have a more active role in transition planning. Although the opinion of the young person should guide the process, it is important that there is scope for the parents to input into	Thank you for your comment. The Guideline Development Group will be making recommendations which may well support your point on the role of parents, but cannot be assumed at this stage.

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			that process where appropriate too. An essential element of transition is ensuring the young person has sufficient understanding and knowledge to self-manage their condition. It would be helpful if the guidance could consider how to assess the young person's clinical understanding of managing their condition as part of the transition process. As mentioned above it would be helpful if this guidance also covered the need to achieve consistency of service provision in transition – whether that is adult or paediatric services – between inpatient and outpatient care.	It is outside of the scope to assess the effectiveness of self-management programmes, but self-efficacy and transition readiness both address your point. Continuity of care is one of the main outcomes listed in the scope.
Diabetes UK	3	4.4	In this section it would be helpful to expand the 'experience of care' bullet point to include both the young person and their parent's experience of care.	Thank you for your comment. Experience of care includes both young people and their carers, as indicated by the last sentence in this section.
Doncaster Metropolitan Borough Council	1	General	I welcome this piece of work and anything that improves the transition process for the young people and their families.	Thank you for your comment and for taking the time to consider the scope.
Doncaster Metropolitan Borough Council	2	General	Having attended the scoping workshop recently held in London I think it is important to ensure that there is an adult perspective on this as the majority of people attending were very much from a Children's background.	Thank you for your comment. Adult services are now listed in scope section 4.3.1.
Doncaster Metropolitan Borough Council	3	General	How does this link in with the EHCP and the process around that.	Thank you for your comment. We are aware of the importance of relating the guideline to the Children and Families Act 2014 and related processes. We will be reviewing existing information on the pathway pilots and the draft new code of practice to inform the baseline service assessment which we

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				present to the Guideline Development Group.
Doncaster Metropolitan Borough Council	4	4.1.1	I realise the list cannot be all encompassing but feel it would be worthwhile adding in young people with Autism/Asperger's	Thank you for your comment. All young people who are using children's health or social care services and undergoing transition are in scope. We have not mentioned specific conditions so as not to exclude any by not listing them.
Doncaster Metropolitan Borough Council	5	4.3.1	Should there be a level 3 which is about working with families and the young people?	Thank you for your comment. The importance of working with young people and their families/carers is emphasised in the scope, in 4.3.1.
Epilepsy Action	1	General	Epilepsy Action welcomes the integration of health and social care into this guidance on transition. We believe that better integration between health and social care, will lead to a coordinated approach to transition across both health and social care. We firmly believe that this will greatly benefit young adults, their families and carers. Crucially it could lead to a drastic improvement in the experience of many vulnerable young adults. This is because a coordinated and integrated approach will ensure that young adults (and their families or carers as appropriate) receive accurate information about how transition across both sectors will happen, relevant support services, appropriate benefits. This in turn should avoid vulnerable young adults feeling that their health and care provisions are in a state of constant upheaval.	Thank you for your comment.
Epilepsy Action	2	3.1.5	The experience of Epilepsy Action is that too many young people with epilepsy do not experience a well-planned, meaningful transition between child and adult services (in health or social care).	Thank you for your comment. Epilepsy is in scope. The final guideline will be particularly aimed at professionals and managers in health and social care services. It may also be relevant to

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			Transitional support for young people has ranged from: • a service discharge letter, • a letter simply stating that their next appointment will be with a member of adult services, • a one-off 'hand-over' appointment with a member from both child and adult services • carefully developed care and transitional plans, • specific interim services, clinics and peer support groups. The need and value of effectively planned transition pathways is undeniable. However, more must be done to influence commissioners and decision makers to appropriately commission effective pathways and services and encourage the take-up of best practice.	commissioners.
Epilepsy Action	3	4.1.1 General	Currently too many young people are 'lost' to appropriate adult health or social care at transition. We believe that the guidance should include 'young adults at risk of been lost to follow up' as a focus in 4.1.1 and should include best practice guidance for avoiding this from happening, and for timely identification and rectification when this problem does occur.	Thank you for your comment. As indicated by the scope, this is one area which the guideline will aim to address.
Epilepsy Action	4	4.1.1	We welcome all of the subgroups listed, but would like to see an additional subgroup: Young adults as risk of being lost to appropriate adult health or social care at transition. To include young people under the care of child health and care service but: • Their condition is well controlled at the age of transition but not cured and expected to relapse (for example epilepsy)	Thank you for your comment. This guideline will include all young people receiving health and social care services and your first point will be raised with the Guideline Development Group. Your points in regards to travellers and young offenders are covered in 4.1.1 in regards to young people in unstable living conditions, and also by the Equality Impact Assessment.

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			• They frequently move addresses (including those from the travelling community), • They are young offenders due to be released or have been recently released. •	
Epilepsy Action	5	4.3.1	The scope has produced a very comprehensive list of key areas. Transition is an excellent time for young adults to have their treatment and diagnosis reviewed. In the case of epilepsy, some syndromes are confined to childhood. It is important that the diagnosis of the syndrome is reviewed so that those who no longer need epilepsy treatment receive the correct support, and that those who have wrongly been diagnosed with a childhood epilepsy syndrome continue to receive appropriate care throughout and after transition. May we suggest 4.3.1.b is amended to read: Care planning, coordination, diagnosis and treatment review (where a health need exists) and assessment.	Thank you for your comment. The introduction to 4.3.1 has been changed and all the areas you mention are in scope.
Epilepsy Action	6	4.4	We believe one key outcome has been missed from 4.4 and we would like NICE to consider an additional outcome. An outcome of an effective transition is that the young adult will be able (as far as their condition and capacity allows) to: • self-manage their health condition or care needs, • actively ensure concordance with their treatment or care protocols, • actively engage in discussions and make informed decisions about their health and support.	Thank you for your comment. The outcomes you suggest are covered by the broader term 'self efficacy'.

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Epilepsy Action	7	General	We welcome the news that the guidance will look at the role of keyworkers, and roles and responsibilities during transition. Epilepsy Action believe that the resulting guidance should make it clear who should be involved in health transitions and care transitions – making it clear that BOTH children's and adults' services should be involved – it's not one group of professionals or the other.	Thank you for your comment. We are aware of the importance of co-ordination and this is emphasised in 4.3.1.
Epilepsy Action	8	General	The role of carers, guardians and parents should also be reviewed. We are very keen for parents, guardians and carers to be involved in transitional planning and delivery – but the ultimate aim must be to ensure that the young person becomes the champion of their own needs and as close to independent as possible (with independence being relative to a person's conditions, needs and capacity).	Thank you for your comment. We are very much including the role of carers in the guideline, and this is also listed in the outcomes.
Genetic Alliance UK	1	3.1.2	Rare Disease UK has found that 71%1 of patients affected by rare conditions do not feel they receive sufficient psychological support in relation to their condition. Patients affected by rare conditions would particularly benefit from professional psychological support during transition. http://www.raredisease.org.uk/documents/RD-UK-Strategy-Report.pdf	Thank you for your comment. We have added your link to our reference list.
Genetic Alliance UK	2	3.1.3	When a diagnosis of a rare condition is given, patients and families often find it difficult to access information about the condition and about the services available to them. This lack of information about rare conditions	Thank you for your comment The Guideline Development Group will be making recommendations which may well support your point, but we cannot assume this at this stage.

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			means that it is difficult for patients and families to play an active role in their care, make informed choices about their treatment options or plan for their future. Information allows patients to actively take part in determining their care pathway; this can help empower patients and allow them take control of the care they receive. Accessing appropriate information is particularly important to patients affected by rare conditions because of the paucity of reliable information and advice that exists and should be included within the patient's care pathway. A 'patient prescription' and access to a care coordinator can also help to overcome these issues (see also comment 12).	All young people who undergo a service transition from children's/adolescent to adult services are in scope, including those with rare conditions. We do not intend to exclude any particular conditions and so will take into account the health and social care needs of all young people using health and social care services.
Genetic Alliance UK	3	3.1.5	Patients with rare conditions also frequently experience problems with medical, psychological, financial, social and other issues at transition periods; this should be considered when making provisions for patients affected by rare conditions who are transitioning.	Thank you for your comment. Young people with rare conditions are covered by the scope as users of children's health and/or social care services. The guideline will only focus on service transitions. Due to the very broad remit in terms of populations there is a need to focus the guideline. It would be a considerable expansion to consider the evidence on how to meet the developmental transitional needs of all groups included in the scope.
Genetic Alliance UK	4	3.1.6	Care for patients with rare diseases is often not provided holistically and does not always include consideration of their non-medical needs. In light of this, patients with rare conditions should be given special consideration and noted as a 'particularly vulnerable group'. A care coordinator can help to overcome these issues (see also comment 12).	Thank you for your comment Young people with rare conditions are in scope, the Guideline Development Group will be making recommendations which may well support your point but this cannot be assumed at this stage.

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Genetic Alliance UK	5	3.2.1	This is especially true for patients affected by rare conditions who need support from a range of specialists and hospital departments making a multidisciplinary and coordinated team approach important. A care coordinator can help to oversee care and treatment and ensure coordination between clinicians, specialists and hospital departments (see also comment 12).	Thank you for your comment We agree that this is a good example of the need for services to work in partnership, and this will be covered in the guideline (see 4.3.1).
Genetic Alliance UK	6	3.1.5 3.2.3	Good practice exists within the rare diseases field and could be translated into best practice in wider scenarios. Patients and families with Lysosomal Storage Disorders who are transitioning from Great Ormond Street Hospital are given the opportunity to informally visit both Royal Free Hospital and National Hospital for Neurology and Neurosurgery to see which hospital would be the best fit for the patient. Those who wish to be treated at Royal Free Hospital will then attend a joint clinic where the GOSH paediatrician, Royal Free Hospital's clinician and paediatrician will also be present. A key role of the paediatrician at Royal Free Hospital is to support transition and management of young adults with Lysosomal disorders. Nurses at the LSD Unit at Royal Free Hospital have noted that patients and families affected by LSD who go through this transition process do not have the feeling of reaching a 'cliff edge' which patients often feel when transitioning.	Thank you for your comment. We agree that this is a good example of current practice and will add it to our reference list.
Genetic Alliance UK	7	3.3	The UK Strategy for Rare Diseases is a key document that contains over 50 commitments to ensure that people living with a rare disease have access to the best	Thank you for your comment. We have added the documents to our reference list.

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			care and treatment that health care systems (working with charities, researchers and industry) can provide. It is the first document of its kind and outlines the standard of care that patients with a rare disease can expect wherever they live in the UK. It has been agreed by all four home nations and should be taken into consideration by NICE. In response to the UK Strategy for Rare Diseases, NHS England has released a Statement of Intent which outlines how they will deliver on the healthcare commitments. Both documents can be viewed here: https://www.gov.uk/government/collections/rare-diseases Rare Disease UK's report: Rare Disease Care Coordination: Delivering Value, Improving Services looks at the difference a named care coordinator can make to patients with rare conditions and is particularly relevant to patients who are transitioning. The report can be accessed here: http://www.raredisease.org.uk/documents/RDUK-Care-Coordinator-Report.pdf	
Genetic Alliance UK	8	4.1.1	Because of the additional problems and issues experienced by patients with rare conditions during transition, rare diseases (especially undiagnosed conditions) should be listed as a sub group or included in the 'long-term, life-limiting and chronic conditions, including those with complex health needs' sub group and should recognise and address these problems.	Thank you for your comment. All young people going through transition from children's to adult services are in scope, including those who are using adolescent services. We try to avoid specifying sub-groups of this population as the guideline aims to be inclusive of a whole range of populations defined by their service use (health and social care) rather than specific conditions or circumstances. Young people

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				with complex health needs using a range of different agencies are recognised as a group for whom transitional care is particularly complicated.
Genetic Alliance UK	9	4.6	A sub group for rare diseases is particularly important because of the high costs associated with orphan medicines. This must be taken into account when carrying out economic analysis.	Thank you for your comment. The guideline will be based on a review of the available evidence and this may or may not emerge from that.
Genetic Alliance UK	10	4.3.2 General	The number of patients affected by rare conditions that transition from child to adult care is increasing as diagnosis and patient outcomes improve due to advances in medical science. It is therefore important to make provisions for patients who may be transitioning with a rare condition for the first time. To ensure that no patient or families fall through gaps it will be important that new guidelines are not condition specific. 4.3.2 notes that areas and issues that will not be covered include ' any services or intervention with no transition component' this is open to misinterpretation, as noted above some patients with rare conditions will be transitioning for the first time. 4.3.2 Should make clear that this does not include services which require transition for the first time.	Thank you for your comment, rare conditions are covered by the text under 4.1.1 which stipulates all young people using health and social care services and undergoing transition from children's to adult services are included.
Genetic Alliance UK	11	General	Most rare conditions are chronic and multisystem and patients need support from a number of specialists. From our experience, we understand that paediatric care is often well coordinated but care becomes fragmented after transitioning into adult services. Structures that were in place to care for and support a	Thank you for your comment. A key concern for the Guideline Development Group will be improving outcomes for young people and improving collaboration and continuity between services.

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			patient under paediatrics should continue to be made available post transition. Clinical teams should ensure that the process of transition is as straightforward as possible and that the care received in adult services takes into account the patient as a whole, rather than just each aspect of the condition. A care coordinator can help to overcome these issues (see also comment 12).	
Genetic Alliance UK	12	General	Rare Disease UK's report Rare Disease Care Coordination: Delivering Value, Improving Services found that patients with rare conditions often receive care and treatment that is poorly coordinated, which has a detrimental impact on their care and the lives of their families. The report found that a named care coordinator can greatly assist in ensuring coordination and continuity of care, so that care is provided as smoothly as possible for the patients they support. Care coordinators are also available to support the practical and emotional needs of patients, families or carers throughout the progression of the condition. They can also provide vital education to other professionals, to enable appropriate care and support to be provided. Despite the proven benefits, only 13% of patients with rare diseases have access to someone to fulfil the care coordinator role2. A named care coordinator is an effective and also cost-effective2 way of making a	Thank you for your comment. We have added the suggested report to our reference list.

