**Transition from children’s to adults’ services – update (2023)**

**Stakeholder consultation comments and responses**

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| ID | Organisation name | Question number | Comments | Response & actions |
| 1 | Association of Paediatric Emergency Medicine (APEM) | General  | We feel that involvement of urgent and emergency care is lacking from the standards, and strongly feel that where services are mentioned, urgent and emergency care units should be included. For example, engagement with adult services may be improved by exploring unplanned attendances to emergency care units and liaising with clinicians to ensure that this is discussed with the young person when they attend (Standard 6, opportunities to engage).  | Thank you for your response. The quality standard covers all health, mental health and social care providers and gives examples of roles that may be involved in developing the transition plan, but it is not a comprehensive list. We expect that local areas will agree which services and clinicians should be involved and this may vary depending on the specific needs of the young person. |
| 2 | Communication Matters (ISAAC UK Ltd) | General | **Appendix A****Recommended standardised communication template content**Key information to be included in a standardised communication template to be attached to an Education, Health and Care Plan (EHCP) to support transition(s). This information is solely focused on use of Augmentative and Alternative Communication (AAC) for communication and does not include information that will be elsewhere in the EHCP documentation.* The most effective way to greet the individual, which could include options like a simple greeting, tactile cues, symbols, or specific objects of reference.
* Information on sensory preferences, e.g., tactile defensiveness or sensitivity to sound.
* Details of other sensory impairments impacting communication e.g., hearing impairment and impact: aided/non-aided, types of hearing aids, lip-reader. Visual impairment and impact: glasses/no glasses, use of magnifier etc. Include details of audiology service and ophthalmology service.
* Tools employed for communication with accompanying photos, to include:
	+ Paper based resources including symbol languages.
	+ Powered systems including symbol languages and text language(s), named hardware, and named software/apps.
	+ Partner assisted communication methods e.g., translation of spoken word (dysarthric speech), scanning, etc.
	+ Personal communication methods e.g., signing, body language, gesture, facial expression, eye movements.
	+ How to establish a non-verbal yes/no for quick communication.
* Information of ownership/supplier of AAC resources used in education:
	+ NHS Specialised services (date last assessed/due)
	+ Local AAC team (date last assessed/due)
	+ Local authority (date resources purchased/review needed)
	+ School (date resources provided/review needed)
	+ Family/charity
* Copies of letters or prescriptions for AAC resources.
* Confirmation of AAC resources and support noted in Section F of the EHCP
* Information about any mounting system with photographic documentation.
* Backup copies of paper-based communication systems e.g., alphabet cards, communication board, etc.
* Copy of existing communication passport used in school.
* Video of young person using the communication system to help adults’ services understand personalised communication methods. Appropriate permissions will need to be established for these to be shared.
* Information on hardware warranties, insurances, and supplier details for troubleshooting, plus details on how to charge, maintain and back up powered devices.
* Information on software/app licences, passwords and supplier details for trouble shooting.
* Training needed for communication partners at an essential personal level and for more generalised interactions. For instance:
	+ Who currently programmes, or updates, vocabulary on both paper based and powered AAC resources?
	+ Who currently takes responsibility for troubleshooting issues with AAC resources, day to day, overnight, weekends and holidays?
	+ Who currently trains communication partners?
* Information around self-advocacy and advocacy needs. This should include:
	+ Details of any planning required for all meetings e.g., providing agenda and areas for discussion in advance to allow for the individual to process questions and plan appropriate responses.

Who is normally invited to a meeting to support the individual’s communication (when needed). | Thank you for this additional information. |
| 3 | Communication Matters (ISAAC UK Ltd) | General | **Definition****AAC** is short for Augmentative and Alternative Communication. AAC is a range of strategies and tools to help people who struggle with speech. These may be simple letter or picture boards or sophisticated computer-based systems. AAC helps someone to communicate as effectively as possible, in as many situations as possible. AAC also includes the use of body language, signing, facial expression, and eye movement to communicate. | Thank you for this additional information. |
| 4 | Derby and Derbyshire Integrated Care Board | General | We also felt to keep the quality standard in line with the integrated care agenda that we also needed to look more widely than just healthcare, we accept that NICE quality standards are healthcare focussed but felt on this specific one we needed to be more inclusive of the wider system. | Thank you for your response. The scope of the quality standard includes health and social care services. We have amended the wording throughout the quality standard to ensure social care is included. |
| 5 | Duchenne UK | General | The quality standard does not mention travel, even under equality and diversity considerations. In the Duchenne muscular dystrophy community, young people will begin to require the use of a powered wheelchair and ventilation in their late teens and early twenties. If they live in a part of the country where transitioning to adult services means they have to travel more, that would be a significant barrier to care. This need to accommodate for complex travel needs should be stipulated to service managers, in addition to examples such as communication boards.In addition, considerations for EDI and comprehensive access to this standard need to go beyond neuro-cognitive and behavioural considerations to include often unheard or underrepresented members of the community. People from lower socio-economic backgrounds, those rurally located, people living in digital poverty, ethnic minorities or families without English as a first language are known to be more difficult to engage in medical services and to trust in care delivery. These issues need to be addressed by the proposed care/transition coordinators to explore individualised ways to develop coordinated, implemented transition plans and attendance/engagement at clinical appointments in adult services. | We have added an equality consideration to ensure young people’s travel needs are considered when deciding whether the annual meeting should take place in person or virtually (statement 3) and when deciding on the format for the introductory meeting with adults’ services (statement 5). Statement 6 also highlights that practitioners should consider any specific needs relating to disability or where someone lives when working with young people who have not attended their initial meetings or appointments in adults’ services. They should consider if reasonable adjustments can be put in place that will encourage future attendance.There is also an existing equality consideration in statement 2 that highlights that transition support should take into account the young person’s: maturity; cognitive abilities; psychological status; needs in respect of long-term conditions; social and personal circumstances (including culture and beliefs); caring responsibilities and communication needs.  |
| 6 | Duchenne UK | General | DMD Care UK is a Duchenne UK initiative translating the international recommendations for standards of care in Duchenne muscular dystrophy (DMD) into a UK context. The project brings together clinical experts and patients in a series of working groups, each group representing a different area of care relevant to DMD patients; for example cardiac, emergency care, or physiotherapy. There is a transition working group currently active developing transition guidelines specifically for DMD with a completion date expected in 2026. Each working group is tasked with reviewing their area of the international standards of care, current practice in the UK and making clinical recommendations in consultation with the wider North Star network (a network of expert DMD clinicians). The working groups will also work to raise awareness of the standards of care and disseminate the recommendations and the rationale behind them. Working with professional bodies for endorsement and input, the WGs ensure acceptance, feasibility and increase adherence for each guideline. Where appropriate, the outputs are written up as papers for publication in peer-reviewed journals (ref cardiac and resp). Where further evidence is needed to support or develop a guideline, the working groups will help to formulate and support research activities.You can learn more about DMD Care UK, the international recommendations published in The Lancet Neurology in 2018, and the transition working group here: https://dmdcareuk.org/ | Thank you for this additional information. |
| 7 | Faculty of Pharmaceutical Medicine | General | Much of the care given during the day involves schools, there appears to be no consideration of the involvement of schools in the strategy.Many rare disease patients are involved in research, which is increasingly of a decentralised nature how will the need for research be integrated into the strategy. | Thank you for your comments. To clarify, the scope of the quality standard includes health and social care services but does not include education for those without an education, health and care plan. We have recognised that the transition plan in statement 2 will be part of a broader plan for young people covered by health and social care or education legislation. The focus of the quality standard is on identifying areas for quality improvement rather than research. |
| 8 | Metabolic Support UK | General | 1. NCEPOD (2023). The Inbetweeners. Available from: https://www.ncepod.org.uk/2023transition/The%20Inbetweeners\_summary%20report.pdf
2. NHS National Services Scotland. Inherited metabolic disorders: Adult and paediatric, National Services Scotland. [online]. 2023. [cited 9 June 2023] Available from: <https://www.nss.nhs.scot/specialist-healthcare/specialist-services/inherited-metabolic-disorders-adult-and-paediatric/#:~:text=Inherited%20metabolic%20disorders%20(IMD)%20are,that%20result%20in%20metabolism%20problems>.
3. Guy’s and St Thomas’s NHS Trust Foundation. Overview: Inherited metabolic diseases (IMD), NHS choices. [online]. 2023. [cited 9 June 2023] Available from: <https://www.guysandstthomas.nhs.uk/our-services/inherited-metabolic-diseases-imd>
4. Evelina. Metabolic diseases, NHS choices. [online]. 2023. [cited 12 June 2023]. Available from: <https://www.evelinalondon.nhs.uk/our-services/hospital/inherited-metabolic-diseases/overview.aspx>
5. Stepien et al. Challenges in Transition From Childhood to Adulthood Care in Rare Metabolic Diseases: Results From the First Multi-Center European Survey. Frontiers in Medicine. 2021; 8.
6. DOHSC. Policy Paper The UK Rare Disease Framework. [online]. 2021. [cited 22 August 2023]. Available from: <https://www.gov.uk/government/publications/uk-rare-diseases-framework/the-uk-rare-diseases-framework>
7. NHS Wales. Wales Rare Diseases Action Plan 2022-2026. [online]. 2022. [cited 31 August 2023].Available from: <https://executive.nhs.wales/networks/implementation-groups/rare-diseases/wales-rare-diseases-action-plan-2022-2026/>
 | Thank you for this additional information. |
| 9 | Metabolic Support UK | General | **Age threshold:** It is good that the age of transition is flexible, however, this flexibility can cause issues in that in some centres the patient may be treated under paediatric services whereas in others they’d be recognised as an adult.**Transition and rare disease:** There is a lack of focus onhealthcare transition within The UK Rare Disease Framework (6), with only the Welsh action plan producing tangible actions to improve this any tangible actions to improve this process (7). As we have explained throughout, our communities face significant issues in periods of transition so more work should be done to ensure NICE quality standards are reflected in these policy documents that are so vital to shaping services for those living with rare diseases. | Thank you for your comments. We note your concern about flexibility in the age of transfer to adult services: the quality standard recognises the importance of reflecting the young person’s individual needs as well as the need to coordinate across services so that the young person is not transferring at different ages in different services.We have shared your feedback on the UK Rare Diseases Framework with colleagues in the Department of Health and Social Care. |
| 10 | NHS England | General  | **Quality statement 1: Young people who will move from children’s to adults’ services start planning their transition with health and social care practitioners by school year 9 (aged 13 to 14 years), or immediately if they enter children’s services after school year 9*** Beginning transition process earlier and ensuring that this is a joint process between health and social care should enable increased planning and allow time to identify the correct services and support to take place and also link into any education plans that would be in place such as EHCP.
* We agree that there needs to be nationally agreed age limits by which transition planning should start, but we suggest consideration around the need to transition plan when discharge would be expected prior to 18

**Quality Statement 3: Young people who will move from children’s to adults’ services have an annual meeting to review transition planning*** Has the option been considered of a minimum of an annual meeting but more frequent if the child's needs indicate a risk needing more frequent review?
* How would this work with an EHCP – would a EHCP annual review be the best placed to do this if the young person has an EHCP?
* We think building into existing processes would be the most sensible thing to do here. Does the research show any benefit in increasing frequency of meetings as young people get closer to transition age but again this could align with existing processes, noting that it won’t always be obvious if children will move from children to adult’s services though.

**Quality statement 5:** **Young people who are moving from children’s to adults’ services meet a practitioner from each adults’ service they will move to before they transfer.*** This is happening more and more in hospitals for specialisms but not community services. It can be a challenge with adult service engagement as there is not equivalent roles and usually back to the GP who is the constant professional.
* It can be a challenge to get relevant adult services engaged at an early stage including limitations around contracts; expectations that SENCOs will lead the transition process which is not always be realistic (including SENCOs will not be involved with children who do not have an ECHP but who need transition pathway); alignment with CHC processes.
 | Thank you for your comments.Please note that this was a partial update of the quality standard which did not include statements 1, 3 & 5. In response to the specific issues raised please note:* There are no recommendations in the NICE guideline on transition (NG43) on the age of transfer to adult services. The recommendations suggest that this should be flexible to reflect the young person’s individual needs as well as the need to coordinate across services so that the young person is not transferring at different ages in different services. This is reflected in the quality standard.
* The rationale for statement 3 recognises that for some young people, the meetings may need to be more frequent than annually, depending on their individual needs.
* The quality standard recognises that some young people will have an EHCP and therefore processes will be in place that meet the requirements in the quality statements.
* We have highlighted the importance of involving the young person’s GP throughout the quality standard including within statement 5.
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| 11 | NHS England | General  | Is there any scope to include a quality measure about the child/family knowing who the person is, what to expect from the role and be able to contact them? | Please note that this was a partial update of the quality standard which did not include statement 4. We have not added any measures but outcome a) is focussed on the young person’s satisfaction with planning for transition and transfer (including their involvement). |
| 12 | NHS England | General  | It is helpful on page 6 to have this reference but there is no link/reference to the legal requirements and the specificity on what they are.  | Please note that this was a partial update of the quality standard which did not include statement 1. A link to the Childrens and Families Act 2014 is included in the source guidance for this statement, NICE’s guideline on transition NG43.  |
| 13 | NHS England | General | We suggest the guidance replaces terms ‘young people with learning disabilities or developmental needs’, to ‘young people with a learning disability or neurodevelopmental needs, or both’. | Thank you for your suggestion. We have amended the wording in statements 1 and 2. |
| 14 | NHS England | General | We think there should be some specific focus upon groups that will have additional needs that will have to be met in a co-ordinated fashion including those in out of area placements.  | Thank you for your comment. The equality and diversity consideration section highlights a range of factors that could lead to additional needs that should be taken into account when developing a co-ordinated transition plan. |
| 15 | NHS England | General | In general, it’s a positive move to have quality standards in this area and reflects our concerns as to the disjointed nature of transitions, particularly for autistic adolescents, and the risks that they are left with. We do caution that these standards implicitly assume that a transition will occur, so we welcome a focus on current provision for transition.  | Thank you for your comment. We confirm that the quality standard covers all young people (aged up to 25) using children’s health and social care services who are due to make the transition to adults’ services. |
| 16 | RCPCH | General | **References** 1. Sable C, Foster E, Uzark K, et al. Best practices in managing transition to adulthood for adolescents with congenital heart disease: The transition process and medical and psychosocial issues: A Scientific Statement from the American Heart Association. Circulation. 2011;123(13):1454-1485. doi:10.1161/CIR.0b013e3182107c56**.** 2**.** Stiefel M, Nolan K. A Guide to Measuring the Triple Aim: Population Health, Experience of Care, and per Capita Cost.; 2012**.** 3. Prior M, McManus M, White P, Davidson L. Measuring the “Triple Aim” in Transition Care: A Systematic Review. Paediatrics. 2014;134(6):e1648-e1661. doi:10.1542/peds.2014-1704 4. Sable C, Foster E, Uzark K, et al. Best practices in managing transition to adulthood for adolescents with congenital heart disease: The transition process and medical and psychosocial issues: A Scientific Statement from the American Heart Association. Circulation. 2011;123(13):1454-1485. doi:10.1161/CIR.0b013e3182107c56**.** 5. Colver A, Longwell S. New understanding of adolescent brain development: relevance to transitional healthcare for young people with long term conditions. Arch Dis Child. 2013;98(11):902-907. doi:10.1136/archdischild-2013-303945. 6. Borlot F, Tellez-Zenteno JF, Allen A, Ali A, Snead OC, Andrade DM. Epilepsy transition: Challenges of caring for adults with childhood-onset seizures. Epilepsia. 2014;55(10):1659-1666. doi:10.1111/epi.12752**.** 7. Gurvitz M, Valente AM, Broberg C, et al. Prevalence and predictors of gaps in care among adult congenital heart disease patients: HEART-ACHD (The Health, Education, and Access Research Trial). J Am Coll Cardiol. 2013;61(21):2180-2184. doi:10.1016/j.jacc.2013.02.048**.** 8. Sheehan AM, While AE, Coyne I. The experiences and impact of transition from child to adult healthcare services for young people with Type 1 diabetes: A systematic review. Diabet Med. 2015;32(4):440-458. doi:10.1111/dme.12639**.** 9. Heery E, Sheehan AM, While AE, Coyne I. Experiences and Outcomes of Transition from Pediatric to Adult Health Care Services for Young People with Congenital Heart Disease: A Systematic Review. Congenit Heart Dis. 2015;10(5):413-427. doi:10.1111/chd.12251. 10. Peter NG, Forke CM, Ginsburg KR, Schwarz DF. Transition From Pediatric to Adult Care: Internists’ Perspectives. Pediatrics. 2009;123(2):417-423. doi:10.1542/peds.2008-0740**.** 11. van Walleghem N, MacDonald C, Dean H. Evaluation of a systems navigator model for transition from pediatric to adult care for young adults with type 1 diabetes. Diabetes Care. 2008;31(8):1529-1530. doi:10.2337/dc07-2247**.** 12. Prestidge C, Romann A, Djurdjev O, Matsuda-Abedini M. Utility and cost of a renal transplant transition clinic. Pediatr Nephrol. 2012;27(2):295-302. doi:10.1007/s00467-011-1980-0. 13. Lugasi T, Achille M, Stevenson M. Patients’ perspective on factors that facilitate transition from child-centered to adult-centered health care: A theory integrated metasummary of quantitative and qualitative studies. J Adolesc Heal. 2011;48(5):429-440. doi:10.1016/j.jadohealth.2010.10.016**.** 14. van Staa AL, Jedeloo S, van Meeteren J, Latour JM. Crossing the transition chasm: Experiences and recommendations for improving transitional care of young adults, parents and providers. Child Care Health Dev. 2011;37(6):821-832. doi:10.1111/j.1365-2214.2011.01261.x**.** 15. Brodie L, Crisp J, McCormack B, Wilson V, Bergin P, Fulham C. Journeying from nirvana with mega-mums and broken hearts: The complex dynamics of transition from paediatric to adult settings. Int J Child Adolesc health. 2010;3(4):517-526. . 16. Okumura MJ, Kerr E a, Cabana MD, Davis MM, Demonner S, Heisler M. Physician views on barriers to primary care for young adults with childhood-onset chronic disease. Pediatrics. 2010;125(4):e748-e754. doi:10.1542/peds.2008-3451 | Thank you for this additional information. |
| 17 | Royal College of General Practitioners  | General  | As a significant number of children and young people with disability or long-term illness enter school late and subsequently undergo “repeated years” due to teacher-assessed needs, illness, or relocation, it would be suitable if all guidance was given in terms of age rather than school years although, a guide to approximate school year could be given after the age in parenthesis.  | Thank you for your feedback. We confirm that we have added details of age as an alternative to school age throughout the quality standard. |
| 18 | Royal College of General Practitioners  | General  | The concept of transition beginning at 14 years is purely historical, possibly based on “annual health checks for patients with learning disability” initially being offered at age 18 years with the criteria later being reduced to 14 years. However, there is limited validity of this. It is widely acknowledged that a child born with evidence of brain damage and a child diagnosed as insulin dependent diabetes will need transition of medical care in later life and that plans should be put in place as soon as possible. This offers reassurance to those adults caring for the child and, on occasions, the child and young person, that long term plans are being made. Equally, a 17 year old suffering brain damage from an RTA and a 17 year old developing severe asthma, need transition planning and both might be missed if the services (ideally the GP) fails to conduct regular 6 monthly/annual reviews of the practice population (as mentioned in the RCGP e-Learning). | Thank you for your feedback. We confirm that starting planning by school year 9 (age 13 or 14) is based on the NICE guideline on transition from children’s to adults’ services for young people using health or social care services NG43. Recommendation 1.2.1 makes it clear that for young people who enter the service after year 9 planning should start immediately.  |
| 19 | Royal College of Occupational Therapists (RCOT) | General | Examples of occupational therapy transition support [Transition Therapy Team | Solent NHS](https://www.solent.nhs.uk/our-services/services-listings/transition-therapy-team/) [occupational\_therapy\_transition.pdf (elft.nhs.uk)](https://www.elft.nhs.uk/sites/default/files/2023-03/occupational_therapy_transition.pdf) [How the Transition Team works with you - Surrey County Council (surreycc.gov.uk)](https://www.surreycc.gov.uk/adults/care-and-support/disability/preparing-for-adulthood/how-we-work-with-you#occupational) [Children's occupational therapy and physiotherapy :: Derbyshire Healthcare NHS Foundation Trust (derbyshirehealthcareft.nhs.uk)](https://www.derbyshirehealthcareft.nhs.uk/services/childrens-complex-health-derby-and-southern-derbyshire/childrens-occupational-therapy-and-physiotherapy) [Transition for Young Adults in Calderdale A4 (cht.nhs.uk)](https://plr.cht.nhs.uk/download/1104/Transition%20for%20Young%20Adults%20in%20Calderdale%20A4)   | Thank you for this additional information. |
| 20 | The Neurological Alliance | General  | **Reporting on the implementation and delivery of current and proposed quality statements.**Response data from our 2021/22 children and young peoples national neurological patient experience survey, My Neuro Survey, shared in response to this consultation highlight shortcomings in the delivery of some existing quality statements and other metrics that are relevant to existing and proposed quality statements.We recommend routine reporting on delivery against quality standards, including associated data sources, in a central and publicly accessible location to promote transparency and accountability. | Thank you for your comment. NICE ensures that data for the measures included in the quality standard can be collected locally. While we are aware that some areas and some national audits are collecting relevant data there is currently no shared national data source for transition. We are aware that NHS England are in the process of developing a national framework for transition with associated performance measures and data collection. |
| 21 | The Neurological Alliance | General | **Mental health and wellbeing support during transition from paediatric to adult services.** Children and young people affected by neurological conditions often report that their condition negatively impacts their mental health and wellbeing. In response to our 2021/22 children and young peoples national neurological patient experience survey, My Neuro Survey, 88% of respondents in England reported their neurological condition made their mental wellbeing much worse (55%) or slightly worse (34%). The transition from paediatric to adult services can also present additional challenges to young peoples mental health and wellbeing. As the parent or carer of a young person who responded to My Neuro Survey noted – “"with the transition to adult services it is extremely troubling to her anxiety levels.” Despite the significant impact of neurological conditions on the mental wellbeing of children and young people with a neurological condition, 52% of respondents to our children and young peoples survey in England reported not being asked about their mental wellbeing by a health or social care professional in the last three years. We would propose an additional quality statement focussed on ensuring young people are asked about their mental health and wellbeing during the transition process and referred or signposted to support through a matched care approach as necessary. | Thank you for your suggestion. Quality statement 3 advocates annual meetings to review transition planning, which should include reviewing a young person’s psychological status, as well as social and personal circumstances.  |
| 22 | The Neurological Alliance | General | **Supporting young people with rare conditions during the transition from paediatric to adult services.** Young people affected by rare conditions, including rare neurological conditions, may experience specific challenges during the transition period. The [England Rare Diseases Action Plan 2023](https://www.gov.uk/government/publications/england-rare-diseases-action-plan-2023/england-rare-diseases-action-plan-2023-main-report) highlights some of these challenges, with a specific focus on coordination of care, and notes planned work with NICE on this quality standard to understand how it could be adapted to ensure it is relevant to the needs of the rare diseases community. We would encourage the inclusion of additional information in this quality standard on how it should be adapted to support the specific needs of young people with rare conditions during the transition process. | Thank you for your comment. This partial update to the quality standard followed a listening event with representatives of the rare diseases community to discuss how the quality standard could better meet their needs. The feedback suggested that the quality standard was helpful but that it was also important to highlight the need to have a transition plan. This was therefore added to the quality standard. We have worked in partnership with DHSC to complete the action in the rare diseases action plan. |
| **Question 1 For draft quality statement 2: Does this quality statement accurately reflect a key area for quality improvement?** |
| 23 | Alder Hey Liverpool | Question 1 | Yes- however consideration needs to be given to 1. The number of service specialities the CYP is under the care of as they may require a healthcare transition care coordinator/keyworker. For any YP under the care of 3 or more specialities a coordinator/keyworker should be assigned
2. Service specific guidance around the age of transition needs to be considered. Some specialities may transfer the YP at 16 years, whilst other specialities who care for the YP may not transfer the YP until 18-19 years (Ie diabetes)

Clinicians need to be complaint completing transition planning with C&YP and documenting this to enable reporting to be accurate and meaningful | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard.The need for a named worker to coordinate care and support is included in statement 4.The definition for a co-ordinated transition plan in statement 2 notes that the plan should coordinate the age of non-statutory transitions to adults’ services, to ensure a consistent approach. |
| 24 | Alexion, AstraZeneca | Question 1 | We strongly agree with the rationale for establishing this statement covering the provision of co-ordinated transition plan for any person who will move from children’s to adults’ services, including the emphasis on planning needing to include all services and interagency teams providing support to the young person, as well as being agreed with the young person and their family and carers.We support the clear emphasis placed on a flexible and personalised approach to transition taken for each young person that caters for their individual needs and preferences, particularly in those instances where developmental or learning disabilities will often make care planning and changes more complex. Close and direct collaboration between different services and teams is critically important. We have observed this specific challenge within specific highly specialised services we have worked with resulting in different approaches to patient care and treatment being applied within the same national commissioned service across different centres based on localised policies. The Genetic Alliance UK report on [Coordinated Care](https://geneticalliance.org.uk/wp-content/uploads/2023/02/ONLINE-Coordinating-Care-Report-2023.pdf) highlighted the same difficulties that can be associated with variation in the age for transition between different services across different providers engaged in an individual’s care and how this impacts on their experience. Moreover, this report includes examples of the practical benefits of a Transition Coordinator within specific services, in line with the Quality Statement 4: access to a named worker to coordinate care and support before, during and after transfer.  | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 25 | ARC Scotland - Scottish Transitions Forum | Question 1 | Yes, this quality statement represents an area of Improvement and features in our Principles into Practice Framework and Principles into practice research publications.  | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 26 | ARNS | Question 1 | This quality statement accurately reflects a key area for quality improvement. All children and young people moving to adult services need to have a coordinated pan of how this will take place. | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 27 | Association of British Neurologists (ABN) | Question 1 | Yes the statement reflects an important aspect of transition care as frequently co-ordinated plans are not in place. Often there are “transfer” plans rather than transition plans in place. | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 28 | Association of Paediatric Chartered Physiotherapists | Question 1 | Yes, this is a key area for quality improvement. Having co-ordinated transition plans will set out clear responsibilities for both children and adult services and promote joint working of both services which is needed to improve transition. Currently there are significant gaps and inequity of access to services for young people and their families following transition. | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 29 | Association of Paediatric Emergency Medicine (APEM) | Question 1 | APEM strongly believes that a co-ordinated transition plan is a key area for quality improvement. We feel that urgent and emergency care providers must be involved in the transition plan, and we feel that this involvement should be clearly specified within the standards where any services are mentioned. Paediatric urgent and emergency care services have some unique issues related to transitioning from paediatric to adult services which we feel could be acknowledged. Particular examples include: 1. The cohort of young people who are cared for by some paediatric services for their long term problems but are not eligible for paediatric services for their unplanned care. e.g. children in the 14 – 17 year old age group may remain under the care of paediatric specialists at a regional unit or specialty area, but would not be accepted in a paediatric emergency department or critical care unit due to their age.
2. Children and young people who are transitioning or transitioned to adult care but remain the age to be accepted in a paediatric emergency department. Particularly in stand-alone departments, adult services can be anxious about crossing the gap between departments.
3. Children and young people who are classed as “frequent attenders” to urgent and emergency care, often with behavioural issues or mental health presentations that can present a risk to life. Unfortunately many of these children and young people are not under the care of a hospital clinician. Communication with adult emergency services is crucial during transitioning age to enable safe, joined up care.

