Transitions from children's to adults' services

Consultation on draft guideline
Stakeholder comments table

Date of consultation from 10/09/15 – 22/10/15

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Action for Sick Children	Full	General	General	Question 1 The biggest impact on practice includes having a named transition worker trusted by the young person and family to liaise across agencies before during and after the transition process. This will be challenging as the worker is likely to come from child services who may struggle to allocate adequate resources to carry out this role effectively within current limited capacity. Without this process being properly commissioned and funded, the benefits will not be achieved. Agreeing pooled budgets across agencies will be challenging. Furthermore the named worker needs to function in a context where there are agreed standards and robust policies across agencies which respective Trust boards and local government sign up to e.g. the Sheffield CAMHS to AMHS agreements. Each Board including adult Trust Boards needs to appoint transition champions who bodies such as CQC hold to account. Without this high level endorsement the named worker cannot ensure the necessary person centered approach. A huge challenge is there being no services to refer young people on to the document mentions young people known to CAMHS who continue to need care but do not reach the threshold for AMHS. Another example is young people with physical health issues/chronic conditions who have psychological support in paediatrics who move to adult services with no psychological service. Non-adherence to treatment is very common in adolescence leading to increased	Thank you for your comment. It is not within the Guideline Committee's remit to make recommendations on commissioning. They did, however, recognise some of the particular challenges related to implementation of the named worker role. These were discussed in detail in relation to the implementation work that supports publication of the guideline and additional detail can be found in the Implementation chapter of the guideline. The Guideline Committee recognised the importance of clear accountability for transition at a senior level. To achieve this, they updated recommendations 1.5.1, 1.5.2 and 1.5.3 to make clear there should be executive and senior management-level responsibility for transitions. The Guideline Committee had extensive discussion, throughout development, about instances where there is no appropriate adult service in place to refer the young person to, post-transition. This informed recommendation 1.5.7 and 1.5.8 which seeks to ensure that, at the locality level, work is undertaken to identify and respond to the needs of young people for whom this is relevant.

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				hospital admissions and disease related complications with the accompanying human and financial costs. The evidence base tells us that psychological support and intervention can improve adherence therefore it is important to ensure its continuity at this vulnerable time. Some psychological care is commissioned across the life span e.g. with Clinical Psychologists appointed to work across services following children from infancy into adulthood e.g. in Cleft lip and palate. The proposed training programme will be challenging to achieve and prioritise. This may be overcome by having transition teams or networks made up of workers from each agency with whom the training could be focused and who effectively would be the overlap between paediatric and adult services. This would require clarity of roles and excellent communication across agencies. Both adult and children's commissioners would need to pool their resources to commission such a service. Although there would potentially be extra funding or reallocation of current resources, research they quote would suggest this would lead to better health outcomes and quality of life with their incumbent financial savings across agencies.	In discussion, the Guideline Committee recognised that different parts of children's and adults services will already be undertaking training on some or all of the components listed. Training has now been moved to the Implementation section. They talked throughout the development phase about the importance of overlap between paediatric and adult services and this is now referenced explicitly in recommendation 1.3.1 which talks about joint appointments, joint clinics and paired practitioner working. Recommendation 1.1.5 also references integrated working, indicating the potential use of joint mission statements and jointly agreed transition protocols and approaches to practice. Clarity of roles and communication was also a theme in discussions and, to this end, key roles (named worker, senior executive lead and senior manager lead) are clearly delineated, in recommendations 1.2.6, 1.2.7, 1.2.8, 1.5.1, 1.5.2 and 1.5.3. There are also several recommendations aimed at service managers explicitly, for example, 1.1.5 and 1.1.6). The previous reference to pooled budgets has been removed from the recommendations as it was noted that this is not within the remit for NICE guidance; however, there is reference to funding mechanisms within the implementation section.
Action for Sick Children	Short	4	17	We agree with this recommendation but feel that the liaison person should be a named consultant physician, surgeon, or psychiatrist. They would help co-ordinate the transition. Further to this, there should be a specific person on every trust board who	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5

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				represents and is responsible children and young people's interests. Indeed, the PALS Service should routinely survey every child who moves to the adult services before, and nine months, after transition.	and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). Specifically, you will note that we have made clearer this is a role not a job title and therefore could be undertaken by someone who is already fulfilling a role of keyworker, coordinator or transition support worker.
Action for Sick Children	Short	5	27	Question 6 : We believe this recommendation should be at the heart of transition. Action for Sick Children represents children, parents and families, and we believe transition should be unique to each child or young person. To do this, children and their families must be central to all decisions and co-production strategies are vital.	Thank you for your comment and support for the recommendations on person-centred approaches.
Action for Sick Children	Short	9	10	This recommendation could be fulfilled in conjunction with charities like Action for Sick Children. We could provide information in the form of leaflets, telephone advice and by coming to hospitals to talk about transition and hear concerns from parents and children.	Thank you for your comments and potential support which could be developed into a shared learning example as part of the implementation work.
Action for Sick Children	Short	12	3	Having in a clear allocation of responsibility in place is important. Individuals, such as executives, should be accountable for transition services but there should also be a named person solely responsible for transition and sitting on every trust board.	Thank you for your comment. The Guideline Committee considered the issue of ownership of transition carefully (recommendations 1.5.1 to 1.5.3) and reviewed these recommendations at Guideline Committee meeting 12 (04.11.15). The wording has been updated to make clearer how these roles would work and where accountability lies.
Alder Hey NHS Foundation Trust	Short	General	General	**In summary.** The GP must be involved in the care of all patients with long term conditions not just those where there is no	Thank you for your comment. The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout

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				specialist service in the adult sector To address the challenge of transition, there needs to be a team of professionals who are trained in both paediatrics and the care of young adults, putting the young person at the heart of what we do, and addressing the needs of 16- to 25-year-olds, (or at the very least 18-19 years); With Transition preparation commencing at the age of 12- 14 years, depending on the speciality. Patients, parents and carers should be involved in planning of transition services, and this can be achieved through workshops, engagement forums. Our trust has had experience of implementing this approach and would be willing to submit its experiences to the NICE shared learning database. Contact Dr Lynda Brook or Jacqui Rogers. Other key stakeholders being any services having input with patients at the age of transition preparation should be involved in the planning. This includes third sector stakeholders. Our trust has had experience of implementing this approach and would be willing to submit its experiences to the NICE shared learning database. Contact Dr Lynda Brook or Jacqui Rogers. Parents should be involved in transition planning with their child if the child expresses this as a wish, or when the child lacks capacity. Annual cohort planning with adult services, particularly for complex patients is necessary. Our trust has had experience of implementing this approach and would be willing to submit its experiences to the NICE shared learning database. Contact Dr Lynda Brook or Jacqui	the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).). Multi-disciplinary team-working is addressed in recommendations 1.1.5, 1.1.7 and 1.2.3. Thank you for your comment. The Committee agreed that the issue of parental involvement is important and complex and, on reviewing these recommendations at Guideline Committee meeting 12 (04.11.15) agreed to strengthen their wording (recommendations 1.2.19 to 1.2.22). The Committee agreed not to be prescriptive in respect of methods but your contributions to the NICE shared learning database would be most welcome. Involvement of all stakeholders – which could include those from voluntary and community sector organisations, if appropriate – is referenced in 1.2.3. The Mental Capacity Act is now referenced explicitly in recommendation 1.2.20. There will also be reference to the MCA in the full guideline text available on the NICE website when the guideline is published. For an example from another social care guideline, see below: https://www.nice.org.uk/guidance/ng22/chapter/recommendations which links to https://www.nice.org.uk/about/nice-communities/public-involvement/your-care

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				Rogers. The recommendations in this guidance may not lead directly to cost savings in the paediatric services, but long term the investment to a good transition services will lead to continued engagement of YP in health services and a saving will be made on emergency admissions as it is anticipated YP who have followed a Transition preparation programme and have experienced a good transition will continue to engage in health services, understand their health, stay well at home and achieve their health and life outcomes.	
Alder Hey NHS Foundation Trust	Short	general	general	These guidelines are generally very good, and aspirational. However, I do feel they will be difficult to deliver in practice for many reasons.	Thank you for your comment. The Guideline Committee considered all recommendations aspirational but achievable, although recognised there may be implementation challenges in some cases. Please see the chapter on implementation for practical suggestions about how challenges could be overcome.
Alder Hey NHS Foundation Trust	short	General	general	Whilst a transition policy should be applicable for all, the guidelines perhaps best fit those who have complex needs and pre-existing multi-agency involvement and review processes, such as EHAT. For those with perhaps only one long-term medical condition, despite it's chronicity and need for follow-up and, therefore, transition to adult services, trying to integrate health, social care and education may seem less of a priority (although arguably the same process should apply to all).	Thank you for your comments which will be considered as part of the work to support guideline implementation. The guideline covers a very wide range of young people and services so it was not possible to list all relevant conditions and needs separately. As a result, the Guideline Committee seeks to establish the broad principles to follow with respect to care and support before, during and after transition. Young people with single conditions are included in the guideline.
Alder Hey NHS	short	general	general	These guidelines fit less well with life-span services where the same team remains involved throughout the care of the patient. Transitional needs still need to be	Thank you for your comments. The guideline covers a very wide range of young people and services so it was not possible to list all relevant conditions and

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Foundation Trust				addressed and the same over-arching principles apply, however, there is no "handover". Cleft and Craniofacial services at Alder Hey are examples of these. The Cleft Service has also been piloting a transition worker project for the past 12 months, on the back of many years of a clinician-led steering group. Contact Maria Knapp (Consultant Clinical Psychologist) or Susana Dominguez-Gonzalez (Consultant Orthodontist) for further information.	needs separately. As a result, the Guideline Committee seeks to establish the broad principles to follow with respect to care and support before, during and after transition. Young people with lifespan conditions are included in the guideline.
Alder Hey NHS Foundation Trust	short	general	general	In terms of psychological difficulties within the context of a medical condition/chronic illness, transitioning from psychological support provided by a paediatric psychology service (e.g. Psychological Services) to an equivalent service in adult health services is almost impossible. Very few services exist. Young people often do not fall into the required criteria to receive adult mental health services, and other statutory (e.g. primary care, Tier 2, IAPT) or non-statutory (charities, counselling service) often do not provide not the specialist expertise around the condition and/or the links with medical professions to enhance holistic care.	Thank you for your comment. The Committee recognised the need to ensure that young people with mental health needs do not "fall through the gap" between Child and Adolescent Mental Health Services and Adult Mental Health Services and, to this end, referenced them explicitly in recommendations 1.5.5 and 1.5.7.
Alder Hey NHS Foundation Trust	short	general	general	Implementation of the guidelines will impact all services within the hospital who look after children whose medical/surgical needs extend into adulthood. This is a huge population. It will be most challenging to implement for those services who do not have an equivalent in adult services to liaise with. Examples of best practice within the hospital currently are those who have this already in place (e.g. Cystic Fibrosis).	Thank you for your comments . Please see the chapter on implementation which provides some practical examples of how challenges could be overcome. In particular, there is a section on maximising opportunities for young people who are disengaged from or do not have access to care and support.
Alder Hey NHS Foundation Trust	short	general	general	The challenges of engaging with social care and education will be huge, if required for every young person.	Thank you for your comments. Please see the chapter on implementation which provides some practical examples of how challenges could be overcome. In particular, there is a section on joint planning, development and commissioning across adults' and children's services.

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Alder Hey NHS Foundation Trust	short	general	general	The challenges of training all staff, whilst necessary, will be costly in terms of time and funding. Ensuring training is multi-disciplinary to incorporate all aspects will also be challenging.	Thank you for your comments. Please see the chapter on implementation which provides some practical examples of how challenges could be overcome. In particular, there is a section on improving front-line practice with young people through training.
Alder Hey NHS Foundation Trust	short	general	general	There is no mention in the guidelines as to who should act as the named worker. It is a good idea for the young person to identify someone, but what if that person is not the best person, or has enough time. In Cleft, we have only been able to progress transition by identifying dedicated sessions within one persons job plan.	Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). The Committee did not think it appropriate to specify who should be the named worker, given the breadth of services and young people covered by the guideline, however some examples of the sorts of roles that could fulfil the tasks have been included in 1.2.6 and in the 'Terms used in this guideline (named worker definition).
Alder Hey NHS Foundation Trust	Short	general	general	I do not feel the document identifies who takes overall responsibility for ensuring transition happens as per the guidelines. Who takes the lead if multiple agencies are involved, or even multiple medical specialities?	Thank you for your comment. The recommendations on ownership (1.5.1, 1.5.2 and 1.5.3) have been updated to make this clearer.
Alder Hey NHS Foundation Trust	short	general	general	The recommendations are too generic and a "catch all" – there are many services and young people within them that this is not as applicable for.	Thank you for your comment. Given the wide range of young people covered by this guideline, its scope was to establish the broad principles to follow with respect to care and support before, during and after transition. A wide range of sub-groups were considered throughout development and the Guideline Committee itself comprised members with diverse experience.

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Alder Hey NHS Foundation Trust	short	general	general	There is no mention of correspondence (e.g. letters being addressed/coped to young person)	Thank you for your comment. The recommendations focus on the principles of person-centred care, and involvement of young people more broadly. This particular issue did not emerge from the evidence or from consensus discussion. It was not possible to reference all methods for communicating with or involving young people, though the Committee recognised that these may be various.
Alder Hey NHS Foundation Trust	short	general	general	There is no mention of parents needing support for transition.	**Parental involvement** Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.

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Alder Hey NHS Foundation Trust	Short	General	general	I think the challenges to transition presently are the lack of confidence that parents (and young people) have in the adult systems. This is often based in their own experiences of adult care (and reality!). In addition, some clinicians view transition as an age-related issue, rather than a developmental issue, set firmly within the individual needs and understanding of the young person. Often young people have been with the hospital for many years, and we are best placed to inform the process from our experience of the child and their family. Consistent structures need to be put in place, training and pathways – but also a reciprocal relationship with the adult services. Parallel services need to be out in place in adult services to assist transition and "transfer", which includes holistic care, such as psychology. Transition needs to be an informed and collaborative process – to do it well will take time, resources, training, and staff who have time to do it well and not simply complete checklists. Adult services also need to be involved.	Thank you for your comments. Please see the chapter on implementation which provides some practical examples of how challenges could be overcome. In particular, there is a section on improving front-line practice with young people through training.
Alder Hey NHS Foundation Trust	Short	General	general	Key audiences are young people and families facing transition and having transitioned, also adult services, and GPs.	Thank you for your comments. These audiences are considered in the guideline and may also be considered further as part of the work to support implementation.
Alder Hey NHS Foundation Trust	Short	General	general	In Alder Hey, my observation is that transition planning starts at a variety of ages and the level of planning is inconsistent. For some it is an age factor – "YP is 16, they need to be referred to the adult clinic." For others, eg. Cardiac, there is a defined young person's clinic where the focus is transition, independence, knowledge about condition. The need for psychological support is high. For lifespan services, eg cleft and craniofacial, transition is less clearly defined but does need to be addressed and supported. For Cleft, the concept of transition is planned to be	Thank you for your comment. The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are.

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				introduced around the age of 10 years, alongside an invite to School Change Day (the first big transition!)	
Alder Hey NHS Foundation Trust	Short	General	general	Each speciality will have their own review appointment scheduling which is not necessarily around transition but around medical needs.	Thank you for your comments. The Guideline Committee reviewed the recommendations on timing and review (under section 1.2) at Committee Meeting 12 (04.11.15) and agreed the edited wording now found in recommendations 1.2.1 to 1.2.4.
Alder Hey NHS Foundation Trust	Short	General	general	Parents absolutely need to be involved as they are key to successful transition. They need to be involved with the development of pathways and information, passports etc, alongside their children. They need to continue to have opportunities to be involved in consultations, as appropriate, and to be able to share concerns. They may also need their own support in stepping back etc.	- Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
Alder Hey NHS Foundation Trust	Short	General	general	I think these recommendations will result in a huge cost and investment from services in terms of resources, staffing, training as well as time (increase in number of meetings, paperwork, documents, reviews).	Thank you for your comment which will be considered as part of the work to support guideline implementation.

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				I think there is an additional cost involvement for the majority of recommendations as to adhere to the guidelines would mean additional staff time. The role of the named worker, in itself, could not be incorporated within an existing job plan.	
Alder Hey NHS Foundation Trust	Short	General	general	In the longer term, if transition works well, positive engagement in services should increase, hopefully leading to increased independence, better health-care and self-management, identification of needs at an earlier stage, information and access to identified support structures to enhance holistic care, engagement in work/further education, improved psychological health and outcomes. This should have a knock-on in cost savings – however, the services have to be there to provide the support and to provide the ongoing support needed for those patients who need it.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
Alder Hey NHS Foundation Trust	short	4	7	How will young people be identified who have transitional needs? Who will take lead responsibility for that?	Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level.
Alder Hey NHS Foundation Trust	short	4	15	The role for the named key worker is far too broad – how can a key worker working in a health setting address all outcomes including health, education, employment etc?	Thank you for your comment. The wording of recommendation 1.2.7 has been updated to make clear it is not the responsibility of the named worker to address all these outcomes, but to 'oversee, coordinate or deliver transition support, depending on the nature of their role'.
Alder Hey NHS Foundation Trust	short	4	26	This is such a wide ranging role which straddles across different agencies, different sectors, different topics. I think this is challenging in practice and is very much a "job" in itself, with an identified person, rather than just part of someone's role.	The Guideline Committee were clear that this is a role not a job title and have made clearer within the guideline that this could therefore could be undertaken by someone who is already fulfilling a role of keyworker, coordinator or transition support worker

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					(recommendations 1.2.5, 1.2.6, 1.2.7 and 'Terms used in this guideline').
Alder Hey NHS Foundation Trust	short	4	26	Difficulties arise when there simply isn't anyone to hand over to!	Thank you for your comment.
Alder Hey NHS Foundation Trust	short	5	22	The length of involvement will vary widely depending on the level of need and complexity, and level of support required.	Thank you for your comment.
Alder Hey NHS Foundation Trust	Short	5	27	I agree that the point of transfer should not be based on rigid age threshold (although Alder Hey seem to be focusing on this and a definition, with "special exceptions". The context of the individual young person always needs to be considered in addition to ensuring the young person receives the best level of care for their needs.	Thank you for your comment and support for the recommendations.
Alder Hey NHS Foundation Trust	short	6	1	This recommendation will be challenging in practice and will require additional meetings/appointments for some young people who do not attend annually for reviews because their underlying condition or treatment plan is relatively stable (e.g. cleft). I'm not sure that for these patients, an annual meeting including all stated professionals will be well attended, prioritise or viable, unless there are obvious and identified concerns.	Thank you for your comments which will be considered as part of the work to support guideline implementation. The Guideline Committee thought it was important for the young person that an annual review meeting is held but agreed to revise rec 1.2.3 to reflect that not all professionals would be expected to attend the review meeting in person.
Alder Hey NHS Foundation Trust	short	6	14	Who is the person that provides the support, when it is identified and needed?	Thank you for your comment which was discussed in Guideline Committee meeting 12 (05.11.15). Given the very wide variety of contexts in which this guideline will be implemented, the Committee agreed not to specify who should help the young person identify a named worker (recommendation 1.2.5).
Alder Hey NHS Foundation Trust	short	6	20	Various documents are used at Alder Hey and/or are under development. They need to be individualised and not simply viewed as a checklist to evidence that	Thank you for your comment. Recommendation 1.3.3 references the need for

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				transition has happened (even if not happened well). There is no mention of cultural or language needs (eg translation) to be incorporated.	information to be in the young person's preferred format which would include responding to any cultural or language needs. The Guideline Committee also reviewed the recommendation on supporting young people to communicate with practitioners and revised the text to make clear this requires them to know what a young person's communication needs are, and to have tools available to help address those needs (see recommendation 1.2.20).
Alder Hey NHS Foundation Trust	short	7	2	Issues re safeguarding need to be considered with peer support mentoring etc.	Thank you for your comment. Recommendation 1.2.15 now includes explicit reference to moderating peer support so as to ensure the safety of those involved.
Alder Hey NHS Foundation Trust	short	7	4	This recommendation is challenging for a named worker who works solely in a health setting to be aware of other services and resources.	Thank you for your comment. This recommendation is not aimed specifically at the named worker. In addition, the Guideline Committee considered all recommendations aspirational but achievable.
Alder Hey NHS Foundation Trust	short	8	12	Developing confidence is not just about providing opportunities, but also providing skills. Some young people will refuse the opportunity to speak alone because they lack the confidence to do so.	Thank you for your comment which provides useful context for implementation.
Alder Hey NHS Foundation Trust	short	8	15	From experience of leading the Cleft Transition project, engagement from adult services and identifying key links has been the most problematic. Whilst the interest may or may not be there, the time is definitely not a priority.	Thank you for your comment.
Alder Hey NHS Foundation Trust	short	8	19	How will a nominated adult service be defined? What If a young person has multiple needs – who takes the lead?	Thank you for your comment. The reference to 'nominated' adults service has been removed as the Committee agreed this was confusing and more than one service may be involved. The Guideline Committee reflected on the issue of young people with multiple conditions, at Guideline

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					Committee meeting 12 (04.11.15) and agreed an additional recommendation was needed, to emphasise the need for integrated working to support this group (recommendation 1.5.10).
Alder Hey NHS Foundation Trust	Short	8	25	Agreed that a personal folder is important and this will take time to prepare and work out with a young person in order to ensure that it accurately reflects their needs etc. Issues of confidentiality will need to be addressed. Sensitivity around preparing this information with the young person may be needed – some young people simply do not know what has happened to them before and/or why. Also needs to take account of psychological issues and psychological needs around medical treatment (e.g. needle phobia)	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Alder Hey NHS Foundation Trust	short	10	22	What is defined as "non-attendance"? Erratic attendance can be just as concerning. At what point can the young person be referred back and is it just the named worker (i.e. unlikely to be the medical consultant)? How does that fit with transition, if the young person can simply return back to the previous service? What if the named worker can't make contact? How will safeguarding work – social care are often reluctant to get involved for non-attendance even as a child.	Thank you for your comment. Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level. The queries you raise are examples of the specifics that need to be considered and defined locally. The Committee reviewed the recommendations on support after transfer (1.4) at Guideline Committee meeting 12 and agreed that specifying 'does not attend meetings or appointments or engage with services' would be understandable to practitioners.
Alder Hey NHS Foundation Trust	short	11	3	The training needs are huge and, if mandatory, careful consideration needs to be given as to how it is delivered, the content, time required, evaluation of training.	Thank you for your comments. The Guideline Committee recognised that training is an important issue and this was discussed throughout development. Please see the chapter on implementation which provides some practical examples of how challenges

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					could be overcome. In particular, there is a section on improving front-line practice with young people through training. The ongoing work on implementation, and the associated Quality Standard development, may provide an opportunity to explore this in more depth
Alder Hey NHS Foundation Trust	Short	12	18	Youth forums are an excellent idea but will require facilitation and representation from all agencies.	Thank you for your comments which will be considered as part of the work to support guideline implementation. The Guideline Committee agreed on the importance of mechanisms to enable young people to feed In to service planning at the locality level and recommendations 1.5.4 and 1.5.5 address this. Recommendation 1.5.5 has been updated to make clear that these should link to existing structures where these exist.
Alder Hey NHS Foundation Trust	short	13	1	Any gap analysis should include psychological services required for young people with chronic medical conditions and disabilities, not just CAMHS services.	Thank you for your comment. The guideline covers a very wide range of young people and services so the list reflected priority groups identified during development as being particularly at risk of 'falling through the gaps' between services, rather than being exhaustive.
Alder Hey NHS Foundation Trust	Short	16	general	Setting up a new service within the adult sector would require involvement from Regional adult services(Neuro/Ortho/Rehab), GP's and Commissioners. Adult therapy, equipment and support services.	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Alder Hey NHS Foundation Trust	Short	16	2 -3	This recommendation will be a challenging as there is not enough emphasis on adult services being an essential part of transition policies and their implementation – it still feels too much like children's services pushing without adult services pulling.	Thank you for your comment. Additional explicit references to adult services have been included in the guideline, to make clear where responsibilities for recommendations are shared (see over-arching recommendation 1.1.5 and recommendations 1.3.2, 1.3.4, 1.4.4).

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Alder Hey NHS Foundation Trust	Short	16	6 -7	This recommendation will be a challenging in terms of culture changes, this could take decades. There is a difference in language, tones and natures used with paediatric, young people and adults, which will need addressing possibly by training. There is also the difference in the way a young person and an adult need to be managed that is not just a communication issue, but a more support issue. Whilst transition preparation will prepare young people for these changes, there needs to be some investment from adult service providers to adapt approach and communication techniques to support young people through transition until they are confident adults. (for further reading see the Kennedy report 2010)	Thank you for your comments which will be considered as part of the work to support guideline implementation. The Committee agreed that training is an important area to address and, to this end, it is referenced in the implementation chapter, specifically in reference to improving front-line practice with young people. Given the wide range of young people covered by the guideline, it was not possible to list every aspect of training. In the implementation chapter, therefore the Committee sought to provide over-arching headings that specify the key broad areas to address.
Alder Hey NHS Foundation Trust	Short	16	8	This recommendation may be challenging in terms of therapeutic drugs used in paediatrics and adult services. Sometimes these are different for example in Nephrology service a drug of choice in paediatrics is not used in adult services This recommendation may be challenging as there is a lack of for example respiratory or neuromuscular physio, this is a particular issue locally but not necessarily an absolute issue nationally This recommendation may be challenging as there is an relating to the lack of an adult pathway for baclofen pumps This recommendation may be challenging as the prescribing of the drug melatonin is not available in the adult service, we believe this to be a National issue	Thank you for your comments which will be considered as part of the work to support guideline implementation. The specifics of implementing recommendations in different specialities will need to be considered at the local level as this guideline is intended to provide generic principles to improve support before, during and after transfer.
Alder Hey NHS Foundation Trust	Short	16	8	Most challenging will be the development of an adult Cerebral Palsy service or similar. Currently there is no Rehab Consultant or team to refer our complex CP children to in the adult sector. They are being	Thank you for your comments which will be considered as part of the work to support guideline implementation. The specifics of implementing recommendations in different specialities will need to

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				discharged with advice to contact their GP if they become symptomatic. Support services in the adult sector for complex needs young adults are limited or non -existent and can depend on their address or day care placement.	be considered at the local level as this guideline is intended to provide generic principles to improve support before, during and after transfer.
Alder Hey NHS Foundation Trust	Short	16	11 -12	Our Trust has developed a Transition toolkit including general 'Ten Step Transition Pathway' in partnership with a local adult Trust. This is part of planning for the adult service providers to develop a service that will take over the care of our 'Complex' cohort of patients, this is planned for Spring 2016. There are two steps within the ten step pathway that outline 'joint' reviews, one led by paediatrics in the paediatric setting, and one led in adults in the adult setting. These joint clinics are incorporated in the pathway for all specialities. Our trust has had experience of implementing this approach and would be willing to submit its experiences to the NICE shared learning database. C Joint clinics may also assist the adult service providers when taking over the care of patients with rare syndromes for example Retts's syndrome; it is anticipated within our Trust, that adult service providers will need the option to contact the paediatric consultant for discussion/advise/ guidance when initially taking over the care of such patients. Our trust has had experience of implementing this approach and would be willing to submit its experiences to the NICE shared learning database. With regard complex patients this will support the understanding and delivery of developmentally appropriate care for these families, however for other specialities the language and approach techniques may not be able to be addressed in two joint reviews, as the adult clinical teams will be communicating	Thank you for your comments which will be considered as part of the work to support guideline implementation and may be a useful example for the shared learning database.

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				directly with the young person. This may be a communication training issue that should form part of a common curriculum of training needs, and should be delivered to professionals together to break down cultural tendencies. This will promote an understanding of each other's roles and contribution's and set a basis for more holistic care and approaches.	
Alder Hey NHS Foundation Trust	Short	16	11 -12	Our complex CP young adults and families would benefit hugely from having the opportunity to discuss their concerns about transition and to form a plan of how these concerns can/will be managed. They need at least a key contact in the adult services to help support and offer advice and most would appreciate a designated Rehab Consultant to deal with their on-going medical issues.	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Alder Hey NHS Foundation Trust	Short	16	11 -12	Currently no transition meetings occur for our complex CP patients unless they are involved in Palliative care.	Thank you for your comments which provide useful contextual information.
Alder Hey NHS Foundation Trust	Short	16	13 -14	This recommendation may be challenging when working with parents and carers of patients with 'complex' long term conditions. Transition preparation will support parents and carers as advocates for this cohort of patients although this will not completely eradicate the fear they have of moving to adult service providers. Parents are acutely aware that decisions made in adult services regarding active and vigorous clinical intervention and resuscitation of their children will be different in adult services to that of the paediatric service. This may limit the effectiveness of transition as parents do not wish their children to move to adult service providers, and voice this very clearly.	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Alder Hey NHS Foundation Trust	Short	16	13 -14	For children with complex CP there is currently no or very little transition planning. They are often discharged from children's services at age of18/19 with no follow up appointment in the adult sector, unless they are involved in Palliative care services.	Thank you for your comments which will be considered as part of the work to support guideline implementation.

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Alder Hey NHS Foundation Trust	Short	16	15 -16	This recommendation may be challenging when working with parents and carers of patients with 'complex' long term conditions, as it is widely recognised that a number of services cease when paediatric care ends. Services such as respiratory and neurology physiotherapy and respite care. These roles are crucial to the health and wellbeing not only of the patient, but of the family and carers. Physiotherapy will help keep these patients well at home, reduce the risk of chest infections, and spasticity or contracture of limbs- both possibly requiring hospital admissions for either antibiotic therapy or surgery such as 'botox' or Tendon Achilles lengthening, bilateral gastrocnemius and bilateral calf releases, and tendon releases in patients arms. The provision of both these services in the adult sector requires significant funding issues. There is also the consideration of job roles necessary to support a good transition have been identified, and the role of the Lead Consultant, the key worker and an engaged GP are pivotal to the success of transition. All of these require significant funding. Training has also been identified as a need for GP's as all GPs are not paediatric trained. (Kennedy report. Recommendation 18).	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Alder Hey NHS Foundation Trust	Short	16	15 -16	For complex CP young adults, parents have to be involved and currently are often dismayed and concerned that there are no plans in place to support them or their children once they leave children's services. The exception is their GP who often, has not been involved in their care, as they tend to refer patients to acute services, who are more familiar with the child's management and treatment.	Thank you for your comments which will be considered as part of the work to support guideline implementation.

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Alder Hey NHS Foundation Trust	Short	16	15 -16	Setting up an adult CP service would have obvious cost implications.	Thank you for your comments which will be considered by NICE as part of their costing work to support guideline implementation. Given the wide range of young people covered by this guideline, the scope of this guideline was to establish the broad principles to follow with respect to care and support before, during and after transition.
Alder Hey NHS Foundation Trust	Short	16	15 -16	An adult based Cerebral Palsy/ Neuro-rehab team with Consultant is required in order to prepare and transition patients to adult services. This should have access or links to additional support services. A list provided by Scope includes Audiology, Clinical psychology, Dieticians, Neurology, Occupational Therapy, Ophthalmology, Orthopaedic Consultants, Orthotists, Community nursing team, Physiotherapy specialities, Wheelchair services/ seating engineer and Speech and language therapy. Social services and further education services.	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Alder Hey NHS Foundation Trust	Short	16	15 -16	By providing an adult service, there may be cost savings; less visits to A+ E and hospital admissions if families are more supported and managed in the community-this would certainly be the case for Respiratory management. There would also be health and social benefits to parents and carers who are often left alone to cope.	Thank you for your comments which will be considered by NICE as part of their costing work to support guideline implementation.
Alder Hey NHS Foundation Trust	Short	17	2 -4	This recommendation may be challenging as there is not enough emphasis on adult services being an essential part of transition policies and their implementation – it still feels too much like children's services pushing without adult services pulling This recommendation pose some questions related to pooled funding? Who will hold the funding, manage, lead and be responsible and accountable for	Thank you for your comment. The previous reference to pooled budgets has been removed from the recommendations as it was noted that this is not within the remit for NICE guidance; however, there is reference to funding mechanisms within the implementation section.

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				outcomes. How will responsibility and accountability be devolved without decentralising? Different organisations have different priorities,. education, health and social care. The need to uphold one vision, possibly using the five outcomes for children as laid out in 'Every Child Matters' (2001-2005) to underpin organisational objectives - • Be healthy • Stay safe • Enjoy and achieve • Make a positive contribution; and • Achieve economic well-being. This recommendation may be challenging as the guidance appears to read largely for single long term conditions patients and does not feel as though it adequately address the multiple transitions and the need for co-ordination between these multiple transitions for the more complex patients	
Alder Hey NHS Foundation Trust	Short	17	4 -6	This recommendation may be challenging as there is no clarity in the guidance of which speciality of patients it refers to, it appears to move between specific transition needs of young people with learning disabilities who will have an annual transition review and other young people who will not; we need to make the difference clear or transparent. The guidance needs to be clear on who exactly it applies to (other than by age) ie what is a condition that requires transition This recommendation may be challenging as professional struggle with the relevant skills and knowledge to find support and they know the systems. Each YP should have an identified named keyworker; therefore It is difficult to understand how a young person can be supported to identify their own named transition keyworker. This seems unworkable and	Thank you for your comments and signposts to good practice which will be considered as part of the work to support guideline implementation. The previous reference to pooled budgets has been removed from the recommendations as it was noted that this is not within the remit for NICE guidance; however, there is reference to funding mechanisms within the implementation section. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7).

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				unrealistic This recommendation may be challenging when working with parents and carers of patients with 'complex' long term conditions, as it is widely recognised that there is no reciprocal adult service who can provide the required care to the young people (YP) in this complex cohort (complex being defined as YP with three or more of the following- a life limiting/threatening conditions/ GMFM 4/5, oxygen dependent, under the care of three or more specialities, technology dependent and severe or profound learning difficulties). This cohort of YP previously did not live into the young adult age bracket, and therefore services for them has not yet been planned, or commissioned. Our Trust has developed a Transition tool kit with a 'Ten Step Transition Pathway' in partnership with a local adult Trust. This is part of planning for the adult service providers to develop a service that will take over the care of our 'Complex' cohort of patients (young people), this service is planned to open in Spring 2016. Our trust has had experience of implementing this approach and would be willing to submit its experiences to the NICE shared learning database. Contact Dr Lynda Brook or Jacqui Rogers.	Given the very wide variety of contexts in which this guideline will be implemented, the Committee agreed not to specify who should help the young person identify a named worker (recommendation 1.2.5).
Alder Hey NHS Foundation Trust	Short	17	7 -8	This recommendation may be challenging in terms of engaging managers in the planning process, and for them to identify this as a priority- possibly due to lack of capacity within their job plans and other conflicting priorities, also a possible lack of understanding of the impact of poor transition on the patient and family as not all managers have clinical back grounds.	Thank you for your comments which will be considered as part of the work to support guideline implementation.

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Alder Hey NHS Foundation Trust	Short	17	12 -14 & 17-18	This recommendation may be challenging for financial reasons. There needs to be significant investment recurrently to support Transition training and the sustainability of the training. Training such as communication techniques when caring for a YP during and following transition on subjects such as adolescent/developmental medicine for adult services receiving these patients: Shared decision making: person centered thinking and planning: implementation of Transition planning and delivery, and ongoing investment for paediatric specialists when supporting adult colleague's when taking over the care of a very complex patient with a rare condition, along with safeguarding and advocacy training. There needs to be funding to support release of staff to attend the training, and additional time in job plans to implement and embed transition in all specialities. There also needs to be investment into Paediatric training for those GPs with no previous training.	Thank you for your comments which will be considered as part of the work to support guideline implementation. Your comments on resource implications will be considered by NICE as part of their costing work to support guideline implementation.
Alder Hey NHS Foundation Trust	Short	17	16	This recommendation may be challenging as the guidance does not appear to clearly differentiate between self-management of long term conditions which should be life-long and start as soon as the child is able to begin to take responsibility for themselves versus transition	Thank you for your comments which will be considered as part of the work to support guideline implementation. Thank you for your comment. The guideline covers a very wide range of young people and services so it was not possible to list all relevant conditions and needs separately. As a result, and recognising that, as you highlight, it needs to address the diverse needs of wide range of young people, the Guideline Committee sought to establish the broad principles to follow with respect to care and support before, during and after transition. Young people with rare illnesses are included in the guideline.
Alder Hey NHS	Short	18	20-21	This recommendation may be a small challenge, however a challenge. Developing robust systems	Thank you for your comments which will be considered as part of the work to support guideline

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Foundation Trust				between adult and paediatric administration service to share information about a YP who may be or may have disengaged from care in adult services. It is anticipated with identified key workers, this will be where and how the system will be developed.	implementation.
Association of Paediatric Anaesthetists of Great Britain and Ireland	Full	General	General	Overall this is an excellent document and it's publication is to be welcomed given the parlous state of transitional arrangements throughout the healthcare system. It contains many examples of good practical planning and suggestions to facilitate robust transitioning.	Thank you for your comment and your support for the guideline.
Association of Paediatric Anaesthetists of Great Britain and Ireland	Full	General	general	Whilst these recommendations are very sensible – questions remain regarding their successful implementation into specific service standards and how clinicians and supporting staff will be given time/funding for measures proposed.	Thank you for your comment. The challenges of implementation have been discussed throughout, and most recently, taking into account consultation comments, in Guideline Committee meeting 12 (5.11.15). The NICE Collaborating Centre for Social Care (NCCSC) has a remit to work with NICE to support implementation of the guideline so we will consider all such comments as part of our ongoing work in this respect. Please also see the Implementation chapter of the guideline which identifies some ways to overcome some of the challenges.
Association of Paediatric Anaesthetists of Great Britain and Ireland	Full	General	general	There is little specific in this document regarding anaesthesia and surgery, however given that virtually all paediatric surgery takes place in children under 16 years of age and that the 16 - 18 years age group tend to get lost in the system we would welcome more robust planning from the early teens for this eventuality for children with progressive or chronic conditions. Grown Up Congenital Hearts (GUCH) and oncology children are examples where patient centred care and	Thank you for your comment. We have not referenced anaesthesia specifically as the scope of this guideline was to establish the broad principles to follow with respect to care and support before, during and after transition. The guideline takes into account a person-centred approach which takes into account the needs of young people going through transition. Following discussion at Guideline Committee 12,

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				careful transitioning is so important. The decision to not transition a child, for example for those approaching 16 years of age but also approaching the end of treatment for say, oncological disease should also be integral to transition arrangements.	however, the group agreed on the importance of addressing the needs of young people with complex and multiple conditions more explicitly; to this end, recommendation 1.5.10 has been included to emphasise the importance of coherent, integrated provision. Recommendation 1.1.5 also references integrated working, indicating the potential use of joint mission statements and jointly agreed transition protocols and approaches to practice.
Association of Paediatric Anaesthetists of Great Britain and Ireland	Full	General	general	We are unable to comment on questions 1,2,3,5,6,7,8, and 9 as these are outside our sphere of expertise. With respect to Q4 above, in current transitional planning is largely ad hoc, and started too close to or even after the 16th birthday and there is no managed transition. We would welcome the formal adoption of 13/14years as the age to start transition planning and the development of a more managed process.	Thank you for your comment and your support for the age threshold indicated in recommendation 1.2.1.
Association of Paediatric Anaesthetists of Great Britain and Ireland	Full	45	General	We are particularly of supportive young people taking responsibility for their care with respect to transition clinics.	Thank you for your comment and support for the guideline.
Association of Paediatric Anaesthetists of Great Britain and Ireland	Full	55	general	We support the use of teen friendly technology such as Facebook/text reminders of appointments.	Thank you for your comment. The Committee discussed young people's use of social media throughout development and agreed not to develop a recommendation on this specifically given the very wide range of young people this guideline covers and the risks associated with this platform for some young people in particular. The benefits of technology to support other aspects of transition, however, are referenced in recommendations 1.2.10, 1.2.11 and 1.3.4.

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Autism Northern Ireland	Short	general	general	This is an admirable document. However for people with Autistic Spectrum Disorders adult services are relatively underdeveloped and it is unlikely that young people in the process of transition will receive the same level of service within adult services as they have been used to in children's services. Regular access to respite, stable and continuous day time opportunities and immediate access to a named worker who will remain with the young person for periods longer than the initial assessment period are rarely funded to the same level as in children's services. Piecemeal day-time opportunities are especially unsuited for young people on the autistic spectrum. The draft guidelines are very good, but for people with ASD, without some funding to ensure that they are put into practice they will be only aspirational.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
Barts Health NHS Trust	Full	general	general	Making people fill in a form to make comments dissuades engagement in this process and demeans the intelligence of all involved. I suggest NICE gets rid of such a restrictive practice.	Thank you for your comment. Alternative approaches to providing feedback are available and NICE are happy to discuss these with stakeholders.
Barts Health NHS Trust	Full	general	general	**Background** At Barts Health NHS Trust, we provide care to a large number of children and young people with a range of chronic conditions across many specialties in medicine and surgery. Currently, there is variable practice between sites and specialties (and conditions within specialties) as to how transition is processed. This response to the draft NICE guideline focuses on the paediatric and adult gastroenterology departments at the Royal London Hospital site, which have a long experience of providing transition services to gastroenterology patients, particularly with Inflammatory Bowel Disease (IBD), hepatology and neurogastroenterology.	Thank you for your comment.

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Barts Health NHS Trust	Full	General	general	**Summary** We strongly support many of the NICE recommendations on transition services in the NHS. However, without a flexibility of practice for young people with a variety of different needs, we will continue to let down a group of patients. Poorly managed chronic illness at this critical time in education and training may have severe economic consequences on individual patients and society, beyond the immediate and long term health implications. We hope you will take this comments into consideration. **References** Goodhand, J., C.R. Hedin, N.M. Croft, and J.O. Lindsay. 2011. Adolescents with IBD: the importance of structured transition care. *J Crohns Colitis* 5:509-519. Heida, A., A. Dijkstra, H. Groen, A. Muller Kobold, H. Verkade, and P. van Rheenen. 2015. Comparing the efficacy of a web-assisted calprotectin-based treatment algorithm (IBD-live) with usual practices in teenagers with inflammatory bowel disease: study protocol for a randomized controlled trial. *Trials* 16:271. Henderson, P., R. Hansen, F.L. Cameron, K. Gerasimidis, P. Rogers, W.M. Bisset, E.L. Reynish, H.E. Drummond, N.H. Anderson, J. Van Limbergen, R.K. Russell, J. Satsangi, and D.C. Wilson. 2012. Rising incidence of pediatric inflammatory bowel disease in Scotland. *Inflamm Bowel Dis* 18:999-1005. Kamperidis, N., J.R. Goodhand, F.A. Chowdhury, Y. Koodun, N.C. Direzke, S. Naik, I.R. Sanderson, N.M. Croft, F.L. Langmead, P.M.	Thank you for your comment and support for the recommendations. While we reviewed some condition-specific evidence, the scope of this guideline was to establish the broad principles to follow with respect to care and support before, during and after transition. The group recognised the breadth of young people to be covered by the guideline, and the wide range of care and support needs they would have. Following review of stakeholder comments and discussion at Guideline Committee meeting 12, the group agreed on the importance of addressing the needs of young people with complex and multiple conditions more explicitly; to this end, recommendation 1.5.10 has been included to emphasise the importance of coherent, integrated provision. Recommendation 1.1.5 also references integrated working, indicating the potential use of joint mission statements and jointly agreed transition protocols and approaches to practice.

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				Irving, D.S. Rampton, and J.O. Lindsay. 2012. Factors associated with nonadherence to thiopurines in adolescent and adult patients with inflammatory bowel disease. *J Pediatr Gastroenterol Nutr* 54:685-689. Kennedy PT, Sandalova E, Jo J, Gill U, Ushiro-Lumb I, Tan AT, Naik S, Foster GR, Bertoletti A Preserved T-cell function in children and young adults with immune-tolerant chronic hepatitis B Gastroenterology. 2012 Sep;143(3):637-45.	
Barts Health NHS Trust	Full	4	10	**1. Scope of the Guideline** While we appreciate that the scope of this guideline has been set we feel it is important to raise this issue again. While some chronic illnesses are diagnosed early in life, others (such as IBD, non-alcoholic fatty liver disease) have their onset in adolescence (Henderson et al., 2012). This means that large numbers of patients are diagnosed in the adolescent period. While transition from paediatric to adult services is critical for these patients, so is the service available to those young people deemed too old at diagnosis for children's services (be that at age 16, older, or occasionally younger). Young people often have a more severe phenotype of disease than their older peers, and general adult gastroenterology/hepatology clinics may not be suitable environments for these patients, often still at secondary school and still growing, especially as growth and puberty can be delayed by such chronic diseases (Goodhand et al., 2011). We would therefore suggest strongly that while NICE	Thank you for your comment. Given the wide range of young people covered by this guideline, the scope of this guideline was to establish the broad principles to follow with respect to care and support before, during and after transition rather than to search for evidence on condition-specific interventions. The Guideline Committee did review all recommendations thinking about different cohorts of young people and considered the recommendations to be widely applicable.

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				may not be able to change the scope of this guideline, it does provide a stronger reflection on the needs of all young people accessing health services, not just those in a traditional transition process. In our experience, this age group often drop out of education and training, with long term consequences for them and a significant impact on society. This may be manifest in poor adherence, which we have demonstrated clearly is more prevalent in our young adult patients (Kamperidis et al., 2012) and is known to be associated with poorer healthcare outcomes. Clearly one of the more challenging issues around implementing many of the recommendations of this guideline are around funding, and in particular joint funding of services between departments. It is likely to fall largely on paediatric services to identify suitable adult services to form such agreements. These negotiations are, in our opinion, much more likely to be successful if there was a feeling of mutual benefit, in that if young adults were seen to receive some of the expertise and services available to those in transition. That is, if (in general, using health care as the example) children's services wish adult services to share some of the cost of providing high quality transition services, then children's services may do well to provide services to young patients who have never been in paediatric services. In our opinion this more flexible approach allows for much better integration between the services and provides a much better model for care.	
Barts Health NHS Trust	Full	10	1	While this draft guideline gives many useful recommendations and does mentioned how important it is to have a patient-centred approach, I think it needs to be even more clearly acknowledged that different departments and trusts need to be flexible to the	Thank you for your comment. The Guideline Committee considered the stakeholder comments at meeting 12 (05.11.15) and agreed that the existing over-arching recommendations on person-

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				specific needs of their patient groups and individual patients.	centred care (1.1.1 to 1.1.4) were sufficient for emphasising a person-centred approach. The Committee reviewed the wording of a number of recommendations at meeting 12 specifically to make clear that the detail of implementation would be aligned with local structures or practice, depending on the young person's needs, 'as necessary' - to reflect different services and contexts (for example, 1.1.4, 1.2.6, 1.2.8, 1.2.20)
Barts Health NHS Trust	Full	25	1	We wholeheartedly support the encouragement of research in this field. Given the age group in question, we wonder whether a specific recommendation in the research section on the use of new technologies could be included. Such studies are underway overseas in IBD (Heida et al., 2015) and in hepatitis B (Kennedy et al 2012). Outcome measures could include adherence, independent health decision making (from carers and/or medical teams), patient experience of care and improve overall health outcomes.	Thank you for your comment. Research recommendations can be made only where we searched for evidence and noted there to be gaps. We did not explicitly search for new technologies, as this was not within scope, so unfortunately cannot make a research recommendation in this area.
Barts Health NHS Trust	Full	33	10	We understand that in order to limit the large amount of poor quality data on transition services, the guideline has limited some of its evidence reviews to only systematic reviews, or those studies with obvious comparator group. This may have led to an underestimate of the issues in this patient group. For example, in the study mentioned above (Kamperidis et al., 2012), young people were compared to adult patients with the same condition, and this displayed some key differences in outcomes and highlights the need for specific management systems for this particular group.	Thank you for your comment. NICE guidance focuses on best available evidence hence this methodological decision. The Guideline Committee also brought a range of experience and knowledge, and research literacy, within which context they assessed the review evidence presented. The review team discussed pros and cons of methodological decisions with the Committee throughout the process.
Birmingham	Short	General	general	I feel this is easy to read and follow but the actual named worker needs more clarification. If this was a	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), more

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Community Healthcare Trust				nurse then guidance needs to be given about where the funding needs to come from. Teams for children in care for health are already over stretched and under funded so to take on this kind of work would be massive. It would however be a great and fulfilling role but the statutory guidance says we have a responsibility up to the age of 18 only so this would need to be changed so the service is commissioned properly. The age limit needs to be set also so again its commissioned for a service post 18 or should this increase due to the staying put agenda? If the services were commissioned properly it would be a great job to do as a nurse.	detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7).
Bracknell Forest Council	Short	General	General	Key audiences- CMHT, Education, adult social care and children's social care	Thank you for your comments. These audiences are considered in the guideline and may also be considered further as part of the work to support implementation.
Bracknell Forest Council	Short	General	General	Unsure if these recommendations will impact on a cost of service.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
Bracknell Forest Council	Short	General	General	Unsure what areas of these recommendations will/may lead to a cost implication.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
Bracknell Forest Council	Short	General	General	There may be potential coast savings, as budgets can be built in advance through well managed transitions.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
Bracknell Forest Council	Short	6	1	Transition starts at 16yrs with some one from adult services attending C.I.N or education reviews	Thank you for your comment which provides useful contextual information.
Bracknell Forest Council	Short	6	1	Reviews are six monthly and held by children's social care	Thank you for your comment which provides useful contextual information.
Bracknell Forest	Short	8	4 8	Attend the six monthly reviews, keep transitions on the	Thank you for your comment. The Guideline Committee reviewed the recommendations on timing

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Council				agenda. Fully part of the process with the young person.	and review (under section 1.2) at Committee Meeting 12 (04.11.15) and agreed the edited wording now found in recommendation 1.2.4.
Bracknell Forest Council	Short	11 8 6	5 22 20	Continuity of social workers for young people can be a challenge. Issues with timely adult service involvement Involving young people with learning difficulties in their transition can be challenging. No identified transition worker within children's services	Thank you for your comment. The Guideline Committee recognised that this may be associated with some implementation challenges for some services. However, they sought to make the recommendations aspirational but achievable. A very wide range of services and young people are covered by this guideline and therefore two appointments, as a minimum, was thought to be appropriate and feasible.
Bracknell Forest Council	Short	11 5	5 27	Continuity of transition worker/social worker. Transition planning starting at 14yrs, or based on individuals needs	Thank you for your comment.
British and Irish Orthoptic Society	full	General	General	From an Orthoptic point of view, and specifically for children with special needs liaison between parents, school and professional is key at transition time. Education of both carers and young people is essential to provide insight into the importance of eye health checks. This can be achieved as in my trust an Orthoptist visits Special Schools and provides this education and provides a "take home "leaflet. The young people themselves are therefore included in the process of self-care. Vision is essential and its loss can have fundamental effects on people who find it difficult or are unable to express any changes that they perceive leading to changes in personality for example aggression and or withdrawal.	Thank you for your comment. On review, the Guideline Committee agreed that reference to liaison with education practitioners needed to be strengthened in the recommendations, given: the critical importance of education sector professionals in supporting young people's development, health and wellbeing, and identifying problems early.To achieve this, the following recommendations now reference education explicitly: 1.1.4, 1.1.6, 1.2.6, 1.2.8, , 1.2.16 and 1.3.3. We have not referenced orthoptist visits specifically as the scope of this guideline was to establish the broad principles to follow with respect to care and support before, during and after transition, not to focus on specific health conditions. The guideline takes into account a person-centred approach which takes into account the needs of young people going through

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					transition.
British and Irish Orthoptic Society	Full	General	General	At my institution (tertiary paediatric centre) transition planning begins at age 12 years.	Thank you for your comment. The group considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are.
British and Irish Orthoptic Society	Full	General	General	The sharing of protocols for care between paediatric and adult services is crucial to the successful implementation of transition services. This needs to happen in a timely fashion some time before a patient is transferred so that the patient and family (if appropriate) is aware of any change in treatment or surveillance plan.	Thank you for your comment and your support for recommendation 1.1.5 which indicates that shared protocols may be useful.
British and Irish Orthoptic Society	Full	General	General	The sharing of examples of good practice would be very useful for any organization panning a transition service	Thank you for your comment which we will consider as part of our implementation work.
British and Irish Orthoptic Society	Full	General	General	The setting up of joint transition clinics between paediatric and adult services should not have a cost implication as the children will be attending a planned appointment, however, it will require cooperation between units to ensure that the appointments happen in a timely fashion and that appropriate staffing is provided.	Thank you for your comment which NICE will consider as part of their costing work to support guideline implementation and to inform implementation work. NICE welcome the opportunity to work with stakeholders to share learning.
British and Irish Orthoptic Society	Full	General	General	The provision of a named person for transition may not result in a cost increase, as it may be an existing member of staff.	Thank you for your comment which will be considered as part of the work to support guideline implementation. Following further discussion at Guideline Committee meeting 12 (04.11.15), we have also made clearer, in recommendation 1.2.6 and in the Definitions section, that the named worker is likely to be an existing member of staff, who may also be

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					already undertaking a coordinating role.
British and Irish Orthoptic Society	Full	General	General	From an Orthoptic point of view and for children with Special needs , a review process that is in place at transition time should include a request for a report on vision and ocular status and a request for attendance at the meeting by the eye health professional involved in that young person's care . This enables transferral of information about how vision impacts on everyday life and if any special conditions need to be addressed. For example a person with nystagmus may use a head position such as a face turn to achieve best vision. If this is not recorded then Physiotherapy could be employed to try and straighten up the head, leading to distress. A loss of visual field may mean that unless it is known and adapted for a young person may constantly not eat food on one side of a plate as it is not seen , but this may be put down to being full if the eye status is not known	Thank you for your comment. We have not referenced orthoptic-related interventions specifically as the scope of this guideline was to establish the broad principles to follow with respect to care and support before, during and after transition. The guideline takes into account a person-centred approach which takes into account the needs of young people going through transition The recommendation for a review meeting to discuss transition planning (1.2.4) emphasises the need to involve all practitioners providing support to the young person, and to involve the young person themselves.
British and Irish Orthoptic Society	Full	General	General	Many young people with learning difficulties attend high street opticians successfully, but for those who are unable to do this then having one person available to co-ordinate and be champion for them are essential. A gold standard approach ,will be to have one named person who is the Adult with Learning disability Liaison , for Ophthalmology In My trust an orthoptist has this role , this an ideal person as Orthoptists have significant eye knowledge and are in the best position to liase with eye staff within a hospital setting and the wider community . As an Orthoptists home visits can be undertaken and visual status determined with the best future management discussed.	Thank you for your comment. Following further discussion at Guideline Committee meeting 12 (04.11.15), we have made clearer, in recommendation 1.2.6 and in the Definitions section, that the named worker is likely to be an existing member of staff, who may also be already undertaking a coordinating role or particularly well-placed to do so.

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British and Irish Orthoptic Society	Full	16	18	Point 1.2.11 It is beneficial to link up patients and families of differing ages who have similar conditions – they often form their own networks (including social media) and can share experiences of transition	Thank you for your comment which was discussed at Committee Meeting 12. The wording of recommendation 1.2.14 has been updated to reflect the fact that peer support may include specific support groups or charities (which could be condition-specific). The Committee discussed young people's use of social media throughout development and agreed not to develop a recommendation on this specifically given the very wide range of young people this guideline covers and the risks associated with this platform for some young people in particular. Recommendation 1.2.14 also now includes a reference to the importance of moderating peer support to ensure safety and wellbeing of the young people involved.
British and Irish Orthoptic Society	Full	17	23	Point 1.2.19 It should be acknowledged that the child's preferences for their on-going care and their hopes for their future may differ from their parents	Thank you for your comment. The Committee recognised and agreed with this point. This was discussed in development and informed recommendation 1.2.20 and 1.2.21. Recommendation 1.2.20 makes explicit reference to the fact that the young person's preferences may differ from their parents'.
British and Irish Orthoptic Society	Full	19	12	Point 1.3.6 In addition to visiting adult services, we would recommend the development of joint transition clinics between paediatric and adult services so that children and young people have a seamless journey from one service to another. This could take place at the adult venue but still have the paediatric practitioners involved	The Guideline Committee did consider evidence on different models of provision for transition and agreed that while there were some examples of transition clinics working well, other approaches could also work well. There is, therefore, a recommendation on developmentally-appropriate provision (1.5.11) which, following discussion of stakeholder consultation comments, was updated to reference 'age-banded' clinics as one example of what such provision may look like in practice.

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British Association for Community Child Health	Short	4	14	Health and Social Care professionals are already stretched to their limits due to financial constraints. Additional funding will need to be provided to increase capacity in order for 'named workers' to be made available in supporting transition.	Thank you for your comment which NICE will consider as part of their costing work to support guideline implementation. Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). Specifically, you will note that we have made clearer this is a role not a job title and therefore could be undertaken by someone who is already fulfilling a role of keyworker, coordinator or transition support worker. The Guideline Committee were clear that this may not necessitate additional funding.
British Association for Community Child Health	Short	5	30	Current service models between adult and child services are rigidly aligned with age. This will be a major challenge to current service models and culture.	Thank you for your comments which will be considered as part of the work to support guideline implementation.
British Association for Community Child Health	Short	6	3	Transition planning and review in most areas are led by schools and education services. There is often little notice to health and social care professionals, making it difficult to attend such meetings.	Thank you for your comment. The Guideline Committee reviewed the recommendations on timing and review (under section 1.2) at Committee Meeting 12 (04.11.15) and agreed the edited wording now found in recommendation 1.2.4 which includes making clear that practitioners could take part in meetings via teleconferencing or video, recognising the pressures on people's time.
British	Short	8	25	A national model of a standard personal folder would be helpful.	Thank you for your comments which will be considered

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Association for Community Child Health					as part of the work to support guideline implementation.
British Association for Community Child Health	Short	9	24	This could be part of the 'Local Offer'	Thank you for your comment.
British Association for Community Child Health	Short	10	13	Is it realistic to expect GPs to be involved in transition process?	The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
British Association for Community Child Health	Short	12	3	Good idea but again unrealistic in implementation. If this is a serious proposal, more detailed 'job description' for these roles will need to be developed, with clear accountability arrangements, and will be part of CQC inspection items.	Thank you for your comment. The Guideline Committee considered the issue of ownership of transition carefully (recommendations 1.5.1 to 1.5.3) and reviewed these recommendations at Guideline Committee meeting 12 (04.11.15). The wording has been updated to make clearer how these roles would work and where accountability lies. Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level.
British Association for Community Child Health	Short	13	1	Who will be responsible for carrying out this gap analysis? Will need to specify.	Thank you for your comment which was discussed in Guideline Committee meeting 12 (05.11.15). We have amended the heading for this section to make it clearer that people planning services should carry out the gap analysis.