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			positive difference to patients and families.	
Genetic Alliance UK	13	General	A significant source of problems during transition can be loss of patient records during transition. It will be worth considering patient-held records or patient passports to deal with this issue.	Thank you for your comment, this seems to be related to our focus on barriers to transition and is duly noted.
HIV Young Person's network	1	General	HYPnet welcomes this piece of work; It reflects practice we are already striving to achieve in the transition of young people with HIV from paediatric to adult settings.	Thank you for your comment.
HIV Young Person's network	2	General	We strongly feel that the sexual health needs of these vulnerable groups should be addressed, including access to sex education, screening for STIs and contraception, but also the wider issue of developing sexuality and healthy relationships in vulnerable groups such as those with a disability or disease that is transmissible such as HIV and Hep B, or genetic conditions that may be passed on to offspring. Consideration should also be given to the risk of child sexual exploitation in vulnerable young people. Special training may be needed in some settings to update care-givers on how to ask sensitive questions around sexual health needs and identify areas of concern.	Thank you for your comment. A key concern for the Guideline Development Group is improving outcomes for young people and encouraging collaborative working across services. However, the focus will be on service transitions, not developmental transitions.
HIV Young Person's network	3	General	Young people with HIV diagnosed early in life, occasionally under the age of 18, may be accessing adult services, or adolescent services which sit within adult services. It would be important to consider their inclusion in this document, or acknowledge that some of the document's principles may be relevant to them.	Thank you for your comment. The issue of children using an adult service will be considered by the Guideline Development Group.
HIV Young Person's network	4	General –	Clarity between 'transfer', the practical event and 'transition', the process that should start early in	Thank you for your comment Transition between services will be the focus of this

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			adolescent care for chronic conditions, with elements that should continue after transfer. The scope should comment on the assessment of readiness for transfer, and who should be doing this; often this is based on a range of factors, not just chronological age. Planning transfer together with the young person and a summary of care received to date passed to new care givers, which is relevant to the specialty. Young people with chronic health conditions often have complex social and psychological needs. Consideration should be given to provision of psychological support in these vulnerable groups, especially as often services currently cease at age 18.	guideline, and there will be an emphasis on integrated services which provide the best outcomes for young people.
HIV Young Person's network	5	4.4	The definition of self efficacy is incorrect – self efficacy is about people's beliefs in their ability to perform specific behaviours. Suggest that attitudes to care and information about care are included in outcomes Condition specific outcomes could also include behavioural outcomes e.g. Adherence.	Thank you for your comment. Information about care would be considered a service output rather than an outcome.
HIV Young Person's network	6	3.1.2	Loss of continuity of care may unavoidable as care-givers are likely to change, but loss to follow up is the pressing issue	Thank you for your comment. The Guideline Development Group will be making recommendations which may well support your point, but this cannot be assumed at this stage.
HIV Young Person's network	7	3.1.5	Perhaps identification of those most likely to be lost to follow up might allow us to target specific groups with extra support.	Thank you for your comment. Loss to follow-up after transfer to adult services is indeed important and reflected in our main outcomes list as part of 'continuity of care'.

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HIV Young Person's network	8	3.2.3	Addition of a section on which transition models are possible would be useful	Thank you for your comment. The guideline will make recommendations based on a review of the evidence and this review will cover research on transition models and their impact.
Leeds Teaching Hospitals NHS Trust	1	3.2.2	Service gaps are not only caused by a lack of relevant adult service - sometimes children's services will end before the adult services will pick up. E.g. some children's community services will end at 16 years and adults services at 18 years.	Thank you for your comment; this is an important point about service co-ordination.
Leeds Teaching Hospitals NHS Trust	2	4.3.1	recommend that the Guidelines Development Group looks specifically at the evidence behind recommending transition key workers with specific qualifications and skills (i.e. youth workers or clinical nurse specialists) and steaming from reviewing this evidence, put in place recommendations for the "minimal qualifications and skills "of dedicated transition key workers. This would facilitate leasing with commissioners and managers for service development.	Thank you for your comment. The guideline will be based on a review of the evidence which may support your point but this cannot be assumed at this point in time.
Leeds Teaching Hospitals NHS Trust	3	4.3.2	Career advice should be integral part of transition preparation when a chronic condition is likely to impact on the suitability of specific career choices (e.g. young people with long-standing arthritis cannot access military careers) Young people with chronic/complex health need access to well informed advice and career counselling should be an important skill of dedicated transition key workers.	Thank you for your comment. The role of the scope is to lay out the areas for consideration; the guideline will provide recommendations based on the best available evidence.
Leeds Teaching Hospitals NHS Trust	4	General	Recommends that a clear definition of what Transition means to be decided upon and stated.	Thank you for your comment. Defining 'transition' is important, and the scope tries to provide it in terms of a planned and co-ordinated approach to

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				planning, transfer and continuing support, emphasising the long-term aspect and that it is not simply the moving of a patient from one set of services to another.
Leeds Teaching Hospitals NHS Trust	5	General	More engagement with the GPs is needed	Thank you for your comment. The importance of GPs is emphasised in section 4.2.1.
Leeds Teaching Hospitals NHS Trust	6	General	Concern about transition being described as a finite process. Transfer is just a part of the transition process - another difficult aspect is when they move to adult services, after transition, and being left to fend for themselves when deemed ready. The transition process should continue to guide them for an amount of time defined by the young person/family's reaction to the move.	Thank you for your comment. The ongoing nature of transition (rather than simply transfer) is reflected in the scope by including adult services, and by having an upper age limit of 25, indicating that we will cover the period before, during and after transfer.
Life Now	1	4.3.1	Suggest Level 3: direct discussion with young adults. This may be implied by Level 1 but needs to be distinctive and separate in order to highlight the role young adults should play.	Thank you for your comment. Section 4.3.1 emphasises activities which involve young people and carers.
Life Now	2	4.5.9	Transition is not simply about the *improvement* of adult services. Attention needs to be given to the specific provision for young adults of buildings dedicated to their needs. Bolt-on units are not the complete answer, nor are the addition of 'a young people's room' or something similar, something of a token gesture. The specific needs of young adults have to be taken far more seriously and that will mean buildings designed with their needs in mind.	Thank you for your comment. The role of the scope is to lay out the areas for consideration; the guideline will provide recommendations based on the best available evidence.
Life Now	3	4.7.2	The provision for young adults is a matter of increased urgency. Publication ought to be a matter of similar	Thank you for your comment. Unfortunately NICE guideline development requires enough time to

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			urgency. October 2015 would be a better end date!	consider the evidence for the prioritised questions and for this guideline with such a wide population focus all scheduled time is needed. The Guideline Development Group will meet in June and agree the prioritised questions. They will then meet every 5 weeks during which the reviewers will consider the evidence for 1 or 2 questions. The Guideline Development Group then develops recommendations based on this evidence before the final guideline is drafted and sent to consultation.
Life Now	4	General	Why is the top age 25? Any age is arbitrary, of course, but perhaps this should be extended to 30yrs to include more young people.	Thank you for your comment. The upper age limit of 25 reflects the planning stipulated by the Children and Families Act 2014.
Marie Curie Cancer Care	1	General	Marie Curie is aware of the importance of ensuring transitions from children's to adult's services for young people with palliative care needs. In 2012, working with the charity Together for Short Lives, Marie Curie produced a report, Don't Let Me Down, which carried out research into experience of transitions for young people with palliative care needs and identified improvements that could be made. It is important that the guideline includes a focus on the transition experiences of those with palliative care needs.	Thank you for your comment. Palliative care is within scope and so evidence around good practice in this area will be considered.
Marie Curie Cancer Care	2	3.1.5	Our report found that for young people with palliative care needs, transition was like a cliff edge. One of the report's recommendations was to begin planning the transition once the young person reached the age of 14, with a 5-year rolling plan involving all relevant local services so that services are tapered to ensure a smoother transition.	Thank you for your comment. Palliative care is within the scope of this guideline and we have made a note of the reference to your report in our reference list.

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			In terms of negative impacts of bad transitions, our research identified greater social isolation. It also found that young people with palliative care needs felt excluded from accessing leisure activities and also that they had little support for their wishes in terms of accessing education and / or employment. The research also found that many of the young people with palliative care needs making the transition to adult services had not been expected to live into adulthood, but had done so as a result of drug and treatment advances. In some instances, these young people were the first people with their conditions to make the transition to adult services, which posed particular challenges for both the young people and those providing services.	
Marie Curie Cancer Care	3	3.3	The Don't Let Me Down report is available online at the following link: http://www.mariecurie.org.uk/Documents/press-and-media/News-Comment/Dont-Let-Me-Down.pdf and could be of use in developing the scope.	Thank you for your comment. We have added the document to our reference list.
Martin House Children's Hospice	1	4.1.1	There is no mention of the young people who do not have the capacity to consent/be involved in the decision making around their care. There are many different issues for this group so we would like to see them being highlighted as an important subgroup. For example the Rotterdam transition profile is not useful in this group as they are often losing skills rather than gaining them.	Thank you for your comment where you raise an important point which has informed the Equality Impact Assessment. Your point will also be forwarded to the Guideline Development Group.
Martin House Children's Hospice	2	4.5	Key questions to include how to ensure the needs of young people who do not have the capacity to	Thank you for your comment. Young people without the capacity to consent are covered by the Equality

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			consent/be involved in the decision making around their care are addressed.	Impact Assessment, and any evidence emerging in regards to this group (and other groups listed in the EIA) will be considered under the relevant review question.
National Children's Bureau & Council for Disabled Children	1	General	It is important that the guideline links and refers to the Children and Families Act and the Care Bill where appropriate throughout the document.	Thank you for your comment Relevant legislation and policy will be taken into account during the guideline development process.
National Children's Bureau & Council for Disabled Children	2	3.1.6	Young people living with serious communicable diseases such as HIV are also particularly vulnerable due to the level of secrecy and stigma surrounding their condition within families, in peer groups and in services – even if an individual is in good physical health and not being supported by CAMHS or social care services.	Thank you for your comment. HIV is within scope, but individuals who are not using health and/or social care services are outside of the scope because this guideline will focus on the importance of improving the transition of young people from children's to adult services.
National Children's Bureau & Council for Disabled Children	3	3.4	The guidance should also refer to the principles of the Winterbourne View Concordat and the working of the Winterbourne View Joint Improvement Programme. Winterbourne View represents some of the most extreme consequences arising from a failure to adequately plan and implement transition to adult services and this guidance will play an important role in ensuring that these failings are not repeated.	Thank you for your comment and for pointing this out. This will be considered.
National Children's Bureau & Council for Disabled Children	4	4.1.2	Young people who are newly diagnosed with a long-term health condition within adult services may struggle to access those services for similar reasons to their peers who are known to paediatric services. This also applies for young people who are entering adult social care services that were not previously under the care of children's services.	Thank you for your comment. The focus of this guideline is the transition between services, not the appropriateness of a service. However, the issue of young people-friendly adult services is now covered under 4.3.1 and also by review question 4.5.9.

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			Young people may not be using children's health or social care services for a number of reasons, for example they or their families may not have appropriate information about what is available to support them. We believe it is important that these groups of young people are included in the scope of the guideline however, if it is appropriate for them not to be covered, a note acknowledging that some of the document's principles will also be relevant for them would be welcome.	
National Children's Bureau & Council for Disabled Children	5	4.2.2	Although housing services are outside the scope of NICE's remit it would be helpful if the guideline refers to the fact that health and social care services need to liaise with housing services.	Thank you for your comment. Your point is very helpful and will be put to the Guideline Development Group.
National Children's Bureau & Council for Disabled Children	6	4.3.1	Another important issue is the information given to young people about their situation and their needs, e.g. the name of a health condition they have been diagnosed with, or their current state of health. There are still cases – for example, many young people living with vertically-acquired HIV – in which individuals are not given information about themselves that they are capable of absorbing and that it is in their best interests to know. (The Children's HIV Association are currently updating their guidance for clinical practitioners on talking to children and young people about HIV, but they have a quality standard on open and honest practice, and an organisational position statement, available online: http://www.chiva.org.uk/professionals/health/social-care/standards.html.)	Thank you for your comment. The role of the scope is to lay out the areas for consideration; the guideline will provide recommendations based on the best available evidence.

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National Children's Bureau & Council for Disabled Children	7	4.3.2	It is important that the guideline references the fact that health and social care services should liaise with other transition support services to ensure an integrated, person-centred experience for young people.	Thank you for your comment. Thank you for your comment. The role of the scope is to lay out the areas for consideration; the guideline will provide recommendations based on the best available evidence. Joint working and information-sharing is emphasised in 4.3.1.
National Children's Bureau & Council for Disabled Children	8	4.4	It is important that outcomes are linked to the Preparing for Adulthood outcomes in the SEND reforms (Children and Families Act 2014) as well as those already listed. This would include outcomes that look at whether young people are informed and able to make choices relating to their transition, including the involvement of families and carers where young people want them to be involved.	Thank you for your comment. The role of family members and carers will be considered in the guideline. The outcomes in the SEND reforms will be considered in terms of long-term outcomes but the primary focus of this guideline will be on experiences related to service transition, and subsequent service outcomes such as continuity of care and quality of life.
National Children's Bureau & Council for Disabled Children	9	4.6	The principle of cost effectiveness is an important principle for the transition guidance, but the scope of this cost effectiveness is important. The savings that can be made from effectives transition may be less immediate or be accrued over a longer period of time, to different service areas as the young person moves into adulthood. The costs of any transition support should be placed in the context of the overall value of transition support should be.	Thank you for your comment. We will consider long-term outcomes as well as immediate service outcomes.
National Rheumatoid Arthritis Society	1	4.0	NRAS strongly endorses the recommendation in the scope for the inclusion of a specific sub-group for young people with long-term conditions, which would run alongside the guideline's focus on general principles of transition across all services.	Thank you for your comment and for taking the time to consider the scope.
National Rheumatoid	2	4.1.1	NRAS strongly supports the age range for transition outlined in the scope.	Thank you for your comment. The role of including young people's preferences and views during