We feel that written information is important for teams in urgent and emergency care to help families understand where the child or young person will be seen if they present with unplanned and planned care, and to ensure communication with adult services if they feel a child should be seen in the paediatric setting. | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard and for your suggestion. Although we have included examples of providers and practitioners who may be included in developing the transition plan, we would expect local areas to specify this based on service provision and the needs of the young person. |
| 30 | British Academy of Childhood Disability (BACD) | Question 1 | Yes absolutely we fully support this quality statement as a key area for quality improvement as it is essential for young people to have a coordinated transition plan put in place early.  | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 31 | British Association of Teachers of Deaf Children and Young People (BATOD) | Question 1 | British Association of Deaf Children and Young People (BATOD) feels the draft quality statement 2 “Young people who will move from children’s to adults’ services have a co-ordinated transition plan. [new 2023]” does accurately reflect a key area for quality improvement.Within education, particularly for deaf children and young people, will often have transition focus as part of their education, health and care plan (EHCp) annual review. BATOD members report Health is often under-represented at those meetings. BATOD members also highlight that there tends to be limited reports from Health colleagues submitted to those review meetings. Any co-ordinated transition plan should streamline with education to maintain the ‘tell it once’ approach and ensure effective multi-professional engagement. | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard.We have clarified in the rationale for this statement that the transition plan will be part of a broader plan for young people covered by health and social care or education legislation. |
| 32 | British Society of Physical and Rehabilitation medicine | Question 1 | **Statement 2 Young people who will move from children’s to adults’ services have a co-ordinated transition plan. [new 2023]**Yes : This is a key area. Please also add explicit the need to include adult services. Most of the Children’s health care organisations, do develop a co-ordinated transition plan from children’s services. Unfortunately the adult care providers are not included in transition planning. The meetings are all organised and attended by the Children services, with little or no representation from adult service providers. This is the key piece missing from the jig saw of transition. There should be a clear transition pathways based on requirements of young adults with complex needs such as neurological disabilities like Cerebral palsy, Complex respiratory disorder and Complex musculoskeletal disorders (e.g. congenital limb deficiencies) | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard.We have emphasised that adult services should be involved in developing the transition plan in the rationale for this statement. |
| 33 | Brittle Bone Society | Question 1 | Transition of care from paediatric to adult rare bone disease is a priority area for quality improvement. If you are seen in an MDT setting then yes the care needs to be co-ordinated. The only issue with this is when you are moving to adult services where there is no MDT – you can only coordinate up to a certain point.Quote from a young person “the process of transition from the kids services was great, I couldn’t understand what all the fuss was about. Then I had my first fracture – I couldn’t just ring up the physio to ask for advice. I had to go back to the GP wait for a referral at what point the issue was either going to get worse or go away on its own. I felt like I had nowhere to turn”I think it should also be noted that with Rare Conditions where children are not seen in an MDT setting due to the fact they do not fall under the HSS remit (of highly specialised or atypical) – I’m not sure who would actually coordinate this. It largely appears to be an AHP role, but often in adult services there is only the Consultant. | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard.We have emphasised the importance of involving the young person’s GP in transition planning in the definition of a co-ordinated transition plan and noted that this will be critical when the young person does not meet the criteria for specialist adult health services or there are no adults’ services in place. |
| 34 | Challenging Behaviour Foundation  | Question 1 |  The CBF welcomes the new standard; we fully support that this is a key area for quality improvement. The statement would be improved by the quality statement specifying the following legal duties: 1. **Care Act 2014 - Transition duties**

There is a legal duty under this legislation to complete a transition assessment for anyone likely to have needs for care and support when they transition to adult social care. A transition assessment should inform all transition care and support plans for any child or young person who is likely to require adult social care.  The transition assessment needs to be completed when it is of significant benefit to the young person or carer (Care & Support Statutory Guidance sections 16.6-16.15[[1]](#footnote-2)). We are a charity which represents family carers who have a family member with a severe learning disabilities and behaviour that could be described as challenging. Families frequently highlight the failure to plan transition ahead of time with delays to decision making resulting in crisis placements.It is unclear in the statement when transition plans and the timing of assessment are to be completed. This is extremely important for children with severe learning disabilities and/or behaviour that challenges and complex health needs. This is expanded upon further in the Care Act Statutory Guidance (section 16.6), which highlights that in more complex cases, it could take some time to carry out an assessment and plan and put care and support in place. Moreover, when transition assessments take place too late, and care support is arranged in a hurry, it can lead to care and support that does not best meet the young person or carer’s needs and runs the risk of being at a more significant financial cost to the local authority then if it had been placed correctly in advance (Statutory Guidance section 16.17). Due to this, we believe that the requirement to assess and plan i**n advance** for children and young people with complex needs should be reflected in the statement.  The statement also does not refer to carers’ (adult and young carers). This is important because it is a legal requirement that preparation for adulthood will not only assess how the needs of the young person may change as they start adulthood but also how carers’, young carers’ and other family members' needs might change (Statutory Guidance section 16.21). The statement would benefit-assessments and support for carers. 1. **Mental Capacity Act (2005)**

The statement would benefit from reflecting that some children and young people lack the capacity to make some (or all) decisions about their future care and support at transition. Children and young people who have severe learning disabilities and or behaviour that challenges or complex health needs are an example of a group of children and young people to whom this is likely to apply. This matters because young people within these populations may lack the capacity to make some decisions around transitioning, for example, it is common for a capacity assessment to decide that a young person with severe learning disabilities lacks capacity to decide where they live. As a result, these individuals must be presented with tailored support to assist them in making their own decisions. This is also a legal requirement, under the Mental Capacity Act (MCA) 2005 Principle 2, to provide support to assist decision making “A person must be given all practicable help before anyone treats them as not being able to make their own decisions. This means you should make every effort to encourage and support people to make the decision for themselves. If lack of capacity is established, it is still important that you involve the person as far as possible in making decisions.”Under principle 4 of the MCA 2005 best-interest decisions must be taken for young people who cannot make their own decisions. Family members must be consulted. The statement would benefit from an amendment to reflect the key points in the Mental Capacity Act 2005 that apply when a young person lacks capacity to make their own decision.  | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard.We have clarified in the rationale for this statement that the transition plan will be part of a broader plan for young people covered by health and social care or education legislation. As the quality standard includes all young people who will move from children’s to adults’ services we do not think it is appropriate to specify the specific legislation that will apply to specific groups of young people.Statement 1 in the quality standard makes it clear that transition planning should start from school year 9 (age 13 to 14 years). The process measure in statement 2 confirms that transition plans should be in place from school year 9 (aged 13 to 14 years).The quality standard includes descriptors for families and carers in all statements and emphasises their involvement in developing the transition plan. Statement 2 also highlights that transition planning should include all services and interagency teams providing support to the young person which will include support for young carers.We have added an equality consideration to statement 2 to highlight that service managers should ensure a range of support is available, and used, to help young people communicate effectively during discussions about the transition plan. This could include having a written record of how a young person prefers to communicate, such as a communication passport or 1-page profile, and using different ways to help the young person communicate, such as communication boards, digital communication tools and advocacy. |
| 35 | Child Growth Foundation | Question 1  | Yes. There are currently too many discrepancies with transition planning not only between different Trusts but between different services within a Trust. Having a co-ordinated plan would help to ensure that all patients receive the same high standard of transition care | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 36 | Children with Exceptional Healthcare Needs networkNSS CEN – NHS Scotland National Services | Question 1 | Yes but there is a need to define ‘coordinated’ with formal endorsement by each clinical and administrative service including ongoing adult services, and within healthcare including both Primary, Acute general, Secondary and Tertiary Care.Any process that aims to be person centred must include appropriate communication support for the young person and those who are their registered primary carers/guardians and universal access to authorised independent advocacy.The transition plan should be genuinely co-produced with the young person and their family/carers and not have them simply ‘involved’ in its creation. | Thank you for your comments.Statement 2 highlights that transition planning should include all services and interagency teams providing support to the young person. We have also highlighted the importance of working with the young person and their family and carers in the rationale and audience descriptors.We have added an equality consideration to statement 2 to highlight that service managers should ensure a range of support is available, and used, to help young people communicate effectively during discussions about the transition plan. This could include having a written record of how a young person prefers to communicate, such as a communication passport or 1-page profile, and using different ways to help the young person communicate, such as communication boards, digital communication tools and advocacy. |
| 37 | Clinical Genetics Society | Question 1 | We agree that development of a concise transition care plan is helpful for children who will need input from adult healthcare services. However we would like to highlight that the content of this document is also clearly important and should be reviewed as part of quality improvement measures.For conditions with a genetic basis, it is important to ensure that age-appropriate information is provided to the young person at the appropriate time, including information about the condition itself, any associated health issues that may occur in adulthood, and information about reproductive options and choices where relevant. The proposed outcomes in the draft eg (a) would not currently capture whether the above information has been provided to the young person and their family. Instead data sources such as patient records would need to be interrogated in more detail to ascertain if this information has been provided.It should also be considered that for children under the care of Clinical Genetics, there is no transition to to an adult service, as geneticists see people of all ages; again what is important is that young people are appropriately informed of any implications from their diagnosis on their health in adulthood and reproductive risk and any reproductive options available to them. Again different outcome measures would be required to look at this aspect of transition other than those proposed in (b). | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard.The focus of this quality standard is on young people who will move from children’s to adults’ services. Young people who remain under the care of the same clinician regardless of age are not included.As the quality standard covers all health and social care services it cannot include all the specific detail that should be included in the transition plan. The equality considerations make it clear however that health and social care practitioners should ensure that transition planning is developmentally appropriate and considers each young person's capabilities, needs and hopes for the future, addressing their biological, psychological and social development in the broadest terms. Transition support should take into account the young person’s: maturity; cognitive abilities; psychological status; needs in respect of long-term conditions; social and personal circumstances (including culture and beliefs); caring responsibilities and communication needs. |
| 38 | Communication Matters (ISAAC UK Ltd) | Question 1 | Yes. It is crucial that children and young people who are Augmentative and Alternative Communication (AAC) users continue to have life-long ongoing support. The right to communicate is fundamental, it is a basic human right. Where a child or young person has an identified and/or an assessed need for AAC and/or speech and language therapy it is essential that must be coordinated with all appropriate services across health, education, and social care throughout life.Every child, young person and adult is unique. That means their communication needs are also individual to them. This need does not stop when they leave education, it is vital that specific communication need information is part of an individual’s transition plan so that adults’ services can continue to provide appropriate support. | Thank you for your comments.We have added an equality consideration to statement 2 to highlight that service managers should ensure a range of support is available, and used, to help young people communicate effectively during discussions about the transition plan. This could include having a written record of how a young person prefers to communicate, such as a communication passport or 1-page profile, and using different ways to help the young person communicate, such as communication boards, digital communication tools and advocacy. |
| 39 | Derby and Derbyshire Integrated Care Board | Question 1 | Children who don’t need to go onto adult services go back to primary care need to be included in a transition pathway. | Thank you for your comment.We have added information to the definition of a co-ordinated transition plan to make it clear the GP should be involved when care reverts to primary care. |
| 40 | Diabetes UK | Question 1 | Yes, many children and young people with diabetes and their families do not have positive experiences of transition and this can be due to lack of planning and coordination. This can have devastating consequences such as increased risk of diabetes related complications. National audits have noted an increased incidence of diabetes-related hospital admissions and a lower proportion of those meeting treatment targets amongst young people at transition age. Diabetes UK’s position is that children and young people should be at the centre of the transition process, and that they should be supported by healthcare professionals who are committed to working together to provide the care and support that children and young people need. This outcome measure would allow service users, healthcare professionals and commissioners to have a greater depth of understanding of the transition service they provide and the data would identify areas for service development and improvement.  | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 41 | Duchenne UK | Question 1  | Draft quality statement 2 states: “Young people who will move from children’s to adults’ services have a co-ordinated transition plan.” It proposes three quality measures; a) the proportion of young people who were satisfied with how their transition went, b) the proportion of young people who do not attend their initial meetings with adults’ services, and c) the proportion of young people who continue to engage with services.Duchenne UK believes this quality statement does reflect a key area of quality improvement. We believe a transition plan is crucial in helping children and young people, as well as their family, carers and clinicians, navigate transition. However, in conversations with our community, and clinicians, we know that sometimes a plan is not produced at all. Recommending a transition plan, and measuring the success and failure of that recommendation, would help ensure that a plan is put into place, and give an insight into whether that recommendation is being followed.  | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 42 | Faculty of Pain Medicine of the Royal College of Anaesthetists | Question 1  | Understanding of the differences in commissioning and provision of services is often poorly understood by both patients and staff. However, this could be a difficult piece of work for regional and supra-regional services, where local provision and age ranges may very from the centralised service A lot of work could be done to improve preparation for children using transition plan. This requires involvement of both children and adult services in a coordinated manner. A prepared plan is vital to the success of transition. | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 43 | Faculty of Pharmaceutical Medicine | Question 1 | Yes the standard does reflect a key area for quality improvement | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 44 | Genetic Alliance UK | Question 1 | Yes, we are pleased to see the addition of a statement specifically mentioning the need for a coordinated transition plan. It may be beneficial to add that there should be a named worker responsible for creating the plan, this could be the same named person identified in statement 5 who supports the transition process.  | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard.We have clarified in the audience descriptors that where a named worker is in place, they will coordinate the transition plan.  |
| 45 | Great Ormond Street Hospital (GOSH) | Question 1 | Yes. However, this has the potential to miss patients who may transition twice, firstly to adolescent services and then to adult services which has not been captured within the document.  | Thank you for your comment.The focus of the quality standard is on transition from children’s to adults’ services and we would expect this to include local service configurations. |
| 46 | Kent and Medway NHS and Social Care Partnership Trust | Question 1 | * The quality statement is too broad and does not provide clarity of what this actually means. Needs specificity and clarity. Also, who is co-ordinating?
* Why would you begin transition from year 9? This is far too early to effectively plan for transition to adult services given the huge changes (practically, physiologically, emotionally and developmentally) a young person will go through from age 13/14 to 18. The likelihood of still requiring mental health input 4 years later would surely be limited to a small proportion of the population. Likewise, surely, we should be empowering young people to equip them with tools to manage their own mental health wherever possible and not create dependencies on services?
* Is this holistic care planning or is this a formal transition process with adult services? Who leads on the coordinated transition plan? Would that be the link worker for CAMHS or AMHS?
* Where does Local Authority come in, especially in more complex cases? Where does the VCSE sector come into this? Parent/care involvement? Education involvement? SEND/LAC/UASC requires consideration
 | Thank you for your comments.As the quality standard covers transitions in all settings across health and social care the specific details about what is included, which services and practitioners are involved and who is coordinating will vary depending on the young person’s needs and will need to be determined locally. We have, however, added care coordinators to the list of practitioners in the audience descriptor for statement 2 and clarified that if a named worker (as per statement 4) is in place they will be responsible for coordinating the transition plan.This quality standard is focussed on young people who will need to transition to adult services because they are likely to have ongoing needs. For this population. evidence suggests that starting transition early (from year 9) is important, as highlighted in the NICE guideline on transition NG43. |
| 47 | Metabolic Support UK | Question 1 | Yes, this is a key area that needs significant improvement, particularly for children with long term, complex health conditions, with a recent report published by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) concluding that clear pathways when transitioning into adult services do not exist for this group (1). To give specificity to this issue, we will use ourselves and our communities as an example. [Metabolic Support UK](https://metabolicsupportuk.org/) are a charity that has, since 1981, supported people living with inherited metabolic disorders (IMDs). We have recently completed a research project labelled [‘Thoughts into Action’](https://metabolicsupportuk.org/news-and-events/thoughts-into-action-report/) (TIA), which aimed to understand the factors that people living with IMDs feel impact on their everyday quality of life, with six areas identified as important, one of which was transition.We agree with the rationale for statement two but must raise the issues faced when children move from specialist paediatric care to general care. Our research found that children living with IMDs often move from support under a specialist IMD service to a generalist service that does not have specialist knowledge and understanding of their IMD (4). This is often due to a lack of IMD specialists within the adult service (4,5). **Statement 2:** What if people come into care on cusp of transition as they won’t have a plan? Where do they sit and who makes the plan?**What should be done?*** **There must be a core piece of research to examine adult care provision with the outcome being a report with clear recommendations on how to improve these services:** If the adult services are not equipped to provide the expected degree of care/services then the transition process will always be rated as being a negative experience.
* **Patients/parents/carers need to be educated about what to expect from the transition to adult care:** There is often a need for these individuals to be confident advocates to ensure they are supported and if this education is not in place, individuals may fall through gaps in the system due to the adult services being vastly overstretched.
* **NICE must clarify who specifically will be responsible for developing transition plans:** Stating that “services should work together” could create ambiguity whereby no one service takes responsibility for developing the plan, meaning a plan will not be created, particularly in the NHS environment which is short on staff and resources.
 | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard and for your comments.We have added information to the definition of a co-ordinated transition plan to make it clear that primary care should be involved when the young person does not meet the criteria for specialist adult health services or there are no adult services in place. It is beyond the remit of the quality standard to suggest areas for further research.As the quality standard covers transitions in all settings across health and social care the specific details about what is included, which services and practitioners are involved and who is coordinating will vary depending on the young person’s needs and will need to be determined locally. We have, however, added care coordinators to the list of practitioners in the audience descriptor for statement 2 and clarified that if a named worker (as per statement 4) is in place they will be responsible for coordinating the transition plan.Providing support and information to young people and their families and carers during transition is included in statement 4 on having a named worker. |
| 48 | Midlands Partnership University NHS Foundation Trust | Question 1 | Yes  | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 49 | National Confidential Enquiry int Patient Outcome and Death (NCEPOD) | Question 1 | Yes. In the recently released NCEPOD report ‘[The Inbetweeners](https://www.ncepod.org.uk/2023transition.html)’ 99/192 (51.6%) organisations reported that there was an overarching transition policy and within this policy, 84/99 stated that all young people going through transition planning have a transition plan in place from early adolescence. However, case reviewers only found evidence in the notes for a transition plan being in place for all specialties involved in a young person’s care in 58/398 (14.6%) cases reviewed, for some specialties in 84/398 (21.1%) and not at all in 256/398 (64.3%) cases. Reviewers also found that in 53.9% of cases the involvement of the young person in their transition planning was poor or unacceptable. | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 50 | National Deaf CAMHS (North) | Question 1 | Yes. The number of young people remaining in the service at point of transition, or throughout the transition period is relatively low for National Deaf CAMHS. However, for CYP in the service, a comprehensive and well thought out transition plan is needed. Availability of specific services for deaf CYP are lower than mainstream services and are often located geographically distantly. Adult services for deaf people are sparse which could result in challenges when developing coordinated transition plans. CAMHS may have different thresholds to adult MH – how are gaps highlighted and acted upon? It is also not simply transitioning from CYP to adult services, it may often be transitioning from a specialist deaf children’s service to a mainstream adult service. This could result in increased anxiety for individuals and families once discharged from CYP services and may exacerbate mental health difficulties or impact ability to engage in services. Consideration of the potential for retraumatisation if plans are not thoroughly considered and if accessibility/communication needs are not met. Quality statements for different audiences, the equality impact statement includes a line about providing interpretation.  It needs to be more explicit in the main document to ensure information and communication is provided in an accessible format for the child, young person, parents/carers e.g. providing British Sign Language/English interpreters, spoken language interpreters, deaf intralinguals, including the translation of written information e.g. BSL videos.  The document references other NICE guidance but to our knowledge there are no NICE guidance about accessibility. Could references to Equality Act 2010 and NHS accessible standards be added to account for this. | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard and for your comments.We have added information to the definition of a co-ordinated transition plan to make it clear that primary care should be involved when the young person does not meet the criteria for specialist adult health services or there are no adult services in place. We have added an equality consideration to statement 2 to highlight that service managers should ensure a range of support is available, and used, to help young people communicate effectively during discussions about the transition plan. This could include having a written record of how a young person prefers to communicate, such as a communication passport or 1-page profile, and using different ways to help the young person communicate, such as communication boards, digital communication tools and advocacy. For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in [NHS England's Accessible Information Standard](https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/) or the equivalent standards for the devolved nations. |
| 51 | National Network of Designated Healthcare Professionals for Children | Question 1 | Yes, but it goes without saying that the quality of the plan is as important as the idea of having a plan in the first place. Poorly designed plans and/or those with ineffective leadership could easily be harmful to the vulnerable individuals that make up this cohort of concern. | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. We have highlighted the key components of the co-ordinated transition plan in the definition. |
| 52 | National Network of Parent Carer Forums | Question 1 | Yes | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 53 | National Organisation for FASD | Question 1 | Yes | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 54 | National Rheumatoid Arthritis Society | Question 1 | Yes. | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 55 | NHS England | Question 1  | * Yes, we do think this quality statement accurately reflects a key area for quality improvement. We know that there is variation in implementation across service providers and it could be beneficial for families to help manage the complex health and care landscape at transition. It will also help education providers in their support for families.
* We suggest clarity is needed on:
* how the coordinated transition plan relates to CYP with have an Education Health and Care Plan (EHCP) or Special Educational needs (SEN) support plan or a Continuing (Health) Care package of care. For those with EHCPs, the plan should speak to and form part of their preparing for adulthood EHCP.
* who is responsible for writing the plan. There is currently no mention of who will lead on the co-ordination and ensuring one version of performance around this. Unless this is stated, achievement may flounder and perceptions of whether a co-ordinated transition plan is in place may differ from service to service and by the child/family.
* For people who are in a mental health inpatient setting, we suggest an emphasis on a ‘multi-agency’ transition plan, given the likelihood of eligibility for EHCP, SEND, Care (Education and Treatment Review (under 25s)
* We suggest it is made clearer that it is important to undertake the necessary engagement with the individual child and family in the development of the transition plan and the key stakeholder to assess if a co-ordinated plan is in place is the child and family/carer themselves.

Yes – one weakness is children who are under 16 at point of referral but owing to delays in access to secondary care are then rejected by paeds as they are over the age of 16 when the first clinic appointment is made. No specific metric in the report around this as this is a common problem in primary care where no plan is in place and adult services have an even longer wait (eg. CAHMS) It would be useful to have this as a metric for systems to capture how many CYP are rejected owing to lack of capacity at point of referral.  | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard and for your comments.We have clarified in the rationale for this statement that the transition plan will be part of a broader plan for young people covered by health and social care or education legislation.As the quality standard covers transitions in all settings across health and social care the specific details about what is included, which services and practitioners are involved and who is coordinating will vary depending on the young person’s needs and will need to be determined locally. We have, however, added care coordinators to the list of practitioners in the audience descriptor for statement 2 and clarified that if a named worker (as per statement 4) is in place they will be responsible for coordinating the transition plan.We have highlighted the importance of working with the young person and their family and carers in the rationale and audience descriptors. We have included an outcome measure to assess satisfaction with planning for transition and transfer (including their involvement) among young people and their families and carers.The focus of this quality standard is on transition from children’s to adults’ services rather than access to children’s services. |
| 56 | NHSE Sheffield response | Question 1 | Yes. | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 57 | NHSE specialised commissioning | Question 1 | [Statement 2](#x__Quality_statement_1:_2) Young people who will move from children’s to adults’ services have a co-ordinated transition plan. **[new 2023]****Rationale** Having a transition plan that is co-ordinated across all services will make it clear when the care and support provided to a young person will move from children’s to adult services and how it will be delivered. Services should work together to develop a coordinated transition plan that is practical to implement and avoids creating gaps in services due to variation in the age for transition between different services. This will help young people and their families and carers to know what to expect and reduce uncertainty and stress.Q1 Response: The intent and spirit of this is good – it could mean that locally an identified team is aware of the different teams who are seeing the patient and the different transition plans that are in place for the patient including identified transfer dates and named sending and receiving consultant specialty members.However it is not clear how practical it will be to create and deliver on, and where the ownership for version control of the document and over care co-ordination of the transition lies. For example where a patient, say a child, has a number of complex diseases and may be seeing multiple clinical teams across (national) quaternary (highly specialised), (regional) tertiary (specialised), and local care (local neurologists and paediatricians who will be working with GPs, school nurses and community teams who are also delivering aspects of care.  | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard.As the quality standard covers transitions in all settings across health and social care the specific details about what is included, which services and practitioners are involved and who is coordinating will vary depending on the young person’s needs and will need to be determined locally. We have clarified that if a named worker (as per statement 4) is in place they will be responsible for coordinating the transition plan. |
| 58 | Nottinghamshire Healthcare NHS Foundation Trust | Question 1 | This is a key area for development and Improvement. The operational approach will be different in those organisations providing Community Care, as there will need to be links with internal and external stakeholders to achieve this.There also needs to be a systemwide approach to the plan to incorporate education and social care for those without an EHCP. | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard.To clarify, the scope of the quality standard includes health and social care services but does not include education for those without an EHCP. |
| 59 | NSA for PCC NHSE | Question 1 | Yes | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard |
| 60 | Paediatric Continence Forum | Question 1 | The Paediatric Continence Forum (PCF) agrees that this quality statement accurately reflects a key area for quality improvement. The rationale is particularly relevant for young people who need bladder and bowel services, as bladder and bowel health issues often affect and are affected by numerous different areas of their lives, including mental health, psychosocial wellbeing, education and employment. Therefore they impact services beyond healthcare, increasing the need for a coordinated approach to transitionResearch shows that transition from paediatric to adult bladder and bowel (continence) services can be poorly managed, and that mental health problems are often not assessed or treated, which could exacerbate existing symptoms and affect treatment adherence. It is important that adult services know that young people transitioning to adult care with bladder and bowel conditions are at an increased risk of mental health problems.The quality statement could be further improved by acknowledging more explicitly that the transition from children’s to adults’ services will vary on a patient by patient basis. Therefore, there must be flexibility and support throughout the transition process.  | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard.Ensuring transition support addresses the young person’s emotional health and wellbeing is included in the NICE guideline on transition (NG43) recommendation 1.1.4.We have highlighted in the rationale and definition for statement 2 that the transition plan should be developed specifically to meet the young person’s individual needs. |
| 61 | RCPCH | Question 1 | Young people from school year 9 and above , who will move from children’s to adults’ services, who have a co-ordinated transition plan, we add to take in consideration ethnicity ( as African, .Asian ) who normally transfer to adulthood transition before 9 years of age, pathological . Early transition as precocious puberty, delayed transition as in constitutional delayed puberty. Transition is a complex and dynamic system addressing Interconnected, overlapping and contextually sensitive components. When viewed as a system, transition includes interacting stakeholders (youth and family members, healthcare providers, administrators and policy makers), services (paediatric and adult health organizations, community/ natural system supports), and actions (transition related interventions (Hamdani 2011). A systems approach to transition can be used to understand the complexities of transition of youth using the International Classification of Functioning (ICF) framework; 1) Personal factors: developmental readiness, self determination skills, self-management skills, autonomy 2) Health factors: condition severity and stability, activity limitations, and 3) Environmental factors: family and peer support, coordinated transfer process, training of service providers, health policy, organizational policy, inter-organizational communication, Resources for services and programs to support transition and the adult system, supportive physical environment (Mitchell 2015). Two areas identified to enhance system change include public policy (health, social and economic) resource allocation and service approaches at an inter-organizational level and training of health care providers at all levels (Hamdani 2011; Nguyen 2013).(1) .  | Thank you for your comments. |
| 62 | Research in Practice | Question 1 | It is an area for quality improvement but the statement should go further than just stating that people will have a co-coordinated plan, it should include co-production and demonstrable involvement of the young person and their family/carers in the development of the plan | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard.We have highlighted the importance of working with the young person and their family and carers in the rationale and audience descriptors for statement 2. We have included an outcome measure to assess satisfaction with planning for transition and transfer (including their involvement) among young people and their families and carers. |
| 63 | Royal College of General Practitioners  | Question 1 | Yes | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 64 | Royal College of Nursing | Question 1 | Yes | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 65 | Royal College of Occupational Therapists (RCOT) | Question 1 | We agree that having a transition plan that is coordinated across services is a key area for quality improvement. RCOT members have identified supporting young people at this pivotal life stage as a priority concern because poor continuity of care risks disengagement from services, affecting outcomes, quality of life and people’s use of specialist health and care services across their lifespan. We believe that ensuring access to culturally appropriate personalised care, support and rehabilitation during the transition phase is particularly important for young people who have difficulty accessing services because of disability or disadvantage. A planned, coordinated approach is vital for young people who lack support to navigate complex health and care systems with different age and qualifying criteria. A coordinated transition plan will reduce the risk of young people ‘slipping through the net’ when children’s and adult services aren’t fully aligned. Working across health, education, social care, employment and other sectors positions occupational therapists well to work in partnership with others during the transition phase. We agree that effective collaboration is essential to meet young people’s needs as they become adults.  | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 66 | Somerset Foundation Trust | Question 1 | Yes | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 67 | Spinal Muscular Atrophy UK | Question 1 | Yes, this is certainly a key area for improvement. The Outreach Team at SMA UK, who support adults and children living with SMA as well as their families do not feel preparation for transition is always being started early enough; they also see an inequity across the UK. It would be wonderful if it did consistently start this early everywhere. The reality is that transition preparation relies on too many variables and it is unfortunately not always a priority for services. For a smooth transition between services, someone in a coordinator role starts to take responsibility when the patient is at the age of 13/14- this provision varies across services around the country. In our experience, early intervention towards transition is not happening everywhere primarily because services are too busy and overwhelmed. Other issues could be high turnover of staff and continuity of staff which disrupts transition planning.Also, we have sometimes seen a reluctance of paediatric services to ‘let go’ of patients, maybe because they know adult services work differently or because they are aware of long waiting lists. | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 68 | Sussex Partnership NHS Foundation Trust | Question 1 | yes | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 69 | The Neurological Alliance | Question 1 | Improving the availability and quality of support for young people, their families and carers during the transition from paediatric to adult services is a key area for quality improvement. The proposed quality statement 2 is welcome in principle however we have a number of reflections about the delivery and process:* **Lack of existing care and support plans for children and young people with neurological conditions**

In response to our 2021/22 children and young people’s national neurological patient experience survey, My Neuro Survey, 73% (n=310) of respondents in England reported not being offered a care and support plan to help manage their neurological condition in the last three years. Given the significant proportion of children and young people reporting not being offered a care and support plan, there are concerns about the deliverability of transition plans without additional resource and support being made available. Additional resource and support should be made available to ensure equitable delivery.* **Need for shared decision-making in developing a transition plan**

In our 2021/22 children and young people’s national neurological patient experience survey, My Neuro Survey, we asked respondents whether they were involved as much as they wanted to be in developing and agreeing their care and support plan, so that it is centred on what matters to them. In responses from those in England to whom it was applicable, 29% (n=67) said yes, definitely; 40% (n=92) said yes, to some extent; 28% (n=64) said no, but I wanted to be more involved; 3% (n=7) said no, but I did not want to be more involved. NHS England guidance on shared decision-making and other materials to support meaningful involvement should be referenced alongside the quality statement. Data and metrics to monitor and track how involved children, young people and their parents or carers feel in developing a transition plan should also be included.* **Importance of a named worker to support transition (as per quality statement 4) to a meaningful transition plan**

In our 2021/22 children and young people’s national neurological patient experience survey, My Neuro Survey, we asked whether respondents had a named worker to support the transition process between paediatric and adult services. 84% (n=182) of respondents in England to whom it was applicable reported that they would find this helpful, but it had not been offered.A named worker to act as a single point-of-contact for young people and their families or carers during transition should be included in a transition plan. Implementation of a central individual who is familiar with services is important for access to: referrals, medical and community resources, and explanation of services in a nonmedical easy to understand language. We recommend clarifying the link between the proposed quality statement and quality statement 4. Additional action is also needed to ensure that the existing quality standard 4 is delivered for young people affected by neurological conditions.* **Ensuring appropriateness of planning**

Transition plans and planning need to be developmentally appropriate. Recognise that intellectual disability and mental health problems occur frequently in young people with neurological conditions. Developmentally appropriate support needs to be provided, and must consider biological, psychological and social development in the broadest terms. * **Multi-agency approach**

It is important to involve and maintain the involvement of a variety of health, care and educational providers throughout transition, making sure current and likely future support needs are identified, documented and identified student support / learning support personnel names and contact details are included in transition documentation. | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard and your feedback.We have noted your concerns about the need for additional resources for transition support and planning.We have amended outcome a) to include satisfaction with involvement in planning for transition and transfer. We have also included a link in the data source to the NCEPOD survey which includes questions about involvement in transition planning for young people and parent carers.We have added information to statement 4 to clarify that the named worker will be involved in coordinating the transition plan and noted in statement 2 that where a named worker is in place, they will coordinate the transition plan.Equality considerations note that it will be important to adapt the transition plan to reflect the needs of young people with a learning disability or neurodevelopmental needs or both. Health and social care practitioners should ensure that transition planning is developmentally appropriate and considers each young person's capabilities, needs and hopes for the future, addressing their biological, psychological and social development in the broadest terms. In addition. transition support should take into account the young person’s: maturity; cognitive abilities; psychological status; needs in respect of long-term conditions; social and personal circumstances (including culture and beliefs); caring responsibilities and communication needs.The definition for a co-ordinated transition plan highlights that planning should involve all services and interagency teams providing support to the young person before and after transfer. The young person’s GP should be involved; and this will be critical when the young person does not meet the criteria for specialist adult health services or there are no adults’ services in place. |
| 70 | The Royal College of Physicians of Edinburgh (RCPE) | Question 1  | The RCPE considers that the quality statement does accurately reflect a key area for quality improvement but that there is a need to define ‘coordinated’ with formal endorsement by each clinical and administrative service including ongoing adult services, and within healthcare including both Primary, Acute general, Secondary and Tertiary Care.Any process that aims to be person centred must include appropriate communication support for the young person and those who are their registered primary carers/guardians and universal access to authorised independent advocacy.The transition plan should be genuinely co-produced with the young person and their family/carers and not have them simply ‘involved’ in its creation. | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard and your feedback.The definition for a co-ordinated transition plan highlights that planning should involve all services and interagency teams providing support to the young person before and after transfer. The young person’s GP should be involved; and this will be critical when the young person does not meet the criteria for specialist adult health services or there are no adults’ services in place. The audience descriptors highlight that where a named worker is in place, they will coordinate the transition plan.We have added an equality consideration to statement 2 to highlight that service managers should ensure a range of support is available, and used, to help young people communicate effectively during discussions about the transition plan. This could include having a written record of how a young person prefers to communicate, such as a communication passport or 1-page profile, and using different ways to help the young person communicate, such as communication boards, digital communication tools and advocacy.We have highlighted the importance of working with the young person and their family and carers in the rationale and audience descriptors for statement 2. We have included an outcome measure to assess satisfaction with planning for transition and transfer (including their involvement) among young people and their families and carers. |
| 71 | Together for Short Lives | Question 1  | Yes. Together for Short Lives has published a *Stepping Up Transition* Pathway. This provides a generic framework that can be adapted locally to plan multi-agency services for young people with life-limiting or life-threatening health conditions as they are growing up and moving into adult services.The pathway can be accessed here: <https://www.togetherforshortlives.org.uk/resource/transition-adult-services-pathway/> The second standard in our pathway states our view that every young person should be supported to plan proactively for their future. They should have the opportunity to be involved in ongoing multi-agency assessments. They should be able to access a single holistic transition plan that reflects their goals, wishes and aspirations for the future.In our third standard, we state that every young person should be offered an advance care plan (ACP) which includes planning for end of life in parallel to planning for ongoing care and support in adult services.In our fourth standard, we state that children’s and adult services should actively work together to enable a smooth transition.If these standards are met, we believe that young people and their families will be able to achieve the following outcomes: * Everything is going according to a young person’s transition plan
* They are encouraged to think about what they may want to do or where they might want to live when they become an adult
* A young person and their family are prepared for changes to the services and support they may receive, in times of both stable and deteriorating health.