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British Association for Community Child Health	Short	14	1	Please give some examples of joint clinics. Also this will probably mean running clinics across different health providers, and there will be management challenges e.g. activities, income, administrative support etc.	Thank you for your comment. The evidence did not enable us to provide examples of joint clinic formats. Your comments on resource implications will be considered by NICE as part of their costing work to support guideline implementation.
British HIV Association	Full	General	general	BHIVA welcomes this guidance.	Thank you for your comment and support for the guidance.
British HIV Association	Full	General	general	Young people with HIV have particular needs and additional concerns regarding information sharing. Safeguards must be available to ensure confidentiality of their diagnosis and some aspects of this guidance means wider information sharing, which may not be in that young person's best interests. Consideration should be given to not disclosing the young person's long-term condition outside the healthcare team if it is not relevant, but pooled budgets may negatively impact this. They will still require a robust transition service and this should be at an appropriate pace, with some requiring a transition clinic into their early 20s.	Thank you for your comment. We have not referenced HIV-related interventions specifically as the scope of this guideline was to establish the broad principles to follow with respect to care and support before, during and after transition. This focus on broad principles rather than condition-specific interventions has been highlighted in the Equality Impact Assessment. Following discussion of stakeholder comments at Guideline Committee 12, however, we have made explicit reference to local information-sharing and confidentiality protocols in recommendation 1.1.7, recognising the importance and complexity of this. The group considered carefully whether or not to define an age threshold for transition (pre- and post-) and agreed on the importance of flexibility in this regard, recognising that the guideline covers a wide range of young people with a wide range of care and support needs.
British HIV Association	Full	General	general	An area of concern is where admission is required, with those over 16 being placed on adult wards. NICE should consider the role of adolescent units.	Thank you for your comment. The Guideline Committee did consider evidence on different models of provision for transition and agreed that while there were some examples of adolescent units working well, other approaches could also work well. There is, therefore, a recommendation on developmentally-

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					appropriate provision (1.5.11) which, following discussion of stakeholder consultation comments, was updated to reference 'age-banded' clinics as one example of what such provision may look like in practice.
British Kidney Patient Association	Short	General	general	The BKPA welcomes this guideline on transition for children and young people to adult services; our experience in supporting families with advice, information, counselling and grants and in supporting and/or funding multi-professional staff to deliver these services illustrates very clearly how variable practice is in the country. However we would like to see some more specific direction such as a statement that each service provider should develop and share a transition policy and make sure that it is consistent with that of other providers.	Thank you for your comment. The over-arching recommendation about integrated working (1.1.5) indicates that jointly agreed protocols and mission statements may be useful. The guideline sets out the broad principles rather than the specifics, which, given the breadth of services and young people covered by the guideline, will be implemented differently at the local level.
British Kidney Patient Association	Short	General	General	Q9: If transition planning is done well the risk of a young person losing their kidney transplant will be reduced by enabling regular shared management of the condition and increasing understand of the importance of medications to retain it; Low adherence increases morbidity and medical complications, contributes to poorer quality of life and an overuse of the health care system. The costs of dialysis compared with transplantation are high, at approx. £30k pa.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
British Kidney Patient Association	Short	6	11	Transition work is still appropriate for someone who does not start it until they are 16+ although of course it should be started much younger where possible. It should be made much clearer that **all** young people are entitled to be empowered about their needs and enabled to understand how to manage their condition, and the system. This is not just a transfer of a young person to someone's else's responsibility.	Thank you for your comment. The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are.

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					Young people who do not undergo transition are not in scope for this guideline.
British Kidney Patient Association	Short	7	15	The use of existing programmes where evidence and user feedback reflects that they are of use should be encouraged. The Ready Steady Go programme is one such example in use in a number of units. http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx	Thank you for your comment and suggestion of a relevant programme which could support implementation.
British Kidney Patient Association	Short	10	13	The GP should always be involved in the transition planning process for a young person in their practice.	The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
British Kidney Patient Association	Short	19	2	It is not only adult and children's services which will need to come together. There are just 13 renal paediatric units in the UK and they also need to come together to share practice. The BKPA is presently supporting the development of a transition network to do this. However the care of children with renal disease is not confined to the tertiary centre and many children live long distances from their tertiary centre and have care delivered by local services. Currently provision of care is not well joined-up across traditional organisational boundaries.	Thank you for your comment. The problem of disjointed services was raised and discussed by the Guideline Committee throughout development and a number of recommendations seeks to address this problem (in particular over-arching recommendation 1.1.3).
British Society of Gastroenterology	Full	General	General	Transitional care for multi speciality patients can be challenging with difficulties of not having one named worker that leads for transition and co-ordinates with all specialties. It would be helpful if the guideline would cover complex multi-speciality transition as a generic transition healthcare professional or even a youth worker who could provide the role of a transition co-ordinator may not be in post in many paediatric services. The need for such a co-ordinator for complex	Thank you for your comment. The Guideline Committee discussed this at their most recent meeting (04.11.15) in light of stakeholder comments. To address this, a new recommendation has been added (1.5.10) to emphasise the need for coordinated provision for young people with multiple conditions. The complex needs of this particular group of young people has also now been highlighted explicitly in recommendation 1.2.7.

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				multi-speciality patients is immense and may need engagement with commissioning bodies.	
British Society of Gastroenterology	Full	General	general	There is an ongoing study (nearing completion) at Sheffield looking at illness perceptions of Young People with Inflammatory Bowel Disease and how these change over time and explore experiences with transition	Thank you for your comment and this reference. NICE guidelines are reviewed after two years and, where appropriate, updated in the light of any new evidence which was not published in time for inclusion in the original guideline.
British Society of Gastroenterology	Full	general	General	1. The main areas in gastroenterology relevant to this guideline is Inflmmatory bowel disease and Liver transplant. Unfortunately apart from the study below there is very little data on the impact of a structured transition programme in IBD and the practice guidleines are based on mainly expert views. There is a further ongoing study in the UK in IBD trnasition 2. The adolescent and young persions section of British Society of Gastroenterology has just finalised its transition consensus guidelines in IBD (due to be published soon) 3. There are a few well established transition and /or adolescent clinics in gastronertology in UK with last survey reporting less than 25% services providing this 4. The models of transition in gastroenterology vary and in some areas it will be difficult to have a joint clinic where both paediatricians and adult team is available. 5. There is wide difference in the number of pediatric gastroenterology centres and clinicians and adult gastroenterology 6. Apart from large centres with big cohorts of patients to establish as regular transition clinic s will be challenging. 7. Named key worker (eg: specialist nurse) would be ideal but has resources implications as only	Thank you for your comment. The Guideline Committee did consider evidence on different models of provision for transition and agreed that while there were some examples of adolescent units working well, other approaches could also work well. There is, therefore, a recommendation on developmentally-appropriate provision (1.5.11) which, following discussion of stakeholder consultation comments, was updated to reference 'age-banded' clinics as one example of what such provision may look like in practice. Throughout guideline development, the Committee recognised that the guideline needed to cover a wide range of young people with a wide range of care and support needs. They agreed, therefore, that there should be some flexibility so that recommendations can be applied appropriately taking into account the local context. In respect of the named worker, following further discussion at Guideline Committee meeting 12 (04.11.15), we have made clearer, in recommendation 1.2.6 and in the Definitions section, that this person is likely to be an existing member of staff, who may also be already undertaking a coordinating role or particularly well-placed to do so.

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				70% of the adult inflammatory bowel disease teams in the country have a specialist nurse and often they are stretched due to other commitmments. 8. There is very limited training available among adult gastroenterologists fr adolescent health and a section to highlight the basic requirements for care givers would be useful. 9. In a given NHS trust specialities may need to share resources to avoid duplication of implementing tranasition 10. Use of IT and Social media in relation to transition and adolescent care particularly in those with Chronic GI disease needs exploration References: 1. Evaluation of Outcomes in Adolescent Inflammatory Bowel Disease Patients Following Transfer From Pediatric to Adult Health Care Services: Case for Transition. Cole R, Ashok D, Razack A, Azaz A, **Sebastian S**. J Adolesc Health. 2015 Aug;57(2):212-7. doi: 10.1016/j.jadohealth.2015.04.012.PMID:26206442 2. The requirements and barriers to successful transition of adolescents with inflammatory bowel disease: differing perceptions from a survey of adult and paediatric gastroenterologists. Sebastian S, Jenkins H, McCartney S, Ahmad T, Arnott I, Croft N, Russell R, Lindsay JO. J Crohns Colitis. 2012 Sep;6(8):830-44. doi: 10.1016/j.crohns.2012.01.010. Epub 2012 Feb 24.PMID:22398082	The use of IT and social media was discussed as part of guideline development based on the evidence that emerged in this respect. The Committee recognised the potential for some benefits but also highlighted associated risks. The group, therefore, suggested some IT-based solutions as examples of how support could be provided based on evidence available and their consensus views (1.2.10, 1.2.11 and 1.3.4).

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				3. Houston Y, Lindsay JO. Jenkins H, McCartney S ,Ahmad T, Arnott I, Croft N, Russell R, **Sebastian S**. Perspectives of Transition Care in Inflammatory Bowel Disease: A Survey of Inflammatory Bowel Disease Nurses. J of Gastrointest Nur 2013; 10(1) 7-11)	
British Society of Gastroenterology	Full	15	8	If the named worker is a health professional, it may be difficult to support the young person for a long period after transfer as this can cause confusion about medical responsibility and this clarity of responsibility is vital for the YP.	Thank you for your comment. The wording of recommendation 1.2.6 has been updated to make clear that the named worker will be appointed 'depending on the young person's needs'. The types of practitioners listed are examples as the guideline seeks to allow flexibility at the local level in terms of implementation. This flexibility might include the development of jointly agreed and shared protocols and approaches to practice (as suggested in recommendation 1.1.5) to ensure clarity of roles and responsibilities within the context of integrated working.
British Society of Gastroenterology	Full	18	5	If a YP is being transferred to an adult service across a wide geographical area then it may not be possible for anyone from the adult service to come to the paediatric service to meet with the YP pre-transfer (alternating appointments however could be set up with the adult and then paediatric service before eventual transfer) . Paediatric units often transfer care to adult services across a wide geographical area and it may not be logistically possible to set up joint clinics with every adult service they transfer to	Thank you for your comment. The Committee recognised the difficulties with out-of-area service use and also the very wide range of young people covered by this guideline. This particular recommendation (1.1.5) therefore provides examples of how meeting with adult services pre-transfer could be achieved, but the list is not intended to be exhaustive and there are other examples, such as the alternating appointments you propose.

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British Society of Gastroenterology	Full	20	8	If the YP does not engage with the adult healthcare services then referring back to the named worker who could have been a health professional in a paediatric service may again cause confusion around medical responsibility for the YP. It may be good to consider involving the primary care practitioner in such circumstances earlier in the process of transition if this can be anticipated or subsequently if not.	Thank you for your comment. The Guideline Committee discussed the role of primary care – specifically GPs - in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).). The intention is that the recommendations set out the broad principles, but the detailed implementation work will vary, depending on the local context.
British Society of Paediatric Gastroenterology, Hepatology and Nutfition (BSPGHAN)	Full	General	general	1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why. a) For neurologically handicapped children / children who require a guardian with coexisting conditions affecting gastroenterology (e.g. GI motility), liver, nutrition (e.g. PEG feeding). b) Different age arrangements cor children with various problems e.g. gastroenterology, endocrinology, nephrology, rheumatology. In our experience these specialties keep children much longer under their care as they have less success to implement earlier transition, but there are usually higher service pressures on children under gastroenterology, hepatology and nutrition. c) Lack of psychological or physiotherapy support. In adult care.	Thank you for your comments. The Implementation section of the guideline contains some detail about how some of the challenges can be overcome. Please see in particular the section on improving frontline practice with young people through training in developmentally appropriate health and social care, and person-centred practice In addition, there is specific reference to the need to pay particular attention to the post-transfer support available for young people with neurodevelopmental disorders (1.5.8), and, following consultation, there is also now explicit reference to age-banded clinics as one example of an approach to delivering developmentally-appropriate services (1.5.11).
British Society of Paediatric Gastroenterology, Hepatology and	Full	General	general	2. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.) Using existing pathways for established transition	Thank you for your comment. Throughout development, the Guideline Committee referenced the importance of building on existing local structures where these were working well. This can be seen, for example, in recommendations 1.1.7 and 1.5.5.

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Nutfition (BSPGHAN)				services e.g. for patients with IBD, liver disease, polyposis, ?coeliac disease, to extend transition pathways to other services.	
British Society of Paediatric Gastroenterology, Hepatology and Nutfition (BSPGHAN)	Full	General	general	3. What are the key audiences we need to consider in structuring the guideline? Patients support groups, national medical and surgical societies, dieticians and other health professionals.	Thank you for your comment. We have made explicit reference to condition-specific groups and non-statutory services in recommendation 1.2.13. We have not listed all condition-specific or specialist practitioners given that the guideline covers a wide range of young people with a wide range of care and support needs.
British Society of Paediatric Gastroenterology, Hepatology and Nutfition (BSPGHAN)	Full	General	general	4. At what age does transition planning start now? Planning starts age 12-14, implemented age 16-18 (aim for 16 years in most centres – but with some centres having excellent services for transition at older age, when funded and resourced).	Thank you for your comment and feedback on current transition planning practice. Recommendations related to the age of transition were reviewed as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15) and it was agreed that the draft wording in 1.2.1 remained appropriate as allowed practitioners some flexibility to start planning earlier than age 13 or 14, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are.
British Society of Paediatric Gastroenterology, Hepatology and Nutfition (BSPGHAN)	Full	General	general	5. How often do review meetings happen at present? Aim for annual review – depends on local service structure to run designated specialist clinics with annual proforma.	Thank you for your comment and feedback on review meetings. The Guideline Committee reflected on this comment in Committee Meeting 12 (04.11.15) and agreed to keep this recommendation (1.2.2) but have added wording to clarify that practitioners may not need to attend in person. They could feed in 'via conferencing or video'. As with all the recommendations, they agreed this was aspirational but achievable.
British Society of	Full	General	general	6. How should parents be involved in transition planning?	Thank you for your comment. Recommendations related to parental involvement were considered again

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Paediatric Gastroenterology, Hepatology and Nutfition (BSPGHAN)				Quastionnaires, invited meetings. Patient support groups.	as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
British Society of Paediatric Gastroenterology, Hepatology and Nutfition (BSPGHAN)	Full	General	general	7. Will these recommendations result in an impact on cost of services? Yes. In most centres experience, transition clinics are not fairly funded, often remunerated at the centre conducting the clinic (mainly the adult centre). The funding of these complex clinics should be fairly split, and if the best outcome of the child was to remain under paediatric care, the service would need adequate funding and resourcing of staffing levels (e.g. psychologist, young people job roles).	Thank you for your comment. NICE consider stakeholder comments on likely costs as part of its resource impact assessment and implementation work to support the guideline's implementation. The focus of the recommendations is on ensuring developmentally appropriate care and support as a principle, rather than on specifying particular models of transition support. This is because the Committee concluded that different approaches could deliver positive outcomes, and therefore that the ways of working were likely to be more important to make recommendations on than the structure. The Committee also agreed that specifying the principles - rather than asking people to implement entirely new service delivery models - also helped ensure recommendations would not have a significant cost

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					impact. Stakeholder comments indicated that age-banded clinics were one useful and commonly accepted way of delivering developmentally-appropriate care and therefore these were included as an example, post-consultation.
British Society of Paediatric Gastroenterology, Hepatology and Nutfition (BSPGHAN)	Full	General	general	8. Which of these recommendations would lead to additional costs? Presence of several professional in clinic simultanesously. Signifiant additional time for comprehensive letter, preparation of folder of patient data for transition meeting, transfer of imaging documents, travel costs.	Thank you for your comment. The Committee did consider cost implications throughout development. In particular, while they noted some stakeholders' could perceive there to be additional costs associated with attending an annual review meeting (1.2.4) they still considered this to be an acceptable and achievable recommendation. This was on the basis that: integrated transition planning - involving all practitioners involved in delivering support - was seen as important and helpful; and, that (post-consultation) the recommendation references use of teleconferencing or video to minimise costs associated with taking part.
British Society of Paediatric Gastroenterology, Hepatology and Nutfition (BSPGHAN)	Full	General	general	9. Will any of these recommendations lead to cost savings? Prevention of unnecessary admissions, shortening of hospital stay in adult centre due to transfer of essential information. Optimisation of medical treatment at time of transfer. Prevention of unnecessary repeat investigations (endoscopy, imaging, complex blood tests).	Thank you for your comment. The Guideline Committee was mindful of potential costs, benefits and resource use when making recommendations.
British Society of Paediatric Gastroenterology, Hepatology and	Full	12	5	We believe that the term " young people" used by NICE is not appropriate to meet patients' requirements and reflecting their age and maturity. We suggest to use the term "children" for the age of 0-15 years and young people for 16-35 years. Accordingly there	Thank you for your comment. This was discussed at Guideline Committee meeting 12 and the Committee agreed to keep the term 'young people'. We included a range of literature from health, social care and education and therefore other age thresholds applied,

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Nutfition (BSPGHAN)				should be representation from both children and young people.	and also considered a number of definitions of this term.
British Society of Paediatric Gastroenterology, Hepatology and Nutfition (BSPGHAN)	Full	12	15	The views and needs from children (1-16) and young people (16-25) need to be taken into account. This applies to the whole document.	Thank you for your comment. The Committee emphasised throughout development the importance of ensuring the young person is at the centre of their care and support and involved throughout. This is referenced explicitly in recommendations 1.1.1, 1.1.4, 1.2.4 (which was updated to this end, following discussion at Guideline Committee meeting 12), 1.2.10 and 1.2.19. A number of other recommendations reflect the need to ensure young people are sufficiently informed about their care and support (for example, recommendations 1.2.7, 1.2.13 and 1.3.4) and supported to express their views (for example, recommendations 1.2.10, 1.2.11 and 1.3.3).
British Society of Paediatric Gastroenterology, Hepatology and Nutfition (BSPGHAN)	Full	15	21 -22	We agree with NICE that the point of transfer should not be rigid, but we believe that NICE should provide a realistic time frame as a guide for paediatricians, adult doctors, and other health professionals. We believe that for many children the age of 16 years would be appropriate. For medical reasons, development/maturity or educational reasons, the transition may be better postponed between the age of 16-18 years. For children with significant developmental needs or hereditary conditions not commonly seen in adult medicine there should be an active process from adult services to provide the appropriate setting to facilitate transition, as the resources of paediatric services are limited but financially and with staffing levels. Some centres may be better staffed/resourced and may be able to provide service longer for young people, whereas other service providers may not have those resources and lack of transition may results in inadequate longer waiting times for younger children to be managed in the	Thank you for your comment. The Guideline Committee considered carefully whether or not to provide a time frame and agreed that this will vary considerably. It is for this reason that they decided it was not appropriate given the very wide range of young people the guideline covers. It is intended that the guideline provides the broad principles for care and support while allowing flexibility in terms of implementation at the local level.

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				paediatric service if transition occurs too late for some conditions.	
Carers Trust	Full	general	general	The draft guidance identifies young carers as a group that should have their support needs considered during transition. It contains some general principles that will support young carers alongside other young people in transition. However, in a number of areas young carers' needs are not recognised or the guidance may perpetuating gaps in support for this particular group. The following detailed comments suggest areas where young carers' needs are not adequately addressed in the guidance or the guidance could exclude young carers from sufficient transition support.	Thank you for your comment. Following discussion about this point at Guideline Committee meeting 12, we have added in reference to young carers' caring responsibilities in one of the over-arching recommendations (1.1.2).
Carers Trust	Full	general	general	The guidance does not refer to evidence about what works for young carers and young adult carers in terms of support at transition. There is evidence available about the demographics of young carers and young adult carers, their needs and resources for professionals. These are referred to in this submission and further information can be provided on request. Also young carers and young adult carers tell us what support they want for transition.	Thank you for your comment. Given the wide range of young people covered by the guideline, we did not search for very specific evidence on sub-groups of young people. The focus of this guideline was to establish the broad principles to follow with respect to care and support before, during and after transition. Following discussion about stakeholder comments at Guideline Committee meeting 12, the Committee agreed that young carers were an important group to reference, and therefore they have been highlighted explicitly in one of the over-arching recommendations (1.1.2).
Carers Trust	Full	general	general	Consider including recommendations for practitioners to involve young carers where transition planning is taking place for a sibling, so that their voice is not ignored within the process and so that their caring role is formally acknowledged and considered. This is an important opportunity to take a whole-family approach and consider whether the young carer has had their needs assessed.	Thank you for your comment. Given the wide range of young people covered by the guideline, we did not search for very specific evidence on sub-groups of young people. The focus of this guideline was to search the literature for evidence that would enable us to establish the broad principles to follow with respect to care and support before, during and after transition. We did not, within this literature, find evidence to inform a recommendation about the role of young carers when siblings are in transition.

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					Following discussion about stakeholder comments at Guideline Committee meeting 12, the Committee agreed that young carers were an important group to reference, and therefore they have been highlighted explicitly in one of the over-arching recommendations (1.1.2) as well as in 1.2.7.
Carers Trust	Full	general	general	Carers Trust can provide information on good practice examples of transition support for young adult carers, developed by services in the Carers Trust Network. There are gaps in the evidence about the most effective approaches for transition support for young carers and young adult carers. However, we know from young carers and young adult carers what support they want for themselves and the people they care for. Evidence and good practice examples relevant to this guidance but not included in the current literature review are: - Audit Commission (2010), 'Against the Odds'; London: Audit Commission. - The Children's Society (2013) Hidden from view: The experiences of young carers (London, The Children's Society). - ADCS, ADASS, The Children's Society and Carers Trust (2015) No wrong doors: working together to support young carers and their families - Practice resources from Carers Trust: https://professionals.carers.org/young-carers-transition - Resources from SCIE http://www.scie.org.uk/care-act-	Thank you for your comment. We did not, within this literature, find evidence to inform a recommendation about transition support for young carers specifically. Following discussion about stakeholder comments at Guideline Committee meeting 12, the Committee agreed that young carers were an important group to reference, and therefore they have been highlighted explicitly in one of the over-arching recommendations (1.1.2) as well as in 1.2.7. The following listed references do not meet our inclusion criteria. They were excluded either on the grounds that the methods reported were not sufficiently detailed, they did not directly respond to our research questoins or that they were not research studies: - Audit Commission 2010 - Children's Society 2013 - ADCS, ADASS, The Children's Society and Carers Trust 2015 - Practice resources from Carers Trust The SCIE Young Carer Transition paper was included.

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				2014/transition-from-childhood-to-adulthood/young-carer-transition-in-practice/index.asp	
Carers Trust	Full	3	21 -26	Young carers should be added to the list of groups at risk of falling into service gaps. Evidence shows the lack of support for many young adults with caring roles and the particular pressures on this group to increase their caring role. They face risks during their transition to adulthood, including their access to education, mental health problems and opportunities to build autonomy. This has been referenced in the NHS England Model specification for children and adolescent mental health services, which identifies young carers and young adult carers as a group needing targeted support during transition periods. It classes them as a vulnerable group. See further research and guidance on this group in: Becker, F. and Becker, S. (2008) Young Adult Carers in the UK: Experiences, Needs and Services for Carers aged 16-24. London: The Princess Royal Trust for Carers http://static.carers.org/files/1738-yac-report-3846.pdf Alexander, C (2014) Time to be Heard: A Call for Recognition and Support for Young Adult Carers (London: Carers Trust) http://www.carers.org/timetobeheardreport Association of Directors of Adult Social Services (ADASS) Carers Policy Network (2015) The Care Act and Whole-Family Approaches http://www.local.gov.uk/documents/10180/5756320/The+Care+Act+and+whole+family+approaches/080c323f-e653-4cea-832a-90947c9dc00c	Thank you for your comment. Following discussion about stakeholder comments at Guideline Committee meeting 12, the Committee agreed that young carers were an important group to reference, and therefore they have been highlighted explicitly in one of the over-arching recommendations (1.1.2) as well as in 1.2.7.

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				ADCS, ADASS, The Children's Society and Carers Trust (2015) No wrong doors: working together to support young carers and their families http://www.local.gov.uk/documents/10180/11431/No+wrong+doors+-+working+together+to+support+young+carers+and+their+families/d210a4a6-b352-4776-b858-f3adf06e4b66	
Carers Trust	Full	6	14 -18	We welcome the reference to the Children and Families Act and the stronger rights for young carers and their families. The guidance should also refer to the right for young carers to receive a transition assessment, contained in the Care Act 2014 and the accompanying Care and Support Statutory Guidance. The Care Act ensures creates a duty on local authorities to provide a transition assessment to young carers. This is similar to an assessment under the Children and Families Act, so, the local authority has to ask who should be involved in the assessment, and there are rules about what the assessment should cover. The assessment should consider how to support young carers to prepare for adulthood and how to raise and fulfil their aspirations. This includes supporting young carers to think about their own outcomes and aspirations, and how they might fulfil their own potential in education, employment and life. There is a duty for the local authority to discuss plans for further and higher education with the young carer, and the local authority should contact higher education institutions so they are aware that the applicant/new student is a young adult carer. See more details in this briefing: http://www.carers.org/sites/default/files/new_rights_for_young_carers_young_adult_carers_and_their_familie	Thank you for your comment. The Committee recognised that, given the breadth of the guideline, there is a very wide range of legislation and policy relevant to the groups and services it covers. The references to legislation within the recommendations, therefore, were not intended to be comprehensive; rather, they were to help clarify how particularly recommendations built on current statutory requirements. The Committee were also mindful not to repeat the provisions of existing legislation. Following discussion about stakeholder comments at Guideline Committee meeting 12, the Committee agreed that young carers were an important group to reference, and therefore they have been highlighted explicitly in one of the over-arching recommendations (1.1.2) as well as in 1.2.7.

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				s_mar_15.pdf See Carers Trust rights guide for young carers and young adult carers about their entitlement to assessment and support in their local area: http://www.carers.org/knowyourrights As indicated above Carers Trust believes that the needs of young carers and young adult carers require further explanation throughout the rest of the document. Practitioners would benefit from additional guidance on the particular needs of this group during transition.	
Carers Trust	Full	7	8	Add reference to young carers and young adult carers, as a group that experiences significant gaps in services.	Thank you for your comment. Following discussion about stakeholder comments at Guideline Committee meeting 12, the Committee agreed that young carers were an important group to reference, and therefore they have been highlighted explicitly in one of the over-arching recommendations (1.1.2) as well as in 1.2.7.
Carers Trust	Full	12	11	Care Act 2014 requires co-production, therefore the word 'considering' should be removed.	Thank you for your comments. 'Consider' has been removed from recommendation 1.1.1.
Carers Trust	Full	12	19 -20	We welcome the support for young people to include their family or carers, however, for this point to adequately consider the needs of young carers/young adult carers it should be reworded to say that transition support: Identifies the support available to the young person, which includes but is not limited to their family or carers and for young carers uses a 'whole-family approach'.	Thank you for your comment. Following discussion about stakeholder comments at Guideline Committee meeting 12, the Committee agreed that young carers were an important group to reference, and therefore they have been highlighted explicitly in one of the over-arching recommendations (1.1.2) as well as in 1.2.7. The Committee agreed that the young person should be supported within the context of their wider family and social networks; to this end, throughout the recommendations, there is reference to the need to address: - education and employment - community inclusion

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					- health and wellbeing including emotional health - independent living and housing options. These areas are included in recommendations 1.2.7,the Training section of the Implementation chapter, and in the definition of 'person-centred' ('Terms used in this guideline').
Carers Trust	Full	13	1 -3	In addition this point should make clear that the young person should be supported find support for the person they provide care to as a young carer, where relevant.	Thank you for your comment. Following discussion about stakeholder comments at Guideline Committee meeting 12, the Committee agreed that young carers were an important group to reference, and therefore they have been highlighted explicitly in one of the over-arching recommendations (1.1.2). Recommendation 1.2.7 references the need to identify 'appropriate support' which could include support for the person they care for.
Carers Trust	Full	13	5 -7	The point about relevant outcomes should include those relating to family relationships and impact of any caring role on the young person's wellbeing.	Thank you for your comment. It was not possibly to list all relevant outcomes and therefore the Committee agreed to the four broad categories of outcomes – listed below - which feature throughout. These were intended to cover family relationships and any caring responsibilities: - education and employment - community inclusion - health and wellbeing including emotional health - independent living and housing options. These outcome areas are included in recommendations 1.2.8,the Training section of the Implementation chapter, and in the definition of 'person-centred' ('Terms used in this guideline').

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Carers Trust	Full	13	11 -14	Suggest adding a reference to liaising with professionals who may work with and support the young person outside the educational sector, for example young carer workers based at carers' organisations. Young people have a right to involve people who can provide additional information for the transition assessment process, which may include those outside the educational sector or some from their family life or network.	Thank you for your comment. Given the breadth of the guideline, it would not be possible to list every type of worker that is likely to be involved in transition support. The Committee therefore used the term 'practitioners' throughout, as a high-level term. These would include young carer workers based at carers' organisations and others who may support them by providing information, or in another way.
Carers Trust	Full	14	7	Suggesting adding point that there is a need to encourage aspiration, as stated in the Care Act 2014 Care and Support Statutory Guidance, chapter 16.	Thank you for your comment. The Guideline Committee considered the suggestion but, on reflection, agreed that the current wording of this recommendation was appropriate.
Carers Trust	Full	17	1 -6	The guidance should also refer to the need to build young people's autonomy in relation to their caring role. Support at transition can often be extremely helpful to young carers and their families to decide on the outcomes they will aim for and put in place plans to support changes to the caring role. This is often important in order for young carers and young adult carers to balance their caring role and key outcomes for education, employment and health.	Thank you for your comment. Following discussion about stakeholder comments at Guideline Committee meeting 12, the Committee agreed that young carers were an important group to reference, and therefore they have been highlighted explicitly in one of the over-arching recommendations (1.1.2) as well as in 1.2.7. The Committee recognised that the specific needs of a young person in their caring role will vary, hence the recommendations are worded to enable flexibility in terms of implementation.
Carers Trust	Full	17	18	There should be an additional paragraph as follows: Young carers and young adult carers have particular needs for support at transition and have new rights to an assessment at transition under the Care Act 2014. The transition approach should support young carers to prepare for adulthood and consider how to raise and fulfil their aspirations, including support for them to consider, apply for and attend higher education. For	Thank you for your comment. Following discussion about stakeholder comments at Guideline Committee meeting 12, the Committee agreed that young carers were an important group to reference, and therefore they have been highlighted explicitly in one of the over-arching recommendations (1.1.2) as well as in 1.2.7.

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				detailed recommendations see Chapter 16 of Care and Support Statutory Guidance https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/366104/43380_23902777_Care_Act_Book.pdf and guidance from SCIE http://www.scie.org.uk/care-act-2014/transition-from-childhood-to-adulthood/young-carer-transition-in-practice/index.asp	
Carers Trust	Full	17	20 -22	The guidance should include the following in addition: Young carers and young adult carers should have opportunities for both private discussions and discussion with family members where appropriate. They should be given opportunities to discuss their caring role, how it is changing or may change and what support would assist with that process. Care should be taken to ensure that the whole-family approach is not confused with joint assessments. The whole-family approach is required for local authorities supporting young carers and their family, whilst joint assessments are an optional mechanism for assessing the family's interconnected support needs. See Children and Families Act The Young Carers (Needs Assessments) Regulations 2015 for further details on how local authorities are required to have regard to the different opinions of young carers and family members. http://www.legislation.gov.uk/uksi/2015/527/pdfs/uksi_20150527_en.pdf	Thank you for your comment. Following discussion about stakeholder comments at Guideline Committee meeting 12, the Committee agreed that young carers were an important group to reference, and therefore they have been highlighted explicitly in one of the over-arching recommendations (1.1.2) as well as in 1.2.7. The need to ensure young people are given opportunity to raise concerns separately from their parents or carers is addressed in recommendation 1.2.21. This would include young people who are carers. The guideline covers a wide range of young people, not only those who will have joint assessments. The Committee were mindful not to repeat current legislation although the guideline should be interpreted within the wider legislative and policy context.
Carers Trust	Full	18	15 -21	Add to the list of topics that can be included in the personal folder: - Where appropriate, information about the person that the young carer carers for, the	Thank you for your comment. The wording of this recommendation is intentionally high-level as the content will vary considerably from one young person to another. There is scope, therefore, to include in this folder, information about a young person's caring role

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				history of support provided to the person they care for and unplanned admissions of the person they care for.	(and detail of the person they care for) if appropriate.
Carers Trust	Full	19	24 -26	Add guidance here that information should also be provided about alternative support for the person that the young person carers for.	Thank you for your comment. Given the very wide range of young people covered by this guideline, it was not possible to list all types of information that could be provided, hence the over-arching wording in the recommendation – 'what to expect from services and what support is available to them' which would cover the information you suggest.
Carers Trust	Full	19	27 -28	Add a reference to specialist carer services, in addition to specialist adult care services.	Thank you for your comment. This detail has not been added as the recommendation was informed specifically by evidence on young people who can 'fall through the gaps' between children's and adults' specialist health services.
Carers Trust	Full	21	1 -7	This list should include a bullet point referring to 'identifying and supporting young carers, young adult carers and their fmailies.	Thank you for your comment. It is intended that supporting young people within the context of their family arrangements is addressed by the over-arching outcome areas specified in this recommendation (and throughout) and the reference to 'supporting young people holistically' (see: details on training within the chapter on Implementation).
Carers Trust	Full	22	5 -10	Guidance should also recommend including young carers/young adult carers and parent/carers in the integrated youth transition forums.	Thank you for your comment. The Committee did not wish to be too prescriptive in this respect hence the wording 'people with a range of care and support needs'. They added in a reference to the need to 'link with existing structures where these exist' (recommendation 1.5.5). The focus of this recommendation was young people's involvement in particular, reflecting the evidence on ensuring young people can feed in at the strategic level.

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Carers Trust	Full	23	18 -26	The transition definition excludes young carers, which is not acceptable. It should include reference to young carers as a group to whom the transition process is relevant and the needs of young people with caring roles being addressed through the process. Add explanation of two further terms 'young carer' "young carer" means a person under 18 who provides or intends to provide care for another person) Children and Families Act 2014 17ZA (3) 'whole-family approach' 'The intention of the whole-family approach is […] to take a holistic view of the person's needs and to identify how the adult's [or child's] needs for care and support impact on family members or others in their support network' From paragraph 6.65 Care and Support Statutory Guidance. Issued under the Care Act. DH 2014	Thank you for your comment. The definition of transition reflects the scope and does not exclude young carers who otherwise meet the criteria for inclusion in the guideline in terms of their service use.
Carers Trust	Full	25	20 -22	We suggest that a reference to whole-family approach for families with young carers or young adult carers needs to be added here. Add to lines 20-22 on page 25: How are the best outcomes for young people during transition and in early adulthood achieved through a whole-family approach? To explain why this is important- Local authorities are required to use a whole-family approach to support young carers and their family in order to prevent and reduce excessive and	Thank you for your comment. Research recommendations can be made only where we searched for evidence and noted there to be gaps. We did not explicitly search for evidence on whole-family approaches so unfortunately cannot make a research recommendation in this area; however, this is encompassed within the broader research recommendation on the effectiveness and cost-effectiveness of different models of transition support.

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				inappropriate caring roles that have a negative impact on their wellbeing. The evidence base and resources available to support this approach need to be strengthened to direct professionals and commissioners towards the most effective approaches for young carers and their families.	
Carers Trust	Full	27 -28	general	We suggest including young carers and young adult carers as a special group for transition. Without appropriate transition support for young carers, young adult carers and their families, this group risk disengaging from services and isolation, educational disadvantage and poor mental health. For example, the guidance could include: Transition in special groups: young carers and young adult carers What is the most effective way of using a whole-family approach to support young carers, young adult carers and their families? Why is this important? Young adult carers face additional and complex considerations when transitioning into adulthood and establishing their independence. Many families do not have adequate support in place to enable the young adult carer to successfully develop and maintain their relationships, education or employment. There is a need for research to examine whole-family approaches and their use during transition to ensure that young adult carers are adequately supported, have good wellbeing and have their aspirations raised. This is particularly urgent as local authorities now have new duties to support young carers during transition and to use a whole-family approach.	Thank you for your comment. Research recommendations can be made only where we searched for evidence and noted there to be gaps. This was not such an area. This group are, however, likely to be covered by a forthcoming NICE guideline.

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Carers Trust	Full	62	21 -30	The guidance should refer to evidence relating to transition and young carers/young adult carers. The evidence detailed and the witnesses have not covered the key resources for this group so references have been added to this submission. Should further information be needed to address these gaps, Carers Trust could provide expert witnesses.	Thank you for your comment. It was not within the remit of the guideline to search for evidence on support for young carers per se; rather, we searched for evidence on young people making the transition from children's to adult health or social care services. Following discussion about stakeholder comments at Guideline Committee meeting 12, the Committee agreed that young carers were an important group to reference, and therefore they have been highlighted explicitly in one of the over-arching recommendations (1.1.2).
Carers Trust	Full	79	21 -25	We welcome the guidance making reference to the problems that carers and their families face with housing and benefits. Young adult carers tell us that this is an issue that affects their transition to adulthood, for example: • Challenges for moving away from the family home to attend a university because of losing Carer's Allowance which may be essential for the family budget. • Reluctance to move out of the family home because their presence is needed to provide care and they lack support to find out about or consider alternative care and support services. • The young adult carer taking up paid work with an impact on their school, college or university studies to support the family's finances • Young adult carers not participating in higher education because of the impact on their caring role on their educational attainment, aspirations and self-esteem. The Time to be Heard (2014) report from Carers Trust cites evidence that 24% of young adult carers in school said they could not afford to go to college or university,	Thank you for your comment. Following discussion about stakeholder comments at Guideline Committee meeting 12, the Committee agreed that young carers were an important group to reference, and therefore they have been highlighted explicitly in one of the over-arching recommendations (1.1.2).

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				while 41% were unsure. It would be helpful for the impact of housing and benefits on young adult carers to be mentioned within the guidance so that practitioners are aware of this issue and consider it within their plans for support.	
Children's Liver Disease Foundation	short	General	General	The age of transition planning is currently variable between units and professionals within units Our feedback suggests transition occurs at a range of ages between 15 years old up to 20 years old. The general feedback from both parents and patients is that they class transition at the stage the children's units say you need to move over to adults soon as opposed to the whole process whereby patients are being encouraged to take more control over their care. Some people stated that they don't class that as planning but merely being told what is happening with their care.	Thank you for your comment which provides helpful context. The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are.
Children's Liver Disease Foundation	Short	General	General	There is a subset of young people who bypass the transition stage. This occurs if they are referred straight to adult services between the ages of 16-18 because they haven't been ill or diagnosed with a liver condition until this age. Young people who have undergone this have described issues with this such as a lack of support, poor communication skills and a lack of understanding of young people. There needs to be additional support for children aged 16-18 who directly enter adult services.	Thank you for your comment which provides helpful context. The guideline covers only those situations where there is an actual transition. People going straight into adult services are not within scope.
Children's Liver Disease Foundation	Short	General	General	The frequency of review meetings is dependent on the unit responsible for care, the young people being seen and their circumstances. Feedback suggests that only some young people have review meetings as part of their transition process and that these may be part of their normal outpatient appointments rather than a separate appointment focussing on transition.	Thank you for your comment which provides helpful context. The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be

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				Some young people who provided feedback had no review meetings, some did not take part in a transition process.	considered as early as for those who are.
Children's Liver Disease Foundation	Short	General	General	Regardless of the involvement of the parent within the young person's transition process, the parent will still need individual consideration regarding their needs as they become less responsible for their child's health. Medical teams need to be mindful of the investment of parents into the child's care. It needs to be respected if young people would like their parents to continue to be involved in their ongoing care. Parents and young people indicated that there needs to be an option for parents to be involved in transition with the extent dependent upon the young person. This needs to be flexible. It was also suggested that parents may need separate support to the young person undergoing transition as it can be more worrying for parents than the young person themselves . Currently this is not always acknowledged. Over time some patients said that they may not need their parents to be involved as much but they would like it to be their decision when the time is right.	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
Children's Liver Disease Foundation	Short	General	General	There is no discussion of identifying disengaged young people pre-transition. It may be possible to identify those at risk of future disengagement in order to provide extra support throughout the transition process.	Thank you for your comment. The evidence on engagement focused on the post-transfer stage, hence this is reflected in recommendations; however, the need to ensure young people are involved in their care, able to access services and supported in the broadest sense (which may include tackling issues of disengagement) is reflected in recommendation 1.2.7.
Children's Liver Disease	short	General	General	There is a heavy focus on supporting young people pre-transfer; however, continued high level support may be needed post transfer according to the young	Thank you for your comment. The Committee agreed with this and the post-transfer recommendations (section 1.4) seek to ensure ongoing engagement, as

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Foundation				person's needs.	appropriate.
Children's Liver Disease Foundation	short	General	General	Having a named healthcare professional for 6 months pre transfer and 6 months post transfer may mean only one or two meetings taking place if patients have annual check-ups. This is therefore not going to benefit the young person.	Thank you for your comment. This time period (recommendation 1.2.9) relates to the length of time the Committee agreed it appropriate for the named worker to be involved, and not to transition planning which: - should start early 'from year 9 (age 13 or 14) at the latest (as indicated in recommendation 1.2.1s and 1.2.3) - should be developmentally appropriate (1.1.2, 1.2.3 and 1.5.11), and - should be reviewed annually (1.2.4) The focus on the longer-term nature of transition planning, and the person-centred approach to supporting young people seeks to deliver benefits to young people.
Children's Liver Disease Foundation	short	General	General	The challenges identified as a patient led charity are challenges for the services to meet and overcome. The challenges identified regarding collaborative care are not specific to transition but are wider challenges currently being addressed across the health and social care system.	Thank you for your comments. Please see the chapter on implementation which provides some practical examples of how challenges could be overcome.
Children's Liver Disease Foundation	short	General	General	The impact on the cost of services will be unit specific. It depends on the level of transition planning which is currently undertaken. We have relationships with a number of liver units around the country, even within one specialty there is wide variety in practice.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
Children's Liver Disease Foundation	short	General	General	As a charity representing children, young people, young adults with liver disease and their families we asked for feedback from a number of young people and their parents regarding the transition process. Additional Comments from respondents are included	Thank you for your comment which provides useful context. The Committee agreed that parental involvement is an important area for the guideline to address and can

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				here: - One parent stated that their child had no support through transition and the result was a difficult time when having their first few appointments in an adult service. - One young person was aged 19 and "slipped through the net" with no appointment for two years. - Others were very positive about the process when support was offered through a "transition day" with the chance for parents to chat and for young people to extend their knowledge. - Pre-transition clinic appointments were also positively discussed as an opportunity for young people to "do the talking" and prepare to take more responsibility. - One individual described how clinicians from the adult service were not knowledgeable on her condition as it is a childhood liver disease. - The inclusion of input from both children's and adults' services within the transition process is welcomed due to the risk of young people being missed or overlooked	also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision. The Committee also talked, throughout the development phase, about the importance of overlap between paediatric and adult services and this is now referenced explicitly in recommendation 1.3.1 which talks about joint appointments, joint clinics and paired practitioner working. The Committee also added explicit references to adult services throughout the guideline, to make clear where responsibilities for recommendations are shared (see over-arching recommendation 1.1.5 and recommendations 1.3.1, 1.3.2 and 1.3.4).

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				and falling out of the system.	
Children's Liver Disease Foundation	Short	1	5	We agree with key audiences identified. The guidelines are especially vital for those who take up the "key worker role" supporting young people through transition.	Thank you for your comment.
Children's Liver Disease Foundation	Short	6	11	Starting to plan transition at age 13/14 latest may be a challenge as our feedback suggests it usually happens at a later stage (when it does happen). This will require additional resources to provide additional support over a longer period of time.	Thank you for your comment which will be useful to inform work on guideline implementation.The Guideline Committee considered all recommendations aspirational but achievable, although recognised there may be implementation challenges in some cases.
Children's Liver Disease Foundation	Short	11	4	It is recommended that the young person should see the healthcare professional at least twice post transition. This may be a challenge to implement as our feedback suggests some young people with liver disease rarely see the same consultant twice at any point in their care. Despite this seeing the same healthcare professional only twice following transition may not be adequate for all young people post transition.	Thank you for your comment. The Guideline Committee recognised that this may be associated with some implementation challenges for some services. However, they sought to make the recommendations aspirational but achievable. A very wide range of services and young people are covered by this guideline and therefore two appointments, as a minimum, was thought to be appropriate and feasible.
Children's Liver Disease Foundation	Short	17	12	The predicted outcomes of training healthcare staff in topics related to transition and young people are vague. Training those who may come into contact with young people, especially within an adult setting is vital but the practicalities of this are unclear.	Thank you for your comment. There is a research recommendation on the effectiveness of different approaches to training on outcomes, as this was a significant gap in the evidence. This recommendation, therefore, was intended to map out the broad areas that training could usefully address. The Committee recognised that people's level of training and the content of training will depend on the role they undertake.
College of Occupational Therapists	Full	General	General	In response to key questions: 1. *Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.*	Thank you for your comment which will inform implementation work. The implementation section also discusses challenges and how to overcome them, in particular noting some practical ways of addressing the

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				The biggest impacts on practice will be: • the additional role of key workers where they are not funded or commissioned. • Required liaison between children's and adult services where no corresponding adult services exist. 2. *What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)* • 'Legislative teeth' around joint commissioning and pooled budgets. • Appointment of a coordinator or extended component of DCO/DMO role. 3. *What are the key audiences we need to consider in structuring the guideline?* • Young people • Professional bodies • CCG's • LA's • Council for Disabled Children. 4. *At what age does transition planning start now?* This varies greatly. Some areas are starting at year 9 in line with guidance from SEND code of practice and this is evolutionary, although good. Where a young person does not have an EHCP we would suggest that the quality of practice is very patchy with a strong element of 'panic' by key professionals involved. It is very much the case	issues related to joint working. The group considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are. We have referenced groups covered by legislation in footnotes to make clear how the guideline seeks to build on these. Recommendations related to review meetings were

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				that children drop off a precipice – especially for those with physical disabilities. 5. *How often do review meetings happen at present?* This also varies greatly. Occupational therapists have reported that they have not been involved in any cross organisational review meetings that were outside of the EHCP process. 6. *How should parents be involved in transition planning?* Parents/carers should be involved as early as possible in order to prepare for the very different scope and aims of adult services. It should also foster more of an independent management philosophy. Where appropriate, parental/carer involvement should also consider how much the young person wants them involved. Young people should be assumed competent from the first meeting. 7. *Will these recommendations result in an impact on cost of services?* Potentially yes – if there are pooled budgets – there may be management and administrative cost savings. However, given the significant pressures on most children's services currently it may be unlikely that significant savings could be made clinically. In accordance with the evidence presented, there will be savings due to a number of young people not relapsing or having increased	considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The only change was to make more explicit that all practitioners, young people themselves and their carers should be involved. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision. Your comments will also be considered as part of the work to support implementation of the guideline.

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				medical difficulties. However no evidence is apparent for transition between therapeutic services where we would suggest there is the biggest difference between children's and adult services. 8. *Which of these recommendations would lead to additional costs?* • Key worker roles. 9. *Will any of these recommendations lead to cost savings?* • Pooled budgets and joint commissioning. • Potentially shared appointments between medical staff for children's and adult services.	
College of Occupational Therapists	Full	13	16	The College is concerned that a joint mission or vision statement will not be sufficient to make meaningful changes to practice. Recommendations for joint commissioning and joint budgets are likely to have more meaningful outcomes.	The remit of NICE guidance is to identify 'what works'. It is then complemented by additional NICE support for commissioners.
College of Occupational Therapists	Full	13	18	We suggest that the recommendation for a named worker should be jointly decided between health and social care. This could include point 1.2.1 (page 14 lines 3-5) as an additional bullet point under 1.1.3.	Thank you for your comment which was discussed in Guideline Committee meeting 12 (05.11.15). Given the very wide variety of contexts in which this guideline will be implemented, the Committee agreed not to specify who should help the young person identify a named worker (recommendation 1.2.5).
College of Occupational Therapists	Full	14	7	Point 1.2.2 describes the named worker. As occupational therapists and physiotherapists work closely with young people they are likely to have the relationship, and will have the skills and expertise to support and ease the transition process. This point	Thank you for your comment. We have added in 'allied health professionals' to the list of example workers that could fulfil this role (see: recommendation 1.2.6 and 'Terms used in this guideline' section, 'A named worker').

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				could read as: • '*could be, for example, a nurse, youth worker or another health or social care practitioner (occupational therapists and physiotherapists)'*	
College of Occupational Therapists	Full	15	17	The document makes reference to the age of a young person when transition planning should commence (13 or 14). We suggest that this is made more prominent in the document. For example it could be included on page 13 as point 1.1.6.	Thank you for your comment. The Guideline Committee reviewed the whole set of recommendations and have now moved the section on 'Timing and review' (in which this recommendation features) up to the front of the overall section on 'Transition planning'.
College of Occupational Therapists	Full	17	11	The support required for the young person to manage their transition will not be sufficient with a further assessment process. Practical advice should be provided which includes relevant information about how to support their occupational performance and participation in home, school and community life. Information relating to their condition should also be available for the young person. This should be accessible such as through the use of web or app-based programmes.	Thank you for your comment. The Committee discussed the need to support the young person "as a whole", taking into account what they would like to achieve and how to promote participation, so far as possible, throughout guideline development. This informed the development of the four over-arching outcome areas referenced throughout, specifically: - education and employment - community inclusion - health and wellbeing including emotional health - independent living and housing options. The Committee intended that these cover various aspects of participation. T These areas are included in recommendations 1.2.7, the Training section of the Implementation chapter, and in the definition of 'person-centred' ('Terms used in this guideline'). The benefits of technology for supporting key aspects of transition are referenced in recommendations 1.2.10, 1.2.11 and 1.3.4.
College of	Full	17	19	It would be useful to suggest that children's services could promote independence in young people in	Thank you for your comment. The Committee discussed the need to support the young person "as a

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Occupational Therapists				preparation for transition.	whole", taking into account what they would like to achieve and how to promote independence, so far as possible, throughout guideline development. This informed the development of the four over-arching outcome areas referenced throughout, specifically: - education and employment - community inclusion - health and wellbeing including emotional health - independent living and housing options. It was the Committee's intention that these would include promoting independence, as appropriate. These areas are included in recommendation 1.2.8, the Training section of the Implementation chapter, and in the definition of 'person-centred' ('Terms used in this guideline').
College of Occupational Therapists	Full	20	1	In addition to the points raised in this section, we believe it is important to seek/include support or involvement of parents or carers when appropriate.	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in

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					recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
College of Occupational Therapists	Full	20	23	The training and development for staff should extend to the independent and voluntary sectors and housing sectors.	Thank you for your comment. The information about training that could usefully support the guideline (see: chapter on Implementation) references 'everyone working with children and young people' recognising that a wide range of practitioners, across voluntary and community and statutory sectors should be engaged.
College of Occupational Therapists	Full	21	7	We would suggest an additional bullet point for training recommendations as follows: • ***the importance of participation*** *in the community for health and wellbeing.* Participation is recognised by the World Health Organisation (2001) as one of the central domains in the International Classification of Functioning, Disability and Health. Participation is linked to health and wellbeing, and is considered vital for children with and without disabilities (Larson and Verma 1999, King et al 2003). <u>References:</u> King G, Law M, King S, Rosenbaum P, Kertoy MK, Young NL (2003) A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. *Physical and Occupational Therapy in Pediatrics, 23(1),* 63-90. Larson RW, Verma S (1999) How children and adolescents spend time across the world: work, play, and developmental opportunities. *Psychological Bulletin, 125(6),* 701-36.	Thank you for your comment. It was not possible to list every element of training; rather, the Guideline Committee sought to provide over-arching headings that cover the main aspects that training should cover. Participation was discussed and informed the reference to the young person's social development, and the need to support young people holistically, taking into account outcomes to be achieved in respect of community inclusion This is now referenced in the information about training within the chapter on Implementation.

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				World Health Organisation (2001) *International classification of functioning, disability and health*. Geneva: WHO.	
College of Occupational Therapists	Full	21	7	We believe that to promote the person-centred principles and culture changes which are advocated for in this document, that these elements should also be included in the training and development of staff.	Thank you for your comment. This is now referenced in the information about training within the chapter on Implementation.
College of Occupational Therapists	Full	21	20	Being a champion and being accountable for transitions are two different things which should be clarified or separated. For example, the senior executive should be accountable and the person undertaking the role of operational champion should be an advocate.	Thank you for your comment. The Guideline Committee considered the issue of ownership of transition carefully (recommendations 1.5.1 to 1.5.3) and reviewed these recommendations at Guideline Committee meeting 12 (04.11.15). The wording has been updated to make clearer how these roles would work.
College of Occupational Therapists	Full	21	26	To add transparency to the transition strategy, this should be published to ensure wider scrutiny.	Thank you for your comment. Thank you for your comment. The Guideline Committee considered the issue of ownership of transition carefully (recommendations 1.5.1 to 1.5.3) and reviewed these recommendations at Guideline Committee meeting 12 (04.11.15). The wording has been updated to make clearer how these roles would work and that the senior manager would be responsible for implementing, reviewing and monitoring the effectiveness of the transition strategy.
CORAM	Full	General	general	This response is being submitted on behalf of the CoramBAAF 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	Thank you for your comment. Looked after children are included in the guideline and were discussed explicitly throughout guideline development. The Committee were mindful not to repeat the provisions of existing legislation and the NICE guideline PH 28 Looked after children and young people and instead have

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				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.	referenced this, where appropriate (e.g. 1.2.18, 1.2.22)
CORAM	Full	General	general	In the view of some of our members, the guidance is too broad and overarching to be helpful.	Thank you for your comment. While we reviewed some condition-specific evidence, the scope of this guideline was to establish the broad principles to follow with respect to care and support before, during and after transition. The group recognised the breadth of young people to be covered by the guideline, and the wide range of care and support needs they would have. Following consultation, the Guideline Committee reviewed stakeholder comments and did make some edits to draft recommendations to make them more specific. These changes included: - making more specific reference to the role of the GP (e.g. in recommendation 1.2.4, 1.2.6, 1.2.7) - being clearer about how young people's communication needs should be supported (1.2.12) - strengthening the recommendations about parental involvement (e.g. 1.1.3, 1.2.4, 1.2.19, 1.2.20, 1.3.7)

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					- referencing the need to signpost to condition-specific support services in 1.2.14 - providing more detail about specific approaches to joint working between adults and children's services which may be useful (1.1.5 and 1.5.10 and 1.5.11).
CORAM	Full	General	general	The guidance would be strengthened by addressing the health and education plans in considerably more detail.	Thank you for your comment. The guideline seeks to build on, rather than replicate, what is in existing legislation. It therefore cross-refers groups of young people to education, health and care plans in footnotes (in recommendations 1.1.6, 1.2.1, 1.2.22 and 1.5.9) rather than addressing the content of these plans in detail.
CORAM	Full	General	General	Q1: With regard to looked after young people/care leavers, the areas of highest impact will be: • 1.1.3 Achieving truly integrated working – see point 3 above. • 1.5 Training and development of all professionals involved with transition planning, as they need to understand the needs of this complex and vulnerable group. This involves a large number of services and individuals and high quality training will require significant funding. • 1.2.3 The remit of the named worker is vast and it will require significant resources to offer this to each care leaver, but what most of them need is a strong and stable relationship with an individual who will take a personal interest, assist with practical support and advocate when needed. • 1.5.7 It is crucial to identify and address the	Thank you for your comment which will be considered as part of the work to support implementation of the guideline.

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				gaps in adult services, as it is well documented that care leavers have high rates of mental health difficulties, substance misuse, homelessness, pregnancy, etc and addressing these effectively will save money but most importantly improve their quality of life and their future prospects. • 1.6.11 these measures should assist with engagement of care leavers, which is crucial to uptake and outcomes of any service.	
CORAM	Full	General	General	Q2: There is a chapter on health practice for care leavers in this book, which could be usefully referenced: Merredew F and Sampeys C (2015) *Promoting the health of children in public care: the essential guide for health and social work professionals and commissioners*, BAAF: London.	Thank you for your comment. The reference would not meet the evidence criteria given that it is a book not a research paper. General support for young people was outside the remit of this guideline; rather, evidence was sought on the specific needs of young people in transition. The support needs of care leavers are addressed in the NICE guideline on Looked After Children and Young people.
CORAM	Full	General	General	Q3: The guidance should address commissioners in addition to those stated.	Thank you for your comment. The remit of NICE guidance is to identify 'what works'. It is then complemented by additional NICE support for commissioners.
CORAM	Full	General	General	Q4: Health promotion for looked after children at all ages and developmental stages should address issues relating to personal care, safeguarding, developing independence and assuming responsibility for their own health. Formal transition planning should start about ages 14 – 15 but is often left until later.	Thank you for your comment. The definition of 'person centred' care includes reference to supporting young people in the broadest sense, to include their health and wellbeing needs, and independent living. Following review of stakeholder consultation comments at Guideline Committee 12, recommendation 1.2.8 also now references explicitly the need to support young people holistically. The group considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year

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					9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are.
CORAM	Full	General	General	Q5: There is a statutory requirement for an annual review of health for all looked after children over five years of age.	Thank you for your comment. The guideline seeks to build on existing legislation rather than repeat it, hence we have not referenced explicitly all statutory requirements relevant to the wide range of young people the guideline seeks to cover.
CORAM	Full	General	General	Q6: There should be a comprehensive and sensitive discussion with a looked after young person concerning their wishes about involving their birth parent/s and carer/s in transition planning, and plans should be negotiated and agreed with them.	Thank you for your comment. Looked after young people's relationship with birth parents is addressed within the existing NICE guideline PH 28 Looked after children and young people. The Committee were mindful not to repeat the provisions of existing legislation and guidance.
CORAM	Full	General	General	Q7 and Q8: None of these recommendations is particularly new or surprising; it is the delivery of them which is challenging. High quality delivery of the recommendations will cost money as they require labour intensive joint working; engagement and relationship building with care leavers; consultation with parents/carers and care leavers; widespread training; and development of adult health services. Our members consistently report lack of capacity / resources as the biggest barrier to delivery of health services. There are many excellent LAC health services that know what needs to be done, but commissioning arrangements do not provide for sufficient time by health professionals with the appropriate competencies to meet service demands.	Thank you for your comment. The Committee recognised that the guideline's success will rely on effective dissemination and implementation. The remit of NICE guidance is to identify 'what works'. It is then complemented by additional NICE support for commissioners. The guideline does, however, make some recommendations about infrastructure (e.g. 1.5.7, 1.5.8, 1.5.10, 1.5.11)
CORAM	Full	General	General	Q9: Effective delivery of services / recommendations which support care leavers smooth transition to	Thank you for your comment which will be considered as part of the work to support the guideline's

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				adulthood will enhance outcomes in health, education and social functioning and ultimately save vast sums in all these services.	implementation.
CORAM	Full	General	General	It would be helpful to have the email address for return of comments on the comments form – as was previously the NICE practice.	Thank you for your comment. An email address should have been provided and NICE will check why this was not the case.
CORAM	Full	12	14	1.1.2 We welcome the principle of person-centred care which is developmentally appropriate and involves the young person's views and needs.	Thank you for your comment and support for the guideline.
CORAM	Full	13	11	1.1.3 We support the principle of integrated working as stated here but it must be recognised that developing a shared mission statement, protocols etc will require considerable investment of time and expertise by all concerned. This is difficult in the face of shrinking budgets and capacity in health and social care teams and should be addressed by the guidance.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
CORAM	Full	14	15	1.2.3 The role of the named worker has a vast remit and should be resourced accordingly. There is considerable scope for confusion when this role can be held by a social care or health professional or youth worker.	Thank you for your comment about the role of the named worker. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). Specifically, you will note that we have made clearer this is a role not a job title and therefore could be undertaken by someone who is already fulfilling a role of keyworker, coordinator or transition support worker.
CORAM	Full	15 16	21 28	1.2.7 and 1.2.14 While we agree that the point of transfer should ideally not be based on a rigid age threshold, in reality the current NHS structures dictate that paediatric services cease at age 18. This is quite	Thank you for your comment. This was something that was discussed throughout guideline development. The current recommendations aim to ensure practitioners do indeed develop more flexible approaches for young

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				problematic for paediatric practitioners and looked after young people leaving care as their needs are often poorly understood by adult health services, particularly mental health. Their needs could often most appropriately be addressed within youth services, but this is not accepted within the NHS, which adheres to rigid age bands. We would support a recommendation to the NHS to consider development of more flexible services for youth in transition. This would be particularly welcome for young people who have been looked after and often have limited supports, many of whom have developed a strong relationship with specialist nurses for care leavers and whose needs will not be recognised and appropriately addressed by adult services.	people in transition (1.2.1) and to make provision for young people who have reduced support when they reach adult services (1.5.5, 1.5.7 and 1.5.8).
CORAM	Full	18	11	1.3.3 We welcome this suggestion.	Thank you for your comment and support for this recommendation.
CORAM	Full	19	27	1.3.9 Following on from point 5, many care leavers do not meet thresholds for adult mental health services despite well recognised mental health difficulties. There is a lack of other relevant sources of mental health support and it can be very difficult to access those which do exist due to high demand or cost.	Thank you for your comment. The Committee recognised the need to ensure that young people with mental health needs do not "fall through the gap" between Child and Adolescent Mental Health Services and Adult Mental Health Services and, to this end, referenced them explicitly in recommendations 1.5.5 and 1.5.7.
CORAM	Full	22	21	We strongly suggest adding young people leaving care to this list, given the issues noted above.	Thank you for your comment. The Committee did not wish to be too prescriptive in this respect hence the wording 'people with a range of care and support needs' which could include young people leaving care. They also added in a reference to the need to 'link with existing structures where these exist' (recommendation 1.5.5) which, again, may include local forums for young people leaving care.