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Arthritis Society			However, we would also like to highlight that some young people receiving care from certain hospital trusts undergo compulsory transition at the age of 16, rather than choosing the time that is best for the young person. This issue needs to be properly addressed during the development of the guidelines.	transition will be addressed in this guideline.
National Rheumatoid Arthritis Society	3	4.3.1	NRAS requests an addition to the listed transition support activities covered by the scope: this is the signposting of young people in transition to additional support services, including voluntary sector support and help lines, self-management training courses, and social services.	Thank you for your comment. The signposting to additional support activities will be included if identified in the review of the evidence.
National Rheumatoid Arthritis Society	4	4.5.5	NRAS strongly endorses the inclusion of a review question in the scope on the contribution and impact of the voluntary and community sectors in supporting transition as this is not an area that is well covered in areas such as paediatric rheumatology.	Thank you for your comment. Please note that this question is now reworded to consider all transition planning and impact (not just that delivered by voluntary sector agencies).
Public Health England	1	General	There are often very significant differences in thresholds for access to services for children and young people and for adults. Many of these thresholds do not recognise emerging problematic behaviours (e.g. in some areas the thresholds for accessing adult services may be set too high and not recognise developing substance misuse). In such circumstances opportunities to provide support or intervention can be missed, which can then lead to more severe problems in early adulthood and disengagement from services.	Thank you for your comment. The problem of different service threshold is important and duly noted.
Public Health England	2	General	Transition is a status (i.e. 'in transition') and a process, not an event. However, the short-term and episodic nature of many social care interventions and the	Thank you for your comment Current problems with transition services are a key concern to this guideline and we distinguish in this

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			pressure on those working with young people can result in too quick handovers of individual case responsibilities and a lack of good joint working.	scope between transition and transfer. Transition is seen as a long-term process which includes the period before, during and after transfer.
Public Health England	3	General	Transition should be managed on the basis of need and the level of maturity of young people, not simply age. The increasing ''life course' basis for commissioning of health and social care services provides an opportunity to move away from age-based services to more needs-based provision.	Thank you for your comment. The issue of age thresholds and readiness for transition is reflected in the scope's consideration of young people and their transition period, without stipulating a lower age, and by going up to 25.
Public Health England	4	General	The scope of the guidance appears heavily directed toward mental health and perhaps needs to include a wider range of needs. This may also provide further opportunities to identify and highlight examples of innovative and good practice.	Thank you for your comment. The range of health of social care needs included in this guideline will be broad, no conditions are excluded, but the scope document is a summary and so cannot mention individual conditions. Young people not accessing health and/or social care services are outside the remit of this scope.
Public Health England	5	General	It would be useful for there to be some exploration of the impact (positive, negative or neutral) that integrated transition management has for young people, and any implications for services around costs and efficiencies.	Thank you for your comment The impact of services may well emerge as a key area in this guideline.
Public Health England	6	General	In the questions section, there should be some questions for adult services about what works well, and what causes problems for them in terms of transition.	Thank you for your comment. We would suggest that the question about what works well in adult services is covered across several of these questions. The Guideline Development Group will review and approve the questions.
Public Health England	7	General	The draft note does not include transfer of young people from youth offending settings to adult prisons but how will we ensure this vulnerable population have their continuing health and social care needs attended to effectively during and post transition, bearing in mind	Thank you for your comment Young offenders are within scope if they are receiving health and social care services, but transitions between facilities is outside the scope of this guideline if the individual is not receiving child

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			that this population is over-represented in those experiencing a range of poor health outcomes including mental health, oral health?	or adolescent health and social care services.
Public Health England	8	4.1.1	The draft scope does not have a clear mention of young people with substance misuse problems, though this is a group worth highlighting in the draft guidance. It's also worth noting that transition from young people's substance misuse services to adult substance misuse services is often fraught with difficulties since adult services' thresholds may be set at different levels than those in young people's services.	Thank you for your comment. Young people with substance misuse problems undergoing service transition, as you are describing, are in scope.
Public Health England	9	3.2.2	It is very important to actively consider the specific needs of young adults when identifying the overall service needs of adult populations, and in the design, commissioning and delivery of these services. If the needs of young adults (18-24) are not recognised and accommodated and adult services only address the needs of older age groups, achieving successful 'transitions' to these services by younger adults will always be problematic, irrespective of what is put into place to manage the process.	Thank you for your comments, which related to the areas of the scope concerning adult services, now covered under 4.3.1.
Public Health England	10	3.2.2	The impact of the variations in criteria applied by different services to differentiate between children and adults: can be problematic, creating confusion and leading to young adults being denied a full service or being offered inappropriate interventions (e.g. vulnerable young adults being unable to access CAMHS inpatient services by virtue of an arbitrary age cut off, and being placed on adult psychiatric wards).	Thank you for your comment. The problem of some young people not meeting the threshold of adult services is recognised and will be covered in the guideline.

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Public Health England	11	5.1	We suggest that NICE PH4 (Interventions to reduce substance misuse among vulnerable young people) is added to the list.	Thank you for your comment. The scope is just a brief summary of the topic area and the related guidance is not intended to be an exhaustive list.
Rethink Mental Illness	1	4.1.1	Rethink Mental Illness welcomes the focus on young people affected by mental illness in the scope. We would support the intention to have recommendations for this and other specific sub-groups where appropriate.	Thank you for your comment.
Rethink Mental Illness	2	4.1.1	Early Intervention in Psychosis (EIP) services support young people aged 14-35 experiencing their first episode of psychosis. EIP care increases a person's chance of recovery and has been found to be both clinically and cost effective. EIP services have a holistic ethos and often support people to access other services, such as physical health and psychological support. As young people may access an EIP service at any point across the age range discussed in the scope, they may bridge both children and adult services during their time under EIP. We would therefore ask that special consideration be given to EIP services. Rethink Mental Illness recently published a report on EIP which is available on our website http://www.rethink.org/lostgen	Thank you for your comment. Transition and transfer will be considered for all services and in particular for services which in themselves operate as facilitators during this period of service provision. We have taken note of your report.
Rotherham Doncaster and South Humber NHS Foundation Trust	1	General	We have reviewed the consultation draft scope and agree with the issues raised and the proposed scope of the guidance.	Thank you for your comment.
Royal College of Nursing	1	General	The Royal College of Nursing is a registered stakeholder for the guidelines 'Transition from children's to adult services for young people using health or social care	Thank you for taking the time to consider this scope.

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			services. The Royal College of Nursing was invited to comment on the draft scope for this guidance. The document was circulated to nurses caring for children and young people across health, education and social care services. Below are comments received from the reviewers:	
Royal College of Nursing	2	General	From a recent workshop 'The Big Discussion' it was clear that there are big issues related to differences in age definitions and cut off ages between health, education and social care services for children and young people. This often causes young people to fall between gaps in services.	Thank you for your comment. The scope does not stipulate a specific age of transfer due to the issue that you raise.
Royal College of Nursing	3	General	It will be important to involve young people and young adults in the guideline development. It will be important to be transparent and clear about the process for doing so, and to include individuals able to give health, social care and education perspectives.	Thank you for your comment. Four places on the Guideline Development Group are set aside for young people or carers, and we are hoping that these will all be filled. A group of young people with experience of transition have also provided comments on the scope.
Royal College of Nursing	4	2	We note that this guideline will complement NICE guidance already in existence, for example in relation to looked after children, but wonder whether the remit of the transition guideline should also include Legal Aid, Sentencing and Punishment of Offenders (LASPOA) arrangements for children under the age of 17 remanded to custody? It would be helpful to clarify.	Thank you for your comment. Young offenders are considered to be in scope when they are using health and social care services. Otherwise they will be outside the remit of this guideline, which will focus on transitional practice for young people within health and/or social care.
Royal College of Nursing	5	3.2.2	This also applies to looked-after children and unaccompanied asylum seeking minors.	Thank you. Vulnerable groups are identified in the Equality Impact Assessment.

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Royal College of Nursing	6	3.2.3	Young people at 'The Big Discussion' highlighted the need for multiagency and multidisciplinary transition planning, particularly for young people with complex health care needs who require input from health, social care and education. A key worker was reported to be crucial.	Thank you for your comment. We agree that this is a good example of the need for services to work in partnership, and this will be covered in the guideline.
Royal College of Nursing	7	3.3	We accept that this is not intended to be a comprehensive list; however, it would be helpful if it also incorporates the Leaving Care Act 2000 and NICE Public Health (PH28) guidance for Looked After Children and Care Leavers, these are important and relevant documents which would inform the development of this guidance.	Thank you for your comment. The Leaving Care Act 2000 is mentioned in 3.4 penultimate bullet. The NICE Public Health guidance for Looked After Children is listed in 5.1, in the fifth bullet.
Royal College of Nursing	8	3.4	As above, we accept that this is not intended to be a comprehensive list; however it would be helpful if it also incorporates the Leaving Care Act 2000, and NICE Public Health (PH28) guidance for Looked After Children and Care Leavers.	Thank you for your comment, the scope will reference the Leaving Care Act and the relevant NICE guidelines.
Royal College of Nursing	9	4.1.1	We are pleased to see that the guideline will cover all young people up to 25.	Thank you for your comment.
Royal College of Paediatrics and Child Health	1	4.1.1	No lower age is defined. The process should begin in early adolescence. Maybe 13 would be a reasonable lower limit. Agree with 25 as the upper limit.	Thank you for your comment. A lower age limit is not set to reflect that transition preparation might start at very different ages depending on the child's maturity and also the nature of and practice within the service.
Royal College of Paediatrics and Child Health	2	4.3.1	Agree that parents/carers require support. Cutting the apron strings is a painful process for parents who have invested 10-15 years of devotion to care of their child with a chronic problem. Anxiety is particularly high in	Thank you for your comment.

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			mothers.	
Royal College of Paediatrics and Child Health	3	4.4	This should include patient reported experience measures. Picker Institute is working on a generic PREM for transition and has already conducted focus groups. They should be invited to give evidence.	Thank you for your comment. The information will be handed to the Guideline Development Group for consideration.
Royal College of Paediatrics and Child Health	4	4.6	Economic analysis should include life-long earnings. Badly managed transition can result in impaired career attainment and therefore reduced earning capacity	Thank you for your comment. The scope is a short summary of the overall coverage of the guideline which is focused on service transitions, not developmental transitions. However, we recognise that for some groups long-term outcomes such as those you mention are relevant.
Royal College of Paediatrics and Child Health	5	General	Studies are in progress in Sickle-cell disease transition. Both RCPCH and RCP have conducted reviews of transition. A prominent comment from young people is that the relationship built particularly with nurse specialists should be sustained throughout the transition until confidence has been generated in the adult service. Direct involvement of young people with chronic conditions would be particularly valuable in drafting these guidelines One reviewers comments are as below: Expressed concerns that this review is just albeit well intention window dressing. Concern are that whether we use the term 'recommendations' or 'guidelines', in either case a document will be being produced lacking teeth in order to compel effective provision. There is now in hand statutory provision through the educational care pathway up to 25 years of age and a principle has already been established for statutory intervention for a specific medically defined group through the Autism Act 2009. There needs to be further statutory provision to protect	Thank you for sharing this case with us which illustrates the high importance of improvement in this area. The NICE guideline can only recommend good practice, not legislate it.

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			what can be an extremely vulnerable group of patients. These patients' needs this statutory protection not only to ensure they have safe care, but also as it gives a wider message that they are indeed valued, respected and matter.	
Royal College of Paediatrics and Child Health	6	General	With regard to this section we have been provided with a link to a document which has been written to support the issues that needed to be taken into consideration during transition of young people with complex needs. Some of the issues have since moved on, in particular the developing 0-25 service, but the issue of continuing care remains an issue because it influences who will be involved in adult services from a funding and personnel point of view. As such, this influences how to progress through the transition process, with the need to work in a multi- agency format and to have a plan to guide the young person and their family through the process. From the case study below, it can be seen that if certain processes are not followed, it is difficult to progress to the correct pathway. The process of transition for many young people is a trailblazing route with adult services having to learn new types of methods of care and acknowledge that a young person with complex needs requires a social aspect to their care and not a primary focus on their health care. I have worked with young people who require ventilation but want to attend music gigs or experience a cruise without their parents although their physical needs are complex. http://www.teamaroundthechild.com/images/stories/journal-pdfs/3denisefranks11.pdf	Thank you for your comments; we have added your case study to our list of literature.

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Royal College of Paediatrics and Child Health	7	General	One of our commentators has developed documentation and a process to enable transition to be taken into account in each of the departments within the hospital. Here is the link to the website that includes the documentation and explanation of the process. Further work is developing on interactive technology to enable young people to progress through the process individually and at their own pace with support as appropriate.	Thank you for your comment. We have noted down the link you provide to a good practice example.
Royal College of Paediatrics and Child Health	8	4.1.1	Document suggests that the focus is on 18 year olds who are transitioning to adult care providers. We would suggest that the transition process should start at a much younger age. Responsibilities should gradually move from parents to the patient from perhaps 13 years of age. We would like to see this more clearly spelt out.	Thank you for your comment. We state that transition does not describe only one move at the age of 18, and this point will be expanded in the guideline.
Royal College of Paediatrics and Child Health	9	General	Critically important to have representation from both adult hospital care and primary care on the review board.	Thank you for your comment. The Guideline Development Group is made up of representatives from across relevant sectors and services including 4 places reserved for young people and carers. The process of appointing members is through an open call where people apply for a position.
Royal College of Paediatrics and Child Health	10	General	Generally well written and we like the plan to look at transition widely beyond areas of immediate and quite well-researched medical areas such as Diabetes services.	Thank you for your comment.
Royal College of Paediatrics and Child Health	11	4.5	It may be worth when considering how to analyse the success of transition services to consider the model proposed by Forbes et al (Forbes A, While A, Ullman R, Lewis S, Mathes L, Griffiths PA. Multimethod review to	Thank you for your comment. This review was identified in the pre-scope search and your recommendation for it is noted.