We note that the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) recently reviewed the barriers and facilitators in the process of the transition of children and young people with complex chronic health conditions into adult health services (<https://www.ncepod.org.uk/2023transition.html>). NCEPOD found that 66% of organisations had a policy stating that young people should be offered the opportunity to be involved in their own transition process. It also found that only 15% of organisations had a transition service that involved young people in the design of the service for all specialties. This suggests that giving young people an opportunity to develop a co-ordinated transition plan should be a priority area to improve.In a recent report *Being curious and confident* for Hospice UK (Shouls S. Being curious and confident: learning from the Hospice UK transition programme for young people with life-limiting conditions: evaluation report. London: Hospice UK; 2023; <https://www.hospiceuk.org/publications-and-resources/being-curious-and-confident>) Susanna Shouls, MSc recommends that the expert voices of young people with lived experiences of transitional care should continue and grow to inform the next steps that need to be taken to improve care outcomes for young people and their families. | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard and your feedback.We have highlighted the importance of children’s and adults’ services working together and with the young person and their family and carers in the rationale and audience descriptors for statement 2. We have included an outcome measure to assess satisfaction with planning for transition and transfer (including their involvement) among young people and their families and carers. We have also referenced the NCEPOD audit toolkit and surveys in the data sources. |
| 72 | UK Cystic Fibrosis Medical Association | Question 1 | This quality statement which states that young people who will move from children to adults service have a co-ordinated transition plan. If each individual has this, then this should improve care, by avoiding gaps in provision of care depending on if they are being looked after in the paediatric or adult clinic. The transition plan should highlight individual needs which will improve the quality of transition. | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 73 | University Hospitals Birmingham NHS Foundation Trust | Question 1 | Yes. Having a personalised transition plan is a key area that would improve young people’s journeys. In addition, it would be a useful tool for communication between professionals within the speciality MDT, and any other internal MDTs also caring for the patient. This benefit would also extend to services external to the organisation, for example primary or social care. | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard. |
| 74 | Versus Arthritis | Question 1 | Yes, the introduction of a co-ordinated transition plan reflects a key area of quality improvement and is welcome. The process of transitioning from children to adult services can be fraught with uncertainty, poor communication, lack of knowledge or sufficient understanding of adult health services. This leaves many young people and their families or carers struggling to navigate new health pathways leading to disjointed care, or more vulnerable young people falling through the gaps. Young people transitioning to adult health services require age-appropriate individualised care that meets their holistic needs, yet the availability of developmentally appropriate and timely healthcare services, including mental health support[[2]](#endnote-2) for children and young people aged 0-24 and their families varies significantly according to location, and lead to challenging transitions to adult services.It is estimated 12,000 children **under 16 years**, have ever been diagnosed with Juvenile Idiopathic Arthritis (JIA herein)[[3]](#endnote-3), a group of arthritis conditions, presenting before children are 16 years old, which are autoimmune diseases where the immune system attacks the body. The severity of the condition varies depending on the type of JIA. The number of people with JIA aged **16 years and over** is unknown. Each year, around 700 people under the age 16 years are diagnosed with JIA while 11–38% of children with JIA have JIA-associated uveitis, an eye condition which can cause eye pain and if untreated can lead to blindness.[[4]](#endnote-4)Versus Arthritis recommends: * Involve young people and their families and/or carers in transition planning and transfer to adult services.
* Improve communication and coordination between all specialities.
* Organise healthcare services to enable young people to transfer to adult services effectively.
* Provide strong leadership at board and speciality level at all stages of transition and transfer.
* NHS should work collaboratively with charity organisations for signposting, holistic care needs, peer support and 121 support through for example health-based youth workers. [[5]](#endnote-5)

For a transition plan to be effective it must be individualised and tailored to meet a young person’s needs. It must be phased, taking place over several years with conversations starting at age 13-14 and not rushed upon referral to adult services. The plan should aim is to build skills and confidence of the young person so when they access adult services they can confidently discuss their health condition and self-advocate with their adult health team. It must also reflect the person’s readiness to transition, their current health status, and their capacity to understand and engage with the process. It’s equally important that young people who go straight to adult rheumatology services without first attending paediatric rheumatology receive age and developmentally appropriate care and support that meets their needs. Paediatric rheumatology in theory will prepare children and young people for adult services sending them out of child services fully confident to speak about their condition with an adult rheumatologist. If a young person misses this preparation, they may struggle to speak confidently about their health condition. Time and consideration must be given to those young people who miss time spent in paediatric services preparing them for transition enabling them to better navigate adult health services. Please see AYPH report on improving access to secondary care for young people to understand specific barriers for this cohort. [[6]](#endnote-6)We agree with the draft standard that transition support should consider the young person’s: maturity; cognitive abilities; psychological status; needs in respect of long-term conditions; social and personal circumstances (including culture and beliefs); caring responsibilities and communication needs. **Further, we recommend the needs of care-experienced young people should be given additional consideration in the quality statements as care leavers require additional support transitioning to adult health services.** Generally, it is well documented that young people who are either lost or not well supported during their transition to adult services are more likely to have worse health outcomes, and evidence shows that young people with JIA from less deprived areas may be more likely to continue accessing specialist MSK services than those from more deprived areas.[[7]](#endnote-7)  | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard and your feedback.Ensuring transition support addresses the young person’s emotional health and wellbeing is included in the NICE guideline on transition (NG43) recommendation 1.1.4.Equality considerations in statement 2 note that health and social care practitioners should ensure that transition planning is developmentally appropriate and considers each young person's capabilities, needs and hopes for the future, addressing their biological, psychological and social development in the broadest terms. In addition. transition support should take into account the young person’s: maturity; cognitive abilities; psychological status; needs in respect of long-term conditions; social and personal circumstances (including culture and beliefs); caring responsibilities and communication needs.We have highlighted the importance of children’s and adults’ services working together and with the young person and their family and carers in the rationale and audience descriptors for statement 2. We have included an outcome measure to assess satisfaction with planning for transition and transfer (including their involvement) among young people and their families and carers.The definition of a co-ordinated transition plan indicates that children’s and adults’ services should work together and with the young person and their family or carers to develop a transition plan for each young person that meets the young person’s individual needs. The process measure confirms that a plan should be in place from school year 9 (13 to 14 years).Care for young people who start using adult services without first using paediatric services is not included in the scope of this quality standard.We have added an equality consideration to ensure that the needs of looked-after young people are included in the transition plan including any need for children’s services to continue beyond the usual transition age and to link to wider pathway plans for care leavers. |
| 75 | WellChild | Question 1 |  Yes coordinated responses are not consistent across the UK and there are only a few areas of good practice. The process is often left to children’s services to coordinate with limited engagement and an unidentified key worker/ coordinator on the adult services side. | Thank you for clarifying that this is a priority area for quality improvement in addition to the existing statements in the quality standard and your feedback.We have highlighted the importance of children’s and adults’ services working together in the rationale, audience descriptors and definition in statement 2. The definition states that planning should involve all services and interagency teams providing support to the young person before and after transfer. The young person’s GP should be involved; and this will be critical when the young person does not meet the criteria for specialist adult health services or there are no adults’ services in place. |
| **Question 2 For draft quality statement 2: Can data for the proposed quality measures be collected locally? Please include in your answer any data sources that can be used or reasons why data cannot be collected.** |
| 76 | Alder Hey Liverpool | Question 2 | Yes data can and will be collected locally however as an organisation we have work to do to achieve this accurately Data is currently collected trust wide from our business intelligence team- however currently this is the number of C&YP accessing services at AHFT ages 14-16 years/ 16-18 years/ 18 years +Transition reporting relating to the numbers of C&YP across the organisation needs cleansing- moving to live dashboards to ensure reporting is accurate. Ie ingrowing toenail and tooth removals are removed as these YP will not require transition planning and transfer to adult providers Clinicians need to be complaint completing transition planning with C&YP and documenting this to enable reporting to be accurate and meaningful | Thank you for confirming that it should be possible to collect data for the proposed quality measures in future. |
| 77 | Alexion, AstraZeneca | Question 2 | For rare and ultra-rare diseases, the Specialised Services Quality Dashboards (SSQD) exists to provide assurance on the quality of care by collecting information about outcomes from healthcare providers for these services. SSQDs are a key tool in monitoring the quality of services, enabling comparison between service providers and supporting improvements over time in the outcomes of services commissioned by NHS England. We would encourage NICE to engage directly with NHSE Specialised Services team to explore where data on transitioning could be more routinely collected through via SSQD for relevant services. Additionally, NICE can also engage directly with those providers at specialist centres where transitioning from children’s to adults’ services takes place to look at how measurement of these data points can be incorporated within routine quality reporting.  | Thank you for your feedback. It is helpful for us to be aware of potential data sources. We are also aware that NHS England are developing a framework for healthcare transition including data collection so we will share your suggestion with them. |
| 78 | ARC Scotland - Scottish Transitions Forum | Question 2 | There are different plans for transitions across different services. If this is to be a coordinated plan across all service how will this data set be managed across all different services to make sure whatever plans they have are coordinated with health and education and social care. You need to define who is part of the plan to ensure the numerator is met. A - We are concerned that using the ready steady go, hello programme might not be the most effective measure to enable the capture of this data as we aren’t sure this programme is in operation across the NHS services. We are also concerned his process or programme is only operating in paediatric services with the hello part not taking place is adult services to ensure the effective representation or information required to capture this outcome measure effectively. B – outcome seems to be adequately covered but again if it’s a coordinated plan how will you know they aren’t going to other meetings. Does the health data capture young people not attending multi-disciplinary meetings for example or only when they have been a on none attender in GPS practices, consultant appointment etc. C- makes sense if this is only exploring health data. Young adults might only attend 12-week appointments in social care like social work for example for assessment and then only if they are eligible for a service will they be able to be tracked. What does this do for tracking unmet need and those who have through attrition from the services they need due to barriers to engagement and how can this information be used to help identify people who need the support but who are not missing form services. How does this Guidelines ensure commissioners work with young people and families at the heart of developing services in a coordinated way?  | Thank you for your feedback. We agree that local providers will need to identify if the transition plan is coordinated across all services relevant to the young person (as per the definition). We anticipate that integrated care systems in England will have a role in improving data collection across health and social care services.We have amended the data source to reflect that the Ready, Steady, Go programme is a possible resource as well as the NCEPOD surveys.We have amended outcome b to focus on the rate of non-attendance at meetings or appointments in adults’ services and envisage that providers could measure this for their own service and that it could also be amalgamated across adults’ services as well.We have amended the data source for outcome c to highlight that ‘continuing to engage’ could be defined as engagement at 1 or 2 years after transfer or the age of the young person (such as 25 years) but can be adapted to fit local service characteristics.The focus of this quality standard is on improving transition from children’s to adults’ services rather than the development and provision of adult services. |
| 79 | ARNS | Question 2 | Data for the proposed quality measures can be collected locally, if there is service provision for this. Currently we are aware that the service provision for this is limited in some centres/Trusts due lack of collection tools and lack of personnel to collect this, | Thank you for confirming that it should be possible to collect data for the proposed quality measures and for highlighting potential local barriers. |
| 80 | Association of British Neurologists (ABN) | Question 2 | Outcomes a and c are reasonable and appropriate. They should be deliverable. Outcome b (Proportion of young people who have transferred from children’s to adults’ services, who do not attend their initial meetings or appointments with each adults’ service) is less likely to be an accurate measure of the co-ordination of the transition plan as this is subject to so many other confounding factors.It will be dependent on an electronic patient record and the individual systems may make data collection more or less easy. Local services would need appropriate IT infrastructure to collect data on individual transition plans. It may be helpful to have a SNOWMED code for the creation of an individual transition plan to allow for coding, automated collection and appropriate reimbursement. Data collection for this on any meaningful or national scale may require dedicated salaried staff for its maintenance, locally and nationally. | Thank you for your feedback. We have amended outcome b) following consultation feedback to:Rate of non-attendance at meetings or appointments in adults’ services for young people who were expected to transfer from children's to adults' services.We understand this data should be easier to collect and services could use age to identify the population if it is not possible to specifically identify young people who were expected to transfer. We understand that NHS England may be developing new SNOMED codes that can be used for transition that will improve data collection in future. |
| 81 | Association of Paediatric Chartered Physiotherapists | Question 2 | The NCEPOD transition toolkit could be useful to help healthcare providers and organisations to audit whether a co-ordinated plan is being implemented and all services involved, including education, by auditing patient records locally in children’s community services and hospital-based services. However, it might be difficult to judge from the records whether transition has just been mentioned ‘in passing’ or whether an ‘in depth’ detailed co-ordinated plan has happened unless a specific transition tool has been used e.g. Ready Steady Go Tool. Having variability in ages of transition across services is not only confusing and challenging for families as well as health care providers but will lead to difficulty coordinating a transition plan with all services involved with a young person and therefore lead to challenges collecting data.  Another barrier might be that multi-disciplinary teams may be using different patient recording systems. Frequently community teams use one system and hospital-based teams use another and young people and families are likely to be seen by many different teams. This makes it difficult to audit all the teams a young person may see for evidence of use of a co-ordinated transition plan to get a true picture of what is happening. It will be more challenging to collect data from adult services – lack of commissioning for specialist adult services for young people with complex disability to transition onto remains a big issue so there will remain gaps in data collection if no appropriate adult services exist. Many adults with complex health needs remain under the care of paediatric services and co-ordinated transition plans will not therefore be found in the records because they are not able to transition them onto services that don’t exist. | Thank you for highlighting some of the challenges in relation to data collection for this statement. We agree that local areas will need to consider these issues when developing their local approach to data collection.The definition of a co-ordinated transition plan includes coordination of the age of non-statutory transitions to adults’ services, to ensure a consistent approach.This quality standard is focussed on young people who are transitioning to adult services. If the young person does not transition to an adult service, they will not be included. It is clear in the definition of the plan however that the young person’s GP should be involved; and this will be critical when the young person does not meet the criteria for specialist adult health services or there are no adults’ services in place. |
| 82 | British Academy of Childhood Disability (BACD) | Question 2 | Yes – some Trusts have adopted the Epic system as an electronic patient record and it has a Healthcare Transition tab where this information can easily be recorded for each young person and their family and data collected.  | Thank you for confirming that it should be possible to collect data for the proposed quality measures. |
| 83 | British Association of Teachers of Deaf Children and Young People (BATOD) | Question 2 | Data for the proposed quality measures be collected locally for deaf children and young people from the audiology and auditory implant services | Thank you for confirming that it should be possible to collect data for the proposed quality measures. |
| 84 | British Society of Physical and Rehabilitation medicine | Question 2  | The data can be collected by the local Children’s and adult services out patient clinic attendance. The data at 12 months from transition to adults as should also be collected to monitor engagement with adult services. The data need to include 1. engagement of the adult services in transition planning: This could be identified by looking at number of adult services providers attending the transition meetings
2. Continuing engagement with the adult teams. The gold standard should be all young adults with a long-term condition should be seen in an adults service at 6 months and at 12 months after discharge from Children’s services. The follow up by adult service at 12 months after transition should be taken as the criteria for successful transition.
 | Thank you for confirming that it should be possible to collect data for the proposed quality measures.Annual meetings to review transition planning are included in statement 3 and the definition highlights that all practitioners providing support should input to the meeting.There are no recommendations in the NICE guideline on transition for follow-up in adults services following transfer. Statement 6 does, however, focus on missed initial appointments in adults services and the need to engage young people following transfer if they do not attend. We have also included an outcome measure on continued engagement with adult services in all statements. |
| 85 | Brittle Bone Society | Question 2 | I guess this depends on the definition of “locally”. Some HSS work with a local hospital and others do it regionally and across various trusts. We also think for this to happen there needs to be an agreed minimal clinical content for the transition plan which should be co-developed with patient groups. | Thank you for your feedback. We have removed ‘locally’ from the data source sections as we recognise that young people may be using specialist services outside their local area. We agree that there will be a need to consider the data across different geographies.As this quality standard covers transitions in all settings across health and social care the specific details about the clinical content included in the plan will vary and will need to be determined locally.  |
| 86 | Child Growth Foundation | Question 2 | An electronic version of Ready, Steady, Go has been integrated into the electronic patient record (EPR’s) at a local Trust. This was after recognition that a paper version, or leaving the document with the patient to bring to appointments, wasn’t suitable. The success of this document however, relies on the professionals seeing the patient to routinely use the document to structure their conversations about transition. This data would need to be pulled from individual EPR’s to review how the document has been completed, it’s not clear how this data could be collected without knowing which individuals should have had the document completed and therefore identifying potential missing data may be difficult.As Trusts move towards being paper light, data should be easier to be collected from EPR’s. Information potentially could be missed if professionals don’t record or fully complete the information regarding transition plans.  | Thank you for your feedback.The Ready, Steady, Go survey questionnaires are identified as a resource that could be used to collect data for outcome a) on young people’s satisfaction with planning (including their involvement). We have not, however, included the Ready, Steady, Go resources as a data source for the process measure on having a co-ordinated transition plan. How to identify if a transition plan is in place will need to be agreed locally.  |
| 87 | Children with Exceptional Healthcare Needs networkNSS CEN – NHS Scotland National Services | Question 2 | Data can be collected locally but the lack of effective IT provision within health and social care limits the potential for shared digital data across healthcare services as well as across health and social care. There is also a need to acknowledge the role of education services for the younger cohort within the ‘transition’ age groups particularly in relation to mental healthcare needs, equipment requirements and social relationship needs.In Scotland the work of the Transitions Forum and development of the Compass app has highlighted the cumulative demands on the young person, parents/carers and professionals when transitions in all services (in healthcare within the service for each specialty) progress in different ways, with different age criteria and to different time scales, | Thank you for your feedback.To clarify, the scope of the quality standard includes health and social care services but does not include education for those without an education, health and care plan. We have recognised that the transition plan in statement 2 will be part of a broader plan for young people covered by health and social care or education legislation.It has been suggested by stakeholders that a [Federated Data Platform](https://www.england.nhs.uk/digitaltechnology/digitising-connecting-and-transforming-health-and-care/) (FDP) could support improved data collection and co-ordination across integrated care systems in future. |
| 88 | Clinical Genetics Society | Question 2 | Yes this is feasible but the proposed data to collect would not provide information about genetic aspects of transition. | Thank you for your feedback. We confirm that as the quality standard covers all health and social care services data collection is focussed on key steps in the transition pathway rather than on specific content within transition planning. |
| 89 | Communication Matters (ISAAC UK Ltd) | Question 2  | Every child who needs Augmentative and Alternative Communication (AAC) resources **should** have an Education, Health and Care Plan (EHCP) which is a statutory working document. Communication need, including the use of Augmentative and Alternative Communication (AAC) resources, should be explicitly included within the EHCP, although the level of support and detail is variable by region, local authority, and individual school. Anecdotally it can be difficult to get both speech and language therapy and/or AAC resources specifically detailed on an EHCP due to the perceived cost, and the approach of ‘signing off’ a child when an intervention is in place and perceived to be working effectively. **The Special Educational Needs and Disability Code of Practice (SENDCoP) 2015 states:3. Working together across education, health, and care for joint outcomes**In section 3.9 *“Joint commissioning arrangements must cover the services for 0–25-year-old children and young people with SEN or disabilities, both with and without EHC plans……... They could include highly specialist services needed by only a small number of children, for instance children with severe learning disabilities or who require services which are commissioned centrally by NHS England (for example some augmentative and alternative communication systems,)”*The numbers of children assessed and re-assessed by specialist AAC centres centrally commissioned by NHS England should be available to NICE.The numbers of children assessed and re-assessed by local AAC teams should be available through local commissioners, however, local teams do not exist in every part of the country, and not all children who need AAC meet the eligibility criteria for either a local or specialised AAC assessment. Details are below:The current guidance from NHS England for centrally commissioned AAC services make for a difficult referral for many young people who need an AAC assessment. The NHS eligibility criteria for specialist assessment means the specialist services only see around 10% of children and young people with the most complex communication needs who may need powered communication aids, with complex access needs (see Child A). A child or young person only remains on the radar of the highly specialist service for the duration of their assessment and initial implementation of resources. Following this ongoing support becomes the responsibility of the local AAC service. As local services vary by region and local authority the continuity of ongoing support, reviews and reassessments are open to variability.* **Young Person A:** A young man with cerebral palsy, he attends a special school with an experienced team of teachers and Speech and Language Therapists (SLTs) who have expertise working with AAC. He started with a paper based (low-tech) communication resource. This was eventually found to be inadequate for his expressive needs. Transitioning to a high-tech system, the school applied for a specialised assessment and received it without issues because he was a power chair user, had limited hand function, and had proven communication competence. His device was funded through the NHS specialised regional hub and he had ongoing technical support for the device. Because it was mounted to his wheelchair, he had access to it at all times in school, at home and in the community. His language and literacy continued to develop, and he loves creative story writing, and over time he learned how to edit his device gaining more independence in his communication.

The remaining 90% of children and young people using AAC should be assessed locally with their resources provided by the local AAC team (See Child B and Child C). There is a shortage nationally of speech and language professionals, especially with AAC expertise. If a child fails to meet the eligibility criteria for a local AAC assessment, or there is no local AAC team then provision of equipment falls to a local authority or is maybe delegated to the school. Without specialist professional AAC input this means children are often provided with an intervention to be implemented by classroom professionals who have little or no AAC experience. Within a school where paper-based symbol communication and the use of classroom tablets are the norm then a child’s specific needs, especially in a special school environment, might not be noted fully on an individual EHCP. * **Young Person B:** A young woman on the autistic spectrum who was ambulant. She is in a special school that has an experienced staff of SLTs and teachers with expertise in AAC. She initially used PECS (Picture Exchange System), but her needs outgrew it. Transitioning her to a high-tech communication device in school proved highly effective. The school however were advised that they wouldn’t be able to apply for NHS funding, as she was able to take the hand of an adult and lead them to what she wanted, and she could access the smart technology the school provided. The school subsequently sought funding through education, and she became the first pupil in her area to secure funding for her communication device through the education system. The challenge was that this funding through education did not offer the same level of technical support as child A, and nor did she receive continuing support once she completed her education. The result of receiving an appropriate AAC resources was her improved communication, and the removal of many behavioural issues. Over time she learned how to edit her device gaining more independence in her communication. This child is at risk of losing her communication device when she transitions out of education and as her communication need has not been recognised as a health need during education, she will not be seen to have an ongoing medical need.

*N.B. The difference between young person A and B is only their mobility and dexterity.*Transition planning should include speech and language therapy, yet these services are not available to many AAC users once equipment or resources have been provided or recommended. Their implementation is often left to classroom specialists. The SENDCoP states:**9. Education, Health and Care needs assessments and plans**9.74 *“However, since communication is so fundamental in education, addressing speech and language impairment should normally be recorded as special educational provision unless there are exceptional reasons for not doing so”.** **Young Person C:** This child has a learning disability and attends a special school. They have never had an assessment for an electronic communication device. The local NHS SLT provision addresses dysphagia issues, and private SLT provision paid for by parents has no AAC experience. The school see the provision of AAC as a luxury and that for a child to be assessed there is a pre-requisite to demonstrate competence with symbol communication. In the classroom pupils access their learning using paper-based resources, including generic symbol cards, topic charts and visual behaviour supports. The symbol set has been chosen by the school because it is the one staff are familiar with. Within the classroom this child and their peers do not focus on learning literacy perse. These resources are rarely, if ever, shared with parents or their network of support in the community. When this young person leaves education there may be no formal communication system to advise to adults’ services.

By contrast, a young person who is an AAC user in mainstream school may have a very different journey. Anecdotal evidence shows there can be a struggle to keep AAC on the EHCP when a young person is literate and fails to meet the eligibility criteria for either the NHS Specialised regional hub or the local AAC service.* **Young Person D:** This young person has attended a mainstream school from the age of 4, they are cognitively able and have achieved in line with expectations for their age and stage of education. They were initially assessed at the age of 3 by a specialised AAC centre (pre-current model) and provided with a symbol-based communication device using a finger to direct input. Over time due to over extension of her finger joint this AAC user subsequently transitioned to using an iPad with stylus on a text-based app. During her education she was well supported by the local authority, with no SLT input for AAC, but allowed to keep her device for use in the community and at home. At 19 she transitioned to higher education and no longer had an EHCP. Moving to a new city meant she had no NHS support services in place. Because of her other technology needs the Disabled Students Allowance could not cover the cost of new AAC equipment. When she asked for a specialised assessment to reassess her communication needs due to problems with holding the stylus she was refused because she no longer met the eligibility criteria due to her literacy levels.

What none of these scenario’s document in relation to AAC is that a young person in both a special and mainstream school may have 1-1 classroom support who acts as a communication partner ongoing, facilitates academic work, and provides under teacher guidance differentiated/adjusted work. If a young person has this level of support for education, then it will have a direct impact for the provision of effective future services in health and social care. | Thank you for your feedback.To clarify, the scope of the quality standard includes health and social care services but does not include education for those without an education, health and care plan. We have recognised that the transition plan in statement 2 will be part of a broader plan for young people covered by health and social care or education legislation |
| 90 | Derby and Derbyshire Integrated Care Board | Question 2 |  in theory yes, if the transition plans are completed, currently there is no mechanism for ensuring that all teams work in a collaborative way....  | Thank you for confirming that it could be possible to collect data for the proposed quality measures.  |
| 91 | Derby and Derbyshire Integrated Care Board | Question 2 | There needs to be a coding for any plans to be recorded as a transition plan so we can pull of the data. There is no code currently either in primary care or secondary/tertiary care to enable this to happen. | Thank you for your feedback. We agree that coding will need to develop to support data collection. |
| 92 | Derby and Derbyshire Integrated Care Board | Question 2 | Currently different providers use different patient data systems so any mandate would need to ensure it can be extracted from all currently used IT systems | Thank you for your feedback. |
| 93 | Derby and Derbyshire Integrated Care Board | Question 2 | Transition back to GP is more challenging to record from both secondary care but also within primary care - how any plans are filed in patient records and how those young people are viewed by primary care (for example – if a young person DNA/WNB to their first adult appointments this would not be flagged to a GP) | Thank you for your feedback. We have highlighted in the definition for a co-ordinated transition plan that the young person’s GP should be involved; and this will be critical when the young person does not meet the criteria for specialist adult health services or there are no adults’ services in place. |
| 94 | Derby and Derbyshire Integrated Care Board | Question 2 | Social care – dashboard that monitors all young people from age 14, open to children disability teams currently but will include mental health. don’t currently map to localities or shared data with health | Thank you for your feedback. |
| 95 | Diabetes UK | Question 2 | Yes the data can be collected locally, but it is important to have a system in place for data collection and a designated person/people who input the data. Healthcare professionals or administrative staff will need to be aware of these systems and have appropriate training in order to use them.  | Thank you for confirming that it should be possible to collect data for the proposed quality measures. |
| 96 | Duchenne UK | Question 2 | It would be very valuable for rare disease communities to understand better how members of their community go through transition. It may be possible for the NHS locally to engage with rare disease registries to identify the number of children and young people in that age cohort in the area who need a transition plan, and survey them. An example is below.Data source: patients registered in the rare disease registry which will record care delivery against NICE and other nationally agreed standards. Numerator – the number in the denominator who report having a co-ordinated transition plan.Denominator – the number of young people registered in the rare disease registry in school year 9  | Thank you for your feedback on how the measures could be adapted for the rare disease community. |
| 97 | Faculty of Pain Medicine of the Royal College of Anaesthetists | Question 2  | Yes, universal adoption of a transition process should generate data that can be collected locally. The challenge is for those services where only a small proportion will actually transition, with significant data collection being undertaken without clinical benefit. Some of the more generic preparation for independence in healthcare will be beneficial to the young adult themselves, but will not have an impact on the service.Examples of data collected locally include those patients actively prepared on a transition plan, and transferred to transition clinics, which is measurable. Data can also be collected in those of transition age 13-14 or year 9 onwards, to assess what transition plan is made, even if no plan has been made to create the denominator. Ideally the plan should be made, even if it looks likely that the child will be discharged before transfer to adults. Data can be collected from adult side by collecting the number admitted into transition clinics, and also the number of 18-25 year olds referred into the service, who have not had official transition, but opportunities missed if they presented to paediatrics previously.  | Thank you for your feedback on data currently collected. |
| 98 | Faculty of Pharmaceutical Medicine | Question 2 | No rare diseases are diverse across the country, some commissioning areas may have only one or two patients, others will have no patients with a transitioning need. If the strategy is to include rare diseases then some centralisation is needed | Thank you for your feedback on the challenges for collecting data specifically for the rare disease community.  |
| 99 | Genetic Alliance UK | Question 2  | Yes.  | Thank you for confirming that it should be possible to collect data for the proposed quality measures. |
| 100 | Great Ormond Street Hospital (GOSH) | Question 2  | Yes, through Electronic Patient Record (EPR) systems, however challenges may arise in collating data from different organisations using different EPR systems. London are creating a universal transition database to be a central pool of info called Universal Care Pathway (UCP), however this would not capture patients outside of the London remit. Therefore need to identify how hospitals can share their plans between organisations. We need to think about patients who are referred to adult service with No Future Activity ‘open referrals’ to adult services.  | Thank you for confirming that it should be possible to collect data for the proposed quality measures. We recognise that sharing data between organisations is a barrier that will need to be overcome.We have highlighted in the definition for a co-ordinated transition plan that the young person’s GP should be involved; and this will be critical when the young person does not meet the criteria for specialist adult health services or there are no adults’ services in place. |
| 101 | Kent and Medway NHS and Social Care Partnership Trust | Question 2  | * Quality measures should be able to be collected locally and should be held by the organisations that are treating them.
* Who would be issuing the care plan/ where would it sit? Who actually does the comprehensive version of the transition plan? How is the number that are eligible for transition counted?
* Data can be collected but the organisation would need new data pathways to be identified and set up. Because there is a lack of clarity in the quality statement it is hard to define what is needed as there is such a broad option of data sources. (Why it can’t be collected). CAMHS/AMHS/GP/Primarycare/Local authority/Education/VCSE/Parents and carers – this shows the breadth but also that it is too wider of a population of data source.
* Who would actually ‘hold’ the data? Who holds the master information and how is it updated? Is it care co-ordinator? How can organisations then update the document who are outside the NHS (ie Social Care)?
* Is this a mix of qualitative and quantitative data?
* Due to the changing nature of an individual’s mental health needs and the mental health services (Funding changes, Government change, policy change etc…), criteria and change in circumstances makes this hard to capture, therefore difficult to analyse and assess.
* The Ready, Steady, Go document and NCEPOD audit toolkit currently recommended for transition data capture are not SEND friendly. Considerable data will be lost as unable to capture these experiences and voices.

Where does the young person’s voice come into this? | Thank you for confirming that it should be possible to collect data for the proposed quality measures.Thank you for highlighting the challenges for collecting data across services that will need to be addressed locally if they wish to prioritise quality improvement on having a co-ordinated transition plan. Outcome c) is focussed on the young person’s voice. We have clarified that the Ready, Steady, Go and NCEPOD surveys are possible sources for data collection but acknowledge that they may not be suitable for all groups. |
| 102 | Metabolic Support UK | Question 2  | Providers of local care may be able to collect, record and share this information via the [Federated Data Platform (FDP)](https://www.england.nhs.uk/digitaltechnology/digitising-connecting-and-transforming-health-and-care/) which aims to provide trusts and ICSs with a set of core capabilities and nationally developed data solutions. Entering this data on the FDP will enable the harmonisation of data across sites meaning increased usability and less staff-time spent translating data. Further to this, the platform has two relevant priorities to this statement, namely: * Population health management – to help integrated care systems proactively plan services that meet the needs of their population.
* Care coordination – to enable the effective coordination of care between local health and care organisations and services, reducing the number of long stays in hospital.