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CORAM	Full	23	9	1.6.11 These are good suggestions which should contribute to improved understanding of young people's needs by adult services, along with better communication between services, and improved engagement with young people.	Thank you for your comment and support for this recommendation.
Council for Disabled Children	Full	General	General	This guidance addresses a significant issue and presents a robust assessment of the current evidence, and we are broadly supportive of the recommendations.	Thank you for your comment and your support for the recommendations.
Council for Disabled Children	Full	General	General	The Evidence review provides an excellent account of the issues and challenges around children and young people's transition to adult services. A concise summary of these issues would be an excellent resource for a range of audiences.	Thank you for your comment and your support for the work. The NCC is currently considering the potential for complementary publications as part of its work to support implementation of the guideline.
Council for Disabled Children	Full	General	General	**Terminology**- The guidance uses the terms disabled young people and young person with disabilities interchangeable. For consistency the term disabled young people should be used throughout the document, reflecting the importance of the social model.	Thank you for your comment which was discussed at Guideline Committee meeting 12 (05.11.15). The term 'disabled young people' is now used throughout.
Council for Disabled Children	Full	General	General	and short **Recommendations**: Currently the recommendations are presented as a long list, with headline recommendation areas, individual recommendations within these areas, and bulletin point recommendations sitting underneath these. The result of this presentation means that the priority recommendations are not easily apparent, and the distinction between recommendations and supporting material A single, clear list of refined recommendations should be presented at the start of the document, with the more detailed elements presented subsequently, clearly arranges as supporting the overarching main recommendations.	Thank you for your comment. The Guideline Committee considered the structure and ordering of the recommendations carefully and are happy with the current presentation. A short version of the guideline is available which provides only the recommendations and details of implementation work.

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Council for Disabled Children	full	General	General	The requirement introduced by the Children and Families Act to publish and review a Local Offer requires it to include information on services for young people with SEN and disability up to the age of 25, and this should include information on local transition plans.	Thank you for your comment. The guideline seeks to build on, rather than repeat, legislation, and therefore the Committee agreed a number of recommendations on information provision for young people and their families (1.2.7, 1.2.13, 1.3.4, 1.3.7 and 1.3.8) which seek to go beyond statutory requirements.
Council for Disabled Children	full	General	General	For children and young people with the most complex health needs the move between Continuing Care for Children and Continuing Healthcare and Funding is a major element of their transition. This importance should be reflected in the guidance, with a recommendation that the development of transition plan must incorporate the development of a process to ensure a smooth transition between the two frameworks	Thank you for your comment. The Guideline Committee recognised the complexity of funding. Following discussion at Guideline Committee meeting 12 (05.11.15) the Committee added in recommendation 1.5.10 to emphasise the particular need to develop integrated approaches to support children with complex healthcare needs.
Council for Disabled Children	Full	General	General	And short Named Worker: While the principle of a named worker may be a positive one, it is not clear from the guidance how this role would or should work in practice, especially in relation to the type of transition the young person is making, and if the model should be adapted from exiting Key Working systems	Thank you for your comment. More detail has been added to make clear that this person may be the same as the keyworker (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7).
Council for Disabled Children	Full	10	General	The NHS Constitution contains specific rights and pledges relating to Transition that should be articulated at this point. NCB and CDC have published a guide to children and young people's experiences and views on the rights in the NHS Constitution. http://www.councilfordisabledchildren.org.uk/nhsconstitution	Thank you for your comment. A reference to the NHS Constitution has now been included in the Context section (pp4-5, full guideline).

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Council for Disabled Children	Full	12 /2	7 /20	And short Terminology: The use of the word consider in relation to coproduction may reflect the strength of the evidence relating to the effectiveness of the recommendation, but the statutory framework for the participation of children and young people requires NHS organisations to involve patients and the public in the development, considerations and decisions relating to decisions that affect them.	Thank you for your comment. 'Consider' has been removed from recommendation 1.1.1.
Council for Disabled Children	Full	13	general	1.1.3 The Children and Families Act places a duty on the Local Authority and partner CCG's and NHS England to establish formal Joint Commissioning Arrangements that set- this statutory duty should be reflected in the recommendations. The Children and Families Act also places a statutory duty on Local Authority and CCG's to integrate services where there is evidence this will lead to improved outcomes.	The remit of NICE guidance is to identify 'what works'. It is then complemented by additional NICE support for commissioners. The remit of NICE guidance is to identify 'what works'. It is then complemented by additional NICE support for commissioners.
Council for Disabled Children	Full	23	15	Young people at 16 should be the primary receiver of health information, and have access to the same rights of confidentiality as their peers. Where there is a need for this to share this information with social workers this should be carried out in line with Working Together to Safeguard Children Guidance and guidance on consent.	Thank you for your comment. The Committee agreed on the importance of ensuring young people have information, and recognised that information provision will take place within the context of existing guidance and legislation.
Council for Disabled Children	Full	171	general	1.5.4 The requirement of Local Authorities to ensure Independent Information Advice and Support Services to children and young people with SEN and disability and their families regarding education, health and social care services up to 25 should also be reflected in this recommendation.	Thank you for your comment. The guideline covers a wide range of young people and therefore there will be a wide range of legislation and guidance relevant, including that relating to information and advice. The Committee were mindful not to repeat current legislation although recognised that the guideline will be interpreted within the wider legislative and policy context.

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Council for Disabled Children	Short	General	General	The list of who is it for should include commissioners of children's and adult's health and social care services. The decisions about resource allocations made by commissioners will be one of the most significant influences on how this guidance is adopted in local areas. There are a number of duties in the Care Act 2014 and Children and Families Act 2014, that place requirements on commissioning bodies to make arrangements for the needs of children and young people, including their transition between children and adult services. These should be the basis of an explicit recommendation about the importance, visibility and content of transition planning within commissioning plans. Also **Recommendations** 1.5 about workforce development may make it appropriate to include Local Education and Training Boards as a listed audience.	Thank you for your comment. The remit of NICE guidance is to identify 'what works'. It is then complemented by additional NICE support for commissioners.
Council for Disabled Children	Short	General	General	A version of the complete guidance should be produced for young people and their parents and carers, setting out clearly what they should expect from their transition process. This should be co-produced and demonstrate the person centred principles set out in the guidance.	The Committee agreed that it will be important for people using services and their families to be clear about what this guideline means they should expect from services. NICE produce a version of the guideline for people who use services and the public.
Council for Disabled Children	Short	16	General	Impact and Challange- Joint responsibility and joint investment in transition, while this has been split into a number of separate challenges, they are so interlinked that to our thinking they represent the single ambitious and fundamental recommendation of this guidance. There will be significant challenges in driving this culture change in adult services, and the implications of this approach for young people who don't meet the	Thank you for your comment which will be considered as part of the work to support guideline implementation.

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				threshold for specialist adult services. GP's and Primary Care teams with have a key role but are currently the least invested in transition processes. If this is not considered then there is a danger of a widening gap 18between young people who are making a transition between specialist services receiving a jointly owned and funded transition process, and those transitioning form a children's specialist services to universal services which do not demonstrate the same level of ownership and investment.	
Council for Disabled Children	Short	19 -20	general	GPs. The guidance states on pages 19 and 20 that efforts should be made to involve GP's in the Transition process, especially where young people will not meet the criteria for adult health services, but the guidance does not make a clear recommendation about the requirements on GP's to take an active role in the transition process, and what that role should consist of.	The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
Council for Disabled Children	Short	23	28	Outcomes Measures: The importance of developing measures of "good transition planning" must involve children, young people and their families defining the outcomes that matter to them and how these support as healthy and successful adult life as possible. The Children's Outcomes Measurement Study (CHUMS) highlights the distinction between the priority outcomes of children and young people with neurodisability and their parents, and professional responsibilities http://www.journalslibrary.nihr.ac.uk/hsdr/volume-2/issue-15	Thank you for your comment. This research recommendation has been removed.
Crohn's and Colitis UK	Full	General	General	We welcome the opportunity to comment on this draft guideline. Our comments relate specifically to our knowledge of transition services for people with	Thank you for your comment and your support for this guideline. The Guideline Committee discussed a range of examples of variations in practice throughout

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				Inflammatory Bowel Disease based on the IBD Standards and evidence from the IBD Audit. There are at least 300,000 people in the UK with Inflammatory Bowel Disease (IBD), the two main forms of which are Crohn's Disease and Ulcerative Colitis. These are lifelong conditions which affect people of all ages, but commonly present in the teens and twenties. There is evidence of increased incidence, especially in young people. The impact of these unpredictable and potentially life-threatening conditions on education, work, social and family life can be devastating. There is no cure. The lifetime costs are comparable to diabetes and cancer. The IBD Standards were produced collaboratively by the leading patient and professional associations involved in Inflammatory Bowel Disease services and care. These are referred to in the recent NICE Quality Standard for Inflammatory Bowel Disease (QS81). Standard A12 states that: **There should be a written policy and protocol for transitional care. A named coordinator should be responsible for the preparation and oversight of transition (for example, an IBD Nurse Specialist).** The IBD audit benchmarks IBD services against the IBD Standards and covers a number of aspects identified within the draft NICE guideline. In terms of transitional care, the IBD organisational audit found that: • 47% of Trusts/Health Boards do not have a transitional care service for young people to support their transfer to adult services by 18-19 years	development. They agreed this guideline provides an opportunity to make care more consistent and also to improve the standard of care and support.

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				• For 55% of services, there is no named coordinator responsible for the preparation and oversight of transitional care, from child to adult services (e.g. IBD nurse specialist) • 54% of IBD services do not have a joint transition clinic with paediatric services • 35% of IBD services do not have a specific paediatric to adult transition policy • 58% of IBD services could not ensure that each young person with IBD had an individual transition plan There is a significant difference in provision in key areas such as psychological support between paediatric and adult IBD services. Therefore, a well-managed transition is especially important. It is hoped that this guideline will provide further support and incentive for appropriate transition planning and stimulate additional research in this area to guide future planning and provision. Sharing of good practice in condition-specific areas such as IBD, but also between services, where relevant, is likely to be an important in driving improvement. Given the value of digital support for self-management for this age group, there are likely to be cost advantages to developing learning and tools in a coordinated way. We would be pleased to provide any further information that may be helpful.	

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Department of Health	Short	General	General	I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.	Thank you for your comment.
Diabetes UK	Short	General	General	The draft guidance refers to involving young people which we strongly support. However, at all stages this must include all service users, not just those who are already engaged. Engaging the disengaged is will take different person centred approaches, flexibility etc. The guidance must also focus on the follow up of disengaged young people wherever they might be. This is a responsibility of both paediatric and adult services.	Thank you for your comment. The evidence on engagement focused on the post-transfer stage, hence this is reflected in recommendations; however, the need to ensure young people are involved in their care, able to access services and supported in the broadest sense (which may include tackling issues of disengagement) is reflected in recommendation 1.2.7.
Diabetes UK	Short	16-17	17 -19, 1-11	We recognise the importance of joint investment in transition services and that these should be prioritised for funding as a poor transition can have a significant detrimental effect on the health and wellbeing of a young person. However we feel that joint investment may be a particular challenge and that practical guidelines on how this could be achieved would be extremely useful.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
Diabetes UK	Short	2	20	We would like to see "consider" removed – transition policies should always involve input from young people and carers. When involving young people it is of the utmost importance that this includes all users of the service, not just those who are already engaged, to ensure that policies are appropriate to all. There must be a particular focus on involving those who are normally less involved/motivated as it will be these young people who are most likely to drop out of the system	Thank you for your comment. 'Consider' has been removed from this bullet in recommendation 1.1.1.
Diabetes UK	Short	3	5	We would like to see "consider" removed – young people should always be involved in producing materials as this helps make them appropriate to the audience	Thank you for your comment. 'Consider' has been removed from this bullet in recommendation 1.1.1.
Diabetes UK	Short	3	9 -29	We strongly support the focus on the young person as an individual and an equal partner in their care	Thank you for your comment and support.

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Diabetes UK	Short	3	24	We would like to see recognition that not all young people transitioning will be in school and that some may be working. Policies must therefore be flexible enough to ensure that working young people can access transition services, for example outside normal working or school hours	Thank you for your comment. Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed policies and processes for implementing the recommendations at the local level.
Diabetes UK	Short	4	15	We support the young person identifying their named worker, but we feel that the person chosen by the young person must be supported/trained to deliver this level of support during transition. There may be training and resource implications to this which will need to be overcome.	Thank you for your comments which will be considered as part of the work to support guideline implementation. Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). Specifically, you will note that we have made clearer this is a role not a job title and therefore could be undertaken by someone who is already fulfilling a role of keyworker, coordinator or transition support worker. The Guideline Committee were clear that this may not necessitate additional funding. Please see also the chapter on implementation which provides some practical examples of how challenges could be overcome, including through improving front-line practice with young people through training.
Diabetes UK	Short	5	24	We would like to see more emphasis placed on an individual length of time for support for a young person. Person centred approaches should be used to take account of the where the young person is at in their life	Thank you for your comment. It is important to note that this time period (recommendation 1.2.9) relates to the minimum length of time the Committee thought it would be appropriate for the named worker to be

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				e.g. school, college, work and from this a suitable length of time for support should be agreed with the young person	involved and not to transition planning and support more widely which: - should start early 'from year 9 (age 13 or 14) at the latest (as indicated in recommendation 1.2.1s and 1.2.3) - should be developmentally appropriate (1.1.2, 1.2.3 and 1.5.11), and - should be reviewed annually (1.2.4) The Committee emphasised throughout development the importance of ensuring that support is person-centred. This is referenced explicitly in recommendations 1.1.1, 1.1.4, 1.2.4 (which was updated to this end, following discussion at Guideline Committee meeting 12), 1.2.10 and 1.2.19. A number of other recommendations reflect the need to ensure young people are sufficiently informed about their care and support (for example, recommendations 1.2.7, 1.2.13 and 1.3.4) and supported to express their views (for example, recommendations 1.2.10, 1.2.11 and 1.3.3).
Diabetes UK	Short	5	27 -30	We strongly support that there should not be a rigid age threshold for transition, and that this should be based on the young person's developmental stage, their capabilities needs and hopes for the future. This is crucial for a smooth transition. We would also like to see included that the transition takes place at a time of relative stability for the young person – both in their medical condition and general life events - wherever possible. The means of doing this relies on ongoing discussion and agreement of goals, and ensuring services are person centred and responsive to the needs of the young person in question – otherwise known as a structured care planning process. We recognise that this may pose a problem to inpatient	Thank you for your comment and support for this recommendation. Recommendation 1.2.2 has been amended to reflect that the point of transfer should take place at a time of relative stability for the young person.

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				care where there are often a rigid ages for admission to a paediatric and adult ward which are not negotiable. This leads to situations where a young person may be managed by a paediatric team but admitted to an adult ward which is wholly inappropriate as it can severely impact on a young person's medical care and emotional wellbeing. It is a particular issue if the child's care is at a children's hospital, as this will mean admission to a different hospital. We feel this issue must be addressed in the guidance.	
Diabetes UK	Short	7	4	While we support the need for a young person to develop and sustain social, leisure an recreational networks, we would welcome practical advice on how this could be done	Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level, however this comment will be considered as part of the work to support implementation of the guideline.
Diabetes UK	Short	8	5 -11	We support the involvement of the young person's parent or carer as they can have a valuable insight into the needs of the young person as well as going through their own transition issues. We feel that the involvement of a parent/carer needs to be managed sensitively, taking the views of both young person and carer into account. How this is managed should be considered on an individual basis. There is evidence of successful clinics where there is a gradual and well planned move away from joint consultations, with young people having the opportunity for independent sessions with clinicians and where there us a specific service for parents. We welcome the commitment to ensuring that "service managers should ensure that a named worker from the nominated adult service meets the young person before they transfer from children's services", but believe that this should not just be a meeting, but a planned and phased introduction to adult services in	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20

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				an organised way.	- referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
Diabetes UK	Short	10	16 -21	Guidance is provided about what to do if a young person has moved to adults' services and does not attend meetings or appointments or engage with services. This is welcome within the NICE guideline. However, it appears to focus very much on services working together that are near to each other. We recommend inclusion of innovative ways of organising joint meetings or clinics with services that may be some distance apart e.g. when young people move to universities. New forms of technology can be used such as virtual clinics and liaison with GPs as many people drop out of the service when they move to different areas. This makes it difficult to continue engagement. Whilst this is challenging for paediatric services and adult specialist services, it is an essential part of ongoing care to follow up and enable open access	Thank you for your comment. Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level. Reference has been added to the Context section to the challenges posed by out of area placements. The benefits of technology for supporting key aspects of transition are referenced in recommendations 1.2.11, 1.2.12 and 1.3.4.
Diabetes UK	short	11	8	We would like to see a reference in this section to the fact that the person chosen by the young person as their named worker may need to be supported/trained to deliver this level of support during transition	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). Specifically, you will note that we have made clearer this is a role not a job title and therefore could be undertaken by someone who is already fulfilling a role of keyworker, coordinator or transition support worker. It may be, therefore, that they already have the necessary skills.

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					Training more broadly – which would include that relating to named workers - is addressed in the implementation chapter, specifically in reference to improving front-line practice with young people.
Diabetes UK	Short	16	1 -16	We feel that adults' services taking joint responsibility with children's services may be a particular challenge, especially when considering transitioning from a children's hospital to an adult service, as the children's hospital may well need to work with a number of adult services including GP, community, hospital specialist services, and mental health services. The named contact has a key role in co-ordinating this care and resources may be helpful to support this. There are also likely to be significant difficulties in paediatric and adult teams taking joint responsibility if a young person transitions from a children's service to an adult service a distance away, for example if they go to university. We would recommend the addition of practical guidance or examples on how this can be achieved.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
Eating Disorders Association (Trading as Beat)	Short	General	General	Question 2: Service users and carers who contributed to our survey on this topic listed the following aspects of good practice: Having a named professional to support transition; Having the opportunity to meet staff from the relevant adult service at the CAMHS before moving from CAMHS to the adult service; Clear advance planning of the transition; Flexibility about age criteria – so that if a CAMHS patient had turned 18 and had nearly finished treatment they could be allow to finish their course of therapy in CAMHS; Close collaborative relationship between CAMHS and adult services; General support and reassurance informed by awareness and acknowledgement from health professionals at both the child and adult service of the	Thank you for your comment. The principles identified are aligned with those that emerged from the evidence reviews (which also included views and experiences data from young people, their parents and carers and practitioners). The Committee also recognised the need to ensure that young people with mental health needs do not "fall through the gap" between Child and Adolsecent Mental Health Services (CAMHS) and Adult Mental Health Services and, to this end, referenced them explicitly in recommendations 1.5.5 and 1.5.7. The Guideline Committee agreed on the importance of

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				difficulties experienced by patients and carers who go through a transition between Child to adult ED treatment. A 'support worker' who completed the survey recommended the production of guidance for families to help them cope with the change in involvement experienced between child and adult services. A parent stated that specific help should be offered to ensure the mental health and wellbeing of parents and help them cope with the challenges of caring for someone with an ED during transition. A text-based support service was also recommended by another participant. It was also suggested that services should offer some kind of support regarding the challenges that coincide with this life stage including employment or going to University. **PLEASE NOTE**: FURTHER INFORMATION ON THE SURVEY WE CARRIED OUT WITH OUR SERVICE USERS (INCLUDING ITS STRUCTURE AND THE RESPONSES GIVEN) AND FULL REFERENCES FOR THE ACADEMIC PAPERS CITED ARE AVAILABLE ON REQUEST FROM BEAT VIA RESEARCH@B-EAT.CO.UK	a named professional to help the young person throughout transition and this is reflected in recommendations 1.2.5 to 1.2.9.
Eating Disorders Association (Trading as Beat)	Short	General	General	Important recommendations made by Arcelus, Bouman and Morgan (2008) include: - Interventions targeting low self-esteem - Early identification of those who will need transition - Plan transition at least 6 months before transition date. - Transition should not occur during a crisis or other period of instability. - Flexible approach based on patient's needs. - Continued family involvement.	Thank you for your comment. It is helpful to see that the recommendations are broadly aligned with these.

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Eating Disorders Association (Trading as Beat)	Short	General	General	A guide for young people produced following the Beat Transitions project, with input from young people with personal experience, highlights the importance of physical health monitoring and wellbeing advice during transitions (Beat, 2015).	Thank you for your comment. The need to address young people's physical health needs and wider wellbeing outcomes during transitions is referenced throughout, for example, in recommendation 1.2.8 as well as in the definition of 'person-centred' ('Terms used in this guideline').
Eating Disorders Association (Trading as Beat)	Short	General	General	Dimitropoulos et al (2012) highlights the issue of social isolation often experienced by people with eating disorders going through transition between services and this could potentially be addressed through the provision of peer support interventions and activities to help encourage social interaction and development of social support network. This could include signposting to or commissioning services through patient-focussed organisations such as Beat. Some young people have encountered problems in trying to maintain social connections during treatment as their service has applied rigid and inflexible visiting hours (Beat, 2015).	Thank you for your comment. Peer support and support for social networks is referenced in recommendation 1.2.11 and 1.2.15.
Eating Disorders Association (Trading as Beat)	Short	General	General	Question 3: Participants argued that people with eating disorders and their carers and relevant professionals should be a key audience considered in structuring this guideline. There are a number of reasons why people with eating disorders may be particularly vulnerable to falling through the 'gap' between child and adult mental health services. These have been well articulated in the academic literature (see: Arcelus, Bouman and Morgan, 2008; Treasure, Schmidt and Hugo, 2005; Dimitropoulos et al, 2012; Dimitropoulos et al, 2015 for good examples). These factors include: - Ambivalence about recovery or even denial of illness and the importance of family as external motivation.	Thank you for your comment. The guideline covers a very wide range of young people and services so it was not possible to list all relevant conditions and needs separately. The Committee recognised, however, the need to ensure that young people with mental health needs do not "fall through the gap" between Child and Adolescent Mental Health Services and Adult Mental Health Services and, to this end, referenced them explicitly in recommendations 1.5.5, 1.5.6 and 1.5.7.

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				- Disruption of normal adolescent cognitive and social development as a result of the eating disorder making it more challenging to engage in treatment in an adult service. - Low self-esteem/self-worth - Sudden change of treatment ethos/philosophical approach used in ED treatment between child- adult services. Common co-morbidities (particularly from late adolescence onwards) necessitating multi-disciplinary treatment	
Eating Disorders Association (Trading as Beat)	Short	General	General	One participant who has experience of transition between child to adult services in the treatment of her eating disorder said that a key audience to consider should be: "*those who voice they're still scared/feel unable to face the next stage of recovery*". Some people with eating disorders may feel distressed about the greater (or total) independence experienced after the transition to adult services (Beat, 2015).	Thank you for your comment which provides useful context. The Committee did recognise the need to ensure that young people with mental health needs do not "fall through the gap" between Child and Adolescent Mental Health Services and Adult Mental Health Services and, to this end, referenced this group explicitly in recommendations 1.5.5 and 1.5.7.
Eating Disorders Association (Trading as Beat)	Short	General	General	The common form of treatment offered in child eating disorders services is Family Based Treatment. Given some evidence which appears to suggest that this treatment may reduced efficacy after 3 years of illness duration, one participant (with personal experience as a patient) stated that people with experience of an ED for longer than 3 years should be a key audience of the guideline. This is supported by research highlighting the disruption that eating disorders can have on normal cognitive and social development. This participant also responded that people who are susceptible to self-harm or suicide and those who have experienced traumatic events should be given special consideration. These individuals may be particularly vulnerable psychologically if their transition is poorly managed as it could lead to feelings of rejection and abandonment, worsening what is likely to already be	Thank you for your comment which provides useful context. It was not in scope to search for effectiveness evidence on this particular intervention and therefore the Committee are not able to make a specific recommendation in this regard. The Committee did recognise the need to ensure that young people with mental health needs do not "fall through the gap" between Child and Adolescent Mental Health Services and Adult Mental Health Services and, to this end, referenced this group explicitly in recommendations 1.5.5 and 1.5.7. The implementation chapter also contains specific suggestions for how to ensure young people who are not eligible for, do not have access to or who disengage with services can be supported.

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				low self-esteem.	
Eating Disorders Association (Trading as Beat)	Short	General	General	Question 4: Age of transition in eating disorders treatment varies considerably (Singh et al, 2008). A parent who responded to this question on our online survey stated: "*On leaving inpatient care at age 17 years 10 months we were told that there was no point in CAMHS providing support because this would need to end on my daughter's 18th birthday and that adult mental health services would not get involved until the day of her 18th birthday because of funding issues. Some degree of overlap between the 2 services is needed as well as the recommendation in the guidelines to remove a fixed age for transfer. Any specific therapy being provided by CAMHS such as CBT should be able to continue beyond any arbitrary transition age if that is in the best interests of the patient. There needs to be a range for the recommended transfer age (perhaps 17 - 19) so that the transfer can take place at a suitable moment in the treatment of any one individual patient*."	Thank you for your comment which provides useful context. The Committee did recognise the need to ensure that young people with mental health needs do not "fall through the gap" between Child and Adolescent Mental Health Services and Adult Mental Health Services and, to this end, referenced this group explicitly in recommendations 1.5.5 and 1.5.7. The implementation chapter also contains specific suggestions for how to ensure young people who are not eligible for, do not have access to or who disengage with services can be supported.
Eating Disorders Association (Trading as Beat)	Short	General	General	A support worker added that: "*It depends when they enter services; I consider 16 as there are experiences of being turned away at 17 because ['']there's no point going to treatment if you are changing in a year, and engage 'mindful watching' instead*[']	Thank you for your comment which provides useful context. The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are.
Eating Disorders Association (Trading as Beat)	Short	General	General	A former CAMHS patient (although they didn't transition to adult services) stated that: "*I think that transitions should be done much later, I think new referrals should join adult services at 21, but camhs patients shouldn't transition until 25*"	Thank you for your comment which provides useful context. The Committee did recognise the need to ensure that young people with mental health needs do not "fall through the gap" between Child and Adolescent Mental Health Services and Adult Mental

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					Health Services and, to this end, referenced this group explicitly in recommendations 1.5.5 and 1.5.7. The implementation chapter also contains specific suggestions for how to ensure young people who are not eligible for, do not have access to or who disengage with services can be supported.
Eating Disorders Association (Trading as Beat)	Short	General	General	Due to the varied rates of cognitive development experienced by young people with eating disorders and the vastly different treatment philosophies/ethos applied between child and adult services' in ED treatment some academics and clinicians have argued for the use of services that breach this transition, with services that can deliver mental heath care from 0-25 years of age.	Thank you for your comment which provides useful context. The Committee did recognise the need to ensure that young people with mental health needs do not "fall through the gap" between Child and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services and, to this end, referenced this group explicitly in recommendations 1.5.5 and 1.5.7. The implementation chapter also contains specific suggestions for how to ensure young people who are not eligible for, do not have access to or who disengage with services can be supported. The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are. The Committee agreed on the upper age limit of 25, by consensus. The Children and Families Act 2014 extended the special educational needs and disability system to a 0-25 system. This means that young people up to the age of 25 could have an education,

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					health and care plan and where that is the case the plans must have a specific focus on preparation for adulthood.
Eating Disorders Association (Trading as Beat)	Short	General	General	Question 6: Those who responded to our survey felt that parents should be consulted with and involved in the transition process. One participant qualified this by saying that parents should be "*involved as much as the young person wants them to be*". Suggestions for how this should be delivered included: - Being asked where they feel their child is in recovery - Being present at handover meetings - Fully informed about the process of transition - Having "*a right to express concerns*" Unfortunately responses to this question generated from our survey, were limited by the low number of parents' who took part in the survey.	Thank you for your comment which provides useful context. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
Eating Disorders Association (Trading as Beat)	Short	General	General	Other survey responses highlighted the need for support to be provided to parents as their role changes. A support worker recommended: "*guidance and information about what the transition means for them; how involved can they be*[?]*, is there flexibility*[?]*, how does this change things at home*[?]."	Thank you for your comment which provides useful context. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The

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					Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
Eating Disorders Association (Trading as Beat)	Short	General	General	Research literature documents that parents can find: "*that they are excluded from decisions about care*" (Treasure, Schmidt and Hugo, 2005, p.399) and this is often a surprising and distressing experience which they have not been expecting after having often been given considerable responsibility and involvement in the child service (this is due to the differing treatment ethos' and cultures of these services). For many young people across the transition age-range, the encouragement and support (and sometimes external motivation/ 'push' to engage in treatment) from parents is essential to their continued engagement with treatment and their ability to make a full recovery (Arcelus, Bouman and Morgan, 2008). The appropriate level and nature of this involvement should account for the wishes and needs of those involved and should be developmentally appropriate (Dimitropoulos et al, 2015).	Thank you for your comment which provides useful context. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers

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					in recommendation 1.3.7 about information provision.
Eating Disorders Association (Trading as Beat)	Short	General	General	Some young people can experience high levels of anxiety if they perceive (perhaps often correctly) that their parents will be excluded from any involvement in care when they move to adult services.	Thank you for your comment which provides useful context. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendation 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
Eating Disorders Association (Trading as Beat)	Short	General	General	Services should be required to help educate and inform parents about EDs and help them develop care skills (such as those taught as part of the 'Collaborative Care Skills' workshops delivered by Beat and other organisations). The importance of parents' understanding of eating disorders was highlighted in Dimitropoulos et. al. (2015).	Thank you for your comment which provides useful context. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end:

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					- referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
Eating Disorders Association (Trading as Beat)	Short	6	7 -8	More detail is warranted on this issue. Moving away from home to attend University often means moving away from a support network to an unfamiliar environment with a new level of independence and risks. This move often coincides with the child to adult service transition (Treasure, Schmidt and Hugo, 2005; Arcelus and Button, 2007). Two participants argued that young people (and their carers) experiencing this added complication to their transition should be a key audience of this guideline, with one participant recommending that Universities and Colleges themselves should also be a key audience, (given the role they can play in facilitating a smooth transition). This may entail the involvement (where desirable) of the University Mental Health Advisor (a position now staffed in many UK universities). Another participant argued that those moving into or out of work should be a key audience for the guideline. Service-users have often reported to us that they have been unable to access treatment due to disputes over who would pay and who could make the referral.	Thank you for your comment and support for the guideline. We have added a reference, in the context section (p9, full guideline), to the complexity of supporting young people who may move out of their local area (which could include those who leave home for university).

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Eating Disorders Association (Trading as Beat)	Short	7	2 -3	We feel that given the danger of social isolation and the importance of emotional support that the wording used for this recommendation should be stronger. The guideline should also specify that such support should be carefully moderated to ensure the safety and wellbeing of the young person (and those providing the peer support/mentoring).	Thank you for your comment. Recommendation 1.2.15 now includes explicit reference to moderating peer support so as to ensure the safety of those involved.
Eating Disorders Association (Trading as Beat)	Short	8	19 -21	A participant in our survey recommended that it should be an option for such a meeting to take place within the child service/CAMHS.	Thank you for your comment. Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level.
Eating Disorders Association (Trading as Beat)	Short	8	25	NHS England has recently produced a 'Passport' for young people moving from one service to another and this may be of interest to the committee in relation to this part of this guideline.	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Eating Disorders Association (Trading as Beat)	Short	11	5	It is not clear why this line refers specifically to a 'social worker' as presumably this role could be occupied by someone from a healthcare service rather than social services.	Thank you for your comment. Recommendation 1.4.5 refers specifically to social care, while 1.4.4 refers specifically to health care.
Eating Disorders Association (Trading as Beat)	Short	13	9 -13	Adult eating disorders services sometimes refuse to accept a transition from CAMHS because the adult service deems that the patient does not have a 'low enough' BMI. This is a perverse and dangerous approach which disregards the recommendations of the NICE Clinical Guidelines on Eating Disorders (NCCMH, 2004) and evidence about the unreliability of BMI as a sole indicator of ED severity, the importance of continuity of care and trust in health services. Services should appreciate that when someone is weight-restored this can be a time of particularly heightened anxiety if psychological factors have not yet been addressed (Beat, 2015). Another unique	Thank you for your comment. The guideline is intended to be read alongside – rather than to replace - existing NICE guidance, such as those related to Eating Disorders.

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				issue experienced in eating disorders treatment transitions is that of generic mental health services refusing to treat patients with EDs as they feel that eating disorders is not within their remit of 'severe mental illnesses' (Arcelus, Bouman and Morgan, 2008).	
Fife Council	Full	125	General	Reference 'Fraser M.' should be 'Mitchell, F.'	Thank you for your comment. This has been corrected.
Genetic Alliance UK	Full	General	General	We are on the whole very happy with the draft guideline, and are hopeful that the emphasis on communication and planning ahead contained in it will lead to significant improvements in how those with rare, genetic and undiagnosed conditions experience transition from children's to adult's services.	Thank you for your comment and your support for the guideline.
Genetic Alliance UK	Short	4	15 -16	We are supportive of the inclusion of a single named worker to coordinate transition care and support, though we would like to see this point strengthened to a must. People affected by rare conditions often have to see many different specialists who can be located across different departments and treatment centres. Patients and carers told us that communication between different healthcare providers is not always consistent. This is a known barrier to receiving high-quality care for many patients with rare conditions but is further exacerbated during periods of transition, especially from paediatric to adult services. As a result, parents and carers often have to shoulder the responsibility of coordinating their child or loved one's care during transition. Genetic Alliance UK considers a named care coordinator and clear care plan to be essential for all rare disease patients, but this is even more the case at times of transition.	Thank you for your comment. 'Must' can be used in NICE guidance only where there is a legal requirement, which is not the case for this recommendation.
Genetic Alliance UK	Short	5	29 -30	Although the guideline acknowledges that transition should be developmentally appropriate, and not based on a rigid age threshold, we feel that the guideline	Thank you for your comment. The Guideline Committee reviewed the wording of this recommendation (now 1.2.1) in Committee Meeting 12

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				should mention the importance of ensuring that the point of transfer occurs at a time that is suitable for the specific needs of the young person and their family. Most clinical transitions happen during teenage years when there are a lot of other important events taking place in an individual patient's life, including taking exams and moving schools, or starting college or university. Patients told us that undergoing transition between health services at a different time makes it easier for them to manage. Many of the patients and families we spoke to wanted to see the specific circumstances of their family given more consideration in the planning of transition.	(04.11.15) and made an edit to make clear that this should take place 'at a time of relative stability for the young person'. This is in addition to the existing text that stipulates it should take account of the young person's 'capabilities, needs and hopes for the future'.
Genetic Alliance UK	Short	13	9 -13	We are concerned that the list of circumstances requiring particular attention for the gap analysis does not include mention of young people with rare conditions, and also those who have not received a complete diagnosis. Young people with a rare or genetic condition face additional challenges accessing care, and this can be particularly problematic at transition. Advances in science and medicine have led to better health outcomes for patients living with a rare condition. Patients who previously would not have survived childhood are now living on into adulthood, a fact which should be celebrated. Better treatments mean that patients affected by rare diseases will be requiring a transition plan for the first time and the challenge now will be for healthcare systems to develop age appropriate services for these patients. The very fact that these diseases are rare means that health and social care professionals are unlikely to have previous experience of the patient's condition, which means that in these cases the best experts in the condition are often the patient and their family. Where families have had to struggle to get a diagnosis	Thank you for your comment. The guideline covers a very wide range of young people and services so it was not possible to list all relevant conditions and needs separately. The bullets indicate the over-arching groups, based on evidence and consensus, who may be particularly at risk of 'falling through the gaps' between services, rather that attempting to provide an exhaustive list. As you highlight, however, the guideline needs to address the diverse needs of wide range of young people, and so the Guideline Committee sought to establish the broad principles to follow with respect to care and support before, during and after transition. This focus on broad principles rather than condition-specific interventions has been highlighted in the Equality Impact Assessment. Young people with rare illnesses are included in the guideline.

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				in the first place, and then to get an appropriate package of care and support put together for their child, to have to go through this all over again as adulthood is reached is a daunting and difficult prospect. This is even more challenging where there is no complete diagnosis, and patients are forced to keep explaining the specifics of their condition to each new health professional.	
Great Ormond Street Hospital	Short	general	general	Lack of emphasis of importance of GPs throughout the whole transition process. Some families at GOSH do not see their GP and rely on local Paediatrician to fill this role. When they move to adult service the GP takes responsibity for coordinating care for a YP they know little about.	The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
Great Ormond Street Hospital	Short	5	29 -30	Being flexible about the age is fine in principle. As a tertiary centre, when local services are rigid and transfer people to adult services at 16 yrs it causes problems and confusion all round.	Thank you for your comments. The Guideline Committee agreed that joint working was an important issue to address and, to this end, referenced it explicitly in recommendations 1.1.5 and 1.5.10 and 1.5.11. 11).
Great Ormond Street Hospital	Short	9	23 -28	This will be very defendant on cognitive ability as it relates to children and young people with learning disabilities. Many of the children who attend GOSH Nerodisability Service would be unable to access this	Thank you for your comment. The Guideline Committee reviewed the recommendation on supporting young people to communicate with practitioners and revised the text to make clear this requires them to know what a young person's communication needs are, and to have tools available to help address those needs (see recommendation 1.2.10). Young people with learning disabilities are included in the guideline. Given the wide range of young people covered by this guideline, the scope of this guideline was to establish the broad principles to follow with respect to care and support before, during and after

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					transition rather than translate the recommendations into specific detail to address the needs of the wide range of groups covered.
Great Ormond Street Hospital	Short	10	1 -9	This will be very defendant on cognitive ability as it relates to children and young people with learning disabilities. Many of the children who attend GOSH Nerodisability Service would be unable to access this	Thank you for your comment. The Guideline Committee reviewed the recommendation on supporting young people to communicate with practitioners and revised the text to make clear this requires them to know what a young person's communication needs are, and to have tools available to help address those needs (see recommendation 1.2.10). Young people with learning disabilities are included in the guideline. Given the wide range of young people covered by this guideline, the scope of this guideline was to establish the broad principles to follow with respect to care and support before, during and after transition rather than translate the recommendations into specific detail to address the needs of the wide range of groups covered.
Great Ormond Street Hospital	Short	10	13	Makes it seem as if GP should only be involved if YP is not continuing into specialist adult care	The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
Great Ormond Street Hospital	Short	11	3 -4	Does this mean in the primary, secondary of tertiary center and how will that be achieved?	Thank you for your comment. This recommendation (now 1.4.4) is intended to refer to the adult services practitioner to whom the young person is transferred from the associated children's service. It may be that there is more than one practitioner, for example, if the young person attends a number of specialties.

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Great Ormond Street Hospital	Short	12	3 -7	This should not be another layer of "management". Ideally they should be very familiar with the constraints of working on the coal face with RTT / CCGs and trust managerial arrangements and look for ways to make it work better	Thank you for your comment. The Guideline Committee considered the issue of ownership of transition carefully (recommendations 1.5.1 to 1.5.3) and reviewed these recommendations at Guideline Committee meeting 12 (04.11.15). The wording has been updated to make clearer how these roles would work and where accountability lies.
Great Ormond Street Hospital	Short	13 -14	1 -6	Very necessary but will need quite a bit of teasing out as many children are seen by a range of consultants ranging from Community to Hospital and primary to tertiary.	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Great Ormond Street Hospital	Short	15	16 -17	Manpower and training./ ways of working The biggest impact on practice is the the lack of an available equivalent service in adult services as there are in Paediatrics services- the therapy services, the schools, the joined up working models.	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Great Ormond Street Hospital	Short	15	18 -19	The adult services will need to be trained to work with a different model of care. The key worker will help the young person to overcome some of the challenges but not all. Parents and carers of LD children s and young people will remain key. It will be good to know which services have good transition service that are working well and look at those models. There are financial implication as the current work force has not increased . Inefficiencies in the current NHS will have to be addressed.	Thank you for your comments which will be considered as part of the work to support guideline implementation. Your comments on resource implications will be considered by NICE as part of their costing work to support guideline implementation.
Great Ormond Street Hospital	Short	18	5	How in practice? Sounds like a good idea Good but in may authorities the EHC plan will not be accesses by the doctors/ surgeons etc and perhaps does not need to be	Thank you for your comment. Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level.
Great Ormond	Short	18	18 -24	Ideally accessible by the team around the child (yp) across health education and social care? There need	Thank you for your comment.

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Street Hospital				to be "levels of access" to information about the child or YP	
Hywel Dda University Health Board	Full	General	General	A stronger definition of the role of paediatricians is needed. This reads a little like a paediatrics document trying to get adults teams to do things.	Thank you for your comment. The Guideline Committee talked throughout the development phase about the importance of overlap and joint working between paediatric and adult services and this is now referenced explicitly in recommendation 1.3.1 which talks about joint appointments, joint clinics and paired practitioner working. Clarity of roles and communication was also a theme in discussions. As the guideline covers a very wide range of young people practitioners in health and social care, the group agreed to delineate only the roles of named worker, senior executive lead and senior manager lead in the guideline, and to specify tasks for senior managers (in recommendations 1.1.5, 1.2.6, 1.2.7, 1.2.8, 1.2.10, 1.5.1, 1.5.2 and 1.5.3). They recognised that many of the actions in the recommendations may be undertaken by different professionals depending on the context and that specific clinical roles and responsibilities may also vary.
Hywel Dda University Health Board	Full	General	General	Section on the complexity of paediatrics wards. The culture is different and is often a cause for friction. Learning difficulty adults on a paediatrics ward because they always have been but the staff are more used to lower volume higher doctor intensity so this leads to problems.	Thank you for your comment. The Guideline Committee discussed the complexity of the paediatric wards as well as supporting young people on adult wards. These discussions informed the recommendation about the need for developmentally-appropriate provision (recommendation 1.5.11).
Kent County Council	Short	general	General	Peer support could be a challenge to implement, however it would be useful to look at other models that have been successful with an understanding of how they are funded	Thank you for your comments. Please see the chapter on implementation which provides some practical examples of how challenges could be overcome..

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Kent County Council	Short	general	General	Due to the changing health landscape we need to think about how we improve integration with health. It is suggested that the Health & Wellbeing boards are used	Thank you for your comments. Please see the chapter on implementation which provides some practical examples of how challenges could be overcome. In particular, there is a section on joint planning, delivery and commissioning of transition services.
Kent County Council	Short	General	general	Need to ensure that both young people and parents are involved in the review and that education support in the process.	Thank you for your comments . Please see the chapter on implementation which provides some practical examples of how challenges could be overcome. In particular, there is a section on improving front-line practice with young people.
Kent County Council	Short	general	General	Need to ensure that young people and parents have access to the right information, in the right format and the right time and is given numerous times to ensure that the information is received.	Thank you for your comments. The Committee agreed information-provision is important and developed a number of recommendations on information provision for young people and their families (1.2.7, 1.2.13, 1.3.4, 1.3.7 and 1.3.8). The nature of information that should be provided will vary, given the wide range of young people that are covered by this guideline, and the individual nature of information needs. The recommendations on information provision therefore do not specific the detail of what should be provided, allowing practitioners flexibility to implement recommendations locally.
Kent County Council	Short	general	General	The guidelines will potentially increase expectations of young people and parents and this could result in a higher demand on the named worker.	Thank you for your comments. Please see the chapter on implementation which provides some practical examples of how challenges could be overcome. training.
Kent County Council	short	general	General	Joint planning of service with education is important to ensure that there is sufficient local education provision which will reduce out of county placement and costs. Education also needs to plan earlier for individuals with	Thank you for your comment. On review, the Guideline Committee agreed that reference to liaison with education practitioners needed to be strengthened in the recommendations, given: the critical importance of

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				a disability and offer full time course which would help to reduce the support packages within the community	education sector professionals in supporting young people's development, health and wellbeing, and identifying problems early. To achieve this, the following recommendations now reference education explicitly: 1.1.4, 1.1.6, 1.2.6, 1.2.8, , 1.2.16 and 1.3.3.
Kent County Council	Short	4	15	Having a singled named worker will be difficult as they will have to coordinate between different services e.g social care, health, education. Currently the Care Manager or Social Worker takes on the liaison role and this is difficult across a large complex authority.	Thank you for your comment. The Guideline Committee considered all recommendations aspirational but achievable. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). Specifically, you will note that we have made clearer this is a role not a job title and therefore could be undertaken by someone who is already fulfilling a role of keyworker, coordinator or transition support worker. It could be, therefore, that a care manager or social worker takes on this role.
Kent County Council	Short	5	24	The named person should support the young person for a minimum of 6 months before and after transfer (the exact length of time should be negotiated with the young person). It is felt that particularly for young people with complex needs, 6 months is too short a time frame and that the named worker should start work earlier.	Thank you for your comment. It is important to note that this time period (recommendation 1.2.9) relates to the length of time the Committee thought it would be appropriate for the named worker to be involved and not to transition planning and support more widely which: - should start early 'from year 9 (age 13 or 14) at the latest (as indicated in recommendation 1.2.1s and 1.2.3) - should be developmentally appropriate (1.1.2, 1.2.3 and 1.5.11), and

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					- should be reviewed annually (1.2.4) The Committee emphasised throughout development the importance of ensuring that support is person-centred. This is referenced explicitly in recommendations 1.1.1, 1.1.4, 1.2.4 (which was updated to this end, following discussion at Guideline Committee meeting 12), 1.2.10 and 1.2.19.
Kent County Council	Short	6	14	The statement offer young people help to become involved in transition planning should be a stronger statement	The Guideline Committee reviewed the recommendation on supporting young people to communicate with practitioners and revised the text to make clear this requires them to know what a young person's communication needs are, and to have tools available to help address those needs (see recommendation 1.2.12).
Kent County Council	Short	6	16	Implementing an effective peer support system will have additional costs, there will need to be training for Young people and staff. It would be useful to detail other models of delivery and the cost benefits long term	Thank you for your comment which will be considered as part of the work to support guideline implementation.
Kent County Council	Short	8	24	Contingency plans can be developed but in practice can be difficult to specify due to changing workforces.	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). Specifically, you will note that we have made clearer this is a role not a job title and therefore could be undertaken by someone who is already fulfilling a role of keyworker, coordinator or transition support worker.

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Kent County Council	Short	8	25	The personal folder; it is felt some of the bullet points are not key documents that should be includes; MCA should be included. To implement in practice the guidelines need to be clear on the purpose of the document and how it will be used.	Thank you for your comment. These are only examples of the types of content that may be useful, based on evidence and expert witness presentations. Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level.
Kent County Council	Short	9	23	It would be good to define 'adult services' , it is assumed that this refers to provision rather than the adult teams	Thank you for your comment. Given the breadth of the guideline and the wide range of services and young people it covers, it was agreed that 'adult services' was an appropriate term.
Kent County Council	Short	11	3	Ensure that the young person see the same healthcare practitioner for the first 2 attended appointments after transition This currently does not happen in practice and will be a challenge for health. Also different practitioners might be required depending on the needs.	Thank you for your comment. While recognising the implementation challenges, the Guideline Committee considered this aspirational but achievable and considered it important to make a recommendation on this point because there was evidence that consistency and relationship-building is important to young people and their families.
Kent County Council	Short	11	9	Training and development for staff should include MCA	Thank you for your comment. The Committee did consider training to be an important area to address and, to this end, it is referenced in the implementation chapter, specifically in relation to improving front-line practice with young people. Given the wide range of young people covered by the guideline, it was not possible to list every aspect of training. In the implementation chapter, therefore the Committee sought to provide over-arching headings that specify the key broad areas to address. The Mental Capacity Act would come under 'the legal context and framework'.
Kent County	Short	12	3	We endorse this point and agree that Senior executive	Thank you for your comment. The Guideline

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Council				and operational champions should be put in place; it will particularly be welcome from a health perspective. It would be good to detail the roles and responsibilities to ensure a consistent delivery approach.	Committee considered the issue of ownership of transition carefully (recommendations 1.5.1 to 1.5.3) and reviewed these recommendations at Guideline Committee meeting 12 (04.11.15). The wording has been updated to make clearer how these roles would work and where accountability lies.
Kent County Council	Short	12	3	Having a senior executive and operational champion could increase costs for the service, due to additional staff resources required to deliver the roles.	Thank you for your comment. The Guideline Committee considered the issue of ownership of transition carefully (recommendations 1.5.1 to 1.5.3) and reviewed these recommendations at Guideline Committee meeting 12 (04.11.15). The wording has been updated to make clearer how these roles would work and where accountability lies.
Kent County Council	Short	12	5	This recommendation will be a challenge to implement across all organisations	Thank you for your comments. The Committee recognised that some recommendations will be challenging to implement for some services however considered them to be aspirational but achievable.
Kent County Council	Short	12	18	Local integrated youth forums are a good idea but there are often not the local support groups around to undertake this work	Thank you for your comments. The Guideline Committee reflected on this recommendation at Meeting 12 and added in reference to the need to link with existing platforms and networks rather than starting new forums. They recognised that there may still be some implementation challenges but supported the idea and considered it aspirational but achievable.
Kent County Council	Short	12	24	The guidelines do not place a strong focus on education's responsibilities. This recommendation will be a challenge as the information is currently not used to inform service planning	Thank you for your comment. On review, the Guideline Committee agreed that reference to liaison with education practitioners needed to be strengthened in the recommendations, given: the critical importance of education sector professionals in supporting young people's development, health and wellbeing, and identifying problems early. To achieve this, the following recommendations now reference education explicitly: 1.1.4, 1.1.6, 1.2.6, 1.2.8, 1.2.16 and 1.3.3.

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Kent County Council	Short	13	17	This is a good recommendation however in practice in a large geographical county this could have challenges to implement successfully; we would also need to understand who would undertake this role and how the information would be used.	Thank you for your comment. The previous reference to pooled budgets has been removed from the recommendations as it was noted that this is not within the remit for NICE guidance; however, there is reference to funding mechanisms within the implementation section.
Kent County Council	Short	13	21	We agree that incentivising adult services via CQUINs is a good idea and could improve transition. Is there a role for CCGs?	Thank you for your comment. The previous reference to CQUINs has been removed from the recommendations as it was noted that this is not within the remit for NICE guidance; however, there is reference to funding mechanisms within the implementation section.
Kent County Council	short	14	1	This section needs to be more robust than just meeting with consultants, in practice it is a challenge to have children and adult service consultants working together.	The focus of the recommendations is on ensuring developmentally appropriate care and support as a principle, rather than on specifying particular models of transition support. This is because the Committee concluded that different approaches could deliver positive outcomes, and therefore that the ways of working were likely to be more important to make recommendations on than the structure. The Committee also agreed that specifying the principles - rather than asking people to implement entirely new service delivery models - also helped ensure recommendations would not have a significant cost impact. Stakeholder comments indicated that age-banded clinics were one useful and commonly accepted way of delivering developmentally-appropriate care and therefore these were included as an example, post-consultation
Kent County	Short	18	11	Practitioners should undertake positive risk	Thank you for your comment.

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Council				assessments to if individual continue to be disengaged	
Kent County Council	Short	18	18	In practice it will be difficult to maintain an up-to-date database that is shared across all departments, it would be useful to have guidance on how this will be achieved and who will be responsible for this. How would this link to client/patient/school databases?	Thank you for your comment. This challenge was recognised but the Guideline Committee thought it was still important to include this recommendations, and the words 'where possible' used to address this.
Kidney Research UK	short	general	general	Question 2: The guidelines correctly call for patient centred care and transition to be tailored to each individual patient's requirements. The experiences and views of our patient contacts support the need for a person-centred approach.	Thank you for your comment and support for the guideline.
Kidney Research UK	short	general	general	Question 2: The idea of the personal folder which is passed on between services is very attractive. Our patient contacts have commented that peer support and considering the individual's social as well as physical needs would have been greatly beneficial to them.	Thank you for your comment and support for this recommendation.
Kidney Research UK	short	general	general	Question 1 and 2: The person-centred aspiration is supported but the resulting practical challenges in terms of resources, both staff time and financial, as well as the plethora of potentially incompatible and difficult to integrate plans will make implementation very challenging. It would be more practical to require Trusts and other provider organisations to use a generic structured framework that can be tailored to the needs of each patient. This would then give the best balance between individualised care and administrative requirements. This common approach would also help young people to move from one location to another as often happens when they go on to higher education. The use of the same structured framework should be encouraged in adult services as this would result in a seamless transition to adult services and allow for the holistic, patient centred approach to continue in adult services. This is especially important as there is a drive for patient-	Thank you for your comments. Please see the chapter on implementation which provides some practical examples of how challenges could be overcome. In particular, there is a section on joint planning, delivery and commissioning of services.

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				centred care in adult services and a recognition that any patient with a long term condition should be empowered and gain the knowledge and skill to manage their condition – whether their care is in primary, secondary or tertiary services	
Kidney Research UK	short	general	general	Question 2: Cultural change within the NHS in both children's and adult services is difficult. - Giving teams resources and tools to use will help overcome challenges and ease implementation. Using a structured framework eg a generic transition programme such as Ready Steady Go* and Hello will support transition, patient empowerment and provide a holistic approach in both children's and adult services. The tool can be used for all sub-specialities and all age groups in both paediatric and adult services and is already resulting in cultural change within the NHS where used. - Providing transition policies for Trusts to adapt for their organisations will also hasten implementation * Implementing transition: Ready Steady Go. Nagra A, McGinnity PM, Davis N, Salmon AP Arch Dis Child Educ Pract Ed. 2015 Jun 10. Pii: edpract-2014-307423. Doi: 10.1136/archdischild-2014-307423. [Epub ahead of print]	Thank you for your comment. Please see the chapter on implementation which provides some practical examples of how challenges could be overcome. In particular, there is a section on joint planning, delivery and commissioning of services.
Kidney Research UK	short	general	general	Question 2: Grouping young people where appropriate so they transition to adult services as a group,	Thank you for your comments. Please see the chapter on implementation which provides some practical

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				benefiting from the shared experience, and lessening the daunting impact of moving to services where there could be decades of difference in age between patients. If the initial five appointments in adult services could be scheduled so that newly transitioned young people are clustered together, that could help morale enormously. (Patient idea)	examples of how challenges could be overcome. In particular, there is a section on improving front-line practice with young people through training.
Kidney Research UK	short	general	general	Question 2: We look forward to seeing greater clarity over how these changes are to be brought about, especially in the light of the point the document itself makes that *'there is a wealth of policy and guidance on agreed principles in respect of good transitional care, but there is also evidence that the principles are often not reflected in practice.*' As one way to aid this, we would recommend the use of language is made more directive, especially changing the words 'consider' and 'should'. (Patient comment)	Thank you for your comment. NICE methodology requires the use of 'consider', 'should' or 'must' to denote weaker, stronger and legally mandated recommendations respectively. The wording of each recommendation was carefully considered by the Committee throughout development. Following consultation, the reference to coproduction in recommendation 1.1.1 was changed from 'consider' to 'should'.
Kidney Research UK	short	general	general	Question 9: We welcome the proposed research areas and would strongly recommend that, when looking at value for money/cost effectiveness, calculations are made carefully, with particular consideration to the long term, as this is where the most change is likely to be seen.	Thank you for your comment. More detailed information has been included in respect of research recommendations, and the need to gather data over a suitable time horizon is now referenced in each case.
Kidney Research UK	short	4 -5	general	Question 1 and 2: We welcome the idea of a named worker, although would ask for greater clarity over who has ownership of/responsibility for the whole process, and the risks in one sole individual being responsible need to be addressed. The named consultant for the young people should be responsible for ensuring the young person is under-going transition with all members of the MDT being involved. A named keyworker as a point of contact for the young people is more practical and effective to a single person co-	Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7).

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				ordinating all care. If the young people are seen by multiple sub-specialties, each sub-speciality is responsible for ensuring that their service is providing good effective transition. If all sub-specialties use the same structured framework this will allow parity of esteem and bench-marking. It is the responsibility of the named consultant to identify the most appropriate adult service for the young people to transition to for their sub-specialty – be it primary, secondary or tertiary services.	
Kidney Research UK	short	5	27	Question 2: *Section 1.2.5* The experience of our patient contacts bears this out, they speak of having 10-year relationships with consultants in childrens' services which they were unwilling to let go of easily. The maturity and confidence levels of the young person are particularly relevant.	Thank you for your comment which provides useful contextual information.
Kidney Research UK	short	10	10	Question 2: *Section. 1.3.9 If a young person does not meet the criteria for specialist adult health services, involve the GP in their transition planning*. **The GP should always be included in the transition process** even if the care is being transferred to adult services.	The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
Kidney Research UK	short	15	general	Question 2: *Terms used. Transition. The process of moving from children's to adults' services. It refers to the full process including initial planning, the actual transfer between services, and support throughout.* Transition is about going from a state of knowing very little about their condition to fully managing their condition and not just making a move to adult services. **A sentence needs to be included about 'empowering young people by equipping them with the skills and knowledge to manage their healthcare in both children's and adult services'.** At present many people still think of transition as moving from children's to adult services with no	Thank you for your comments. Thank you for your comment. The Committee discussed the need to support the young person "as a whole", taking into account what they would like to achieve and what information and support they need, throughout guideline development. This informed the development of the four over-arching outcome areas referenced throughout, specifically: - education and employment - community inclusion - health and wellbeing including emotional health - independent living and housing options.