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			identify components of practice which may promote continuity in the transition from child to adult care for young people with chronic illness or disability London: National Coordinating Centre for NHS Service Delivery and Organisation; 2001.) who subdivided the process of transition into a series of 'continuities', a useful way of considering the process which will vary widely from centre to centre (NIHR report: HS&DR - 08/1504/107: The Transition from Paediatric to Adult Diabetes Services: What Works, for Whom and in What Circumstances?)	
Royal College of Paediatrics and Child Health	12	3.1.3	Vital to involve Parents/Carers and where possible, young people themselves.	The guideline will cover activities that involve young people and carers in transition planning and delivery (see 4.3.1). Young people with experience of transition will be represented on the Guideline Development Group.
Royal College of Paediatrics and Child Health	13	3.1.6	Of the highlighted vulnerable groups, those with co-morbid mental health problems are perhaps the most important given the shortage of Child Psychiatrists and other members of local CAMHS teams.	Thank you for your comment. Young people with complex needs and service use are covered by the scope and recognised as an important group.
Royal College of Paediatrics and Child Health	14	3.4	We hope that the Care Bill finishes its journey through Parliament.	Thank you for your comment.
Royal College of Paediatrics and Child Health	15	4.3 (h)	A 'Barrier' to add is the conflict in many cases between the young person's needs and the Ofsted demands.	Thank you for your comment. We will consider the evidence on 'barriers' carefully.
Royal College of Paediatrics and Child Health	16	4.5.1 2 3	Stresses again the importance of involving parents/carers and, where possible, the young people.	Thank you for your comment.
Royal College of Paediatrics and	17	4.6	There may be financial shortcomings in those areas most affected by recent Government cuts in LA funding	Thank you for your comment. The NICE guideline cannot recommend priorities for funding.

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Child Health			resulting in the seemingly ubiquitous 'Post Code Lottery'.	
Royal College of Paediatrics and Child Health	18	6	Social Care Guidelines deserve to be emphasised especially in view of the national shortage of social workers, especially those dealing with children.	Thank you for your comment.
Royal College of Paediatrics and Child Health	19	General	Transition to Adult services of a disparate group of young people has been a problem for many years as more complex cases are living longer with often no TEAM to transfer such young people to.	Thank you for your comment. It has been noted.
Royal College of Paediatrics and Child Health	20	General	See below an extract from a paper about the 7 principles of Transition: Transition to adult services: Generic Principles 1.Defined and agreed timescales Transition period aged 13 to 25 years. Initial discussions to commence at 13 years (if appropriate) with gradual rise in autonomy of young person who should be at centre of shared decision making. 2.Identification of Stakeholders This should involve the young person, family or carers, health professionals from primary, secondary and tertiary care as appropriate as well as professionals from social care, education and voluntary sector. 3.Definition of mode of transfer/ transition of care This is likely to involve paediatric medical and/or nursing professionals working with either the GP or an adult health professional in secondary /tertiary care. Transfer of secondary/tertiary care should involve joint paediatric/adult health professionals working together,	Thank you for your comment. The paper has been added to our literature list.

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			possibly in joint clinics, rather than written referral only. 4.Clarification of review arrangements Review arrangements may be a combination of face to face clinics with medical/nursing professionals, telephone, text, email or telemedicine contacts. All should be discussed and agreed in advance. 5. Named / identified keyworker. This is likely to be a nurse who knows and is acceptable to the young person & family who will initiate and review the Transition programme and liaise with others as necessary. Suitable resources (including appropriate Job Planning and training) should be made available to facilitate this provision. 6. Written Transition Plan. This should be prepared by the keyworker after discussion and agreement with young person and/or family & all stakeholders. It should be flexible and regularly reviewed with the young person. 7. Evaluation and audit process. Review and audit should be embedded into the process from the start. This should include patient satisfaction, complaints, clinical incidents, clinical outcomes and adherence to management plans. Identified gaps in service provision should involve commissioners as soon as possible.	
Royal College of Paediatrics and Child Health	21	General	What happens at 25 yrs? Does this not merely shift the transition process from 18 to 25 yrs?	Thank you for your comment. The scope distinguishes between transfer and transition. The transfer would still happen around 18, but the transition support would be provided after the

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				transfer.
Royal College of Paediatrics and Child Health	22	General	Transition covers up to 25 yrs of age, paediatricians do not currently have the skills or expertise to deal with people over 18 yrs old.	Thank you for your comment. The guideline will assess the evidence on how to plan and support young people's transition from children's to adult services and this includes whether services need to change to accommodate this, and whether staff needs to be trained (see section 4.3.1).
Royal College of Paediatrics and Child Health	23	General	Local services and pathways are being developed, and the need for a lead/designated doctor has been identified. If this is a paediatrician, would this discourage adult specialities from being proactive. Should the lead be community based to incorporate primary care with additional paediatric support?	Thank you for your comment. The role of the scope is to lay out the areas for consideration; the guideline will provide recommendations based on the best available evidence.
Royal College of Paediatrics and Child Health	24	General	There will be a strong mental health element to the majority of cases, and CAHMS is an essential common thread for all.	Thank you for your comment. CAMHS are included in scope.
Royal College of Paediatrics and Child Health	25	General	Are forensic physicians included in the consultation and subsequent working group? I note that transition from Youth Offending Institutes to prison are excluded, but this does not cover the health needs of CYP seen by doctors working in the new health care systems recently transferred from the HO. Some of these CYP will have unmet +/- previously undetected medical conditions e.g. ADHD, ASD.	Thank you for your comment. The transition within health and social care of young offenders is in scope, and we note your point about forensic physicians.
Royal College of Paediatrics and Child Health	26	General	How do other countries manage transition? I would imagination there are other health systems where there is not such demarcated age groups.	Thank you for your comment. This is a good point and highlights the importance of looking beyond UK literature when it comes to evaluated approaches and also models of care.

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Royal College of Paediatrics and Child Health	27	4.2.1	"All settings in which a transition from children's to adult health or social care services takes place including primary, community, residential, secondary care and secure settings" Please can we also include Tertiary and higher levels of care? i.e. specialised and highly specialised children's services.	Thank you for your comment. Specialist children's services are in scope.
Royal College of Paediatrics and Child Health	28	General	The scope is excellent. An important area to be considered is patient and family choice. It would be helpful if the guidance could consider the potential area of conflict between organisational capacity of 'children's hospitals' to care for children older than 16 years and patient choice and readiness for transition. This is an important concept for equality of opportunity	Thank you for your comment, which is indeed highly relevant to the guideline work and will be forwarded to the Guideline Development Group.
Royal College of Paediatrics and Child Health	29	General	**Equality of opportunity- access to health and social care** NICE guidelines provide recommendations on what works and this CG is particularly aimed at professionals and managers in health and social care services, in both children's and adult services. This document has an opportunity to strongly reinforce that **health and social care should be fully integrated and both should share the same, joint outcomes for young people**. Currently this is not the case and until this principle is achieved, young people will not universally get integrated and therefore best health and social care outcomes.	Thank you for your comment. We appreciate the policy drive and the importance of joined-up services.
Royal College of Paediatrics and Child Health	30	4.1.2	**Equality of opportunity and aadolescent medicine** Further emphasis is required to ensure that standards	Thank you for your comment. The remit for this guideline is to focus on transition as a sticking point in continuity of care, however your point is important

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			are set out to cover all patients with chronic health problems, and not just those within a transition process. There are patients aged under 18, and in some cases under 16 being cared for by adult services in the UK and these patients might not receive the same attention to their needs as those undergoing a formal transition process. It is important that this guidance captures all young people , since :- A] Young adults have the greatest non-adherence rates for medication (Good hand et al, APT, 2013, Nov; 38(9):1097-108), which may affect their long term health outcomes. Not all adult providers would provide support for young people in complying with complex treatment regimens if they were not undergoing a formal period of transition B] Safeguarding young people under 16 in adult services might be looked after by professionals in adult departments who are not fully aware of correct safeguarding procedures.	as it relates to whether adult services are appropriate for their youngest service users. This is now reflected in 4.3.1 and also by review question 4.5.9 which focuses on how adult services can be improved. However, the main focus of this guideline is on transition practice and support.
Royal College of Paediatrics and Child Health	31	General	**Equality of opportunity and AGE** This guideline will cover all young people in transition (it is stated that this is aged up to 25). **Referral to services –adult or Children's' services?** Clarity of the age appropriateness of patients seeking access to the right health care provider is required. Major changes in referral practices might inadvertently occur with the recommendation that the upper limit of	Thank you for your comment. We agree that it is important to emphasise that while transition support goes beyond the age of 18, the transfer from one service to another tends to happen around that age.

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			transition is 25 years if some referrers believe that Children's and YP's services manage young people up until 25 years of age. Most YP are ready to transfer by the age of 16- 18 years. The guidelines would need to give clear guidance about the appropriate age for young people to enter adult services, particularly if professionals are seeking access for new conditions and to empathise that the transition is usually completed when children leave school **Timing of transition** If explicit recommendations were not made to start transition early so that it is usually completed by stay age 18, it could inadvertently encourage units not to start transition arrangements until the children and young people have left education. While not universal, the situation could end much worse than the current practice as the young people might not engage with transition aged > 16 when they have left school and are more independent from their parents. **Facilities for young people in children's trusts** Standalone children's Hospitals and paediatric units in co-located hospitals would find it difficult to arrange inpatient facilities and YP aged 18-25 years to access children's A & E departments. The practical difficulties of having a minor and an adult (by legal age definition) in the same ward would have to be managed carefully as well as informed policies regarding parental responsibilities safeguarding and consent procedures for (vulnerable) young people in	

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			children's units who happen to be over the age of 16 years. Adolescent wards in children's hospitals would overcome this and would need to be emphasised if evidence exists for this provision.	
Royal College of Paediatrics and Child Health	32	4.1.1 4.3.1 4.5.1	**Equality of opportunity** (4.1.1 Section 4.3.1 Section 4.5.1; This section clearly mentions that transitioning children with mental health needs; looked after children; and children with life limiting symptoms and chronic illnesses are the vulnerable groups and can be easily overlooked. Although they may form a small minority of the population, they are the most vulnerable group and clear and specific guidelines need to be provided for their transition. This principle does not feature in Key areas covered) and review questions (although a disclaimer within the section documents that not all key review questions have been asked) Particularly vulnerable groups are identified as those with complex health and social care needs and young people with life-limiting conditions. This document recognises that service gaps are caused by a lack of relevant adult services e.g. **neurodisability, palliative care, & mental health services,** It would be useful to identify and state barriers to transition and what gaps in healthcare provision exist,	Thank you for your comment. Your point about our main populations will be carried into the analysis of research which covers the key areas listed in section 4.3.1. Barriers to transition will be covered as indicated under 4.3.1. Your point on gaps in local provision will be highlighted to the Guideline Development Group.

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			since there is an opportunity to state that there should be **equity of access to appropriate services wherever an YP lives** and that patients should be signposted to appropriate services by their doctors if a service isn't offered locally.	
Royal College of Paediatrics and Child Health	33	General	References – please consider this useful NACC document produced on Transition for young people with Inflammatory Bowel Disease (IBD) http://www.ibdtransition.org.uk/	Thank you.
Royal College of Paediatrics and Child Health	34	4.1.1	Should young carers be included in the list:- How / where will the needs of young carers be addressed / picked up – the impact on them, and involvement of them in the transition process if they are carers for another young person. If they are a young carer to a parent need a support plan to enable their own transition into adulthood too.	Thank you. A key area to be covered is involvement of carers of young people in transition, including young carers. Young carers will be within scope if they care for another young person in transition or if they themselves are experiencing transition into adult services.
Royal College of Paediatrics and Child Health	35	4.1.1	What about those young people impacted by complicated bereavement – may access third sector support rather than statutory health or social care.	Thank you for your comment. This guideline will focus on all young people who are accessing health and social care services. Voluntary and community sectors are covered as providers of transitional care.
Royal College of Paediatrics and Child Health	36	4.2.2	Housing may be relevant in considering transition especially in light of the 'bedroom tax' the capacity to have a live-in carer in the family home as a step to independent living may be denied if in local authority housing. Also the trauma of having to move if young person moves out – this is stressful enough time for parents. Most parents like to be able to provide a 'fall	Thank you for your comment. Housing is very important to transition; however, this guideline is focused specifically on how the transition is managed for young people who need health or social care services. Transition models which support transition by including a housing component are included.

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			back' position for their young adult children if they need it, and for them still to be able to come home and stay when they want.	
Royal College of Paediatrics and Child Health	37	4.4	Need to ameliorate the financial cost to the individual young person / family e.g. access to services if live remotely / and or rural.	Thank you for your comment. The role of the scope is to lay out the areas for consideration; the guideline will provide recommendations based on the best available evidence.
Royal College of Paediatrics and Child Health	38	General	Equality of opportunity is a key aspect of transition for all young people and adolescence as the young person grows up and becomes more independent. Opportunity to be involved in decision-making, to develop the skills to become independent, the right to be seen by professionals independently of carers and to develop the necessary skills to do so, to have access to confidential services, to have access to professionals trained in adolescent health.	Thank you for your comment, we agree that equality is important and the Equality Impact Assessment does address some of this in terms of service access.
Royal College of Paediatrics and Child Health	39	3.1.5	There is a large body of evidence of the perspective of young people in the following reference which has not been included Lugasi T, Achille M, Stevenson M. Patients' perspective on factors that facilitate transition from child-centred to adult –centred health care: a theory integrated metasummary of quantitative and qualitative studies. *J Adol Health* 2011;**48**:429-440.	Thank you for your comment. The scope is a brief summary of the topic area. Thank you for the additional information, which we have added to our list of relevant references.
Royal College of Paediatrics and Child Health	40	General	The potential role of primary care and the GP is under represented in the document particularly with reference to continuity	Thank you for your comment. The document tries to focus primarily on children and young people's needs rather than service provision although we recognise that these go hand in hand. Section 4.2 does mention the role of GPs and primary care. However, we want to emphasise that the scope does not include young people who do not use

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				specialised health care services or social care, i.e. the general population.
Royal College of Paediatrics and Child Health	41	General	The potential role of the youth service is underrepresented particularly as they are the agency with the most appropriate age range i.e. up to 25!	Thank you for your comment. We agree that the youth service could have a role in supporting young people's transition, however the focus of this guideline will be on transitions in health and social care services with the aim of getting this right, rather than developmental transitions and those happening outside of health and social care.
Royal College of Paediatrics and Child Health	42	3.3	The references are incorrect and should read Department of Health. *Transition: getting it right for young people. Improving the transition of young people with long-term conditions from children's to adult health services*. Department of Health Publications, 2006, London Department of Health. National Service Framework for Children, Young People and Maternity Services . Standard 4: Growing up into Adulthood. October 2004	Thank you for your comment, we have corrected the references.
Royal College of Paediatrics and Child Health	43	4.4	At present the evidence for these scales is still limited: Stinson J, Kohut SA, Spiegel L, White M, Gill N, Colbourne G, Sigurdson S, Duffy KW, Tucker L, Stringer E, Hazel B, Hochman J, Reiss J, Kaufman M. A systematic review of transition readiness and transfer satisfaction measures for adolescents with chronic illness. *Int J Adolesc Med Health*. 2013 Jul 6:1-16	Thank you for your comment. This review was identified in the pre-scope search and is in our database.
Royal College of Paediatrics and Child Health	44	General	Understanding the age and developmental specific needs of young people in the transition process needs more prominence particularly with respect to expertise and training needs of staff. This has specific relevance	Thank you for your comment. The role of the scope is to lay out the areas for consideration; the guideline will provide recommendations based on the best available evidence.