Sites may also be able to record this data more effectively through actions carried out in response to the [NHS long term plan](https://www.longtermplan.nhs.uk/), which aims to provide better access to digital tools and patient records for staff, and improvements to the planning and delivery of services based on the analysis of patient and population data.**Considering the specific data collected:*** **For outcome A:** There must be a stipulation that the individual has a coordinated transition plan.
* **For outcome B:** There will need to be clarification as to how this will be measured if the young person has multiple services
* Data should also be collected on the use of TIER Ready, Steady, Go forms to ensure families gain the knowledge and skills to manage their condition into adulthood.
* Consideration must be given to the geographical locations of the services that children are transitioning to e.g., paediatric patients in SW England will fall under Bristol Services and will then transition to either Birmingham or London adult services. How will this type of transition be measured equally against centres such as GOSH transitioning to UCLH which are a short distance from each other?
* There should be work to examine any consistencies between time spent travelling to appointments vs number of patients lost to follow up.
 | Thank you for confirming that it should be possible to collect data for the proposed quality measures.Outcome a) is focussed on young people’s satisfaction with planning (including their involvement). We expect that if the young person has a transition plan this is likely to improve their satisfaction overall. This will be more helpful as an outcome measure as it includes all young people who have transitioned from children’s to adults’ services rather than just those who had a transition plan.We have amended outcome b) following consultation feedback to:Rate of non-attendance at meetings or appointments in adults’ services for young people who were expected to transfer from children's to adults' services.We understand this data should be easier to collect and services could use age to identify the population if it is not possible to specifically identify young people who were expected to transfer. We understand that NHS England may be developing new SNOMED codes that can be used for transition that will improve data collection in future. The Ready, Steady, Go survey questionnaires are identified as a possible resource that could be used to collect data for outcome a) on young people’s satisfaction with planning (including their involvement). We have not, however, included the Ready, Steady, Go resources as a data source for the process measure on having a co-ordinated transition plan. How to identify if a transition plan is in place will need to be agreed locally.We have removed ‘locally’ from the data source sections as we recognise that young people may be using specialist services outside their local area. We agree that there will be a need to consider the data across different geographies. |
| 103 | Midlands Partnership University NHS Foundation Trust | Question 2  | There is provision for a transition check list in RIO that will capture this data for those services actively involved in transition pathways.Services not on RIO would need to look at replication on their systems where permitted or look at alternative means of data collection.Services that do not keep CYP on their caseloads that are a referral in, and discharge service would not use a checklist and not specifically record transition using code – this would make extraction of data very difficult and inconsistent. | Thank you for confirming that it should be possible to collect data for the proposed quality measures. We understand that NHS England may be developing new SNOMED codes that can be used for transition that will improve data collection in future. |
| 104 | National Confidential Enquiry int Patient Outcome and Death (NCEPOD) | Question 2  | Yes – good audit tools have been suggested in the NCEPOD ‘[The Inbetweeners](https://www.ncepod.org.uk/2023transition.html)’ report. | Thank you for confirming that it should be possible to collect data for the proposed quality measures. |
| 105 | National Deaf CAMHS (North) | Question 2 | Transition data could be collected within Deaf CAMHS or mainstream CAMHS but coordination of this may be challenging.  | Thank you for confirming that it should be possible to collect data for the proposed quality measures. We understand that NHS England may be developing new SNOMED codes that can be used for transition that will improve data collection in future. |
| 106 | National Network of Designated Healthcare Professionals for Children | Question 2 | Our view is that this is a good idea, but the data should be collected for this purpose, and data for other purposed should not be recruited to answer the question. Data should be gathered from the young people themselves about their experiences, and probably also from supportive adults, such as parents or social workers in the case of children in care. Looked after children should not be inadvertently excluded from such efforts. A significant confounding factor is the digital incompatibility that plagues multiagency working: this will need to be considered in designing data collection systems for this purpose.  | Thank you for your feedback. Outcome a) is focussed on the young person’s (and their families and carers) satisfaction with planning for transition and transfer (including their involvement).We have added an equality consideration to ensure that the needs of looked-after young people are included in the transition plan including any need for children’s services to continue beyond the usual transition age and to link to wider pathway plans for care leavers.We understand that there is potential for a [Federated Data Platform](https://www.england.nhs.uk/digitaltechnology/digitising-connecting-and-transforming-health-and-care/) (FDP) to support improved data collection and co-ordination across integrated care systems in future. |
| 107 | National Network of Parent Carer Forums | Question 2 | Yes – local parent carer forums would be able to engage with parents of cyp at transition to help with this data on a local level | Thank you for your feedback. |
| 108 | National Network of Parent Carer Forums | Question 2 | Quality statement 2 quality measure outcome b) lists the numerator as “proportion of young people who have transferred from children’s to adults services, who do not attend their initial meetings or appointments with adults services”. The denominator listed as “The number of young people who have transferred from children’s to adults services”.This could potentially be interpreted wrongly. The denominator should be the number of young people who were expected to be transferred, or referred from children’s to adults services. The “number transferred” could be interpreted as the number who’s care has continued in adult services, which wouldn’t include those who are lost during transfer.The NNPCF welcomes the inclusion of patient and parent carer satisfaction with transfer to adult services as measurable outcomes. Will these be reported separately, or will they be included together? | Thank you for your feedback.We have amended the wording for outcome b) to clarify that the denominator should be the number of young people who were expected to transfer from children’s to adults’ services.We have suggested that outcome a) should include young people and their families and carers and highlighted separate survey resources for these populations. Local areas will need to agree how they report on this. |
| 109 | National Organisation for FASD | Question 2 | FASD (Fetal Alcohol Spectrum Disorder, is a lifelong neurodevelopmental condition caused by prenatal alcohol exposure that affects 2-4% of the population, making it more prevalent than autism.For people with FASD, the Management plan (Statement 5, NICE QS204) should be taken into account.TIER ready steady go documentation may not fully reflect the needs of young people with FASD who may have significantly better expressive language skills that do not reflect their rate of comprehension. People with FASD do not always have good insight into what they can do. People with FASD often display the frontal lobe paradox in that they may be able to verbalise a correct course of action in a test or interview setting, yet not be able to put this into practice in real life. Not recognising this can put young adults with FASD at particular risk during transition. | Thank you for your feedback.We have amended the data source for outcome a) to make it clear that the examples of questionnaires could be useful but expect the approach will need to be adapted to meet local needs. |
| 110 | National Rheumatoid Arthritis Society | Question 2 | Yes as per the sources mentioned in your documentation. (Reasons why data may not be collected locally) As per the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report into transitioning, there may be a lack of awareness of good practice in transitioning from children’s to adult services. Also, as this is not a commissioned service, and in the current NHS landscape of post-pandemic recovery it is challenging for teams to deliver joined up care. | Thank you for your feedback. |
| 111 | NHS England | Question 2 | * There are a number of clinical record systems that may impact on a smooth process. This also includes access to tertiary centre records as not all records are at local level. If there is one overall transition plan, is it clear what service would hold the responsibility for this?
* All care / transitions plans should be uploaded on the care planning element of the patient record however there is no way of measuring this other than localised audits. For children with an EHCP it could be included within that process and data collected but not all children and young people have an EHCP.
* We suggest it would be beneficial to identify the person/team with accountability and responsibility for the co-ordination. Who that is will depend on the situation. For those with EHCPs, casework officers could be responsible. In some cases, social workers. But need to also consider those without an EHCP or a social worker.

Yes – data available both from commissioners as to number of referrals and providers re rejections. | Thank you for your feedback.As the quality standard covers transitions in all settings across health and social care the specific details about which services and systems are included and who is coordinating will vary and will need to be determined locally. It has been suggested by stakeholders that a [Federated Data Platform](https://www.england.nhs.uk/digitaltechnology/digitising-connecting-and-transforming-health-and-care/) (FDP) could support improved data collection across integrated care systems in future. |
| 112 | NHSE Sheffield response | Question 2 | Easily | Thank you for confirming that it should be possible to collect data for the proposed quality measures. |
| 113 | NHSE specialised commissioning | Question 2 | Q2 Response: Whilst the above teams mentioned may be able to confirm the number of cases they are managing and for whom they have created a transition plan, there would need an identified team or organisation identified locally for each patient to ‘manually’ collate transition data from various clinical teams (where the patient is under the care of a number of teams/has different care issues). This increases the risk of the data not being meaningful and data accuracy could be variable depending on when the patient was seen by different teams and if the plan is updated regularly enough. | Thank you for your feedback. We agree that data will need to be collated and coordinated across providers in order to provide a comprehensive assessment of transition for young people. |
| 114 | Nottinghamshire Healthcare NHS Foundation Trust | Question 2 | This may not be as straight forward in community services who deliver episodic care, as young people may come in and out of the services until age 18 yrs. (or 19 yrs. if in full time education). We currently collect reporting data to identify people early who may need transition planning or discharge planning at different ages. From 16 yrs. we collect data on those people who have transition planning and those who transfer to an adult service. We would not be able to achieve this from yr9 due to episodic care.All data is collected through a set of local coding on S1.It also needs to be considered that for some paediatric services in the community, there is no equivalent adult service to refer on to, so care will go back to the G.P. | Thank you for your feedback on data collection that may be feasible locally.The definition for a co-ordinated transition plan highlights that planning should involve all services and interagency teams providing support to the young person before and after transfer. The young person’s GP should be involved; and this will be critical when the young person does not meet the criteria for specialist adult health services or there are no adults’ services in place. |
| 115 | NSA for PCC NHSE | Question 2 | Possibly – if specialties monitor this as a quality indicator. In future for PCC we may be able to add this in on national audit but may not apply as most of these children are primarily managed by another specialty. | Thank you for your feedback on data collection that may be feasible. |
| 116 | RCPCH | Question 2 | Resources: Includes people, time, space and funds While a significant amount of qualitative data is available related to patient, parent and health care provider perceptions of barriers to successful transition and related transfer outcomes, there is a lack of research to definitively define and identify transition practice outcomes. This further supports the need for a review of both the published research literature and descriptions of current practices to determine common principles to foster a national Guideline with recommendations for transitioning from paediatric to adult health care. The Guideline Development Group must include a smaller group composed of: Community of Practice for Transition from Paediatric to Adult Health Care. Members include young adults, families, health care providers, researchers and administrators, representing paediatric, adult, rehabilitation, community and mental health organizations. The Guideline Development Group must conduct a literature search for practice guidelines, global programming, policy statements, systematic reviews, and relevant research studies related to the transition to adult care. | Thank you for your feedback.We confirm that the quality standard is based on the existing [NICE guideline on transition from children’s to adults’ services for young people using health or care services (NG43).](https://www.nice.org.uk/guidance/ng43) |
| 117 | Research in Practice | Question 2 | The process measures are possible to answer using local data (though defining ‘coordinated’ may be necessary to accurately measure against this standard). The outcome measure (satisfaction) would be strengthened if interrogating YP/family experience of being involved in the development of the plan. Equivalents to ‘patient surveys’ in social care services do exist (eg exit questionnaires) but are not standardised. | Thank you for your feedback.We have added further detail to the definition of a co-ordinated transition plan to confirm that the young person and their family or carers should be involved, along with all services providing support before and after transfer and the young person’s GP.We have added satisfaction with their involvement in developing the transition plan to outcome a). |
| 118 | Royal College of General Practitioners  | Question 2 | We believe that arrangements for transition should be made the responsibility of primary care however, it is important to note that adequate funding will need to be allocated to primary care to provide this given the workload and workforce limitations. Although GP teams would coordinate the arrangements, ideally the patient and their carers should own the plan. Additionally, coordination could be led by a transition officer (nominated by the local ICS).It is important to note that most of these arrangements can be the responsibility of non-clinical staff (as suggested in the RCGP e-Learning) with the majority of the clinical activity undertaken in secondary care teams who are becoming increasingly active in transition due to the increased numbers of patients involved. The GP team has the essential role of coordinating the transition, adapting it to the needs of the patient, carers, local facilities and circumstances.  | Thank you for your response. We have not identified any specific co-ordination arrangements in the statement as this is likely to vary depending on the setting and the young person’s needs. We have, however, included GPs in the descriptors for health and social care practitioners throughout the quality standard. We have also clarified in the definition of a co-ordinated transition plan that the young person’s GP should be involved; and this will be critical when the young person does not meet the criteria for specialist adult health services or there are no adults’ services in place |
| 119 | Royal College of Nursing | Question 2 | Information could be obtained locally. However, due to there being a variety of electronic systems within acute services and the community, all of the data may not be available for all teams to see. Acute hospitals, community mental health services and primary healthcare may have different systems. | Thank you for your feedback. We agree that there will need to be co-ordination of data. It has been suggested by stakeholders that a [Federated Data Platform](https://www.england.nhs.uk/digitaltechnology/digitising-connecting-and-transforming-health-and-care/) (FDP) could support improved data collection and co-ordination across integrated care systems in future. |
| 120 | Royal College of Occupational Therapists (RCOT) | Question 2 | RCOT members note long term concerns about the poor integration of health and social care IT systems making it difficult to collect reliable data across organisations. The ease and accuracy of data collection must be assessed locally to understand how easy it will be to determine the number of eligible young people who need and have a coordinated transition plan.   RCOT members are concerned that some young people may be missing from the data if, because of long waiting lists, they have not been able to access a service before moving to adult services. This is a particular risk for those with mental health needs that present during late adolescence for whom a transition plan would ensure continuity of care at this critical life stage. How will this ‘un-met’ need for a transition plan be captured?  An assumption is made in the Quality Statement is that there are appropriate adult services for young people to transition to. This is not always the case. Whilst physically disabled young adults who do not have a learning disability, including those with muscular dystrophy, cerebral palsy and dyspraxia/developmental coordination disorder have often received occupational therapy support as children, there are rarely equivalent adult services to transition to. Their data will not be captured in numbers attending initial or subsequent meetings. How will this unmet need be reported?   | Thank you for your feedback. We agree that there will need to be co-ordination of data. It has been suggested by stakeholders that a [Federated Data Platform](https://www.england.nhs.uk/digitaltechnology/digitising-connecting-and-transforming-health-and-care/) (FDP) could support improved data collection across integrated care systems in future.We note your concern about waiting lists for young people to access paediatric services. The focus of this quality standard is on transition from children’s to adults’ services rather than access to children’s services, however.We have clarified in the definition of a co-ordinated transition plan that the young person’s GP should be involved; and this will be critical when the young person does not meet the criteria for specialist adult health services or there are no adults’ services in place. We would expect these young people should be included in transition planning. |
| 121 | Somerset Foundation Trust | Question 2 | Data collection is and will be problematic due to a. Recent mergers of NHS Trusts into one Somerset Foundation Trust as each organisation has separate IT systemsb. Data Sharing between Tertiary centres eg Bristol Children’s Hospital OR cross geographic border hospitals eg RUH in Bath is currently poor. | Thank you for confirming the challenges for data collection locally. It has been suggested by stakeholders that a [Federated Data Platform](https://www.england.nhs.uk/digitaltechnology/digitising-connecting-and-transforming-health-and-care/) (FDP) could support improved data collection and co-ordination across integrated care systems in future. |
| 122 | Spinal Muscular Atrophy UK | Question 2 | In rare conditions like SMA, care is managed by a specialist centre, often far from the patient’s local community. Management of the condition locally is coordinated separately. Therefore, any transition plan would need to be managed by someone who could co-ordinate between sites and services.There would need to be a person to collect data in different areas and one person to co-ordinate who crosses all services. The volume of data created by working in this way may be difficult to manage.  | Thank you for your feedback. We have removed ‘locally’ from the data source sections as we recognise that young people may be using specialist services outside their local area.We have clarified in the audience descriptors that where a named worker is in place, they will coordinate the transition plan. |
| 123 | Sussex Partnership NHS Foundation Trust | Question 2 | *yes - we can collect via electronic patient records system - not reliably recorded though*  | Thank you for confirming that it may be possible to collect data for the proposed quality measures and flagging concerns about reliability. |
| 124 | The Neurological Alliance | Question 2 | A variety of approaches should be used to collect the data necessary to monitor the equitable delivery of the proposed quality standard.Data and insights from young people and their parents or carers should be collected using routine patient surveys and other Patient Reported Experience Measures (PREMS). Approaches to collecting data and insight from clinical colleagues and local systems should also be considered and routinely compared with patient reported data and insights to ensure alignment and identify any areas of divergence.Paediatric and adult service health professionals and service managers should work together to plan and monitor, and agree on mechanisms to share information and data for service improvement. | Thank you for your feedback on the approach to data collection.  |
| 125 | The Royal College of Physicians of Edinburgh (RCPE) | Question 2  | Data can be collected locally but the lack of effective IT provision within health and social care limits the potential for shared digital data across healthcare services as well as across health and social care. There is also a need to acknowledge the role of education services for the younger cohort within the ‘transition’ age groups particularly in relation to mental healthcare needs, equipment requirements and social relationship needs.In Scotland the work of the Transitions Forum and development of the Compass app has highlighted the cumulative demands on the young person, parents/carers and professionals when transitions in all services (in healthcare within the service for each specialty) progress in different ways, with different age criteria and to different time scales, | Thank you for your feedback.To clarify, the scope of the quality standard includes health and social care services but does not include education for those without an education, health and care plan. We have recognised that the transition plan in statement 2 will be part of a broader plan for young people covered by health and social care or education legislation.It has been suggested by stakeholders that a [Federated Data Platform](https://www.england.nhs.uk/digitaltechnology/digitising-connecting-and-transforming-health-and-care/) (FDP) could support improved data collection across integrated care systems in future. |
| 126 | Together for Short Lives | Question 2 | We believe that this data can be collected. | Thank you for confirming that it should be possible to collect data for the proposed quality measures. |
| 127 | UK Cystic Fibrosis Medical Association | Question 2 | The data could be collected using the electronic patient records, but we may need to give some clerical support for this locally. Data collected at annual review when portCF is filled out may be able to be used, however there will need additional time for database managers or CF co-ordinators for providing this information. In hospitals whereby EPIC is in place, we may be able to collect data this way.  | Thank you for your feedback on the approach to data collection. |
| 128 | University Hospitals Birmingham NHS Foundation Trust | Question 2 | This data is not easily collected. Some specialities may hold registers or records of young people in transition, but this is in the minority in my experience. There is no Trust wide flag / alert to identify the patients that this measure would apply too. This is reflected in the NCEPOD recommendation number 10, there is no single, nationally agreed code to identify young people at any stage of transition within an organisation.It would be a challenge to identify patient records to even pull to then audit if there was a transition plan in place. A snapshot or dip sample audit by speciality using local knowledge of patients would be possible, but this would not be replicable or give assurances across the organisations transition activity. Reflecting on the process for the NCEPOD audit, data pulls were complex and required human review of cases to ensure that they were actually transition patients. Given there is no clear way to identify young people in transition, the only option is to search by date of birth. This creates huge volumes of young people without long term conditions, or with long term conditions that were attending for care outside of their disease pathways, for example minor injuries, maternity services or sexual health. It is hugely labour intensive and not a reliable process resulting in far from robust assurance.To coordinate a transition plan across pathways within a single organisation would be a challenge given that pathways may require transition at different points in time due the young person’s individual circumstances or the nature of service provision. Central electronic records and systems could support this but only if patient records had a process to identify transition plans that were completed. There would need to be infrastructure or process for young people transitioning into multiple pathways to identify a Consultant or team to take responsibility for the coordination of the plan, otherwise there is a risk that this would be repeated or omitted. This would require additional workforce in the shape of a navigator for example to coordinate across pathways and ensure that there was not repetition and that communication lines were open.To then coordinate with external services in cases whereby young people have complex needs met by community, primary care and hospices for example would be a huge challenge. Not least because of the need for IT infrastructures to enable the shared viewing of a centrally held document. You could make this patient held, but this is not without its issues and complexities. Given that transition as a process may take several years, to measure satisfaction would be complex. You would need to measure young people and parent carers satisfaction separately and they may not agree. Patient surveys are poorly completed by this cohort of patients. For example, in our organisation we have identified that young people under 25 are underrepresented across all feedback collected. | Thank you for your feedback on the challenges for data collection.We understand that NHS England may be developing new SNOMED codes that can be used for transition that will improve data collection in future. We agree that there is a need to develop data collection and for resources for improved co-ordination.It has been suggested by stakeholders that a [Federated Data Platform](https://www.england.nhs.uk/digitaltechnology/digitising-connecting-and-transforming-health-and-care/) (FDP) could support improved data collection and co-ordination across integrated care systems in future. |
| 129 | Versus Arthritis | Question 2 | Data on JIA treatment and care can be gathered from the following sources: * GP patient records
* Paediatric rheumatology
* Adult rheumatology

There is a lack of quality, accessible data on JIA prevalence, incidence, and treatment for all ages, particularly for 16 years + and this remains a serious issue. The UK Paediatric Rheumatology Clinical Studies Group[[8]](#endnote-8) suggests that to improve available data on children and young people with MSK conditions, opportunities to collect data in hospital settings should be maximised, data collection should be streamlined, and alternative patient-centred means of collating digital data should be explored. Further, Versus Arthritis and the British Society for Rheumatology have developed a JIA biologics register to measure the safety and effectiveness of biologics and biosimilar treatment for juvenile idiopathic arthritis.[[9]](#endnote-9) The register provides a very important data set that is enabling us to see long term impact of living with JIA in childhood and into adulthood which will shape care and treatment. It also provides greater insight into transition data e.g. two thirds of young people continue care when previously was thought to be less. | Thanks for your feedback on the challenges for data collection for JIA and young people with MSK conditions. |
| **Question 3: For draft quality statement 2: Do you think this statement would be achievable by local services given the net resources needed to deliver it? Please describe any resource requirements that you think would be necessary for this statement. Please describe any potential cost savings or opportunities for disinvestment.** |
| 130 | Alder Hey Liverpool | Question 3 | With investment this quality statement can be delivered. To deliver this quality statement resource would be required to develop capacity within clinicians job plans to deliver transition planning to C&YP and their families/carers; to develop and document a transition plan for the YP and document this in YP electronic patient records and to communicate and plan with adult providers to deliver joint transition/transfer clinics. Also with investment to adult services they would have capacity to provide a tour and introduction to adult environment prior to the YPs first visit to an adult health care facility No cost savings can be identified  | Thank you for confirming that the quality standard can be delivered if there is investment in resources for transition.  |
| 131 | ARC Scotland - Scottish Transitions Forum | Question 3 | Local services would need to be able to be better coordinated to be able to share this information. ARC Scotland Scottish Transitions forum have created a tool called COMPASS that helps young people and families let people know through data sharing if they have a plan or a coordinated plan and who has helped them. It’s a digital tool and would helpfully help evidence the guidelines you are suggesting from a service user point of view. You can read more about this in the principles of good transitions and the principles into practice framework at pn2p.scot  | Thank you for sharing details of how co-ordination has been improved in Scotland which can support improved data collection. |
| 132 | ARNS | Question 3 | We believe that this standard would be met if adequate resources, which include the personnel are in place to do this. We are aware that even some stand-alone Children’s Hospitals to not have adequate transition leads or transition teams in place to support the clinicians in fulfilling good quality transition and transfer to adult care.Not clear that there would be any cost savings, but if a young person’s transition was supported by professionals that had clear plans/pathways in place, this would improve the quality of the transfer for the young person and this may lead to young people attending the appointment with adult team. This in turn would prevent wasted hospital appointments. | Thank you for confirming that the quality standard can be delivered if adequate resources are in place. |
| 133 | Association of British Neurologists (ABN) | Question 3 | It might be achievable to have a co-ordinated plan from one service to another but would require considerable investment in workforce and potentially IT systems. The difficult deliverable will be co-ordinating it across multiple different adult services simultaneously and the increase in numbers in clinics required which with current workforce challenges would not be feasible. For this to be delivered there would need to be: 1. an increase in the number of transition care co-ordinators and specialist nurses in each area to help co-ordinate the various services2. an increase in specialist transition clinics (and therefore workforce increases in specialist nurses and consultants) across adult and child services which could potentially be virtual to allow multiple specialists available. 3. Information resources appropriate for the condition as well as appropriate for intellectual ability of the young person.4. Mulitple agency working across community services, hospital services, different trusts and primary care all with different record keeping systems would make this extremely challenging to be done well and may also require IT/admin resources 5. Additional time for MDT outpatient consultations would have to be appropriately coded/reimbursedThis extra provision could ultimately save money by reducing appointment DNA’s and reducing unnecessary hospital admission and primary care attendances due to lack of care provision. On a societal level, investing in young people with chronic medical conditions may well have long term economic benefits of increasing workforce and reducing long term benefit requirements. It may also reduce long term mental and physical health costs to the NHS as well as the social care cost savings. This is however a mission to provide a step change in quality of care which will require investment as any increase in quantity of care would. | Thank you for confirming that the quality standard could be delivered if there is appropriate investment in resources for transition and the potential benefits of doing so. |
| 134 | Association of Paediatric Chartered Physiotherapists | Question 3 | This will be challenging for existing paediatric physiotherapy teams. Frequently a multitude of services, both acute and community, will be involved with a young person so incorporating and co-ordinating all of these would be extremely challenging. Coordinating care between one speciality alone is challenging, i.e. Paediatric physiotherapy to adult physiotherapy. There is disparity already within age of transition, i.e. MSK service 16years, community service 18 or 19years. Within adult and paediatric community services there is a big difference between service models and delivery and what they will provide. Even within Adult Learning Disability physiotherapy team and adult community neurorehabilitation teams there is a big variation on what they will offer. Co-ordinating services at least within disciplines would be a good start but this is still a huge challenge. A resource from the adult physiotherapy teams would be useful for paediatric teams to give to young people transitioning as they will have more awareness/ knowledge on what can be offered but this is still just one small area so co-ordinating all services is challenging and who will take overall responsibility for this. A named worker / transition co-ordinator could support this but in practice will be difficult to implement without additional funding to ensure resource available for this.The other challenges facing families and YP is that within paediatrics they may have a paediatrician that coordinates care and links with therapies but a GP does not have the same joined up care or time to spent with the families. A central resource like the local offer/online having all the information for various services may be beneficial but unsure how this would be coordinated and access to this for all patient groups / languages’ needs would need to be considered to ensure equity of access to information.The lack of adult specialty services to support young people with chronic complex needs will impact onto the achievability of this statement and of transition overall. On leaving children services many young people and adults with complex needs end up under the care of their GP because there are not specialised services to provide holistic long-term care. This includes young people with complex lifelong physical disabilities such as cerebral palsy, rett syndrome and acquired brain injury. With no clear specialty service who can provide holistic care transition continues to prove very challenging. e.g. NICE QS191 quality statement 2: Annual review recommended by NICE for adults with CP who have complex needs should have an annual review with a healthcare professional with expertise in neurodisabilities. Young people and families are remaining under the care of their paediatric providers as an adult as without this they no longer have access to the services with expertise that they need. Commissioning of adult neurodisability specialist services who will offer screening / annual reviews are required in order to support coordinated transition plans and ultimately support successful transition into adult services. | Thank you for your feedback on the challenges for implementing this quality standard. |
| 135 | British Academy of Childhood Disability (BACD) | Question 3 | Some local services may need additional support to achieve this statement e.g. a clinical nurse specialist or transition co-ordinator to support the transition process or development of specific transition clinics e.g. joint between paediatric and adult clinicians. This would lead to cost savings in the long term by ensuring a smooth transition process and improved engagement of young people and families with adult services. | Thank you for confirming that the quality standard can be delivered if adequate resources are in place and the potential benefits of doing so. |
| 136 | British Association of Teachers of Deaf Children and Young People (BATOD) | Question 3 | Members report transition pathways with services are already in place with established transition meetings routinely occurring for the various transition pathways eg in house adult services (mainstream, and complex), transition to external adult services (NHS and other commissioned providers) (mainstream, and complex). However, the outcomes are not effective due to poor supporting infrastructure, in particular ineffective secure data-sharing/communication platforms between Health departments, between Health and education (local authorities and education settings).Co-ordinated transition plans should be accessible to all deaf children and young people eg Plain English, non-jargon based accessible reports. Related meetings should be held in acoustically suitable meeting spaces and accessible to the individuals needs of the deaf child/young people eg qualified registered British Sign Language interpreters, speech to text relay, lip-speakers. The adult audiology services need access to the assistive listening technology information that ensures the compatible with the hearing aid models required for the young person to maintain effective access to their further/higher education and employment environments. | Thank you for your feedback on the challenges for implementing this quality standard for deaf young people. |
| 137 | British Society of Physical and Rehabilitation medicine | Question 3 | No. Currently there is no resources in adult services for looking after the young adults. The transition teams in adult services mostly do develop protocol, educational material, engage in meetings, create awareness, conduct audits, etc. There is a genuine lack of services which actually see and manage young adults after transition. This requires allocation of resources to health care professionals who actually see and manage young adults. The roles on education, creating awareness etc, could be done in a more centralised fashion. This is ensure uniformity of services. The local resources should be allocated to hands-on care. The document need to specify the competencies and skills required and responsibilities of care coordinator/ Case manager. BSPRM recommend that the case manager should be a non-medical member of MDT, and should be employed by the host NHS trust or ICB . The case manager will take on board the overall responsibility.  | Thank you for your feedback on the challenges for implementing this quality standard.Statement 4 is focussed on a named worker and includes a definition for this role. |
| 138 | Brittle Bone Society | Question 3 | Every service has a different level of funding so would depend on the resources at each individual hospital/trust. Also having a coordinated transition plan is great if there is a service to transition to.And again what is meant by “local”. Child may live in Manchester, be in seen in kids services in Sheffield and be transitioned to an adult service in Sheffield (no input therefore needed locally form Manchester). Sharing a minimal clinical content will reduce variability of care and ensure at least a minimum standard is delivered. | Thank you for your feedback. We have emphasised the importance of involving the young person’s GP in transition planning in the definition of a co-ordinated transition plan and noted that this will be critical when the young person does not meet the criteria for specialist adult health services or there are no adults’ services in place.We have removed ‘locally’ from the data source sections as we recognise that young people may be using specialist services outside their local area.As this quality standard covers transitions in all settings across health and social care the specific details about the clinical content included in the plan will vary and will need to be determined locally. |
| 139 | Challenging Behaviour Foundation  | Question 3 | Yes, we believe that this statement is achievable by local services as existing legal duties (Care Act 2014) are in place that mandate assessing needs and planning to meet these needs as a mandatory requirement for all young people who are likely to need adult social care to have a transition assessment. Additionally, under the Children and Families Act, there are also existing legal requirements for children with an Education, Health and Care Plan (EHCP) to plan for transition. The Care and Support Statutory Guidance section 16.11 states that preparation for adulthood must occur at the beginning of year 9. The transition assessment should be undertaken and should inform a plan for the transition from children to adult care and support.Due to existing legal duties to plan for transition we believe that this statement is achievable for children and young people with complex needs who we represent, and local services should allocate sufficient resources to achieve it. A holistic transition plan increases the chances of a successful transition - and decreases the likelihood of support and services breaking down or being insufficient for the person's needs which in turn leads to crisis and greater human and financial costs. | Thank you for confirming that the quality standard can be delivered and the potential benefits of doing so. |
| 140 | Child Growth Foundation | Question 3 | Monitoring of patients moving through transition needs to be accurate as it is easy for patients to ‘get lost’ in the system. It relies on a professional to have some way of keeping records of who should be moving to adult services and when; databases have been used successfully in a local Trust to ensure that anyone moving up to adult services is followed up appropriately. This has also reduced the ‘was not bought/did not attend’ rate in that service (cost saving) | Thank you for your feedback and information on how improvements in transition have been implemented locally.We have amended outcome b) to focus on the rate of non-attendance at meetings or appointments in adults’ services for young people who were expected to transfer from children's to adults' services. |
| 141 | Children with Exceptional Healthcare Needs networkNSS CEN – NHS Scotland National Services | Question 3 | This could be achievable by local services if the role of coordinator is defined and recognised across all services with clear job description, appropriate training and supervision and the authority to implement the person centred/co-created plan in the locality where the young person currently lives and in whatever locality they will move to in adulthood. | Thank you for your feedback on implementing the quality standard. |
| 142 | Clinical Genetics Society | Question 3 | Funding for provision of ‘transition clinics’ is a longstanding challenge in Clinical Genetics with limited available resources. Specific genetics transition clinics are provided for some types of genetic conditions, in some geographic areas, but there is no clear national or standardised approach to provision, or any funding from commisioners to support this aspect of our service. Given how stretched Clinical Genetics services are currently, it is difficult to identify any other potential cost savings or areas for disinvestment. | Thank you for your feedback on the challenges for implementing this quality standard. |
| 143 | Communication Matters (ISAAC UK Ltd) | Question 3 | Augmentative and Alternative Communication (AAC) users, whether using paper based or powered resources, are a small but unique group of individual young people who need ongoing and individualised support. This requires a greater investment in support during the period of transitions throughout life, and not less support, cost saving or disinvestment. Putting in place robust resources before transition to support young people ongoing, and for the longer term, will reduce mental health costs, and ultimately other health and social care costs over life. There is evidence that many young people once they have access to robust AAC have less behavioural issues. Without robust communication it is impossible to achieve the fundamentals of life from saying you are hungry or thirsty to discussing pain or expressing views and opinions. Without a speech and language therapist in adult life it is virtually impossible to achieve an AAC assessment (or reassessment), get alternative support when equipment breaks down or when equipment becomes obsolete. Outside of education there is no-one to support developing vocabulary for life and this can ultimately lead to social isolation rather than AAC users being able to contribute effectively within their families and communities. There are other transition scenarios where the support of health and social care professionals would benefit AAC users such as moving into independent living and training communication partners. | Thank you for your feedback on the challenges for implementing this quality standard for AAC users. |
| 144 | Derby and Derbyshire Integrated Care Board | Question 3 | The shared care record is of vital in transition, but this is only for health. We feel that the due to the use of EHCPs, there could be potential savings could come from a shared system/shared care record across a system rather than individually (doesn’t yet include transition nor does shared care yet include social care)  | Thank you for your feedback on the challenges for implementing this quality standard. |
| 145 | Diabetes UK | Question 3 | This statement is achievable by local services but the practical considerations of having the right workforce with suitable workloads are essential to make it so. In particular, having a designated transition lead, such as a transition nurse, in post is vital to ensuring a smooth and seamless transition from children to adult services. A designated transition lead would also provide a point of contact between health care professionals and children, young people, their families and carers. There are a number of resources available that can support the process of transition planning which are not particularly costly to implement – for example the Ready, Steady, Go programme - but having a designated person to lead on transition is essential. There is little benefit in having a transition plan but a lack of healthcare professionals to deliver it successfully.  | Thank you for your feedback on the challenges for implementing this quality standard. |
| 146 | Duchenne UK | Question 3 | Transition and care coordinators for groups of diseases are important to deliver this statement locally. Without dedicated, trained staff to develop individualised transition plans with families and clinical teams and manage their implementation, this statement will not be achievable across the UK and delivery will be patchy at best. For neuromuscular diseases for example, this has previously been provided in part by charity funding. This has not been sustainable or reliable and allocated funding to provide this coordinator role is essential to achieve nationwide adherence to this recommendation. Cost savings would be significant because care and transition would be effectively coordinated to maximise efficiency of appointments, minimise travel for patients – many with disabilities – facilitate MDT coordination for clinical staff, reduce missed appointments, increase treatment adherence and promote independence for young adult patients as they leave paediatric and enter adult services. Signposting to additional support services – including psychosocial support - to promote independence and high quality of life has the potential to decrease the costs of avoidable more acute intervention later on. | Thank you for your feedback on the challenges for implementing this quality standard and the benefits of doing so. |
| 147 | Faculty of Pain Medicine of the Royal College of Anaesthetists | Question 3 | Partially, data collection is achievable but may require additional provision of local resources – clinical, nursing, admin time. Having an improved pathway will ultimately ensure a smoother transition of care which will be a cost saving compared to a young adult failing to engage and representing with greater need later.  | Thank you for your feedback on implementing the quality standard. |
| 148 | Faculty of Pharmaceutical Medicine | Question 3 | Extra resources will be needed to coordinate care for rare disease as there are few patients with them some extra resources for national coordination will be needed and linkage to the existing databases | Thank you for your feedback on implementing the quality standard. |
| 149 | Genetic Alliance UK | Question 3 | Yes, a named person responsible for a young person’s transition process may be best placed to coordinate the collection of this data. There is also the extra work necessary to write the plan and deliver it. In a challenging economic environment, the future value of this small investment needs to be clearly stated.We believe this will be cost-saving in the medium term. There is clear evidence to show that there are better health outcomes from a successful transition. For many conditions this translates to better management with fewer crises and acute care episodes which should translate to a cost-saving for the health service.The consequences of a poor transition, such as poor mental health and poor compliance with treatment are expensive and would be reduced.  | Thank you for your feedback on implementing the quality standard and the benefits of doing so. |
| 150 | Great Ormond Street Hospital (GOSH) | Question 3 | If specialist services are required, then a coordinator should be able to facilitate this, however this is also dependent on how many services are involved with the young person, as there may not be a lead for each condition. There can be big implications for local services. Concerns around young people attending appointments and whether there is an established transition service.Should we think about social care or a transitional support worker? Youth support workers could be useful, these would support up until 25yrs but cover the social side of transition and not the specialist input required for some health conditions, ensuring an holistic approach to transition can be achieved. There needs to be clear understanding and identification of who bridges the gap between children-adult services. Linking in with Education Health and Care Plan (EHCP) – is a Team Around the Family (TAF) meeting helpful? We have held TAF meetings leading up to transition so that all children’s services know what they are doing to prepare and also the family are informed. This has worked well. OI example – transition clinic where GOSH and Stanmore meet with the young person for first meeting and there is a pre meeting between the professionals to hand over any concerns/issues.There are challenges between simple/complex transition in that health has moved on over the years and children who would previously been palliative or low life expectancy in their early years are now living longer and the adult health setting is not resourced or educated to take them. This poses a barrier and adult centres will not accept the referral. E.g., cleft is only done in children and there is no adult f/u – therefore gosh keep cleft into adulthood to mitigate for this if there are complexities. A new model of adolescent/adult care is required that are given the skills and education to take this new patient group.A standardised digital patient and family survey form that can be accessed by any organisation to generate feedback to reduce duplication and reduce paper use with a central hub to collate data which can be separated into organisation specific groups.  | Thank you for your feedback on the challenges for implementing this quality standard. |
| 151 | Kent and Medway NHS and Social Care Partnership Trust | Question 3 | * This is not achievable by local services due to the current supply/demand; there are too many children/young people needing support, without the infrastructure or resources to deliver this level of input.