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				empowerment. Empowerment needs to be stressed. Empowerment and the holistic approach needs to continue in adult services	It was the Committee's intention that these would include equipping them with the skills to become more autonomous so the request specific addition has not been made. These areas are included in recommendation 1.2.8, the Training section of the Implementation chapter, and in the definition of 'person-centred' ('Terms used in this guideline').
Lincolnshire County Council	Full	General	general	Question 1: Working in an integrated way may prove most challenging in practice as this will require both Health, Education and Social Care to engage to ensure a smooth transition. In our experience difficulties may arise as each organisation has own priorities, policies and procedures. An additional barrier is information sharing. This will require a cultural shift across all agencies. Using person-centred approaches may for some require a shift in practice to ensure that the young person remains at the centre and that their views are fully taken into account. All too often decisions are made without the full involvement of the young person. This may link to developing users, families and professionals understanding of the Mental Capacity ACT. A challenge will be to ensure that there are clear processes, joint working protocols, policies and procedures which are full embedded into the culture of all professionals and there is clear and accessible information for users, families and professionals supporting them.	Thank you for your comments. The Guideline Committee recognised the challenges posed by integrated working and the over-arching recommendation 1.1.5 in particular seeks to address this. Recommendation 1.1.5 also suggests the use of joint protocols (including for information-sharing) and 1.1.7 also emphasises the importance of information-sharing in respect of safeguarding. Following discussion at Guideline Committee meeting 12 (04.11.15), the Mental Capacity Act is now referenced explicitly in recommendation 1.2.20. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). The need for effective handover between children's

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				Having a clear understanding of roles and responsibility may present a challenge in relation to identifying a named worker to work with the young person to coordinate their transition care and support. Nationally/guidance clear guidance and protocols/expectations about what different partners should be doing is needed. Clear pathways for users are needed which are appropriate for their needs and circumstances. Ensuring a smooth transition requires a multi-agency approach and there should be opportunity to link with previous workers (across services/agencies) who know the young person best when person reaches adulthood. This may prove challenging as currently young people may cease to have contact with previous practitioners when they reach 18. A challenge in relation to smooth Transition may be with regards to the young persons primary support, from our experiences this can label people at an early age and therefore they may become 'trapped' by that label as their needs change in the future.	and adults' practitioners, and for there to be some continuity in terms of the practitioners young people see has been addressed in recommendations 1.1.5 , 1.3.5, 1.4.4 and 1.4.5.
Lincolnshire County Council	Full	General	general	Question 2: To help overcome some of these challenges users need: Access to good up to date information advice spanning, health, social care, education and housing (including what to expect). This may reduce developing a dependency. Clarity on the role of and access to housing may be an area that the guidance can be more explicit.	Thank you for your comments. Following discussion at Guideline Committee meeting 12 (04.11.15), housing has now been referenced explicitly in recommendations 1.1.4, 1.2.8 and 'Terms used in this guideline – Person-centred'). The Committee agreed information-provision is important and developed a number of recommendations on information provision for young people and their families (1.2.7, 1.2.13, 1.3.4, 1.3.7

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				Clear pathways and responsibilities are required which are accessible and span all services. In our experience this is especially challenging for users moving from health services as a child/young person to adult health services. Our experiences support the clear and consistent message that A clear process/pathway is required for transition from children's services to adult social care but also spanning education, housing and health. The outlined personal folder/information pack discussed in paper is something that we have had available previously for young people and believe that this is will be of benefit. It may be beneficial to include clarity in the guidance around information sharing and responsibilities. From our experiences having joined up information with regards education, health and care is essential. Areas we have identified include support for users and parents/carers with financial information when a young person moves into adulthood, this can include: Court of Protection, Guardianship, Deputyship, DOLS, and other matters such as setting up a bank account. We believe that the proposed guidance will support a smooth transition however there is a need to ensure that during transition people are informed who is now responsible for coordination. Clear guidance will be required to ensure that users are supported to understand practitioners roles and responsibilities. A consistent message has been the need to minimising ambiguity. A suggestion from discussions has been to ensure that while recognising an users	and 1.3.8). The nature of information that should be provided will vary, given the wide range of young people that are covered by this guideline, and the individual nature of information needs. The recommendations on information provision therefore do not specific the detail of what should be provided, allowing practitioners flexibility to implement recommendations locally. Recommendation 1.1.5 indicates the use of joint protocols (including for information-sharing) and 1.1.7 also emphasises the importance of information-sharing in respect of safeguarding. The Committee agreed that it will be important for people using services and their families to be clear about what this guideline means they should expect from services. NICE produce a version of the guideline for people who use services and the public.

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				individual needs and aspirations a pathways for Transition similar to the End of Life Pathway is in place.	
Lincolnshire County Council	Full	General	general	Question 3: Key audiences: Young people and their families. Adults Care, Children Services, Public Health, Health, Education, Housing, Third Sector organisations. Ensure that the guidance is in formats which are appropriate and outlines responsibilities for all people at different levels within organisations from practitioner to members.	Thank you for your comments. The NICE Collaborating Centre for Social Care has a remit to produce complementary products to support guideline implementation so your comments will be considered as part of this work.
Lincolnshire County Council	Full	General	general	Question 4: What age does transition planning- This should happen when developmentally appropriate and of benefit to the person. Usually this begins at age 14 in Lincolnshire. Our experience makes us mindful of those that finish education at 16 as they may hit a void before accessing Adult Services (or may not) at 18. It may be beneficial to look at cohort of those who leave education at 16 and their experiences. We believe that there is an opportunity in the proposed guidance to address this.	Thank you for your comment. The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, if appropriate. The Committee agreed about the need to ensure transition support is developmentally appropriate and this is referenced in recommendations 1.2.1 and 1.5.11 explicitly. The recommendations are relevant to a very wide range of young people, including those who leave education at 16. We also sought data on views and experiences of young people explicitly as part of our search strategy.
Lincolnshire County Council	Full	General	general	Question 5: Review meetings happen….	Thank you for your comment.

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Lincolnshire County Council	Full	General	general	Question 6: How should parents be involved in transition planning? Parents being involved is a key part of transition planning and parents should be involved as fully as the young person wishes in transition planning. To ensure a young person choices and wishes are heard they should be supported to communicate their preferences for their parents involvement. They must also include the opportunity to raise concerns/comments away from their parents and access to advocacy services. Good practice includes work in the curriculum about what is important to the young person and making parents aware of processes and provision of information at an early stage. From experience; despite a plethora of legislation and guidance there are examples where decisions have been made by professionals and parents not to include young people in decision making. A challenge is developing a good understanding across agencies around the Mental Capacity Act From our experiences sometimes if there is conflict between the young person/family and professionals, the young person/families opinions may be dismissed. It is important that the guidance recognises the power imbalances ensuring young person and family are involved as much as possible and their opinions and choices respected. .	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendation 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision. The Committee emphasised throughout development the importance of ensuring the young person is at the centre of their care and support. This is referenced explicitly in recommendations 1.1.1, 1.1.2, 1.2.4 (which was updated to this end, following discussion at Guideline Committee meeting 12), and 1.2.19.
Lincolnshire	Full	General	general	Question 7: Will these recommendations result in an impact on cost of services?	Thank you for your comment which will be considered as part of the work to support guideline

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County Council				Support before transfer and after transfer may have a cost implication. From discussion a concern was how this can be achieved without a transition team. Further discussions highlighted that the issue may however be more about the impact on capacity of teams already working with individual and extending their involvement.	implementation.
Lincolnshire County Council	Full	General	general	Question 8: Which of these recommendations would lead to additional costs? A challenge may be in the double up of children, and adults practitioners the impact being as a result of the cost of attending reviews and other meetings associated with transition. The level of support outlined from the named worker may also have an additional cost.	Thank you for your comment which will be considered as part of the work to support guideline implementation.Thank you for your comment which will be considered as part of the work to support guideline implementation.
Lincolnshire County Council	Full	General	general	Question 9: Will any of these recommendations lead to cost savings? The guidance draw good practice together and should lead to a more efficient transition with less duplication and better coordination potentially may reduce the amount of separate interventions. This has the potential to improve the experience of transition for everyone. Identifying issues early. Poling of budgets may lead to less conflict i.e. when education funding ceases (person reaches full educational potential). Taking a 'strengths based approach' focusing on what	Thank you for your comment which will be considered as part of the work to support guideline implementation.

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				is positive and possible for the young person may lead to cost saving and better outcomes for users. Supporting them to build confidence about their own care and support over time may lead to less dependency on statutory services. Accessing information and support early (prevent, reduce, delay). Closer working may reduce the impact of time taken to deal with complaints and maintaining the integrity of organisation.	
Liverpool City Council Children's Services	Short	General	general	Current practice is 17 years of age. However, with the implementation of the Transition Team transition planning will start from Year 9. For young people leaving care, this will start when young people are aged 15 and a half.	Thank you for your comment which provides useful context. Thank you for your comment. The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are.
Liverpool City Council Children's Services	Short	2	20	Joint commissioning will have a huge impact on practice and will be challenging in how we implement a joint strategy between Health, Children's Services and Adult Services. Provider Services will have to be encouraged to be more flexible for young people and their carer's in the delivery of joined up care planning. There are limited examples of existing regional pooled budgets for better post aged 16 plus options and support. Co-producing transition policies and strategies with young people and their carers will be challenging given the limited human resources in Health, Children's Services and Adult Services. Pooled budgets between the two services would be	Thank you for your comments which will be considered as part of the work to support guideline implementation.

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				enormously beneficial but potentially hugely challenging for the authority to administer	
Liverpool City Council Children's Services	Short	6 -10	general	Young people, parents and carers, Children's Services workforce, appropriate Adult Services workforce, Health, Education/Employment, Housing key partners and voluntary sector organisations, procurement representatives from Children's Services and Adult Services.	Thank you for your comment.
Liverpool City Council Children's Services	Short	6	1	Child in Need Reviews for disabled children occur twice yearly, as a minimum.	Thank you for your comment which provides useful contextual information.
Liverpool City Council Children's Services	Short	8	General	Parents should be involved via the review process, consultation and parent/ carer forums. Parents should also be a part of strategic boards and have access to advocacy if appropriate.	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about

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					information provision.
Liverpool City Council Children's Services	Short	13	21	Yes. The impact on cost of services will be in relation to training costs in respect of all staff delivering direct care involving face to face interaction with young people. The cost of developing pooled budgets across Children's Services and Adult Services. Incentivising Adult Services to invest in transitions.	Thank you for your comment. The previous reference to pooled budgets has been removed from the recommendations as it was noted that this is not within the remit for NICE guidance; however, there is reference to funding mechanisms within the implementation section.
Liverpool City Council Children's Services	Short	16	General	The joint planning of services from Children's Services to Adult Services. Currently Children's providers are significantly more costly than Adult Services providers. There are differences in terms of legislative requirements/drivers and culture in relation to meeting the needs of disabled children in comparison to meeting the needs of disabled adults. .	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Liverpool City Council Children's Services	Short	16	General	In the long term there is potential for cost savings in relation to commissioning and joint review systems.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
Liverpool City Council Children's Services	Short	16	24	Liverpool has a representative from Adult Social Care on its SEND Partnership Group. Agenda items are inclusive of the transition strategy and regional governance. There is a score card in place to track progress made	Thank you for your comment which provides useful context and may also be a helpful example for the shared learning database.
Martin House – hospice care for children and young people	short	general	general	We are aware of a submission to this consultation by Together for Short Lives and we wish to lend our support to the comments made in that submission.	Thank you for your comment.
Martin House – hospice care for	Short	General	General	Under principles, we would like there to be stronger recognition that not all children and young people will be verbal or able to communicate easily and that	Thank you for your comment. The Guideline Committee reviewed the recommendation on supporting young people to communicate with

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children and young people				support must be available to support these young people.	practitioners and revised the text to make clear this requires them to know what a young person's communication needs are, and to have tools available to help address those needs (see recommendation 1.2.12).
Martin House – hospice care for children and young people	Short	General	General	EHC plans need to be more prominent in the guidelines for relevant children, rather than a footnote.	Thank you for your comment. Children with Education, Health and Care plans are included in the guideline and were discussed explicitly throughout guideline development. The Committee were mindful not to repeat the provisions of existing legislation and existing guidance, such as the NICE guideline PH 28 Looked after children and young people and instead have referenced this, where appropriate (for example, 1.2.18, 1.2.22). The guideline should be implemented in the context of the wide range of legislation relevant to the diverse groups of young people covered by the recommendations.
Martin House – hospice care for children and young people	short	3	8	We believe that 'using person-centred approaches' should be the first over-arching principle and recommend that this be placed at the top of the list.	Thank you for your comment. The Guideline Committee agreed that young people's involvement in all aspects of transition ought to be the first recommendation as this relates to design, delivery and evaluation of services. They agreed that person-centred planning should follow from this, given that it describes how this involvement should take place. The order of these recommendations therefore remains unchanged.
Martin House – hospice care for	short	3	17 -18	We are unsure what is meant here by 'psychological status'. Is it referring to mental health? How will it be tested and by whom? Further clarity is needed.	Thank you for your comment. The Committee chose this wording to reflect mental health and wellbeing.

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children and young people					
Martin House – hospice care for children and young people	short	3	24 -26	We would like to see learning and education included as a relevant outcome and also that 'a good death' be considered as a relevant outcome for young people with a life-limiting or life-threatening condition.	Thank you for your comment. On review, the Guideline Committee agreed that reference to liaison with education practitioners needed to be strengthened in the recommendations, given: the critical importance of education sector professionals in supporting young people's development, health and wellbeing, and identifying problems early. To achieve this, the following recommendations now reference education explicitly: 1.1.4, 1.1.6, 1.2.6, 1.2.8, 1.2.16 and 1.3.3. The Committee did consider the request to refer explicitly to 'a good death' but did not wish to include this explicitly. There is already a guideline in development on end of life care for infants, children and young people. They thought the over-arching outcome areas specified – education and employment, community inclusion, health and wellbeing including emotional health, and independent living and housing options - were sufficient. Wellbeing at end of life would be included within these.
Martin House – hospice care for children and young people	Short	4	7 -9	1.1.4 should also include service managers in education. There needs to be greater detail about **how** young people with transition support needs will be proactively identified and who will do that. What are the criteria? Will there be a register? Schools will be key in this process.	Thank you for your comment. On review, the Guideline Committee agreed that reference to liaison with education practitioners needed to be strengthened in the recommendations, given: the critical importance of education sector professionals in supporting young people's development, health and wellbeing, and identifying problems early.To achieve this, the following recommendations now reference education explicitly:1.1.2, 1.1.3, 1.1.4, 1.2.7, 1.2.11, 1.2.15, 1.2.16, 1.3.3 and 1.5.1.

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Martin House – hospice care for children and young people	Short	5	15 -21	Include learning and education in this list. Note that not all young people can, or want, to achieve independent living and there will be a need to continue to provide respite care for many adults with complex needs.	Thank you for your comment. On review, the Guideline Committee agreed that reference to liaison with education practitioners needed to be strengthened in the recommendations, given: the critical importance of education sector professionals in supporting young people's development, health and wellbeing, and identifying problems early. To achieve this, the following recommendations now reference education explicitly: 1.1.4, 1.1.6, 1.2.6, 1.2.8, , 1.2.16 and 1.3.3.
Martin House – hospice care for children and young people	Short	7	9	1.2.13: Condition-specific organisations will be in a good position to offer support to many young people with complex needs, e.g. Muscular Dystrophy UK.	Thank you for your comment and support for this recommendation.
Martin House – hospice care for children and young people	Short	7	16	Include learning and education in this list.	Thank you for your comment. On review, the Guideline Committee agreed that reference to liaison with education practitioners needed to be strengthened in the recommendations, given: the critical importance of education sector professionals in supporting young people's development, health and wellbeing, and identifying problems early. To achieve this, the following recommendations now reference education explicitly: 1.1.4, 1.1.6, 1.2.6, 1.2.8, , 1.2.16 and 1.3.3.
Martin House – hospice care for children and young people	Short	7	24	We recommend that young people with life-limiting or life-threatening conditions be identified here, and elsewhere in the guidelines, as a special interest group (in addition to those with disabilities in education, those with long-term conditions and looked after children). For those with life-limiting conditions, most of whom have highly complex needs, the emphasis should be on **enabling them to live their life to the full** in the short time they have left. There isn't the luxury of time	Thank you for your comment. The guideline covers a very wide range of young people and services so it was not possible to list all relevant conditions and needs separately. Young people with life-limiting conditions are covered by the guideline.

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				to put things right later. It is estimated that there are over 40,000 children (under 19) with a life-limiting or life-threatening condition in England (2010).	
Martin House – hospice care for children and young people	Short	8	12	1.12.20: Whilst we support this paragraph, our own focus group and research work does provide evidence that many young people with life-limiting conditions who rely on their parents for care **do** still want their parents to be closely involved once they are in adult services.	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
Martin House – hospice care for children and young people	Short	9	10	1.3.4: We support this paragraph but note that there are currently very few age-appropriate **specialist palliative care** services available for young adults in England. Most adult specialist palliative care services are aimed at the older population, especially the over 75s, and do not have the appropriate skills, knowledge or environment for young adults, especially those with life-limiting, paediatric conditions. There needs to be more work done on identifying the gaps in service	Thank you for your comments. The Committee discussed whether to talk about age-appropriate or developmentally appropriate and agreed that the focus should be on ensuring transition support is developmentally appropriate and this is referenced in recommendations 1.1.2 and 1.5.11 explicitly. Please see also the NICE guideline on Care of dying adults in the last days of life.

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				provision for this group of young people and then **urgently** providing services to meet those gaps.	
Martin House – hospice care for children and young people	Short	10	14	1.3.9: We believe this is right – GPs have a vital role to play - but are concerned about implementation of this recommendation and how realistic it is. Who will fund the extra capacity that this role will require in GP practices? The question of where the extra resources will come from to deliver the recommendations is an issue throughout this document. Specifically, GPs often have little to do with life-limited children, many of whom have very rare conditions, when they are under the care of paediatric services and therefore may not understand their condition or their needs. Martin House has identified the relationship with GPs as being an area requiring further research in paediatric palliative care.	The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1). The role of primary care in transition has been identified as an area for research. Young people needing end of life care could be included in this.
Martin House – hospice care for children and young people	Short	11	9 -20	1.5.1: We think this is crucial. The Yorkshire and Humber Strategic Clinical Network Transition Task and Finish Group is working on developing a set of competencies for all NHS staff to cover these areas.	Thank you for your comment and support.
Martin House – hospice care for children and young people	Short	12	18	1.5.5: Also, work with existing forums, where they exist. Some of those run by specific condition groups, e.g. Muscular Dystrophy, are especially effective.	Thank you for your comment. This recommendation has been updated to make reference to the need to 'link with existing structures where these exist'.
Martin House – hospice care for children and young people	Short	13	6 -8	This is certainly the case for young people with life-limiting conditions – see comment 13.	Thank you for your comment.

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National AIDS Trust	Short	General	General	Transition occurs at a time when young people are managing increasing independence and autonomy alongside emerging sexual and social identities. If the process is not managed well and young people choose to disengage from care, resulting poor adherence and self-management can lead to drug resistance, disease progression and increased risk of onwards transmission. There are, therefore, medical, social and economic consequences for individual and public health. In order to minimise these risks, NAT is concerned that these generic guidelines must allow for the circumstances of young people negotiating stigma, confidentiality and disclosure as their health and social care provision changes to adult services. Although advances in treatment mean that fewer and fewer children are being born with HIV, the potential decreasing expertise in social support services targeted at this diminishing cohort make guidance of this sort particularly critical.	Thank you for your comment which provides useful context.
National AIDS Trust	Short	General	General	Question 2: Young people living within HIV are often in the position that their parents are also living with HIV. This can complicate the transition process as young people may not feel like they have confidentiality in their parent's clinic. For example, they may be concerned that sensitive issues such as sexual behaviour and drug use will be discussed with their parents. This particularly applies in certain areas (e.g. sparsely populated areas) where there is no choice of alternative clinics. NAT recommends that the guidelines include a reference to situations where parents and children are patients in the same clinics and to make clear that this may need to be discussed with the young person and planned for.	Thank you for your comment which provides useful context. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person

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					regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
National AIDS Trust	Short	General	general	Question 9: It is well-recognised that transition is a time when people living with HIV can be lost to follow-up, with potential long term financial and public health cost implications associated with disease progression and increased rates of transmission. NAT believes that investment in establishing joined-up approaches to transition and adequate HIV-specific training for health and social care staff would help to retain people living with HIV in treatment and thus reduce these long term costs.	Thank you for your comment which provides useful context. Please see the chapter on implementation which provides some practical examples of how challenges could be overcome. In particular, there is a section on joint planning, delivery and commissioning of transition services.
National AIDS Trust	Short	3	30	Question 2: NAT supports the recommendation that health and social care service managers should work together in an integrated way. CHIVA Standards of Care for Infants, Children and Young People[1] and British HIV Association (BHIVA) Standards of Care for People Living with HIV[2] both recognise the complexity of young people living with HIV successfully transitioning to adult care and the need for management through a multidisciplinary team. NAT	Thank you for your comment and support for the recommendation on integration. A reference to confidentiality has been included in recommendation 1.1.7. The Guideline will be inform a Quality Standard which may link to or reference other standards, as appropriate.

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				recommends that the guidelines include reference to condition-specific standards which will be able to provide more information to those supporting young people living with HIV. However, integrated working must still reflect confidentiality. Many young people living with HIV will not have disclosed their status in their educational establishment or to other carers. Therefore, a principle must be applied across these guidelines that a young person must consent to information, such as their HIV status, being disclosed, before it is shared. [7] Standard 6 in Paediatric HIV Psychology Group, 'Psychological Management of Children and Young People Living with HIV: Standards for Care' 2014 [http://www.chiva.org.uk/files/4514/2900/7023/Psychological_Standards_for_Care.pdf] [8] Children's HIV Association, 'CHIVA Standards of Care for Infants, Children and Young People with HIV (including infants born to mothers with HIV), 2013 [http://www.chiva.org.uk/files/5614/2900/7268/CHIVA_standards2013.pdf] [9] British HIV Association, 'BHIVA Standards of Care for People Living with HIV', 2013 [http://www.bhiva.org/documents/Standards-of-care/BHIVAStandardsA4.pdf]	Safeguarding and confidentiality were discussed and informed the bullet on 'the legal context and framework related to supporting young people through transition, including consent and safeguarding' . This can now be found in the information about training within the chapter on Implementation. Recommendation 1.1.7 references the need to ensure information-sharing is undertaken in line with local policies on this and confidentiality.
National AIDS Trust	Short	4 and 13	7 14	Question 2: It is well recognised that transition is a time when young people living with HIV may be lost to follow-up because of real and perceived fears concerning the new environment of adult care. Studies have identified that lack of confidence in negotiating	Thank you for your comment which provides useful contextual information. Thank you for your comment. The guideline covers a very wide range of young people and services so it was not possible to list all relevant conditions and

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				adult services, stigma associated with HIV and fear of ending life-long patient/carer relationships are barriers to effective transition.[3,4] Moreover it can be particularly difficult for young people to move from paediatric clinical services into adult provision in sexual health clinics that can seem both alienating and irrelevant. These challenges of transition must be addressed through joined-up working of paediatric and adult services. Again, NAT recommends that the guidelines include reference to condition-specific standards which will provide more detail than generic guidance. For example, CHIVA guidance[5] recognises three distinct models of transition which take into consideration the specific concerns relating to HIV care: integration of services in a family clinic; 'handing over' care from paediatric to adult specialist services; and creating a specialist youth clinic.[6] [10] Bundock, H., Tudor-Williams, G., McDonald, S. et al. 'Crossing the Divide: Transitional Care for Young Adults with HIV- Their Views', 2011, AIDS Pt care & STDs, 25(8):465-73	needs separately. As a result, and recognising that, as you highlight, it needs to address the diverse needs of wide range of young people, the Guideline Committee sought to establish the broad principles to follow with respect to care and support before, during and after transition. Young people with HIV are included in the guideline.

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				[11] Children and Young people HIV Network, 'Just Normal Young People: Supporting young people living with HIV in their transition to adulthood', 2011 [http://www.ncb.org.uk/media/470465/justnormalyoungpeople-hivnetworktransitionreport.pdf] [12] CHIVA, 2010 *ibid* [13] See Children and Young People HIV Network, 2011 *ibid* for examples of best practice.	
National AIDS Trust	Short	4 and 8	15 19	Question 2: NAT welcomes both the recommendations to have a named worker co-ordinating transition care and support, and that a named worker from the nominated adult service should meet the young person before transition. However, NAT believes that it is important for a named lead in adult services to be involved in co-ordinating transition, rather than just meeting with the young person living with HIV. This is in line with standard 9 in CHIVA Standards of Care which states that "A lead for transition should be identified in both adult and paediatric services".[7] [14] CHIVA, 2013 *ibid*, p.27	Thank you for your comment. We did not find evidence on this specifically, additional explicit references to adult services have been included in the guideline, to make clear where responsibilities for recommendations are shared (see over-arching recommendation 1.1.5 and recommendations 1.3.1, 1.3.2, 1.3.4, 1.4.4).
National AIDS Trust	Short	7	1 26-28	NAT welcomes the recognition in the guidelines that it is important to build independence among young people. However, the recommendations emphasise independence only in relation to social support services. NAT would welcome strengthened	Thank you for your comment. Self-management of medical conditions is addressed explicitly in recommendation 1.2.17.

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				recommendations on independence in relation to the medical condition management and decision-making as well as around broader social independence. This is in line with CHIVA guidance on 'encouraging autonomy'.[8] CHIVA recommends that autonomy is encouraged in the young person prior to transition by increasing time spent alone with paediatric healthcare professionals and by introducing the young person to the adult healthcare team. [15] CHIVA, 2010 *ibid*, p. 7	
National AIDS Trust	Short	8	4 , 10	Question 6: NAT supports the recommendations made with respect to the involvement of parents and carers. However, sometimes a parent or carer will not be aware of a young person's HIV status. The guidelines should recognise that the young person's consent should also be sought when sharing information with parents and carers.	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers

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					in recommendation 1.3.7 about information provision.
National AIDS Trust	Short	9	10	Question 2: NAT welcomes the recommendation to keep young people and their families (where approved by the young person) informed about the transition process, but would like to see the guideline strengthened and its importance stressed. The Children's HIV Association (CHIVA) guidance on transition[9] states that every young person should have a documented transition plan and that having written information about transition services available in a clinic "can help both young people and their carers see the way forward". The Paediatric HIV Psychology Group Standards for Care[10] documents the importance of maintaining a plan for psychological wellbeing during the transition process from child to adult health services. Standard 6 advocates a clear, planned and structured transition process, and notes evidence that good transition programmes have provided clinical benefits whereas studies have identified poorer clinical outcomes when the transition process was not given sufficient attention. [6] Children's HIV Association, 'CHIVA Guidance on Transition for adolescents living with HIV', 2010 [http://www.chiva.org.uk/files/1214/2857/8197/transitio	Thank you for your comments and support for the guideline.

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				n.pdf], p.7	
National AIDS Trust	Short	10	19	Question 6: NAT recognises the importance of making every effort to re-engage young people who have been lost in follow-up, and recognises that involving relevant professionals and family members could be an effective strategy. However it is important that confidentiality be respected across and after the transition period. Not all care and support staff, family members, and GPs will know the HIV-status of the young person, and this should be carefully considered when contacting these individuals.	Thank you for your comment. Following discussion of stakeholder comments at Guideline Committee 12, however, we have made explicit reference to local information-sharing and confidentiality protocols in recommendation 1.1.7, recognising the importance and complexity of this.
National AIDS Trust	Short	11	9	Question 2: NAT recognises that training of health and social care staff can be understood as a lesser priority at a time of increased pressure on resources for public services. However, given the lack of understanding about HIV among non-specialist health and care staff, NAT recommends that guidelines on staff training and development include reference to stigmatised conditions and patients' rights concerning disclosure and confidentiality.	Thank you for your comment. The Committee did consider training to be an important area to address and, to this end, it is referenced in the implementation chapter, specifically in relation to improving front-line practice with young people. Given the wide range of young people covered by the guideline, it was not possible to list every aspect of training. In the implementation chapter, therefore the Committee sought to provide over-arching headings that specify the key broad areas to address. Patients' rights could come under 'the legal context and framework'.
National AIDS Trust	Short	13	9	Adults living with HIV are routinely ineligible for statutory social care, and while the importance of support services in relation to treatment adherence and self-management is widely recognised such provision is increasingly threatened. Thus NAT suggests that people living with stigmatised conditions, such as HIV, are included in the list of young people who are paid particular attention in the gap analysis for service provision.	Thank you for your comment. The guideline covers a very wide range of young people and services so it was not possible to list all relevant conditions and needs separately. The guideline's focus on broad principles rather than condition-specific interventions has been highlighted in the Equality Impact Assessment. Young people with HIV are included in the guideline.

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National Association of Paediatric Chartered Physiotherapists	Short	general	general	Special schools tend to transition well as they share school teams on site, but poor availability if age appropriate placement for Physical and Multiple Learning Disability PMLD /Gross Motor Function Classification Score 5 (GMFCS) indicating severe disabilities.	Thank you for your comment which provides useful context.
National Association of Paediatric Chartered Physiotherapists	Short	general	general	Equipment- could we not aim to provide the transitioning child with the adult sized equipment they now require and let them keep it , reducing transition anxiety and appointments.	Thank you for your comment. The review work did not find any effectiveness evidence to indicate that a recommendation on providing transitioning children with adult sized equipment could be made.
National Association of Paediatric Chartered Physiotherapists	Short	general	general	Generally, this approach seems holistic and person-centred	Thank you for your comment and support for the guideline.
National Association of Paediatric Chartered Physiotherapists	Short	general	general	Most of the adult services don't exist for this client group	Thank you for your comment. The Committee recognised the need to ensure that young people do not "fall through the gap" where they are not eligible for support when they reach adult services, or services are not available. This informed recommendations 1.5.5, 1.5.6 and 1.5.7.
National Association of Paediatric Chartered Physiotherapists	Short	general	general	Transitional social workers (Adult team) are already considerably overstretched and it is impossible to chase up those who do not attend or who do not engage.	Thank you for your comment. The Guideline Committee included a range of stakeholders with experience of practice in health and social care. They considered the recommendations that try to address disengagement and follow-up – 1.4.1 to 1.4.3 - to be aspirational but achievable. In addition, please see the chapter on implementation which provides some practical examples of how challenges could be overcome. In particular, there is a section on maximising opportunities for young people who have

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					become disengaged or who are not eligible for adults' services to access care and support.
National Association of Paediatric Chartered Physiotherapists	Short	general	general	The strong inclusion of the young person and the services highlighted here will require considerable investment. However, a good transition may save the NHS in many ways`; less complaints, better mental health, less reliance on services and more independence for families.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
National Association of Paediatric Chartered Physiotherapists	Short	general	general	Transitioned young person to become a transition champion to advocate for others ? Hemihelp magazine regularly publish stories of young people who have done unusual things and give inspiration to all their readers.	Thank you for your comments and example which will be considered as part of the work to support guideline implementation.
National Association of Paediatric Chartered Physiotherapists	Short	general	general	Could a new post be created to continue the role of Paediatrician- a chronic conditions specialist, who has experience of the childhood conditions and understands their background, so that parents and adolescents don't have to fear the great unknown all over again.	Thank you for your comment. The Committee did not wish to be too prescriptive in the guideline – setting out instead the broad principles rather than the specifics of implementation. This was in recognition of the fact that that local implementation will vary.
National Association of Paediatric Chartered Physiotherapists	short	2	20	Guidance should be planned with both children's and adult services, along with input from families- logistically could be difficult to complete, but feasible to create a representative "working party" between services and perhaps with young people/parents post transition.	Thank you for your comments. The Guideline Committee agreed that joint working was an important issue to address and, to this end, referenced it explicitly in recommendations 1.1.5 and 1.5.10 and 1.5.11. Please see also the chapter on implementation which provides some practical examples of how challenges could be overcome. In particular, there is a section on joint planning, development and commissioning of transition support.
National Association of	short	5	15	Single named worker- sounds great/helpful, logistically would add time and potential cost to caseloads	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and

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Paediatric Chartered Physiotherapists					responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). Specifically, you will note that we have made clearer this is a role not a job title and therefore could be undertaken by someone who is already fulfilling a role of keyworker, coordinator or transition support worker. The Guideline Committee were clear that this may not necessitate additional funding.
National Association of Paediatric Chartered Physiotherapists	short	5	24	6 months before and after as minimum for named worker- logistically how would this work with individuals being discharged/transferred from paediatric to adult services- would they both need to have have an "open" case?How would funding work? If a more flexible transfer age or team is to be established, how would this be funded?	Thank you for your comment. It is important to note that this time period (recommendation 1.2.8) relates to the minimum length of time the Committee thought it would be appropriate for the named worker to be involved and not to transition planning and support more widely which: - should start early 'from year 9 (age 13 or 14) at the latest (as indicated in recommendation 1.2.1s and 1.2.3) - should be developmentally appropriate (1.1.2, 1.2.3 and 1.5.11), and - should be reviewed annually (1.2.4) The Committee emphasised throughout development the importance of ensuring that support is person-centred. This is referenced explicitly in recommendations 1.1.1, 1.1.2, 1.2.4 (which was updated to this end, following discussion at Guideline Committee meeting 12), 1.2.9 and 1.2.19.
National	short	5	27	SEN schools tend to do annual person centred review until final year, when transition meetings are termly	Thank you for your comment which provides useful contextual information.

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Association of Paediatric Chartered Physiotherapists				and multi-agency	
National Association of Paediatric Chartered Physiotherapists	short	8	22	Contingency plan- difficult to staff in already stretched services	Thank you for your comment. The Committee recognised that this was challenging, but thought it important that there was always contingency in place to ensure consistent transition support. They also considered all recommendations aspirational but achievable, although recognised there may be implementation challenges in some cases. However your comment will be considered as part of work to support implementation of the Guideline.
National Association of Paediatric Chartered Physiotherapists	short	8	25	Should this be done in conjunction with schools and education health plans (EHP) where appropriate, where they already produce 1 page profiles, goals, summary of health info?	Thank you for your comment. Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level. While not all young people covered by the guideline will have an EHCP, it is possible, where these exist, for practitioners to agree that one-page profiles could be developed in collaboration with education practitioners.
National Association of Paediatric Chartered Physiotherapists	short	9	4	To include level of mobility; transfer -ability; access -ability	These are only examples of the types of content that may be useful, based on evidence and expert witness presentations. Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level.
National Association of Paediatric Chartered	short	9	20	Also include realistic specialist career advice here; not just benefit advice, which although important reduces expectations and presumes that they will never work.	Thank you for your comment. This is covered elsewhere in the guideline, development of the four over-arching outcome areas referenced throughout, specifically: - education and employment

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Physiotherapists					- community inclusion - health and wellbeing including emotional health - independent living and housing options. These areas are included in recommendation 1.2.8, the Training section of the Implementation chapter, and in the definition of 'person-centred' ('Terms used in this guideline').
National Association of Paediatric Chartered Physiotherapists	short	10	22	Is this a feasible expectation? Are there communication networks in place to link back? Is the key worker able to keep the individual on their caseload?is the named worker going to be able to support this? Does the named worker have enough knowledge in this area?10	Thank you for your comment. While recognising the implementation challenges, the Guideline Committee considered this aspirational but achievable. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7).
National Association of Paediatric Chartered Physiotherapists	short	11	9	Mostly this is normal practice currently for training AHPs, especially community workers who are more likely to be in positions to be supporting transition of long term patients. It may be a training need for more specialist areas/acute teams/adult teams.	Thank you for your comment and support for this recommendation.
National Association of Paediatric Chartered Physiotherapists	short	12	3	Gap analysis and pooled budgets- who will fund these and under what directive?	Thank you for your comment. Funding is not within the remit of NICE guidance which seeks to set out 'what works'. The Committee intended that gap analysis takes place at a locality level and therefore this is likely to be a task that commissioners would undertake. It will be complemented by a resource for commissioners. The previous reference to pooled budgets has been

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					removed from the recommendations as it was noted that this is not within the remit for NICE guidance; however, there is reference to funding mechanisms within the implementation section.
National Association of Paediatric Chartered Physiotherapists	short	12	15	Very general statement and promise- who will fund it?	Thank you for your comment. This has been edited so that it is a 'consider' recommendation to reflect the fact that this is based on weaker evidence. Funding is not within the remit of NICE guidance which seeks to set out 'what works'. It will be complemented by a resource for commissioners.
National Association of Paediatric Chartered Physiotherapists	short	12	18	What is meant by "integrated" in this context? Not all young people identify as being disabled even if they have additional needs. In whose interest is it to have focus groups of transitioning children when each young person's needs are different, especially if our aim is to integrate them into their community as much as possible?	Thank you for your comment. The focus is on joined-up forums, that is to say, so young people do not have to give the same feedback several times to several different organisations.
National Association of Paediatric Chartered Physiotherapists	short	13	17	Pooled budget makes sense to help the flow of funding provision for equipment and staff- but logistically how does it work?	Thank you for your comment. The previous reference to pooled budgets has been removed from the recommendations as it was noted that this is not within the remit for NICE guidance; however, there is reference to funding mechanisms within the implementation section.
National Development Team for Inclusion	Full	1	5	Report needs to pay more attention to the Preparing for Adulthood aspects of the SEN reforms and the wellbeing outcome in the Care Act Both pieces of legislation require everyone working with young people SEND to plan for key life chances, employment, independent living, being part of your community and good health. The SEND code requires everyone including social care to support people to achieve these life outcomes.	Thank you for your comment. Young people with special educational needs are included in the guideline and were discussed explicitly as part of guideline development, as was the need to address wellbeing. The Committee were mindful, however, not to repeat the provisions of existing legislation. The Committee discussed the need to support each young person "as a whole" and to recognise them in the wider context. To this end, the recommendations make reference to those supporting young people needing to take account of the following areas:

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					- education and employment - community inclusion - health and wellbeing including emotional health - independent living and housing options. These areas are included in recommendation 1.2.8,the Training section of the Implementation chapter, and in the definition of 'person-centred' ('Terms used in this guideline').
National Development Team for Inclusion	Full	7	24	There is also a much greater emphasis on diagnosis in adult mental health services	Thank you for your comment.
National Development Team for Inclusion	Full	8	17	I think it would be good to use this opportunity to re-emphasise the opportunity for local authorities to integrate care and support from 0-25 across education, health and care. Planning needs to happen early to ensure everything is in place for when someone turns 18. Especially for those in out of area provision	Thank you for your comment. There is an over-arching recommendation (1.1.3) about integrated working across children's and adults' services in health and social care services. The Committee also discussed the particular need for early planning in respect of young people in out of area provision, which informed recommendation 1.2.2).
National Development Team for Inclusion	Full	10	1	Person centred care and support to mirror the Care Act	Thank you for your comment. The context section of the guideline references the Care Act to make the implementation context clear. The existing over-arching recommendations on person-centred care (1.1.1 to 1.1.4) were thought to be sufficient for emphasising a person-centred approach.
National Development Team for	Full	11	7	Include the Children and Families Act. Both Care Act and Children and Families Act focus on life outcomes and a social model in the former these are Wellbeing outcomes and in the latter Preparing for Adulthood	Thank you for your comment. Young people with special educational needs are included in the guideline and were discussed explicitly as part of guideline development, as was the need to address wellbeing.

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Inclusion				outcomes. NICE guidelines must highlight professionals and commissioners responsibilities to support young people and their families to plan for these outcomes. Both acts require professionals to work together to focus on improving outcomes as well as a good transfer from children to adult services. This could be stronger and must reflect the SEND code of practice.	The Committee were mindful, however, not to repeat the provisions of existing legislation. The Committee discussed the need to support each young person "as a whole" and to help them achieve the wider outcomes they would like to. To this end, the recommendations make reference to those supporting young people needing to take account of the following areas: - education and employment - community inclusion - health and wellbeing including emotional health - independent living and housing options. These areas are included in recommendation 1.2.8, the Training section of the implementation chapter and in the definition of 'person-centred' ('Terms used in this guideline').
National Development Team for Inclusion	Full	12	7	Co production, person centred life outcome focus are key to positive transitions. Employment, independent living, being part of your community and good health.	Thank you for your comment and support for the guideline.
National Development Team for Inclusion	Full	16	18	Include young people who have been through transition	Thank you for your comment on the recommendation about peer support groups (1.2.14). The Committee agreed that the wording of this recommendation should not be overly prescriptive, however, has been updated to reflect the fact that peer support may include specific support groups or charities (which could be condition-specific). The recommendation does not preclude the involvement of young people who have been through transition.

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National Development Team for Inclusion	Full	16	25	Include universal provision and the local offer	Thank you for your comment. The Committee have considered the wording of all recommendations carefully, to ensure they allow flexibility in terms of implementation at the local level. The need to align recommendations with local arrangements is referenced explicitly in 1.1.5, 1.5.5 and 1.5.7. In terms of universal provision, the Guideline Committee thought it most important to strengthen reference to GP involvement in the guideline, following discussion in meeting 12 (04.11.15) taking into account stakeholder comments. To this end, they have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
National Development Team for Inclusion	Full	18	5	this could happen through a review process that the young person has direct input to. have a look at http://www.preparingforadulthood.org.uk/media/385562/2upload.pfatoolkit.pdf	Thank you for your comment and reference to the toolkit which is helpful for us to consider as part of our work to support implementation of the guideline.
National Development Team for Inclusion	Full	19	19	Insufficient mention of personal budgets including personal health budgets and personal education budgets and the integration of those to support better life outcomes for young people	Thank you for your comment. Personal budgets are included as an example in recommendation 1.3.7.
National Development Team for Inclusion	Full	20	4	Should this reference the Mental Health Act	Thank you for your comment. The guideline covers a wide range of young people and therefore there will be a wide range of legislation and guidance relevant, including the Mental Health Act. The Committee were mindful not to repeat current legislation although recognised that the guideline will be interpreted within the wider legislative and policy context.

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National Development Team for Inclusion	Full	21	6	Person centred approaches!	Thank you for your comment. This is now referenced in the information about training within the chapter on Implementation.
National Development Team for Inclusion	Full	24	20	Needs expanding and some examples	Thank you for your comment. The definitions are intended to be succinct and the Guideline Committee considered the wording appropriate.
National Development Team for Inclusion	Full	28	18	this section needs to be more robust Joint approaches are pivotal to success in joint commissioning and reflected in current policy specifically in relation to young people who are at risk of poor outcomes such as those with Learning Disabilities and challenging behaviour.	The remit of NICE guidance is to identify 'what works'. It is then complemented by additional NICE support for commissioners. A number of recommendations indicate joint approaches including, for example, over-arching recommendation 1.1.3, 1.2.2, 1.1.5,1.3.5, 1.6.9 and 1.6.11.
National Development Team for Inclusion	Full	49	15	Person centred and accessible information rather than age appropriate this is more in keeping with national strategies such as Valuing People	Thank you for your comment and support for the guideline.
National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC)	FULL	General	general	**NIHR (NETSCC) Submission** **Methodology:** NETSCC has reviewed the portfolio of studies across its 4 four programmes. The studies of relevance to service research are all from the Health Services & Delivery Research Programme, and the prior Service Delivery and Organisation programme. The following are the studies that give some evidence relevant to the draft recommendations. More detail is available via the portfolio tab on the NETSCC website for each study. GAPS: The research to date does not have service studies of	Thank you for your comments and the references.

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				transition of some important groups- such as those with sensory impairments, potentially life limiting diseases such as cystic fibrosis and childhood cancers, which will have quite specific pathways of care, and where the costs and other adverse consequences of poor transition may be particularly high. As research topic this could be referred to NETSCC to commission research to produce common interventions and organisational processes. In addition, we draw your attention to the recommendations that could be part of our next prioritisation process (currently open) are indicated below *. **Active** 1) HS&DR 14/21/52: Young people with Attention Deficit Hyperactivity Disorder (ADHD) in transition from children's services to adult services (Catch-uS): a mixed methods project using national surveillance, qualitative and mapping studies. PI Tamsin Ford (University of Exeter). 29/01/2015 -31/10/2018. Status: Post contract set up. 2) HS&DR 13/54/25: Transitions from paediatric to adult services for sickle cell disease (SCD): a prospective qualitative study examining young adult patients' experiences. PI Cicely Marston (LSHTM). Status: active. 01/04/2015-31/08/2018 3) HS&DR 12/136/70: The impact of different patterns of care on the long-term outcome of adolescent conduct disorder: a mixed methods study comparing multisystemic therapy (MST) and management as usual (MAU). PI Peter Fonagy (UCL). Status: active. 01/01/2014- 31/12/2017. 4) HS&DR 14/19/51: A Rapid Evidence synthesis of Outcomes and Care Utilisation following Self-care support for children and adolescents with long term	

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				conditions (REfOCUS): Reducing care utilisation without comprising health outcomes. PI Penny Bee (University of Manchester). Status: active. 01/03/2015 – 30/06/2016. **Published** 1) HS&DR 11/1024/08: An evidence synthesis of risk identification, assessment and management for young people using tier 4 inpatient child and adolescent mental health services. PI Ben Hannigan (Cardiff University) Published 2015 Vol 3 (22). http://www.journalslibrary.nihr.ac.uk/hsdr/volume-3/issue-22#abstract 2) HS&DR 08/1613/117: Transition from CAMHS to adult mental health services (TRACK): a study of policies, process and user and carer perspective. PI Swaran Singh (University of Warwick). Published 2010. http://www.nets.nihr.ac.uk/projects/hsdr/081613117 3) HS&DR 08/1504/107: The transition from paediatric to adult diabetes services: what works, for whom and in what circumstances? PI Davina Allen (Cardiff University) Published 2010 http://www.nets.nihr.ac.uk/projects/hsdr/081504107 4) HS&DR 08/1109/011: Transitions from child to adult health and social care services for people with disabilities or chronic diseases: what is good practice in ensuring continuity of care? PI Alison White. Published 2002. Forbes A, While A, Ullman R, Lewis S, Mathes L, Griffiths P, aided by Ritchie G, Donlan P and Fenwick K. A multi-method review to identify components of practice which may promote continuity in the transition from child to adult care for young people with chronic illness or disability. http://www.nets.nihr.ac.uk/projects/hsdr/081109011 http://www.nets.nihr.ac.uk/__data/assets/pdf_file/0003/	

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				81237/BP-08-1109-011.pdf (2002) 5) 08/1305/068: The contribution of nurses, midwives and health visitors to child health and child health services: a scoping review. PI Alison White (King's College London). Published 2005 http://www.nets.nihr.ac.uk/__data/assets/pdf_file/0003/64470/FR-08-1305-068.pdf	
National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC)	FULL	25	7	**1 Transition support for young adults** o What approaches to providing transition support for those who move from children's to adults' services are effective and/or cost-effective? 14/21/52: Young people with Attention Deficit Hyperactivity Disorder (ADHD) in transition from children's services to adult services (Catch-uS): a mixed methods project using national surveillance, qualitative and mapping studies. PI Tamsin Ford (University of Exeter). 29/01/2015 -31/10/2018. Status: Post contract set up. 13/54/25: Transitions from paediatric to adult services for sickle cell disease (SCD): a prospective qualitative study examining young adult patients' experiences. Status: active. 11/1024/08: An evidence synthesis of risk identification, assessment and management for young people using tier 4 inpatient child and adolescent mental health services. 08/1504/107: The transition from paediatric to adult diabetes services: what works, for whom and in what circumstances 08/1613/117: Transition from CAMHS to adult mental	Thank you for your comment.

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				health services (TRACK): a study of policies, process and user and carer perspective. PI Swaran Singh (University of Warwick). Published 2010. 08/1109/011: Transitions from child to adult health and social care services for people with disabilities or chronic diseases: what is good practice in ensuring continuity of care? PI Alison White. Published 2002.	
National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC)	FULL	25	18	Published 2002. **2 The role of families in supporting young adults discharged from children's services** o What is the most effective way of helping families to support young people 4 who have been discharged from children's services (whether or not they meet criteria for adults' services)? 08/1613/117: Transition from CAMHS to adult mental health services (TRACK): a study of policies, process and user and carer perspective. PI Swaran Singh (University of Warwick). Published 2010. 08/1504/107: The transition from paediatric to adult diabetes services: what works, for whom and in what circumstances 08/1109/011: Transitions from child to adult health and social care services for people with disabilities or chronic diseases: what is good practice in ensuring continuity of care? PI Alison White. Published 2002.	Thank you for your comment.
National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre	FULL	26	7	**3 The role of primary care in supporting young people discharged from children's services*** o What are the most effective ways for primary care services to be involved in planning, implementing and following-up young people in transition (whether or not they meet criteria	Thank you for your comment.

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(NETSCC)				for adults' services)? 08/1109/011: Transitions from child to adult health and social care services for people with disabilities or chronic diseases: what is good practice in ensuring continuity of care? PI Alison White. Published 2002. * Given the paucity of research on GP provision in this field and the known pressures on primary care, along with the pressure to transform p[primary care, this topic would be of particular interest to NETSCC.	
National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC)	FULL	26	20	**4. The consequences and costs of poor transition** o What are the consequences and the costs of young people with ongoing needs not making a transition into adults' services, or being poor supported through the process? HS&DR 14/21/52: Young people with Attention Deficit Hyperactivity Disorder (ADHD) in transition from children's services to adult services (Catch-uS): a mixed methods project using national surveillance, qualitative and mapping studies. PI Tamsin Ford (University of Exeter). 29/01/2015 -31/10/2018. Status: Post contract set up.	Thank you for your comment.
National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC)	FULL	27	1	**5 Support to carers and practitioners to help young people's independence** o What is the most effective way to help carers and practitioners support young people's independence? 08/1613/117: Transition from CAMHS to adult mental health services (TRACK): a study of policies, process and user and carer perspective. PI Swaran Singh (University of Warwick). Published 2010. 08/1504/107: The transition from paediatric to adult	Thank you for your comment.

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				diabetes services: what works, for whom and in what circumstances.	
National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC)	FULL	27	10	**6 Supporting young people to manage their conditions** o What is the relationship between transition and subsequent self-management? 13/54/25: Transitions from paediatric to adult services for sickle cell disease (SCD): a prospective qualitative study examining young adult patients' experiences. Status: active 14/19/51: A Rapid Evidence synthesis of Outcomes and Care Utilisation following Self-care support for children and adolescents with long term conditions (REfOCUS): Reducing care utilisation without comprising health outcomes. Status: active 08/1109/011: Transitions from child to adult health and social care services for people with disabilities or chronic diseases: what is good practice in ensuring continuity of care? PI Alison White. Published 2002.	Thank you for your comment.
National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC)	FULL	27 -28	23 -3	**7 Transition in special groups: young offenders institutions*** o What is the most effective way of supporting young offenders transitioning from children's to adults' health and social care services? Relevant primary outcome in -12/136/70: The impact of different patterns of care on the long-term outcome of adolescent conduct disorder: a mixed methods study comparing multisystemic therapy (MST) and management as usual (MAU). PI Peter Fonagy (UCL). Status: active. *The health of young offenders , as well as looked after	Thank you for your comment and signpost to active research in this area. Researchers submitting proposals for future research in line with the guideline's research recommendations should take into account work already in progress.

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				children, and of particular priority in the NHS/Public Health, so would be interest to NETSCC programmes, and where there is a paucity of prior research on organisational interventions. **8 Transition in special groups: looked-after young people*** o What is the most effective way of supporting care leavers in transitioning from children's to adults' health services? *See comment above.	
National Kidney Federation	Full	general	general	Whilst we recognise this document is a generic draft guideline it is to be thoroughly welcomed. The pathway of care for Chronic Kidney Disease patients whether on dialysis or transplanted requires complex ongoing support from a multidisciplinary team. Aside from the treatment itself, education and empowerment is central to what is a long-term condition and for those who suffer CKD from a young age can often be described as a 'career'. We believe through our 'kidney community' that an age to start transition should be as early as possible to give time to an individual and their learning needs and while this can be variable an age of 11 years old has been suggested through the *'Ready, Steady, Go'* programme which was highlighted at a recent Home Therapies Conference. Transition into adult services for young adult kidney patients accompanied by a package of full support both through named contacts and with education will hopefully provide confidence and familiarity which could hopefully minimise risks associated with non-concordance of medication or treatment. Having such a guideline in place will strengthen the support for more disease-specific programmes which as the one	Thank you for your comment and support for the guideline.

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				mentioned we believe support and empower patients in their long-term health.	
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	General	General	Q1: Biggest impact on named worker responsible for young person once transitioned. They may have to learn about, health issues, social issues, educational issues that they have been through and how this has impacted on their adult life Q2: Shared IT systems to have full information and full access to relevant information. Have joint educational events for child and adult services including health and education and social care. Financial support needed for training events, multidisciplinary team working to provide good service to youngperson but difficulty in having central place suitable for all. Time consuming and impact on current workload. Q3: Key audiences at secondary/high schools as teenage years/adolescence there/ Also parents/carers. Q4: Transition starting in different areas from age 11-13 average depending also on child development. Q5: Depends on transition service available locally. Q6: Parents should be involved at the decision process for taking transition forward Q7: Definite increase in costs particularly as more time consuming so likely more staff needed. Time out initially for education sessions. Q9: Potentially with good transition should lead to smoother transfer to adult services and have more support for the young person which may lead to better self management/empowerment in managing health	Thank you for your comments. Please see the chapter on implementation which provides some practical examples of how challenges could be overcome. In particular, there is a section on joint planning, delivery and commissioning of transition services, as well as improving front-line practice with young people through training. Teenagers and parents and carers were considered as key audiences throughout guideline development. The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review

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				and well-being. Leading perhaps to less reliance on services and long term costs savings	- referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	General	General	Is this guideline too big to combine both social and health care together with achievable results?	Thank you for your comment. The guideline does indeed cover a wide range of young people and services. The Guideline Committee considered all recommendations aspirational but achievable, although recognised there may be implementation challenges in some cases.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	General	General	Is NICE aware of other documentation on transition such as 'Ready Steady Go Hello'?	Thank you for your comment. The Committee did indeed recognise that a wide range of guidance on transition exists. This guideline seeks to define the broad principles of care and support for transition.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	General	General	Feedback from all services and young person and family about transition process.	Thank you for your comment. The Guideline Committee agreed on the importance of mechanisms to enable young people to feed In to service design and evaluation at the locality level and, in addition to the over-arching recommendation 1.1.1, recommendations 1.5.4 and 1.5.5 also address this more specifically.

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National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	3	22	Will this be achievable?	Thank you for your comment. The Guideline Committee considered all recommendations aspirational but achievable, although recognised there may be implementation challenges in some cases. Please see the chapter on implementation which provides some practical examples of how challenges could be overcome.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	4	4 -6	Some areas may have difficulty in establishing documents which are' jointly agreed'	Thank you for your comment. This is provided only as an example in recommendation 1.1.4.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	4	6	Would consider changing protocols to guidelines	Thank you for your comment. The Guideline Committee agreed with the word protocols which reflected the evidence.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	4	14	'named worker' should be noted to be someone they trust and who knows them, and who t they agree to be named worker	Thank you for your comment. These points are intended to be covered by the existing recommendation wording - 'The named worker should be someone with whom the young person has a meaningful relationship' (within 1.2.6) The Committee discussed the wording of 1.2.5, taking into account your comment, and agreed it was appropriate as it is.
National Paediatric	Short	4	15	Who should help them identify a named worker? Can there be more than 1? E.g from health and other from education?	Thank you for your comment which was discussed in Guideline Committee meeting 12 (05.11.15). Given the very wide variety of contexts in which this guideline will be implemented, the Committee agreed not to specify

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Respiratory and Allergy Nurses Group (NPRANG)					who should help the young person identify a named worker (recommendation 1.2.5).
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	4	22	What is meant by meaningful relationship?	Thank you for your comment. This was intended to reflect the fact that this person should know and be known to the young person; someone the young person feels comfortable with.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	5	12	How can the named person help in this way	Thank you for your comment. The wording of recommendation 1.2.7 has been updated to make clear it is not the responsibility of the named worker to undertake all of these tasks, but to 'oversee, coordinate or deliver transition support, depending on the nature of their role'
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	5	23	What is meant be 'relevant legislation'?	Thank you for your comment. The guideline covers a wide range of young people and therefore there will be implementing the guidance within the context of a wide range of legislation and guidance. The Committee were mindful not to repeat current legislation and nor would it be possible to list all legislation that may be applicable to the young people and services covered by the guideline.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	5	24	6 Months may not be an adequate length of time to know enough about the young person to support them	Thank you for your comment. It is important to note that this time period (recommendation 1.2.9) relates to the minimum length of time the Committee thought it would be appropriate for the named worker to be involved and not to transition planning and support more widely which: - should start early 'from year 9 (age 13 or 14) at the latest (as indicated in recommendation 1.2.1s and 1.2.3)

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					- should be developmentally appropriate (1.1.2, 1.2.3 and 1.5.11), and - should be reviewed annually (1.2.4) The Committee emphasised throughout development the importance of ensuring that support is person-centred. This is referenced explicitly in recommendations 1.1.1, 1.1.2, 1.2.4 (which was updated to this end, following discussion at Guideline Committee meeting 12), 1.2.9 and 1.2.19.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	5	30	Need a maximum age limit perhaps note 'transfer by age XX'? as child services staff may not be adult focused/trained as most young people in paediatric health care are seen as adults once 16 or 18	Thank you for your comments. The Guideline Committee did not think it appropriate to specify a maximum period of time for the named worker to provide support post-transfer (recommendation 1.2.9) given the very wide range of young people covered by this guideline. The Committee agreed about the need to ensure transition support is developmentally appropriate and this is referenced in recommendations 1.1.2 and 1.5.11 explicitly.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	6	3	change involve to invite	Thank you for your comment. The Guideline Committee reviewed the recommendations on timing and review (under section 1.2) at Committee Meeting 12 (04.11.15) and agreed the edited wording now found in recommendation 1.2.4 which includes making clear that practitioners could take part in meetings via teleconferencing or video, recognising the pressures on people's time.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	6	9	Who are these groups? What legislation?	Thank you for your comment. This detail is provided in the footnote associated with recommendation 1.2.1. Specifically: 'For young people with education, health and care (EHC) plans, this **must** happen from year 9, as set out in the Children and Families Act 2014. For young people leaving care, this **must** happen from age 15-and-a-half.'

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National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	6	16 -19	Need examples of good practice – of what is available and works effectively	Thank you for your comments which will be considered as part of the work to support guideline implementation. Further implementation work will seek to identify further examples of good practice.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	6	22	Are there examples of these being used in areas? Are they effective for both young person and practitioner?	Thank you for your comment. We included examples only where these emerged from evidence.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	7	9	What are 'non statutory services'?	Thank you for your comment. Statutory services are organisations required by law. Non-statutory services are those which provide services but which are not enshrined in law.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	7	11	What is the criteria? What is a statutory adult service?	Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed criteria to be used to implement the recommendations at the local level. Statutory services are organisations required by law.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	10	3 -5	There can be big gaps between agencies, and between child and adult agencies.	Thank you for your comments which will be considered as part of the work to support guideline implementation.

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National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	10	19 -21	How vigorous will the 'chasing up' be with the young person if they fail to engage?	Thank you for your comment. Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	10	24	Why refer back to named person in childrens services if young person has moved to adult services?	Thank you for your comment. Recommendation 1.2.9 makes clear that the named worker should support the young person for at least six months following transition. This was to ensure there is continuity and consistency for the young person, before and after the point of transfer.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	12	15	Unclear what 'independent advocacy' involves	Thank you for your comment. The Guideline Committee agreed this term was appropriate for describing provision of independent support to the young person in accessing or using the help they need.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	15	16 -17	Biggest impact on named person/worker responsible for young person once transitioned, particularly challenging if they fail to engage with adult services	Thank you for your comments which will be considered as part of the work to support guideline implementation.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	15	18	Parents/carers/guardians should be involved from the start of the journey while encouraging and empowering the young person to become independent	Thank you for your comment.

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National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	16	2 -3	Need to have a mutual understanding of each others services	Thank you for your comment.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	16	8 -9	Communication skills and systems, involvement of family and the inpatient environment	Thank you for your comments which will be considered as part of the work to support guideline implementation.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	16	18	Children often seen in specialist tertiary centres transitioning to Primary care or secondary care	Thank you for your comment.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	17	2 -6	This will be a major challenge both financially and fromchildrens and adult services having an understanding of how the other works, and resources available.	Thank you for your comment. The previous reference to pooled budgets has been removed from the recommendations as it was noted that this is not within the remit for NICE guidance; however, there is reference to funding mechanisms within the implementation section.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	17	9	Funding to include time for care pathway development, handover and multidisciplinary team working. This should be commissioning criteria	Thank you for your comment. Commissioning is not within the remit for NICE guidance, however, NICE will produce a complementary resource for commissioners to support the guideline implementation.

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National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	18	1	Advocacy needs also particularly for vulnerable children and young people. Also need to educate adult services on child, young person specific needs	Thank you for your comment.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	18	14	Robust system needed to have shared records preferably IT system with system in place to alert of any concerns	Thank you for your comment. It was not within the scope of this guideline to search for evidence on the effectiveness of shared records per se.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	18	14	Particular risk groups also any vulnerable children and young people, neglect, financial problems	Thank you for your comment. The guideline covers a very wide range of young people and services so the list reflected priority groups identified during development as being particularly at risk of 'falling through the gaps' between services, rather than being exhaustive.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	20	18	Qualitative questionnaire comparing practice, follow up and unscheduled care	Thank you for your comments which will be considered as part of the work to support guideline implementation
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	21	5	Research needed in Primary care on chronic conditions and self management	Thank you for your comments. Primary care for chronic conditions was not within the scope of the guideline.