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			to issues of sexuality in view of the development of sexual identity during adolescence.	
Royal College of Paediatrics and Child Health	45	General	I have been working as part of a steering group with staff at Southampton University Hospitals Trust to develop documentation and a process to enable transition to be taken into account in each of the departments within the hospital. Attached is the link to the website that includes the documentation and explanation of the process. Further work is developing on interactive technology to enable young people to progress through the process individually and at their own pace with support as appropriate. http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx	Thank you for your comment. The link has been added to our reference list.
Royal College of Paediatrics and Child Health	46	General	I am part of the pathfinder Children and Young Person Development Service that is implementing the 0-25 service in Southampton, in particular the 16-25 sub group that is working to engage adult services as part of the process. http://www.southampton.gov.uk/learning/supportforlearning/send_pathfinder/	Thank you for your comment. We have added the work at Southampton to our reference list for good practice examples.
Royal College of Physicians (RCP)	1	General	The RCP is grateful for the opportunity to respond to the draft scope consultation. In doing so, we have liaised with our experts on the RCP Young Adult and Adolescent Steering Group who has returned the following comments from the perspective of equality of opportunity.	Thank you for your comment.
Royal College of Physicians (RCP)	2	4	Section 4 What the guideline will cover We note that section 4 - What the guideline will cover	Thank you for your comment. We agree that developmental transitions are highly relevant to the guideline recommendations, but the primary focus

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			says the following "Transition in this guideline is defined as a purposeful and planned transition from children's to adult services. This is consistent with the definition of 'transition' in the National service framework for children, young people and maternity services (Department of Health 2004). Developmental transition, although highly relevant to this topic, is not the primary focus of this guideline." If we understand this statement correctly the guidelines are not addressing the wider issues of growing up with a long term condition. In our opinion addressing developmental transition is central to the process of health service transition and by including them in the guideline scope would genuinely be promoting equality with the rest of society by ensuring that life chances are as equitable as possible.	of this guideline will be service transitions. Due to the very broad remit in terms of populations there is a need to focus the guideline. It would be a considerable expansion to consider in depth the evidence on how to respond to the developmental transitional needs of all groups included in the scope.
Royal College of Physicians (RCP)	3	4.1.1	Section 4.1.1 Groups that will be covered These sections fail to represent young people presenting directly to adult services over the age of 16 and up to the age of 25, potentially having been seen in primary care under the age of 16 early in the evolution of the symptoms of their condition before being referred to adult services. This is to fundamentally discriminate against young people who seek care through their GP and who are referred in to adult secondary care who have all the same issues as those entering adult care from paediatrics. We think this should be covered in the scope by acknowledging young people entering adult services whether they come from paediatrics or primary care.	Thank you for your comment. The guideline will focus primarily on how services can improve the transition and transfer of service users from children's to adult services, and the omission of those not receiving children's services is therefore to contain the guideline within this remit. A lower age limit is not set to reflect that transition preparation might start at very different ages depending on the child's maturity and also the nature of the service. We agree that young people who require care from multiple providers is an important subgroup and

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			We applaud the adoption of the upper age of 25 to allow for developmental delay and the achievement of relative psychosocial stability but wondered whether the scope should detail the lower age as well that should be considered as the age range spanning transition. The majority of the literature and guidance would place the lower age between 11 and 13 years of age. Standard terminology is WHO definition of adolescence 10-19 and Arnett 2000 definition of young or emerging adulthood to 25. We suggest that young people who require care from multiple providers should be emphasised as a particular group for focus.	have emphasised this in the scope (4.1.1).
Royal College of Physicians (RCP)	4	4.2	*4.2 Settings* 4.2.1 & 2 Settings that will be covered and not be covered We support the mention of primary care and the issue of transition but feel this could be emphasised throughout the document. They provide a unique opportunity for equality as all young people have access to a GP. They raise the possibility of providing genuine continuity for young people whether they are transferring to adult services or into primary care. `They are also a potential safety net for young people failing to engage with specialist services which may be at a distance from home. We also suggest that the issues of accessibility of settings, particularly specialist care, should be considered. Specialist care may be some distance away so reviewing models for access to specialist care and	Thank you for your comment. The importance of primary care is noted, and as you say is also mentioned in the scope. The accessibility of care is important both geographically and in terms of eligibility.

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			provision of care locally should be included. This is particularly important to promote equality from a socioeconomic perspective, reducing cost of travel and lost earnings.	
Royal College of Physicians (RCP)	5	4.3.1	*4.3 Activities* 4.3.1 Key areas and issues that will be covered Transition support is typically initiated at two levels: Level 1: As organisational frameworks, which specify how services should work together to deliver person-centred care for young people in transition (for example protocols for joint working and sharing of information). Level 2: Interventions to help professionals put the frameworks into practice. This includes, for example, providing transition keyworkers, transition clinics, young people's support workers in adult services, information and advice services. We suggest that adding a level 3 focussing on intervention focussing on young people themselves and the people around the young person would reflect patient centred care. The guideline will cover: a) activities to ensure that young people are involved in, and informed about, the way that their transitions from children's services are planned and delivered We suggest that this statement should reflect the need to review interventions that embrace a holistic and developmental approach to transition which we feel should be part of the scope.	Thank you for your comment and for taking the time to consider the scope so carefully. Section 4.3.1 now emphasises interventions which involve young people (and/or carers) in transition planning and practice. Developmental approach: The guideline will only focus on service transitions. Due to the very broad remit in terms of populations there is a need to focus the guideline. It would be a considerable expansion to consider in-depth the evidence for how to address the developmental transitional needs of all groups included in the scope. Newer communication methods: ICT-based interventions will be included if they are specifically targeted at improving the transition from children's to adult health and social care services. Involving yp in evaluation and design: Young people are encouraged to apply to sit on the Guideline Development Group, and there are four spaces secured for young people and/or carers. The review team would consider young people's involvement in an evaluation as an important aspect of evidence gathering.

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			We suggest that the guideline should also cover newer communication methods for this group, which would benefit ease of access to services, e.g. text, email, face time consultations, internet based. This aspect would promote equality as it would address access issues for some groups of young people which can be challenging, for example, young people with mobility difficulties or find it difficult to attend because of education or first job. We suggest also that this statement should reflect the role of involving young people in the evaluation and design of services. a) care planning, coordination and assessment b) interventions to support effective transitions (such as the services or support provided by transition workers, peer support groups and transition clinics) We suggest that the issue that transition interventions that work cross specialties and therefore cross institutions and communities should be explored and discussed to promote equality rather than some young people in some specialties receiving more support than in others. We also suggest that DNA policies particularly in adult services should be considered as part of this statement. d) support for parents, families and carers of young people in transition We suggest that this statement should focus on more than support for parents, families and carers and explore	Inter-agency transition interventions: These will be covered by the scope as long as they are targeted at the listed population groups, to facilitate their service transition from children's to adult services. DNA policies: Your point will be shared with the Guideline Development Group. Active role for the people around the young person: The development of the NICE guideline will consider high quality evidence on any intervention which supports young people's transition from children's to adult services, including those which have involved a wider range of people than professionals and young people. Training: Training of primary care staff will be included as long as it was focused on the transition of young people from children's to adult services. Primary care: Primary care is included in all considerations as stipulated in 4.2.1 We thank you for your point about the main barrier to transition being inequality of access to care. This point will be raised with the Guideline Development Group.

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			interventions promoting an active role for the people around the young person. This should a include management of expectations is a key factor in successful transition. It is frequently reported that it is issues around families and carers that are most important and most difficult to manage. e) organisational frameworks for transition f) training of staff working with young people in transition, in children's and adult services and the effect of training Training in primary care should be included. a) joint working between children's and adult services (health and social care, and with education services where education is leading the transition planning) We suggest that this statement should emphasis the role of primary care for the following reasons:- improving continuity; some young people are transferred to primary care; and also those failing to engage with specialist services; provision of local care if specialist services are a distance from home. g) Barriers to, and facilitators of, good practice in transition planning (a key issue because of the current disconnection between existing policy guidance and practice). Failure to implement previous transition guidance has been attributed to the lack of developmentally and age appropriate care for adolescents and young adults in children and adult services due to lack of training and also through design of services. This is the key area of	

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			inequality in the health service.	
Royal College of Physicians (RCP)	6	4.3.2	4.3.2 Areas and issues that will not be covered Transition support for young people which is not related to their service use. Sometimes organisations offer general support to all young people approaching adulthood (for example, careers advice). This type of support is not covered by this guideline, unless it forms part of a support package for transition from children's to adult services. We feel that for transition to move on and provide equality for all young people with long term conditions and provide them with equal opportunities for as full and healthy an adult life as possible a broader remit is required. Some additional suggestions, as well as addressing social, educational and vocational aspects, include:- The importance of linking physical health with mental health and appropriate provision of services through the transition period should also be highlighted with associated screening of young people with long term conditions. A public health angle also needs to be introduced for the guidelines to improve long term health. There is evidence that young people with long term conditions are more likely to demonstrate risk taking behaviours (including smoking, alcohol, drugs and sexual risk) (Suris et al.). It is also important to address obesity and physical activity (CMO report).	Thank you for your comment. The role of the scope is to lay out the areas for consideration, the guideline will provide recommendations based on the best available evidence. The guideline will only focus on service transitions. Due to the very broad remit in terms of populations there is a need to focus the guideline. It would be a considerable expansion to consider the developmental transitional needs of all groups included in the scope. There are considerable challenges in terms of transition from children's to adult services in both health and social care and the guideline will focus on these.

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Royal College of Physicians (RCP)	7	4.4	*4.4 Main outcomes* The main outcomes that will be considered when searching for and assessing the evidence are: Self-efficacy (young people's ability to undertake the activities they want to, as independently as possible). A key marker of self-efficacy (and transition readiness) is young people being given clear opportunities to be seen independently from their parents. We suggest this should be highlighted. • **transition readiness (as measured by relevant scales, for example, the Rotterdam Transition Profile)** At present the evidence for these scales is still limited (Stinson J et al. *Int J Adolesc Med Health*. 2013 Jul 6:1-16) • **continuity of care & implications for continuity & promotion of continuity of care** Monitoring involvement of primary care is key to continuity as well as in secondary and tertiary care. **Outcomes will be considered for young people and their families and carers.** We also suggest that social, educational and vocational outcomes should be included to reflect the life course and holistic approach.	Thank you for your comment. We consider all the listed outcomes as complementary to each other, and we are aware of the limited evidence for some of the scales used.
Sickle Cell Society	1	General	The transition from children's services to adult's services has been a challenging area for young people with sickle cell in NHS services and we believe will be equally	Thank you for your comment. The guideline development team will review studies on young people's views and we have noted down your work

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			challenging in social care. This is relevant because based on work with young people with sickle cell it can be very different in relation to the level of support, quality of service and expertise offered by professionals in the transition to adult services. Some have described it as isolating and negative. We have recently conducted Focus groups of young people, carers and adults with sickle cell with the Picker Institute. There is a clear sense of isolation together with psycho- social issues, which are not supported by social care, who see this as the responsibility of the NHS, although this psychology support is also limited in the NHS. This is relevant because social care is an integral part of Local Authorities. Transition in social care that is not effective, can therefore have an adverse impact on young people with sickle cell disorder. Education and access to employment are important elements of a holistic Local Authority approach. Subject to capacity and resources, the Society would be interested in principle to being commissioned to undertake further Focus Group on this topic, having regard to the unique perspective that can be provided by young people with sickle cell.	in this area.
Skills for Care	1	4.2.2	Concern that housing is not seen as an important setting to cover. Many housing providers are also providers of social care. Not making the guidance take more account of housing is an oversight.	Thank you for your comment. Housing is very important to transition; however, this guideline is focused specifically on how the transition is managed for young people who need health or social care services. Transition models which support transition by including a housing component

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				are included.
Skills for Care	2	4.3.1 f	Training is too narrow a definition here. This also needs to cover learning and development and preregistration education for all professional groups.	Thank you for your comment. We are focusing on transition-specific training and will include all research which has evaluated this.
South East Coast Strategic Clinical Network	1	General	The needs of young people with life limiting illness and the emotional turmoil that often accompanies transition needs to be taken into account. The role of psycho-social care and adult mental health services being central to successful transition should be made explicit. Support for parents and carers will also be key at this time and the role of voluntary sector organisations needs to be emphasised.	Thank you for your comment. The co-ordination of services is in scope, and so are young people with life limiting illnesses.
South East Coast Strategic Clinical Network	2	4.3.1 - f	Training needs assessments will need to be undertaken to ensure that nursing and medical staff are competent to manage young people in all care settings. Competency assessment will be required and this needs to be made more explicit. The needs of young people with learning difficulties and the additional services and training that will be required to support them during transition is not made clear within the guideline scope.	Thank you for your comment. The role of the scope is to lay out the areas for consideration; the guideline will provide recommendations based on the best available evidence.
South East Coast Strategic Clinical Network	3	3.2.3	Engagement with adult care is key to successful transition but at present adult services are often not structured to support joint working practices. Using the example of the diabetes best practice tariff where each provider unit must have a policy for transition to adult services would ensure clarity around what is expected of all members of the multi-disciplinary team during the transition process. It would also provide a measureable outcome.	Thank you for your comment. The Guideline Development Group will be making recommendations which may well support your point, but cannot be assumed at this stage.