In terms of potential cost savings or opportunities for disinvestment, the digitalisation of some of the services could contribute to this outcome. However, it is important to note the issue of tech poverty and the implications of this for the general population. | Thank you for your feedback on the challenges for implementing this quality standard. |
| 152 | Metabolic Support UK | Question 3 | Effective transition plans ensure that resources are expended in the right areas and that the patient is receiving the correct care. This means although resources will be expended on developing the transition plans, then there will be resources saved due to patients receiving the right care, at the right location, at the right time.Given the additional resources that may be needed, there may be a case to approach the integrated care boards responsible for overseeing the [integrated care systems](https://www.kingsfund.org.uk/publications/integrated-care-systems-explained) (ICS) to make a case for allocating ring-fenced funding specifically for the development of effective transition plans to enact this quality statement. This may be a particularly good route to explore given the four key aims of ICS, shown below:* Improving outcomes in population health and health care
* Tackling inequalities in outcomes, experience and access
* Enhancing productivity and value for money
* Helping the NHS to support broader social and economic development.

With regards to our communities, persons living with IMDs are at particular risk of falling out of care during periods of transition due to the lack of knowledge about these conditions and lack of services.Resources need to be allocated to ensure continuity of care so the NHS can uphold the principle to “do no harm” as failing to effectively transition our communities to adult services means the worsening of symptoms which can lead to disability and potentially death. | Thank you for your feedback on implementing the quality standard and the benefits of doing so. |
| 153 | Midlands Partnership University NHS Foundation Trust | Question 3 | Services that provide continuity of care across children to available adult services could achieve this. However commissioning gaps and omissions restrict onwards transfer or referral potentially creating uncoordinated continuous care,Capacity and demand are also an issue for services - particularly where waiting lists are ongoing post pandemic. There are no transition leads to co-ordinate- this could lead to fragmented inconsistent transition journeys.No cost saving has been identified. | Thank you for your feedback on the challenges for implementing this quality standard. |
| 154 | National Confidential Enquiry int Patient Outcome and Death (NCEPOD) | Question 3 | ‘[The Inbetweeners](https://www.ncepod.org.uk/2023transition.html)’ report showed that there was only senior executive or managerial input into transition in around 50% of organisations. Plans can save time by coordinating efforts and save money by improving health outcomes but these are both difficult to measure and cross organisational boundaries – so investment in transition services will cost money in one part of the system and potentially save money in another. Having a plan is not the same as using it and the discussions with the young person may well take more time if done well. Clinical nurse specialists as key workers have a central role but under 40% of young people had a documented key worker to help implement the plan. | Thank you for your feedback on implementing the quality standard and the benefits of doing so. |
| 155 | National Deaf CAMHS (North) | Question 3 | This statement would need a lot of consideration about who holds responsibility for coordinating transitions and what input would be needed from specialist services (e.g. Deaf CAMHS), if any. This is needs to be clear so that young people do not fall between the gaps, otherwise there is also no accountability. | Thank you for your feedback on implementing the quality standard. |
| 156 | National Network of Designated Healthcare Professionals for Children | Question 3 | We now live in a world of integrated care systems which should be used to facilitate this standard. Having a transition plan is a must-do, but for them to succeed, there will need to be guidance for plan ownership and guidance for the methodology to draw up such plans. We have no views on cost savings or disinvestment.  | Thank you for your feedback on implementing the quality standard. |
| 157 | National Organisation for FASD | Question 3 | Staff need to be trained in understanding FASD and the persons needs during transition. NICE QS 204 highlights the need for training. There needs to be a specialised FASD key worker to manage the transition. | Thank you for your feedback on implementing the quality standard. |
| 158 | National Rheumatoid Arthritis Society | Question 3 | A co-ordinated transition plan would most probably be developed with the family and a paediatric nurse specialist. Non-specialist nurses would be much less aware of the young person’s needs, medication regime etc. and so delivery of this would require the appropriate number of nurse specialists and we are aware of the current workforce shortages. In Juvenile Idiopathic Arthritis (our specialty) there have been adult rheumatologists who have historically seen numbers of children with Juvenile Idiopathic Arthritis and developed a level of expertise in paediatric rheumatology. Some / many of these consultants have now retired, which has meant these young people have had to travel further to the nearest paediatric rheumatology centre, adding further workload to often, already, overstretched services. Where an adult rheumatologist with an expertise in paediatric rheumatology has retired, and the service has not been re-commissioned to treat children and young people, savings will have been made. | Thank you for your feedback on the challenges for implementing the quality standard. |
| 159 | NHS England | Question 3 | * Adult services also need to be fully engaged, both strategically and operationally, in order for the plans to be successful and accurate.
* Challenges around engaging adult services in this. Clarity about what this would involve, who coordinates and who holds the plan would be crucial.
* For children with EHCPs this would align with the year 9 annual review but for children on SEN support this would be harder.
* In our view, it could be achievable as it should already be a core part of the conversation in key meetings e.g Care Programme Approach/reviews, CETR and monitoring sessions.

Yes but would require implementation of a transition pathway for most services that does not currently exist. Cost savings would be achieved through fewer GP appointments for re-referral to adult services. | Thank you for your feedback on implementing the quality standard and the benefits of doing so. |
| 160 | NHSE Sheffield response | Question 3 | Annual meeting as minimum, may need more frequent meetings. Meetings must be multidisciplinary and include psychosocial care and need admin support. All subspecialities must communicate with each other and across services – children’s to adult and vice versa, and include social care and education as required. | Thank you for your feedback. The rationale for statement 3 makes it clear that meetings may need to be more frequent than annually to meet individual needs. The definition makes it clear that all practitioners providing support should input to the meeting. |
| 161 | NHSE specialised commissioning | Question 3  | Q3 Response: there would need to be clarity of whom and how staff in primary care would be identified as transition plan co-ordinators. It is likely that more resources would be needed and that this might need to be negotiated into GP contracts.This is likely best for local services to comment on but ideally they would need some co-ordination roles to do the oversight, management and chasing of information and data for the local transition plans. | Thank you for your feedback on implementing the quality standard. |
| 162 | Nottinghamshire Healthcare NHS Foundation Trust | Question 3 | National coding set.Shared record keeping systemsConsideration for digital collaborative Transition plans.Systemwide Transition steer for collaboration.National Guidance – what constitutes a Plan? Where is it held? Etc. | Thank you for your feedback on implementing the quality standard. We understand that NHS England may be developing new SNOMED codes that can be used for transition that will improve data collection in future.We have highlighted to our guideline surveillance team that further clarity on the transition plan may be helpful.  |
| 163 | NSA for PCC NHSE | Question 3 | Not really feasible in PCC alone.Maybe able to be tracked in LTV | Thank you for your feedback on implementing the quality standard. |
| 164 | RCPCH | Question 3 | Models and Transition Programming :Transition models and interventions have been studies amongst different patient groups demonstrating some success in achieving better outcomes for their population (Crowley 2011; Koshy 2009; Prestidge 2012; Nieboer 2014; Tuchman 2010). Through development and research over the past 20 years, standard components of transition models have been suggested to include; • An organizational timeline, policy or guideline for transition; • Coordinated tools and interventions (readiness preparation)for all stakeholders (youth/ families and care providers); • Standardized care processes and transfer documentation; • Tracking patients requiring, utilizing, and lost to follow-up; • Monitoring impact and evaluation (patient health outcome, patient experience and cost savings); and • Experience of youth and families for further improvements (Canadian Paediatric Society 2014; Brodie 2010; Grant 2011; Nieboer 2014; Mcmanus 2015; Joly 2015; Suris 2015; Tuchman 2010; Van Staa 2015).A Shared Management Approach: These components can only be operationalized through a sharedManagement approach between the youth themselves, families and care providers (Amari 2011; Gall 2006).  | Thank you for your feedback. |
| 165 | Research in Practice | Question 3 | To deliver a good quality, evidence-informed and co-produced plan for transition including all of the key partners and stakeholders would have a resource implication- and it is the practice that should be taking place. If transitions into adult services are done well, this can support cost avoidance later (where costs are incurred through ineffective / unsuitable care packages) and can play an important part in reducing risk (current research highlights the role of ineffective transitions planning in SARs and CSPRs for 16-25 year olds – Cocker, in press).  | Thank you for your feedback on implementing the quality standard and the benefits of doing so. |
| 166 | Royal College of General Practitioners  | Question 3 | Increased funding to primary care will be needed to undertake the following:* Initial case finding which would be more efficiently undertaken if a patient’s needs for future transition of medical care were recorded at the age when the disability or long-term illness was first identified.
* 6 monthly repeat case finding to check and record patients who have recently joined the practice or developed long-term illness or disability.
* Recall
* Review repeated (annually or 6 monthly) until satisfactory transition occurs.

Additionally, funding will be required to train members of respective adults' services on anthropometric, emotional, and developmental growth of children and young people as well as on the management and processing of pharmacological requests and laboratory data. Furthermore, appropriate communication aids relevant to the needs of children and young people, will require funding.  | Thank you for your response. Feedback from stakeholders at consultation suggested that more resources are required for transition generally and in particular investment is needed in staff and IT systems to support coordination across services. There was agreement however that improving transition is an important priority and a suggestion that Integrated Care Systems are ideally placed to address some of the barriers currently in place. On balance, stakeholders felt that the new statement on having a transition plan does not require additional resources to those already needed to implement improvements in transition generally. |
| 167 | Royal College of Nursing | Question 3 | In terms of a co-ordinated transition plan, there is often reference to there being a named co-ordinator or key worker. This may be difficult to achieve depending on the case load numbers. Often, clinical staff do not have time factored within their job plans to take on this important role. For this to be achieved, there needs to be careful planning as to what the role entails and how time can be realistically factored into job plans. | Thank you for your feedback on implementing the quality standard. |
| 168 | Royal College of Occupational Therapists (RCOT) | Question 3 | Transitional care is not just about the move to adult services. It is about equipping young people with the skills and knowledge to participate in their communities and live healthy meaningful lives. Occupational therapists work across health, education, social care, employment and other sectors so are positioned well to support and coordinate transition plans. We are skilled in carrying out ‘what matters to me’ conversations, using this information to develop transition plans that address individual goals and priorities. This is particularly important as young people grow and take greater responsibility for managing their own health, care and wellbeing.   However, like all health and social care professionals we are facing unprecedented workforce challenges. Consideration must therefore be given to ensure appropriate staffing levels - including occupational therapists - to enable effective transition planning and support.     | Thank you for your feedback on the challenges for implementing the quality standard. |
| 169 | Somerset Foundation Trust | Question 3 | Yes but it is dependent on buy in from clinicians. As the NCEPOD report recommends Transition activity needs to be included in job plans in both children’s and relevant adult services. | Thank you for your feedback on implementing the quality standard. |
| 170 | Spinal Muscular Atrophy UK | Question 3 | A co-ordinated plan would need an allocated transition worker to take responsibility and organise review meetings etc. This is happening in different ways in geographical pockets across the country, so it would be good to look at what is already being done in different areas and share best practice. For example, EHCP processes includes a yearly review, so could this co-ordinated transition plan use these existing processes and resources. Transition planning feels ad hoc currently and for a co-ordinated plan, this needs a national approach.  | Thank you for your feedback on implementing the quality standard. |
| 171 | Sussex Partnership NHS Foundation Trust | Question 3 | this would represent a challenge given all the other pressures on system at present - a service model whereby transitions workers are embedded in AMHS community teams would aid this process and also ensure involvement from AMHS during the transition process | Thank you for your feedback on the challenges for implementing the quality standard. |
| 172 | The Neurological Alliance | Question 3 | As highlighted in response to question 1, given the challenges identified with delivering care and support plans and ensuring access to a named worker to support the transition process between paediatric services (quality statement 4), there are significant resource concerns around the deliverability of the proposed quality statement. This includes workforce concerns both in term of number of staff and job planning to ensure adequate time is allocated to codesigning personalised transition plans. Effective planning and support during the transition process, including through equitable delivery of the proposed quality statement, could deliver cost savings as well as improving patient outcomes and experience. Potential cost savings include reduced DNAs, urgent and emergency care admissions and primary or secondary care appointments necessary for referral back on to a care pathway for people who are removed from pathways and unable to access the routine care and support necessary to effectively manage their condition due to challenges with the transition process. | Thank you for your feedback on the challenges for implementing the quality standard and the benefits of doing so.We have amended outcome b) to focus on the rate of non-attendance at meetings or appointments in adults’ services for young people who were expected to transfer from children's to adults' services. |
| 173 | The Royal College of Physicians of Edinburgh (RCPE) | Question 3 | This could be achievable by local services if the role of coordinator is defined and recognised across all services with a clear job description, appropriate training and supervision and the authority to implement the person centred/co-created plan in the locality where the young person currently lives and in whatever locality they will move to in adulthood. | Thank you for your feedback on implementing the quality standard. |
| 174 | Together for Short Lives | Question 3 | **Do you think this statement would be achievable by local services given the net resources needed to deliver it?**We believe that the statement would be achievable if services have access to the resources to implement it – and if commissioners, young people and their families have the support they need to fulfil their roles.**Please describe any resource requirements that you think would be necessary for this statement** We believe that adult palliative care services need to acknowledge, plan and develop their services around the needs of young people with life-limiting or life-threatening conditions. They need to:* work alongside children’s services to help them to prepare for transition to their care
* feel more confident about talking with young people
* better understand young people’s health conditions
* create environments that better cater for their needs.

Adult palliative care teams should consider providing specific team members who focus on the care of young adults. These team members could also link in with young adults who develop conditions in adulthood, as there will be crossover into this patient population.Services need access to equitable and sustainable funding - and sufficient skilled and experienced people – to provide services that can meet NICE quality standards. Professionals working in children’s and adult palliative care services, whether in the NHS or the voluntary sector, including children’s hospices, need sufficient time to plan transition with young people with life-limiting or life-threatening conditions. We estimate that there is a £301million gap in NHS spending on children’s palliative care in 2023/24.Our research shows that, in 2022/23, children’s hospices provided an increasing level of around the clock care and support that should be funded by NHS in hospices and in family homes, including:* services to manage symptoms, including pain, to 51% more children
* short breaks for respite to 9% more children and families
* end of life care to 4% more children.

The costs of providing this care grew by 13% from £3.61 million in 2021/22 to £4.07 million in 2022/23. Nearly all (93%) of children’s hospices say this resulted from the higher costs of recruiting and retaining staff. Two thirds (66%) attributed them to higher energy prices. Just over half (59%) said costs were higher because they had increased their activity.Current integrated care board (ICB) funding is patchy and nowhere near the level that will sustain the crucial hospice services that children and families need. In 2022/23, children’s hospices received an average of £532,923 from NHS clinical commissioning groups and ICBs, which is 23% less than they received from CCGs (the predecessors of ICBs) in 2021/22.Overall this funds 13% of children’s hospices’ charitable expenditure, but there is wide variance between individual children’s hospices: three children’s hospices received over 30% of their charitable expenditure from CCGs/ICBs, whereas in contrast 10 others received 5% or less of their charitable expenditure from CCGs/ICBs. While models of children’s hospice services vary between providers, this level of variation in funding cannot be justified.NHS England (NHSE) plans to continue £25 million of grant funding for children’s hospices in 2024/25. We welcome this, although we await news of how the money will be distributed to children’s hospices. We continue to call for children’s hospices to have access to equitable, multi-year NHS funding to make sure the lifeline care and support they provide is sustainable for the long-term.Currently, there are too few professionals with the skills and experience needed to provide children’s palliative care in hospitals, children’s hospices and in the community. Together for Short Lives has found that:1. **There are too few community children’s nurses (CCNs) employed by the NHS:** CCNs provide the bedrock of children’s palliative care. If safe staffing levels recommended by the Royal College of Nursing (RCN) were being adhered to, 5,500 CCNs would be working in England. Yet, as of June 2023, there were only 893 community children’s nurses employed by the NHS in England. While other NHS nurses do provide community-based care to children, this is an indicator of the shortages in this crucial part of the sector.
2. **There are too few specialist children’s palliative care consultants:** The Royal College of Paediatrics and Child Health (RCPCH) estimates that 40-60 specialist children’s palliative care consultants are needed in the UK. Worryingly, there are currently only 18 in England. This suggests a significant deficit of 22-42 consultants.
3. **The growing vacancy rate in the non-medical care and support vacancy rate in children’s hospice charities is higher than in the NHS – and posts are increasingly difficult to fill:** In 2022, the average vacancy rate for roles equivalent to Agenda for Change bands 2-9 inclusive (including nurses) for children’s hospices charities in England is 18.4%. The average vacancy rate for roles equivalent to Agenda for Change bands 5-9 inclusive (which we have historical data for) is 18.6%, compared to 12.2% in 2019, 11% in 2016 and 10% in 2015. The NHS nursing vacancy rate in quarter three of 2021/22 was 10.5%[1], which is also worryingly high. Two thirds (67%) of vacant posts in children’s hospices were proving hard to fill (vacant for three months or more), which is unchanged from 2019. 65% reported that posts were hard to fill in 2016 and 57% in 2015. Just under a quarter (24%) of posts had been vacant for over 12 months, compared to 25% in 2019.
4. **There are too few skilled professionals to fill vacant posts in children’s hospices:** 92% of children’s hospices cite an overall lack of professionals as a significant or very significant factor in the vacancy rates they are experiencing, compared to just over a half (58%) in 2019.
5. **There are shortages among other health and care professionals who support seriously ill children and their families:** in England in 2021, the overall vacancy rate for children and family social workers in England was 17%.

We believe that additional resources may be needed to make sure NHS commissioners are aware of the guidance and best practice available to them to plan and fund services that work together, and with young people, and their families and carers, to develop and agree a co-ordinated transition plan for the move to adult services.Many young people with severe cognitive impairments will need support to articulate and reach their goals in life. Independence may look different for these young people, but the same strengths-based approach should be used to enable them to communicate their future aspirations and plan ahead within a person-centred framework. This approach should enable them to develop socially, emotionally and psychologically so they can lead fulfilling lives in which they are supported to achieve their goals.Parents have identified some key areas that they would like to see improved and which would help them to feel more prepared and confident in supporting their young person into adulthood, for example:* Understanding more about their family’s rights.
* Learning how the health and care system works when moving from children’s to adult services.
* Learning tips and techniques to help increase their confidence when meeting professionals.
* Being able to make the best use of time when meeting with practitioners.

We believe that families need more support to help them better understand how the care and support offered by adult palliative care services will differ to those offered by children’s services. This is particularly important as transitions often occur at a time when the young person’s health is deteriorating.Families and carers of young people may need support to be involved in process of developing a transition plan. This may include breaks from providing care to enable them to attend meetings and provide information. Such breaks would need to provided by professionals and services who can meet the often complex needs of young people with life-limiting or life-threatening conditions.**Please describe any potential cost savings or opportunities for disinvestment**The transition from paediatric to adult healthcare is associated with an increase in emergency hospital visits for young people with life-limiting conditions, but not for young people with diabetes or no long-term conditions (Jarvis, S., Flemming, K., Richardson, G. et al. Adult healthcare is associated with more emergency healthcare for young people with life-limiting conditions. Pediatr Res 92, 1458–1469 (2022). <https://doi.org/10.1038/s41390-022-01975-3>). By investing in approaches which ensure that young people can access high quality, sustainable palliative care when and where they need it, including at home and in hospices, NHS organisations may be able to reduce the demand for unplanned and emergency acute care.A cost consequence analysis of projects funded by Together for Short Lives’ *Improving Transitions for Young People Fund* found that they represented relatively low cost interventions which apparently generated substantial benefits for patients and families (<https://www.togetherforshortlives.org.uk/app/uploads/2022/06/YHEC-TFSL-Improving-Transition-for-Young-People-Final-Report-4.5.22.pdf>)  | Thank you for your feedback on the challenges for implementing the quality standard and the benefits of doing so. |
| 175 | UK Cystic Fibrosis Medical Association | Question 3 | The data can be collected on this locally using the ready steady go programme, but there will need to be increased provision of services. There could be cost savings if transition is performed well, then there will be less need for a young person needing admission, and additional care. Also, if a young adult does not engage in adult services, they may end up presenting late, not on the correct treatments with long term lung disease. | Thank you for your feedback on implementing the quality standard and the benefits of doing so. |
| 176 | University Hospitals Birmingham NHS Foundation Trust | Question 3 | I do not think that currently local services would be able to achieve this. I think that individual pathways would be able to implement the use of a transition plan into their services, but to be able to share this would require extensive resource both internally and across the wider system.Resource requirements would include,* Workforce – with time to complete the transition plan in the first place i.e. clinic time, time acknowledged in job plans, MDT members with transition or young adult in their job title. New infrastructure and roles to coordinate young peoples with complexity across multiple specialities to include MDT coordination, navigator posts etc
* Training for the workforce (tiered to reflect the level and engagement intensity of work with young people) to understand the developmentally appropriate health care needs of young people and be able to adapt this to each individual young person and their situation to then complete a holistic plan.
* Systems and processes in place to be able to share any plans both internally within an organisation and externally with relevant providers
* Data systems that enabled identification of young people in transition to audit the standard (amongst many other things)
* Administrative support to support the clinical staff delivering all of the above