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National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	21	5	Guidance throughout childrens services to empower families in managing health conditions. Encouraging them to engage with advice centres such as citizens advice, local council on support available.	Thank you for your comments. The research recommendations are sufficiently broad to allow researchers to propose studies that address any of the key aspects of the topic. Advice-seeking could be one element of work related to the role of primary care.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	21	18	Provide them with places to go for advice. Direct to relevant websites. Financials support for getting to appointments, prescription costs	Thank you for your comments . The research recommendations are sufficiently broad to allow researchers to propose studies that address any of the key aspects of the topic. Advice-provision could be one element of work related to the role of primary care.
National Paediatric Respiratory and Allergy Nurses Group (NPRANG)	Short	21	23	Primary care should be involved from the start of diagnosis through planning of care	The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).
Newcastle University Institute of Health and Society	Full	General	general	We think the broad recommendations of the Guideline are well judged and presented.	Thank you for your comment and support for the guideline.
Newcastle University Institute of Health and Society	Full	General	general	**Terminology.** We think terminology is very important and needs to be consistent – otherwise Commissioners and Providers may use terms differently, leading to misunderstanding and lack of action. We think there is some inconsistency in the draft Guideline. We agree the key definition of Transition (Full, Page 3 Line 8) is the correct one a "purposeful and planned process….." (DH and DfES reiterating the	Thank you for your comment and your support for the definition of 'transition' used.

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				Blum et al definition). And we agree about the distinction between Transition and Transfer Full, Page 6 Line 7. We will point out later where we think there is inconsistent use of these terms in some parts of the Guideline.	
Newcastle University Institute of Health and Society	Full	General	general	**Definitions.** We suggest that the section 'Terms Used' on Full, Pages 23 and 24 is moved to come after 'Recommendation Wording' on Full, Page 11. We also suggest that 'Developmentally Appropriate Health and Social Care' is defined in broad terms and placed in this section – we would be pleased to suggest a form of words if you wish. Allan Colver allan.colver@ncl.ac.uk	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), we have added a definition of 'developmentally appropriate' to the guideline (see 'Terms used in this guideline).
Newcastle University Institute of Health and Society	Full	General	general	**Transition Readiness.** This is mentioned in Full, Pages 17, 28, 33, 36, 38 48. We realise there is a considerable literature on this topic and a review of instruments to measure it. However, we are of the view that it is a flawed concept. First, if it were to have meaning, it should be 'Transfer readiness', not 'Transition readiness'. Transition is a process lasting some years and the idea of a point when a person is ready is meaningless. However, even if 'Transfer' readiness is intended, we think it is also flawed. It suggests there is a time, which can be measured and a cut off decided, when suddenly the person is ready to transfer from the children's health team to the adult team. In practice a young person will sometimes have the maturity to do this and perhaps some months later, especially if stressed for other reasons, might have less maturity for this. What is important is that both the paediatric	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), we have changed 'transition readiness' to 'transfer readiness', as suggested.

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				service and adult services provide 'Developmentally Appropriate Health and Social Care'. If they do this, the services will be able to manage the fluctuating maturity of the young person and will be able to respond appropriately. It also means that providers can set an age (whether 15, 16, 17 or 18) which suits both services (this seems helpful for administrative reasons) knowing that once transferred, the care will remain developmentally appropriate.	
Newcastle University Institute of Health and Society	Full	General	general	**Commissioning.** We think more attention should be paid in the Guideline to this. Apart from footnotes to commissioning documents, commissioning is only mentioned on Full, Page 54 Lines 9 &13, Page 63 Line 4, Page 82 Line 9 and covers 'feeding into the commissioning processes' and 'joint commissioning'. We realise that NICE cannot instruct Commissioners what to commission. However, we wonder whether there could be a specific recommendation about Commissioning. For instance that every Commissioning Organisation (NHS England, Clinical Commissioning Group, Health & Wellbeing Board) should make its expectation for transition explicit; and such an explicit statement should include how the statement has been agreed between child and adult commissioners of health or social care; and how agreed between commissioners of health, educational and social care.	Thank you for your comment. The remit of NICE guidance is to identify 'what works'. It is then complemented by additional NICE support for commissioners.
Newcastle University Institute of Health and Society	Full	General	general	**Large number of recommendations**. The draft Guideline contains many recommendations. Regarding Recommendations Full, Pages 12-23, there are 54 numbered points; this rises to 120 if the bullet points are included. We think (and have some evidence from our research)	Thank you for your comment. Given the wide range of young people covered by this guideline, its scope was to establish the broad principles to follow with respect to care and support before, during and after transition.

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				that in due course Commissioners and Providers would welcome a much smaller checklist of guidance that would enable them to be specific to staff about effective interventions. This would allow and require a consistency of approach across Transition and avoid each provider choosing the options they preferred from a large list. We hope that the results and recommendations of the Research Programme on Transition funded by NIHR Programme Grants for Applied Research will be able to inform this process. The research is not due to report until Summer 2017 but we hope it might then influence the operationalisation of the February 2016 NICE Guideline and any subsequent revisions. Contact Allan Colver allan.colver@ncl.ac.uk	A Quality Standard will be developed focusing on priority areas for performance improvement from the guideline – aimed at providers and commissioners. NICE guidelines are reviewed after two years and, where appropriate, updated in the light of any new evidence which was not published in time for inclusion in the original guideline.
Newcastle University Institute of Health and Society	Full	General	general	**Responsibilities of Adults Services**. Whilst the Guideline does frequently mention adult services, there are few places (Page 8 Line 17 (overarching principle); Page 13 Line 19 (both be proactive); Page 21 Line 16 (ownership); Page 23 Line 4 (pooled budgets) where it is clearly stated that Adult Services share with Paediatric Services the responsibility for planning and ensuring high quality transition. Often there is an impression that adult services are just there to receive young people. We suggest that the importance and responsibility of adult services are emphasised more strongly in the Guideline.	Thank you for your comment. Additional explicit references to adult services have been included in the guideline, to make clear where responsibilities for recommendations are shared (see over-arching recommendation 1.1.5 and recommendations 1.1.5, 1.3.2, 1.3.4 and section 1.4).
Newcastle University Institute of Health and Society	Full	General	general	**Your question 1. Which areas will have the biggest impact on practice and be challenging to implement?** We think there are two areas that would have the biggest impact on practice:	Thank you for your comments which will be considered as part of the work to support guideline implementation. The Implementation chapter of the guideline highlights some of the key challenges and ways to overcome them.

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				1. **Ownership**. As discussed in Full, Page 21. We think it is essential that transition is championed by senior executives and embedded in the managerial ethos and the expectations of child and adult health and social care providers. It will never be sustainable if only delivered in the short term by enthusiastic clinicians and field workers. **2. Developmentally Appropriate Health and Social Care.** As discussed on Full, Page 23. As an over-arching ethos to guide service design and delivery, this seems to us an essential principle. It may be challenging to implement; certainly training will be required.	
Newcastle University Institute of Health and Society	Full	General	general	**Regarding the research recommendations**, we think there are three key ones: 1 Continuing transition support for those in young adult and adult services. Page 25 Line 7. 2 'The role of primary care' Page 26 Line 7. Such research may be difficult because it is hard to formulate precise research questions; also primary care sometimes finds it difficult to speak with a single voice. 3 Supporting young people to manage their conditions Page 27 Line 10.	Thank you for your comment. The detail (population, intervention, comparators and outcomes, study design and timeframe) of possible future research on transition support for young adults, the role of primary care and self-management has now been included in the 'Recommendations for research' section. In addition, on reviewing stakeholder comments, the Guideline Committee noted that primary care involvement – specifically GP involvement - is critical to successful transition and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations:1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).
Newcastle University Institute of Health and Society	Full	6	24	We think the phrase 'Transition to adulthood is a time when young people' would be more consistent with the definition if written 'Transition occurs during the period when young people'.	Thank you for your comment. This sentence has been edited as per your suggestion.

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Newcastle University Institute of Health and Society	Full	14 -15 19	general	**Named worker.** We think this section could be clearer. Also we do not agree that this new person 'Named Worker' should be introduced at all. Two types of worker have been proposed in the literature as helping transition and there is preliminary evidence that both types may help. 1. A 'Co-ordinator' who works actively between children's and adult services. This person may or may not know an individual young person; the role is administrative and managerial to ensure that services in general are well linked and optimal procedures are in place. 2. A 'Key Worker' who will know the young person well and be part of their care team. It is likely that this person will change once the young person has transferred to adult services. For instance if a physiotherapist was the key worker and he/she worked in children's services, there would need to be a different key worker in adult services. Key worker models have been shown to work well but over thirty years there have been great difficulties in their implementation. We think the Guideline's concept of 'Named Worker' is close to that of 'key worker'. We think it is potentially confusing to introduce a new term 'Named Worker'. When 'Named Worker' is first introduced in the Guideline Full Page 14 Line 3, it is mentioned as a SINGLE named worker. But then by Line 12 it is recognised it should initially be someone in children's or young people's services but should hand over their responsibilities to someone in the relevant adult service when appropriate. Then on Page 18 Line 5	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). Specifically, you will note that we have made clearer this is a role not a job title and therefore could be undertaken by someone who is already fulfilling a role of keyworker, coordinator or transition support worker.

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				service managers should ensure a 'Named Worker' from the nominated adult service meets the young person before they transfer; But if that is the case, the 'Named Worker' is not already known by and working with the young person.	
Newcastle University Institute of Health and Society	Full	15	10 -11	**Engagement of a 'Named Worker' for a minimum of 6 months**. We were very concerned by this proposal. As defined, Transition is a process lasting usually some years. By proposing the 'Named Worker' should be involved for 'a minimum of 6 months before and after transfer', Commissioners and Providers may also choose this 6 months as their maximum. It seems to fly in the face of the Guideline's excellent section on Full Pages 12 and 13 for person-centred approaches throughout transition. Also it brings up again the idea that the 'Named Worker' can cross between services – which we have argued is unrealistic; and your own document appreciates this as explained in our previous Point 13.	Thank you for your comment. This time period (recommendation 1.2.9) relates to the length of time the Committee thought it would be appropriate for the named worker to be involved not to transition planning which: - should start early 'from year 9 (age 13 or 14) at the latest (as indicated in recommendation 1.2.1 and 1.2.3) - should be developmentally appropriate (1.1.2, 1.2.3 and 1.5.11), and - should be reviewed annually (1.2.4) Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). Thank you for your comment. The Guideline Committee considered all recommendations aspirational but achievable, although recognised there may be implementation challenges in some cases.
Newcastle University Institute of Health and Society	Full	15	16 -17	We think the phrase 'practitioners should start planning for adulthood' would be better expressed as 'practitioners should start planning transition'.	Thank you for your comment. This wording was chosen to reflect the fact that young people's transition should be considered within the context of their wider development and context.

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Newcastle University Institute of Health and Society	Full	15	18	The phrase 'entering the service close to transition age', should be 'entering the service close to the point of transfer'.	Thank you for your comment. We have replaced 'transition age' with the text you have suggested (recommendation 1.2.1)
Newcastle University Institute of Health and Society	Full	20	18	We think 'after transition; should be 'after transfer'.	Thank you for your comment. This error has been corrected.
Newcastle University Institute of Health and Society	Full	23	8 -17	**Developmentally Appropriate Health and Social care.** We particularly like your use of the phrase 'Developmentally Appropriate Health and Social care' which you use in in the Short version page 17, Line13. We think this same phrase should be used in the full version and short version where at present 'developmentally appropriate care' or 'developmentally appropriate service provision is used: Full, Pages 12, 15, 23 and 55; short version Page 13 Line 24, 25, Page 18 Line 3. Also as a concept 'Developmentally Appropriate Health and Social care' could perhaps be introduced and defined/explained in the Introduction alongside other definitions in the section 'Terms Used' currently in Full, Pages 23 and 24. See our Point 3 above. However, we think the content of this section Full, 1.6.11 could be strengthened. More could be made of it than just the two examples of 'joint clinics' and 'pairing with an adult service provider'. These two examples do not even specifically demonstrate 'developmentally appropriate health and social care' per se; each could easily be provided in a non-developmentally appropriate way.	Thank you for your comment and support for the term. We have now included a definition of 'developmentally appropriate'. The recommendation wording (developmentally appropriate services) reflects the fact that guideline audiences may also include representatives from other sectors (e.g. education). The references in other areas of the guideline have been updated for consistency. Recommendation 1.5.11 has been updated to include reference to 'age-banded clinics'

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Newcastle University Institute of Health and Society	Full	25	7 -17	**Research.** We broadly agree with this recommendation but think the guideline should avoid giving the impression that research is less needed in paediatric services. We agree more research has been done around paediatric services. However, the implication is that paediatric services do it well which is often not the case. In many paediatric services, an over protective approach in the 13-16 year olds is just as much an unsolved problem in need of research as failure to prepare young people for adult services is a major problem in need of research.	Thank you for your comment. We have added a qualifier to this paragraph to make clear that there are research gaps across both children's and adults' services.
Newcastle University Institute of Health and Society	Full	28	20 -28	**Research.** Again we broadly agree with this recommendation. However we do not understand why the Guideline states 'Transition Readiness' is an outcome tool. We comment earlier that we do not think the concept 'Transition Readiness' is useful or indeed meaningful; and we certainly do not understand how it can be used as an outcome. It might possibly be useful as a process measure, indicating that discussions about maturation have taken place. Documentation about transition is important, especially if it reminds professionals and young people to talk about areas of developmental maturation where they are beginning to feel more confident or should be aiming to acquire such confidence.	Thank you for your comment. This recommendation has now been removed.
Newcastle University Institute of Health and Society	Full	136	20	The phrase 'age appropriate' is used. We think this should be 'developmentally appropriate'. Especially during the years of transition, age and stage of development are not synchronous across individuals.	Thank you for your comment. 'Age-appropriate' has been replaced with 'developmentally appropriate' (recommendation 1.5.11).
Newcastle University Institute of Health and Society	Short	1	general	In the Guideline's opening statement, paragraph 2 'Who is it for?', young people are included in the list of those who will read it, alongside providers of care and commissioners. We suggest that for the final Guideline, there is a separate version specifically	Thank you for your comment. NICE produce a version of the guideline for people who use services and the public.

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				aimed at young people and co-produced with young people? The current document is unlikely to engage young people.	
NHS England	Short	General	General	Thank you for the opportunity to comment on the above Clinical Guideline. I wish to confirm that NHS England has no substantive comments to make regarding this consultation.	Thank you for your comment.
Nottingham Children's Hospital	Full	19	27	I am concerned that the recommendation to involve the GP in transition planning is only recommended *if* the young person does not meet the criteria for special adult health services. Even if they do, the GP should be involved, as they may be asked to complete interim reviews, and provide repeat prescriptions etc. See page 128 line 10-13.	Thank you for your comment. The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
Oxford University Hospitals	Short	5	24	6 months is a very short overlap time into adult care for the provision of support from the named worker. Ideally there should be continuity of care with the same named worker for at least 12 months before and after transfer to adult care.	Thank you for your comment. It is important to note that this time period (recommendation 1.2.9) relates to the minimum length of time the Committee thought it would be appropriate for the named worker to be involved and not to transition planning and support more widely which: - should start early 'from year 9 (age 13 or 14) at the latest (as indicated in recommendation 1.2.1s and 1.2.3) - should be developmentally appropriate (1.1.2, 1.2.3 and 1.5.11), and - should be reviewed annually (1.2.4) The Committee emphasised throughout development the importance of ensuring that support is person-centred. This is referenced explicitly in recommendations 1.1.1, 1.1.2, 1.2.4 (which was updated to this end, following discussion at Guideline Committee meeting 12), 1.2.9 and 1.2.19.

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Oxford University Hospitals	Short	10	15 -21	In my experience it is essential to have community outreach from secondary or tertiary care into the community to engage with non attendees. This is perhaps best achieved by a youth worker who can work 1:1 in both the hospital and community setting and bridge the gap. I think community outreach should be mentioned in this section.	Thank you for your comments. There was no evidence to support a recommendation on community outreach, however, recommendation 1.2.6 (and the definition of 'named worker' in Terms used in this guideline) make clear that this could be someone in a number of roles, including, for example, a youth worker.
Oxford University Hospitals	Short	11	3 -4	Continuity of care following transfer is essential to build up trust in the adult healthcare team. It will usually take more than 2 clinic appointments to achieve this and I suggest the young person sees the same health care practitioner for a period of at least 2 years after transfer.	Thank you for your comment. The Guideline Committee sought to make the recommendations aspirational but achievable. A very wide range of services and young people are covered by this guideline and therefore two appointments, as a minimum, was thought to be appropriate based on evidence, perceived cost and the wide range of services.
Oxford University Hospitals	Short	15	16 -17	The biggest impact will be achieved by successful engagement of adult health care providers as paediatric units are already well versed in the importance of transition planning. Adult clinicians have failed to engage to a significant degree and this will be a major challenge. In addition an integrated communication channel between paediatric and adult services needs to improve in many centres.	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Oxford University Hospitals	Short	15	18 -19	It is essential to incentivise adult health care providers with perhaps a CQuin for good transition practice. Furthermore there needs to be additional budget resource to allow joint clinical hand over clinics and integrate a support individual such as a youth worker into the adult service model. Currently young adult care has minimal funding and support structures in comparison to paediatric care.	Thank you for your comment and support for the recommendations. The previous reference to CQUIN has been removed from the recommendations as it was noted that this is not within the remit for NICE guidance; however, there is reference to funding mechanisms within the implementation section.
Oxford University Hospitals	Short	17	7 -11	It is important that this document does not forget the substantial number of teenagers and young adults (16-25) who present initially directly to adult care and do	Thank you for your comments. Young people who first enter services as adults are out of scope for this guideline.

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				not transition. They are often very difficult to manage and engage and are a forgotten population amongst all the efforts focused on paediatric presenters. In our experience they make up 48% of the young adults with kidney failure managed in adult care aged 16-25. Can this group be represented somewhere in this document otherwise we have a danger of preferential services for transitioned 19 year olds versus 19 year olds presenting directly to adult care for the first. Both groups have major issues	
Oxford University Hospitals	Short	22	1 -4	Please refer to an article we published in the British Medical Journal which does give some evidence on the outcome and cost effectiveness of an integrated model of paediatric to adult transition of kidney transplant patients from London to Oxford: BMJ 2012; 12:08; 10344	Thank you for your comment and the reference.
Oxleas NHS Foundation Trust	Short	General	General	Whilst the 'overarching principles' (1.1) are broadly helpful to all young people, perhaps it would be prudent to recognise more specific areas where issues are common place? For example, young people with learning disabilities. The SEND code of practice (2014) describes young people with learning difficulties. The definition includes those with long term conditions such as asthma, epilepsy, diabetes and even cancer. NHS services in adulthood are often challenged with unpicking education categories, particularly where learning disabilities is concerned. Eligibility for adult NHS specialist services is dependent on diagnosis. Only 2 of the 3 core elements of learning disability are identified in education (age = under 18 and IQ = less than 70). Typically, statements of educational need or new EHC plans are dependent on an Educational Psychology assessment that often limited to IQ (WISC	Thank you for your comment. Young people with learning disabilities are included in this guideline and referenced explicitly in recommendation 1.5.5. We have not condition-specific interventions or assessments as was it was not within scope to search for these data, however some condition-specific evidence emerged and this informed discussions. The scope of this guideline was to establish the broad principles to follow with respect to care and support before, during and after transition.

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				or the use of the British Ability Scale). This is insufficient to identify a cognitive impairment in line with the BPS definition of learning disability – one that includes adaptive functioning. I would recommend routinely offering adaptive functioning assessments to all young people considered in education terms, to have moderate learning difficulties, from the age of 14 – 16 years of age. In terms of savings, this would eliminate the need for protracted and costly debates between adult teams arguing whether someone has a learning disability or not. It would assist in the timely identification of appropriate support and from a broader population perspective, assist primary care to identify their LD adult population eligible for QOF and health checks. Ultimately, it is an opportunity to improve data and commissioning knowledge of a population with known health inequalities and poorer outcomes.	
Real Life Options	Short	general	general	We are uncertain how the joint approach will be established within current contracting practice? Will the named person in effect be the contract manager?	Thank you for your comment. The Guideline Committee did not wish to be prescriptive about contracting practice; rather it sought to establish the broad principles of care and support for transition and allow flexibility in terms of implementation at the local level.
Real Life Options	Short	general	general	We want to be certain that there will be a solid framework in place in terms of responsibilities and joint working.	Thank you for your comment. The Guideline Committee recognised the challenges posed by integrated working and recommendation 1.1.5 also suggests the use of joint protocols to support this. Following discussion at Guideline Committee meeting 12 (05.11.15) the Committee added in recommendation 1.5.10 to emphasise the particular need to develop integrated approaches to support

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					children with complex healthcare needs.
Real Life Options	Short	General	General	We have questions as to where the responsibility will sit for monitoring against outcomes.	Thank you for your comment. The Guideline Committee considered the issue of ownership of transition carefully (recommendations 1.5.1 to 1.5.3) and reviewed these recommendations at Guideline Committee meeting 12 (04.11.15). The wording has been updated to make clearer how these roles would work and that the senior manager would be responsible for implementing, reviewing and monitoring the effectiveness of the transition strategy.
Real Life Options	Short	2	20 and 5	We would want to see the word 'considering' removed – we feel this should be a matter of course.	Thank you for your comment. 'Consider' has been removed from this bullet in recommendation 1.1.1.
Real Life Options	Short	4	7	We are concerned about how the process will be undertaken if an individual who has been receiving children's services who is not eligible for adults services. If the transition is to no service it is important to also see this as a transition that needs supporting.	Thank you for your comment. The Committee recognised the need to ensure that young people do not "fall through the gap" where they are not eligible for support when they reach adult services, or services are not available. This informed recommendations 1.5.5, 1.5.6 and 1.5.7.
Real Life Options	Short	6	18	The guidelines need to be consistent with the Care Act 2014 in terms of there being access to advocacy. A young person in transition has a right to an independent advocate, when going through a support planning process or assessment.	Thank you for your comment. The Committee were mindful of the provisions of the Care Act and sought to build on, rather than replicate these, however, these provisions apply only to certain young people and a wide range of young people are covered by this guideline. The recommendation aims to allow flexibility at the local level.
Real Life Options	Short	8	4	Ensuring effective communication with families and carers is essential. Care needs to be taken to work sensitively in this environment whereby the individual is placed at the centre with recognition that this is the process of them moving into adulthood. Sometimes this process can feel brutal for families and the understanding of an individual and their support needs	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that

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				that is understood by families can be lost. It is also vital that the specialist support that can be delivered by providers is part of the transition process at an early stage so that it can be developed.	these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
Real Life Options	Short	16	1	The guidelines do not reflect that much social care provision is provided from the voluntary and independent sector. The guidelines seem to assume large monolithic organisations such as local authorities or NHS trusts. Social care providers need to be brought in as partners in the transition process and the development of services.	Thank you for your comment. The guideline wording aims to reflect that fact that practitioners will come from a variety of settings. Voluntary and community sector organisations are encompassed within the broad terms used (for example, 'adults and children's services, across health, social care and education' in recommendation 1.1.4) and referenced explicitly
Real Life Options	short	16	17	We have concerns around pooled budgets and where the control would be. In particular we would want care to be taken in who would be the lead body. We feel that essentially this is the right approach but would want there to be very solid guidelines.	Thank you for your comment. The previous reference to pooled budgets has been removed from the recommendations as it was noted that this is not within the remit for NICE guidance; however, there is reference to funding mechanisms within the implementation section.
Real Life Options	Short	17	12	We would want to see more clarity about the expected impact of training. For example ensuring that all staff have an understanding of person centred practice. We would want there to be consistency in practice across the board.	Thank you for your comment. There is a research recommendation on the effectiveness of different approaches to training on outcomes, as this was a significant gap in the evidence. This recommendation, therefore, was intended to map out the broad areas that training could usefully address. The Committee

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					recognised that people's level of training and the content of training will depend on the role they undertake.
Real Life Options	Short	18	6	Information held about children in a local authority area, for example in statements, needs to be maintained for the adult population, this is not only for those who become disengaged or are not eligible for adults services. This enables a local authority to plan effectively and to develop the market appropriately.	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Roche Diabetes Care UK	Short	General	General	Roche Diabetes Care UK welcomes these NICE draft guidelines on *Transition from children's to adults' services for young people using health or social care services* and its aims to improve the planning, delivery and experience of care of young people in their transition from children's to adults' services. According to Diabetes UK (*Diabetes State and Facts, May 2015*), there are approximately 31,500 children and young people with diabetes, under the age of 19, in the UK. This is likely to be an underestimate as not all children over the age of 15 are managed in paediatric care. Although there are existing agreed principles of good transitional care for children and young people with diabetes in the NHS (*Transition: getting it right for young people, March 2006*), these principles are often not reflected in practice, with transition support often patchy and inconsistent.	Thank you for your comment which provides useful context, and for your support for the guideline. The Committee agreed there are problems with transitional care and the recommendations in the guideline seek to address these.
Roche Diabetes Care UK	Short	General	General	**Q1.** Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why. Young people struggle with the social, cultural and	Thank you for your comments. The Committee discussed the need to support the young person "as a whole" and in their wider context throughout guideline development. As the term 'holistic' can be interpreted differently, this was not used, in favour of spelling out

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				physical changes during adolescence; living with diabetes only serves to compound this. It is essential therefore that the transitional process be a multi-faceted active process that attends to the medical, psychosocial, educational and vocational needs of adolescents as they move from child to adult centered care. It is widely accepted that children and young people with type 1 diabetes (T1D) have particular needs which differ from those of adults. With regards to transitional care issues, age-banded clinics and adult and paediatric colleagues working closely together are currently used within the NHS and are welcomed by young people. The challenge continues to be provision of quality care that is accessible and patient centred and helps the young person to experience an individualised approach to their care provision. This is particularly relevant for insulin pumps services. Insulin pump initiation rates are much higher for children and young people, compared to adults. A joint Department of Health and JDRF audit in 2013 reported that 19 per cent of under-18s with Type 1 are using a pump, compared to just 6 per cent of adults. For both categories, this is still much lower than comparable European countries. (*The United Kingdom Insulin Pump Audit – Service Level Data*, May 2013) Although there are numerous examples of best practice in transitional diabetes care throughout the NHS, quality of the individual children and young people and adult services will be the single biggest	the areas of a young person's life to take account of in planning and delivering services, specifically: - education and employment - community inclusion - health and wellbeing including emotional health - independent living and housing options. These areas are included in recommendations 1.2.8, the training section within the Implementation chapter and in the definition of 'person-centred' ('Terms used in this guideline'). The Committee also emphasised throughout development the importance of ensuring the young person is at the centre of their care and support. This is referenced explicitly in recommendations 1.1.1, 1.1.4, 1.2.4 (which was updated to this end, following discussion at Guideline Committee meeting 12), 1.2.7 and 1.2.19. The Committee agreed there are problems with transitional care and the recommendations in the guideline seek to address these. Please also see the chapter on implementation which provides some practical examples of how challenges could be overcome. In particular, there is a section on improving front-line practice with young people through training.

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				influence on how successful transitional plans can be developed and implemented. Creating joined up transitional care, in addition to standard care, when there isn't enough capacity or resources, will directly impact the level of care provided to all patients. With 19 percent of young people on pumps, but only 6 per cent of adults initiated, poorly developed implantation plans could lead to a drain on resources once transition has been completed, delay the transition or in a worst case scenario, leave a young person on an insulin pump without access to type and quality of care required.	
Roche Diabetes Care UK	Short	General	General	**Q2** What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.) Learning from what other clinics have done and sharing best practice are key to overcoming the implementation challenge. In Bristol, young adults making the transition from paediatric to adult care are offered dedicated clinics where consultants from both sides attend to ensure that the handover of care is as optimal as possible. Drs at the Bristol Royal Infirmary work closely with the paediatric endocrinology colleagues at the Bristol Royal Hospital for Children. In Shropshire, the Paediatric Diabetes Team has developed a dedicated Teenage Diabetes Clinic, focused on giving teens the skills they need to feel confident in taking charge of their own healthcare. They have also teamed up with Norfolk and Norwich	Thank you for your comments which will be considered as part of the work to support guideline implementation. Thank you also for the examples given, which could be submitted as part of the shared learning database.

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				Hospital to produce podcasts. These podcasts have been devised by young people with diabetes together with the diabetes team and are targeted at young people aged 14 and over and contain very useful information about how to cope with life and diabetes, including diabetes myths. Other best practice which has been slowly adopted across the NHS include having a joint appointment before full transition eg having the paediatric team and adult team together doing the patients review. This showed the patient the integration of the service and allowed the family to get to know the new staff Like with most disease areas, it is unlikely that there will be a 'one size fits all' approach. Among the factors which may need to be taken into account locally will be the historical division between paediatric and adult services, suitable venue, poor communication, inadequate multidisciplinary team provision, a co-ordinated approach and, perhaps most importantly, the views of the service users – the young people themselves. Being in full-time education means taking time off school to attend appointments, waiting in busy & overrun hospital clinics, this would not appear to be an ideal environment to see young people. Where clinics are struggling to keep young people engaged in their diabetes care, the NHS will need to consider alternative tools and methods to maintain that contact, either via social media, tele-health (Skype consultations)	
Roche Diabetes Care UK	Short	General	General	**Q3.** The key audiences we need to consider in structuring the guideline are the patients themselves,	Thank you for your comments. These were considered to be key audiences during guideline development.

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				their carers, schools and healthcare professionals.	
Roche Diabetes Care UK	Short	General	General	**Q4.** In England, transition between children and adult care tends to happen between aged 12-14. This is significantly different than in Scotland, where the average transition age is 19. There is even talk of extending young people clinics to aged 25 in some Scottish Trusts.	Thank you for your comment which provides useful context.
Roche Diabetes Care UK	Short	General	General	**Q6.** Parents are a key partner in transition planning for diabetes services, having played a significant carer role in earlier years. While transitioning to adult services implies the young person is taking on greater responsibility for their own care, parents should be educated of treatment targets, blood glucose targets or lifestyle advice.	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.

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Roche Diabetes Care UK	Short	General	General	**Q9.** Better joined up care as a result of these recommendations will lead to better use of specialist secondary care appointments, more clinically efficient medicines usage and improved blood glucose control. This will result in immediate capacity savings in both secondary and primary care, releasing resources and appointment for other patients, but also improved clinical outcomes and blood glucose control, contributing to better longer-term health outcomes and reduced costly complications.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
Roche Diabetes Care UK	Short	2	16	**Recommendations** Roche Diabetes Care welcomes the recommendations, overarching principles and focus on involving young people and carers in all aspects of service design, delivery and evaluation. **Named worker** A named worker to support and help navigate diabetes care is key to the implementation of a successful transition service. This should include direct and informal support, as well as out of hours contact details. **Involving young people** In addition to a named worker, diabetes clinics should be offering peer support, coaching, mentoring, advocacy and the use of mobile technology to engage and interact with young people. Depending on that interaction, services and information could be delivered via digital communication and tele-health tools.	Thank you for your comment and support for the guideline. The detailed comments will be considered as part of the work to support implementation of the guideline. The scope of this guideline was broad. As a result, the Guideline Committee sought to establish the broad principles to follow with respect to care and support before, during and after transition rather than to be prescriptive about the detailed methods or approaches that may be involved in implementing recommendations such as those relating to the named worker and involving young people. The benefits of technology to support other aspects of transition, however, are referenced in recommendations 1.2.10, 1.2.11 and 1.3.4. The Guideline Committee considered the issue of accountability for transition carefully (recommendations 1.5.1 to 1.5.3) and reviewed these recommendations at Guideline Committee meeting 12 (04.11.15). The wording has been updated to make clearer how these

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				Supporting infrastructure In developing the local services, diabetes clinics need to ensure there are nominated staff accountable for transition strategies and policies, as well as operational champions to oversee jointly planned children's to adults' services, as well as their implementation.	roles would work and that the senior manager would be responsible for implementing, reviewing and monitoring the effectiveness of the transition strategy.
Royal College of Anaesthetists	Short	General	general	Q2: A priority for funding would be appropriate. We would advise developing joint commissioning arrangements between health education and social care services. Good and thorough training in person—centred planning would help. Building good links with special schools and child protection teams could help overcome any challenges.	Thank you for your comment. Please see the chapter on implementation which provides some practical examples of how challenges could be overcome. In particular, there is a section on improving front-line practice with young people through training.
Royal College of Anaesthetists	Short	General	general	Q3: Given that the key audiences are adult and children's services across health, education and social care, it would probably be more effective to have separate meetings / seminars for the 3 groups, to avoid the discussions becoming too vague and generalised. The 'general public' should also have one or two presentations / public meetings.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
Royal College of Anaesthetists	Short	general	general	We envisage that the implementation of the recommendations will lead to an increase in costs. Staff training, resources, multimedia materials, recruitment of leads and champions (and their activities) will all need to be paid for. However an effective transition service could result in cost savings in other areas and services.	Thank you for your comment which will be considered as part of the work to support guideline implementation.

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Royal College of Anaesthetists	Short	general	general	We are concerned that, due to financial constraints, the time limit of six months to complete the transfer will be adhered to too strictly and this may not be enough for difficult and complex cases.	Thank you for your comment. This time period (recommendation 1.2.8) relates to the length of time the Committee thought it would be appropriate for the named worker to be involved not to transition planning which: - should start early 'from year 9 (age 13 or 14) at the latest (as indicated in recommendation 1.2.1s and 1.2.3) - should be developmentally appropriate (1.1.2, 1.2.3 and 1.5.11), and - should be reviewed annually (1.2.4)
Royal College of Anaesthetists	Short	general	general	We feel that further details are required about the role of adults services in working with children's services during transition. The two services differ widely in both culture and structure. We are also concerned that the age range at which guideline is directed to is too wide; there is a considerable difference between the needs of a teenager and those of a 25 year old.	Thank you for your comment. Additional explicit references to adult services have been included in the guideline, to make clear where responsibilities for recommendations are shared (see over-arching recommendation 1.1.3 and recommendations 1.1.5, 1.3.2, 1.3.4, 1.4.4). The scope of this guideline was broad. As a result, and recognising that, as you highlight, it needs to address the diverse needs of wide range of young people, the Guideline Committee sought to establish the broad principles to follow with respect to care and support before, during and after transition.
Royal College of Anaesthetists	Short	6	1	1.2.6 states "Hold an annual meeting to review transition planning." We would recommend that meetings are held 2 or 3 times a year as 1 meeting per year seems very limited.	Thank you for your comment. The Guideline Committee reviewed the recommendations on timing and review (under section 1.2) at Committee Meeting 12 (04.11.15) and agreed the edited wording now found in recommendation 1.2.4 but did not agree to change the frequency of meetings recommended.

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Royal College of Anaesthetists	Short	6	11	1.2.8.11 stating that practitioners should start planning for adulthood from Year 9 (age 13 or 14) at the latest. We support this, as this is probably the most difficult age groups with regard to teenage development.	Thank you for your comment and support.
Royal College of Anaesthetists	Short	8	5	We support 1.2.18: "Ask the young person how they would like their parents or carers to be involved throughout their transition." We also agree with discussing the transition with the young person's parents or carers to understand their expectations of the process. We believe it is right to give young people the chance to raise concerns and queries separately from their parents (1.2.20), but this could cause problems. All parents are different so you cannot have a "one size fits all" transition model.	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
Royal College of General Practitioners	Full	General	General	Improving transition was one of the priorities identified by the Children's Outcomes forum and Jackie Cornish, the National Director, has considered it important enough to add to her title. Prime examples include failed kidney transplants (specialist) or emerging struggles with acceptance of type 1 diabetes and the	Thank you for your comment which help to show the importance of effective transitions in saving costs. These will be considered as part of the work to support guideline implementation.

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				effect on life and work/student life. These result in enormous added costs with "having to start all over again", increased admissions and mental health implications. (JA)	
Royal College of General Practitioners	Full	General	General	Whereas in many cases specialist services for children outstrip adult ones (such as specialist diabetic nurses, epilepsy nurses or respiratory nurses attached to paediatric units) in mental health the provision for children is lucking.. GPs have been asked not to refer except for emergencies. Many 14-15 year olds are told to "wait until they are 16" and can be referred to adult mental health services. Young people are upset and worried by the client base in adult mental health and the stigma, whereas earlier support might have stopped the conditions progressing. It is difficult to talk about transition when GPs are being asked to make the first referral to adult services at 16, the "transition" is then managed totally by the GP in consultation with social care and education. (JA)	Thank you for your comment. The group considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are. The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
Royal College of General Practitioners	Full	General	General	In learning disability the provision is slightly better with meetings about every 6 months and liaison with the school or college. A problem is that social care workers and key workers keep changing. If the GP can be involved at least this could give some continuity of the "named GP" recommended in the CMO's report is adopted. Other priorities and pressure on appointments and time mean that the GP is often unable to attend meetings outside the practice. (JA)	Thank you for your comment. The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).). The need for there to be some continuity in terms of the practitioners young people see has been addressed in recommendations 1.1.5 , 1.3.5, 1.4.4 and 1.4.5.

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Royal College of General Practitioners	Full	General	General	There could be incentives for being the "named GP" for children and young people as with older people. (JA)	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), the guideline now indicates consideration of having a named GP (recommendation 1.1.9).
Royal College of General Practitioners	Full	General	General	With learning disability (and with many other conditions) the involvement of parents depends on the capacity of the child/young person and by careful and respectful management of the child/young person previously so they don't feel as if it is all out of their control. (JA)	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), the Mental Capacity Act is now referenced explicitly in recommendation 1.2.20.
Royal College of General Practitioners	Full	General	General	Parents often feel side-lined and disempowered where things don't go well or there is a hiatus, as they take the blame. GPs need to keep good relationships with the parents and see to their needs as individuals. This may mean a safeguarding referral for early help if needs cannot be met in other ways. (JA)	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision. They agreed that GP involvement is critical and, to this

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					end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).
Royal College of General Practitioners	Full	General	General	GPs can help by writing letter to the clinics or local authorities where there are problems. Major challenges for implementation – the proper care of parents and carers and advocacy for the child. (JA)	Thank you for your comment. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1). Your comment about the implementation challenges will be considered as part of the work on implementation support.
Royal College of General Practitioners	Full			Age of transition starting – depends on the type of service to which transitioning and facilities, as well as willingness of child and their parents. (JA)	Thank you for your comment. The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, if appropriate. This was in recognition of the wide range of young people, and services, covered by this guideline.
Royal College of General Practitioners	Full	General		And short Primary Care is only mentioned in the full guideline in four contexts- one that we should be involved by the named worker in planning transition services for an individual. Secondly asking what the role of primary care should be in the care of young people discharged from children's services and saying that they could find no research. Thirdly the named worker should contact the GP if a yp disengages. Finally, young people leaving care may change GP. This is in the context of all stakeholders believing that primary care should be a fundamental part of transition for all young people. **The guidelines have been produced because of concerns that young people**	Thank you for your comment. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).

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				fall through the gap at the time of transition to adult services with at times serious, life-changing consequences. Primary care and particularly GPs have known the child and their family throughout and can fill that gap. I believe the lack of involvement of primary care is a barrier to implementation. GPs should be involved throughout the process. (MD)	
Royal College of General Practitioners	Full	General		And short Should young people with LTC or in vulnerable groups have a named GP? (MD)	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), the guideline now indicates consideration of having a named GP (recommendation 1.1.9).
Royal College of General Practitioners	Full	general	general	In the context section, need some reference to hard to reach groups – e.g. LAC, particularly those who are housed out of county (MD)	Thank you for your comment. References to young people moving away from, or using services out of their local area is now included in the Context section.
Royal College of General Practitioners	Full	general	general	In the context section, need to make some reference to the importance of maintaining a good relationship with parents/carers as well as their children, (MD)	Thank you for your comment. A reference to parental involvement and the complex nature of supporting young people in the context of their family has now been included in the Context section.
Royal College of General Practitioners	Full	general	general	In the context section, some reference to the fact that paediatricians often provide holistic care to children with LTC; because of this, the child/young person and their family may use primary care less than those without LTC. . (Contact a Family 2011 'Making GP practices more welcoming for families with disabled children: information for GP practice teams) Adult specialist services do not provide the same level of holistic care. C+YP with LTC need to be shown how to use primary care appropriately. (MD)	Thank you for your comment. A reference to the complex nature of long-term conditions has now been included in the Context section.
Royal College of General Practitioners	Full	3	6	All young people move from children's to adult services. Even without LTC they move from consulting with parents to consulting alone. This transition has some important similarities and requirements as for those with LTC e.g. maintaining a good trusting DPR with both parent and child. (MD)	Thank you for your comment. The Committee agreed that building and maintaining collaborative, trusting relationships between services, young people and their families and carers is central to effective transitions and a number of recommendations address this (for example, 1.1.3, 1.2.7, 1.2.19 and 1.3.7).

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Royal College of General Practitioners	Full	3	11	Many young people transition to primary care where there is no equivalent adult service or the thresholds to adult services are different e.g. children with asthma (MD)	Thank you for your comment. This was discussed explicitly and informed the development of recommendations 1.5.5 and 1.5.7.
Royal College of General Practitioners	Full	3	19	**Primary care can provide that continuity and there is evidence that outcomes are improved when this occurs:** **Freeman, G. et al ' Continuity of Care : an essential element of modern general practice?'** **Family Practice 2003 20: 623-627** (MD)	Thank you for your comment. The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
Royal College of General Practitioners	Full	3	31	Poorly managed transition can lead to disengagement which may have significant morbidity and mortality (MD)	Thank you for your comment. This problem was discussed by the Guideline Committee during development. One of the over-arching aims of the guideline is to improve management of transition so that young people's outcomes (on a range of dimensions) are improved accordingly.
Royal College of General Practitioners	Full	4	8	Should specify young people who transition to primary care rather than adult specialist services or say adult services including primary care. (MD)	Thank you for your comment. This recommendation relates to adult specialist services.
Royal College of General Practitioners	Full	4	11	ALL young people use health services and all young people entering adult services have used children services. (MD)	Thank you for your comment. Young people whose first point of entry to the health or social care system was as an adult (and who had therefore not used paediatric or children's social care services) were agreed to be out of scope.
Royal College of General Practitioners	Full	5	4	' a new and rapidly evolving landscape of guidance legislation and increasing knowledge about brain development' (MD)	Thank you for your comment. The additional reference was not included in the guideline as the context seeks to provide a broad overview only and the reference was very specific. However, the context section does already reference the fact that transition between services takes place within the context of

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					developmental transition more broadly.
Royal College of General Practitioners	Full	6	25	Perhaps not relevant to this exact line but needs to be included somewhere in context: Many young people leave home at this time to go on to further education or employment. This can disrupt their transition to adult services and is a risk factor for poor transition- need to register with a new GP/new consultant, (MD)	Thank you for your comment. We have now included a reference to young people moving out of area (p9, full guideline).
Royal College of General Practitioners	Full	7	23	Many are discharged to primary care because they don't meet the thresholds for AMHS. E.g. those in the autistic spectrum/ with ADHD/ moderately severe affective disorder (MD)	Thank you for your comment. The Committee recognised the need to ensure that young people with mental health needs do not "fall through the gap" between Child and Adolescent Mental Health Services and Adult Mental Health Services and, to this end, referenced them explicitly in recommendations 1.5.5 and 1.5.7.
Royal College of General Practitioners	Full	10	general	Again not sure if this is the place to reference the you're welcome criteria and to talk about what is accepted good practice- no research evidence but the view of experts is that the following is accepted good practice. Patient centred practice in this setting involves: Addressing the child rather than the parent (from a very young age) Explaining about confidentiality and its limitations – ideally with parent/carer present Seeing the young person alone for part of the consultation when developmentally appropriate Teaching young people health literacy – how to register with a GP/ what is appropriate use of health services Following up DNAs (MD)	Thank you for your comment. The Committee emphasised throughout development the importance of ensuring the young person is at the centre of their care and support. This is referenced explicitly in recommendations 1.1.1, 1.1.4, 1.2.4 (which was updated to this end, following discussion at Guideline Committee meeting 12), 1.2.10 and 1.2.19. Following discussion at Guideline Committee 12 (04.11.15), the Committee agreed to add in reference to local confidentiality and safeguarding policies to recommendation 1.1.7. The need to see the young person separately from their parents had already been addressed in recommendation 1.2.21. All recommendations on parental involvement were reviewed at Committee meeting 12 with edits made to strengthen these recommendations.

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					The need to ensure young people are registered with a GP is now included as a separate recommendation (1.1.8), following discussion of stakeholder comments at Committee meeting 12.
Royal College of General Practitioners	Full	13	general	1.1.5: On safeguarding sharing information. Not all information should be shared with all services. It's always "need to know". It would be appropriate to add a qualifier – according to GMC or local guidelines. Otherwise there could be problems with confidentiality and a worsening of relationships or safeguarding risks? Consent is usually required for sharing and this should be separately obtained from a general consent to share medical and social info. (JA)	Thank you for your comment. This detail has now been added to recommendation 1.1.7.
Royal College of General Practitioners	Full	17	general	1.1.20: Need for chaperone now when raising ideas separately from parents (after 2015 Dr Bradbury case). I refer to this case too when raising the danger of abuse of vulnerable young people from the professionals and carers themselves. (JA)	Thank you for your comment. Recommendation 1.2.20 now makes explicit reference to the need to 'follow the principles of the Mental Capacity Act and other relevant legislation' which would include safeguarding duties.
Royal College of General Practitioners	Full	18	general	1.3.3 : "Care interventions" needs to be more specific – immunisations, operations? Not just how often care is given and by whom. Medication too? (JA)	Thank you for your comment. The Committee reflected on this recommendation (1.3.3) in Committee meeting 12 (05.11.15) and agreed to revise the wording for clarity. This particular bullet now refers, more simply, to 'information about their health condition, education and social care needs'. The Committee did not want to be overly prescriptive in this respect, recognising that this will vary considerably from one person to the next given the very wide range of young people covered by this guideline.
Royal College of General	Full	19	general	1.3.9: Involve the GP when things haven't worked or there isn't an appropriate adult service? This should not be so. The GP's view should be sought early on.	The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical

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Practitioners				(JA)	and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
Royal College of General Practitioners	Full	134	18 -26	The vignettes and systematic analysis are very useful and relevant. They highlight necessary major themes. (JA)	Thank you for your comment and support for the work.
Royal College of General Practitioners	Full	135	0 -19	For example : Our adult ADHD service is 50 miles away and is difficult to access – major problem with transitioning children/young people who often discontinue their meds at transition as mentioned. (JA)	Thank you for your comment. Please see the Implementation chapter section on maximising opportunities for young people who have become disengaged or who are not eligible for adults' services to access care and support.
Royal College of General Practitioners	Full	151		Useful chart and questions. (JA)	Thank you for your comment and support for the work.
Royal College of General Practitioners	General	General	General	This is a comprehensive document and its tenor cannot be challenged. It would be helpful to have some indication of the shape and size of the problem. The epidemiology is key to determining the level of resource required, thus the numbers involved and the diagnostic groupings e.g. Diabetics, Cystic fibrosis, Congenital cardiac disorders post-op requiring follow up. The populations involved will have different prognoses- some can expect to recover over time e.g. ADHD, some will die young e.g. Duchenne muscular dystrophy, some will have chronic conditions worsening over time e.g. Type 1 Diabetics, some will be in long term follow up because of previous surgery and may need further surgery e.g. cardiac operations, others will manage chronic but essentially stable conditions e.g. epilepsy. Depending on the condition,	Thank you for your comment and support for the guideline. The context is intended to provide only a brief overview of the area and it was not within the scope of the guideline to search condition-specific literature (although specific conditions did feature in evidence reviewed).

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				the arrangements will be different. Plain dialogue between patient, family and the key professional groups with tailored and costed plans are essential to ensure compliance, involvement and to give the young man or woman control and responsibility at a time of change. Much of secondary care is episodic and life changing, general practice provides the essential continuity and trust built over time with patient and family and shared care with other services. Each practice could be encouraged to identify patients making this journey and take a co-ordinating role for patient, family and services with the additional resources required. Health promotion for this group-diet, exercise, alcohol, drug use, sexual relationships is particularly important as well as attention to financial support, housing, work and education and the key worker role is sensible. The time of transition from child to adult services is fraught. It would be helpful to show some examples where this has been successful as well as where there have been problems and to involve the patient support networks and NGO's e.g. MIND, RNID. (PS)	
Royal College of General Practitioners	Short	general	general	GPs are identified as the key record holder for children. It is vital that health and social care services keep primary care informed during transition. There are late sequelae for children with some LTC e.g.cancer (MD)	Thank you for your comment. The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
Royal College of General Practitioners	Short	1	5 +	' in their transition move from children's to adult services in both primary and secondary care.' (MD)	Thank you for your comment. The introductory text has been left as per the draft as the guideline covers health and social care and the detailed context is provided in the full guideline.

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Royal College of General Practitioners	Short	5	8	(1.2.3) Young person should have a named GP; named worker should facilitate an interval appointment with the GP as part of the transition process if moving from child to adult services or as the start of management in primary care.. This would be an extended appointment to teach health literacy/ appropriate use of primary care/ explain confidentiality/ how to consult alone/ to take over primary care appropriate management of the condition / explore other health needs and behaviours. (MD)	The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline including the recommendation to consider a named GP (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
Royal College of General Practitioners	Short	5	24	Six months before and after transfer is too short (MD)	Thank you for your comment. It is important to note that this time period (recommendation 1.2.9) relates to the minimum length of time the Committee thought it would be appropriate for the named worker to be involved and not to transition planning and support more widely which: - should start early 'from year 9 (age 13 or 14) at the latest (as indicated in recommendation 1.2.1s and 1.2.3) - should be developmentally appropriate (1.1.2, 1.2.3 and 1.5.11), and - should be reviewed annually (1.2.4) The Committee emphasised throughout development the importance of ensuring that support is person-centred. This is referenced explicitly in recommendations 1.1.1, 1.1.2, 1.2.4 (which was updated to this end, following discussion at Guideline Committee meeting 12), 1.2.9 and 1.2.19.
Royal College of General Practitioners	Short	7	10	This should include signporting to primary care and ensuring they are registered with a GP Attention should be paid to establishing health self management in areas other than the LTC – e.g.sexual health/ mental health – exploring wellbeing using the HEADSSS algorithm for example (MD)	The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).

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Royal College of General Practitioners	Short	8	5 -10	This will vary with time and should be checked at every appointment. (MD)	Thank you for your comment. Recommendation 1.2.19 now includes the word 'regularly' to emphasise your point that this will vary over time.
Royal College of General Practitioners	Short	8	12 -14	This opportunity to be seen alone should be offered both in paeds/primary care and adult services as part of the routine consultation when developmentally appropriate. (MD)	Thank you for your comment. The recommendations on parental involvement are not specific to one service. Recommendation 1.2.19 emphasises the importance of asking young people regularly about their preferences in respect of parental involvement.
Royal College of General Practitioners	Short	8	18 -26	Support before transfer – this section ought to include best practice in consulting – addressing the child rather than the parent/carer; explaining about confidentiality and its limitations/seeing the child alone as part of the routine. (MD)	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision. The Guideline Committee agreed that, as with all recommendations, they will be implemented within the

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					context of existing guidance and legislation.
Royal College of General Practitioners	Short	9	21	How to use a GP (extra bullet point). (MD)	Thank you for your comment. The Guideline Committee did not think this necessary here but reference to GP involvement has been strengthened throughout the guideline (see recommendations:1.1.6, 1.2.2, 1.2.6, 1.2.7 and 1.4.1).
Royal College of General Practitioners	Short	10	13 -14	The GP should be involved in transition planning whether or not the young person is moving to adult services. The paediatrician is ideally the primary person to communicate with the GP. (MD)	The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
Royal College of General Practitioners	Short	10	16	Disengagement can be life threatening; involving the GP should be a separate bullet point – this should be ongoing contact until the yp has been contacted/re-engaged. This will be easier if the young person has had the interval appointment outlined in point 18. (MD)	The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
Royal College of Nursing	General	General	General	The Royal College of Nursing (RCN) welcomes proposals to develop the health and social care guideline on transition from children's to adult's services. The RCN invited members who work with children and young people to review the draft document and comment on its behalf. The following comments reflect the views of our members.	Thank you for your comment. interpreted within the wider legislative and policy context.
Royal College of Nursing	General	General	General	The guideline could be more explicit about the relevant legislative changes and stress the importance of both adult and children's services having a good understanding of these (Care Act 2014, SEND reform 2014).	Thank you for your comment. These two pieces of legislation are referenced in recommendations and context sections. The guideline covers a wide range of young people and therefore there will be a wide range of legislation and guidance relevant, including the Mental Health Act. The Committee were mindful not to repeat current legislation although recognised that the guideline will be

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Royal College of Nursing	General	General	General	There is not enough clarity in the guideline about what will happen for those young people who can currently access health services for example until the age of 25.	Thank you for your comment. The guideline was not intended to be a comprehensive document; rather to focus on those aspects of transition support stakeholders and the Committee considered to be the most important to address. The aim of the guideline is primarily to address general principles of transitions where there is an actual transfer between services.
Royal College of Nursing	General	General	General	The guideline does not address sufficiently the lack of services available in adults (e.g., where Child Adolescent Mental Health Services (CAMHS) patients do not meet the criteria for Adult Mental Health Services (AMHS) or where other specialist health services for children and young people cease at 16 years.	Thank you for your comment. The Committee also recognised the need to ensure that young people with mental health needs do not "fall through the gap" between Child and Adolescent Mental Health Services and Adult Mental Health Services and, to this end, referenced them explicitly in recommendations 1.5.5 and 1.5.7. There is also a research recommendation related to this problem.
Royal College of Nursing	General	General	General	The draft guideline is not very clear about the commissioners' role in transition and service planning.	Thank you for your comment. The remit of NICE guidance is to identify 'what works'. It is then complemented by additional NICE support for commissioners; however, recommendation 1.5.7 has been updated to make clear that the gap analysis work should inform commissioning.
Royal College of Nursing	General	General	General	The guideline only mentions GP involvement a couple of times. The GP is key to co-ordinating transition for some young people and must be involved in a young person's transition from an early stage. We would suggest this needs greater emphasis and should not just be in respect of those young people for whom there is not a clearly identified adult specialist.	Thank you for your comment. The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
Royal College of Nursing	General	General	General	The guideline could be clearer about health and social care's particular roles and responsibilities. For example, who is ultimately responsible for supporting	Thank you for your comment which was discussed in Guideline Committee meeting 12 (05.11.15). Given the very wide variety of contexts in which this guideline will

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				the young person to identify the key worker?	be implemented, the Committee agreed not to specify who should help the young person identify a named worker (recommendation 1.2.5).
Royal College of Nursing	General	General	General	Cost implication on implementing the guidelines: - There could be additional cost / time implications for health personnel attendance at Education Health and Care Planning meetings and annual reviews.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
Royal College of Nursing	General	General	General	We are pleased to see that NICE clearly states that 'The point of transfer should not be based on a rigid age threshold'	Thank you for your comment and support for this recommendation.
Royal College of Nursing	General	General	General	The RCN has published several pieces of guidance for members including: 1. RCN 2008, *Lost in transition (Moving young people between child and adult health services)*. Publication code: 003 227 www.rcn.org.uk 2. RCN 2007, *Adolescent transition care RCN guidance for nursing staff* Publication code: 004 510 www.rcn.org.uk 3. RCN 2012, *Health care service standards in caring for neonates, children and young people* Publication code: 004 608 www.rcn.org.uk 4. RCN 2014, *Specialist and advanced children's and young people's nursing practice in contemporary health care: guidance for nurses and commissioners* Publication code: 004 579 www.rcn.org.uk	Thank you for your comment and references which may be useful to consider as part of the work to implement the guideline.
Royal College of Nursing	General	General	General	Preparation for independence can be achieved with the help of documentation such as *Ready Steady Go* programme used by University Hospital Southampton.	Thank you for your comment and signposting to this programme which may be relevant for implementation work.
Royal College of	Short	1	12	Transition is the process of moving, transfer to adult services is the actual move.	Thank you for your comment. Transfer and transition are defined in the 'Key terms used in this guideline'

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Nursing					section.
Royal College of Nursing	Short	4	15	Our members consider that this will be very difficult to achieve in some circumstances and may be better to change to read: *ensure that a named worker is provided and for the young person to be involved where they are able*; (RCN 2007, Adolescent transition care RCN guidance for nursing staff Publication code: 004 510 www.rcn.org.uk)	Thank you for your comment. The Guideline Committee considered all recommendations aspirational but achievable, although recognised there may be implementation challenges in some cases.
Royal College of Nursing	Short	6	7	Our members consider that transition planning should be started early for everyone, around 11 or 12 years old where it is identified that they will need on-going health input.	Thank you for your comment. The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are.
Royal College of Nursing	Short	6	24	Suggest add that professionals should be easily contactable using effective communication means including secure text and/or email.	Thank you for your comment. The guideline covers a very wide range of young people and services so it was not possible to list every aspect of young people's interaction with practitioners. As a result, the Guideline Committee sought to establish the broad principles to follow with respect to care and support before, during and after transition.
Royal College of Nursing	Short	10	18	This is very important but currently difficult to achieve in some areas as resources and staffing in adult services are not enough to provide current level of service.	Thank you for your comment. The Guideline Committee considered all recommendations aspirational but achievable, although recognised some of the implementation challenges, many of which are addressed in the implementation section of the guideline. Your comments will also be considered as part of the ongoing work to support guideline implementation.