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South East Coast Strategic Clinical Network	4	3.1.6	Young people with learning difficulties and those with co-morbidities will require additional input from multiple agencies. Their important role in the transition process needs to be made clear within the NICE guidance.	Thank you for your comment. We agree that this is a good example of the need for services to work in partnership, and this will be covered in the guideline (see 4.3.1).
South East Coast Strategic Clinical Network	5	4.4	The Rotterdam Transition Profile does not adequately reflect young people in UK society nor take into account those with additional needs and an alternative assessment should be used.	Thank you for your comment. We are aware of the limited evidence for transition measures. We hope that the outcomes listed will complement each other, and that the inclusion of young people's and their carers' views will help with that.
South East Coast Strategic Clinical Network	6	General	Ward and clinic environments in both paediatric and adult care setting and within primary care do not currently meet the needs of young people. Guidance needs to be given about minimum expected standards within each health care setting. This would provide a measurable intervention.	Thank you for your comment. This would be the expectation of the guideline recommendations.
South East Coast Strategic Clinical Network	7	General	More emphasis needs to be placed on the role of new technologies in supporting young people's health and as a way of engaging with this client group	Thank you for your comment. New technologies may emerge as an important area in the existing evidence but this cannot be assumed at this time.
South East Coast Strategic Clinical Network	8	General	The needs of young people with life limiting illness and the emotional turmoil that often accompanies transition needs to be taken into account. The role of psycho-social care and adult mental health services being central to successful transition should be made explicit. Support for parents and carers will also be key at this time and the role of voluntary sector organisations needs to be emphasised.	Thank you for your comment Integrated services are a key concern of this guideline. We have made every effort to represent the views of carers in the guideline development process and they will hopefully be represented on the Guideline Development Group.
South East Coast Strategic Clinical	9	General	Patient and public engagement is a key element in good transition. NICE should signpost young people to	Thank you for your comment. The role of voluntary sector organisations may well

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Network			voluntary sector organisations that may be able to offer additional support during transition. Voluntary sector organisations act as advocates for patients and families and will have access to a rice source of patient experiences that can help to inform practice. The use of youth forums and audit of transition will help inform practice over time.	emerge from the evidence, but this cannot be assumed at this stage.
South East Coast Strategic Clinical Network	10	4.3.1	The SCN support the role of the key worker in transition as a navigator to ensure a smooth pathway into adult services. A generic transition check list drawn up in collaboration with young people would help to ensure that all key issues have been discussed.	Thank you for your comment. The role of the scope is to lay out the areas for consideration; the guideline will provide recommendations based on the best available evidence.
South East Coast Strategic Clinical Network	11	3.2.4	An example of good practice can be seen in the 'Ready, Steady, Go' initiative developed by University Hospital Southampton.	Thank you for your comment; we have added your suggestion to our reference list.
South West Yorkshire Partnership NHS Foundation Trust	1	4.3.1	Second bullet point, section b) Think it should highlight the need for all parties to be clear and signed up to the care planning, assessment and co-ordination to reduce the number of referrals made that do not fit criteria. Communication in the earliest stages, particularly when a young person is accessing children's services at aged 17 should be actively encouraged.	Thank you for your comment. The role of the scope is to lay out the areas for consideration, the guideline will provide recommendations based on the best available evidence.
South West Yorkshire Partnership NHS Foundation Trust	2	4.3.1	Second bullet point, section e) co-ordinated through regional hubs that then link up with national guidance? Allowing local issues to be considered?	Thank you for your comment. The role of the scope is to lay out the areas for consideration; the guideline will provide recommendations based on the best available evidence.
South West Yorkshire Partnership NHS	3	4.4	Second bullet point – I agree some form of identifying "appropriate transition" is important, but inherent in this is the need for service configuration to support longer	Thank you for your comment. The longer-term aspect of transition is supported elsewhere in the scope, for example in 4.1.1.

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Foundation Trust			transition processes that fall out of "usual business" for children or adult services	
South West Yorkshire Partnership NHS Foundation Trust	4	4.5.9	I wonder if a better question is "how all services can ensure a transition with improved outcomes for young people", rather than just asking adult services to improve. Those discussions should include all aspects of the young person's familial and professional system, as well as the wider literature.	Thank you for your comment. The questions about the impact of models and interventions and about factors that contribute to successful transitions both address the question 'how can services improve'. The question about adult services is there to emphasise that the transition doesn't just start in good time before the transfer, it also continues on after transfer.
South West Yorkshire Partnership NHS Foundation Trust	5	General	I wonder if core to areas of interest a thread throughout should be around safeguarding or vulnerability concerns both in relation to transition, but more relevant to those at increased risk of these issues.	Thank you for your comment. The scope is a summary document which cannot give an exhaustive account of what will be covered.
South West Yorkshire Partnership NHS Foundation Trust	6	General	Will be important to think about governance broadly and perhaps different models of governance that involve some degree of shared governance?	Thank you for your comment. The guideline will consider different models for transitional care and governance might be part of that. We will also put this point to the Guideline Development Group.
St. Oswald's Hospice	1	General	Competency, capacity and UK capacity legislation are not mentioned once. A fundamental part of transitions is enabling young people to take up the responsibility of making decisions and helping parents to relinquish that responsibility. To make no mention of these issues is a remarkable omission for a document that concerns many individuals with complex conditions which can permanently or temporarily cause cognitive impairment. Consent and making care decisions in advance are a key part of service transition and capacity is at their core. Sadly this seems to be a pattern for NICE who have	Thank you for your comment. This guideline focuses on service transitions and it is beyond its scope to focus on developmental transitions, although we are highly aware of the relevance and relationship between the two. The importance of young people's involvement and the role of carers are in scope. Young people without the capacity to consent are covered by the Equality Impact Assessment, and any evidence emerging in regards to these groups (and other groups listed in the EIA) will be

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			made the same omission for the scoping document on Long Term Conditions for Older People. The House of Lords Select Committee on the 2005 Mental Capacity Act have recognised this problem but they will be disappointed to learn that yet another NICE document is unaware of UK capacity legislation.	considered under the relevant review question.
Standing Commission on Carers	1	General	It would be useful to refer up-front to the Children and Families Act's introduction of an Education, Health and Care Plan. The extension of the age range that this will cover (i.e. a move away from the Statement of SEN, which was strictly school-based) means that there should be new opportunities for better transition planning. In this context the new guidelines are of particular significance and could have a major impact on the outcomes of the new legislation.	Thank you for your comment. Relevant legislation and policy will be taken into account.
Standing Commission on Carers	2	General	It would be helpful to give equal weight to transition from children's health, education and social services. Education, whether in school, college or other establishments has a major impact on outcomes and the delivery of health and social care services should be matched to the education and training aspirations of the young person. The Education, Health and Care Plan referred to above is relevant here.	Thank you for your comment. The link to education is highly relevant and we agree that this will need to be considered by the Guideline Development Group.
Standing Commission on Carers	3	4.2.1	We feel that further clarification is needed about groups not to be covered. Currently it is proposed that 'young people who are not using children's health or social care services will be excluded'. However, because of pressure on resources, many disabled young people and their families are not	Thank you for your comment and you raise an important point which we will take to the Guideline Development Group. The scope's focus on making adult services young people-friendly is partly addressing this, but the main focus of this guideline is to improve young people's transition into adult services when they have previously been using

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			currently using social care services because of 'rationing' arrangements at local level. The children and young people are still disabled and in adult life will continue to need support. The new provisions in the Children and Families Act around parent carers' rights to assessment and support may impact on numbers requesting support in the future. Currently the majority of families caring for a disabled child or young person rely primarily on education to support them, with maybe a small direct payment for leisure or sitting services. Similarly, all children and young people use some children's health services of some kind. Some may also use such services intensively at one time in their lives (e.g. cardiac surgery or similar) but not at a later transition stage. Some will have intermittent needs, with periods of respite or remission where no additional support is needed. However this state of well-being may not be permanent. Many of these children and young people (who are not *currently* using any public services specifically for their disability) will nonetheless be claiming and eligible for a range of disability allowances and benefits. It might be best to add an additional disqualifier, namely young people who are not in receipt of allowances or benefits such as PIP, relating to a disability or long term condition. One of the purposes of transition planning is to anticipate future need and in some cases children and young people may be relatively well in their late adolescence and early 20s, but conversely be likely to	children's or adolescent services.

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			have escalating levels of need as they get older. But they may have a condition or disability where deterioration is likely and planning for their futures as adults will be vital.	
Standing Commission on Carers	4	4.2.1	We assume that education and training settings will be included, but it is not clear that this is the case in 4.2.1	Thank you for your comment. Education and training settings are in scope as long as the young person in question is receiving or using health or social care services (4.3.1).
Standing Commission on Carers	5	General	We feel strongly that there should not be a blanket exclusion of housing services. The inadequacy of the family home for a disabled adult may well be a trigger factor in a young person either having to move out of the family home, possibly into some residential setting, or living in circumstances which are inappropriate to the desired outcomes of maximum independence. We also note that many families have coped well with a disabled child but find his or her increasing weight and possibly increasing disability increasingly difficult to manage well. The provision of appropriate aids, appliances and adaptations can be life-changing for a young disabled person and may reduce or even eliminate the need for personal care and support.	Thank you for your comment. Your thoughts will be passed to the Guideline Development Group.
Standing Commission on Carers	6	General	We are pleased to see specific references to support for parents and carers/families of young people in transition. Too often the needs of families who may have been carers for many years, who may be ageing themselves and developing health needs, have been overlooked. Given the current national policy focus on personalisation, we would also like to see a specific reference to personal budgets and direct payments, i.e.	Thank you for your comment We have made every effort to represent the views of carers and families in the guideline development process. It may be that personalisation emerges as an issue in the literature, but this cannot be assumed at this stage.

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			a recognition that the model for the provision of support for this generation of young people will be different**.**	Improving outcomes for young people is a key aim of the guideline development process.
Standing Commission on Carers	7	General	We would like to see the main outcomes including 'achievement of maximum potential' (noting that transition arrangements should be as ambitious as possible with regard to future independent living, possible further education, training and employment and community engagement in adult life). We would also like to see a reference to support for parents and families. This might best be expressed as 'support for family life' as in their early twenties; some young disabled people will have families of their own. Transition can have major implications for families, particularly in the later years as the young person moves into adult life. Families may find it hard to adjust, may feel too tired to carry on or may have difficulty in adjusting to their adult child's evolving maturity.	Thank you for your comment. The focus of this guideline is on service transition, and so we would focus primarily on outcomes related to that. Section 4.3.1 includes activities which involve young people and their carers. The guideline will only focus on service transitions. Due to the very broad remit in terms of populations there is a need to focus the guideline. It would be a considerable expansion to consider the evidence on how to meet the developmental transitional needs of all groups included in the scope.
Standing Commission on Carers	8	General	Again, we are pleased to see families as well as young people featured in the review questions. Given the policy shift towards personalisation mentioned above, it would be useful to have a specific question on personalisation and the use of personal budgets/personal health budgets and direct payments, i.e. the move towards self-directed care and support. The above section could be a sub-section of question 4.5.6 (support models and interventions designed to improve the transition process).	Thank you for your suggestion. We can only cover about 10 review questions and the Guideline Development Group will be involved in prioritising these.

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Standing Commission on Carers	9	General	We agree that the analysis will endeavour to take a long-time horizon approach to explore the impacts of transition on quality of life, education and employment etc. We are pleased to see that families and carers will also be considered as there can be very considerable financial and other consequences for families, many of whom have sacrificed better employment prospects in order to carry on caring. We note that in some cases transition arrangements may exacerbate family pressures, as the end of education means for many families the end of day-time occupation and replacement care for young people with complex needs may be unaffordable. With reference to families, it would also be useful to consider the role of young carers (usually, siblings) during transition. Young carers are recognised for the first time in the Children and Families Act and the forthcoming Care Act.	Thank you for your comment. We are committed to looking into experiences of transition for young people and families. Young carers are in scope as carers, and also if they are themselves accessing health or social care services and therefore will be moving on to adult services.
Standing Commission on Carers	10	General	In a number of recent reviews of transition planning, two questions have frequently been raised and negative answers associated with poorer outcomes for the young people concerned. We suggest adding these questions to the list of review questions for the next stage of this exercise, namely: Is there a transition plan and is it regularly reviews and updated [a surprising number of young people in transition do NOT have a plan and the absence of a good plan inhibits integrated approaches to transition planning and commissioning].	Thank you for your comments. Your first question is important for services, however we will be focusing on research studies in terms of the review questions although of course will also include good practice examples from the UK. We would suggest your second question is covered by current review question 4.5.6. The Guideline Development Group will review all questions.

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			Is there a lead professional (or other, perhaps a key worker from a third sector organisation) who takes responsibility for the coordination and delivery of the plan? Again, there is evidence that fragmented planning and ownership of the transition process can lead to poorer outcomes and greater dissatisfaction for the young person and family.	
Teenage Cancer Trust	1	General	The current focus of the scope is transition from children's to adult services for young people using health or social care services. It will be important for the scope to also include adolescent, or teenage and young adult (TYA) age-specific services throughout the document. For example, young people with cancer are most likely to transition between paediatric and TYA oncology services, and/or between TYA and adult services, while only a minority will transition directly between paediatric and adult care. Existing NICE Guidance on Improving Outcomes in Children and Young People with Cancer (2005) stipulates that all young people aged 13-18 must be treated in age-appropriate facilities by age-specific Teenage and Young Adult Multi-Disciplinary Teams, and that those aged 19-24 must be given the choice to be referred to these services. Effective implementation of this guidance should therefore mean that those young people with cancer who are in treatment at a time of transition will normally move either into or from age-specific adolescent services, or from a 13-18 TYA service to a 16-24 TYA service, rather than from children's to adult services. Although the notification process is not yet followed for 100% of new cases, it is	Thank you for your comment. This is a very important point and the scope now emphasises that some young people use adolescent services and therefore transition from them rather than children's services.