Cost saving – investing in young people has been shown to save money in the long term as they are our adult patients of the future. There is extensive evidence to demonstrate that a quality transition experience reduces morbidity and mortality. Self-confident and health literate young people can manage their own health needs and this ultimately reduces contact with health in times of crisis. Investing in a good transition process would be a short term investment long term gain. | Thank you for your feedback on the challenges for implementing the quality standard and the benefits of doing so. |
| 177 | Versus Arthritis | Question 3 | Yes, but this requires leadership at executive level and across trust services to ensure coordination and implementation. We recommend that local trusts follow the recommendations set out in the NCEPOD Inbetweeners Report. [[10]](#endnote-10)Local trusts/boards should convene an overarching transition team to provide a one stop shop model of holistic care. The team should include:* A senior exec with responsibility for developing transition policy and strategies.
* A senior manager responsible for the implementation of the transition policy and strategies.
* Engage with young people and their parents/carers to be involved in the design of services
* Co-ordinate the age when transition starts.
* Co-ordinate the transition if multiple specialties are involved.
* Provide access to a key worker before, during and after transfer (this seems the most salient recommendation, after point 1).
* Ensure young person is transferred at a time of relative stability and that their readiness for transfer is assessed holistically.[[11]](#endnote-11)
 | Thank you for your feedback on implementing the quality standard. |
| 178 | WellChild | Question 3 |  No – short staffing levels and transition is not routinely written in to job descriptions unless it is a specific focus of a clinical role. Transition should be embedded in to band 7 and up clinical roles as standard or specific transition professionals need to be identified/employed in some areas both on the adult and child services side. Children who are disabled or have complex needs are now living longer so the resources and services which pick them up in adult services need to be better prepared to receive them. | Thank you for your feedback on the challenges for implementing the quality standard. |
| **Question 4 For draft quality statement 6: We have suggested that this statement could be measured based on attendance at any of the first 3 meetings or appointments in adults’ services. Is this a helpful definition of initial appointments? If not, please suggest an alternative.** |
| 179 | Alder Hey Liverpool | Question 4 | Ensuring YP attend and remain engaged with adult health care services is hugely important to the health and life outcomes of each YP; to keep them health and well and prevent avoidable health deteriorations that may lead to an avoidable ED presentation or hospital admission.Measuring attendance to capture compliance of YP attending adult services (after transition/transfer) would be for adult services to deliver. This would require a whole system approach across each adult organisation, which would require investment.An alternative would be to invest in embedding the 10 steps transition pathway nationally which has two joint transition appointments, one at step 6 where paediatrics lead the consultation with the YP and family/carer( if YP wishes them present) and adult service also present. The second joint visit is step 9 and would be held and led by adult services with the YP and someone from the clinical team from paediatrics. This would be the first appointment and the YP would then be discharged from paediatric care, however follow up appointments for the YP in adult services would need to be closely to for the first year or until the YP is confident and settled into adult services  | Thank you for your feedback.To clarify, statement 5 is focussed on meeting a practitioner from adults’ services before transfer. Statement 6 is focussed on follow up if the young person does not attend their initial meetings or appointments in adults’ services. |
| 180 | Alexion, AstraZeneca | Question 4 | We agree that this definition is proportionate. | Thank you for your support for the proposed definition. |
| 181 | ARC Scotland - Scottish Transitions Forum | Question 4 | We think this is a good measurement for Health care but this might be different for services who work in coordination with health such as social work or social care services. | Thank you for your support for the proposed definition. We have amended the definition to ‘any one of the first 3 meetings or appointments or any meeting or appointment within the first 12 months in each adults’ service but can be adapted to fit local service characteristics’ to reflect the variation across services. |
| 182 | ARNS | Question 4 | Yes 3 meetings/appointments would be a helpful definition of initial appointments. However, it needs to be noted that some young people will be transferred to more than one professional in adult care – will this be 3 meetings/appointments with each professional or 3 in total in adult care facility. | Thank you for your feedback.The data source makes it clear that this should be the first 3 meetings/appointments in each adults’ service. |
| 183 | Association of British Neurologists (ABN) | Question 4 | Most trusts will be under enormous pressure to deal with the ever growing list of new patient referrals. Two appointments may be more pragmatic.Also the interval for 3 appointments could be much longer than 6-12 months. Putting a temporal limit on would be useful.Could you say: “Either 3 meetings/appointments or 12 months, whichever comes first”. | Thank you for your suggestion. We have amended the data source for the process measure to suggest a timescale of within the first 12 months as an alternative. |
| 184 | Association of Paediatric Chartered Physiotherapists | Question 4 | This update is important and yes helpful as many young people / families may attend the first appointment and then disengage because they were unsatisfied. Instead of measuring this on attendance at any of the first 3 meetings or appointments it may be more effective to measure attendance over a longer term e.g. are they still engaged at one year and two years – this would be more meaningful. Paediatric services could also be providing a follow up review a year after they’ve left paediatrics (virtual / telehealth) to ensure transition into adult services has gone as per the co-ordinated plan so that if there are issues they can support re-engagement with adult services. This could also be one of the roles of a transition co-ordinator.  | Thank you for your suggestion. Longer term engagement is captured in outcome b) Proportion of young people attending adults’ services after transfer from children’s services who continue to engage with services (defined as engagement at 1 or 2 years after transfer or engagement at a specific age (such as 25 years) but can be adapted to fit local service characteristics).There are no recommendations on paediatric follow-up review after transfer to adults’ services in the NICE guideline on transition (NG43). |
| 185 | British Academy of Childhood Disability (BACD) | Question 4 | Perhaps this should be based on the first 2 meetings or appointments rather than 3, to avoid a long delay in young people being reviewed in adult services and therefore a gap in care / treatment.  | Thank you for your feedback. We have amended the definition to ‘any one of the first 3 meetings or appointments or any meeting or appointment within the first 12 months in each adults’ service but can be adapted to fit local service characteristics’ to reflect the variation across services. |
| 186 | British Association of Teachers of Deaf Children and Young People (BATOD) | Question 4 | BATOD partially agrees with that the “statement could be measured based on attendance at any of the first 3 meetings or appointments in adults’ services.” However, members report the deaf young people transitioning to higher education ie relocating from home to a new area for university, college, employment are often overwhelmed with all the new transitions experiences. Therefore, the wording may need to recognise the scenario of adult services, particularly third party commissioned services, that are in a new geographical location for the young person. | Thank you for your feedback. We confirm that this statement will apply if the young person has been transferred from children’s to adults’ services in a new geographical area. It will not apply, however, if the young person is transferring from one adult service to another adult service in a new area. |
| 187 | British Society of Physical and Rehabilitation medicine | Question 4 | Yes. We should also monitor the efforts made to contact the person. A routine DNA letter each time they miss an appointment is not sufficient. There should be a designated person who will make attempts to ring the person, do a home visit if required, contact GP, contact children’s hospital , contact social services, schools, parents etc to understand the reasons behind non-engagement.  | Thank you for your feedback. The definition of further opportunities to engage in statement 6 makes it clear that this should not just be a standard letter after each missed appointment. |
| 188 | Brittle Bone Society | Question 4 | Many young people transitioning are possibly moving away from home, going to Uni. May only have 1 appointment per year. Change address, change phone numbers etc. Not sure how realistic this is in practice, however in theory yes it is helpful. | Thank you for your feedback. We have amended the definition to ‘any one of the first 3 meetings or appointments or any meeting or appointment within the first 12 months in each adults’ service but can be adapted to fit local service characteristics’ to reflect the variation across services. |
| 189 | Challenging Behaviour Foundation  | Question 4 |  This quality statement at present does not fully reflect some of the difficulties faced by young people with severe learning disabilities and complex health needs and their families, which could result in them missing initial appointments. Some young people with severe learning disabilities whose behaviour challenges, find change difficult, and also attending meetings may be problematic. For example, the young person may refuse to attend a number of appointments due to this difficulty with change and/or experience of anxiety, or because of when or how the meetings are arranged. It would be helpful to highlight in this statement: 1. **Reasonable adjustments**

Under the Equality Act 2010, there is a legal duty to make reasonable adjustments for disabled people. In terms of this population, services are legally required to make adjustments to assist young people and their families to overcome difficulties they may face with transitioning into adult services. To avoid discrimination against these individuals' services are legally required to make reasonable adjustments to their policies and procedures to ensure equality of access. As a result, it would be helpful to specifically reference the duty to make reasonable adjustments to overcome barriers to attendance Reasonable adjustments should be recorded as a reasonable adjustment flag. This is an anticipatory duty and therefore reasonable adjustments should be planned in advance. For further information see: [Reasonable Adjustment Flag - NHS Digital](https://digital.nhs.uk/services/reasonable-adjustment-flag)Furthermore, a policy that imposes a blanket rule of discharge after three missed appointments may be unlawful. Policies should specifically reference that reasonable adjustments will be made to any standard criteria to discharge a person after non-attendance. Examples of reasonable adjustment for children and young people with severe learning disabilities include: 1. Providing photos of the building and staff for family carers/support staff to show to the person in advance of their appointment.
2. Desensitisation – offering the opportunity for the person to visit the building just to familiarise themselves with the environment without having to engage with the professionals and have an appointment.
3. Working with the person and people who know them to identify an alternative environment that they would be comfortable in to hold the meetings/ appointments
4. **Communication**

Some young people with severe learning disabilities lack capacity to make the decision about whether or not to attend an appointment themselves. Therefore, best interests' decisions may need to be made. Family carers report that correspondence does not always go to the right person at transition or is not always addressed to the relevant person when their relative in unable to read and write and manage their correspondence. This may lead to appointments being unintentionally missed.  Therefore, the approach to further engagement opportunities may need to take a different path for young people who lack capacity to consent to attendance at an appointment in line with the Mental Capacity Act 2005. Due to this, ensuring that the right person receives the information for the adult services transition appointment is vital.  | Thank you for your feedback.We have added an equality consideration to highlight that health and social care practitioners should consider any specific needs relating to disability when working with young people who have not attended their initial meetings or appointments in adults’ services. They should consider if reasonable adjustments can be put in place that will encourage future attendance.We have also highlighted in the audience descriptors that young people who do not attend their initial meetings or appointments and do not respond to follow-up are not discharged from the service but are referred back to the named worker or children’s service.There is an existing equality consideration that highlights that service managers should ensure a range of support is available, and used, to help young people communicate effectively when adults’ services engage with them.  |
| 190  | Child Growth Foundation | Question 4 | Yes however contact by adult services should not wait until 3 missed appointments. Engagement with the young person should be initiated/ attempted straightaway a plan can be formed together | Thank you for your feedback. We have amended the audience descriptors to make it clear that further opportunities to engage should be offered after any one of the initial appointments are missed. |
| 191 | Children with Exceptional Healthcare Needs networkNSS CEN – NHS Scotland National Services | Question 4 | This is an acceptable first step but needs to be better defined to acknowledge how these appointments have been issued with regard to the impact on the young person and their carers as well as the transport required to access the adult clinical settings, the number of different sites and specialties involved. Is this covering 3 out of all the adult appointments, are there agreed priority appointments, has the young person and their carers been involved in the planning of the appointments with support for communicating any need to alter appointments? | Thank you for your feedback.We have amended the definition to ‘any one of the first 3 meetings or appointments or any meeting or appointment within the first 12 months in each adults’ service but can be adapted to fit local service characteristics’ to reflect the variation across services.The definition of further opportunities to engage identifies that practitioners should try to understand the reasons for not attending and identify any changes that could be made to encourage attendance in future. |
| 192 | Clinical Genetics Society | Question 4 | As detailed above this outcome measure is not relevant to assessing the transition aspects of genetic conditions, as Clinical Genetics services cover paediatric and adult patients. | As previously, please note that the focus of this quality standard is on young people who will move from children’s to adults’ services. Young people who remain under the care of the same clinician regardless of age are not included as no transition is required. |
| 193 | Communication Matters (ISAAC UK Ltd) | Question 4 | This would work, providing the young adult is on the radar for appointments for adult services. However, there is an assumption that young people using Augmentative and Alternative Communication (AAC) have been receiving ongoing speech and language therapy support or AAC support. Sadly, this is not the case for most young people. It is much more likely that they have either been provided with resources and then with an effective intervention in place ongoing implementation is left to classroom professionals, and they are signed off from ongoing therapy. Or alternatively have never received an AAC assessment (See case studies A, B, C, D above). If asked young people using AAC resources, and their families, would like to be receiving ongoing communication support but this is not the case at present. If they have not been receiving individual appointments in an educational setting, and this is not noted in their Education, Health and Care Plan (EHCP) then it is likely they will ‘fall off a cliff face’ of provision and ongoing support because they will not get invited to an initial meeting with adults’ services regarding their communication needs. This is exacerbated if a young person moves into higher education as ongoing all requests for support or assessment have to initially go through a new GP who doesn’t have specialist knowledge of AAC, nor the young person, for instance, in the case of adults with cerebral palsy there is no existing care pathway despite NICE guidance. Whilst guidance has been adopted for adults with learning disabilities the NICE guidance is in this specific case of more focused on behaviour and AAC is not mentioned specifically, yet AAC strategies are known to be hugely beneficial. The existing NICE guidance for adults with autistic spectrum disorders and cerebral palsy suggests that whilst AAC might be beneficial there is little/no research with adults to back this up and recommends further research is needed. Individuals who are entering adults’ services with established AAC strategies and resources should not be at risk of losing essential communication tools because no research exists for their cohort(s). | Thank you for your feedback.Please note that the focus of this quality standard is on young people who will move from children’s to adults’ services. If they have been discharged from paediatric services they will not be covered by this quality standard. If young people using AAC are transitioning with other health and care services however we have included an equality consideration to ensure that service managers ensure a range of support is available, and used, to help young people communicate effectively when adults’ services engage with them. This could include having a written record of how a young person prefers to communicate, such as a communication passport or 1-page profile, and different ways to help the young person communicate, such as communication boards, digital communication tools and advocacy. |
| 194 | Derby and Derbyshire Integrated Care Board | Question 4 | very helpful statement as these young adults are often not followed up. Reasonable adjustments to be considered – still need to potentially need to continue to use 'was not brought' if a young person with a disability relies on being accompanied to an appointment/ | Thank you for your feedback.We have added an equality consideration to highlight that health and social care practitioners should consider any specific needs relating to disability when working with young people who have not attended their initial meetings or appointments in adults’ services. They should consider if reasonable adjustments can be put in place that will encourage future attendance.As the statement is focussed on attendance in adult services, we have not amended the wording to ‘was not brought’. We have, however, clarified in the audience descriptors that ‘were not brought to’ could be an alternative to ‘do not attend’. |
| 195 | Derby and Derbyshire Integrated Care Board | Question 4 | This is of particular significance  | Thank you for your feedback. |
| 196 | Diabetes UK | Question 4 | We would advise changing the basis of this statement to state action is taken if young person does not attend 2 of their initial appointments. For a young person with diabetes, missing 3 appointments could potentially mean they would not be seen again for a year or more. This could have significant negative consequences for diabetes management, especially if annual reviews are missed and key measures like average blood glucose has not been checked. They could also potentially miss access to other services they may require such as mental health support and pre-conception. It is important that appointments are tailored to meet the needs of the individual and a flexible approach is taken where possible, especially as many young people will be embarking on college, university or employment and may require appointments at days/times when they are available, for example during holiday when they return home from University.  | Thank you for your feedback.We have amended the definition to ‘any one of the first 3 meetings or appointments or any meeting or appointment within the first 12 months in each adults’ service but can be adapted to fit local service characteristics’ to reflect the variation across services.We have amended the audience descriptors to clarify that practitioners should give young people further opportunities to engage before referring back to the children’s service or named worker rather than discharging them from the service. |
| 197 | Duchenne UK | Question 4 | If the aim is to gauge whether or not the child or young person engages with their *initial* appointments, then a criterion of the first 3 meetings or appointments in adults’ services is adequate. This is because while there are problems with this criterion (noted in the paragraph below), regardless of the inconsistencies it would be a measure of success for initial engagement.The problem with this measure is that it could be defined in vastly different ways. Would 3 different meetings on the same day with the cardiac specialist, respiratory specialist, and the endocrine specialist count as success? Would it be the meeting with the named individual responsible for coordinating the transition once a year for 3 years? Perhaps it’s a meeting with their GP? We can foresee a large variance in how this could be counted/recorded.Furthermore, attendance at an appointment is not a measure of engagement. Perhaps a measure of attendance to (at least part of) an appointment without a parent or carer would be more indicative. Sometimes this may not be appropriate – clinicians could be asked to assess whether the young person has engaged with the appointment (although there are clear operator bias issues here). Clinicians should be guided to ensure they speak and interact directly with the patient (young person/adult with the condition) rather than to the parent, carer or accompanying person. This will be hard to measure but is important to promote to increase the chances of engagement. | Thank you for your feedback.We have amended the definition to ‘any one of the first 3 meetings or appointments or any meeting or appointment within the first 12 months in each adults’ service but can be adapted to fit local service characteristics’ to reflect the variation across services.We appreciate that attendance is a proxy measure for engagement with services. It can, however, be monitored across most systems and services and we therefore feel it is the most appropriate measure to use.There is an equality consideration so that service managers ensure a range of support is available, and used, to help young people communicate effectively when adults’ services engage with them. |
| 198 | Faculty of Pain Medicine of the Royal College of Anaesthetists | Question 4 | Potentially, the initial period within adult services can be quite daunting so engagement initially with nursing staff or AHP may be more acceptable than consultant or medical appointments which may be perceived as daunting or more formal.It also depends on what is classed as appointments in adult services. If it refers to consultant new appointment, and follow up, then this is not achievable or measurable, as the management plan may be either to refer on to physio, psychology or self-management, and rarely be seen again in adult pain clinic. It could be better described as engaging for initial appointments at each service which is deemed appropriate, eg attendance at initial consultant review, and engagement with onward services, such as physio or psychology. | Thank you for your feedback. We expect that local areas will agree which clinicians should be involved and this may vary depending on the specific needs of the young person.We have amended the definition to ‘any one of the first 3 meetings or appointments or any meeting or appointment within the first 12 months in each adults’ service but can be adapted to fit local service characteristics’ to reflect the variation across services. |
| 199 | Faculty of Pharmaceutical Medicine | Question 4 | If the person transitioning is involved in a research program, which many are, can the appointments be linked to attendance at research visits. How long will the named worker be with the person transitioning. What measures are in place for caregiver support | Thank you for your feedback.We expect that local areas will be responsible for any co-ordination of appointments with research visits.The NICE guideline on transition (NG43) highlights that the named worker should support the young person for the time defined in relevant legislation, or a minimum of 6 months before and after transfer (the exact length of time should be negotiated with the young person). (recommendation 1.2.9)Please see the [NICE guideline on supporting adult carers NG150](https://www.nice.org.uk/guidance/ng150) and the [associated quality standard (NG200)](https://www.nice.org.uk/guidance/qs200) for information on support for carers, |
| 200 | Genetic Alliance UK | Question 4 | Yes, although it is important to understand that young people who require transition from paediatric to adult services often live with chronic or life long conditions, such as rare genetic conditions. It is therefore not uncommon that a young person falls ill on one or more of their first appointments with adult services. Further opportunities to engage should therefore not be limited. | Thank you for your feedback. |
| 201 | Great Ormond Street Hospital (GOSH) | Question 4 | Who will be responsible for the young person if they do not attend their initial adult appointments? / At what point would service ownership officially transfer from paediatric services to adult services. Currently paediatric services are needing to do additional work for patients lost to follow up when transferred into adult services. Should there be a time frame in addition to three meetings as patient appointments may reduce in frequency in adult settings and potentially miss safety risks. Appointment frequency will also vary based on services; therefore 3 appointments may not occur within the first year. What happens if there are delays due to national wait times first appointment is over 1 year from initial referral? Who is responsible and funded to look after these patients if pathway is completed from paediatric point of view? Should there be alerts for safeguarding concerns/vulnerabilities? How would this differ for Looked After Child (LAC) as a national responsibility up to 25years, therefore this should be reflected in the document as to who takes lead for this cohort of patients. Therefore, it must be clear about the differences required for safeguarded children/young adults.Paediatric nurses must spend lots of time following up outpatient appointments to ensure children are not missed if there are delays in the adult services due to long waiting times. Is this guidance in keeping with the National Was Not Bought guidance? How does this match with Adult Did Not Attend (DNA) guidance. DNA terminology of adults rather than I ‘Was Not Bought’Significant anxiety felt by child on transition about the unknown and scary prospects of adult care – could there be consideration of a title change to the appointment that might remove some of the anxiety – importance of languageWill there be transition clinic including paediatric and adult services to transition more effectively and age appropriate to bridge the children-adult gap. This would reduce anxiety and support both child and medic. | Thank you for your feedback.The focus in statement 6 is on adult services offering further opportunities to engage if the young person does not attend their initial meetings or appointments following transfer. The definition of further opportunities to engage indicates that if adult services are not able to engage the young person, they should refer them back to the named worker or the children’s service.We have amended the definition to ‘any one of the first 3 meetings or appointments or any meeting or appointment within the first 12 months in each adults’ service but can be adapted to fit local service characteristics’ to reflect the variation across services.We have added an equality consideration to statement 6 to make it clear that health and social care practitioners should consider any specific needs relating to disability, leaving care or where someone lives when working with young people who have not attended their initial meetings or appointments in adults’ services. They should consider if reasonable adjustments can be put in place that will encourage future attendance.As the statement is focussed on attendance in adult services, we have not amended the wording to ‘was not brought’. We have, however, clarified in the audience descriptors that the statement applies to young people who do not attend (or were not brought to) their initial meetings or appointments following transfer. We would expect that offering further opportunities to engage may include consideration of the title of the appointment but will be responsive to the young person’s needs.Statement 5 is focussed on meeting a practitioner in each adults’ service before transfer and we understand that joint appointments and clinics with paediatric services are one way that this is being implemented. |
| 202 | Kent and Medway NHS and Social Care Partnership Trust | Question 4 | * There needs to be a clearly defined path for meetings and definition of 3 meetings gives services a direction of work.
 | Thank you for your feedback. |
| 203 | Metabolic Support UK | Question 4 | This needs to clarify what is meant by the first three meetings. Is this the third meeting attended in adult services independently or does it include any joint clinics or adult service appointments where the patient has been supported by a healthcare professional as part of the transition process. This could be interpreted differently.**Process (statement 6):** Assumptions made that every no-show is contacted. In an environment where staff are already stretched e.g., IMD services, this may not be the case. | Thank you for your feedback.The focus in statement 6 is on attendance at the initial meetings or appointments following transfer from paediatric services. We would not expect joint clinics to be included in this as they should be held before transfer. |
| 204 | Midlands Partnership University NHS Foundation Trust | Question 4 | Is this statement assuming all adult services will offer 3 appointments? I don’t think this is widely available? If this is not the case this is not measurable.I think this needs to be more specific to the first meeting – and an assumption that the CYP will be offered at least 2 appointments and will have a period of time that is open so they can contact adult services for an appointment. | Thank you for your feedback.We have amended the definition to ‘any one of the first 3 meetings or appointments or any meeting or appointment within the first 12 months in each adults’ service but can be adapted to fit local service characteristics’ to reflect the variation across services.This statement has been broadened beyond the first meeting because stakeholders suggested that young people may attend the first but not subsequent appointments. |
| 205 | National Confidential Enquiry int Patient Outcome and Death (NCEPOD) | Question 4 | Yes. In ‘[The Inbetweeners](https://www.ncepod.org.uk/2023transition.html)’ report we found instances of significant poor health outcomes due to non-engagement with adult services. Looking at the first meeting only will not capture those young people who disengage after an initial poor experience in adult care. | Thank you for your feedback. |
| 206 | National Deaf CAMHS (North) | Question 4 | Concerns raised about potential access/communication barriers contributing to failure to attend appointments which may impact future engagement with services. All documentation/methods of communication should reflect the YP and family’s preferences/needs which links back to the accessibility points mentioned above. Difficulties accessing communication support initially may result in lack of trust in services and impact engagement/transition. Contacted by adult services in the way that the young person prefers e.g. video call with a BSL/English interpreter, at a time that facilitates engagement for them such as afternoons.  Have they nominated someone to help/facilitate this e.g. advocate/carer? | Thank you for your feedback.The statement includes an equality and diversity consideration to ensure communication needs are addressed. |
| 207 | National Network of Designated Healthcare Professionals for Children | Question 4 | Three appointments is good and mirrors a lot of local “was not brought “ (formerly did not attend) policies. Access to services for complex patients is critical and should be a consideration when young people are not brought or do not attend.  | Thank you for your feedback. |
| 208 | National Network of Parent Carer Forums | Question 4 | Whilst this is a reasonable measure of “initial appointments” it does not reflect the needs of families. Engagement work should start earlier, and not wait for 3 missed appointments. Where 1 appointment is missed, engagement work should begin. We should be enabling families to engage with appointments from the start, not waiting until several have been missed – especially when many hospital trusts have policies of discharging patients after 1 hospital appointment.  | Thank you for your feedback.We have amended the definition to ‘any one of the first 3 meetings or appointments or any meeting or appointment within the first 12 months in each adults’ service but can be adapted to fit local service characteristics’ to reflect the variation across services.The audience descriptors and definition clarify that young people who do not attend their initial meetings or appointments and do not respond to follow-up are not discharged from the service but are referred back to the named worker or children’s service |
| 209 | National Organisation for FASD | Question 4 | People with FASD are likely to need support to attend meetings. Letters to people with FASD should be easy-read but some people with FASD may still struggle to open the letter, others will struggle with comprehension, some with remembering the appointment and getting to the appointment (or all of them). Reasonable adjustments should be made and not assume a failure to engage. | Thank you for your feedback.The statement includes equality and diversity considerations to ensure reasonable adjustments are in place and communication needs are addressed. |
| 210 | National Rheumatoid Arthritis Society | Question 4 | 3 appointments may be okay if the gap between appointments does not amount to more than 2 or 3 months, but given the current backlogs of people waiting to be seen, this may not be possible. Therefore, if the gaps between the appointments amounted to anything longer than 3 months, we feel this could be unsafe for the young person. We think 2 failed appointments would be safer, and in an ideal world a phone call should be made after the first did not attend (DNA) to identify the cause. We believe it is helpful to include the new outcome measure to capture ongoing engagement with adult services.  | Thank you for your feedback.We have amended the definition to ‘any one of the first 3 meetings or appointments or any meeting or appointment within the first 12 months in each adults’ service but can be adapted to fit local service characteristics’ to reflect the variation across services. |
| 211 | NHS England | Question 4 | * We suggest there could also be a focus on; number of appointments offered, and number attended. This could be taken from electronic data.
* Perhaps something about giving choice of on-line and F2F meetings where appropriate and that both count.