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Royal College of Nursing	Short	11	22	The use of formal training courses should also be considered, for example Transition modules offered by national academic institutions such as York University.	Thank you for your comment. There was insufficient effectiveness evidence to justify stand-alone recommendations on specific training packages such as those you suggest, though the Committee recognised that a wide range of training is already on offer.
Royal College of Nursing	Short	12	25	This also needs to include inpatient healthcare data.	Thank you for your comment. This recommendation is intended to include data from all areas, including in-patient healthcare.
Royal College of Nursing	Short	15	3	This should also include preparation of young person and their parents/carers.	The Committee did consider training to be an important area to address and, to this end, it is referenced in the implementation chapter, specifically in reference to improving front-line practice with young people. Given the wide range of young people covered by the guideline, it was not possible to list every aspect of training. In the implementation chapter, therefore the Committee sought to provide over-arching headings that specify the key broad areas to address.
Royal College of Paediatrics and Child Health	Full	General	General	Need more reference to the role of primary care than there currently is, e.g. 1.3.9 primary care should be involved irrespective of whether they meet the criteria for specialist adult health services. There is no mention of the 14+ annual GP health check for people with learning disability LD - and for all those with health needs and LD, there should be a real link with that annual process to facilitate transition.	Thank you for your comment. The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1). The guideline seeks to build on, rather than repeat the requirements of current policy and legislation. The Committee noted that there are a range of activities happening currently – which would include the 14+ annual health check – that will complement the

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					recommendations.
Royal College of Paediatrics and Child Health	Full	General	general	**Terminology.** We think terminology is very important and there is some inconsistency in the draft guidance particularly around the differences between transfer and transition.	Thank you for your comment. We have updated the guideline following consultation, to make clear the differences between transfer and transition.
Royal College of Paediatrics and Child Health	Full	General	general	A definition for developmentally appropriate health care is needed somewhere – and reference to the You're Welcome quality criteria and the Ambresin AE 2013 systematic review of youth friendly health services are useful frameworks to reference in this regard.	Thank you for your comment. This has now been added (see: 'Terms used in this guideline).
Royal College of Paediatrics and Child Health	Full	General	general	**Transition Readiness.** This is mentioned on pages 17, 28, 33, 36, 38 48. We realise there is a considerable literature on this topic although many of these are still under validation processes. Furthermore many of these are actually transfer readiness tools rather than transition readiness tools. There is also the concern as to who is determining transition readiness – the young person, the parent, the paediatric services or institutional policy. Is it physical, psychological, social or vocational transition readiness or all of these? And It is much more of a process rather than an outcome measure.	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), we have changed 'transition readiness' to 'transfer readiness', as suggested. The Committee agreed that determining transfer readiness is complex and that this will vary, given the wide range of young people that are covered by this guideline, their varying health and social care needs and the wide range of practitioners who may be supporting them. The recommendations on transfer readiness, therefore do not specify who should determine this, allowing practitioners flexibility to implement recommendations locally.
Royal College of Paediatrics and Child Health	Full	General	general	**Commissioning.** There is no reference to the proposed NHSIQ generic specification for transition for commissioners.	Thank you for your comment. The remit of NICE guidance is to identify 'what works'. It is then complemented by additional NICE support for commissioners.
Royal College of Paediatrics and	Full	General	general	**Number of recommendations**. The draft guidance contains many recommendations, many of which have been in national guidance for over a decade –	Thank you for your comment. Please see the implementation chapter of the guideline which highlights some of the challenges associated with

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Child Health				consideration of how to ensure that it will be implemented this time around will be important prior to the final draft.	ensuring the recommendations have traction in the health and social care sectors, as well as ways to overcome them. Specifically, please note the focus on ensuring relevant agencies and professionals share responsibility for implementation by actively reviewing local practice and systems and developing joint arrangements and protocols in response.
Royal College of Paediatrics and Child Health	Full	General	general	Some recommendations will be unrealistic in many specialties with large numbers of patients, e.g. an annual meeting with key professionals involved with an individual young person.	Thank you for your comment. The Guideline Committee reflected on this comment in Committee Meeting 12 (04.11.15) and agreed to keep this recommendation (1.2.4) but have added wording to clarify that practitioners may not need to attend in person. They could feed in via teleconferencing or video'. As with all the recommendations, they agreed this was aspirational but achievable.
Royal College of Paediatrics and Child Health	Full	General	general	**Question 1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why?** Developmentally Appropriate Service Provision will have the biggest impact on practice as this is the context which underpins effective transition. Young people do not exist in individual services but move between them and experience first-hand the differences and gaps. Currently transition is perceived in isolation and needs to be considered in the context of developmentally appropriate service provision in order to address these gaps. However service provision and staff training are potential barriers to implementation.	Thank you for your comment. Please see the implementation chapter of the guideline which highlights some of the challenges identified by the Guideline Committee and stakeholders, as well as how to overcome them. In particular, there are a number of suggestions for how training on transitions – for all those supporting young people – could help to ensure more holistic provision.
Royal College of	Full	General	general	And short A key audience will be young people - A version specifically aimed at and ideally co-produced with	Thank you for your comment which will be considered as part of the work to develop outputs that can support guideline implementation. NICE will produce a version

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Paediatrics and Child Health				young people will be important in this regard.	of the guideline for people using services and the public.
Royal College of Paediatrics and Child Health	Full	General	general	**Question 4. At what age does transition planning start now?** Transition planning if often transfer planning and is started too late if not at all; should start in early adolescence 10-13. At this stage it is not so much of talking about adult care/transfer but talking about the change from paediatric to adolescent care – evolving autonomy, generic health issues, being seen independently of parents etc.	Thank you for your comment. The group considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are.
Royal College of Paediatrics and Child Health	Full	General	general	**Question 5. How often do review meetings happen at present?** Depends on what you mean by review meetings. As a paediatric rheumatologist, few of my patients have a statement and as a result don't have formal interagency reviews. One of our commenter has noted that in their adolescent clinic however, transitional care is reviewed at every clinic visit as part of adolescent rheumatology care.	Thank you for your comment. The Guideline Committee reviewed the recommendations on timing and review (under section 1.2) at Committee Meeting 12 (04.11.15) and agreed the edited wording now found in recommendation 1.2.4.
Royal College of Paediatrics and Child Health	Full	General	general	**Question 6. How should parents be involved in transition planning?** Parents should be introduced to transition planning well before adolescence even starts as they often find it more difficult than the young people. Programmes which have included specific transition plans for parents as well as the young people have showed significant improvements in parental reports.	Thank you for your comment. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review

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					- referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision. -
Royal College of Paediatrics and Child Health	Full	General	general	**Question 7. Will these recommendations result in an impact on cost of services?** Yes.	Thank you for your comment which will be considered as part of the work to support guideline implementation. will be considered as part of the work to support guideline implementation.
Royal College of Paediatrics and Child Health	Full	General	general	**Question 8. Which of these recommendations would lead to additional costs?** Named worker roles – not in job descriptions currently therefore will be additional work; peer support, mentoring, multi-professional meeting, training.	Thank you for your comment. Thank you for your comment which will be considered as part of the work to support guideline implementation. The Guideline Committee was mindful of potential costs and resource use when making recommendations. In particular, they discussed the role of the named worker (1.2.5 to 1.2.10). They noted that while some stakeholders' could perceive there to be additional costs associated with implementing this role, they did not think significant additional expenditure was necessary. This was on the basis that the named worker role comprises a set of tasks to be done by an existing worker, rather than the creation of a new post. Furthermore, it is likely that the worker allocated these tasks will be undertaking many of them already (perhaps under a different title, such as 'keyworker', 'transition worker' or 'personal adviser'. The purpose of this recommendation is to ensure there is formal responsibility for ensuring a coordinated approach to transition, recognised by all parties

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					involved in providing care and support.
Royal College of Paediatrics and Child Health	Full	General	general	**Question 9. Will any of these recommendations lead to cost savings?** Potentially yes. If young people are engaged in managing their own health, health outcomes will hopefully improve. We know that poor adolescent health leads to poor adult health and outcomes such as vocational outcomes (see Hale et al., 2015) which has obvious cost implications to society.	Thank you for your comment. Thank you for your comment which will be considered as part of the work to support guideline implementation.
Royal College of Paediatrics and Child Health	Full	2	18	Completely support involvement of young people in all decisions and design and evaluation of services that affect them. We are not clear how young people should be involved in service delivery however, if this means health and social care services.	Thank you for your comment. The Guideline Committee agreed on the importance of mechanisms to enable young people to feed In to service design and evaluation at the locality level and, in addition to the over-arching recommendation 1.1.1, recommendations 1.5.4 and 1.5.5 also address this more specifically. The reference to 'service delivery' in over-arching recommendation 1.1.1 is intended to promote a 'coproduction' approach, that is to say, one in which young people are put at the heart of their services, and are supported to exercise choice and control, as appropriate, rather than being passive recipients of care. This recommendation does not provide more specific the detail given that this guideline could be relevant to a very wide range of services.
Royal College of Paediatrics and Child Health	Full	4	10	The guidance states that it does not cover young people entering adult services who have not used children's health and social care services. This is confusing – does it mean that have never ever used children's services as few young people would have	Thank you for your comment. Young people whose first point of entry to the health or social care system was as an adult (and who had therefore not used paediatric or children's social care services) were agreed to be out of scope.

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				got away without ever having been to something in secondary care…or are they referring to young people not being referred to adult services from paediatric services. ALL young people undergo transition to adult services irrespective of their health status.	
Royal College of Paediatrics and Child Health	Full	12	7	We are advocates for co-production – but also realise that this requires both funding and expertise to do it effectively and in a meaningful way - it is difficult to imagine how such funding will materialise in today's NHS.	Thank you for your comments. 'Consider' has been removed from recommendation 1.1.1.
Royal College of Paediatrics and Child Health	Full	14 -15, 19	general	**Named worker.** Terminology is critical here as to whether this is the same or different to a transition coordinator and/or key worker. If a young person is in multiple services do they have multiple named workers - or does one of them take the lead – and in practice who decides this? Having a named key worker for every young person in some services is aspirational but not realistic in practice when the team is small and when posts within the team are rotational posts. This will be difficult in practice. However a team member who undertakes the role of transition coordinator is more realistic….	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). Specifically, you will note that we have made clearer this is a role not a job title and therefore could be undertaken by someone who is already fulfilling a role of keyworker, coordinator or transition support worker.
Royal College of Paediatrics and Child Health	Full	15	4	Why is employment mentioned but not education e.g. 1.2.3.	Thank you for your comment. On review, the Guideline Committee agreed that reference to liaison with education practitioners needed to be strengthened in the recommendations, given: the critical importance of education sector professionals in supporting young people's development, health and wellbeing, and identifying problems early. To achieve this, the following recommendations now reference education explicitly: 1.1.4, 1.1.6, 1.2.6, 1.2.8, , 1.2.16 and 1.3.3.

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Royal College of Paediatrics and Child Health	Full	15	8 -11	As defined, Transition is a process lasting usually some years. In reality 'a minimum of 6 months before and after transfer', is transfer planning NOT transition.	Thank you for your comment. This time period (recommendation 1.2.9) relates to the length of time the Committee thought it would be appropriate for the named worker to be involved not to transition planning which: - should start early 'from year 9 (age 13 or 14) at the latest (as indicated in recommendation 1.2.1s and 1.2.3) - should be developmentally appropriate (1.1.2, 1.2.3 and 1.5.11), and - should be reviewed annually (1.2.4)
Royal College of Paediatrics and Child Health	full	15	13	Timing refers to timing of transfer rather than when transition should start. 1.2.8 advocates that this should start early – some would say at birth for congenital conditions. Transition planning for parents should start before adolescence starts	Thank you for your comment. The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are.
Royal College of Paediatrics and Child Health	Full	15	16 -17	The phrase 'practitioners should start planning for adulthood' is used. We feel it might be more appropriate to refer to 'transfer to adult services'. Also, the phrase 'entering the service close to transition age', should be 'age of transfer' or 'transfer age'.	Thank you for your comment. This wording was chosen to reflect the fact that young people's transition should be considered within the context of their wider development and context.
Royal College of Paediatrics and Child Health	Full	15	23	An annual meeting for all young people with long term conditions involving all practitioners is totally unrealistic for all young people with long term conditions due to the numbers of patients compared to the relatively few professionals in the teams looking after them.	Thank you for your comment. The Guideline Committee reflected on this comment in Committee Meeting 12 (04.11.15) and agreed to keep this recommendation (1.2.2) but have added wording to clarify that practitioners may not need to attend in person. They could feed in 'via conferencing or video'. As with all the recommendations, they agreed this was aspirational but achievable.

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Royal College of Paediatrics and Child Health	Full	17	7	It is not only young people with disabilities that need such planning – but young people with relapsing and remitting health conditions such as asthma, arthritis, diabetes.	Thank you for your comment. It was not within the remit of the guideline to search for specific interventions for these conditions which is why they are not referenced.
Royal College of Paediatrics and Child Health	Full	17	23	Parents often find transition more challenging than young people. Parental needs particularly around "letting go" need to be supported and such input needs to start much earlier often in childhood before adolescence starts. More generally needs to be included around this as in practice this can be challenging with current resources and numbers of personnel.	Thank you for your comment. The Committee recognised and agreed with this point. This was discussed in development and informed recommendations 1.2.19 to 1.2.22. Recommendations 1.2.1 to 1.2.3 1.2.1 about when transition planning should take place do not preclude people starting planning (or aspects of it) earlier, to reflect the individual.
Royal College of Paediatrics and Child Health	Full	17	27	It is not just their concerns about adult services but about sensitive issues such as sexual health, substance use etc. which is difficult to adequately address with parents in the room.	Thank you for your comment. The Committee reflected on this recommendation (1.2.21) in Committee meeting 12 (05.11.15) and agreed it is intended to cover anything that the young person does not want or feel able to discuss with their parents or carers there. The word 'any' was added before 'concerns or queries'.
Royal College of Paediatrics and Child Health	Full	18	5	Meeting in person - this is unrealistic for all young people with long term health conditions who may be moving to a geographically distant adult service with respect to many paediatric tertiary hospital services. However contact should be made and the potential of skype consultations etc. in this regard may be worth considering in the future.	Thank you for your comment. The Committee recognised the difficulties with out-of-area service use and also the very wide range of young people covered by this guideline. This particular recommendation (1.1.5) therefore provides examples of how meeting with adult services pre-transfer could be achieved, but the list is not intended to be exhaustive and there are other examples, such as the use of technology, as you propose.
Royal College of Paediatrics and Child Health	Full	18	11	Currently there are examples of such folders, many of them designed for young people, yet held by the parents.	Thank you for your comment.Please see the implementation chapter which provides examples of how to overcome some of the challenges related to implementation. In particular, there is a section on

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				Work is still needed with respect to the associated health literacy issues which surrounds young people holding their own records. This will take significant time. There is also the issue of training health professionals to respect and take note of such records - particularly if designed and written by the young people themselves rather than by health professionals. A simple strategy to get started would be to reinforce copy letters for patients.	improving front-line practice with young people through training in developmentally appropriate services and person-centred practice.
Royal College of Paediatrics and Child Health	Full	19	5	Information about benefits is not the only information required particularly as many young people with long term conditions will not be entitled to any such benefits, e.g. signposting for other generic health related issues, rights under the equality act, travel advice would be similarly important.	Thank you for your comment. Given the very wide range of young people covered by this guideline, it was not possible to list all types of information that could be provided, hence the over-arching wording in the recommendation – 'what to expect from services and what support is available to them' which would cover the information and signposting you suggest.
Royal College of Paediatrics and Child Health	Full	19	27	Primary care should be involved irrespective of adult specialists.	Thank you for your comment. The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
Royal College of Paediatrics and Child Health	Full	20	2	This is particularly important for the 16-18 year olds with respect to safeguarding. It might be worth highlighting this age group specifically.	Thank you for your comment. The Committee agreed that safeguarding is an important issue but, on consideration, noted that the guideline covers a wide range of young people with varying care and support needs The Committee did not think it appropriate therefore to specify the 16-18 group in particular.
Royal College of Paediatrics and Child Health	Full	20	8	What does "engage with adult services" actually mean in practice? Attend first appointment or first 3 appointments??? It is also important that primary care is informed in such circumstances and not just the referring team.	Thank you for your comment. The Committee reviewed this wording at meeting 12 (04.11.15) and agreed that 'engage with adult services' was a widely understood term which could cover a range of activities (such as communicating with practitioners on the phone or via

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					email). The Committee agreed that, given the wide range of young people covered by the guideline, it would not be appropriate to specify this in more detail. The Guideline Committee discussed the role of primary care – specifically GPs - in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).). The intention is that the recommendations set out the broad principles, but the detailed implementation work will vary, depending on the local context.
Royal College of Paediatrics and Child Health	Full	20	17	This will be challenging in large adult services with respect to doctors in view of training rotations – however another health professional such as the clinic nurse may be more consistent.	Thank you for your comment.Please see the implementation chapter which provides examples of how to overcome some of the challenges related to implementation. In particular, there is a section on improving front-line practice with young people through training in developmentally appropriate services and person-centred practice.
Royal College of Paediatrics and Child Health	Full	21	1	Understanding adolescent development is one aspect as is training in how to specifically address how this developmental status impacts the long term condition as well as how the long term condition impacts on the development. Another key aspect alongside consent and safeguarding is a young person's rights to confidentiality – very important from a young person's perspective and frequently confused with consent legislation in practice.	Thank you for your comment. It was not possible to list every element of training; rather, the Guideline Committee sought to provide over-arching headings that cover the main aspects that training should cover. Safeguarding and confidentiality were discussed and informed the bullet on 'the legal context and framework related to supporting young people through transition, including consent and safeguarding' . This can now be found in the information about training within the chapter on Implementation.
Royal College of	Full	21	9	Standalone experiential learning such as through shadowing must be accompanied by effective debriefing to be of true educational value.	Thank you for your comment. Given the wide range of services, organisations and practitioners involved in supporting young people, the variety of training

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Paediatrics and Child Health					currently taking place and the lack of evidence on effectiveness of specific training interventions, the Guideline Committee did not wish to be more prescriptive in this respect. Shadowing is provided only as an example. This detail can now be found in the information about training within the chapter on Implementation.
Royal College of Paediatrics and Child Health	Full	21	16	A better strategy would be a lead for Adolescent and young adult care including transition	Thank you for your comment. The Guideline Committee considered the issue of ownership of transition carefully (recommendations 1.5.1 to 1.5.3) and reviewed these recommendations at Guideline Committee meeting 12 (04.11.15). The wording has been updated to make clearer how these roles would work.
Royal College of Paediatrics and Child Health	Full	22	5	Such groups need exit strategies themselves as young people grow up. They also need to be facilitated. (see RCPCH 2010 document "Not just a phase").	Thank you for your comment. The Committee did not wish to be too prescriptive in this respect, recognising that local implementation will vary and that these will take place within the context of existing guidance on good practice.
Royal College of Paediatrics and Child Health	Full	23	8 -17	**Developmentally Appropriate Service Provision.** As above. The developmentally appropriate concept should be defined and supported by references to the "You're Welcome Quality criteria and the Ambresin AE systematic review 2013 of youth friendly care. These are as true for transitional care services as any service where young people are seen. E.g. joint clinics are not always developmentally appropriate with multiple professionals from both paediatrics and adult in one room….also may not	Thank you for your comment and support for the term. We have now included a definition of 'developmentally appropriate'. The recommendation wording (developmentally appropriate services) reflect the fact that guideline audiences may also include representatives from other sectors (e.g. education). The references in other areas of the guideline have been updated for consistency. Recommendation 1.5.11 has been updated to include reference to 'age-banded clinics'

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				always be possible due to geography and numbers of patients…other models include young adult clinics (Crowley R 2011; Bent 2002] which are by definition more d4evelopmentally appropriate.	
Royal College of Paediatrics and Child Health	Full	23	9	Should be children, young people and adults.	Thank you for your comment. This sentence has now been updated to include young people (see recommendation 1.5.11)
Royal College of Paediatrics and Child Health	Full	27	11	We are concerned that self-management is not already considered integral to transition and is just discussed in the research section. This is core to transitional care and developmentally appropriate health care and should be highlighted in the body of the guidance as well as emphasising the need for further research in this area.	Thank you for your comment. Self-management is referenced explicitly in recommendation 1.2.17 and is also encompassed within the four over-arching outcome areas (specifically 'independent living') referenced throughout the guideline, which are as follows: - education and employment - community inclusion - health and wellbeing including emotional health - independent living and housing options. These areas are included in recommendation 1.2.8, the Training section of the Implementation chapter, and in the definition of 'person-centred' ('Terms used in this guideline').
Royal College of Paediatrics and Child Health	Full	28	20 -28	**Research.** 'Transition Readiness' is a process rather than an outcome tool.	Thank you for your comment. This recommendation has now been removed.
Royal College of Paediatrics and Child Health	Full	29	1	Transition training should be considered in the context of training in adolescent and young adult health. There is evidence to support the impact of adolescent training	Thank you for your comment. The research recommendations stem directly from the gaps in evidence in our reviews. Researchers can, of course, propose projects that address these research questions in different ways.

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Royal College of Paediatrics and Child Health	Full	136	20	The phrase 'Age appropriate' is used. We would argue that this should be age and developmentally appropriate. Age is a poor surrogate for developmental status as the research on pubertal timing and in neuroscience is revealing. However it is also important for young people with cognitive impairment as they need both age AND developmentally appropriate services. A 20 year old with significant learning disability still has a 20 year old physical body with 20 year old physiology, pharmacokinetics etc.	Thank you for your comment. 'Age-appropriate' has been replaced with 'developmentally appropriate' (recommendation 1.5.11).
Royal College of Paediatrics and Child Health	General	General	general	E.g. 1.2.19 parents often find transition more challenging than young people. Parental needs particularly around "letting go" need to be supported and such input needs to start much earlier often in childhood before adolescence starts. More needs to be included as to how parental needs will be addressed.	Thank you for your comment. The Committee agreed that the issue of parental involvement is important and complex and, on reviewing these recommendations at Guideline Committee meeting 12 (04.11.15) agreed to strengthen their wording (recommendations 1.2.19 to 1.2.22).
Royal College of Paediatrics and Child Health	General	General	general	References are surprising. • No inclusion of Lugasi 2011 – which is a useful review of the qualitative literature • No references to youth friendly services e.g. Ambresin 2013 • Reference only the postal survey (McDonagh 2004) from the multicentre rheumatology study which was the first UK objective evaluation of an evidence based programme but none of the other papers from this research including the interventional one is referenced (McDonagh 2007) - perhaps it was because the rheumatology study did not look at post transfer – however it did address transition and consider short term outcomes.	Thank you for your comment. We have provided information below about why the references you suggest were not included. Lugasi 2011 - There was extensive qualitative literature on views and we therefore agreed an approach to sampling this literature with the Guideline Committee. Ambresin 2013 – The Guideline Committee did consider use of the term 'youth-friendly' or 'young people friendly' services as this came up in discussions however they agreed, instead to use the terminology 'developmentally appropriate'. McDonagh 2014 – We excluded papers that focused

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					only on developmental transition rather than pre- and post-service transfer; however, Janet McDonagh was also an expert witness.
Royal College of Paediatrics and Child Health	Short	General	general	There's no comment about hospital admissions during and shortly after transition. For conditions such as brittle asthma or sickle cell disease, where emergency admissions may be more likely, suggest young person is offered choice of admission to children's ward (i.e. where previously admitted) or adult ward for about 1 year post transition. Thus the shock of the change is lessened. Most of the young people took up this offer. This will only work if paediatric team and adult team located on same site.	Thank you for your comment. Given the very wide range of young people covered by this guideline, it was not possible to search condition-specific literature. The Guideline Committee sought to establish the broad principles to follow with respect to care and support before, during and after transition.
Royal College of Paediatrics and Child Health	short	General	general	In practice, different elements of them may be very hard for individual areas/services to achieve but at least it provides a framework against which services can be measured which is good.	Thank you for your comment and support for the guideline.
Royal College of Paediatrics and Child Health	short	General	general	Pleased to see that this covers health and social care.	Thank you for your comment and support for the guideline.
Royal College of Paediatrics and Child Health	Short	General	general	We like the fact it is encouraged to make the transition process tailored to the patient.	Thank you for your comment and support for the guideline.
Royal College of Paediatrics and Child Health	Short	General	general	These guidelines are brilliant and if they are used properly by services we think this could have a big positive impact on transition for many young patients.	Thank you for your comment and support for the guideline.
Royal College of Paediatrics and	Short	General	general	The RCPCH would like to review the embargoed version of thus prior to publication, with the view to endorse post-publication as usual.	Thank you for your comment and offer to review the guideline at embargoed release stage and your support for the guideline.

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Child Health					
Royal College of Paediatrics and Child Health	Short	General	general	Is there too great a focus on social care within this guidance, to the detriment of children with health care issues?	Thank you for your comment. The scope of the guideline was health and social care and the recommendations reflect discussions about the evidence relating to both. The Guideline Committee agreed with the balance of recommendations.
Royal College of Paediatrics and Child Health	Short	General	general	There is no mention of the age for transition or length of time to start discussions prior to transition- this may well be different for children with social versus health care needs.	Thank you for your comment. The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are.
Royal College of Paediatrics and Child Health	Short	General	General	There is so much focus on transition – but so little on care throughout the life course – there is huge disparity between the model of service for children/young people and adults. The GP – who is the primary health provider for all – should be empowered to be more involved in childhood (this has training implications for GPs and other primary care professionals). A helpful reference is the RCPCH CYPHealth Outcomes Forum Report (link - https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/410482/CYPHOF_Report_2014-15.pdf). Paediatricians often take the primary and secondary care role. This creates difficulties for young adults – as adult secondary care services function in a very different way. The expectation of what services can	Thank you for your comment. The focus of this guideline is transition and it was not within scope to search for evidence on life-long approaches to providing support. The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).

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				provide for families therefore needs to be explicit. Many of the challenges occur; or areas of dissatisfaction are centred around expectation vs what can actually be delivered.	
Royal College of Paediatrics and Child Health	Short	General	General	There is little mention of the vulnerable either sexually or financially in addition to physical and emotional/ learning needs. This may have safeguarding implications and the guidelines must signpost YP, where appropriate, and professionals to the appropriate safeguarding processes.	Thank you for your comment. The scope of this guideline was broad. As a result, it was not possible to identify all vulnerable groups of young people; rather, the Guideline Committee sought to establish the broad principles to follow with respect to care and support before, during and after transition. Safeguarding is referenced therefore in recommendation 1.1.7 which is an over-arching recommendation. This has also been updated to reflect the need to link with local policies. It is also referenced in recommendation 1.4.1.
Royal College of Paediatrics and Child Health	Short	General	General	The document is to be commended for its holistic and comprehensive approach to transition. In practice much that is recommended does not happen because the human resource to implement a person centred approach across health, social care and education is not available. Specialist paediatric health services are often centralised; liaison with local social, education and adult health services at considerable distance and on multiple sites is very time consuming. Implementation of this guidance would produce significant associated cost pressures.	Thank you for your comment and support for the guideline. Please see the chapter on implementation which provides some practical examples of how challenges could be overcome. .
Royal College of Paediatrics and Child Health	Short	General	General	The RCPCH are open to ways of collaborating, with respect to the gaps identified in the research section, and through our recommendations to policy developments. The 2014 RCPCH report, *Why children die: death in infants, children and young people in the UK* (link -	Thank you for your comment and support for the guideline.

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				http://www.rcpch.ac.uk/index.php?q=child-health/standards-care/health-policy/child-mortality/child-mortality#A) is a useful reference to consider. Recently the RCPCH Health Policy Team provided a response to the DH's Public Health Outcomes Framework (Refreshing the Public Health Outcomes Framework (2015)), however, we didn't see this mentioned in the draft guideline. There are implications in the RCPCH response for young people who will be going through transition, which note that they *suggest adopting the WHO age bands of 0–4, 5–9, 10–14 and 15–19 years. For measures which apply to school-aged children, the education system age bands matching education transition points should be aligned, with an aim to have a unique identifier number, and effective cross reference to social care and youth justice data sets*. Collecting outcome data is very important.	
Royal College of Paediatrics and Child Health	short	General	general	The guidelines correctly call for patient centred care and transition to be tailored to each individual patient's requirements. This aspiration is supported but the resulting practical challenges in terms of resources, both staff time and financial, as well as the plethora of potentially incompatible and difficult to integrate plans will make implementation very challenging. It would be more practical to require Trusts and other provider organisations to use generic structured framework that can be tailored to the needs of each patient. This would then give the best balance between individualised care and administrative	Thank you for your comments which will be considered as part of the work to support guideline implementation. The Guideline Committee agreed strongly that the young person should be engaged and at the heart of their care. Person-centred care is referenced explicitly in recommendations 1.1.1, 1.1.4, 1.2.4 (which was updated to this end, following discussion at Guideline Committee meeting 12), 1.2.7 and 1.2.19.

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				requirements that could be delivered. This common approach would also help YP to move from one location to another as often happens when they go on to higher education. The use of the same structured framework should be encouraged in adult services as this would result in a seamless transition to adult services and allow for the holistic, patient centred approach to continue in adult services. Especially as there is a drive for patient centred care in adult services and a recognition that any patient with a long term condition should be empowered and gain the knowledge and skill to manage their condition- whether their care is in primary, secondary or tertiary services.	
Royal College of Paediatrics and Child Health	short	General	general	The named consultant for the young person (YP) should be responsible for ensuring the YP is undergoing transition with all members of the MDT being involved. A named keyworker as a point of contact for the YP is more practical and effective to a single person co-ordinating all care. If the YP is seen by multiple sub-specialties, each sub-speciality is responsible for ensuring that their service is providing good effective transition. If all sub-specialties use the same structured framework this will allow parity of esteem and bench-marking. It is the responsibility of the named consultant to identify the most appropriate adult service for the YP to transition to for their sub-specialty- be it primary, secondary or tertiary services.	Thank you for your comment. We have made clearer that the named worker is a role rather than a specific job (see: Terms used in this guideline, recommendations 1.2.5, 1.2.6 and 1.2.7) and it therefore could be undertaken by the named consultant)..
Royal College of Paediatrics and Child Health	short	General	general	It is very important that YP who are >16 years whose first presentation with a long term condition is in adult services should also have their needs met and should not be excluded from transition- they should have	Thank you for your comment. Young people whose first presentation with a long term condition is in adult services were not in scope for this guideline.

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				access to structured, holistic programme. Need cultural change within the NHS.	
Royal College of Paediatrics and Child Health	Short	1	General	'Who is it for' The guidance states that it is for all young people using health or social care services. It would be better to state that it is for all young people who need health services, based on previous assessed needs. This is important because some young people do not keep appointments in the tricky teenage years. They need transition just as much as those who do keep appointments and it is important for the guidance to include plans for this most vulnerable group.	Thank you for your comment. This was deliberated at the scoping stage and the wording agreed. The guideline excludes young people who have not used services.
Royal College of Paediatrics and Child Health	Short	3	8	Completely agree to use of person-centred approaches. However, there needs to include here reference to following the best interests decision-making processes of the Mental Capacity Act 2005 where a young person does not have the capacity to make their own decisions about aspects of their care at the time of transition. This should include reference to appointing an independent mental capacity advocate (IMCA) if need be.	The Mental Capacity Act is now referenced explicitly in recommendation 1.2.20. There will also be reference to the MCA in the full guideline text available on the NICE website when the guideline is published. For an example from another social care guideline, see below: https://www.nice.org.uk/guidance/ng22/chapter/recommendations which links to https://www.nice.org.uk/about/nice-communities/public-involvement/your-care
Royal College of Paediatrics and Child Health	Short	3	8	Should line 24 not include educational attainment?	Thank you for your comment. On review, the Guideline Committee agreed that reference to liaison with education practitioners needed to be strengthened in the recommendations, given: the critical importance of education sector professionals in supporting young people's development, health and wellbeing, and identifying problems early. To achieve this, the following recommendations now reference education explicitly: 1.1.4, 1.1.6, 1.2.6, 1.2.8, , 1.2.16 and 1.3.3.

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Royal College of Paediatrics and Child Health	Short	3	15	"..is developmentally appropriate, taking into account their maturity, cognitive abilities, needs in respect of long-term conditions, social and personal circumstances and psychological status" This statement is to be welcomed and allows for flexibility in approach, which is frequently necessary. Flexibility, however, will tend to complicate and increase resource requirement for the transition process.	Thank you for your comment and support. Your comment on resource implications will be considered as part of the work to support guideline implementation.
Royal College of Paediatrics and Child Health	Short	4	7	Should the service mangers be encouraged to meet to make sure the services they provide are complimentary?	Thank you for your comment. Service funding and charging structures are not within the remit for NICE guidance; however, section 1.5 on Supporting Infrastructure was intended to cover issues of accountability and strategic management.
Royal College of Paediatrics and Child Health	Short	4	7	This aspect would be greatly helped by prospective data capture at the point of care about all young people's health and social care needs, this information being shared, with appropriate governance in place, across agencies and used to inform the Joint Strategic Needs Assessment in the local area as well as inform planning for transition services.	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Royal College of Paediatrics and Child Health	Short	4	10	Completely agree.	Thank you for your comment and support.
Royal College of Paediatrics and Child Health	Short	4	15	Agree to having a named worker to support transition. However, this role should not be underestimated, as specialist transition services will bear witness. In Sunderland they have a transition specialist team for young people with learning disabilities. This involves two nurses (one post currently vacant) and a support worker. These practitioners are employed specifically to support the transition of young people with LD from14 years of age. The workers are extremely hard-working and support young people and their families well. The work that they do could not be simply 'bolted	Thank you for your comments which will be considered as part of the work to support guideline implementation. Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). You will note the addition of

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				on' to a person's day job. If effective transition support is to be achieved, it must be fully and appropriately resourced. The NICE guidance should please make this explicit. Many young disabled people do not have social workers. Their health workers are unlikely to have the capacity to assume the role of 'named key worker', no matter how good the relationship that they have with the young person and their family. (Families may want them to be their named worker, but they simply may not have the capacity to do this.) This is especially pertinent given the long list of expectations of the named worker that are given in 1.2.3 and the significant length of time (a year or more) as specified in 1.2.1 that they are expected to provide this additional support for.	text to make clear that this person is not expected to do everything, but to 'oversee, coordinate or deliver transition support, depending on the nature of their role'.
Royal College of Paediatrics and Child Health	Short	5	27	Completely agree.	Thank you for your comment and support.
Royal College of Paediatrics and Child Health	Short	6	1	Whilst it is aspirational to hold an annual review to include all practitioners providing support for the young person, this will not be possible in practice for most services, that are currently struggling to provide basic clinical care and support and simply do not have time to get to every planning meeting about every child or young person. It would be helpful for the NICE guidance to acknowledge this and add a caveat that where practitioners cannot attend in person, an update report laying out the active issues, health conditions, agreed outcomes and actions would be most helpful to inform the person-centred discussions.	Thank you for your comment. The Guideline Committee reviewed the recommendations on timing and review (under section 1.2) at Committee Meeting 12 (04.11.15) and agreed the edited wording now found in recommendation 1.2.4 which includes making clear that practitioners could take part in meetings via teleconferencing or video, recognising the pressures on people's time.
Royal College of	Short	6	3	"involve all practitioners providing support to the young person and their family or carers" A laudable	Thank you for your comment. The Guideline Committee reviewed the recommendations on timing

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Paediatrics and Child Health				statement that in practice is just not always achievable. Children with complex needs can sometimes be involved with many (six or more) health services as well as social care and education services. Co-ordinating meetings is practically very difficult.	and review (under section 1.2) at Committee Meeting 12 (04.11.15) and agreed the edited wording now found in recommendation 1.2.4 which includes making clear that practitioners could take part in meetings via teleconferencing or video, recognising the pressures on people's time.
Royal College of Paediatrics and Child Health	Short	6	7	Transition planning should start early for ALL young people, not just for those in out of area placements. This needs to be more specific as to what 'early' means, which should be no later than 14 years.	Thank you for your comment. The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are.
Royal College of Paediatrics and Child Health	Short	6	9	Agree.	Thank you for your comment and support.
Royal College of Paediatrics and Child Health	Short	6	14	Sounds good in theory, but not sure how this translates into practice?	The Guideline Committee reviewed the recommendation on supporting young people to communicate with practitioners and revised the text to make clear this requires them to know what a young person's communication needs are, and to have tools available to help address those needs (see recommendation 1.2.12).
Royal College of Paediatrics and Child Health	Short	6	20	It will be the clinicians who will be putting such communication support tools in place rather than managers. Again, this needs to be factored in, in terms of the resources that teams need in order to meet the additional support requirements for effective transitions.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
Royal College of	Short	7	general	In building independence p.7, it would be good to add a statement that young people transitioning from child to adult healthcare should have some education	Thank you for your comment. This was considered by the Guideline Committee at meeting 12 (04.11.15), however they agreed that the current over-arching

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Paediatrics and Child Health				(informal) on the differences in how children's /adult healthcare works.	outcome areas were appropriate.
Royal College of Paediatrics and Child Health	Short	7	2	Again, there needs to be reference in this point to the specific support needs of young people who are assessed to lack the capacity to make their own decisions about aspects of their care, which must follow the best interests decision-making processes of the Mental Capacity Act 2005.	There will be reference to capacity, and specifically the MCA in the full guideline text available on the NICE website when the guideline is published. For an example from another social care guideline, see below: https://www.nice.org.uk/guidance/ng22/chapter/recommendations which links to https://www.nice.org.uk/about/nice-communities/public-involvement/your-care
Royal College of Paediatrics and Child Health	Short	7	4	Completely agree for those with the capacity to use such networks. There needs to be reference to the additional supports needs of parent carers where young people are completely dependent on them for everything, including support to make sense of the likely reduction in overall care and support available in adult services compared to children's services.	Thank you for your comment. The need to provide support to parents and carers is referenced explicitly in recommendation 1.2.7.
Royal College of Paediatrics and Child Health	Short	7	9	Agree with this, which should be in the local offer.	Thank you for your comment and support.
Royal College of Paediatrics and Child Health	Short	7	12	It is not clear what the specific expectations of health workers are in terms of supporting young people into employment and towards independent living. This needs greater clarity in the guidance if it is to be meaningfully translated into practice on the ground.	Thank you for your comment. This recommendation was identified as duplicating information contained elsewhere in the guideline (specifically 1.1.4 and 1.2.8) and has therefore been deleted.
Royal College of Paediatrics and Child Health	Short	7	12	Should a bullet point for educational goals be included?	Thank you for your comment. On review, the Guideline Committee agreed that reference to liaison with education practitioners needed to be strengthened in the recommendations, given: the critical importance of education sector professionals in supporting young people's development, health and wellbeing, and identifying problems early. To achieve this, the following recommendations now reference education

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					explicitly: 1.1.4, 1.1.6, 1.2.6, 1.2.8, , 1.2.16 and 1.3.3.
Royal College of Paediatrics and Child Health	Short	7	20	Fine to have peers and friends as active participants, but may make arranging the meetings logistically complex, ensuring that the needs of the peers and mentors are supported in the meetings as well and that the focus remains on the index young person and their best interests, rather than going off on someone else's agenda.	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Royal College of Paediatrics and Child Health	short	7	24	CYP with several long term conditions will likely transition at different points for each "condition." Their named transition supporter needs to be aware they may be going through several transitions.	Thank you for your comment which is helpful for context. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). The Committee have now also included explicit reference to supporting young people with multiple conditions, or those using a mix of services in 1.2.7 and 1.5.9.
Royal College of Paediatrics and Child Health	Short	7	24	There is comment about children with LTCs. This guideline should be applicable to those with learning difficulty, autism, etc. and yet there is little about assessing YP competence in decision making/self-care and social vulnerabilities.	Thank you for your comment. Recommendation 1.2.17 includes explicit reference to assessment of ability to self-manage which the Guideline Committee considered to be sufficient.
Royal College of Paediatrics and Child Health	Short	7	24	Again, this is great for young people who are able to aspire to independence, but those with the most complex needs cannot and this needs to be specifically addressed within the guidance at every step. The additional support required by families whose young people are completely dependent on them for all of their needs is considerable at transition, who usually face the prospect of less care and support in adult services and are worn out with continual and relentless	Thank you for your comment. The guideline covers a very wide range of young people and services so it was not possible to list all relevant conditions and needs separately. Young people with complex needs are covered by the guideline. An additional recommendation has been included (1.5.10) to make clear that young people involved with multiple specialties need more coherent provision.

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				self-advocacy.	
Royal College of Paediatrics and Child Health	Short	8	5 -17	Again this is laudable for those young people who are able to express a view on this, but those who are not able to need to have their needs protected in the guidance too, in their best interests.	The Mental Capacity Act and other relevant legislation is now referenced explicitly in recommendation 1.2.20. There will also be reference to the MCA in the full guideline text available on the NICE website when the guideline is published. For an example from another social care guideline, see below: https://www.nice.org.uk/guidance/ng22/chapter/recommendations which links to https://www.nice.org.uk/about/nice-communities/public-involvement/your-care
Royal College of Paediatrics and Child Health	Short	8	10	This is suggesting that all services should provide information on all of these aspects, which may well be outside the practitioner's own competence to advise about. This should not be used as an opportunity to shift responsibility from social care to health for providing aspects of support and information that falls outside of the health domain.	The Committee's recommendations on information provision for young people and their families (1.2.7, 1.2.13, 1.3.4, 1.3.7 and 1.3.8) aimed to ensure that responsibility for this was shared, as appropriate. The nature of information that should be provided will vary, given the wide range of young people that are covered by this guideline, and the individual nature of information needs. The recommendations on information provision therefore do not specific the detail of what should be provided by whom, allowing practitioners flexibility to implement recommendations locally.
Royal College of Paediatrics and Child Health	Short	8	19	This is good, but it is not clear how service managers will have a handle on this, unless they have excellent data about the needs of the young people in the local area. Many disabled young people don't have any social care input at all, so the managers in children's services won't know that they need to communicate with managers in adult services.	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Royal College of Paediatrics and	Short	8	22	Please see comments already above on the additional duties expected of a named worker, which the guidance as currently written is expecting the person to	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and

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Child Health				deliver on top of their day job, which I do not think is deliverable (as an experienced clinician in the field). It will be tricky indeed to hand the baton on for the named worker role, without this being adequately resourced with protected time for the duties expected.	responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). Specifically, you will note that we have made clearer this is a role not a job title and therefore could be undertaken by someone who is already fulfilling a role of keyworker, coordinator or transition support worker.
Royal College of Paediatrics and Child Health	Short	8	23 -29	This is great and works very well where there is a properly resourced transition support team in place to accompany young people and their families to appointments and to visit new services, but will be a very big ask for the named worker on top of their day job.	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). Specifically, you will note that we have made clearer this is a role not a job title and therefore could be undertaken by someone who is already fulfilling a role of keyworker, coordinator or transition support worker.
Royal College of Paediatrics and Child Health	Short	8	25	The transition folder is a brilliant idea.	Thank you for your comment and support.
Royal College of Paediatrics and Child Health	Short	8	25	Is this to be expected of the named worker? Of course it is great to encourage young people and families to keep folders of important documents and many already do this.	Thank you for your comment. Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level. Where young people and families already keep folders of important documents and this

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					is working well, practitioners may want to build on this.
Royal College of Paediatrics and Child Health	Short	10	1	As in many of the sections above, the specific and complex needs of those who are not able to make decisions for themselves about their own care has not been addressed in this section. The specific expectations of additional support for the parent carers of these most complex young people must be included and made explicit here if the guidance is to be equitable for all.	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
Royal College of Paediatrics and Child Health	Short	10	10	It is not clear what alternative support is implied here, examples would be most helpful, thank you.	Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detail here. Overall, the recommendation is aimed at ensuring people do not 'fall through the gaps' between services.
Royal College of Paediatrics and Child Health	Short	10	13	Is there any way the GP could be more involved in the transition process? They could be a form of safety net so the patient doesn't get lost in the system.	The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to

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					GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
Royal College of Paediatrics and Child Health	Short	10	13	The GP should be integral to all transition planning, not just brought in where the criteria are not met for specialist adult services. The GP is the primary point of care for all adults. There is so very much to be done to re-empower GPs to be central to the care and support of disabled young people. This guidance please needs to really emphasise this. The advice should explicitly state that GP should be integral and primarily responsible for an individual's health throughout the life course.	The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
Royal College of Paediatrics and Child Health	short	10	13	*1.3.9 If a young person does not meet the criteria for specialist adult health services, involve the GP in their transition planning*. **The GP should always be included in the transition process** even if the care is being transferred to adult services.	The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
Royal College of Paediatrics and Child Health	Short	10	15	This is very tricky indeed. The guidance is suggesting that for those families who do not engage, it is up to the named worker (yet another task for them!) to sort it out. It is not in the gift of the named worker to 'ensure that the young person sees the same health practitioner for the first 2 attended appointments after transition' or has the same social worker through the process. These service delivery issues are completely out of an individual practitioner's control and definitely will not be under the control of a named worker, even if the worker is a dedicated transition support specialist. Yet again, the needs of those who cannot advocate for	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). Recommendation 1.4.4 which relates to continuity of health practitioner post-transfer is not aimed at the named worker.

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				themselves is omitted in this section. What about their safeguarding needs, if there is a perception that needs are not being adequately assessed and met? This is a major omission from the guidance, not to even mention safeguarding pathways.	
Royal College of Paediatrics and Child Health	short	10	21	In event of non-attendance at adult clinic, in first 12-18 months post transition suggest also inform someone from Paediatric team previously involved – they may have more sway (having established relationship over years in past) in encouraging attendance.	Thank you for your comment. Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level.
Royal College of Paediatrics and Child Health	Short	11	8	Completely agree about training. See www.disabilitymatters.org.uk which has a range of free resources to support staff training in these areas, resources that have been co-produced by disabled young people, parent carers and other experts.	Thank you for your comment and support.
Royal College of Paediatrics and Child Health	Short	11	8	Excellent inclusions.	Thank you for your comment and support.
Royal College of Paediatrics and Child Health	Short	12	1	Completely agree that having a supportive infrastructure is essential and transition champions. However, due attention must be given to the burden of additional expectations and responsibilities that this guidance suggests should be placed on the 'named worker', apparently completely on top of their day job, which in my professional opinion will not be safe or sustainable without creaks in other parts of their roles.	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). Specifically, you will note that we have made clearer this is a role not a job title and therefore could be undertaken by someone who is already fulfilling a role of keyworker, coordinator or transition support worker.

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Royal College of Paediatrics and Child Health	Short	12	1	Excellent inclusions.	Thank you for your comment.
Royal College of Paediatrics and Child Health	Short	12	1	Suggest using 'Accountability' rather than ownership for the title of this section.	Thank you for your comment. The Guideline Committee considered the issue of ownership of transition carefully (recommendations 1.5.1 to 1.5.3) and reviewed these recommendations at Guideline Committee meeting 12 (04.11.15). The wording has been updated to make clearer how these roles would work and where accountability lies.
Royal College of Paediatrics and Child Health	Short	12	15	Completely agree that independent advocacy should be available for all young people after transition. This also needs to be available, if differently delivered, for parent carers of young people whose needs are so complex that they cannot use such a service for themselves, other than within the framework of MCA best-interests decision-making, when they may well need an independent mental capacity advocate appointing if decisions need to be made about their health or care.	The Mental Capacity Act is now referenced explicitly in recommendation 1.2.20. There will also be reference to the MCA in the full guideline text available on the NICE website when the guideline is published. For an example from another social care guideline, see below: https://www.nice.org.uk/guidance/ng22/chapter/recommendations which links to https://www.nice.org.uk/about/nice-communities/public-involvement/your-care
Royal College of Paediatrics and Child Health	Short	12	18	Completely agree, excellent idea. The Council for Disabled Children probably have the best inventory of existing youth forums that include disabled young people	Thank you for your comment and support.
Royal College of Paediatrics and Child Health	Short	12	24	Agree	Thank you for your comment.
Royal College of Paediatrics and Child Health	Short	13	1	Excellent idea and much needed. Who will have responsibility for doing this?	Thank you for your comment which was discussed in Guideline Committee meeting 12 (05.11.15). We have amended the heading for this section to make it clearer that people planning services should carry out the gap analysis.

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Royal College of Paediatrics and Child Health	Short	13	5	Please don't forget young people who are totally dependent on their parent carers for all their care and cannot make decisions for themselves as they do not have the capacity to do so.	Thank you for your comment. The guideline covers a very wide range of young people and services so the list reflected priority groups identified during development as being particularly at risk of 'falling through the gaps' between services, rather than being exhaustive
Royal College of Paediatrics and Child Health	Short	13	14 -23	We support this and advocate for interagency strategic partnerships for disabled children and young people.	Thank you for your comment and support.
Royal College of Paediatrics and Child Health	Short	13	25	Joint clinics work well and families like them. If families have been well prepared and proactively supported with the whole transition process, a single joint appointment is likely to be sufficient rather than the many suggested, which may be logistically difficult to arrange.	The focus of the recommendations is on ensuring developmentally appropriate care and support as a principle, rather than on specifying particular models of transition support. This is because the Committee concluded that different approaches could deliver positive outcomes, and therefore that the ways of working were likely to be more important to make recommendations on than the structure. The Committee also agreed that specifying the principles - rather than asking people to implement entirely new service delivery models - also helped ensure recommendations would not have a significant cost impact. Stakeholder comments indicated that age-banded clinics were one useful and commonly accepted way of delivering developmentally-appropriate care and therefore these were included as an example, post-consultation
Royal College of Paediatrics and Child Health	Short	13	25	What about those with severe intellectual disability - we would like to see more support mentioned for them and their parent/carers who often feel excluded at this point since this is about both health and social care some mention should be made of housing, transport, employment - is in 1.2.14 but no explicit link to carrying	Thank you for your comment. The guideline covers a very wide range of young people and services so it was not possible to list all relevant conditions and needs separately. As a result, and recognising that, as you highlight, it needs to address the diverse needs of wide range of young people, the Guideline Committee

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				through needs to these services.	sought to establish the broad principles to follow with respect to care and support before, during and after transition. Young people with severe intellectual disability are included in the guideline.
Royal College of Paediatrics and Child Health	short	15	2	*Terms used. Transition. The process of moving from children's to adults' services. It refers to the full process including initial planning, the actual transfer between services, and support throughout.* Transition is about going from a state of knowing very little about their condition to fully managing their condition and not just making a move to adult services. **Please include a sentence about ' empowering young people by equipping them with the skills and knowledge to manage their healthcare in both children's and adult services.** At present many people still think of transition as moving from children's to adult services with no empowerment. Empowerment needs to be stressed. Empowerment and the holistic approach needs to continue in adult services	Thank you for your comments. Thank you for your comment. The Committee discussed the need to support the young person "as a whole", taking into account what they would like to achieve and what information and support they need, throughout guideline development. This informed the development of the four over-arching outcome areas referenced throughout, specifically: - education and employment - community inclusion - health and wellbeing including emotional health - independent living and housing options. It was the Committee's intention that these would include equipping them with the skills to become more autonomous so the request specific addition has not been made. These areas are included in recommendation 1.2.8, the Training section of the Implementation chapter, and in the definition of 'person-centred' ('Terms used in this guideline').
Royal College of Paediatrics and Child Health	short	15	16	*Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why* **Changing the definition of transition will have a big impact on practice. There is still a misconception amongst some healthcare professionals, who confuse transfer with transition. Clarifying that transition must also empower the patient by**	Thank you for your comments which will be considered as part of the work to support guideline implementation.

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				equipping them with the skills and knowledge to manage their condition in children's and adult services and not just 'the process of moving from children's to adult services'. See comment above	
Royal College of Paediatrics and Child Health	short	15	18	*What would help users overcome any challenges? (for example, existing practical resources or national initiatives, or examples of good practice.)* Cultural change within the NHS in both children's and adult services is difficult. i) Giving teams resources and tools to use will help overcome challenges and ease implementation. Using a structured framework e.g. a generic transition programme in both children's and adult services such as Ready Steady Go and Hello (see Implementing transition: Ready Steady Go. Nagra A, McGinnity PM, Davis N, Salmon AP Arch Dis Child Educ Pract Ed. 2015 Jun 10) will support transition, patient empowerment and provide a holistic approach in both children's and adult services. The tool can be used for all sub-specialities and all age groups in both paediatric and adult services and is already resulting in cultural change within the NHS where used. ii) Providing transition policies for Trusts to adapt for their organisations will also hasten implementation.	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Royal College of Paediatrics and	Short	18	general	This section needs to be strengthened in terms of ensuring that, where required, it is not just about sharing safeguarding information, there may be	Thank you for your comment. The focus of this recommendation is on information-sharing though we recognise that additional action may be relevant.

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Child Health				requirements to progress this through safeguarding mechanisms and common assessment frameworks.	
Royal College of Physicians	Full	General	General	The RCP is grateful for the opportunity to respond to the draft guideline consultation. In doing so, we wish to endorse the submission made by the British Society of Gastroenterology (BSG) and to highlight the comments of the RCP Young Adult and Adolescent Steering Group, as follows. In general, the guideline is felt to be generic but useful. We believe that the guidance would be improved if there was a focus on the real challenge of providing developmentally appropriate care across children's and adult services and also an emphasis on young people getting best care utilising where that exists in children's or adult services or primary care. Some overarching comments include recognising the needs and role of carers, including planning for acute admissions as part of transition planning, more involvement of primary care in the process and more clarity on the named worker.	Thank you for your comment and support for the guideline. The scope of this guideline was to establish the broad principles to follow with respect to care and support before, during and after transition. Recommendations related to parent and carer involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision The Guideline Committee discussed the role of primary care, and GPs in particular, in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1). Following discussion at Guideline Committee meeting

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					12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7).
Royal College of Physicians	Full	General	General	1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why. If the role of a named worker with an administrator is properly defined and supported by commissioners and providers this potentially could have the biggest impact. However ,this is potentially at an increased cost. 2. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.) Complete buy-in by commissioners and providers. 3. What are the key audiences we need to consider in structuring the guideline? Everybody and the guideline should be written to address them directly and not get lost, including separate sections for children's and adult services regardless of repetition. 4. At what age does transition planning start now?	Thank you for your comments which will be considered as part of the work to support guideline implementation. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are.

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				Varies but should start in early adolescence 11-13, the more interesting question is when should it finish? 5. How often do review meetings happen at present? In health it depends on condition and depends whether you mean clinic attendance. If clinic attendance is the intended meaning then most will at least be seen every 12 months. 6. How should parents be involved in transition planning? A careful balanced approach with children's services encouraging parents in person centred planning is required. It is vital parents are involved to give the best chance of success. 7. Will these recommendations result in an impact on cost of services? If the named worker administrator concept is embraced then there will be a cost implication. However, it is hoped that this would be balanced by improved attendance and better outcomes. 8. Which of these recommendations would lead to additional costs? Named worker and administrator 9. Will any of these recommendations lead to cost savings? If they are all followed it could potentially lead to cost savings. At least if the recommendations are implemented then future	The Committee also noted the need for dedicated transition support post-transfer and this is addressed in recommendations 1.2.8 in particular. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15 and strengthened (see 1.1.4, 1.2.19, 1.2.20 and 1.3.7). The Committee emphasised throughout development the importance of ensuring the young person is at the centre of their care and support. This is referenced explicitly in recommendations 1.1.1, 1.1.2, 1.2.4 (which was updated to this end, following discussion at Guideline Committee meeting 12)and 1.2.19. Thank you for your comments on costs which will be considered as part of the work to support guideline implementation.

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				research will be more discerning – based on a bedrock of good practice.	
Royal College of Physicians	Full	4	9	While we commend the guidelines for reflecting that the process continues into young adulthood some questions were posed reflecting the need for flexibility in this age potentially for some extending to an older age. Where does the cut-off age of 25 come from? Is this based on any specific piece of evidence? Is this an appropriate cut-off for all of the possible conditions that young adults undergoing transition may have?	Thank you for your comment. The Guideline Committee recognised the wide range of young people and services covered by this guideline. The Committee agreed on the upper age limit of 25, by consensus. The Children and Families Act 2014 extended the special educational needs and disability system to a 0-25 system. This means that young people up to the age of 25 could have an education, health and care plan and where that is the case the plans must have a specific focus on preparation for adulthood.
Royal College of Physicians	Full	8	3	As well as the fragmentation between different elements of health and social care, it is worth considering the fragmentation of medical subspecialty care in adult services relative to paediatric services. There is no adult equivalent of a paediatrician and most secondary care services are designed and commissioned to meet specific needs in a single encounter – many trusts actively celebrate a reduction in their Follow up:New ratio, while CCGs tend to fund follow up appointments at a reduced rate relative to new patient appointments, actively encouraging discharge from services.	Thank you for your comments which will be considered as part of the work to support guideline implementation. Funding is not within the remit of NICE guidance. Please also see the Implementation chapter which identifies some of the challenges and how to overcome them. In particular, this chapter contains information about how to improve joint working where there is no equivalent adult service to that available for children.
Royal College of Physicians	Full	8	9	In the context of meeting complex needs across health and social care for young adults with neurological impairment, physicians in rehabilitation medicine are usually experienced in considering the wider needs of participation and independence, with an ability to engage with allied services such as seating, therapies and orthotics. More could be made of this within the guideline, especially as related to cerebral palsy and other acquired neurological diseases of early life.	Thank you for your comment. The Guideline Committee reflected on the issue of young people with multiple and complex conditions, at Guideline Committee meeting 12 (04.11.15) and agreed an additional recommendation was needed, to emphasise the need for integrated working to support this group (recommendation 1.5.10).