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			important to recognise this model within the scope and guideline as an alternative route for transition. These periods of transition may occur during the same treatment phase, or a young person may relapse and return to access treatment and care within a different part of the health service. Furthermore, as such age-appropriate care is enshrined in NICE Guidance until at least age 24, it is important to note that some may not transition from adolescent to adult services until at least the age of 24.	
Teenage Cancer Trust	2	3.3	The Policy section of the scope could be expanded to include: • NHS England service specification on Transition to Adult Services (currently being consulted on) • TYAC (Teenage and Young Adults with Cancer) Best Practice Statement on Transition (to be published 2014) • Smith S, Case L, Waterhouse K, et al. *A Blueprint of Care for Teenagers and Young Adults with Cancer* (2012)	Thank you for your comment. The scope is a brief summary of the topic area. Further work will be conducted during the development phase, and we have added your suggestion to our reference list.
Teenage Cancer Trust	3	4.3.1 4.4	When listing the outcomes that will be considered when assessing evidence it is important to consider the measurement tools that will be used to assess these. A key difficulty in ascertaining the impact of transition and other elements of a service, for young people is a lack of PROMs and patient experience measures for those under 16.	Thank you for your comment. We are aware of the paucity of well-established transition tools and have identified a systematic review which will support this work.
Teenage Cancer Trust	4	5.1	The Published NICE Guidance list should include: • National Institute for Health and Clinical Excellence (2005), *Guidance on Cancer*	Thank you for your comment. The scope is just a brief summary of the topic area. We have added the references to our reference list.

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			Services: Improving Outcomes in Children and Young People with Cancer • National Institute for Health and Care Excellence (2014), *Children and Young People with Cancer: Quality Standard*	
The Association for Family Therapy & Systemic Practice AFT	1	2	ADHD NICE guidance (2008). It would be useful for ADHD services to promote access to psychological therapies etc. even if not taking medication.	Thank you for your comment. The Guideline Development Group will be making recommendations which may well support your point, but this cannot be assumed at this stage. We will be taking into account existing guidance documents to inform our recommendations.
The Association for Family Therapy & Systemic Practice AFT	2	3.1.1	Need to consider initiatives to engage 'hard to reach young people' and others who may find accessing 'traditional health services' difficult.	Thank you for your comment. The guideline covers a wide population and a decision has been made to therefore focus particularly on transition practice.
The Association for Family Therapy & Systemic Practice AFT	3	3.1.5	It does feel for many young people that as they reach their 18th birthday they are reaching a cliff edge. Where there is some likelihood a young person may go onto adult services, some CAMHS do have a good practice with the local AMHS (Adult Mental Health Service) to have a minimum of one joint meeting. This is useful to plan transition, but also from the age of 17.5 to decide if they meet thresholds, to sign post to alternatives and to make links should they need referring in future. However, very few young people in CAMHS meet adult criteria at point of discharge and although there are some alternative support type 3rd sector agencies, there are not enough services.	Thank you for your comment. We agree that this is a good example of the need to work in partnership. Joint working between services is included in scope (see 4.3.1).
The Association for Family Therapy &	4	3.1.6 3.2.2	People with ADHD and ASD are particularly disadvantaged as often they do not meet the criteria for	Thank you for your comment. All young people who use mental health services

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Systemic Practice AFT			accessing adult mental health services and there is a lack of service provision for adults with ADHD. Impacts on quality of opportunity for young people with ADHD being able to access a service for their continuing healthcare needs. Evidence of impact of ADHD on employment, mental health, relationships etc. equality of access for psychological therapies Access to psychological therapies is limited for people with ADHD-Medication? Seen as the treatment of choice.	are within scope, and we are aware of the problem of young people not meeting the threshold of adult service provision at transition stage.
The Association for Family Therapy & Systemic Practice AFT	5	3.2.1	Due to lack of service provision some young people are referred to GP's who may not be aware they are the only healthcare professionals offering support.	Thank you for your comment. GP services are in scope and mentioned specifically in section 4.2.1.
The Association for Family Therapy & Systemic Practice AFT	6	4.1.1	Clarity and flexibility about the timing of transition. Embed in practice that transition is a process.	Thank you for your comment. We will emphasise that transition is not the same as transfer, but a longer-term process leading up to and continuing after transfer.
The Association for Family Therapy & Systemic Practice AFT	7	General	Importance of engaging young people in developing this guidance – what are their views about what they want and would find helpful.	Thank you for your comments. As part of the process of guideline development, we are consulting with a group of young people. Young people are also recruited to the Guideline Development Group.
The Association for Family Therapy & Systemic Practice AFT	8	General	Challenge is implementing guidance / protocols into practice	Thank you for your comment. The scope recognises the disconnection between existing policy and practice and therefore the guideline will address implementation of transition guidance.
The Association for Family Therapy & Systemic Practice	9	General	Joint work between the services in preparation for positive transitions. Enhancing relationships trans agencies to ensure that holistic transitional needs are	Thank you for your comment. We agree this is a good example of the need for services to work in partnership, and this will be covered in the

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AFT			addresses	guideline.
The Association for Family Therapy & Systemic Practice AFT	10	General	A key difficulty is different thresholds, so sometimes things have to reach a crisis for a young person to be transitioned	Thank you for your comment.
The Association for Family Therapy & Systemic Practice AFT	11	General	A further difficulty is the way parents and carers are less involved in the therapeutic work offered to a young person who is accepted into AMHS. They are offered minimum information and support unless involved in family therapy or in a few places across the country in a family therapy clinic that includes both CAMHS and AMHS Clinicians. Often young people would give consent for their parents to be more involved if this was checked out and offered more routinely and actively.	Thank you for your comment. The role of carers is important and they are covered by the scope.
The Association for Family Therapy & Systemic Practice AFT	12	General	Availability of a range of support and therapeutic services other than AMHS for young people leaving CAMHS due to age cut off.	Thank you for your comment. The problem of many young people not meeting the threshold of adult services is important and recognised by the development team.
The British Association for Counselling and Psychotherapy	1	General	The British Association for Counselling and Psychotherapy (BACP) welcomes the opportunity to comment on the draft scope of the guideline on *Transition from Children's to Adult Services.*	Thank you for your comment. Thank you for taking the time to comment on this scope.
The British Association for Counselling and Psychotherapy	2	General	The transition to adulthood is itself complex and challenging, and the challenges are more severe when moving between children's and adult services, particularly for those suffering from mental ill health and/or accessing, and dependent upon, a number of children's services. BACP believes this transition should be structured to provide maximum support for the young person during	Thank you for your comment. This guideline aims to help improve outcomes for young people experiencing transition. Your comments will be passed on to the Guideline Development Group.

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			this period, to ensure that the care and support provided will continue and be effective into their adult life.	
The British Association for Counselling and Psychotherapy	3	3.1.5	We welcome NICE's recognition of the poor outcomes associated with poor transition; in particular that it creates anxiety and can lead to negative educational and employment effects.	Thank you for your comment. The guideline development process is committed to making recommendations which can improve outcomes for young people who use health and social care services.
The British Association for Counselling and Psychotherapy	4	3.1.6	We also welcome NICE's recognition that children with poor mental health, and those with complex needs, are particularly vulnerable to poor transitions.	Thank you for your comment.
The British Association for Counselling and Psychotherapy	5	3.2.2	This sections acknowledges the service gaps caused by a lack of relevant adult services, or because young people do not meet the qualification criteria for their local adult services. BACP believes that too many people of all ages are excluded from accessing both children's and adult services due to provision gaps created by treatment criteria which are not responsive to potential users' circumstances. BACP strongly suggests that where a young person approaching or at the age of transition needs equivalent follow-on adult care, but cannot access such an equivalent, whether due to lack of provision or exclusionary treatment criteria, that there be a duty on the current children's services which they access to provide continuous care for that person as long as is necessary, or until access to an equivalent adult service has been found, regardless of the formal cut-off age for that service.	Thank you for your comment. The Guideline Development Group will be making recommendations which may well support your point, but this cannot be assumed at this stage.

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			This would be in line with the aim for *"continuity of care"* listed among the Main Outcomes (section 4.4, p9). As well as preventing the 'cliff-edge' phenomenon which so many young people fear and experience, this would also provide both information and an incentive for local commissioners to fill the gaps in provision, and encourage provision according to individuals' needs rather than a systemic abdication of responsibility, particularly for those with the most complex needs and who are therefore most vulnerable, brought about through inflexible treatment criteria.	
The British Association for Counselling and Psychotherapy	6	4.3.1.g	BACP suggests that, for the avoidance of doubt, this guidance explicitly mention the need for commissioned voluntary and community sector services to be involved in joint care and transition planning where relevant.	Thank you for your comment. The role of the scope is to lay out the areas for consideration; the guideline will provide recommendations based on the best available evidence.
The British Association for Counselling and Psychotherapy	7	4.6	BACP welcomes the intention for the guideline developers to go beyond purely clinical outcomes by considering economic aspects, including the consequences of poor transition for educational and employment outcomes. This section also lists some potential sub-groups which could be analysed in terms of the effectiveness and cost-effectiveness of interventions. While we welcome the suggestions for sub-group analyses of a number of vulnerable groups, such as those with complex needs, conduct disorders or learning disabilities, as well as looked-after young people and young parents, we would also suggest a sub-group	Thank you for your comment. Mental health service users are in scope and will be included where appropriate. We emphasise that this guideline focuses on service transition and not developmental transitions, but the economic analysis will incorporate long-term outcomes when possible.

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			analysis of those accessing children's mental health services, as we know that mental health difficulties lead to poorer attendance, behaviour and attainment in education (and thereby poorer employment prospects later on), which can be avoided or ameliorated by appropriate provision. The provision of mental health services to young people participating in further or higher education improves both attainment and course completion, and the loss of access due to poor transition could therefore lead to worse educational and employment outcomes.	
The British Association of Social Workers (BASW)	1	General	Carers. It is appreciated that the focus of the document needs to be young people and we acknowledge that the main emphasis of the work needs to be on outcomes for young people. However it is our experience that a crucial factor in influencing outcomes is the impact on friends and family carers. There is recognition of the issue in the draft question on "What are the experience of families and carers in respect of young people's transitions" (QW4.52 and 4.53). However we feel that there needs to be a further recognition of the potential impact of outcomes on young people relating to the experience of friends and family carers. For example if family and friends are not fully engaged, or feel they are fully engaged in the process of transitions then there is an increased likelihood of misunderstanding and conflict between the views of professionals and family and friends, which may have an impact on the process of transition for young people. There also needs to be reference to the Carer's assessment process in the Care Bill as there may be a correlation between the existence of and or quality of the carer's assessment and the	Thank you for your comment. The role of the scope is to lay out the areas for consideration; the guideline will provide recommendations based on the best available evidence.

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			outcome for the young person.	
The British Association of Social Workers (BASW)	2	General	Exclusion of young people who have not been in contact with health or social care services. (4.1.2). It is rare, but not impossible that some young people who should have received health and social care services may have slipped through the net of children's services and they are only identified when they are "adults", but possibly still would have been eligible for children's health or social care services. We therefore feel that there needs to be an exception to allow for that possibility. (One scenario could be as a result of immigration). There also needs to be recognition of the international dimension generally as it could be construed from the text that there must have been access to England or UK children's services. This would of course be illegal and discriminatory, but there is a risk that readers may interpret the guidelines from a UK / England perspective only. (Please also see comment 4 below which relates to the definition in the Care Bill of eligibility for assessment).	Thank you for your comment. This guideline is primarily about the transition process from children's to adult services. While the question about adults' services being appropriate for young adults is related to this, it is not the primary focus of the guideline.
The British Association of Social Workers (BASW)	3	General	Definition of health and social care services. Although it seems self-evident what health and social care services are, it is possible in the increasingly complex world of out-sourced services that some young people may be seen as not having received health or social care services. For example some young people could be "self-funded", or they may be accessing specialist services in the voluntary or private sector via self or family referrals – for example advocacy services, or specialist educational services, or youth services. One solution to the issues raised in two and three above could be to have a phrase that captures the ethos, such	Thank you for your comment. The guideline intends to capture young people not in receipt of traditionally defined health and social care and this would include self-funders, for example. We have made a note of your point about the Care Act and the statutory regulations and guidance.

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			as "would have reasonably been expected to have accessed, or been eligible for health and social care services." (Reference will also need to be made to both the Care Act (when it becomes law and the statutory regulations and guidance to support the Care Act). The Bill to date states: "Where it appears to a local authority that a child is likely to have needs for care and support after becoming 18, the authority must, if it is satisfied that it would be of significant benefit to the child to do so and if the consent condition is met, assess whether the child is likely to have needs for care and support after becoming 18 and, if so, what those needs are likely to be".	
The British Association of Social Workers (BASW)	4	General	We note that there has been a general avoidance of the mention of specific disabilities, and BASW support that, however we are also aware that young people with specific disabilities and conditions may feel excluded, for example there is not mention specifically of sensory disability. (There is however mention of mental health). The impact of the approach that does not use condition specific labels is supported, however we feel that there needs to be a clearer statement that the intention of the guidance that it will be inclusive and that it has been deliberate that specific conditions have not been detailed and the reasons for that. If that is not made clearer there is a danger that certain people may feel excluded. We would be pleased to be involved as a key stakeholder in the next stage of the production of the guidelines.	Thank you for your comment. We have made a note of this point.

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The Jennifer Trust for Spinal Muscular Atrophy	1	4.2.2	Housing is a major factor for individuals who want to live independently of their parents/carers. Need for more adapted properties/lifetime homes or adaptations in general is crucial within appropriate housing, changes around means testing for adults for disabled facilities grant but not for children. If young person works this may have implications for contributions towards essential adaptations to their home.	Thank you for your comment. Housing is very important to transition; however, this guideline is focused specifically on how the transition is managed for young people who need health or social care services. Transition models which support service transition by including a housing component are included.
The Jennifer Trust for Spinal Muscular Atrophy	2	4.6	Possible economic implications for young people due to the impact of personal health budgets, potential for insufficient funds to live safely and independently.	Thank you for your comment. Personal budgets will be considered.
The Jennifer Trust for Spinal Muscular Atrophy	3	General	Possible inequality of access to transitional services by families from ethnic backgrounds, also cultural issues around young people with disabilities living independently of their parents.	Thank you for your comment. The guideline will cover young people with disabilities and the Equality Impact Assessment identified important groups such as ethnic minorities who may require special consideration.
The Jennifer Trust for Spinal Muscular Atrophy	4	General	Poor socio-economic situation of some families may make engagement with transitional services challenging as with other services.	Thank you for your comment. The Equality Impact Assessment recognises explicitly the importance of socio-economic status and any evidence that emerges in relation to this issue will be considered under the relevant review question(s).
The Jennifer Trust for Spinal Muscular Atrophy	5	General	Those young people whose needs are predominantly health based and possibly of a life limiting nature may be exposed to inequalities around care provision once they enter adult services. For example, they may access children's hospice for respite as children/young people but adult hospices run very differently to children's hospices, they focus primarily on symptom control and imminent end of life care.	Thank you for your comment. Young people with life limiting conditions are in scope and will be covered by the guideline. We recognise the importance of hospices and the different cultures encountered in adult settings.