Yes this provides commissioners with a clear definition | Thank you for your feedback. We have included an outcome measure on rate of non-attendance at meetings in statements 1 to 5 in the quality standard. For statement 6, however, we have focused the measures on young people rather than appointments.We would expect that consideration of the format for the meeting will be considered when offering further opportunities to engage in response to the young person’s needs. |
| 212 | NHSE Sheffield  | Question 4 | Sounds good. | Thank you for your feedback. |
| 213 | NHSE specialised commissioning | Question 4  | See NICE document page 30[Statement 6](#x__Quality_statement_56:) Young people who have moved from children’s to adults’ services but do not attend their initial meetings or appointments are contacted by adults’ services and given further opportunities to engage. **[2016, updated 2023]****Rationale**Young people need to engage with adults’ services so that they continue to receive the care and support they need. When young people disengage from services during transition it can affect their future health, mental health and social care needs.Q4 response: yes this is as good a way of measuring the data there is, provided that there is clarity of the minimum data set that will need to be prospectively collected. Due to timing of appointments where multiple clinicians/service are seen, it is possible that there is always a delay in the timeliness of the data. It is, though, an extremely good idea that someone is identified locally to contact the young person to check if their care and support plan is still right and whether they need any other help to get back in touch with the service.It is important to be realistic about what adult services may offer, which may not be the same as paediatric services. It will not be a like-for-like, especially in local adult services. | Thank you for your feedback.We have amended the definition to ‘any one of the first 3 meetings or appointments or any meeting or appointment within the first 12 months in each adults’ service but can be adapted to fit local service characteristics’ to reflect the variation across services. |
| 214 | Nottinghamshire Healthcare NHS Foundation Trust | Question 4 | This is a suitable measure. | Thank you for your feedback. |
| 215 | NSA for PCC NHSE | Question 4 | I think it is but again – does not necessarily apply to PCC as we do not have outpatient services and most children are under joint care of another specialty.Could apply to LTV | Thank you for your feedback. |
| 216 | RCPCH | Question 4 | The Triple Aim developed by the Institute for Health Care Improvement, has been proposed as a framework for evaluation of transition efficacy and impact ( 2). The Triple Aim consists of three measures: patient experience of care, population health and cost. Patient experience of care includes satisfaction, enablers and barriers to care. Population health includes adherence to care guidelines, disease specific outcomes, mortality, patient-reported outcomes of quality of life and functional status, self-care skills, and process of care. Cost measures include service use, short term and longitudinally, gaps in care, cost of no shows, and cost per patient accessing outpatient care versus emergency care versus inpatient care ( 3). A recent international Delphi survey, showed consensus to start planning transition at an early age (at least one year before transfer boundary) and if developmentally appropriate (Peters 2011; Suris 2015). Studies on readiness to transfer also recommend; relatively stable disease/ conditions; youth has a relationship with a community-based physician; and demonstrates independence in health care. The process is complete once the young adult not only transfers to the adult system but is actively participating (to the level of his/her ability) in activities, appointments, health care surveillance, self management and decision making (Leung, 2011; Telfair 2004). A “one size fits all” model for preparing youth to transfer to adult care is not possible. Transition needs to be an individualized, coordinated and collaborative process between the youth, family and paediatric and adult care providers, occurring over time and spanning both adolescence and early adulthood (4) . Understanding of this unique developmental period, by paediatric and adult providers, can help to facilitate transition for those with special health care needs (5). Additionally, a growing pool of quantitative data reflects poor clinical outcomes post transfer. For example, prior to initiating a transition program in Manitoba, 40% of young adults with type 1 diabetes dropped out of adult health care 3 resulting in an increased risk of amputation, blindness and even death. Another study found that prior to initiating a transition program in British Columbia kidney transplant patients had worse health outcomes, including a (6) percent incidence of graft loss and/or death within two years of transfer 4Youth with chronic health conditions may also experience gaps in care during the years immediately following transfer(7) . Data show transitioning from paediatric to adult care is associated with decreased clinic attendance (8), impeding the management of a chronic health condition and leading to an increased risk that young adults will not receive care until after complications arise (9).  | Thank you for your feedback. |
| 217 | Research in Practice | Question 4 | It probably needs to be broader than ‘attend’ there’s something about them attending and reporting a positive experience of feeling engaged. There’s a problem with the framing of this quality statement as its rationale *is Young people need to engage with adults’ services so that they continue to receive the care and support they need. When young people disengage from services during transition it can affect their future health, mental health and social care needs.*This is placing the onus on the young person to ‘attend’ and ‘engage’ there is no onus in the statement for adults services to adapt their offer to actively support and engage young people in transition. The framing of young people disengaging is not helpful- it’s not that they are disengaging it is often that the services are not set up in a way that meets their needs. | Thank you for your feedback.We have revised the wording in the rationale to emphasise the role of services to support young people to engage and meet their needs. |
| 218 | Royal College of General Practitioners  | Question 4 | This recommendation is not in line with the recent guidance to change “DNA” to “was not brought” on recording non-attendance at paediatric outpatient clinics. It should be amended to state that if a CYP does not attend the **first** appointment, the GP and patient/carer/named worker should be contacted as we know this reveals a high incidence of addressable social and practical problems. Access to the adult services needs to be suitable for the disabilities and emotional, physical, and developmental growth of the child/young person. It is important to acknoweldge that more CYP with disability are born into families living in socioeconomic deprivation and if the family is not living in such deprivation initially, the presence of a CYP with disability in the family often reduces the socioeconomic standard of the family. | Thank you for your response. As the statement is focussed on attendance in adult services, we have not amended the wording to ‘was not brought’. We have, however, clarified in the audience descriptors that the statement applies to young people who do not attend (or were not brought to) their initial meetings or appointments following transfer. The statement was originally focused on attendance at the first appointment only, but stakeholders suggested that it should be broadened as some young people may attend the first appointment and then not attend after that. We have amended the definition to make it clear that the young person should be contacted if they do not attend any one of the first 3 meetings or appointments or any meeting or appointment within the first 12 months in each adults’ service. We have suggested, however, that this definition can be adapted to fit local service characteristics. |
| 219 | Royal College of Nursing | Question 4 | This is helpful.A few points for consideration:There may be large time gaps between appointments. How frequently are the offered appointments? If it may be a 6 monthly review how soon after the non-attendance would the young person/family/carer be contacted? Also, it is important to explore the reasons for non-attendance and that there is a clear local policy that is adhered to.Some young people may be entering adult services at different ages, for example, a young person living with type 1 diabetes may remain within children’s services up until their 19th birthday. At the point of their care moving to adult services they may well be moving away for college/university etc – there needs to be clarity as to how the clinical teams are managing this additional transition within a young person’s life. Our understanding is that one can only be registered with one primary health care provider at a time. If a young person is moving away, do they maintain registration with their ‘home’ primary care provider or do they transfer to another provider where their college/university is? Do they then have to transfer back during term time etc? This is not an easy process to navigate, so due consideration needs to be given to the impact and feasibility of navigating this transition. | Thank you for your feedback.We have amended the definition to ‘any one of the first 3 meetings or appointments or any meeting or appointment within the first 12 months in each adults’ service but can be adapted to fit local service characteristics’ to reflect the variation across services.We have added information to the definition of ‘further opportunities to engage’ to clarify that ‘the adults service should try to understand the reasons for not attending and identify any changes that could be made to encourage attendance in future’.We confirm that this quality standard will apply if the young person has been transferred from children’s to adults’ services in a new geographical area. It will not apply, however, if the young person is transferring from one adult service to another adult service in a new area. |
| 220 | Royal College of Occupational Therapists (RCOT) | Question 4 | We agree that monitoring and enabling young adults’ engagement with adult services at the point of transition from children’s services is essential, and that it is appropriate to measure attendance at any of the first 3 appointments in adult services. This requires accurate and consistent coding, including capturing non-attendance and cancellations by the individual and/or service provider.   | Thank you for your feedback. |
| 221 | Somerset Foundation Trust | Question 4 | The definition is problematic as it is dependent on clinical need. For diabetes that would be reasonable but for rarer disease where appointments might be annual this would require monitoring for 3 years. Also paediatric colleagues would need access to adult IT systems | Thank you for your feedback.We have amended the definition to ‘any one of the first 3 meetings or appointments or any meeting or appointment within the first 12 months in each adults’ service but can be adapted to fit local service characteristics’ to reflect the variation across services. |
| 222 | Spinal Muscular Atrophy UK | Question 4 | We have worked with many young people who have missed appointments, not because they don’t want to engage with the service, but because the appointment hasn’t been accessible for them. Considering other means of access should be prioritised, discussing with the individual and their family how any barriers could be overcome and identifying the best communication methods for them.Services should provide appointments that are realistic for people with different needs, eg reasonable time to allow for travel, accessible building, parking and the option of virtual appointments should be given where appropriate.  Appointments are more likely to be attended and engaged in if services don’t threaten to discharge. Young people are more likely to engage with services if they provide information on what the processes are and what will happen at the appointments as well as individualised information for them and what will they get out of it. If the above is unclear, people are more likely to disengage and drop off the radar.  | Thank you for your feedback.We have added an equality consideration to statement 6 to make it clear that health and social care practitioners should consider any specific needs relating to disability, leaving care or where someone lives when working with young people who have not attended their initial meetings or appointments in adults’ services. They should consider if reasonable adjustments can be put in place that will encourage future attendance.There is also an equality consideration that requires service managers to ensure a range of support is available, and used, to help young people communicate effectively when adults’ services engage with them.We have also highlighted in the audience descriptors that young people who do not attend their initial meetings or appointments and do not respond to follow-up are not discharged from the service but are referred back to the named worker or children’s service. |
| 223 | Sussex Partnership NHS Foundation Trust | Question 4 | 3 DNAs is our standard following which the DNA policy should be followed - key issues are ensuring the young person was actually aware of the appointments, that some flexibility was offered, that lead practitioner in AMHS has made attempts to contact not just by letter but also text as this is often preferred means of contact.  | Thank you for your feedback. |
| 224 | The Neurological Alliance | Question 4 | The suggested measure based on attendance at any of the first 3 meetings or appointments in adults’ services is a helpful definition of initial appointments. This should refer to the first 3 appointments that are suitable for the patient as well as the service. If a patient or service rearranges an appointment this should not be counted as one of the first 3 meetings or appointments. | Thank you for your feedback.We have amended the definition to ‘any one of the first 3 meetings or appointments or any meeting or appointment within the first 12 months in each adults’ service but can be adapted to fit local service characteristics’ to reflect the variation across services. |
| 225 | The Royal College of Physicians of Edinburgh (RCPE) | Question 4  | This is an acceptable first step but needs to be better defined to acknowledge how these appointments have been issued with regard to the impact on the young person and their carers as well as the transport required to access the adult clinical settings, the number of different sites and specialties involved. Is this covering 3 out of all the adult appointments, are there agreed priority appointments, has the young person and their carers been involved in the planning of the appointments with support for communicating any need to alter appointments? | Thank you for your feedback.We have amended the definition to ‘any one of the first 3 meetings or appointments or any meeting or appointment within the first 12 months in each adults’ service but can be adapted to fit local service characteristics’ to reflect the variation across services.We have added an equality consideration to statement 6 to make it clear that health and social care practitioners should consider any specific needs relating to disability, leaving care or where someone lives when working with young people who have not attended their initial meetings or appointments in adults’ services. They should consider if reasonable adjustments can be put in place that will encourage future attendance. |
| 226 | Together for Short Lives | Question 4 | Yes | Thank you for your feedback. |
| 227 | UK Cystic Fibrosis Medical Association | Question 4 | We think that this is a good measurable standard/outcome measure, but propose that a questionnaire might be a more accurate reflection of the transition process and may be more tailored to the response of individuals.We would also suggest if there is non-attendance at the first few appointments that checks need to be made that the contact details and addresses are correct, and only then would we call this true non engagement. | Thank you for your feedback.Statements 1 to 5 include outcome focussed measures on young people and their families and carers satisfaction with planning for transition. We have, however, added patient or client surveys as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services in statement 6.The definition of further opportunities to engage specifies that the adults’ service should try to contact them and their family or carers. We would expect checks of contact details to be part of standard processes for follow up. |
| 228 | University Hospitals Birmingham NHS Foundation Trust | Question 4 | While this is helpful to a point and an improvement on the original standard, I think that this is very pathway dependent and would need to be set locally given the clinical risk of DNA / WNB. For example, annual hearing aid checks carry a low risk but frequent reviews post renal transplant would carry more significant risks of harm. This is also dependent on the individual young person and their circumstances. There would need to be a shared agreement between paediatric and adult elements of the pathway around metrics to ensure that they were practical in the context of the clinical risks posed.  | Thank you for your feedback.We have amended the definition to ‘any one of the first 3 meetings or appointments or any meeting or appointment within the first 12 months in each adults’ service but can be adapted to fit local service characteristics’ to reflect the variation across services. |
| 229 | Versus Arthritis | Question 4 | We agree that young people should not be removed from adult services for missing an initial appointment. The young people in Versus Arthritis’ young person’s panel have spoken about missing their initial meetings through no fault of their own (appointment not communicated by text, letter) and being removed from adult services lists. When a young person misses the first initial appointment, it is recommended that HCPs contact the young person to ascertain the reasons for missed appointments and where possible offer an appointment at another convenient time. We also recommend that care-experienced young people should be given extra consideration as their lives can be unpredictable. We recommend that a transition ‘flag’ be added to the electronic patient record to show the person is new to the service and must be contacted in the event of non-attendance. This will enable the health professional to see that the person has recently transitioned from paediatric health services and must be contacted for follow up. The impact of being removed from adult services could be detrimental to the young person’s health. For example, being removed could lead to them struggling to access their medication, fall off their medication, or their disease could get worse. Fundamentally, all of this can be avoided by following up with a person if they not attend their first few medical appointments in adult services.  | Thank you for your feedback.We have added an equality consideration to statement 6 to make it clear that health and social care practitioners should consider any specific needs relating to disability, leaving care or where someone lives when working with young people who have not attended their initial meetings or appointments in adults’ services. They should consider if reasonable adjustments can be put in place that will encourage future attendance.We understand that NHS England may be developing new SNOMED codes that can be used for transition that will improve data collection in future. |
| 230 | WellChild | Question 4 | Yes agreed | Thank you for your feedback. |
| **Question 5 For draft quality statement 6: Can structure measure a) on arrangements to monitor and assure transitions from children’s to adults’ services be measured in practice? If so, how? Please let us know of any examples where this is already collected.** |
| 231 | Alder Hey Liverpool | Question 5 | To measure and monitor transition and the compliance of attendance in adult services for the YP, joined up electronic patient records would be an accurate method to capture this; this may be costly.At AHFT a SOP based on the 10 steps transition pathway has been co-produced with paediatric, adult acute and community health care providers to support the safe and seamless handover/transfer of care of our most complex YP who have neuro-disability, via a MDT meeting (usually held virtually- meet and greet) with the YP and family, paediatric and acute/community adult services in attendance. This model ensures that all services are invited/aware of the date of transfer of care of the YP; the YP and family meet their new teams, are given contact numbers. Annual cohort meetings identify these complex C&YP and therefore we are aware when each YP leaves paediatric care and is formally transferred to adult services and discharged from AHFT  | Thank you for your feedback.We have added data sharing platforms as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 232 | ARC Scotland - Scottish Transitions Forum | Question 5 | In social care there are systems in a place if people do not attend appointments or assessments or reassessments or reviews. These vary across authority and what systems they use to track this. If transitions meetings are happening in schools (from year nine as stated in previous guidelines) then these meeting should/must /might occur as part of education planning and this would be a good place to start tracking attendance or none attendance.  | Thank you for your feedback. |
| 233 | ARNS | Question 5 | Yes, a structured measure would be useful and be a valuable measurement in assessing the quality of the transfer. No examples of a tool available to share, but if there is a robust pathway in place for the transfer of care. Communication networks, are usually in place and posters and papers have already been presented at National and international conferences about the young person’s feedback. It might be worth approaching Alder Hey Respiratory Nursing team, as they have presented on the transition of care from Paediatric Severe asthma services to adult Asthma Services.  | Thank you for your feedback.We have added patient or client surveys as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 234 | Association of British Neurologists (ABN) | Question 5 | Yes outcome a) is measurable – services usually have an indicator of number of DNAs in place already and patients who have been discharged after DNA. This is the only example we know about. The problem is these young adults will be mixed in with other outpatients and separating out this data will be potentially challenging.The best measure of transition would be some form of patient related feedback (PROM) about their experience, given by child and parent, however this would be much harder to collect. | Thank you for your feedback.We have added patient or client surveys as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 235 | Association of Paediatric Chartered Physiotherapists | Question 5 | In many areas there is no equivalent adult service commissioned (e.g. like the role of the paediatrician or children’s therapy team) so coordinated services and review appointments for young people stop. Young people then have to wait for there to be ‘a problem’ or deterioration with their functional skills to meet the criteria for healthcare reviews in adult services. In these instances, how would these attendances be measured unless the expectation is on measuring their attendance with primary care.This would be challenging from the paediatric side unless they are notified by adult services (sent letters informing them the young person has failed to attend). Some young people may not require adult appointments immediately/may not need the adult services for 6-12 months therefore cannot be referred directly but need to self-refer. Their engagement and their ability to negotiate services could only then be via patient survey. There also may not be any appropriate adult service for the young person to access. Adult therapy services are not commissioned to provide annual reviews / screening to detect issues / deterioration – services are reactive not proactive for adults with disability as they will provide an assessment / therapy only once a problem has been identified and they’ve been asked to help. This relies on the young person/family or their GP identifying when an issue is occurring and it may be too late by the time this is identified to prevent functional deterioration / pain. This expectation of young people / families identifying when they need to access services and self-refer will impact onto measuring engagement with adults’ services. This also contributes to the issue of young people / families disengaging with adult services as they do not feel they can meet their needs.The Education Health care plans can remain in place until a young person is 25 but in practice they usually stop once the young person is in adult services at the end of Year 13 (age 19 years). For young people with learning disabilities deterioration may be picked up at the GP’s annual check but this depends on whether this is included in the template they use and whether the young person has been brought to the appointment. There is a misunderstanding of GPs annual check and the annual reviews recommended for young people with disability and complex health needs should be carried out by an adult healthcare professional with expertise in neurodisability – this service has not been commissioned and is lacking.  | Thank you for your feedback.If young people are not required to attend meetings or appointments in adults’ services they will not be included in statement 6.We have amended the definition of attendance at initial meetings or appointments to ‘any one of the first 3 meetings or appointments or any meeting or appointment within the first 12 months in each adults’ service but can be adapted to fit local service characteristics’ to reflect the variation across services, including primary care. Statement 6 requires adult services to refer back to the named worker or the children’s service if they are not able to engage young people in the adult service.  |
| 236 | British Academy of Childhood Disability (BACD) | Question 5 | In some services this is collected already e.g. Highly Specialised Services who need to report the proportion of young people who have a transition plan in place. For joint transition clinics with both paediatric and adult clinicians working together this could be monitored based on the number of referrals received versus how many patients attend the transition clinic as new referrals each year.  | Thank you for your feedback.We have added local audit as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 237 | British Association of Teachers of Deaf Children and Young People (BATOD) | Question 5 | BATOD is aware there are challenges for some deaf young people due to local commissioning arrangements. For example, there may be no commissioned adult audiology services for individuals with mild deafness levels in some geographical areas.  | Thank you for your feedback. |
| 238 | British Society of Physical and Rehabilitation medicine | Question 5 | The Reasonable adjustments done also should be audited ( Sending out appointment letters considering neurodiversity needs were appropriate, booking the appointment at a time slot more convenient to young adult like appointments after 11 am and location of the appointment etc).  | Thank you for your feedback.We have added local audit as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 239 | Brittle Bone Society | Question 5 | One outcome could be an appointment within the first year of adult service | Thank you for your feedback.We have amended the definition of attendance at initial meetings or appointments to ‘any one of the first 3 meetings or appointments or any meeting or appointment within the first 12 months in each adults’ service but can be adapted to fit local service characteristics’ to reflect the variation across services. |
| 240 | Challenging Behaviour Foundation  | Question 5 | The number of reasonable adjustment flags in place could be a data source to capture the use of reasonable adjustment in order to support transition and meet Equality Act duties. | Thank you for your feedback.We have added local audit as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 241  | Child Growth Foundation | Question 5 | Locally data can be pulled to see when the young person’s last clinic in child services was and when their first attended adult appointment was. If the young person is already ‘lost’ to follow up however this would be really difficult information to find. Where this data has been collected successfully is usually when there is a key worker identified for transition in a service eg a specialist nurse. Data could be pulled from GP surgery records to know if the young person has disengaged with services during the transition period | Thank you for your feedback.We have added local audit as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 242 | Children with Exceptional Healthcare Needs networkNSS CEN – NHS Scotland National Services | Question 5 | There is no consistent approach to monitor outcome of transition other than recording non attendance with the assumption that notification to the GP is adequate to trigger appropriate intervention. There should be an agreed standard for action following non attendance with an integrated approach for clinical review and enquiry into reason for non-attendances to reduce the chances for recurrence.A standard for annual Primary Care review for this population group would ensure this outcome measure and can provide local services to have ongoing direct involvement with their patients who may be unfamiliar with the Primary Care team including local pharmacy and community services. | Thank you for your feedback.We have clarified in the definition of ‘further opportunities to engage’ that adults services should try to understand the reasons for not attending and identify any changes that could be made to encourage attendance in future.Annual reviews in primary care are recommended for some people in adults’ services. There are, however, currently no recommendations on annual review in primary care for all young people following transition. |
| 243 | Communication Matters (ISAAC UK Ltd) | Question 5 | We are not aware of any way of currently monitoring and measuring transitions from children to adults’ services for those who use Augmentative and Alternative Communication (AAC) resources. At the present time provision of AAC resources is patchy throughout England. * A young person who has been assessed at a specialist regional centre will not remain on their case load ongoing but return to being supported locally.
* Those who are assessed by a local AAC team may often be provided with an intervention and once it is being used effectively with general classroom support may be signed off by the team as having their needs met.

Those who fail to meet the eligibility criteria for either a specialist or local assessment may not have their generalised communication support detailed on their Education, Health and Care Plan (EHCP) as it is seen as standard school support and not an individual need. | Thank you for your feedback. |
| 244 | Derby and Derbyshire Integrated Care Board | Question 5 | current data collection is very team and condition specific. We can currently look at data but there is not a formal process is in place. Flagging and coding transition patients would then be able to monitor.  | Thank you for your feedback.We have added local audit as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 245 | Derby and Derbyshire Integrated Care Board | Question 5 | If we can track first adult appointments– we could potentially use a 'first adult appointment' code, consistency will be key to its application. | Thank you for your feedback.We have added local audit as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 246 | Diabetes UK | Question 5 | We are not aware of any specific examples in practice but note that this information has to be recorded reliably and accurately to be useful, as we know there is a range of computer systems used for this purpose within different trusts which record information different and do not always communicate with one another. It is also important that systems record a reason for DNA for example as this is very important context to help understand the factors that may make missed appointments more likely for some, and suggest solutions to reductions them. | Thank you for your feedback.We have added local audit as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 247 | Duchenne UK | Question 5 | Duchenne UK is not placed to comment on current internal NHS arrangements, and what can and cannot be monitored. However, elsewhere in the quality standard questionnaires from the TIER Ready, Steady, Go programme and the National Confidential Enquiry into Patient Outcome and Death transition from child into adult healthcare report are cited. While prescribing individual survey and questionnaire templates would be unwise, perhaps the quality statement could seek documentary and procedural evidence of such surveys, using the above citations as examples. | Thank you for your feedback.We have added patient or client surveys as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 248 | Faculty of Pain Medicine of the Royal College of Anaesthetists | Question 5 | Yes, this could be captured quite easily from identified appointments.Grouping young adult appointments together into specified clinics will allow follow up data to be captured and allow for a more appropriate environment for the young person.Some services already have dedicated transition clinics, and can measure attendance at first review and collect data on engagement and follow up. This could also be measured from the paediatric side on patients entered into transition plan, though data may not be readily available. To help this process of data collection, children could be placed on a transition list tool at age 13-14 or year 9, and their progress monitored as they progress to transition. This would require a separate data collection tool, which could facilitate easy data entry and allow observation of progress along the transition plan and should allow the forward planning for clinic provision. This could be transferred over to adults to complete data on follow up and engagement.  | Thank you for your feedback.We have added local audit as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 249 | Faculty of Pharmaceutical Medicine | Question 5 | For rare diseases the number of healthcare professionals involved can be very large. Sickle cell disease is an example where a large number of potential interactions with the health care providers having a single point of contact is not feasible and will lead to inequities and inequitable distribution of care. For rare diseases the process should link to registries of disease. In practice therefore, under the proposed arrangements measurement is not possible for rare diseases | Thank you for your feedback on the challenges of measurement for young people with rare diseases. |
| 250 | Great Ormond Street Hospital (GOSH) | Question 5 | Yes – monitor how many appointments have been offered within a 1 year period for a patient if first appointment missed. How would this work where multiple health providers are involved? Can there be a flag where appointments are missed and how would systems communicate to raise awareness where care is in different centres? Could there be monitoring of reason why appointment was not attended – e.g. if patient has gone to university, appointment schedules may not meet the needs of the young persons availability. This would identify barriers and could provide input to support young people attending. Our new transition tab in Epic allows us to document the status of patients transition journey (not started, in progress, on hold, complete) which can be completed by all specialities involved and includes the hospital the patient will transition to and the level of engagement from the young person prior to transfer. Which can help the adult services understand the young persons level of engagement prior to their initial appointment. This element is auditable, and data can be collected to aid in Quality Improvement work.  | Thank you for your feedback.We have added local audit and data sharing platforms as examples of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 251 | Kent and Medway NHS and Social Care Partnership Trust | Question 5 | * Can be measured in practice. Every initial appointment can be recorded and a DNA can be equally recorded and reported on. A clear digital record/point would have to be created in order to indicate if they attended any of their first three appointments in Adult Services.
 | Thank you for your feedback.We have added local audit as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 252 | Midlands Partnership University NHS Foundation Trust | Question 5 | This is difficult to monitor – there are some services such as children’s diabetes and children’s epilepsy where joint clinics are held as part of transition pathways, and familiarity with practitioners is available. This is not formally measured or collected currently – it will be recorded in patient records. | Thank you for your feedback. |
| 253 | National Confidential Enquiry int Patient Outcome and Death (NCEPOD) | Question 5 | This should be amenable to audit along the lines suggested. The NCEPOD report includes audit tools. | Thank you for your feedback.We have added local audit as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 254 | National Deaf CAMHS (North) | Question 5 | This is complex due to the scarcity of available services for Deaf CYP and adults. Individuals may not access services in their immediate locality which could be difficult to track and monitor transitions. | Thank you for your feedback. |
| 255 | National Network of Designated Healthcare Professionals for Children | Question 5 | We agree that this would be manageable in theory but may be complex in practice. For example, patient attendance data at outpatient services is routinely recorded on an individual basis but not easily reported as a cohort. Systems may need to be modified to enable this latter to happen.  | Thank you for your feedback.We have added local audit as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 256 | National Network of Parent Carer Forums | Question 5 | Local parent carer forums would be able to report back to local ICBs on whether this is happening in practice and how well it works for parent carers and CYPs | Thank you for your feedback. |
| 257 | National Rheumatoid Arthritis Society | Question 5 | We assume that DNA patients will be automatically be captured in patient data in all units, therefore, it should be possible for a member of the secondary adult service team to set up a second appointment and a letter be sent or for a member of the team to call that young person to find out why they have not attended their appointment. As a national patient organisation, we don’t currently know how this is being handled in each unit.  | Thank you for your feedback. |
| 258 | NHS England | Question 5 | * We suggest this should be part of a transition policy and would need to be measured by local audits and would be with joint meetings with both children and adult services.
* We suggest exploring quality measures co-developed with young people and families?
* We suggest that positive stories about transition are collected to inform feedback to cyp and families about what good looks like?

Yes – I would suggest as part of transition paperwork a clear section for initial meeting with adult services and next steps for clarity to CYP and family. Similar to maternity notes. | Thank you for your feedback.We have added local policy and audit as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 259 | NHSE Sheffield response | Question 5 | Audit meetings attended and contributions from attendees, also note that the young person’s questions are answered/ concerns addressed. | Thank you for your feedback.We have added local audit as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 260 | NHSE specialised commissioning | Question 5  | Q5 Proposed response:Clarity is needed on each level of care and where the responsibility to submit data to the (to be) identified transition plan co-ordinator in primary care sits.As a case study in highly specialised services which are quaternary level providers, the team send a letter to the local team and to the GP after each appointment and this includes when the transition process has been started at age 12 and continues until age 16 or 18 depending on the service and the age at which adult services can take transfers. The HSS teams also works with the young person on understanding their readiness for transition through a Trust specific or other transition process such as the Ready Steady Go process initially developed by the Alstrom Syndrome service and in use in many hospitals/rare disease services. | Thank you for your feedback.We have added local audit as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 261 | Nottinghamshire Healthcare NHS Foundation Trust | Question 5 | Through the use of a recording template, we are able to monitor the number of young people we have transferred care to in adults service. Some of these services will be in other provider organisations. It would need our template to be organisational wide to capture data on young people transferring to adult services in our own organisation, but these may also use different recording platforms(e.g S1 and Rio).Adult services would need to set up a way of tracking young people transferred into their service, and an assurance process around contacting if they do not turn up for first 3 initial appointments. | Thank you for your feedback.We have added local audit and data sharing platforms as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 262 | RCPCH | Question 5 | Effective transition plans should be part of the health care record and include dates, services, health education goals, identification of adult services and providers; (American Academy of Paediatrics & Physicians 2011; Rosstad 2013). Implementing the recommendations for transition into practice will require a systematic process. At a minimum, this will require a process to evaluate transition-related outcomes at the individual and clinical level, identify facilitators and barriers to transition, and allow for refinement and improvement overtime  | Thank you for your feedback. |
| 263 | Research in Practice | Question 5 | There’s nothing in the measure about the quality of experience, so the measure does not tell us how successful the transition has been. | Thank you for your feedback.We have added patient or client surveys as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 264 | Royal College of General Practitioners  | Question 5 | The primary care records offer ideal means of monitoring attendance (highlighted in the RCGP e-Learning) and appropriate funding will be needed for the non-clinical work involved. | Thank you for confirming that the primary care record could be used to monitor attendance following transition. We have amended the data source for this measure to highlight that data can be collected from information recorded locally by healthcare practitioners and provider organisations, such as local policy and audit, data sharing platforms and patient surveys. |
| 265 | Somerset Foundation Trust | Question 5 | Patient satisfaction measures may be better | Thank you for your feedback.We have added patient or client surveys as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 266 | Spinal Muscular Atrophy UK | Question 5 | We are not aware of this data being collected currently, although in some areas, local services probably do this. A way to do this could be to survey young adults following transitioning through services. But data needs to be qualitative, to hear people’s thoughts and experiences. Data should be collected from young adults now in adulthood, e.g. after transition, to gain the full picture of their experience. Patient representative groups may be able to help with this process.  | Thank you for your feedback.We have added patient or client surveys as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services. |
| 267 | Sussex Partnership NHS Foundation Trust | Question 5 | The DNAs should be recorded in electronic patient records although if free text they may not be directly captured in performance data and would need someone to check manually which may be a barrier to data collection. | Thank you for your feedback. |
| 268 | The Royal College of Physicians of Edinburgh (RCPE) | Question 5 | There is no consistent approach to monitor outcome of transition other than recording non attendance with the assumption that notification to the GP is adequate to trigger appropriate intervention. There should be an agreed standard for action following non attendance with an integrated approach for clinical review and enquiry into reason for non-attendances to reduce the chances for recurrence.A standard for annual Primary Care review for this population group would ensure this outcome measure and can provide local services to have ongoing direct involvement with their patients who may be unfamiliar with the Primary Care team including local pharmacy and community services.In addition transition which often involves several joint child-adult clinics should allow for continued follow-up in the child services until completion of transition occurs as a fall back to non-attendance of adult services. This is captured in the current NHS systems.  | Thank you for your feedback.We have clarified in the definition of ‘further opportunities to engage’ that adult services should try to understand the reasons for not attending and identify any changes that could be made to encourage attendance in future.Annual reviews in primary care are recommended for some people in adults’ services. There are, however, currently no recommendations on annual review in primary care for all young people following transition.The focus in statement 6 is on adult services offering further opportunities to engage if the young person does not attend their initial meetings or appointments following transfer. The definition of further opportunities to engage indicates that if adult services are not able to engage the young person, they should refer them back to the named worker or the children’s service. |
| 269 | UK Cystic Fibrosis Medical Association | Question 5 | PortCF already collects some information on Transition and can be used. There will need some financial support for this however, in order for this to happen. Administrative staff are being cut by the NHS and this can have an impact across the UK. | Thank you for your feedback. |
| 270 | University Hospitals Birmingham NHS Foundation Trust | Question 5 | Again, there is a need for data / coding / flagging to robustly monitor this in practice. In our organisation we have a DNA / WNB policy which is safeguarding driven for children and vulnerable adults, of which transition is the 6th pathway. However, Clinicians need to be aware that the young person who has not attended is in transition to then adhere to this element of the policy. Currently we are reliant on human factors to ‘know’ this, Services would need a way to ‘flag’ or code the patients in transition, to enable measurement. | Thank you for your feedback.We have added local audit as an example of evidence of local arrangements to monitor and assure transitions from children’s to adults’ services.We understand that NHS England may be developing new SNOMED codes that can be used for transition that will improve identification of young people in future. |
| 271 | Versus Arthritis | Question 5 | Registers such as the JIA Register ([JIA Register | British Society for Rheumatology](https://www.rheumatology.org.uk/improving-care/registers/juvenile-idiopathic-arthritis)) are important for research. Key findings on transition in last few years have come from the JIA registers in combination with wider data sets. Use of mapping tools like the rheumaps[[12]](#endnote-12) project Aberdeen University funded by Versus Arthritis links patient location to local community data.  | Thank you for your feedback. |
| **Question 6 For draft quality statement 6: Is it helpful to include the new outcome measure b) to capture ongoing engagement with adults’ services (1 year after transfer) for this statement?** |
| 272 | Alder Hey Liverpool | Question 6 | It is important for adult health care providers to monitor attendance at least for the first year when a YP transfers to their service. The YP should be well prepared to attend adult services following transition planning in paediatric care. However we do know YP may be a little chaotic and not good with planning (frontal lobe still developing) ; they may lack funds to travel to attend clinic appts. It is important that adult providers contact the YP to discuss what may be preventing/hindering them to attend appointments, and help put support in place to promote attendance until the YP is really settled into adult healthcare, knows the team and is confident attending. | Thank you for your feedback. |
| 273 | Alexion, AstraZeneca | Question 6 | We are supportive of rationale for this specific outcome measure. | Thank you for your feedback. |
| 274 | ARC Scotland - Scottish Transitions Forum | Question 6 | yes | Thank you for your feedback. |
| 275 | ARNS | Question 6 | Yes, please see above answer (for number 5) | Thank you for your feedback. |
| 276 | Association of British Neurologists (ABN) | Question 6 | It is helpful to include a measure of continued engagement, however a restriction of 1 year is too short. Patients who are stable are often seen at 1 year for follow up and therefore placing a 1 year restriction may prevent capture for those who chose to delay their appointment slightly to fit in around university timings and other commitments. It may give a false result of the number who are being lost to follow up. A timing of 24-36 months would be more appropriate for many conditions. | Thank you for your feedback.We have amended the data source to suggest that this could be defined as engagement at 1 or 2 years after transfer or engagement at a specific age (such as 25 years) but can be adapted to fit local service characteristics. |
| 277 | Association of Paediatric Chartered Physiotherapists | Question 6 | Yes, this would be helpful to include as will be more meaningful to capture ongoing engagement and could also be measured at 2 years and longer given many of the young people transitioned have lifelong conditions.  | Thank you for your feedback.We have amended the data source to suggest that this could be defined as engagement at 1 or 2 years after transfer or engagement at a specific age (such as 25 years) but can be adapted to fit local service characteristics. |
| 278 | British Academy of Childhood Disability (BACD) | Question 6 | Absolutely yes, this is very helpful to capture and will help promote engagement of young people with adult services.  | Thank you for your feedback. |
| 279 | British Association of Teachers of Deaf Children and Young People (BATOD) | Question 6  | BATOD partially agrees with this outcome. As noted above, the engagement needs flexibility to accommodate the complexities deaf young people often experience when relocating from the family home to a new area for university, college, employment. | Thank you for your feedback. |
| 280 | British Society of Physical and Rehabilitation medicine | Question 6 | Yes. It is essential to monitor continuing engagement with the adult teams. The gold standard should be all young adults with a long-term condition should be seen in an adults service at 6 months and at 12 months after discharge from Children’s services. The follow up by adult service at 12 months after transition should be taken as the criteria for successful transition. | Thank you for your feedback. |
| 281 | Brittle Bone Society | Question 6 | This is challenging as subsequent ongoing engagement will vary by disease. At the minimum, newly transitioned patients should be aware of how to access their designated adult service for urgent queries and have a named clinical team.  | Thank you for your feedback. |
| 282 | Child Growth Foundation | Question 6 | Yes. Young people may attend their first adult appointment however disengage shortly after that resulting in the same risks to their health. It may also be useful to know how many appointments they should have attended (and either missed or attended) during that time as different services will have different follow up schedules (ie some may be every 3 months others may be every 6 months) | Thank you for your feedback. |
| 283 | Communication Matters (ISAAC UK Ltd) | Question 6 | Providing education have ensured the needs of Augmentative and Alternative Communication (AAC) users are appropriately captured within an Education, Health and Care Plan (EHCP) and it is noted ongoing engagement is needed with adults’ services then yes measuring engagement could work. However, we are aware that the current system is failing young people throughout their school lives and particularly those who are transitioning. We have grave concerns that unless there is better support within education this will continue to be an issue at the point of transition to adult services.We note that within the equality impact assessment there is a recommendation (highlighted in yellow below in response to Q8) for all young people transitioning to have a written record of how they communicate. We believe that there should be a standardised template for this, which includes the use of AAC strategies e.g., paper, and powered resources, body language, facial expression, sign and eye pointing, and the role of communication partners in both their daily lives and learning for life. This document should pick up the needs of any young person who uses any form of AAC (or other communication impairment), and they should be automatically seen by a speech and language therapist with AAC expertise when transitioning into adults’ services. Attached under Appendix A are recommendations of what to include within a standardised communication template. | Thank you for your feedback and for details of the standardised communication template which local areas may wish to consider to record young people’s communication needs. |
| 284 | Derby and Derbyshire Integrated Care Board | Question 6 | yes definitely. GDPR potential issues could be in play, following up manually | Thank you for your feedback. |
| 285 | Diabetes UK | Question 6 | It is helpful to include this new outcome measure as many young people with diabetes are lost to the system at period in their life when they may require additional support. More accurate data will allow for service development and improvement and allow the wider system to learn from services where engagement is higher. It is also important to understand the level of engagement a year after transfer as this may be a time when young people become disengaged if they have not had positive experiences in adult services.  | Thank you for your feedback. |
| 286 | Duchenne UK | Question 6 | Not only do patients transition from children’s to adult’s services at different ages, depending on their individual needs, they may also transition to different areas of care at different ages too. The progression and states of the condition are more important than biological age, and care reflects this. In one area of care patients may continue seeing children’s services, years after transferring to adult’s services in another speciality, for the simple reason that the age of transition isn’t universal for each area of care. This is particularly relevant for children and young people with rare and complex conditions who have multidisciplinary care teams.Transition is a process, not a single event, but measuring ‘one year after transfer’ forces it to be seen through the lens of an event. Doing so may not capture the intended measure: ongoing engagement with adults’ services. Instead, an age-based criteria may be considered. For instance, their 26th birthday (one year after they are no longer covered by this quality standard).  | Thank you for your feedback.We have amended the data source to suggest that this could be defined as engagement at 1 or 2 years after transfer or engagement at a specific age (such as 25 years) but can be adapted to fit local service characteristics. |
| 287 | Faculty of Pain Medicine of the Royal College of Anaesthetists | Question 6 | Yes, it is helpful to include these as many hospitals are currently discharging non-attenders from further follow-up. Engagement with the first few appointments has been identified as a critical time and so identification and follow up of these patients is important. Patients who are discharged are then difficult to identify once lost to follow up or discharged so systems to flag young non- attenders following a transition pathway should be set to capture data and offer clinical review before discharge. Ideally, transition clinics that refer patients across should keep details, to ensure engagement and offer multiple chances and flag up those appointments missed for active review. | Thank you for your feedback. |
| 288 | Genetic Alliance UK | Question 6 | Yes. | Thank you for your feedback. |
| 289 | Great Ormond Street Hospital (GOSH) | Question 6 | Yes – they may attend first appointment and then disengage from service (I do not know numbers or up to date examples for this) However, I think it is important to know this information. If this does happen within services, QI work can take place to see how to improve the service for young people to continue attending the adult services. It shows ongoing engagement/attendance rather than just the first then disengage – more longitudinal | Thank you for your feedback. |
| 290 | Kent and Medway NHS and Social Care Partnership Trust | Question 6 | * This would be very difficult to capture, as treatment with adult services may well have been completed/discontinued. If someone has left the service, and, for example, has gone into employment, we no longer have consent to access the record and report on them.