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				There are existing models of transition which work well in this context that could be discussed or highlighted.	
Royal College of Physicians	Full	10 & 12	13 & 12	Within the person-centred care section there needs to be a sentence documenting that in some circumstances, due to need/capacity issues of the young person, the parent/carer/advocate will need to be substituted into the thinking of services. Therefore, where the document says 'person centred' does there need to be something about the necessity for a sensitive, respectful, 'aware of the interests of all' conversation/dynamic dialogue about when/how decisions are made by young people and carers, mindful of the autonomy of the young person and in consideration of the family/carers who may continue to be vital in the care of the individual young person. So then, in 1.1.2 where we cannot treat the young person as an equal etc because of capacity etc there is no conflict in the way the guideline is written because it will be the carers etc who will be substituted in as the equal part.	Thank you for your comment. The Committee agreed that parental involvement can also be complex. Recommendations related to parental involvement, capacity and preference were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
Royal College of Physicians	Full	12	7 &11	It is believed that there is sufficient evidence for these recommendations to say 'should' co-produce rather than 'consider'.	Thank you for your comments. 'Consider' has been removed from recommendation 1.1.1.
Royal College of Physicians	Full	12	21	Education and careers needs to be added in.	Thank you for your comment. On review, the Guideline Committee agreed that reference to liaison with education practitioners needed to be strengthened in the recommendations, given: the critical importance of education sector professionals in supporting young people's development, health and wellbeing, and

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					identifying problems early. To achieve this, the following recommendations now reference education explicitly: 1.1.4, 1.1.6, 1.2.6, 1.2.8, , 1.2.16 and 1.3.3.
Royal College of Physicians	Full	14	3	It would be appropriate to also include the phrase '& carers where deemed more appropriate'.	Thank you for your comment. This particular bullet point (within recommendation 1.2.7) addresses young people's involvement specifically. The Guideline Committee reviewed, and made some updates to, the recommendations on parent or carer involvement (recommendations 1.2.19 to 1.2.22) taking into account stakeholder comments about the variability of circumstances and the complexity of involvement.
Royal College of Physicians	Full	14	3 -15	While nobody would disagree with the general recommendations of named workers and administrators, it needs to be clear to both providers' and commissioners' whose responsibility it is to fund and support this recommendation,	The remit of NICE guidance is to identify 'what works'. It is then complemented by additional NICE support for commissioners. The implementation chapter of the guideline identifies some specific actions for providers and commissioners to help overcome implementation challenges and the guideline will also be accompanied by a Quality Standard and support plan.
Royal College of Physicians	Full	15	8	The named worker should also support the carer.	Thank you for your comment. Recommendation 1.2.7 indicates that the named worker should 'support the person's family, if appropriate'.
Royal College of Physicians	Full	15	13	While this is obviously a good idea it should be stated who will provide it and how.	Thank you for your comment. Given the wide range of young people covered by this guideline, and the wide range of practitioners involved in supporting the young people to whom the guideline relates, the recommendations are worded to allow flexibility in respect of local implementation.
Royal College of Physicians	Full	15	18	The use of the term "transition age" is confusing. The recommendation should state that for young people presenting after the age of 13 or 14 transition planning should start immediately	Thank you for your comment. This has now been amended to 'point of transfer' (recommendation 1.2.1)

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Royal College of Physicians	Full	16	20	A recommendation around support groups for careers/parents/families to aid 'letting go' should be added.	Thank you for your comment. There was no evidence to indicate this warranted a separate recommendation, however, based on stakeholder feedback about the importance and complexity of parental involvement, recommendations related to this area were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
Royal College of Physicians	Full	17	7	The concept of a transition out of education is important. While young people involved with specific educational services may have therapy/medical components, there is no equivalent in the adult world and, perhaps, the need for ongoing input needs to be made distinct from the desire for it.	Thank you for your comment. On review, the Guideline Committee agreed that reference to education needed to be strengthened in the recommendations, given: the critical importance of education sector professionals in supporting young people's development, health and wellbeing, and identifying problems early. To achieve this, the following recommendations now reference education explicitly: 1.1.4, 1.1.6, 1.2.6, 1.2.8, , 1.2.16 and 1.3.3.
Royal College of	Full	17	11	It would be important to acknowledge the transition of	Thank you for your comment. The Committee agreed that parent and carer involvement is complex and

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Physicians				the carer too.	discussed throughout development the transitions they make in parallel with the young person's. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
Royal College of Physicians	Full	18	4	Support before transfer: friendship groups for looked after children ARE VITAL!	Thank you for your comment. The Committee agreed that supporting a young person in the context of their family and/or social networks is important. It is intended that social networks are considered and this would come under the over-arching outcome area of 'community inclusion'.
Royal College of Physicians	Full	18	5	While the concept of a named worker is a good one, again without being a bit more specific this may be too easy to become 'someone else's' responsibility.	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make

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					clear what this person's role would involve (recommendation 1.2.7).
Royal College of Physicians	Full	18	11	The young person's ownership of information is really important. Adult services should not have to beg paediatric services for access to correspondence that may have been generated over the years. There may be a case for giving the young person their own information pack on transition to use in contact with whichever service requires it.	Thank you for your comments. Please see the implementation chapter which provides examples of how to overcome some of the challenges related to implementation. In particular, there is a section on joint planning, development and commissioning of services involved in transition across children's and adults' health and social care.
Royal College of Physicians	Full	18	22	The replication of therapies in adult services as they are present in children's services is neither realistic nor appropriate. Part of the transition process is moving from being "done to" to "doing". Being autonomous and engaging in exercise programs or other self directed activities that do not involve oversight by a therapist is an important aspect of rehabilitation and perhaps a case could be made for preparing for transition by managing expectations in the context of what the health service can realistically be prepared to provide and what has an evidence base.	Thank you for your comment. The Committee recognised the importance of building autonomy and considering self-management where the young person has health needs. This is referenced in recommendation 1.2.17.
Royal College of Physicians	Full	19	7	As previously it was stated that there were named workers across children's and adult services it is important to reflect on the role of a children's and adult named worker working alongside each other or an overarching named worker.	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7).
Royal College of Physicians	Full	19	7	This section needs to include recommendations about advising the patient-carer 'unit' about how to access emergency and urgent care in their secondary and tertiary adult	Thank you for your comment. Given the very wide range of young people covered by this guideline, it was not possible to list all types of information that could be provided although recognise that emergency care may

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				service.	be particularly relevant for some young people and their families. The over-arching wording in recommendation 1.3.4 'what to expect from services and what support is available to them' is intended to cover a wide range of information and guidance.
Royal College of Physicians	Full	19	15	We would like to see the careers being given information. Also support for the carer/parent is needed	Thank you for your comment. Recommendation 1.3.4 makes reference to information being provided to families and carers as well as to the young person.
Royal College of Physicians	Full	19	27	The GP should be involved even if specialists are involved. The recommendation should define "criteria".	Thank you for your comment. The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
Royal College of Physicians	Full	20	1	Support before transfer reads very differently to support after transfer. Starting with some recommendations following positive engagement followed by looking out for those with poor engagement.	Thank you for your comment. The recommendations were developed based on the evidence available and agreement that the guideline should focus on the particularly intractable problems in respect of supporting young people through transition. The Guideline Committee reviewed the recommendations at Committee Meeting 12 (04.11.15) and made a number of edits to both of these sections to reflect stakeholder comments.
Royal College of Physicians	Full	20	8	This recommendation is not clear. Is the recommendation that adult services following an assessment about engagement should inform the children's named worker? As previously it was stated that there were named workers across children's and adult services it is important to state which named	Thank you for your comment. Thank you for your comment. The Committee reviewed this wording at meeting 12 (04.11.15) and agreed with it. It relates to a situation when adult services expect to see a young person but the young person does not turn up or make contact. Given the wide range of young people covered by the

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				worker.	guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level. In recommendation 1.2.6, it is noted that handover from one named worker to another takes place 'as appropriate' so it is not possible to specify more detail in recommendation 1.4.2 and 1.4.3.
Royal College of Physicians	Full	20	11	As previously it was stated that there were named workers across children's and adult services it is important to state which named worker.	Thank you for your comment. Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level. In recommendation 1.2.6, it is noted that handover from one named worker to another takes place 'as appropriate' so it is not possible to specify more detail in recommendation 1.4.2 and 1.4.3.
Royal College of Physicians	Full	20	22	Does this need to be more explicit about involving other providers eg. vol sector, housing. Also needs to involve engagement in community stuff as a real source of support.	Thank you for your comment. The information about training that could usefully support the guideline (see: chapter on Implementation) references 'everyone working with children and young people' recognising that a wide range of practitioners, across voluntary and community and statutory sectors should be engaged.
Royal College of Physicians	Full	22	8	Again the issue of the atomisation of adult services relative to paediatric health-care structures is an issue. Is this related to a specific diagnostic group, a particular clinical problem or a particular age group?	Thank you for your comment. The Committee did not wish to be too prescriptive in this respect hence the wording 'people with a range of care and support needs'. They added in a reference to the need to 'link with existing structures where these exist' (recommendation 1.5.5). The focus of this recommendation was young people's involvement in strategic level planning of transition services.
Royal College of	Full	22	13	Needs to specify who should be performing this gap analysis.	Thank you for your comment. The Committee did not wish to be too prescriptive in this respect, however,

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Physicians					they added in a reference to the need to 'link with existing structures where these exist' (recommendation 1.5.5) and a sentence has been added that this work should 'inform local planning and commissioning of services'.
Royal College of Physicians	Full	23	5	What about "incentivising" paediatric services in the same way. Why is this solely within the preserve of adult services?	Thank you for your comment. The Guideline Committee discussed this at length and the recommendation was focused in this way to reflect evidence on the particular challenges of involving adult services.
Royal College of Physicians	Full	23	8	This recommendation falls a long way short of developmentally appropriate and is either about "meeting the adult services" or "communication between children's and adult services". No mention of age banded clinics (adolescent or young adult) in both children's or adult services have been made and it is this model that lends itself to being "developmentally appropriate". The inclusion of this approach should be included.	Thank you for your comment. Recommendation 1.5.11 has been updated to include reference to 'age-banded clinics'
Royal College of Physicians	Full	23	19	The named worker needs a more careful job description to become viable and standards to work to.	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7).
Royal College of Physicians	Full	24	3	It should be stated that transfer occurs during transition.	Thank you for your comment. Definitions of both 'transition' and 'transfer' are already included in the guideline and transfer is referenced within the

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					transition definition (see: Terms used in this guideline' section).
Royal College of Physicians	Full	24	18	Person centred: need to add in education	Thank you for your comment. This has now been added.
Royal College of Physicians	Full	25	7	Is this generic or condition-specific?	Thank you for your comment. We have added in detail to make clear that research on self-management before, during and after transitions could focus on broad principles or be condition-specific.
Royal College of Physicians	Full	26	13 -14	Where is the evidence for the effectiveness or necessity for ongoing life-long therapeutic input?	Thank you for your comment. Research recommendations can be made only where we searched for evidence and noted there to be gaps. We did not explicitly search evidence on life-long therapeutic input so unfortunately cannot make a research recommendation in this area. This issue is encompassed, however, within the broader research recommendation on models which seeks to establish the evidence on the effectiveness and cost-effectiveness of different approaches.
Royal College of Physicians of Edinburgh	Short	General	General	2. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.) Fellows have suggested a range of examples, including: An initiative may be helpful to assist in developing a transition programme within each Trust to introduce a dedicated service environment with the necessary resources in place including staff, equipment and training. An analysis of provision across Trusts nationally may be helpful in this regard. One example given of good practice is the current	Thank you for your comments, good practice example and the background information which provides useful context. Your comments will be considered as part of the work to support guideline implementation. Please see also the chapter on implementation which provides some practical examples of how challenges could be overcome. In particular, there is a section on improving front-line practice with young people through training.

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				transplant clinic in Oxford for transition patients which is led by one consultant and takes place outside the secondary care hospital in the local gym. This allows a mix of clinic attendance and socialising with others. Failed transition is extremely important and has many potential causes. In order to address this, a home visit by nursing staff from paediatric and adult services together can be extremely useful in re-starting the engagement process. Another practical point is to highlight to parent and young person at the start of transition is the anticipated timetable for achieving completion. A "moving walkway" model can be very helpful, where each successive visit increases the role of the adult team in a planned and expected way until transition is complete. Patients are much more comfortable with the process if they know what is ahead. 3. What are the key audiences we need to consider in structuring the guideline? Patients; carers; families; clinicians; nurses and all specialists who may be required to follow up those patients with long term conditions in secondary care and the support services – such as physiotherapy, psychological medicine, substance abuse services, crisis teams. 4. At what age does transition planning start now? Transition planning varies between each person. The age range up to 25 years seems a little arbitrary with little evidence base. No detail is given as to what will happen after 25 years. This leads back to the shared decision with patient, family and/or carers. The	The audiences you identify were seen as key throughout guideline development. The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are. The Committee agreed on the upper age limit of 25, by consensus. The Children and Families Act 2014 extended the special educational needs and disability system to a 0-25 system. This means that young people up to the age of 25 could have an education, health and care plan and where that is the case the plans must have a specific focus on preparation for adulthood.

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				commencement should perhaps start after 14 years with a 2 year transition phase of joint clinics and ensuring the infrastructure is in place. However, maturity and puberty may define when individuals should move to adult services. 5. How often do review meetings happen at present? This depends on resources locally to allow visits to clinicians, nurses, and other interested parties in a multidisciplinary team format. In some services there are no review meetings. However in the first instance, for most services, around every 4 months is commonplace. 6. How should parents be involved in transition planning? Parents should be involved at all stages of transition planning but the young person should also be given the opportunity to meet with staff alone and discuss their own concerns or wishes without parents being present. Parents should also be encouraged to allow young people to become more independent as they become older. 7. Will these recommendations result in an impact on cost of services? Depending on the final structure and recommendations proposed there may be a significant financial impact on services including: - Extra resources for staffing: for example, specialist nurses and youth workers - Additional time in clinics - Infrastructure resources to adjust environments	Thank you for your comment. The Guideline Committee reviewed the recommendations on timing and review (under section 1.2) at Committee Meeting 12 (04.11.15) and agreed the edited wording now found in recommendations 1.2.1 to 1.2.4. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.

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				- Training and education for staff - Consideration of new technologies and drugs as they develop In some cases there may be increased cost in the short term which then leads to longer term savings. 8 Which of these recommendations would lead to additional costs? The recommendations are a holistic package, with the areas listed in question seven appearing throughout different recommendations. As stated in question seven, in some cases there may be increased cost in the short term which then leads to longer term savings. 9 Will any of these recommendations lead to cost savings? Possibly, yes. An example of where there may be longer term savings is recommendation 1.2: youth workers and trained staff engaging with patients may improve compliance and attendance leading to more effective care and reduced complications and resource requirement.	
Royal College of Physicians of Edinburgh	Short	2	20	Fellows expressed concern that a barrier to integrated working as described in the guideline may be the resource required in the current challenging financial climate.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
Royal College of Physicians of Edinburgh	Short	4	18	In terms of impact, the named worker/youth worker is important and has been demonstrated to be highly successful in, for example, renal transplant transition where medication compliance and attendance are key problems. Fellows have indicated that consistent access to a named person may be more challenging due to financial constraints.	Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level.
Royal College of Physicians of Edinburgh	Short	5	13	There may be challenges for a young person being able to travel independently to appointments, particularly in remote and rural areas. This issue is	Thank you for your comment. The need to support young people to access appointments is referenced explicitly in recommendation 1.2.7.

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				discussed further in the RCPE publication Think Transition: Developing the essential link between paediatric and adult care (2008) http://www.cen.scot.nhs.uk/files/16o-think-transition-edinburgh.pdf pages 30- 35.	
Royal College of Physicians of Edinburgh	Short	8	15	Parents are instinctively wary of a new team and protective of the young person, feeling the loss of the long-trusted paediatric team. It is important to recognise this challenging dynamic and the validity of the parents' role in successful transition. Unless these issues are explicitly recognised and managed then the young person will sense the parent's distrust and this will compromise transition. Transition receives parents together with young patients; transition ends with adults attending adult clinics and taking responsibility, with parents willingly accepting this.	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Royal College of Physicians of Edinburgh	Short	11	9	Education and training of staff on rare conditions is essential and may be challenging – many of the rare genetic and metabolic disorders are rarely seen and are less often managed by adult specialists. Co-ordinating services and linking with specialists in these rare disorders is important. Historically, in some disorders such as thalassaemia major survival was limited to 20 years, and moving forward the care of patients with these conditions is crucial when considering transition from children's to adults' services. Education remains key in managing conditions unfamiliar to either many adult clinicians or paediatricians.	Thank you for your comment. The Committee did consider training to be an important area to address and, to this end, it is referenced in the implementation chapter, specifically in reference to improving front-line practice with young people. Given the wide range of young people covered by the guideline, it was not possible to list every aspect of training. In the implementation chapter, therefore the Committee sought to provide over-arching headings that specify the key broad areas to address.
Royal College of Physicians of Edinburgh	Short	14	1	1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why. It may be challenging to put in place the infrastructure to set up a joint "transition clinic". The numbers of patients and time allotted between paediatric and adult appointments can be very different. This will vary	Thank you for your comments which will be considered as part of the work to support guideline implementation.

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				between each specialist service and becomes more complex for those in need of multiple specialist services due to the nature of their condition. For each medical/surgical speciality there will need to be a leading clinician and nurse and, while the numbers are likely to be small, this would have an impact on staffing requirements. The environment remains a challenge, with busy adult clinics filled with predominately older patients. This represents a significant disincentive for transition, and consideration might be given to a dedicated "adolescent" centre for young people's clinics in some specialties during the transition period	
Royal College of Speech and Language Therapists	Short	3	16	The RCSLT suggest adding 'communication needs' as many young people with communication and learning disabilities require creative alternatives to written text and verbal conversation to understand their options and to communicate their aspirations.	Thank you for your comment. The Guideline Committee reviewed the recommendation on supporting young people to communicate with practitioners and revised the text to make clear this requires them to know what a young person's communication needs are, and to have tools available to help address those needs (see recommendation 1.2.12).
Royal College of Speech and Language Therapists	Short	4	12	The RCSLT suggests adding: 'particularly for young people in out-of-borough school/educational settings'.	Thank you for your comment. This change has not been made to the specific recommendation, however, we have added a reference, in the context section, to the complexity of supporting young people who may move out of their local area (which could include those who leave home for university). Furthermore, on review, the Guideline Committee agreed that reference to liaison with education practitioners needed to be strengthened in the recommendations, given: the critical importance of education sector professionals in supporting young people's development, health and wellbeing, and identifying problems early. To achieve this, the

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					following recommendations now reference education explicitly: 1.1.4, 1.1.6, 1.2.6, 1.2.8, , 1.2.16 and 1.3.3.
Royal College of Speech and Language Therapists	Short	4	15	'A single named worker' - this role is very difficult to operationalise across health, social care and educational agencies and between children/adult services within current provision.	Thank you for your comment. The Guideline Committee considered all recommendations aspirational but achievable.
Royal College of Speech and Language Therapists	Short	5	26	The RCSLT question who would assess the young person's (YP's) level of cognitive ability and what impact would this have on funding?	Thank you for your comment which will be considered as part of the work to support guideline implementation. Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level. They noted that tasks should be completed by the most appropriate professional within the multi-disciplinary team (and, in this case, it may be someone who already has a remit for assessment).
Royal College of Speech and Language Therapists	Short	6	3	'Practitioners' - in adult services, practitioners are rarely involved in reviews until assessment and eligibility for learning disability services has been clarified	Thank you for your comment. The Guideline Committee reviewed the recommendations on timing and review (under section 1.2) at Committee Meeting 12 (04.11.15) and agreed the edited wording now found in recommendation 1.2.4 which includes making clear that practitioners could take part in meetings via teleconferencing or video, recognising the pressures on people's time.
Royal College of Speech and Language Therapists	Short	6	20	Where a YP is situated in a special school there will be facilities to ensure a range of tools regarding communicating effectively are available, but for those young people who are out of education - or even in a mainstream school, where speech and language therapy (SALT) is not available – this will not be	Thank you for your comment. Recommendation 1.3.3 references the need for information to be in the young person's preferred format which would include responding to any cultural or language needs.

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				currently possible. The level of language that the practitioner should use with the YP also needs to be addressed if they are to access the information e.g. the services accessible/available.	The Guideline Committee also reviewed the recommendation on supporting young people to communicate with practitioners and revised the text to make clear this requires them to know what a young person's communication needs are, and to have tools available to help address those needs (see recommendation 1.2.12).
Royal College of Speech and Language Therapists	Short	6	22	The RCSLT would like to suggest 'talking mats' as a method of gaining client views. Explanation of augmentative and alternative communication (AAC) is needed, (not digital communication tools).	Thank you for your comment. The Guideline Committee reviewed the recommendation on supporting young people to communicate with practitioners and revised the text to make clear this requires them to know what a young person's communication needs are, and to have tools available to help address those needs (see recommendation 1.2.12).
Royal College of Speech and Language Therapists	Short	8	19	A named worker from adult services (see point 9, above)	Thank you for your comment.
Royal College of Speech and Language Therapists	Short	9	4	The RCSLT suggest adding 'or hospital passport' (into the list of what the folder could contain).	These are only examples of the types of content that may be useful, based on evidence and expert witness presentations. Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level.
Royal College of Speech and Language Therapists	Short	9	10	The RCSLT suggests amending to add: 'with dysphagia information included, i.e. speech and language therapists' recommendations, with specialist utensils, etc'.	Thank you for your comment. The guideline covers a very wide range of young people and services so it was not possible to list all relevant conditions and needs separately. The wording reflects the intention to set out the principle rather than the detail.
Royal College of	Short	9	13	With regards 'accessible format' the RCSLT suggest adding: 'to include ways of engaging with and offering choice to those with profound and severe disabilities'.	Thank you for your comment. Accessibility options listed in 1.3.4 are only examples rather than an exhaustive list. Given the breadth of the guideline and

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Speech and Language Therapists					the wide range of groups that it covers, the Committee thought this appropriate.
Royal College of Speech and Language Therapists	Short	9	15 -16	The RCSLT would like to add 'symbols/photographs' as an example used to support written information.	Thank you for your comment. Accessibility options listed in 1.3.4 are only examples rather than an exhaustive list. Given the breadth of the guideline the wide range of groups that it covers, the Committee thought this appropriate.
Royal College of Speech and Language Therapists	Short	10	3 -5	The RCSLT suggest amending or adding 'potential training needs', as 'personal budgets' may not be familiar to named person from children's services.	Thank you for your comment. The reference to personal budgets was agreed to be appropriate and is defined in the Think Local Act Personal 'jargon buster', a link to which is provided in the guideline.
Royal College of Speech and Language Therapists	Short	10	12	RCSLT members would like to comment that increasingly there are limited adequate alternatives on offer, due to austerity and cutbacks in voluntary and non-statutory services.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
Royal College of Speech and Language Therapists	Short	10	13	A large proportion of YPs with speech, language and communication needs (SLCN) do not meet the criteria for specialist adult services and the RCSLT is unclear how the GP would be able to assist with this.	The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15). They agreed that GP involvement is critical to support coordination and help ensure, as part of the team of people supporting the young person, that he or she does not 'fall through the gaps between services'.To this end, there is now more explicit reference made to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
Royal College of Speech and Language Therapists	Short	10	22 -24	The RCSLT would like to feedback that unless it is part of the person's care package review, follow-up is unlikely to occur within current resources.	Thank you for your comments which will be considered as part of the work to support guideline implementation.

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Royal College of Speech and Language Therapists	Short	11	3 -7	(1.4.4- 1.4.5) Good practice such as this cannot always be guaranteed, especially in multi-disciplinary teams (MDTs) with roles in assessment and review shared across health and social care. Joint record-keeping within MDTs can ensure information is shared appropriately and tasks carried forward where necessary.	Thank you for your comment. The Guideline Committee recognised that this may be associated with some implementation challenges for some services. However, they sought to make the recommendations aspirational but achievable. A very wide range of services and young people are covered by this guideline and therefore two appointments, as a minimum, was thought to be appropriate and feasible.
Royal College of Speech and Language Therapists	Short	11	9 -14	A significant increase in funding would be required to plan and implement the appropriate training to enable all those working with a young person to understand and support their communication needs	Thank you for your comment which will be considered as part of the work to support guideline implementation.
Royal College of Speech and Language Therapists	Short	11	13	The RCSLT would like to recommend the addition of the five good communication standards developed in response to the Winterbourne View: '…and extend knowledge of the Five Good Communication Standards RCSLT (2013) featured in Ensuring Quality Services (Local Government Association 2014) and also referenced by the Care Quality Commission (CQC) in its recommendations around best practice, enabling all assessors and providers to know what good communication looks like.'	Thank you for your comment. The guideline covers a wide range of young people and therefore there will be a wide range of legislation and guidance relevant. The Committee were mindful not to repeat existing guidance although recognised that the guideline will be interpreted within the wider legislative and policy context.
Royal College of Speech and Language Therapists	Short	12	5 -6	A senior executive must have training in supporting clients with communication needs, i.e. with the ability to implement strategies to gather pupil voice.	Thank you for your comment. The Guideline Committee considered the issue of ownership of transition carefully (recommendations 1.5.1 to 1.5.3) and reviewed these recommendations at Guideline Committee meeting 12 (04.11.15). The wording has been updated to make clearer how these roles would work and where accountability lies. Given the wide range of young people covered by the

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					guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level.
Royal College of Speech and Language Therapists	Short	13	5	RCSLT members highlight that they would support the need to undertake a 'gap analysis', as they already recognise that resources for YP's with anything but the most severe SLCNs, are extremely limited. Once the gap has been quantified there will be the expectation that this gap will be filled, which is not possible with current resources.	Thank you for your comment and support. The Guideline Committee acknowledged that there will be some challenges associated with implementation. Please see the implementation chapter which also provides some examples of how these may be overcome. Further work will be undertaken to support implementation of the guideline.
Royal College of Speech and Language Therapists	Short	18	25	A pupil does not need to attend the meeting in person (if this will induce anxiety, or is inaccessible due to learning disability, etc). In this case, video material of the pupil sharing their views could be watched instead and is deemed acceptable.	Thank you for your comment. This is a useful example of how this recommendation could be implemented.
Royal College of Speech and Language Therapists	Short	22	1 -10	This is especially true for young people with SLCN who's needs are unmet once the young person leaves the education system, and then has no access to suitable speech and language services (outside of those provided within community teams for people with learning disabilities which are not appropriate to these young people).	Thank you for your comment.
Royal College of Speech and Language Therapists	Short	23	4	Historically, SLCN in young offenders has not been screened for due to a lack of awareness of the issue. This has resulted in poor commissioning of speech and language therapy. However this is due to change with the introduction of AssetPlus. Our data shows that the number of speech and language therapists to support children and young people in the youth justice sector has increased, both in YOTs and youth accommodation. While some teams and establishments do have a speech and language	Thank you for your comment.

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				therapy service embedded within their service, this picture is patchy with some YOTs and YOIs having no service at all. This work focuses on identifying and supporting young people with communication needs, training staff to understand communication needs and ensuring that information regarding services is accessible and appropriate to the YP's needs. This emerging area of SALT is innovative, evidence-based and should be extended.	
Royal College of Speech and Language Therapists	Short	23	4 -6	Over 60% of people who offend have speech, language and communication needs. However, there is significant under identification of SLCN in the justice system. For example in one study in Leeds, all individuals with later identified SLCN only 8% were previously known to the local service. This area warrants further investigation, (see K Bryan et al 2009 Language and Communication Difficulties in Juvenile Offenders)	Thank you for your comment which provides useful contextual information.
Royal College of Surgeons of England	Short	General	general	This guideline seems heavily weighted to transition within social care and does not address the issues that may occur in health care as well. Ideally the two types of services should have separate clinical guidelines	Thank you for your comment. The scope of the guideline was health and social care and the recommendations reflect discussions about the evidence relating to both. The Guideline Committee agreed with the balance of recommendations. The referral for this guideline required it to address both health and social care, informed particularly by the need to ensure more coherent provision.
Royal College of Surgeons of England	Short	General	general	There is no discussion about young people (YP) who are managed by multiple services and their transition e.g. surgery and paediatrics	The Guideline Committee did, however, reflect on the issue of young people with multiple conditions, at Guideline Committee meeting 12 (04.11.15) and agreed an additional recommendation was needed, to emphasise the need for integrated working to support this group (recommendation 1.5.10).

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Royal College of Surgeons of England	Short	General	general	There is no mention of transition of YP with rare illnesses	Thank you for your comment. The guideline covers a very wide range of young people and services so it was not possible to list all relevant conditions and needs separately. As a result, and recognising that, as you highlight, it needs to address the diverse needs of wide range of young people, the Guideline Committee sought to establish the broad principles to follow with respect to care and support before, during and after transition. Young people with rare illnesses are included in the guideline.
Royal College of Surgeons of England	Short	General	general	There is no mention of management of long term follow up e.g. YP who have had cancer often require very long term follow up	Thank you for your comment. The guideline covers a very wide range of young people and services so it was not possible to list all relevant conditions and needs separately. As a result, and recognising that, as you highlight, it needs to address the diverse needs of wide range of young people, the Guideline Committee sought to establish the broad principles to follow with respect to care and support before, during and after transition. Young people who require long-term follow up are included in the guideline.
Royal College of Surgeons of England	Short	General	general	There are particular issues that pertain to children who have long term chronic illness that are not mentioned and which may not be well managed in adult services e.g. growth delay, potential psychological issues	Thank you for your comment. The guideline covers a very wide range of young people and services so it was not possible to address the very specific physical and psychological issues that may affect different groups. The Guideline Committee instead sought to establish the broad principles to follow with respect to care and support before, during and after transition. Young people with long-term chronic illness are included in the guideline. The Guideline Committee did, however, on the issue of young people with multiple conditions,

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					at Guideline Committee meeting 12 (04.11.15) and agreed an additional recommendation was needed, to emphasise the need for integrated working to support this group (recommendation 1.5.10).
Royal College of Surgeons of England	Short	General	general	It should be made explicit that many of these YP are developmentally younger than their age, and may lack the emotional maturity to manage this process at an age when other YP are fully independent	Thank you for your comment. The guideline covers a very wide range of young people and services so it was not possible to address the very specific physical and psychological issues that may affect different groups. The Guideline Committee instead sought to establish the broad principles to follow with respect to care and support before, during and after transition. Young people with a range of differences in terms of their development are included in the guideline. The need to ensure services are developmentally appropriate, taking into account maturity and cognitive ability, is also referenced explicitly in recommendation 1.1.2.
Royal College of Surgeons of England	Short	General	General	Q1: Which areas will have the biggest impact on practice and be challenging to implement? • Transfer of those with long term medical or complex histories, especially if multiple services involved in care • Patients with rare illnesses managed in few specialist paediatric centres • Those who have completed treatments that require long term follow up but may not require active treatment e.g. post cancer care, spina bifida patients • Those with intermittent/ relapsing patterns of illness • This is a very mobile population, so transfer of information to services across different geographical	Thank you for your comments. Please see the chapter on implementation which provides some practical examples of how challenges could be overcome.

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				areas needs to be considered	
Royal College of Surgeons of England	Short	General	General	Q2. What would help users overcome any challenges? • Loss to follow up after transition is a concern, especially if they feel unsupported and become disengaged with adult healthcare services • Improved education and support to anticipate the impact of these changes	Thank you for your comments. Please see the chapter on implementation which provides some practical examples of how challenges could be overcome.
Royal College of Surgeons of England	Short	General	General	Q3. What are the key audiences we need to consider in structuring the guideline? • Adult and paediatric services need to work jointly to develop an agreed transition service. Often transition arrangements are developed in an ad hoc way and a single specialist paediatric service may have very different arrangements with the adult services they send patients to for transition. Ideally clinical networks e.g. paediatric surgical networks, should be supporting the development of these services at a regional level	Thank you for your comments which will be considered as part of the work to support guideline implementation. Adult and paediatric services are indeed key audiences for the guideline and were considered throughout development. The guideline committee also thought it important to make recommendations about specific elements of joint working between adults and children's services (1.1.5 and 1.5.10 and 1.5.11).
Royal College of Surgeons of England	Short	General	General	Q4. At what age does transition planning start now? • This will be very different for social care as opposed to healthcare. For those with chronic illness transition may be a lengthy process and not occur until after the traditional 'adult' age	Thank you for your comment. The group considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are.
Royal College of Surgeons of England	Short	General	General	Q5. How often do review meetings happen at present? • This differs within different services, but often the actual transition would occur at a single joint meeting between children's and adult services. There would have been additional planning/ meetings within	Thank you for your comment which provides useful context. Thank you for your comment. The Guideline Committee reviewed the recommendations on timing and review (under section 1.2) at Committee Meeting 12 (04.11.15) and agreed the edited wording now found in recommendations 1.2.1 to 1.2.4.

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				the children's services prior to this meeting	
Royal College of Surgeons of England	Short	General	General	Q6. How should parents be involved in transition planning? • With the consent of YP, unless there is capacity issues	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
Royal College of Surgeons of England	Short	General	General	Q7. Will these recommendations result in an impact on cost of services? • Yes- good transition care does require some service investment	Thank you for your comment which will be considered as part of the work to support guideline implementation.
Royal College of Surgeons of England	Short	General	General	Q8. Which of these recommendations would lead to additional costs? • Setting up transition clinics, education, named key workers	Thank you for your comment which will be considered as part of the work to support guideline implementation.

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Royal College of Surgeons of England	Short	General	General	Q9. Will any of these recommendations lead to cost savings? • If managed correctly may help in long term management of healthcare and may possibly impact on the percentage of young adults that disengage with services	Thank you for your comment which will be considered as part of the work to support guideline implementation.
Royal College of Surgeons of England	Short	5	general	Should there be more explicit advice on education needs of YP on how adult healthcare works and the differences they can expect?	Thank you for your comment. The Committee agreed information-provision is important and developed a number of recommendations on information provision for young people and their families (1.2.7, 1.2.13, 1.3.4, 1.3.7 and 1.3.8). The nature of information that should be provided will vary, given the wide range of young people that are covered by this guideline, and the individual nature of information needs. The recommendations on information provision therefore do not specific the detail of what should be provided, allowing practitioners flexibility to implement recommendations locally.
Royal College of Surgeons of England	Short	7	general	Whilst worthwhile this process requires monitoring and proper governance to ensure support is appropriate and reduce potential risks	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Royal College of Surgeons of England	Short	10	general	Is this advice sufficient? Disengagement with healthcare in YP can have a long lasting negative impact on healthcare management	Thank you for your comment. These recommendations have been subject to minor edits following discussion at Guideline Committee 12 but overall were thought to be sufficient.
Royal Mencap Society	Full	General	General	It is important that every young person should be able to influence decisions about their lives irrespective of their capacity under the Mental Capacity Act to do so. Creative techniques should be used to ensure this can happen and co-production should be ensured wherever possible	Thank you for your comment. The Committee emphasised throughout development the importance of ensuring the young person is at the centre of their care and support. This is referenced explicitly in recommendations 1.1.1, 1.1.4, 1.2.4 (which was updated to this end, following discussion at Guideline

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					Committee meeting 12), 1.2.10 and 1.2.19.
Royal Mencap Society	Full	General	General	It is important that, at all times, professionals and interventions should be aware of, and respond to, the communication needs of young people and staff should be suitably skilled to meet these needs	Thank you for your comment. The Guideline Committee reviewed the recommendation on supporting young people to communicate with practitioners and revised the text to make clear this requires them to know what a young person's communication needs are, and to have tools available to help address those needs (see recommendation 1.2.12). Recommendation 1.3.4 also references the need to ensure information provided is accessible.
Royal Mencap Society	Full	General	General	It is important that the guidance is fully able to respond to the needs of young people with complex health needs who may require particular support and pre-planning during their transition to adult services	Thank you for your comment. While we reviewed some condition-specific evidence, the scope of this guideline was to establish the broad principles to follow with respect to care and support before, during and after transition. The group recognised the breadth of young people to be covered by the guideline, and the wide range of care and support needs they would have. The Guideline Committee did, however, reflect on the issue of young people with multiple conditions, at Guideline Committee meeting 12 (04.11.15) and agreed an additional recommendation was needed, to emphasise the need for integrated working to support this group (recommendation 1.5.10).
Royal Mencap Society	Short	2	17	1.1 – This should also make reference to the need to use accessible information, such as easy read, in order to aid the comprehension of the young person so they could be involved more effectively. In addition to this, there should be creative ways for people to communicate who don't use formal	Thank you for your comment. The Guideline Committee reviewed the recommendation on supporting young people to communicate with practitioners and revised the text to make clear this requires them to know what a young person's communication needs are, and to have tools available to help address those needs (see recommendation

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				communication such as those set out in Mencap's Involve Me tool: https://www.mencap.org.uk/involveMe	1.2.12).
Royal Mencap Society	Short	3	8	1.1.1 – There should also be a bullet point stating that the person-centred approaches should ensure that transition support ties in properly with other transitions happening in a young person's life at the time e.g. the transition into further education	Thank you for your comment. Supporting the young person in the context of their life as a whole is addressed by specifying the over-arching outcome areas in recommendation 1.1.4, specifically: - education and employment - community inclusion - health and wellbeing including emotional health - independent living and housing options. These areas are also included in recommendations 1.2.8 and 1.2.11 as well as in the definition of 'person-centred' ('Terms used in this guideline').
Royal Mencap Society	Short	4	5	This bullet point should also make mention of the need for pathway planning for children and young people to ensure services are available locally to meet their needs	Thank you for your comment. There was no evidence to indicate that this should be included. Given the wide range of young people covered by this guideline, the scope of this guideline was to establish the broad principles to follow with respect to care and support before, during and after transition.
Royal Mencap Society	Short	4	7	1.1.4 – This should be underpinned by effective data collection to ensure future needs are adequately flagged e.g. through JSNAs, EHC Plans, schools arrangements (e.g. through SEN Support), utilising the local authority's duty to identify all children and young people in the area with SEND, etc	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Royal Mencap Society	Short	4	17	1.2.2 – In order to ensure the effectiveness of this worker, Mencap believes it is important that they are able to make certain decisions or demand the input of other professionals. We would therefore urge that it is	Thank you for your comment. The Guideline Committee considered all recommendations aspirational but achievable.

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				stated that the named worker has the necessary power within their organisation to do this	
Royal Mencap Society	Short	5	15	Within this list, in order to align it more closely with the transition outcome areas in the Children and Families Act it should also explicitly include housing as a separate bullet point	Thank you for your comment. Housing has now been included throughout the guideline where the high-level outcomes to be considered are referenced (recommendations 1.2.6, 1.2.7 and Terms used in this guideline).
Royal Mencap Society	Short	5	22	We urge caution about specifying a period of time for the support worker to support a young person. While it is important to help manage workload and expectations of the young person, we would prefer this section to state that the defined time is the point at which a review should take place to determine whether the young person requires support for a longer period	Thank you for your comment. It is important to note that this time period (recommendation 1.2.8) relates to the length of time the Committee thought it would be appropriate for the named worker to be involved and not to transition planning and support more widely which: - should start early 'from year 9 (age 13 or 14) at the latest (as indicated in recommendation 1.2.1s and 1.2.3) - should be developmentally appropriate (1.1.2, 1.2.3 and 1.5.11), and - should be reviewed annually (1.2.4)
Royal Mencap Society	Short	5	27	1.2.5 – Mencap would like to see included clarification about the definition of "significant benefit" when it comes to the timing of the transition planning – specifically that it would benefit the individual and that this should be established in consultation with the individual	Thank you for your comment. The Guideline Committee reviewed the wording of this recommendation (now 1.2.1) in Committee Meeting 12 (04.11.15) and made an edit to make clear that this should take place 'at a time of relative stability for the young person'. This is in addition to the existing text that stipulates it should take account of the young person's 'capabilities, needs and hopes for the future'.
Royal Mencap Society	Short	6 6	14 14	1.2.9 – The bullet points setting out the ways of involving young people in their transition planning seems to place the young person as a very passive presence e.g. input from others, rather than support to jointly plan or co-produce which is more focused on the young person's individual wishes. We would like to see	Thank you for your comment. These examples were driven by the evidence reviewed. The Mental Capacity Act is now referenced explicitly in recommendation 1.2.20. There will also be reference to the MCA in the full guideline text available on the

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				this realigned. There should also be mention of the Mental Capacity Act and clearer guidelines or signposting to more information on this	NICE website when the guideline is published. For an example from another social care guideline, see below: https://www.nice.org.uk/guidance/ng22/chapter/recommendations which links to https://www.nice.org.uk/about/nice-communities/public-involvement/your-care
Royal Mencap Society	Short	6	20	1.2.10 – Mencap would like to see accessible information such as easy read included in the list of tools made available to young people by service managers. In addition to this, tools like Mencap's Involve Me should be utilised to offer creative ways for people to communicate who don't use formal communication methods: https://www.mencap.org.uk/involveMe	Thank you for your comment. Recommendation 1.3.3 references the need for information to be in the young person's preferred format which would include responding to any cultural or language needs. The Guideline Committee also reviewed the recommendation on supporting young people to communicate with practitioners and revised the text to make clear this requires them to know what a young person's communication needs are, and to have tools available to help address those needs (see recommendation 1.2.12).
Royal Mencap Society	Short	7	20	1.2.15 – This should make mention of the fact that liaison with educational practitioners should, where relevant, include the SENCO	Thank you for your comment. On review, the Guideline Committee agreed that reference to liaison with education practitioners needed to be strengthened in the recommendations, given: the critical importance of education sector professionals in supporting young people's development, health and wellbeing, and identifying problems early. To achieve this, the following recommendations now reference education explicitly: 1.1.4, 1.1.6, 1.2.6, 1.2.8, , 1.2.16 and 1.3.3. Given the wide range of practitioners who may be involved in a young person's support, the Guideline Committee did not think it appropriate to specify detailed roles.

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Royal Mencap Society	Short	7	24	1.2.16 – Mencap urges caution on this point. While we fully support the empowerment of young people to be able to manage their own condition, it is essential that an assessment of their ability to do this is reviewed regularly and is viewed in a variety of different settings and contexts. Mencap finds that, for some people with a learning disability, practical application of skills depends on a number of factors including the environment in which they are doing it, who they are with, how they are feeling, etc.	Thank you for your comment. Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level and recognised that careful consideration will be needed in this respect.
Royal Mencap Society	Short	8	5	1.2.18 – Mencap believes it is important to mention that, for children under the age of 16 who might be planning their transition under the new arrangements, primary decision making responsibility still lies with their parents. This should not detract from the ability of a child to express their preference, however. For those young people over the age of 16, they should be given advocacy to make decisions independently of their parents, should they want to. Parents and children/young people should be encouraged to discuss their transition preferences before professionals are involved in the process	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.

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Royal Mencap Society	Short	9	2	Mencap would welcome easy read being specified as an example of a young person's preferred format	Thank you for your comment. Accessibility will be referenced within an over-arching statement when the guideline is published on the NICE website.
Royal Mencap Society	Short	9	3	These bullet points should also include a history of someone's wider support/needs e.g. health and education, including whether they receive and EHC Plan	Thank you for your comment. Recommendation 1.3.3 has been updated to include reference to 'information about their health condition, education and social care needs'.
Royal Mencap Society	Short	9	10	1.3.4 – Mencap urges caution that the information provided to young people and their families/carers should go beyond the support available to them. We would like to see information about the range of available services in the area and their rights to them as well	Thank you for your comment. The Guideline Committee reviewed this recommendation and considered it appropriate. This was on the basis that they wanted recommendations to be achievable, and this particular recommendation is aimed at managers of services who may not be able to access information about the potentially very wide range of support available to the children in their care.
Royal Mencap Society	Short	10	15	1.4 – This section need to include the fact that follow up engagement with a young person should be done within a time frame that does not endanger the young person's right to receive the services for which they are eligible	Thank you for your comment. The guideline covers a wide range of young people and therefore there will be a wide range of legislation and guidance relevant, including that relating to a young person's right to access services within a certain time frame. The Committee were mindful not to repeat current legislation although recognised that the guideline will be interpreted within the wider legislative and policy context.
Royal Mencap Society	Short	11	9	1.5.1 – Mencap believes that training for staff should include involving children and young people in their work in a meaningful way and in meeting the needs of young people with complex health needs	Thank you for your comment. The Committee did consider training to be an important area to address and, to this end, it is referenced in the implementation chapter, specifically in relation to improving front-line practice with young people. Involving young people in training is referenced here.

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Royal Mencap Society	Short	12	10	It would be useful for the senior executives and operational-level champions should engage with designated representatives under the Children and Families Act, such as the Designated Health Officer representing a CCG	Thank you for your comment. The Guideline Committee considered the issue of ownership of transition carefully (recommendations 1.5.1 to 1.5.3) and reviewed these recommendations at Guideline Committee meeting 12 (04.11.15). The wording has been updated to make clearer how these roles would work and where accountability lies. Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level.
Royal Mencap Society	Short	12	19	Feedback on existing service quality and highlighting any gaps should be done in conjunction with reviewing the local area's local offer which should help to identify gaps in local provision and should seek the feedback of local parents on services and information about them	Thank you for your comment and support.
Royal Mencap Society	Short	12	24	1.5.6 – Mencap would like to see more data collected from, for example, joint commissioning priorities (under the SEND reforms)	Thank you for your comment. Please see section 1.5 which now includes references to using existing data (1.5.6 and 1.5.8).
Royal Mencap Society	Short	13	5	1.5.8 – The gap analysis should also include information about gaps that might exist if education and training is not involved in a young person's life. It should also have a special focus on those who have to access out of area provision as well, in order to help plan their ability to move back to their home authority	Please see section 1.5 which now includes references to using existing data (1.5.6 and 1.5.8). We have added a reference, in the context section (p9, full guideline), to the complexity of supporting young people who may move out of their local area.
Royal Mencap Society	Short	13	9	Groups to which particular attention should be paid should include people who have learning disability or autism and challenging behaviour, as well as those with PMLD who need specialist services often commissioned by NHS England	Thank you for your comment. The guideline covers a very wide range of young people and services so it was not possible to list all relevant conditions and needs separately. The bullets indicate the over-arching groups, based on evidence and consensus, who may

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					be particularly at risk of 'falling through the gaps' between services, rather that attempting to provide an exhaustive list.
Royal Mencap Society	Short	13	17	Pooled budgets should be across education, as well as health and social care in order to align more faithfully with the SEND reforms	Thank you for your comment. The previous reference to pooled budgets has been removed from the recommendations as it was noted that this is not within the remit for NICE guidance; however, there is reference to funding mechanisms within the implementation section.
Royal Mencap Society	Short	16	10	Commissioners, managers and practitioners should also identify joint local priorities against which to commission	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Royal Mencap Society	Short	17	2	The barriers to pooling funding could be overcome by the joint commissioning duties under the SEND reforms which requires CCGs and local authorities to jointly plan and commission services across education, health and social care and establish joint priorities	Thank you for your comment. The previous reference to pooled budgets has been removed from the recommendations as it was noted that this is not within the remit for NICE guidance; however, there is reference to funding mechanisms within the implementation section.
Royal Mencap Society	Short	18	23	Mencap believes examples of the types of shared information should be included in the guidance, for example information on Children in Need, those on EHC Plans, those on SEN Support, those identified with SEND, and information in JSNAs and Joint Health and Wellbeing Strategies	Thank you for your comment and for providing additional examples that could support implementation work.
South East Strategic Clinical Network (hosted by NHS England)	Full	General	general	We recognise that many key themes have been identified and explored throughout the thorough and well researched document. However one topic that does is not addressed specifically is the difficulty encountered by young people entering **further/ higher education**. This was raised by parents, young people and professionals during our consultation periods.	Thank you for your comment and support for the guideline. We have added a reference, in the context section (p9, full guideline), to the complexity of supporting young people who may move out of their local area (which could also include those who leave home for university). The Guideline Committee discussed the role played by GPs in these (and other) circumstances at Guideline

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				Young people with diagnosed long term conditions leaving home during term time may wish to remain registered with local GPs and /or secondary care consultants whilst still at college/ university. This arrangement may lead to difficulties if there are prescription requirements during term time or complications requiring professional advice. Likewise the young person may be reluctant to register with new GPs and / or secondary care consultants for care for 8-10 week terms for three years. Problems can also arise if young people develop new health conditions eg mental health difficulties, inflammatory bowel disease or type 1 diabetes whilst at university etc. We encountered a number of examples of problems encountered, ranging from poor communication between two sets of GPs and hospital consultants (term and vacation time) to disagreements about funding for services such as insulin pumps. Such problems were in addition to the inevitable disturbance/ excitement caused by entrance to higher/further education with its attendant pitfalls for young people with additional health requirements. Suggestions made included:- 1. Transition planning to take place before leaving home with liaison between named health professionals providing home and term time care, even if one service may be used only in emergencies. 2. There should be nationally agreed pathways for	Committee meeting 12 (04.11.15) taking into account stakeholder comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).). The Committee also reflected on the issue of young people with multiple conditions, at Guideline Committee meeting 12 (04.11.15) and agreed an additional recommendation was needed, to emphasise the need for integrated working to support this group (recommendation 1.5.10). Funding pathways are not within the remit of NICE guidance. We did not, within these reviews, find evidence to inform a recommendation on electronic records, however, the benefits of technology to support other

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				transfer of funding responsibility between commissioners allowing seamless transition of both practical and financial support to young people with long term conditions in higher/further education. 3. The use of technology such as electronic records could prove invaluable in such situations. It is hoped that this may go some way to reassure not only the young people themselves but also their parents, carers and families.	aspects of transition are referenced in recommendations (1.2.11, 1.2.12 and 1.3.4).
St George's University Hospitals NHS Foundation Trust	Short	General	General	1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why. **Current structure of hospitals and financial climate. Convincing members that this is an essential need for support of this group. Due to financial situation maybe seen by many as superfluous** 2. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)- **reassurance that this will not compromise other areas of practice in terms of resource allocation. Rather it will automately improve overall finance because of the amunt of morbity affecting such cases when the transition process is not done properly** 3. What are the key audiences we need to consider in structuring the guideline?	Thank you for your comments which will be considered as part of the work to support guideline implementation.. Please also see the chapter on implementation which provides some practical examples of how challenges could be overcome. In particular, there are sections that specify what commissioners, managers and practitioners can do to help implement the recommendations. Thank you for identifying these audiences. They were also considered to be key by the Guideline Committee and referenced throughout development discussions.

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				Clinical workers in the hospital for reassurance but also managers in order for appropriate financial support to be put in place 4. At what age does transition planning start now? **14-16 years** 5. How often do review meetings happen at present? **Monthly in my unit driven by me and quarterly at the regional level** 6. How should parents be involved in transition planning? **Through out both in the type and the degree as well as timing will differ for different young adults/family** 7. Will these recommendations result in an impact on cost of services? **In the short term. We have a charity supported young adult worker** 8. Which of these recommendations would lead to additional costs? **Staffing** 9. Will any of these recommendations lead to cost savings? **Longer term yes because of improved patient expereirnece**	The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are. The Guideline Committee reviewed the recommendations on timing and review (under section 1.2) at Committee Meeting 12 (04.11.15) and agreed the edited wording now found in recommendations 1.2.1 to 1.2.4.
Student Minds	Full	General	General	1. *Student Minds is the UK's student mental health charity. We deliver research-driven training and support to equip students to bring about positive change on their campuses*	Thank you for your comments. We have added a reference, in the context section (p9, full guideline), to the complexity of supporting young people who may move out of their local area (which could include those

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				through campaigning and facilitating peer support programmes. *2.* From our experience of working with university students and conducting research around the experiences of students accessing care, we would like to emphasise the importance of addressing the transition to university for students entering Higher Education, which typically occurs at the same time as the transition from children's to adults' services, followed by ongoing transitions between home and university support services at the beginning and end of each term. *3.* This comment is informed in particular by Student Minds 2013 report 'University Challenge: Integrating Care for Eating Disorders at Home and at University'. Using surveys and qualitative interviews with individuals with eating disorders, the research found that NHS services are not adapted to the transient nature of student life and that there is little targeted support for the specific needs of students. Although our research initially focused on eating disorders, through our consultation process we have found that the same issues apply to students accessing support for any mental or physical health problem. *4.* There are more than 2.5 million young people in the UK in higher education, and we believe more should be done to stop students from 'falling through the gaps' in mental health service provision. The transition to university	who leave home for university). We have not referenced eating-disorder specific interventions as it was not within our remit to search for these data. The scope of this guideline was to establish the broad principles to follow with respect to care and support before, during and after transition. The Committee considered the needs of young people with mental health conditions explicitly throughout guideline development and agreed the recommendations were applicable, and, aspirational but achievable for those young people. The Committee also recognised the need to ensure that young people with mental health needs do not "fall through the gap" between Child and Adolescent Mental Health Services and Adult Mental Health Services and, to this end, referenced them explicitly in recommendations 1.5.5 and 1.5.7. The Guideline Committee discussed the role played by GPs in these (and other) circumstances at Guideline Committee meeting 12 (04.11.15) taking into account stakeholder comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).

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				involves moving away from established support networks and students receiving specialist support may be leaving behind established therapeutic relationships with clinicians. In the process of this transition, students are commonly discharged from the specialist service that has been supporting them at home. Registering with a new GP, in a new city, commonly leaves gaps in the treatment and support these students receive. This transition is a crucial time for the delivery of support to students with mental health issues. *5.* Student Minds have found, in their University Challenge research, that students are experiencing practical challenges in accessing vital medical support as they move between their registered GP services at university and visiting their home GP service as a temporary patient during the university vacations. When accessing care as a temporary patient, students report having limited access to services ranging from blood tests to psychological support. *6.* Students are also specifically disadvantaged because of their academic calendar. Waiting lists for talking therapies are long, and it can take months to progress up a waiting list to receive care. It is not uncommon for students to reach the top of the waiting list for specialist care in their university locality when they are back at home during the holidays or when they are about to sit university exams. If patients cannot attend the sessions assigned to them,	Thank you for your comments about how this guideline relates to other guidance which we will consider as part of our work to support implementation of the guideline. Service funding is not within the remit for NICE guidance.

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				they are usually dropped off the waiting list and required to go through the referral process again. *7.* To address these issues the following steps have been recommended by Student Minds: • **Best practice Guidance for CCGs and GPs around student transitions.** Student Minds are in discussions with representatives from the NHS, Department of Health and RCGP about making this happen. • **NHS services to adhere to guidelines on funding care for transient populations**. The University Challenge research found that students find it difficult to access care when they are registered with a GP as temporary residents. Under the current NHS guidance, this should not be the case; students should have access to appropriate healthcare services at university and at home. • **Shared access to notes:** Ensuring that the services supporting the student, both home and university, have access to the same information and discuss the individual's care plan, should reduce the risk of students 'falling through the gap'. • **A national register of contacts:** Appropriate support should be put in place before students arrive at university. The	Recommendation 1.1.5 indicates the use of joint protocols (including for information-sharing) and 1.1.7 also emphasises the importance of information-sharing in respect of safeguarding. We did not find, within the development work, evidence to inform a recommendation on a national register of contacts, university-specific services or technologies to support students as a distinct group.

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				current structure of the NHS makes it difficult for professionals from one area of the country to request or arrange comparable support to be provided in another area of the country. Designing a national register with useful contacts such as GPs, specialist services, university mental health advisers and support groups may alleviate the difficulties faced when trying to work out who to refer to or who to pass information onto. • **Ensure that services commissioned by CCGs work for university students:** Few local health or social care commissioners commission specific services or health interventions for this transient group. There is a clear need for interventions and adjustments to be made that appreciate the unique circumstances associated with being a student. • **New technologies to be used in all NHS trusts to maintain support with students whilst they are not in the area** • **Representation of student experience on health boards:** Traditionally students have had very little, if any, influence on shaping local NHS services. In Leeds however, the Leeds Student Health and Wellbeing Partnership are a "multi-agency group that addresses the mental health and wellbeing of students" which was recommended following their Student Mental Health Needs Assessment (June	The Guideline Committee agreed on the importance of mechanisms to enable young people to feed In to service planning at the locality level and recommendations 1.5.4 and 1.5.5 address this. Recommendation 1.5.5 has been updated to make clear that these should link to existing structures where these exist.

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				2007). The group brings together representatives from NHS Leeds (Public Health, Commissioning, Primary Care), Leeds Partnership Foundation Trust (Psychology, Psychiatry, Crisis Resolution) and the university and colleges in the city, to develop ways in which partners can work together to collect uniform and robust data; to influence the delivery of services to ensure continuity of care and improve access for students to services. *8.* Further information including quotes about young people's experiences can be found in the Student Minds 'University Challenge' report, which we believe to be largely representative of most students' experience who are accessing mental health services. 9. These recommendations are particularly important since university students are a vulnerable population. The years when a young person is at university (18-25) coincide with the age of onset for various acute difficulties such as schizophrenia and bipolar disorder. Students with severe mental health difficulties are at 'considerable risk' of academic failure and dropping out (Royal College of Psychiatrists, 2011). Students in crisis, particularly if they have complex mental health needs, face an extensive and	

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				bureaucratic process to have their experiences recognised as mitigating circumstances at university. The extra barriers to support imposed by this process can exacerbate an already difficult time for a student. In addition, tragically, recent reports suggest that the occurrence of suicide in the student population is increasing. When managed well and when the right support is in place however, students experiencing mental health difficulties can flourish. Student Minds, University Challenge: integrating care for eating disorders at home and university, 2013 http://www.studentminds.org.uk/uploads/3/7/8/4/3784584/university_challenge.pdf	
Suffolk County Council	Short	General 10	General 15	Question 7: Will these recommendations result in an impact on cost of services? Question 8: Which of these recommendations would lead to additional costs? Question 9: Will any of these recommendations lead to cost savings? It would be really helpful to frame these questions around costs over time. The challenge for Transitions is investing resources today into cost savings and better outcomes for tomorrow. We have managed to make this case fairly well in the	Thank you for your comment which will be considered as part of the work to support guideline implementation. Please see also the chapter on implementation which provides some practical examples of how challenges could be overcome. In particular, there is a section on joint planning, development and commissioning of services which includes reference to financial mechanisms, and a section on working with disengaged young people. The evidence on engagement focused on the post-transfer stage, hence this is reflected in recommendations; however, the need to ensure young people are involved in their care, able to access services and supported in the broadest sense (which may include tackling issues of disengagement) is

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		18	6	development of early years services, so how can nationally influential bodies such as NICE help make this case in early adult services? Post Transfer care is likely to lead to additional costs, but it is in the report because there is evidence that it is cost effective over time. Offering services to disengaged young people could be incredibly cost effective over time across the health and care system as a whole, for example in reducing the need for acute services (as evidenced in the full review).	reflected in recommendation 1.2.7.
Suffolk County Council	Short	8 7	4 1	Question 6: How should parents be involved in transition planning? Seeing this as part of the "developmentally appropriate planning " is key: that parents are supported to make the transition from supporting a young person to supporting a young adult. This transition should be recognised, understood and valued in our practice. In Suffolk we are starting to use the practice of a PATH (Planning Alternative Tomorrows with Hope) to help involve young people and families with a range of professionals and other supporters in more effective transitional planning. (This is a nationally recognised model.)	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information

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				For many young people without a supportive family network, it is important to support them to develop their own networks of support. This takes skill and time.	provision.
Suffolk County Council	Short	16	4 11	Question 1: This recommendation will be a challenging change in practice because … The question is framed in a way that presupposes it's adults needing to be more like children's when the message is actually both need to value Transitions as a particular phase. The challenge is the underdevelopment of adolescence and young adult models of service delivery, alongside the commissioning and planning infrastructure to support this (as very well referenced in your full document and the requirement for further research on the impact of adolescence and young adult services). Reviewing the systems won't be sufficient. Commissioning bodies need to understand the incentives around existing behaviours and practices. Question 2: What would help users overcome these challenges is… In a complex system such as Transitions, it will take dedicated commitment over time to shift that complex system. A clear message that "Transitions is a phase that happens across 14-25 years that we all have a role in" would help.	Thank you for your comments which will be considered as part of the work to support guideline implementation. The Guideline Committee considered recommendations carefully and agreed they were aspirational but achievable. Your comments on resource implications will be considered by NICE as part of their costing work to support guideline implementation.

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				The research that NICE are recommending around the cost effectiveness of 'double running' (joint working) would help. Commissioners/Managers/Leaders having an understanding of what 'developmentally appropriate' means in practice would be helpful. For example, we have three relevant outcomes in Suffolk for our Mental Health and Learning Disability services (CCG and County Council): ""I am learning about what I need to manage my own health and wellbeing as an adult" "I am starting to be part of the world of work and the social life of my community" "I am ready for change, I know what's about to happen, I have my plan."	
Suffolk County Council	Short	16	19	Question 1: This recommendation will be a challenging change in practice because … There are significant restrictions around the use of funding which get in the way of pooling resources more effectively. Some of these are central government led, some are local drivers and practice. One example is the lag funding model through the Education Funding Agency . In order to commission alternative education provision to meet changing and small-scale needs, the Local Authority needs to	Thank you for your comment. The previous reference to financial incentives such as CQUIN have been removed from the recommendations as it was noted that this is not within the remit for NICE guidance; however, there is reference to funding mechanisms within the implementation section.

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		17	7	underwrite this education provision. This combination (limited ability to manage financial risks locally, and rigid national policies) makes it harder in practice. Question 2: What would help users overcome these challenges is… Exemplars in different contexts. Not just the single long-term health conditions (indicative cost effective practice in the NICE evidence review). At the moment, the incentives are not there for commissioners and managers to prioritise funding. What can NICE and other statutory organisations do to influence these?	
Suffolk County Council	Short	17	12	Question 1: This recommendation will be a challenging change in practice because … The training in person-centred practice has happened, but the incentives to put it into practice aren't there. The notion of developmentally appropriate is not well understood.	Thank you for your comment. There is a research recommendation on the effectiveness of different approaches to training on outcomes, as this was a significant gap in the evidence. This recommendation, therefore, was intended to map out the broad areas that training could usefully address. The Committee recognised that people's level of training and the content of training will depend on the role they undertake.
		17	20	Question 2: What would help users overcome these challenges is… Ofsted and CQC knowing, understanding and communicating person-centred and developmentally appropriate practice. The draft Ofsted and CQC	

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				inspection framework for SEND (under the 2014 Acts) needs to be able to distinguish between a process and practice (and outcomes). NICE could use the systematic evidence of implementing person-centred practice in social care and education settings to inform how it supports it to be implemented now. (And as above…) Commissioners/Managers/Leaders locally having an understanding of what 'developmentally appropriate' means in practice would be helpful. For example, we have three relevant outcomes in Suffolk for our Mental Health and Learning Disability services (CCG and County Council): ""I am learning about what I need to manage my own health and wellbeing as an adult" "I am starting to be part of the world of work and the social life of my community" "I am ready for change, I know what's about to happen, I have my plan."	
Suffolk County Council	Short	18	6	Question 1: This recommendation will be a challenging change in practice because … Practitioners frequently know who the young people are who either (a) are disengaged from services or (b) are not eligible for services.	Thank you for your comments which will be considered as part of the work to support guideline implementation.

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			16	The problem is the reality of ever diminishing resources, including commissioning capacity to innovate and develop new services models . If we share information better we may get more effective at risk management, but this is only one part of the solution. The other is radical system changes. Question 2: What would help users overcome these challenges is… We can't continue to run additional databases locally. These are expensive workarounds. Central Government engagement in support for local redesign of data systems. For example, we are looking to build a system that works across adult health and social care, but the data requirements from the DfE regarding NEET figures make it problematic to design a system that works for Transitions workers.	
Teenage Cancer Trust	Full	General	General	Teenage Cancer Trust is the only UK charity dedicated to improving the quality of life and outcomes for the seven young people aged between 13 and 24 diagnosed with cancer every day[11]. We fund and build specialist units in NHS hospitals and provide dedicated staff, bringing young people together so they can be treated by teenage cancer experts in the best place for them.	Thank you for your comment and your support for the guideline.