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The Royal College of Psychiatrists	1	3.1.2	Services that do not have a specific cut-off point but have a gradual and planned transition to other services e.g. from CAMHS to adult mental health services depending on the developmental stage of the young person, may protect young people from multiple losses occurring at the same time, e.g. in education; health and possibly parental support. It may also be possible for some aspects of care to be continued in CAMHS while other aspects of care are transitioned into adult services, e.g. weekly or twice weekly psychotherapy may continue in CAMHS but there may be a transfer from a CAMHS psychiatrist to an adult psychiatrist.	Thank you for your comment. The scope does emphasise the importance of planned and co-ordinated transitions and the complexity involved will be addressed by the guideline.
The Royal College of Psychiatrists	2	3.1.3	Appropriate information and advice also includes written information about the services and what can be expected, as well as condition specific information.	Thank you for your comment. The guideline will be based on the best available evidence around effective transitions and will provide action orientated recommendations for good practice.
The Royal College of Psychiatrists	3	3.1.5	The 'cliff edge' described is exacerbated by services where there is a single date cut off i.e. 18th birthday rather than allowing some overlap i.e. transition meeting with new service in the few months before they turn 18, to develop the plan and ensure all in place. Could the use of 'overlapping' services be explored?	Thank you for your comment. The scope treats transition as a long-term process, and different from transfer, which is part of transition. The guideline development process aims to review the best available evidence and provide action-orientated recommendations; Accordingly, the approach of 'overlapping' services will be reviewed if it has been rigorously researched.
The Royal College of Psychiatrists	4	3.2.1	'Young people with long-term conditions will move onto adult healthcare service' – it should be noted that in practice this may mean that they will move from one doctor i.e. a community paediatrician who manages several conditions to several specialities in hospital services increasing the number of appointments and	Thank you for your comment. The impact of poor transitions is of concern to this guideline, and we agree that young people with complex health care needs and multiple conditions are particularly vulnerable in this respect.

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			transferring the overall co-ordination of care back to primary care. Will the quality/experience of this be addressed?	
The Royal College of Psychiatrists	5	3.2.2	It should be recognised that when young people are nearing the end of their period of time in a child centred provision, transition requires an increased level of input and multidisciplinary working, and perhaps increased time and resources should be put aside to attend to each individual case. Additional service gaps include those children who are technology/ equipment dependant or require parental feeding due to the complexity about the responsibilities that can be delegated to parents compared with social care staff and boundaries between funding streams.	Thank you for your comment. The scope is a brief summary of a very complex topic area, including what you outline. Service co-ordination is in scope.
The Royal College of Psychiatrists	6	3.3	"Guidelines for services for Young People (14-25 years) with learning difficulties/disabilities and mental health problems/challenging behaviour". Authors Shoumitro Deb, Nick le Mesurier, Niyata Bathia. Published Sept 2006.	Thank you for your comment. The scope is a brief summary of the topic area. Thank you for the additional information, which we have added to our reference list.
The Royal College of Psychiatrists	7	4.3.1	NHS England (Children and Young People Transition to Adult Services) recommends that there are specific clinicians dedicated to ensuring effective transition in services, with the remit of working with young people and their families. They also recommend an executive lead for transitions in the senior management structure. This would ensure that organisational frameworks are put in place.	Thank you for your comment. The role of the scope is to lay out the areas for consideration; the guideline will provide recommendations based on the best available evidence.
The Royal College of Psychiatrists	8	4.6	For the sub-group analysis, I would suggest that they look specifically at children with learning disabilities and challenging behaviour who need a huge amount of	Thank you for your comment. Outcomes for carers are in scope, and so are young people with learning disabilities who are using health and/or social care

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			transition planning. Will the quality of life analysis include the quality of life of the young person and their carer/s? The transition process can be even more stressful for the families than the young person due to their changing relationships and support issues.	services.
The Royal College of Psychiatrists	9	General	Some young people have experienced holistic and thorough care for their mental and physical health care needs from secondary specialist services. Transition is also about a planned return and good communication with their GP who may be expected to provide some of this care as they enter adult services. Some young people do not need secondary care in adult services, and a good return to the care of the GP and primary care is also important.	Thank you for your comment. GP services are included in scope for the very reason you state here.
The Royal College of Psychiatrists	10	General	There is a group of young people for whom it is particularly difficult to effect a good transition. This is the group with multiple problems but no one specific that hooks them into a service. What they need then is a longer term care management approach to help them through into early adult life with an adult who can act as a role model and advocate. An example would be post abuse, poor parenting, potential for personality disorder adolescent gang membership etc. Etc.	Thank you for your comment, the scope and the Equality Impact Assessment both recognise that some groups of young people will be accessing a range of services and that managing these transitions might be particularly complex.
The Who Cares? Trust	1	General	We welcome a guideline on transition from children's to adult services and are particularly pleased to see the inclusion of looked after children listed explicitly as one of the groups that will be covered.	Thank you for your comment.
The Who Cares? Trust	2	3.1.3	We agree that transition should be purposeful and planned with young people and their families and carers – but where children are in local authority care, we	Thank you for your comment. Looked after children are included in the scope of this topic and the list of activities in 4.3.1 includes

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			would suggest that the professionals who work with them are also included in the planning of transition.	the involvement of young people and carers.
The Who Cares? Trust	3	4	We would like to see looked after children and care leavers included as a sub-group that might have specific recommendations made for it – we feel that the unique circumstances of looked after children and care leavers may require specific recommendations to be made. For example, looked after children and care leavers can remain the responsibility of children's services up until they are 25 and can therefore spend longer than their peers with feet in both children's and adult services.	Thank you for your comment. The guideline remit states that focus should be on general principles across all services, rather than a focus on specific services/conditions. However, we recognise the importance of making recommendations for young people in a particular situation where their situation differs. Looked after young people are specifically mentioned in the last bullet in 4.1.1.
The Who Cares? Trust	4	4.1.1	We would suggest that care leavers are included in the list (either with or separately to children in local authority care). A young person could be a care leaver at 16 and yet still be transitioning from children's to adult services for the next few years. Care leavers have additional vulnerabilities, including the fact that they are highly likely to be living independently.	Thank you for your comment. All young people receiving social care services are included, including care leavers.
Together for Short Lives & Help the Hospices	1	4.1.2	We believe that children and young people who are not using children's health or social care services, but who are likely to in future (up to the age of 25) because of a long-term condition should be included within the scope of the guideline.	Thank you for your comment. To ensure focus and clarity, the guideline will only cover young people who are currently receiving health and social care services at the time of transition, not those who have never received services or have stopped receiving them.
Together for Short Lives & Help the Hospices	2	4.1.2	We also believe that young people up to the age of 25 entering into adult health or social care services who were not previously under the care of children's health or social care services should be included within the scope. The lack of age-appropriate services for young adults is a significant problem - for example in the availability of	Thank you for your comment. The focus of this guideline is the transition between services, not the appropriateness of a service. However, the issue of young people-friendly adult services is now covered under 4.3.1 and also by review question 4.5.9.

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			short breaks for young adults with life-threatening or life-limiting conditions. This guideline should address this issue.	
Together for Short Lives & Help the Hospices	3	4.2.2	We understand that housing services are outside the scope of NICE's remit. However, we ask that the guideline refers to the fact that health and social care services need to liaise with housing services. This would help to bring about integrated, person-centred services for young people; make sure that appropriate referrals are made; and ensure that housing services can begin to make arrangements for a young person who wishes to live independently as soon as possible. This is particularly important for young people who need palliative care, many of whom die while waiting for housing.	Thank you for your comment. Your point is very helpful and will be put to the Guideline Development Group. Do note that the guideline is based on a review of the evidence and this needs to support any recommendations that are made.
Together for Short Lives & Help the Hospices	4	4.3.2	In keeping with comment 4, we ask that the guideline references the fact that health and social care services should liaise with other transition support services to ensure an integrated, person-centred experience for young people.	Thank you for your comment. The role of the scope is to lay out the areas for consideration, the guideline will provide recommendations based on the best available evidence.. Joint working and information-sharing is emphasised in 4.3.1.
Together for Short Lives & Help the Hospices	5	4.4	In addition to the outcomes listed in this section, we ask that an outcome is included which considers the extent to which young people are informed and able to make choices relating to their transition. We also ask that this outcome takes into account the extent to which young people are able to involve their parents, families and carers in these decisions where they wish to do so.	Thank you for your comment. You make an important point, which will be covered by the outcomes 'self-efficacy' and 'transition readiness'.
Together for Short Lives & Help the Hospices	6	4.6	We ask that the subgroup analysis takes into account young people with life-threatening or life-limiting conditions, for whom poorly planned transitions can	Thank you for your comment. Young people with life-threatening or life-limiting conditions are in scope and will be included in analyses.

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			have a particularly negative impact.	
Voluntary Organisations Disability Group	1	4.1.1	The age from which this guidance should be used should be explicitly stated. We think this should be from age 14.	Thank you for your comment. A lower age limit is not set to reflect that transition preparation might start at very different ages depending on the young person's maturity and also the nature of the service.
Voluntary Organisations Disability Group	2	4.2.2	The exclusion of housing services is unhelpful as: a. Housing is crucial for many young people for whom continuing to live with their family is not an option; b. The age of transition for young people with complex and multiple disabilities is often delayed due to a lack of suitable housing; c. Rents payable by local authorities under the Children's Act for Looked After Children are higher than rents covered by Housing Benefit; this destabilises young people at the point of transition.	Thank you for your comment. Housing is very important to transition, however, this guideline is focused specifically on how the transition is managed for young people who need health or social care services. Transition models which support transition by including a housing component are included.
Voluntary Organisations Disability Group	3	4.3.1	We welcome the focus on person-centred approaches and joint working between children's and adults' teams.	Thank you for your comment.
Voluntary Organisations Disability Group	4	4.3.1	We think that "finance" is a key area that should be covered. Currently families are often left to find their own way through benefit changes when the young person reaches 18. Also there is a much greater use of Personal Budgets in adult services compared with children's services and this is a significant cultural shift for young people and their families.	Thank you for your comment. Your point may well be part of the evidence on 'barriers' to transition. Funding of services is not covered by NICE guidelines.
Voluntary Organisations Disability Group	5	General	We think there should be greater emphasis on the involvement of families who, in many instances, continue to provide more care than is delivered by paid services after the young person has reached adulthood.	Thank you for your comment. The role of the scope is to lay out the areas for consideration; the guideline will provide recommendations based on the best available evidence.
Wandsworth Borough Council	1	General	This is a comprehensive scope. I understand why you have had to limit it to young people receiving a health or	Thank you for your comment, which we agree with. We are aware of the importance of relating the

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			social service. My main comment though, is that, the guidance will be published in February 2016, some 18months after the effects of the SEND reforms in the Children and families Act2014 come on line. Many Local Authorities have been working hard to improve their joint working arrangements for the last 18 months and are now concluding on the shape of the service. Is there any way for this to be delivered more quickly or to be linked in with other national initiatives, such as the Preparing for Adulthood agenda? It seems like another example of not joining up effectively.	guideline to the Children and Families Act 2014. Unfortunately NICE guideline development requires enough time to consider the evidence for the prioritised questions and for this guideline with such a wide population focus all scheduled time is needed.
Youth Justice Board for England and Wales	1	General	The YJB welcomes the opportunity to respond to this consultation on the scope of NICE's guideline for transitions. The period of transition between youth and adult justice services is one of heightened risk for young people, and this is further compounded when they are receiving health services. We therefore think that a guideline on transitions in health and social care will be highly beneficial in guiding services and improving delivery. We have particular concerns about the unfortunate omission in the scope of the guideline of transitions between youth and adult custody (where the individual is in receipt of health or social care services). The YJB would also strongly support the inclusion of guidance which considers the needs of those young people who are moving from custody to the community	Thank you for your comments. We will share your point about the needs of those young people who are moving from custody to the community during their transition to adulthood with the Guideline Development Group.

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			during their transition to adulthood. Whilst it is an issue extending beyond the appropriate scope of this guidance we would suggest that the guidance considers the differing commissioning landscape between custodial health care (where NHS England are responsible for commissioning health services) and community provision (where Clinical Commissioning Groups (CCGs) are responsible for commissioning health services) and Local Authorities have responsibility for commissioning substance misuse services. At present, we are specifically concerned that young people and young adults are unable to access relevant health services to address their needs on release from custody and that treatment options are not available on release. This guidance would provide a further opportunity to reinforce good practice and expectations. We would be happy to work with you further to develop this. We hope that you find our comments helpful in shaping the guidance, which covers a topic of particular interest to our Board. Some specific comments are noted below.	
Youth Justice Board for England and Wales	2	3.3	It would be useful for the guideline to take account of some of the youth justice guidance which looks at transitions which can be found here: http://www.justice.gov.uk/youth-justice/youth-to-adult-transitions alongside the NOMS/MoJ recent guidance for care leavers. We would be happy to provide specific documents and to discuss these with you if it would be helpful.	Thank you for your comment and for signposting the various guidance. We have added this to our reference list.

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Youth Justice Board for England and Wales	3	4.1.1 4.2	As noted in comment 1 (above), there are significant issues related to the resettlement of young people leaving custody with health needs and this becomes compounded when they are also transitioning to adulthood. We believe that there is significant benefit in identifying this group in the guideline because of the commissioning anomalies that exist between custodial and community settings (as outlined above).	Thank you for your comment. Young offenders are included in the scope as long as they are using health or social care services, but it is not within the remit of this guideline to consider transitions within the criminal justice system.
Youth Justice Board for England and Wales	4	4.3.2	This paragraph states that young people moving between youth and adult custody will be excluded from the guideline. As noted in comment 1 (above), this is an unfortunate omission because often people transitioning in custody will have health needs and will not only be moving to different areas/establishments but to different healthcare providers. We would like to request that this omission is revisited.	Thank you for your comment. All young people receiving or using health and social care services are included, irrespective of their legal status or housing situation at the time of the transition. However, this guideline will not provide recommendations for housing or offending services for how to support transition. The focus of this guideline is on health and social care transitions.