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				Through education of young people about the signs of cancer and working with health professionals to improve their knowledge, we work to significantly improve young people's experience of cancer. And through our own research and collaboration with our partners in the NHS, across the UK governments, and organisations both nationally and internationally, we strive to improve outcomes for young people. Teenagers and young adults with cancer have a very specific set of psychosocial and physical needs which have to be met in order to secure the best outcomes for each patient. Young people with cancer may transition between paediatric and adolescent oncology services, between adolescent and adult services, or in some cases directly between paediatric and adult care. 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. When managed appropriately, the young person will experience a flexible transition, retaining choice and control. When this is not achieved, however, the patient and their family can experience anxiety, may feel they lack required information, may lose trust in the professionals leading their care, and can suffer delays in accessing treatment and services. We welcome the broad content of this NICE guideline, which could dramatically increase the quality of the transition experience, but urge NICE to consider the following suggestions in order to secure the best outcomes for young people. North West Cancer Intelligence Service (2013)	

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Teenage Cancer Trust	Full	General	General	We were disappointed to note that the draft guideline made only brief reference to the existence of adolescent, teenage or young adult services. Describing transition as a move from child to adult services does not adequately represent specialist services for teenagers and young adults; experience of the process as part of such an environment will inevitably be different to a move from paediatric services. We suggest that teenage and young adult services, and the important role that they can play in aiding transitions, are more strongly acknowledged in the guideline.	Thank you for your comment. Our evidence reviews found mixed quality evidence that transition clinics can improve condition-specific outcomes for young people transitioning from paediatric to adult services. The transition clinics that were evaluated by these studies were either set within paediatric services but including adult team members, or set in adult services but focusing on young adults only. Some were in combination with training or the provision of a transition co-ordinator. We also noted that some studies evaluating transition clinics did not find any impact on condition-specific outcomes, and so this is an area of uncertainty. The Committee therefore agreed that, rather than specify a transition service, the guideline should: - make clear that services should be developmentally appropriate (recommendation 1.5.11) - set out the principles that all services should follow to support transition and the associated roles and responsibilities - provide examples of how services could support transition (for example, in recommendation 1.3.5).
Teenage Cancer Trust	Full	General	General	We were delighted to note that the World Health Organisation included a smooth transition process in its recent publication outlining the global standards which adolescent health services should achieve[12]. We suggest that NICE consider these standards as part of	Thank you for your comment and the reference which will be considered as part of the work to support implementation and development of the Quality Standard, along with other standards, as appropriate.

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				their analysis of the issue's context. [5] World Health Organisation (2015), Global Standards for quality health care services for adolescents	
Teenage Cancer Trust	Full	4	14	We welcome the requirement for a 'named worker' to help a young person navigate the different areas of transition. Key workers, such as Clinical Nurse Specialists in cancer care, have been found to have a significant impact on patient experience[13]. This accords with our own determination to ensure consistent care for teenagers and young adults with cancer; as part of our work we fund key workers who carry out both medical care and psychosocial support in our units and across the community. The familiarity and security provided by such continuity helps teenagers and young adults to tackle a range of challenges throughout their cancer journey, which can include transition to adult services. [3] Ibid	Thank you for your comment and support for the named worker recommendations.
Teenage Cancer Trust	Full	7	8	We were pleased to see that the role of charities in providing care and services to young people as they move through transition has been recognised in the draft guideline.	Thank you for your comment and support for the guideline.
Teenage Cancer Trust	Full	11	9	We welcome the emphasis laid upon the importance of training healthcare professionals about methods of communicating with young people. The National Cancer Patient Experience Survey has repeatedly shown that young people's experiences within the healthcare system are consistently worse than older	Thank you for your comment and support for the guideline.

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				cancer patients, particularly with regard to communication[14]. [2] Department of Health (2010, 2012, 2013, 2014), National Cancer Patient Experience Survey	
Teenage Cancer Trust	Full	12	18	We are pleased that the concept of gathering feedback from teenagers and young adults has been raised in this draft guideline, but suggest that a more formal system of data collation should be considered. For example, although the National Cancer Patient Experience Survey informs many decisions about adult cancer care, there is no such survey for patients under 16, meaning that their opinions go unheard. Similarly, while there is NICE Guidance for the standards required of adult patient experience, there is no equivalent guidance for young people.	Thank you for your comment. There was insufficient evidence to inform a recommendation on nationwide data collection and audit. However, the Committee emphasised throughout development the importance of ensuring the young person is at the centre of their care and support and involved throughout. This is referenced explicitly in recommendations 1.1.1, 1.1.4, 1.2.4 (which was updated to this end, following discussion at Guideline Committee meeting 12), 1.2.10 and 1.2.19. A number of other recommendations reflect the need to ensure young people are sufficiently informed about their care and support (for example, recommendations 1.2.7, 1.2.13 and 1.3.4) and supported to express their views (for example, recommendations 1.2.10, 1.2.11 and 1.3.3).
Teenage Cancer Trust	Full	19	5	We agreed to note that the proposals in this draft guideline apply to all young people up to the age of 25. However, it will be important to ensure that this principle translates into practice. For example, existing NICE Guidance states that following diagnosis, all young people with cancer up to the age of 25 should be offered a choice of age-appropriate care and notified to the Principal Treatment Centre for cancer where Teenage Cancer Trust units are based.	Thank you for your comments. Please see the implementation chapter which provides examples of how to overcome some of the challenges related to implementation. In particular, there is a section on joint planning, development and commissioning of services involved in transition across children's and adults' health and social care.

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				However, research suggests that this currently only happens in around half of cases[15]. This lack of access to appropriate care could be mirrored across transition pathways unless a firmer stance is taken on the practical extension of the age bracket to 25. [4] O'Hara C, Khan S, Flatt G, North West Cancer Intelligence Service (2011), How many teenagers and young adults with cancer are being referred to specialist care in England?	
The Association for Family Therapy and Systemic Practice in the UK	Short	General	General	The transition between children's and adults' services involves the young person and their family / carers transitioning between services which are very different in culture and structure (page 16, line 6). The occasional joint planning meeting (involving staff from both children's and adults' services) and/or visits to adults' services does not go far enough to help the young person and their family / carers negotiate this change. A service which is clearly identifiable as a young people's transition service, funded by pooled budgets across organisations (page 13, line 16), which provides support across a wide age range e.g. 16 to 22 years, will help: • the young person and their family / carers to manage the transition from children's to adults' services within a timeframe which is more closely aligned with the other developmental tasks the young person and their family / carers are negotiating at this time • staff from children's and adults' services to build trust in each others' ways of working	Thank you for your comment which provides useful context. The Guideline Committee did consider evidence on different models of provision for transition and agreed that while there were some examples of transition clinics working well, other approaches could also work well. There is, therefore, a recommendation on developmentally-appropriate provision (1.5.11) which, following discussion of stakeholder consultation comments, was updated to reference 'age-banded' clinics as one example of what such provision may look like in practice. Please see also the chapter on implementation which provides some practical examples of how challenges could be overcome. In particular, there is a section on joint planning, development and commissioning of services which includes reference to financial mechanisms.

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				• staff from children's and adults' services to share information appropriately • staff from children's and adults' services to help families and carers also to negotiate this transition There are a number of good practice examples in physical health care, for example, transition clinics which cover a wide age range and which are staffed by staff from both children's and adults' services.	
The Association for Family Therapy and Systemic Practice in the UK	Short	General	General	Question 1. Setting up young people's transition services as outlined above will be most challenging to implement because this involves negotiating pooled budgets across organisations, and investment in such services may not give rapid financial benefits to the organisations involved. Rather financial benefits are more likely to come in the future, from adults who are more settled in the context of their local communities, support systems, relationships and lives. This does not fit the political context, which is looking for cost savings within short time frames.	Thank you for your comments which will be considered as part of the work to support guideline implementation..
The Association for Family Therapy and Systemic Practice in the UK	Short	General	General	Question 1. The work involved in engaging young people, and then motivating them to continue to take part in their care cannot be underestimated. It is likely to be intensive with each young person at first, i.e. minimum of weekly contact	Thank you for your comments which will be considered as part of the work to support guideline implementation. The Guideline Committee agreed strongly that the young person should be engaged and at the heart of their care. Person-centred care is referenced explicitly in recommendations 1.1.1, 1.1.4, 1.2.4 (which was updated to this end, following discussion at Guideline Committee meeting 12), 1.2.7 and 1.2.19. At meeting 12, the Guideline Committee also reviewed the recommendation on supporting young people to communicate with practitioners and revised the text to make clear this requires them to know what a young person's communication needs are, and to have tools

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					available to help address those needs (see recommendation 1.2.20).
The Association for Family Therapy and Systemic Practice in the UK	Short	General	General	Question 1. The named worker role has a lot of responsibility attached. Workers in this role will need the full support of their agencies to undertake this role well. If a young person chooses a worker in a senior role (e.g. Consultant Psychiatrist or Psychologist, or Social Worker Team Manager) then this will have implications for the wider service provision. It may be that agencies try and recruit specifically to this role.	Thank you for your comments which will be considered as part of the work to support guideline implementation. Following discussion at Guideline Committee meeting 12 (04.11.15), more detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7).
The Association for Family Therapy and Systemic Practice in the UK	Short	General	General	Question 2. There are a number of good practice examples in physical health care, for example, transition clinics which cover a wide age range and which are staffed by staff from both children's and adults' services.	The Guideline Committee did consider evidence on different models of provision for transition and agreed that while there were some examples of transition clinics working well, other approaches could also work well. There is, therefore, a recommendation on developmentally-appropriate provision (1.5.11) which, following discussion of stakeholder consultation comments, was updated to reference 'age-banded' clinics as one example of what such provision may look like in practice.
The Association for Family Therapy and Systemic Practice in the UK	Short	General	General	Question 3. Key audiences need to include: • commissioners and council leaders • leaders of children's and adults' services, and committed and enthusiastic practitioners in the children's and adults' services • young people and their families / carers	Thank you for your comments which will be considered as part of the work to support guideline implementation. Thank you for identifying these audiences. They were also the intended audiences for the guideline, considered to be key by the Guideline Committee and referenced throughout development discussions.

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The Association for Family Therapy and Systemic Practice in the UK	Short	5	29	Question 4. Transition planning starts around age 16 but often involves nothing meaningful until much closer to the young person's 18th birthday. The point of transfer does often happen on a rigid age threshold, e.g. the young person's 18th birthday.	Thank you for your comment which provides useful context. The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are.
The Association for Family Therapy and Systemic Practice in the UK	Short	General	General	Question 6. Parents should be actively involved to share the tasks so that there is a mix of formal (professional) and informal (family, friends, community) support systems identified for the young person. Parents and other carers could be involved to the extent that the young person wants this. It can be helpful to revisit conversations about whether and to what extent the young person would like their parents / other carers to be involved. It can also be helpful to be creative about this, for example, if the young person does not want to meet with their parents, would they be willing to consider views put forward by parents or siblings by email for example.	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.

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The Association for Family Therapy and Systemic Practice in the UK	Short	General	General	Question 7. These recommendations are likely to have an impact on the cost of services, by extending the input from both children's and adults' services, and through the increased intensity of work around the engagement of the young person, named worker input, and working with families. However this impact on the cost of transition services is an investment in the young person's wellbeing, their ability to form healthy relationships and engage in their local community, which can be offset against future cost of services (such as increased health costs and use of emergency services).	Thank you for your comments which will be considered as part of the work to support guideline implementation.
The Association for Family Therapy and Systemic Practice in the UK	Short	General	General	Question 8. As above	Thank you for your comment.
The Association for Family Therapy and Systemic Practice in the UK	Short	General	general	Question 9. Long term savings should been seen in areas such as reduction in DNA health appointments, reduction in Accident and Emergency use, reduction in crisis intervention	Thank you for your comment which will be considered as part of the work to support guideline implementation.
The Association for Family Therapy and Systemic Practice in the UK	Short	12	18	The establishment of local integrated youth forums for transition sounds useful and a good way of involving young people. If it is difficult to establish forums involving young people with a range of care and support needs, it would be useful to establish youth forums for transitions which are more service specific (e.g. for mental health care) rather than not establish these forums at all.	Thank you for your comment and support.
The Association	Short	22	11	The concept of independence can be unhelpful when applied in isolation. Independence suggests that	Thank you for your comment.

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for Family Therapy and Systemic Practice in the UK				young people increasingly take greater responsibility for their own decisions, actions and self-care. However, independence does not mean that young people or adults need to hold this greater responsibility in isolation. Humans are social beings and supportive relationships continue to be important throughout our lives; people are independent in the context of relationships. This is important for both children's and adults' services to work with, and may go some way towards bridging the cultural gap across children's and adults' services.	
The British Society for Paediatric Dentistry	Full	General	General	Our Society has had sight of the response from the Royal College and should like to endorse this document. I have personally found over 30 years working in the Community and treating children with additional needs who make the transition into adults with special needs, that this transition does not have a seamless passage. The transition is often traumatic and a source of stress for the parents of these children too as the benefits and support suddenly alter. I would think that a smooth transition is more cost effective than allowing things to decline and then having to pick up the pieces later. This consultation is to be welcomed and hopefully will result in the improvement of support and care for children and families who have already faced much in their lives. It would be good to think that instead of having to fight for help and support a lot of the time this would not be the case in future.	Thank you for your comment and your endorsement of the guideline.
The Encephalitis Society	Full	General	general	Question 1: The model is excellent. It would make a massive positive difference when in place. Areas with biggest impact on practice would include: united multi-professional working; the cessation of sudden-cut-offs	Thank you for your comment and support for the guideline.. Please see the Implementation chapter which provides some examples of how to overcome implementation challenges. In particular, there is now a

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				as recommended; and the change in 'policy' 'practice' and 'atmosphere'. It would be very challenging indeed to implement because of aspects such as: lack of knowledge, skills and experience (e.g. re Acquired Brain Injury (ABI) resulting from Encephalitis) as our experience is that even hard-working, caring professionals do not have the necessary knowledge and experience; and, as set out in the document, staff are just not always available. So the biggest challenges seem to be: staff levels, extent of staff training (stressed full doc p20 section1.5), but could never cover everything in enough depth, and the need for area-based staff specialisms. Having the staff means: financial implications, long-term planning; and either controlling exits to private practice or building on the right to access to it. Our experience of implementation of the SEND regs and guidance is that scores for implementation would range from nearly 100% to clear failure. In summary, the biggest impact and challenges are: existence of sufficient practitioners; their knowledge, skill & experience; recognition followed by practice that specialism of professionals involved is absolutely essential in the field of ABI.	section on the over-arching transition-specific training needed by those working to support young people moving between services. In developing these principles, the Guideline Committee recognised that different people will need different levels of training depending upon the role they play as part of a young person's package of care or support.
The Encephalitis Society	Full	general	General	Question 2: Training, monitoring, sufficient practical resources, ready access to advice and guidance, detailed written guidance in respect of specific needs (e.g. Encephalitis), examples of good practice that cover a sufficient range and complexity of need – with clarity regarding how the resources were made available. Summary: staffing, practical abilities, support, guidance & funding.	Please see the Implementation chapter which provides some examples of how to overcome implementation challenges. In particular, there is now a section on the over-arching transition-specific training needed by those working to support young people moving between services. In developing these principles, the Guideline Committee recognised that different people will need different levels of training depending upon the role they play as part of a young person's package of care or support.

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The Encephalitis Society	Full	General	General	Question 3: Audience will be very wide indeed which will make the structure very complex. Guidelines should consider a range of audiences including: those involved in 'steering' (e.g. service managers), 'professionals' (re full range of people involved); and service users, their families and providers. Attention to reading comprehension levels and so forth is essential. This is hard in practice, as simplified documentation cannot always spell out every issue. SEND materials, for example, were produced very clearly, but people can find the guidance difficult to follow.	Please see the Implementation chapter which provides some examples of how to overcome implementation challenges. In particular, there are recommendations specifically for commissioners and managers, as well as frontline practitioners. The guideline will also be supported by complementary guidance for commissioners and NICE also produce a version of the guideline for people using services.
The Encephalitis Society	Full	General	General	Question 5: Our experience is that schools do review annually. Our experience of care reviews is limited. We have the example of a case in a London Borough, where they said that they simply don't have the staff to consider the care needs, attend meetings, and so forth.	Thank you for your comment. The Guideline Committee reviewed the recommendations on timing and review (under section 1.2) at Committee Meeting 12 (04.11.15) and agreed the edited wording now found in recommendation 1.2.4.
The Encephalitis Society	Full	General	General	Question 6: Our experience of transition planning post-Encephalitis is that parents or their role-equivalent should be fully involved, with care taken that young people's views have precedence including consideration of their feelings, capabilities and understanding of the future. After ABI, detailed, specialist neuropsychologist's recommendations would be good to have to help guide decisions about involvement. So, how parents should be involved depend on the 'condition' of the young person, and management of meetings should depend on the young person's wishes and needs. Our experience is that some good practitioners get things just right. But staff have also been at a meeting where there wasn't really any outcome due to the fact that the	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their

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				young person had difficulty following what was happening and communicating which wasn't well managed. Ensuring appropriate, genuine involvement is complex. The draft guidance goes some way towards addressing this, but our opinion is that the consequences of 'invisible' ABI are often not well understood. Further guidance is needed about how parents should be involved when a young person has an ABI. Another point covered in the document, is that the young person may well be at home post- 18… and maybe for many years longer. If this is the provision being assumed, parents' views are essential. At the same time, the rights of young people post 16 to support, guidance and advocacy are fundamental, as included in SEND legislation.	views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
The Encephalitis Society	Full	General	General	Question 7: Yes. We are often informed that Health and Care services do not have the resources required. Also, based on our experience, the full implementation of the excellent standards set out in the draft would usually require more staff, further training and greater specialisation.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
The Encephalitis Society	Full	General	General	Question 8: Recommendations that require further staffing, further staff time per young person and comprehensive staff training lead to additional costs.	Thank you for your comment which will be considered as part of the work to support guideline implementation. Thank you for your comment which will be considered as part of the work to support guideline implementation.
The Encephalitis Society	Full	General	General	Question 9: It may be that costs are saved in the long term. This is, of course, not certain post ABI.	Thank you for your comment which will be considered as part of the work to support guideline implementation. Thank you for your comment which will be considered as part of the work to support guideline implementation.

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The Encephalitis Society	Full 1.26	General	General	Question 4: Education requires the Annual review from year 9 to include transition planning, with health and social care service involvement. We are informed that this often does not happen. The upshot is that the Health and Social Care guidance emphasis is excellent – but refer back to question 1 above.	Thank you for your comment. On review, the Guideline Committee agreed that reference to liaison with education practitioners needed to be strengthened in the recommendations, given: the critical importance of education sector professionals in supporting young people's development, health and wellbeing, and identifying problems early. To achieve this, the following recommendations now reference education explicitly: 1.1.6, 1.2.1, 1.2.8, 1.2.16 and 1.3.3.
The Maypole Project	Short	2	20	Co-producing transition policies; emphasis must be placed on how the policies and strategies are delivered – readable, age appropriate and sufficient resources put into place to assist with this	Thank you for your comment which will be considered as part of the work to support guideline implementation. Please see the chapter on implementation which provides some practical examples of how challenges could be overcome.
The Maypole Project	Short	3	9	Ensure that a "person centred" approach is also centred on the child as a unique individual and is REAL not rhetorical. Emphasis here on not raising expectations which cannot be met. Line 19 – treating the young person as an "equal partner" needs to be acknowledged as being difficult, if not impossible at tmes, to achieve.	Thank you for your comments. Please see the chapter on implementation which provides some practical examples of how challenges could be overcome. In particular, there is a section on improving front-line practice with young people through training.
The Maypole Project	Short	4`	13	Transition planning – 17 the named worker first priority should be "someone with whom the young person has a meaningful relationship (line 21) before their role is taken into consideration	Thank you for your comment. The Guideline Committee recognised the importance of ensuring the young person is involved in identifying someone appropriate. Recommendation 1.2.5 aims to address this.
The Maypole Project	Short	4	13	Ideally would be someone who could work with the young person from childhood through to adulthood and onwards	Thank you for your comment.
The Maypole Project	Short	5	4	May or may not be the person who can also "support the young person's family" – this is frequently better carried out by another professional unless that "named	Thank you for your comment. The wording of recommendation 1.2.7 has been updated to make clear it is not the responsibility of the named worker to

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				worker" is sufficiently trained, skilled and supervised	undertake all of the tasks listed, but to 'oversee, coordinate or deliver transition support, depending on the nature of their role'.
The Maypole Project	Short	5	18	Emotional health should be prioritised here – it needs to be ongoing, flexible and is an essential element in the young persons well being at this time when they can feel excessively vulnerable.	Thank you for your comment. The Committee discussed the need to support the young person "as a whole", taking into account what they would like to achieve and their emotional health, , throughout guideline development. This informed the development of the four over-arching outcome areas referenced throughout, specifically: - education and employment - community inclusion - health and wellbeing including emotional health - independent living and housing options. These areas are included in recommendation 1.2.8, the Training section of the Implementation chapter, and in the definition of 'person-centred' ('Terms used in this guideline').
The Maypole Project	Short	6	13	Involving young people is essential in this	Thank you for your comment. The Committee emphasised throughout development the importance of ensuring the young person is involved and at the centre of their care and support. This is referenced explicitly in recommendations 1.1.1, 1.1.2, 1.2.4 (which was updated to this end, following discussion at Guideline Committee meeting 12), 1.2.9 and 1.2.19.
The Maypole Project	SHORT	7	12	Autonomy needs to be at an age and developmentally appropriate level – again emotional health should be prioritised	Thank you for your comment. The Committee discussed the need to support the young person "as a whole", taking into account what they would like to achieve and their emotional health, , throughout guideline development. This informed the development

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					of the four over-arching outcome areas referenced throughout, specifically: - education and employment - community inclusion - health and wellbeing including emotional health - independent living and housing options. These areas are included in recommendation 1.2.8, the Training section of the Implementation chapter, and in the definition of 'person-centred' ('Terms used in this guideline').
The Maypole Project	Short	7	19	Signposting – there need to be services available. Frequently when children transfer to adult services there is nothing available. C	Thank you for your comment. The Committee recognised the need to ensure that young people do not "fall through the gap" where they are not eligible for support when they reach adult services, or services are not available. This informed recommendations 1.5.5, 1.5.6 and 1.5.7.
The Maypole Project	Short	7	25	Young people should be helped to manage their own condition. THIS must be done individually as many young people who have co-existing conditions – i.e. chronic condition plus learning disability may not be able to achieve this.	Thank you for your comment. Given the wide range of young people covered by the guideline, the Committee did not want to be prescriptive about the detailed processes for implementing the recommendations at the local level and recognised that careful consideration will be needed in this respect.
The Maypole Project	Short	8	4	Support for parents and carers is essential	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers

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					in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision. -
The Maypole Project	Short	9	10	Information provided should always be: Written, spoken, explained in developmentally appropriate way, provided with support in place where necessary for the issues to be explored, and also repeated in order that questions are raised and answered effectively.	Thank you for your comment. Accessibility options listed in 1.3.4 are only examples rather than an exhaustive list. Given the breadth of the guideline the wide range of groups that it covers, the Committee thought this appropriate.
The Maypole Project	Short	11	8	Training and development for staff MUST include: Self awareness. Many transitions we have experienced have been made more difficult, or even blocked, through issues from the professional themselves. Experiential, explorative training should include issues around "letting go" of a young person as they need to move to adult services –and all of the implications here. Also training MUST include: Loss – all children with any additional health or social needs will have faced loss. Transition means change, change = loss. An understanding of and developmental approach to loss across abilities is essential.	Thank you for your comment. The Committee did consider training to be an important area to address and, to this end, it is referenced in the implementation chapter, specifically in relation to improving front-line practice with young people. Given the wide range of young people covered by the guideline, it was not possible to list every aspect of training. In the implementation chapter, therefore the Committee sought to provide over-arching headings that specify the key broad areas to address.
The Maypole	Short	12	1	Supportiing infrastructure: Most important element of this whole proposal is to ensure that any team	Thank you for your comments. Please see the chapter on implementation which provides some practical

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Project				lead/ownership/named worker is known about by families including the child/young person. This is where previous transition "care pathways" have been seen not to have worked "on the ground". This information needs to be provided in an appropriate way and be provided repeatedly to families as they approach the age of their child's transition across services.	examples of how challenges could be overcome. In particular, there is a section on joint working which includes reference to coordinating care and involving young people and families. .
The National Rheumatoid Arthritis Society	Short	General	General	If a young person moves away from home, relocates with work, attends university etc, it cannot be assumed that they will have gone through the transition process. What is in place for a temporary move away?	We have added a reference, in the context section (p9, full guideline), to the complexity of supporting young people who may move out of their local area (which could include those who leave home for university).
The National Rheumatoid Arthritis Society	Short	General	General	From examples we have seen over the last decade, young people have moved from paediatric to adult care much later than historically was common practice (possibly following wider access to biologics)	Thank you for your comment which provides useful context.
The National Rheumatoid Arthritis Society	Short	6	13	All transition documents (processes, protocols, best practice etc) should be fully inclusive and available in formats that a young person can readily access without challenges; e.g. iPad or mobile phone friendly. The delivery of information about transition should be staggered; too many instructions and too much information in one sitting can be overwhelming. The same applies to the information supplied to the Healthcare Professionals in the rheumatology multi disciplinary team. Transition guidelines and the connected documents/information sources should relate to young people and so they are an important audience to consider when developing these guidelines.	Thank you for your comment. The Committee agreed that accessibility of information and ensuring young people have support to communicate is important. The Guideline Committee reviewed the recommendation on supporting young people to communicate with practitioners and revised the text to make clear this requires them to know what a young person's communication needs are, and to have tools available to help address those needs (see recommendation 1.2.12).
The National	Short	9	22	The "named worker" role should be as consistent as possible throughout the UK, i.e a recognisable title and	Thank you for your comment. Following discussion at Guideline Committee meeting 12 (04.11.15), more

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Rheumatoid Arthritis Society				responsibilities. Regular review opportunities to share best practice nationally would be recommended. In the event a young person relocates, perhaps because of further education or moving home, the "named worker" will be a recognisable term and so any relocation where a patient is under the care of a new team will be less stressful. Equally important is that the "named worker" support is still provided to a young person that has been diagnosed later, i.e. possibly the age where someone with an earlier diagnosis would typically have transitioned; the transition may be different and it may not be phased in the same way, but the "named worker" can support this. Where JIA is diagnosed later, and they go straight into adult care, the patient still needs transitional support.	detail has been added to make the role and responsibilities of the named worker clearer (see: Terms used in this guideline, recommendation 1.2.5 and 1.2.6) and also added more information to make clear what this person's role would involve (recommendation 1.2.7). Specifically, you will note that we have made clearer this is a role not a job title and therefore could be undertaken by someone who is already fulfilling a role of keyworker, coordinator or transition support worker.
The National Rheumatoid Arthritis Society	Short	10	15	Teenagers are particularly vulnerable to poor mental health and a poor, inconsistent, rushed transition can cause stress, leading to anxiety, depression and self harm. Inclusive access to a mental health professional during this time is strongly recommended and should be part of the multidisciplinary team supporting the parents/carers as well as the patient. Parents sometimes struggle to let go and need continued support from HCP's on how to allow teenagers to become independent adults, to learn to problem solve and make their own decisions.	Thank you for your comment which provides useful context. The Guideline Committee reviewed the recommendations taking into account young people with mental health needs and considered them relevant to this group. In addition, they recognised the need to ensure that young people with mental health needs, in particular, do not "fall through the gap" between Child and Adolescent Mental Health Services and Adult Mental Health Services and, to this end, referenced them explicitly in recommendations 1.5.5 and 1.5.7,
The Royal College of Psychiatrists	Short	general	general	Q1: Moving to a flexible, developmentally determined transition will create major challenges for services who are managing at the interface of child and adult services (see point 4 above).	Thank you for your comments which will be considered as part of the work to support guideline implementation.

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The Royal College of Psychiatrists	Short	general	general	Q2: Joint training between child and adult service staff and providers and multiagency training.	Thank you for your comment. Please see the chapter on implementation which provides some practical examples of how challenges could be overcome. In particular, there is a section on joint planning, development and commissioning of transition support.
The Royal College of Psychiatrists	Short	general	general	Q3: Children and young people, parents and carers, service provider and service commissioners, local authorities, CCGs and schools.	Thank you for your comments and for identifying these audiences. They were indeed within the intended audiences, also considered to be key by the Guideline Committee and referenced throughout development discussions.
The Royal College of Psychiatrists	Short	general	general	Q4: Transition planning depends on the nature of the disorder and the services. In congenital heart disease, transition planning starts at birth, in sickle cell and diabetes at 13-14, and in CAMHS at 17, but might be possible earlier with chronic conditions.	Thank you for your comment which provides useful context. Thank you for your comment. The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are.
The Royal College of Psychiatrists	Short	general	general	Q5: They vary enormously and should be dependent on need.	Thank you for your comment which provides useful context.
The Royal College of Psychiatrists	Short	general	general	Q6: Parental involvement should be negotiated on an individual basis. For some children with complex conditions and developmental disorders parents are central to all aspect of transition. For neurotypical young people this may not be necessary and they may or may not decide to include their parents in transition planning. Young people should be encouraged to think	Thank you for your comment. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end:

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				carefully if they actively choose to not include their parents.	- referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
The Royal College of Psychiatrists	Short	general	general	Q7: Yes.	Thank you for your comment.
The Royal College of Psychiatrists	Short	general	general	Q8: Named worker and additional support before and after transition.	Thank you for your comment.
The Royal College of Psychiatrists	Short	general	general	Q9: Possibly through reduced DNA rates.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
The Royal College of Psychiatrists	Short	2 -4		The Royal College of Psychiatrists fully supports the concept of person centred care, but service providers should recognise that sufficient time needs to be given to clinicians in order to meaningfully deliver it.	Thank you for your comments which will be considered as part of the work to support guideline implementation.
The Royal College of Psychiatrists	Short	3 -3	30 -06	It is important to recognise that different agencies currently use different ages for transition - for physical health it is 16 years old, for mental health and social care it is 18 years old. Differences in transition ages	Thank you for your comment. The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year

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				create tensions between different agencies. Transitions from children's residential care to adult social care and child and adolescent mental health to adult mental health can be particularly traumatic for the young people concerned.	9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are.
The Royal College of Psychiatrists	Short	4 -5	general	We support the role of a named worker but believe that if the named worker fulfilled all of the responsibilities listed it would lead to a significant increase in workload and cost.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
The Royal College of Psychiatrists	Short	5 -6	general	The concept of 'flexible' and 'developmentally appropriate' (including transition before the child/adult threshold) is very welcome. However, the implementation of the concept will need careful thought. Inappropriate implementation of 'flexible' arrangements could enable services receiving the transitioning patient to contrive reasons why the transition should not happen (for example, they could claim the 'flexibility' to prioritise their service needs and not the needs of the young person making the transition). Furthermore, commissioning and funding is not flexible. If we are to transition after 18 for some, there must be agreement to transition before 18 for others. Or for some funding to come to Child and Adolescent Mental Health Services to reflect a slower transition. The research of Professor David Foreman (RCPsych) has shown that 16-18 year olds transferring to CAMHS without adequate funding has caused the reduction of services for under-5s. There is a risk this proposal will bring even further attrition. The same arguments stand if the transition is at 25.	Thank you for your comments. Please see the chapter on implementation which provides some practical examples of how challenges could be overcome.
The Royal College of	Short	7	5 -17	Involving parents and carers in transition is essential, especially young people with complex conditions. However, this needs to be balanced with the need/wish of the young person for greater autonomy. Training for	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement

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Psychiatrists				both adult and children's services staff will be needed to deliver this in an effective and sensitive way.	were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
The Royal College of Psychiatrists	Short	10	general	Additional time will be needed for named workers to deliver effective pre- and post- transition support.	Thank you for your comment. Pre and post transition support is already an integral part of many transition support services.
The Royal College of Psychiatrists	Short	16	17 -18	The 0-25 service model needs very careful evaluation. We have concerns that if it is not very carefully implemented that it will lead to draining of resources from younger age adults to higher risk, older age groups. This has been seen in some areas of the UK already and previously occurred when CAMHS services were extended from 16 to 18 without additional resourcing.	Thank you for your comments which will be considered as part of the work to support guideline implementation.
Together for Short Lives	Full	General	General	The following audiences should be considered when constructing these guidelines: • Young people, parents, carers: The guidelines should reflect the difficulty that young people	Please see the Implementation chapter which provides some examples of how to overcome implementation challenges. In particular, there are recommendations specifically for commissioners and managers, as well

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				with complex of life-limiting conditions face in finding services to transition to. This can be highly stressful and transition plans become futile if there are no services available that can manage their complex needs. • Service providers: Primary care, secondary care, tertiary care, voluntary services, winder agencies (social care, education, housing, employment). • Short breaks providers: the guidance should support age-appropriate short breaks for young people. These are critical for both the young person, as they help develop independence and social skills, as well as their parents, as it gives time to re-charge their batteries and spend time with each other or other siblings. • Commissioners: CCG, local authorities (children's and adults' services)	as frontline practitioners. The guideline will also be supported by complementary guidance for commissioners and NICE also produce a version of the guideline for people using services. The guideline covers a wide range of young people and services so it was not possible to list all relevant conditions and needs separately. As a result, the Committee sought to establish the broad principles to follow with respect to care and support before, during and after transition. Young people with complex life-limiting illnesses are covered by the guideline.
Together for Short Lives	Full	7	20	We support the comments submitted to this consultation by South East Strategic Clinical Network regarding the difficulties that young people experience entering further education. We concur with their suggestion that there should be greater flexibility for these young people in terms of registering with a primary care provider, so that if they wish to then they can remain registered with their GP at home while collecting prescriptions at university.	Thank you for your comment. We have added a reference, in the context section (p9, full guideline), to the complexity of supporting young people who may move out of their local area (which could include those who leave home for university). The Guideline Committee discussed the role played by GPs in these (and other) circumstances at Guideline Committee meeting 12 (04.11.15) taking into account stakeholder comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).1). It was not possible from the evidence to be more specific about processes for ensuring GP registration.

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Together for Short Lives	Full	9	4	The issue of developmental transition is problematic for young people with severe cognitive impairments. It is difficult to work towards preparing a young person and their supporting team to move on because 'letting go' becomes a grey area for parents and professionals. The guideline should set out that profoundly disabled young people should be treated as adults in terms their personal care and sexuality. They should also be treated as adults in a developmentally appropriate way by adult services.	Thank you for your comment. Given the wide range of young people covered by this guideline, the scope of this guideline was to establish the broad principles to follow with respect to care and support before, during and after transition rather than to search for evidence on condition-specific interventions. The Guideline Committee did review all recommendations thinking about different cohorts of young people and considered the recommendations to be widely applicable. The Committee agreed that the issue of parental involvement is important and complex and, on reviewing these recommendations at Guideline Committee meeting 12 (04.11.15) agreed to strengthen their wording (recommendations 1.2.19 to 1.2.22). The Committee also agreed on the need to support the young person "as a whole" taking into account their personal and social needs (not just their health and social care needs) when planning and delivering services. The four categories set out below are intended to encompass these needs and to be relevant to all young people the guideline covers: - education and employment - community inclusion - health and wellbeing including emotional health - independent living and housing options. These areas are included in recommendation 1.2.8,the Training section of the Implementation chapter, and in the definition of 'person-centred' ('Terms used in this guideline').

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Together for Short Lives	Full	10	11	Many young people value the input of their parents in their decision-making process. If it is the wish of young people and their parents, information and advice should be provided to their parents well into young adulthood. Parents/carers are likely to remain significant carers for young people as they transition to adult services and often act in a 'keyworker' role.	Thank you for your comment. The Committee agreed that parental involvement is an important area for the guideline to address and can also be complex. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
Together for Short Lives	Full	14	3	Named workers (or transition co-ordinators) are very important: they enable young people to articulate their aspirations and to plan for services from the wide variety of agencies that they require in order to fulfil these aspirations. Named workers can also assist with funding issues and discuss the use of personal budgets with the young person.	Thank you for your comment and support for the named worker recommendations.
Together for Short Lives	Full	14	7	It is unclear who will fund the work of the named worker. Would this be the NHS, local authority or voluntary sector? This should be established in the guidance. Similarly, the guideline does not specify which adult service the responsibilities should be handed over to. Should this be health, social services	Thank you for your comment. The Guideline Committee agreed that, given the breadth of young people and services covered by this guideline, it would not be appropriate to specify which adult service the responsibilities would transfer to

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				or voluntary sector?	(1.2.9) allowing flexibility at the local level.
Together for Short Lives	Full	14	10	While the recommendation states that the named worker should have an existing relationship with the young person, the guideline does not set out how the young person will be offered a choice to select their named worker. Furthermore, it should set out how existing staff will get extra capacity to deliver this additional workload.	Thank you for your comment. The Guideline Committee agreed that, given the breadth of young people and services covered by this guideline, and the wide range of practitioners supporting them, it would not be appropriate to specify which specific practitioner should help the young person select a named worker.
Together for Short Lives	Full	14	20	In order to discuss the young person's options with them and to effectively co-ordinate services on their behalf, the named worker may require training. The guideline should set out how this training will be provided and funded.	Thank you for your comment. You will note that, following discussion at Guideline Committee 12 (04.11.15) we have made clearer this is a role not a job title and therefore could be undertaken by someone who is already fulfilling a role of keyworker, coordinator or transition support worker (see recommendations 1.2.5, 1.2.6, 1.2.7 and 'Terms used in this guideline'). It may be, therefore, that the practitioner already has the necessary skills. This may not be the case, and NICE will consider this as part of their costing work to support guideline implementation. It is not within NICE's remit to make recommendations on funding mechanisms.
Together for Short Lives	Full	16	6	We welcome the inclusion of co-production with the young person – this enables young people to engage with their care and enables services to learn what young people want and how they can adapt and improve their services. However, it should be recognised that this vital cultural shift will require time and resources.	Thank you for your comment which will be considered as part of the work to support guideline implementation.

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Together for Short Lives	Full	16	12	When developing new tools to help young people communicate effectively with practitioners (for example web apps), these tools should be shared across disciplines, sectors and agencies. These will save time and costs, although they should not be offered at the expense of genuine co-production. Engagement is a critical part of the process.	The Guideline Committee reflected on this comment in Committee Meeting 12 (04.11.15) and agreed that it was not appropriate to recommend sharing tools across disciplines. This is because this recommendation (1.2.10) is aimed at ensuring service managers provide their own practitioners with the relevant tools to involve young people, and these may differ from one service to the next given the very wide range of young people this guideline covers.
Together for Short Lives	Full	16	28	Not all young people, including many with profound learning disabilities, will be able to live fully independent lives. However, their individual needs and things that make them feel happy and fulfilled should be considered with them and their families.	Thank you for your comment. The Committee discussed the need to support the young person "as a whole", taking into account what they would like to achieve and how to promote independence, so far as possible, throughout guideline development. This informed the development of the four over-arching outcome areas to take account of in planning and delivering services, specifically: - education and employment - community inclusion - health and wellbeing including emotional health - independent living and housing options. Addressing these would include discussing with the young person what they need and want. These areas are included in recommendation 1.2.8, the Training section of the Implementation chapter, and in the definition of 'person-centred' ('Terms used in this guideline').
Together for Short Lives	Full	20	23	We welcome the inclusion of training for those working with young people in transition. However, the guidance does not clarify who is responsible for ensuring that the training is consistent.	Thank you for your comment. Given the wide range of services, organisations and practitioners involved in supporting young people, the variety of training currently taking place and the lack of evidence on effectiveness of specific training interventions, the

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					Guideline Committee did not wish to be more prescriptive in respect of the information about training (see: chapter on Implementation).
Together for Short Lives	Full	22	1	The existing 'Ready Steady Go' transition programme is a useful tool for healthcare settings. The Preparing for Adulthood programme, funded by the Department for Education, also provides useful resources.	Thank you for your comment and reference to existing resources which could support guideline implementation.
Together for Short Lives	Full	22	5	The proposed 'local, integrated youth forums' should link in to the Regional Action Groups that form Together for Short Lives' Transition Taskforce. This taskforce looks at practical ways to improve transition for young people for young people with life-limiting and life-threatening conditions. This includes looking at different ways of developing partnerships between children and young people's palliative care services and a wider range of services including social care, housing and employment.	Thank you for your comment. Following discussion at Guideline Committee 12, the Committee added in a reference to the need to 'link with existing structures where these exist' (recommendation 1.5.5).
Together for Short Lives	Full	23	25	There remains a large degree of confusion around the language used in 'transition' and many people don't understand what this term means. Guidance should contain a simple explanation of the term, i.e. that it refers to the process of preparing and planning to move from children's to adult's services as well as the actual transfer itself.	Thank you for your comment. Definitions of both 'transition' and 'transfer' are already included in the guideline (see: Terms used in this guideline' section).
Together for Short Lives	Full	25	2	We welcome the intent to conduct further research in specific areas of transition services. However, young people need action to be taken now and so more services should be prototyped and piloted so that they can be evaluated – including their cost-effectiveness.	Thank you for your comment. The Guideline Committee recognised that there can be a time lag in respect of research; however, the recommendations provided in the guideline aim to deliver improvements to services in the shorter term.
Together for Short Lives	Full	26	21	Questions concerning the consequences and costs of inadequate transition services should include the cost of emergency hospital admissions when young people drop out of the system. There are also wider, indirect	Thank you for your comment. Detail has been added to indicate that gathering a range of costs could be useful.

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				economic factors to consider, such as the increased likelihood of the young person entering education and subsequently finding paid employment. Additional factors to consider include: • Equipment costs. Currently, made-to-measure equipment often has to be returned to children's services when a young person enters adults' services, even though the equipment fits them perfectly. Improved joined up working would reduce this waste. • Having a singular, national approach may reduce the cost of developing lots of different guidelines and approaches. However, there are additional costs in implementing the recommendations of this guidance, including: • Delivering comprehensive training • Funding for named workers (*see comment 2*) • Holding transition clinics • Time taken to co-produce services and engage with young people	
Walsall Healthcare NHS Trust	Full	General	General	It is such a relief to see such a comprehensive guideline which will be a useful tool for professionals supporting Children and Young People though periods of transition – thank you.	Thank you for your comment and support for the guideline.
Walsall Healthcare NHS Trust	Full	General	general	1.2.9: Peer to Peer support can be seen as a challenge for many professionals as with diminishing resources, some staff feel this is something they cannot achieve. It is important that professionals give consideration and thought to those they support, can they introduce young people to one another informally or put patents who are in isolation in contact with one another. It is important that they engage with children, young people, parent/ carers and other services and realise this can be achieved with very little. Locally we	Thank you for your comment. Peer support is provided as only one example of the way that young people may be involved in their transition planning, given that it emerged from evidence. It may be that services achieve this via different methods. The Committee discussed the need to support the young person "as a whole" and in their wider context throughout guideline development. The Guideline Committee agreed it was important to spell out the

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				use peer mentoring and support. We have also utilised the support of youth workers and pool our resources where possible. Leaders and managers need to give their staff the space and time to be creative and innovative in their approach.	areas of a young person's life to take account of in planning and delivering services, to avoid ambiguity, specifically: - education and employment - community inclusion - health and wellbeing including emotional health - independent living and housing options. These areas are included in recommendation 1.2.8,the Training section of the Implementation chapter, and in the definition of 'person-centred' ('Terms used in this guideline').
Walsall Healthcare NHS Trust	Full	General	General	I think that although the guidance mentioned Person Centred Care, It should include and give examples of holistic care as the two can be very different interpretations. Holistic working prompts professionals and their families to think wider. There is a lot of emphasis nationally re meaningful and achievable outcomes. Transition into adulthood should be about the "whole person" – thinking of interconnecting factors, education, social and leisure for example.	The Committee discussed the need to support the young person "as a whole" and in their wider context throughout guideline development. As the term 'holistic' can be interpreted differently, this was not used, in favour of spelling out the areas of a young person's life to take account of in planning and delivering services, specifically: - education and employment - community inclusion - health and wellbeing including emotional health - independent living and housing options. These areas are included in recommendation 1.2.8, the Training section of the Implementation chapter, and in the definition of 'person-centred' ('Terms used in this guideline').
Walsall Healthcare NHS Trust	Full	General	General	Where other services have failed to engage children and young people targeted transition support can have a very different outcome, occasionally professionals feel that due to previous lack of engagement that young people and their families will not work effectively with transition processes and targeted work, we have	Thank you for your comment. The Committee emphasised throughout development the importance of ensuring the young person is at the centre of their care and support. This is referenced explicitly in recommendations 1.1.1, 1.1.4, 1.2.4 (which was updated to this end, following discussion at Guideline

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				often found this not to be the case. It is important for young people and their families to develop a relationship of trust with lead professionals, this will take time and consistency.	Committee meeting 12), 1.2.10 and 1.2.19.
Walsall Healthcare NHS Trust	Full	General	General	As a Case Manager in a Health Transition Team I feel we implement this approach well, it would be good to be able to share our experiences and learning where possible. We were mentioned in the NHS confederation report (2012) "Children and young people's health and well-being in changing times" as an example of good practice and have been nominated for previous national awards for our work in transition and engagement with young people (highly recommended at the HSJ). More recently we have employed young people as healthcare apprentices who can relate to the needs of those we work with.	Thank you for your comments which will be considered as part of the work to support implementation of the guideline.
Wargrave House School	Full	General	general	General comment: the recommendations proposed to be undertaken by providers would pose no problems for our service and would be welcomed if formalised.	Thank you for your comment and support for the recommendations.
Wargrave House School	Full	General	general	We would be willing to share our processes, internal structure in place to achieve positive transition outcomes and experiences if required.	Thank you for your comment and willingness to support implementation of the guideline by sharing your experiences and protocols.
Wargrave House School	Full	General	general	The young person themselves, in terms of easy read resources and explanation of the process (we always ensure that the information provided to our service users is in a format they will understand, and where understanding is limited, seek to inform on an individual basis with involvement of families / carers and advocates. All stakeholders would need to be considered.	The Committee agreed that it will be important for people using services and their families to be clear about what this guideline means they should expect from services. NICE produce a version of the guideline for people who use services and the public.
Wargrave House School	Full	General	general	Formal transition planning at Wargrave House School begins at age 14.	Thank you for your comment. The Guideline Committee considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility

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					for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are.
Wargrave House School	Full	General	general	Review meetings take place at least annually but more frequently if there is a change of need or the child is Looked After.	Thank you for your comment. The Guideline Committee reviewed the recommendations on timing and review (under section 1.2) at Committee Meeting 12 (04.11.15) and agreed the edited wording now found in recommendation 1.2.4.
Wargrave House School	Full	General	general	Parents of children at our provision are fully involved at all stages. They are the best advocates for the young person and their views are sought regularly about their aspirations for their child, both formally and informally.	Thank you for your comment. The Committee emphasised throughout development the importance of ensuring the young person is at the centre of their care and support and involved throughout transition. This is referenced explicitly in recommendations 1.1.1, 1.1.4, 1.2.4 (which was updated to this end, following discussion at Guideline Committee meeting 12), 1.2.10 and 1.2.19.
Wargrave House School	Full	General	general	There should be little impact on the cost of our services as transition planning systems are already in place.	Thank you for your comment which will be considered as part of the work to support guideline implementation.
Wargrave House School	Full	General	general	We can only envisage an increase in cost from the social care sector, particularly for those authorities who do not currently operate a named keyworker system.	Thank you for your comment which will be considered as part of the work to support Thank you for your comment which will be considered as part of the work to support guideline implementation.
Wargrave House School	Full	General	general	We can envisage that the cost saving will come with the timely and appropriate placing of young people in adult services that meet their needs, ie efficiency savings. In our opinion, the time put into identifying and acquiring appropriate provision should ensure improved success and better outcomes for the individual.	guideline implementation.Thank you for your comment which will be considered as part of the work to support guideline implementation.

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West Sussex County Council	Full	General	General	The recommendations for these guidelines set out a clear and common sense approach to transition for young people moving between Adult's and Children's services. There are areas which will be challenging to implement and these will require effective cooperation between Local Authority departments and partners. There are areas where there should be greater clarity on who the recommendations apply to, in particular when recommending that one organisation should involve another e.g. involving Primary Care in transition planning, it should be emphasised that it is equally important for both organisations to engage with the process.	Thank you for your comment which will be considered as part of the work to support
West Sussex County Council	Full	General	General	There is no reference to therapeutic services in the guidance. e.g. Occupational Therapy. There is a cohort of young people not known to social work professionals who may be in receipt of Occupational Therapy but who may not require a social care assessment until they are older. Engagement of therapy across health and social care and the transition across children to adults can be problematic particularly where SW and OTs are not working together as cohesively as they could. Some reference to joined up working in this area would be beneficial.	Thank you for your comment. The scope of this guideline was to establish the broad principles to follow with respect to care and support before, during and after transition and it was not possible, therefore, to reference all cohorts of young people that would be covered by the guideline. The Guideline Committee did, however, reflect on the issue of young people with complex health needs, at Guideline Committee meeting 12 (04.11.15) and agreed an additional recommendation was needed, to emphasise the need for integrated working to support this group (recommendation 1.5.10). The need for practitioners to work in a cohesive way more broadly is addressed by over-arching recommendation 1.1.5 which also includes some examples of how this could be achieved.
West Sussex County Council	Full	14	20	There could be potential conflict here with the duty in the Care Act to provide independent advocacy in relation to the assessment process for people who need support to understand the process. Guidance should be clear about what sort of advocacy the	Thank you for your comment. The Committee were mindful of the provisions of the Care Act and sought to build on, rather than replicate these. The recommendation aims to allow flexibility at the local level.

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				named worker should undertake. i.e. It would not be the role of a Children's Social Worker to provide advocacy around the adults assessment process.	
West Sussex County Council	Full	14	23	Involving primary care in any form of planning where there is no acute medical need is challenging. GPs in particular are usually very reluctant to attend multi-disciplinary meetings unless there are acute needs or safeguarding concerns. Guidance should also place an emphasis on the need for Primary Care to engage with transition planning.	Thank you for your comment. The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).) to emphasise the importance of their involvement, and help to encourage this.
West Sussex County Council	Full	16	25	West Sussex County Council has Prevention Assessment Teams, whose role is to work with customers who do not appear to meet the eligibility for funded social care provision to assess needs and support them with information advice and short term support to assist them to overcome particular issues. This includes young people known to Children's Services who my not meet the eligibility for funded adult social care.	Thank you for your comment. The Committee recognised the need to ensure that young people do not "fall through the gap" where they are not eligible for support when they reach adult services, or services are not available. This informed recommendations 1.5.5, 1.5.6 and 1.5.7.
West Sussex County Council	Full	17	23	There may be issues around consent and/or mental capacity for young people over 16. This guidance needs to be consistent with the Mental Capacity Act and discuss best interest approaches for young people who lack capacity.	The Mental Capacity Act is now referenced explicitly in recommendation 1.2.20. There will also be reference to the MCA in the full guideline text available on the NICE website when the guideline is published. For an example from another social care guideline, see below: https://www.nice.org.uk/guidance/ng22/chapter/recommendations which links to https://www.nice.org.uk/about/nice-communities/public-involvement/your-care
West Sussex County Council	Full	18	11	Facilitating folders in a large variety of formats could be challenging for case recording systems. This information will only be valuable if it can be effectively	Thank you for your comments. Please see the implementation chapter which provides examples of how to overcome some of the challenges related to

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				transferred between Children's and Adults' services.	implementation. In particular, there is a section on joint planning, development and commissioning of services involved in transition across children's and adults' health and social care.
West Sussex County Council	Full	19	20	It is not entirely clear what this means. It this in relation to Commissioned Services vs Direct Payments? This is likely to be challenging in practice. Changing mechanisms of care delivery is often bureaucratic. This is likely to be particularly challenging for young people with complex needs.	Thank you for your comment. The Guideline Committee agreed that this was not clear and agreed to edit this recommendation so that it now reads 'different ways of managing their care'.
West Sussex County Council	Full	19	27	Engaging primary care in transition planning can be challenging. Emphasis should also be placed on the need for primary care to be proactive in engaging with transition planning when this is requested.	Thank you for your comment. The Guideline Committee discussed the role of GPs in meeting 12 (04.11.15) taking into account your comments. They agreed that GP involvement is critical and, to this end, have made more explicit reference to GPs throughout the guideline (see recommendations: 1.1.8, 1.1.9, 1.2.4, 1.2.6, 1.2.7 and 1.4.1).).
West Sussex County Council	Full	20	17	This could be challenging in practice and not something that Local Authorities would find be able to enforce.	Thank you for your comment. The Guideline Committee considered all recommendations aspirational but achievable, although recognised there may be implementation challenges in some cases.
West Sussex County Council	Full	20	19	This is current practice, however, this may not always be possible due to staff turnover, sickness etc.	Thank you for your comment on recommendation 1.4.4 which will be considered as part of work to support implementation of the Guideline. The Guideline Committee reviewed recommendations and considered them aspirational but achievable.
Youth Justice Board for England and Wales	Short	General	General	**General Comments/Background** The YJB oversees the youth justice system in England and Wales and is responsible for monitoring the performance of youth justice services, including multi-agency Youth Offending teams (YOTs), and	Thank you for your comment which provides useful background. There is a research recommendation on transition where young people are in young offenders' institutions.

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				commissioning secure accommodation providers. Youth Offending Teams' (YOTs) main aim is to prevent offending and reoffending by children and young people in their area. There are 157 YOTs across England and Wales and they are managed by their local authority. The YJB commissions secure places across four under-18 young offender institutions (YOIs), three secure training centres (STCs) and nine secure children's homes (SCHs) to ensure there are sufficient places to meet the demand decided by the courts. There are currently around1000 children and young people held in secure youth justice settings across England and Wales. The YJB strongly believes that the secure estate for young people should be distinct from the adult system in order to specialise in addressing the specific needs of young people and to focus on their safety and wellbeing. The point of transfer from youth to adult justice services is a critical time for a young person and for the justice professionals who must ensure that the young person's health and welfare are properly safeguarded and that any risks they pose to the public are minimised. We have created our own framework to provide advice to those who manage young people transitioning to adult services. With this in mind, the YJB has provided a response based purely on the transitions of services for those within the criminal justice system (CJS) and have answered the questions relevant to our processes and responsibilities.	

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Youth Justice Board for England and Wales	Short Short	General 13	 1.5.8	**Question 1: Which areas will have the biggest impact on practice and be challenging to implement?** Children and young people within the CJS are likely to require multiple service transitions based on their more complex needs. Each requires good management and co-ordination by the agencies involved. The consultation document does not make any reference to transitions for children and young people within the criminal justice system despite them being a specialist group of individuals, especially due to their potentially complex transition. Serious incidents such as self-harm occur in the highest numbers at ages 17-18 and also re-offending rates are at their highest for 18-24 year olds. It is therefore vital that the transitions across all services are well managed to reduce any serious risks and to have a positive impact on the individuals involved. Information must be kept up to date and shared in a timely manner before the transfer takes place. It is important the information is understood by the receiving parties so that they can easily identify and address what the risks and key issues are. Understanding the gap in services from youth to adult services for children in the CJS is a challenge for Youth Offending Staff. Young people within the CJS are used to extended support and may become more at risk or vulnerable if specific services they have been accustomed to are no longer available.	Thank you for your comments which will be considered as part of the work to support guideline implementation. There is a research recommendation on transition where young people are in young offenders' institutions.

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Youth Justice Board for England and Wales	Short	General	General	**Question 2: What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)** The Youth Justice Board in conjunction with the National Offender Management Service (NOMS) have developed a framework for managing the transition of young people from youth to adult justice services in the community – Y2A Transitions Framework. [further information can be provided if requested] An example of good practice to understand the service gap has been developed by Oxfordshire Youth Offending Service (YOS) and Thames Valley Probation. The two services conduct joint workshops to: • Understand each other's service and systems • Increase understanding of how to engage with young people. The workshops both look at the differences and consider the similarities between the services. Group exercises include case studies on information transfers and YOS and probation workers consider the current transition arrangements with a view to promoting good practice.	Thank you for your comments and signpost to good practice examples which will be considered as part of the work to support guideline implementation. There is a research recommendation on transition where young people are in young offenders' institutions.
Youth Justice Board for England and Wales	Short	General	General	**Question 3: What are the key audiences we need to consider in structuring the guideline?** It is important that the multi-agency staff involved in the transition (Youth Offending Services, National Probation Services and Community Rehabilitation Companies), the children and young people	Thank you for your comments which will be considered as part of the work to support guideline implementation. There is a research recommendation on transition where young people are in young offenders' institutions.

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				themselves, as well as their families (if they are a positive influence in their life) are clear about the transition process. This is particularly important for those with complex needs which often includes mental health or behavioural issues. The transition from youth to adult justice services can be a traumatic enough experience for the individuals involved. While this always needs to be well managed, for those with additional health and social care needs it becomes even more complex. **Recommendation 1.2.1** - Reference to a named worker - for individuals within the CJS this should be their YOT worker as they will have already built up a relationship and plan with the young person and will understand their individual needs.	
Youth Justice Board for England and Wales	Short	General	General	**Question 4: At what age does transition planning start now?** Transfer to adult services should not be a sudden and unplanned event. A young person's sentence length will determine whether transitional arrangements need to be put in place. These may be written into a young person's sentence plan, and therefore be in place at the beginning of the young person's sentence/order to ensure they are fully integrated. The transition plan will consider the individual's maturity and risk factors in order to safeguard the young person, minimise risk to the public, and reduce reoffending. For individuals within the YJS, our protocols recommend that a plan is in place at least 6 months before the transition of services at 18 years. While a child may be	Thank you for your comment. The group considered carefully whether or not to define an age threshold for transition and agreed that the terminology used in recommendation 1.2.1 - 'year 9 (age 13 or 14 - at the latest' allowed some flexibility for practitioners to start earlier, while also helping ensure that transition for young people not covered by legislation would be considered as early as for those who are. There is a research recommendation on supporting transition when the young person is in a Young Offenders' Institute.

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				chronologically 18 years old, they all mature at different rates and services therefore need to operate in line with an individual's rate of maturity and social development to ensure they are effective in addressing their individual needs.	
Youth Justice Board for England and Wales	Short	General	General	**Question 6: How should parents be involved in transition planning?** Transitions can be a fragile time for the young person and it is therefore of great importance to keep the young person and their family – if they are part of their positive support network - informed about the process, and what can be expected when the transfer of responsibility has taken place. Young people's services can often be far more supportive than adult services and the individuals involved need to understand what to expect in this next phase of their journey. For those children who have previously been in care/looked after, they may be subject to increased risks and will be entitled to further support from children's services in the form of a pathway plan outlining the level of continued engagement with the local authority.	Thank you for your comment which provides useful context. Recommendations related to parental involvement were considered again as part of the discussions at Guideline Committee meeting 12, following consultation (04.11.15). The Committee agreed that these should be strengthened and, to this end: - referenced involvement of parents and carers in recommendation over-arching recommendations 1.1.4 - referenced involvement of parents and carers in recommendation 1.2.4 about annual review - referenced the need to ask a young person regularly about parental involvement in recommendation 1.2.19, to recognise that their views and preferences may change over time - referenced capacity explicitly in recommendation 1.2.20 - referenced involvement of parents and carers in recommendation 1.3.7 about information provision.
Youth Justice Board for England and Wales	Short	General	General	**Question 9: Will any of these recommendations lead to cost savings?** In the spirit of invest to save, the investment in active inter-agency (youth to adult) transition planning will potentially save on costly acute services further down the line. Poor transition pathways could result in the	Thank you for your comment which will be considered as part of the work to support guideline implementation.

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				young person becoming increasingly vulnerable, meaning they will require a much higher degree of health and social care support, along with any additional victims of crime.	