There is too much data access for a whole year - it requires extra and extensive use of resources, that does not currently exist. It is a lot of data to access and has no impact on quality care delivery | Thank you for your feedback.We agree that for this measure to be helpful it will be important to ensure the population includes young people who were expected to continue engaging with adult services.We have highlighted in the data source that the definition of continuing to engage can be adapted to fit local service characteristics. |
| 291 | Metabolic Support UK | Question 6 | Yes, outcome measure B is important to capture, understanding why patients fail to attend may improve services. For our communities, this may be the lack of adult services that are “counterparts” to the paediatric services. For this outcome, however, we must define clearly what engaging with services means I.e., is this responding to NHS communications or attending appointments.For some IMD patients, only annual follow up appointments are required to ensure adequate management. Considering the age group, particularly for those conditions with more manageable conditions, we would suggest extending this to measurement at Y1 and Y2 as a minimum to provide longer term measurement and reduce numbers lost to follow up as they develop greater independence and reduced reliance on parents. | Thank you for your feedback.We have amended the data source to suggest that this could be defined as engagement at 1 or 2 years after transfer or engagement at a specific age (such as 25 years) but can be adapted to fit local service characteristics. We agree that local areas will need to define what should be included in this measure based on the characteristics of the service. |
| 292 | Midlands Partnership University NHS Foundation Trust | Question 6 | Yes but emphasis should be on adult services to monitor this and provide their data  | Thank you for your feedback.We confirm that statement 6 is for adult services. This is highlighted in the supporting information. |
| 293 | National Confidential Enquiry int Patient Outcome and Death (NCEPOD) | Question 6 | Yes, this would capture a drift away from adult services by disaffected young people. | Thank you for your feedback. |
| 294 | National Deaf CAMHS (North) | Question 6 | Yes.This could be useful to help identify further gaps/barriers to engagement in adult services and could provide further evidence for the need for an 18-25 deaf service as part of a coordinated transition plan. | Thank you for your feedback. |
| 295 | National Network of Designated Healthcare Professionals for Children | Question 6 | A year is a long time in a young people’s lives to wait before checking that support is being provided The principle of understanding engagement is good, but the reason for not doing so is also very important to understand. So we would advocate for a shorter period such as three months, but with a recognition that for some this may be far too short a period. For example, dental care is not always an urgent matter, but as another example. gastroenterology engagement can be needed in a few weeks.  | Thank you for your feedback.We confirm that the process measure will ensure that young people are followed up if they do not attend any of their initial meetings or appointments. Outcome measure b) is focussed on the impact on longer term engagement. |
| 296 | National Network of Parent Carer Forums | Question 6 | Yes this would be helpful – and a good measure to ensure processes are working to ensure a good transition | Thank you for your feedback. |
| 297 | National Organisation for FASD | Question 6 | Failure to engage should be seen as a organisational failure to enable the patient to engage. | Thank you for your feedback. |
| 298 | National Rheumatoid Arthritis Society | Question 6 | Yes. | Thank you for your feedback. |
| 299 | NHS England | Question 6 | * We do think that capturing engagement is helpful and we see the merit to look at longer term outcomes. It also encourages services to continue to target young people who have recently transitioned to ensure they embed their engagement with adult services. We also think there should be data collection around the challenges and barriers that young adults experience when attending adult services; and being mindful that it may be the way that the service is set up that impacts on non-attendance.
* In line with this, we suggest it should be clearer as to the ways that non-attendance can be examined; e.g. is it related to the necessity to attend a new unfamiliar environment, is it about sensory considerations, and where do we discuss the issue of capacity to consent to treatment etc – we are moving from Parental Responsibility through competency (as per Gillick) and onto capacity as adults. We think that should be mentioned somewhere here.
* We suggest this statement could be stronger in the emphasis placed on adults services to reach out to individual young people and families to understand reasons for non-attendance and to take steps to address constraints, particularly if they are due to lack of reasonable adjustments or scheduling during the school day. We are cautious that as it reads could encourage a ‘did not attend’ culture that doesn’t capture what reasonable adjustments have been made by services to engage young people. We suggest some kind of qualitative measure that includes feedback from families that have been through the transition process would be helpful here
* We suggest including the need to ensure a crisis plan is in place/shared agreed before transition as a safety net for disengagement?

Yes – provides clarity | Thank you for your feedback.We agree that feedback from young people will be helpful for local services to understand in order to overcome any barriers to using the service. We have therefore included patient or client surveys as evidence of local arrangements to monitor and assure transitions in structure measure a).We have clarified in the definition of further opportunities that adult services should try to understand the reasons for not attending and identify any changes that could be made to encourage attendance in future.We have added an equality consideration to highlight that health and social care practitioners should consider any specific needs relating to disability, leaving care or where someone lives when working with young people who have not attended their initial meetings or appointments in adults’ services. They should consider if reasonable adjustments can be put in place that will encourage future attendance. |
| 300 | NHSE Sheffield response | Question 6 | Yes | Thank you for your feedback. |
| 301 | NHSE specialised commissioning | Question 6  | Q6 Proposed response: it would be very helpful to include the new outcome measure to capture ongoing outcome with adult services one year after transfer as this is a test of whether the young person has taken on the service offer(s) made by the respective clinical teams across the NHS and has engaged with them and if they need additional support to do so. This is because sometimes a young person may be overwhelmed at first in being made responsible for co-ordinating their own care in place of their parents/carers and having to engage with one or more service providers (who may be different to their paediatric providers) on their care. Some young people may fail to organise getting to their appointments or may have visual, hearing, learning or neurological deficits or difficulties which may it more difficult for them to organise their appointments in addition to managing their condition and their daily needs and may therefore lose out on receiving care, ongoing management or support they may very much need to access as a result. | Thank you for your feedback. |
| 302 | Nottinghamshire Healthcare NHS Foundation Trust | Question 6 | Unsure | Thank you for your feedback. |
| 303 | NSA for PCC NHSE | Question 6 | I agree it would be helpful. | Thank you for your feedback. |
| 304 | RCPCH | Question 6 | It is recommended, that the results of the readiness assessment, be used as part of the transition plan and reviewed annually, to: track progress towards self-management; identify areas for education, intervention, psychological and emotional support; assess other targeted efforts, and have dedicated time to develop and implement written action plans that include timelines for review (Betz 2004; Cincinnati 2008; Flume 2004; McCurdy 2006; McLaughlin 2008; Reiss 2005; Schwartz 2011). | Thank you for your feedback. |
| 305 | Research in Practice | Question 6 | The outcome needs to collect data on the experience from the young person, not just whether they continued to attend services. Follow up data would be useful in understanding longer-term involvement. | Thank you for your feedback.We agree that feedback from young people will be helpful for local services to understand in order to overcome any barriers to using the service. We have therefore included patient or client surveys as evidence of local arrangements to monitor and assure transitions in structure measure a). |
| 306 | Royal College of General Practitioners  | Question 6 | The RCGP e-Learning suggests that practices undertake a 6 monthly/annual review of progress and once the original register of “CYP needing support with medical transition” is completed, the updating of the register can be done efficiently. | Thank you for your feedback. We have retained this measure and clarified that it could be defined as engagement at 1 or 2 years after transfer or the age of the young person (such as 25 years), but can be adapted to fit local service characteristics |
| 307 | Royal College of Nursing | Question 6 | Yes, this is helpful. | Thank you for your feedback. |
| 308 | Royal College of Occupational Therapists (RCOT) | Question 6 | We agree it is appropriate to capture engagement with adult services one year after transfer from children’s services.   | Thank you for your feedback. |
| 309 | Somerset Foundation Trust | Question 6 | Patient satisfaction measures may be better | Thank you for your feedback. We agree that feedback from young people will be helpful for local services to understand in order to overcome any barriers to using the service. We have therefore included patient or client surveys as evidence of local arrangements to monitor and assure transitions in structure measure a). |
| 310 | Spinal Muscular Atrophy UK | Question 6 | Does recording if they have been to an appointment really capture the full picture? For example, what are the reasons why they have the gone or not gone. Sometimes adults are still waiting to be seen 1 year after transfer to adults' services due to long waiting lists. Therefore, following up 1 year after transfer is not going to give an accurate picture, perhaps yearly appointments up to the age of 25 would capture this data more accurately. | Thank you for your feedback.We agree that feedback from young people will be helpful for local services to understand in order to overcome any barriers to using the service. We have therefore included patient or client surveys as evidence of local arrangements to monitor and assure transitions in structure measure a).We have amended the data source to suggest that this could be defined as engagement at 1 or 2 years after transfer or engagement at a specific age (such as 25 years) but can be adapted to fit local service characteristics. |
| 311 | Sussex Partnership NHS Foundation Trust | Question 6 | 1 year post transition is a good time to review engagement and care plan - a post transition CPA to mirror the pre-transition CPA would be good practice | Thank you for your feedback. |
| 312 | The Neurological Alliance | Question 6 | It is helpful to include and capture ongoing engagement with adults’ services and the suggestion of monitoring and reviewing engagement 1 year after transfer is proportionate. There are a variety of reasons why young people affected by neurological conditions might not complete the transition process to adults services and some are likely to be referred back to an adult care pathway at a later point. To better understand the reasons why a young person might not complete the transition to adults’ services, a short patient survey could be used for those who subsequently re-enter an adult care pathway as identified through this outcome measure. | Thank you for your feedback.We agree that feedback from young people will be helpful for local services to understand in order to overcome any barriers to using the service. We have therefore included patient or client surveys as evidence of local arrangements to monitor and assure transitions in structure measure a). |
| 313 | The Royal College of Physicians of Edinburgh (RCPE) | Question 6 | Ongoing engagement in certain transition specialities such as transplant medicine is easily captured in tertiary care services from the appointments systems. It is clear from this that this is a critical state as children become independent and attendance in some drops significantly. | Thank you for your feedback. |
| 314 | Together for Short Lives | Question 6 | Yes | Thank you for your feedback. |
| 315 | UK Cystic Fibrosis Medical Association | Question 6 | We would recommend that that the new outcome measure of attendance for the first 3 meetings with adults service be an easy measure to achieve. It would help us to identify some non engagement, and help us to work on ways to improve engagement.It would be good to then capture ongoing engagement and look at reasons for non-engagement. They may not all be due to poor transition, but rather practical issues with the individual depending on where they end up doing further education etc. | Thank you for your feedback.We agree that feedback from young people will be helpful for local services to understand in order to overcome any barriers to using the service. We have therefore included patient or client surveys as evidence of local arrangements to monitor and assure transitions in structure measure a). |
| 316 | University Hospitals Birmingham NHS Foundation Trust | Question 6 | Yes to some degree as long as the comments outlined in question 4 & 5 are addressed. | Thank you for your feedback. |
| 317 | Versus Arthritis | Question 6 | Yes, we recommend that health boards monitor ongoing engagement one year after transfer to ensure young people are getting the care and support that they need. At very basic level outcome measures should capture whether young person is still receiving care, and if not - why not (e.g. in remission and discharged, lost contact after three attempts to engage), It should capture diversity, inclusion and equality data info (e.g. are there differences across the background, location and circumstance). Qualitative quality marker should measure how the transition worked for young person (including communication) and quality of care.  | Thank you for your feedback.We agree that feedback from young people will be helpful for local services to understand in order to overcome any barriers to using the service. We have therefore included patient or client surveys as evidence of local arrangements to monitor and assure transitions in structure measure a). |
| 318 | WellChild | Question 6 | Yes – more emphasis is needed on adult services taking responsibility so that the young adult doesn’t fall back repeatedly on children’s services | Thank you for your feedback. |
| **Question 7 Please let us know about any practical resources that have been developed to improve awareness of this quality standard among young people and their families and carers.** |
| 319 | Alder Hey Liverpool | Question 7 | unsure | Thank you for your feedback. |
| 320 | Alexion, AstraZeneca | Question 7 | We are not aware of any specific resources that exist to promote awareness of this quality standard among young people and their families and carers. However, we would recommend direct engagement and collaboration with charities and patient organisations across a spectrum of conditions on resources that could be tailored for these specific audiences throughout this period of their care journey. Within rare diseases,  | Thank you for your feedback. |
| 321 | ARC Scotland - Scottish Transitions Forum | Question 7 | ARC Scotland – Scottish Transitions form have developed COMPASS for parents, carers young people and professionals. Each different version of the tool points to the NICE guidelines to help make sure people know their rights and entitlements to effective transitions and explains the NICE transitions guidelines to the user group  | Thank you for your feedback. |
| 322 | ARNS | Question 7 | Nil known | Thank you for your feedback. |
| 323 | Association of British Neurologists (ABN) | Question 7 | None known | Thank you for your feedback. |
| 324 | Association of Paediatric Chartered Physiotherapists | Question 7 | Use of Ready Steady Go transition tool.Local transition documents used and are given out to families with a list of onward services they might need to access in the future.Continuation of holistic assessments / annual reviews for young people with physical disabilities beyond children’s services e.g., continuation of the national CPIP (cerebral palsy integrated pathway) programme which currently stops at age 16 years. CPIP has been developed further and CPIP 2.0 will soon be launched in children services which will enable paediatric services to use the programme to follow up children with other neurodisability conditions as well as Cerebral palsy. Continuation of CPIP into adult services would help to support transition and long-term healthcare by offering reviews from appropriate adult services to detect functional deterioration and issues early and identify when other services are needed to be accessed.  | Thank you for your feedback. |
| 325 | British Academy of Childhood Disability (BACD) | Question 7 | In BACD we have circulated information about the consultation period for this quality standard electronically to members in our e-newsletter. Our members include families and carers of children and young people with disabilities.  | Thank you for your feedback. |
| 326 | British Association of Teachers of Deaf Children and Young People (BATOD) | Question 7 | In 2014 National Deaf Children’s Society (NDCS) created ‘My life, my health’ in collaboration with young people<https://www.ndcs.org.uk/media/1792/my_life_my_health_report_from_yab_2014.pdf>NDCS quality standards transition from paediatric to adult audiologyhttps://www.ndcs.org.uk/media/4481/qs\_transition\_from\_paediatric\_to\_adult\_audiology\_2011.pdf | Thank you for your feedback. |
| 327 | Brittle Bone Society | Question 7 | Not entirely sure what this actually means? If you are literally meaning do they know the link to go to this specific Quality standard and view online – then there are no practical resources that I am aware of.However as a Patient Organisation we talk about transition in general terms and Independent Living. We are developing best practice pathways for adults with severe OI which will include a section on transition. | Yes, the question is about any resources you are aware of that have been developed to raise awareness of the current quality standard. |
| 328 | Clinical Genetics Society | Question 7 | I am not aware of any practical resources specifically available for young people regarding the transition aspects of genetic conditions. I think there is scope to consider creating such patient resources, for example age appropriate educational videos/ information leaflets. | Thank you for your feedback. |
| 329 | Communication Matters (ISAAC UK Ltd) | Question 7 | None known. | Thank you for your feedback. |
| 330 | Derby and Derbyshire Integrated Care Board | Question 7 | We would like to develop or use a consistent approach for condition specific resources for specific issues. Developing resources in encouraging young people to attend transition appts and first adult appointments. Looking at developing system wide transition resources that would need to span health and social care. | Thank you for your feedback. |
| 331 | Derby and Derbyshire Integrated Care Board | Question 7 | In our ICB area we are developing a transition passport that follows young people through their transition regardless of the clinical pathway and also social care/education. | Thank you for your feedback. |
| 332 | Faculty of Pain Medicine of the Royal College of Anaesthetists | Question 7 | None in addition to those already mentioned in the document.Some hospitals are able to access dedicated clinical support (specialist nurses) to help plan their transition pathways | Thank you for your feedback. |
| 333 | Great Ormond Street Hospital (GOSH) | Question 7 | The reviewing group was not aware of this new guidance, until provided for review and comments. However, we appear to be following the guidance despite not having read it before. With the aim to bring the transition age down to 12 years which is the recommended age through transition clinics to reduce anxieties and form bonds prior to moving hospital settings. However, factors for delays include resource. Time, staffing, wider NHS pressures. Strikes, cuts. Currently admin teams or transition nurses at GOSH will contact patients to confirm they have had their first clinic appointment (speciality specific). We have developed a pathway within Epic to ensure patients are not missed from being seen if still waiting for initial appointment in adult services.We have developed new transition tab within Epic to support clinicians document transition process especially for complex patients under multiple specialities to improve communications and aim to reduce variations in adult settings the patient is transitioned to. This information will then be available in their patient portal to allow them more autonomy and independence in managing their own health through the transition journey and better prepare them for adult services.  | Thank you for your feedback. |
| 334 | Kent and Medway NHS and Social Care Partnership Trust | Question 7 | * A leaflet has been co-produced with young people in line with national standards to offer advice regarding the process of transition from Children and Young People’s Services to adult mental health services.

We, as an organisation, are currently in the development phase of producing a NICE guidelines informed transition video to create a practical resource for young people and their families/carers. | Thank you for your feedback. |
| 335 | Metabolic Support UK | Question 7 | **T-KASH transition tools from Breaking Down Barriers (**[**https://breaking-down-barriers.org.uk/t-kash-transition-tools/**](http://ttps://breaking-down-barriers.org.uk/t-kash-transition-tools/)**)****Roald Dahl-Transition of Care resources (**[**https://www.roalddahlcharity.org/what-we-do/roald-dahl-nurses/transition-of-care/**](https://www.roalddahlcharity.org/what-we-do/roald-dahl-nurses/transition-of-care/)**)** | Thank you for your feedback. |
| 336 | Midlands Partnership University NHS Foundation Trust | Question 7 | We are in the process of familiarising staff with the quality standards in the first instance. | Thank you for your feedback. |
| 337 | National Confidential Enquiry int Patient Outcome and Death (NCEPOD) | Question 7 | ‘[The Inbetweeners’](https://www.ncepod.org.uk/2023transition.html) report has had exposure on social media and has been presented at over 30 meetings to groups interested in transition including many ICBs. | Thank you for your feedback. |
| 338 | National Network of Designated Healthcare Professionals for Children | Question 7 | We have no experience that we could call upon. (there were 90 colleagues in the discussion) | Thank you for your feedback. |
| 339 | National Rheumatoid Arthritis Society | Question 7 | We don’t know.  | Thank you for your feedback. |
| 340 | NHS England | Question 7 | * Mental health trusts often have a transition plan for children and young people based on the standards above - “My moving on plan”
* Autism Central - [Autism Central for Parents and Carers | Autism Central](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.autismcentral.org.uk%2F&data=05%7C01%7Crebecca.dewar2%40nhs.net%7C2dcb8ed9993144f3af1c08dbd18526b1%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638334142027029096%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=YllOoaCInQHOBYrXannxI%2FZ4wznm%2FxjQk7El9idsxI0%3D&reserved=0)
* [Keyworker services](https://www.england.nhs.uk/learning-disabilities/care/children-young-people/keyworkers/)
* [Overview | Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education | Guidance | NICE](https://www.nice.org.uk/guidance/ng213)
* Children and young people’s continuing care national framework - GOV.UK (www.gov.uk)

N/A | Thank you for your feedback. |
| 341 | NHSE specialised commissioning | Question 7 | Q7 Response:Alstrom Syndrome UK Ready Steady Go which has been implemented by Birmingham Women’s and Children’s NHS Trust Other Trusts have a Trust-specific transition approach | Thank you for your feedback. |
| 342 | Nottinghamshire Healthcare NHS Foundation Trust | Question 7 | None I am aware of. | Thank you for your feedback. |
| 343 | NSA for PCC NHSE | Question 7  | Not sure | Thank you for your feedback. |
| 344 | Paediatric Continence Forum | Question 7 | The PCF is currently in the process of updating the Children’s Continence Commissioning Guide (CCCG). The CCCG advises all interested stakeholders on how to commission and run integrated, nurse-led, community-based paediatric continence services. These are clinically effective, improve the lives of children and their families and generate significant cost savings for the NHS. The transition from children’s to adults’ services should be an integral part of such service design. | Thank you for your feedback. |
| 345 | RCPCH | Question 7 | Research about the young adult (19-24 years) emerging into adulthood shows an interest in developing guidelines for this population to ensure that they are maintaining health care in the adult setting (Sable 2011; Telfiar 2004). The transition plan spans several years with concrete goals and a timeline. Whenever possible, a written transition plan should be. developed at least 3 years before the transfer of care is planned to occur and should be updated at least annually (New York 2011). It is essential for youth to be actively involved in creating the transition plan including their needs, views and preferences. The plan needs to be accurate and up to date, as well as serve as a flow of information between the youth and health care providers. (BC Medical Association 2012; Alberta 2007; Leung 2011; Suris 2015; Tuchman 2010). Transition can be expected to be more complex and generally more difficult for youth with multi-system issues, co-morbidities and physical and or cognitive disabilities. Increasing complexity will require parent/family/ care givers involvement in all levels of transition planning and identify areas for extended support (Alberta 2007; American Academy of Pediatrics - Committee on Disabilities 2005; Antle 2009; British Columbia Government 2009; Binks 2007; Racine 2014; Sable 2011). | Thank you for your feedback. |
| 346 | Royal College of General Practitioners  | Question 7 | **RCGP e-Learning “Better Transitions: Improving young people’s transfer from paediatric to adult services” (2021)** — available at no cost on the RCGP website and distributed by “***together for short lives”*** | Thank you for highlighting this resource. |
| 347 | Somerset Foundation Trust | Question 7 | None as of yet | Thank you for your feedback. |
| 348 | Spinal Muscular Atrophy UK | Question 7 | Alstrom Syndrome UK (ASUK) and Breaking Down Barriers have developed a model and resources to support professionals working with young people transitioning into adults' services, called T-KASH (transition knowledge and skills in health care): [T-KASH Transition Tools | Breaking Down Barriers (breaking-down-barriers.org.uk).](https://breaking-down-barriers.org.uk/t-kash-transition-tools/) As part of this, Marie McGee, National Transition Co-ordinator at ASUK, has created assessment templates called My Life, My Future (MLMF). The T-KASH model covers 12 areas that concern young people and families. The resources could be used across services help focus professionals in transition planning and for consistency for young people and families. | Thank you for your feedback. |
| 349 | Together for Short Lives | Question 7 | Together for Short Lives’ new edition of the *Stepping Up Transition Pathway* for 2023 builds on previous editions and has been updated to include new service examples from projects that were funded through our *Improving Transition for Young People Programme*, which we led during the period 2017-2022. It is updated with new evidence and to reflect developments in transition for young people with life-limiting or life-threatening conditions.The pathway can be accessed at <https://www.togetherforshortlives.org.uk/resource/transition-adult-services-pathway/>  | Thank you for your feedback. |
| 350 | UK Cystic Fibrosis Medical Association | Question 7 | I am unsure of any practical resources which have been developed to improve awareness of this quality standard | Thank you for your feedback. |
| 351 | University Hospitals Birmingham NHS Foundation Trust | Question 7 | Nil. | Thank you for your feedback. |
| 352 | Versus Arthritis | Question 7 | Members of Versus Arthritis’ young people’s panel had never heard of the NICE Quality standards. We recommend that self-management, youth work and youth led peer support programmes include reference to NICE standards and wider care standards so that young people and their parents/carers know what to expect. | Thank you for your feedback. |
| 353 | WellChild | Question 7 | [8 Principles for Transition: Guidance | WellChild](https://www.wellchild.org.uk/for-professionals/research-resources/8-principles-for-transition/#:~:text=Guidance%20and%20tools%20from%20WellChild%2C%20WellChild%20Nurses%20across,needs%20requiring%20transition%20from%20children%20to%20adult%20services.)  | Thank you for your feedback. |
| **Question 8 What are the challenges to implementing the NICE guidance underpinning this quality standard? Please say why and for whom. Please include any suggestions that could help users overcome these challenges (for example, existing practical resources or national initiatives).** |
| 354 | Alder Hey Liverpool | Question 8 | This is a continuing challenge, which must be addressed to safeguard the YPs health and life outcomes. Ensuring YP are well prepared in childrens services, can manage their LTCs and are empowered to do so and be independent is essential.Following up with the YP if they do not attend an adult consultation is also vital to ensure YPs health and life outcomes are maximised  | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 355 | Alexion, AstraZeneca | Question 8 | Overall, the content of the updated quality standard reflects the key areas for improvement for people with rare diseases. As part of implementation, we would support concerted actions to drive better awareness and adoption by healthcare services.We see there to be clear overlap between the ambitions of this quality standard and commitments within the Rare Disease Framework and the Rare Disease Action Plan for England in 2023, specifically in relation to the strategic priority of better coordinated care. We would encourage direct collaboration with NHS England colleagues as part of their work to include the definition of coordination of care in all new and revised services specifications for patients with rare diseases, and ensure the priorities of the UK Rare Diseases Framework are embedded across NHSE highly specialised services (Action 21). Building on the findings of CONCORD, NHS England has stated that it will ensure all new and revised service specifications for patients with rare diseases are mapped against the definition of care coordination as set out in [Defining Coordinated Care for People with Rare Conditions: A Scoping Review](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7319081/).Finally, we would also encourage NICE to give further consideration to the development of a dedicated Quality Standard for Rare Diseases as part of new topic prioritisation, in line with discussions that have taken place as part of the UK Rare Diseases Forum. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 356 | ARC Scotland - Scottish Transitions Forum | Question 8 | We think young people discharged for non-attendance should have other mechanism to follow them up with. Non-attendance is something due to failed transitions processes, not because of a lack of will on the young persons behalf or because they do not understand the system rather than refusal to engage. A lot of young people might not understand what the importance of these meetings and follow ups are. The NHS should and must provide information in easy-to-understand ways about why these follow up meetings are important and how young people can self-refer. It can be a very confusing time for young people as they move from attending a single appointment with one specialist in paediatric services to many different consultants with many different appointment times, roles, expectations and personal communication styles. This can be very complicated for first time experiencers of adult services after the wrap around care they receive in young people’s services. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 357 | ARNS | Question 8 | We believe that one of the challenges in implementing will be due to a lack of staff and data collection tools, in some areas. Coupled with some areas not having pathways in place to transfer young people to adult care. Alongside this, there often appears a lack of understanding and knowledge from the parents, young people and children that their care will need to transfer. However, having key personnel with transition being their main role will be able to educate families and support the clinical staff in doing so will reduce this. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 358 | Association of British Neurologists (ABN) | Question 8 | The challenge is limited resources and competing challenges within the NHS. Funding would need to be appropriate to the time needed for MDT working. Investment in IT services and co-ordination of IT across different agencies would be potentially required.The need for transition co-ordinators, specialist nurses as well as medical specialists and social/mental health services is high and unmet.With increasing therapeutic options requiring secondary care input and monitoring, engagement of young people with their treatment could well be a good investment for society as well as the individual.The advent of virtual appointment during the pandemic will be one resource that has been developed that will benefit this group although will not replace face to face appointments for all. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 359 | Association of Paediatric Chartered Physiotherapists | Question 8 | There remains a huge inequity of healthcare provision for young people with disability with a lack of equivalent adult specialist services once they leave paediatric services. It would help if young people were ‘prepared’ for this and knew when they needed to contact GPs about onward referrals for further physio/ OT assessment in adult services for specific issues.No set pathway which bridges both services, very different service acceptance criteria’s make it difficult to directly refer (i.e. onto adult community neurorehabilitation physiotherapy teams).Continuation of paediatric surveillance programmes such as CPIP into adult services would provide an opportunity for the future to change how we provide healthcare to individuals with childhood onset lifelong conditions. This could be used to support the transition pathway into adult services for young people with physical disability and aid commissioning of adult specialty services to transition these young people onto.  | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 360 | British Academy of Childhood Disability (BACD) | Question 8 | In some settings challenges may exist for professionals in terms of the resources needed to implement this NICE guidance. Practical resources already available e.g. Ready Steady Go and Growing Up and Gaining Independence may help. Having a joint approach between paediatric and adult services is key. Further development of joint transition clinics across services would help overcome these challenges, along with the appointment of key professionals to help support the transition process e.g. clinical nurse specialists or transition co-ordinators.  | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 361 | British Association of Teachers of Deaf Children and Young People (BATOD) | Question 8 | Clarification is required on how it is proposed young deaf adults engage with adult services. There is an emphasis on young adults to transition and engage via all these meetings etc but the practicalities are not all covered.1 – In some areas, it is incredibly challenging for deaf people to contact their services. Will all services have a clear coherent and accessible way of contacting them (e.g. email that is answered in an appropriate length of time, British Sign Language (BSL) on demand video relay service an option etc?) 2 – How is it services propose to ‘engage’? Are services clear on young deaf adults’communication needs? An accessible information standard already exists <https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/> However, BATOD members are aware through their work with deaf young people and through engagement with deaf colleagues that reception areas are often not “deaf friendly. Listening conditions are poor, so that deaf young people and adults are not able to understand receptionists or to hear names being called out. Some professionals who work often with deaf individuals e.g. audiologists can sometimes themselves be not easy to follow or understand etc.Many deaf children and young people lack an understanding of their rights to be able to challenge poor service delivery.Existing communication and secure information sharing platforms present challenges to effective implementation of existing transition processes in place in audiology, auditory implant and education services. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 362 | British Society of Physical and Rehabilitation medicine | Question 8 | 1. Lack of involvement of Rehabilitation medicine specialists who could potentially take over the role of neuro disability Paediatricians in Children’s services. British Society of Physical and Rehabilitation Medicine (BSPRM) is the leading professional body for doctors who are specialists in Rehabilitation medicine and other healthcare professionals involved in the field of rehabilitation medicine in the UK. The Society is dedicated to advancing the knowledge and practice of rehabilitation medicine in the UK, and to promoting excellence in patient care. We represent physicians, surgeons, nurses and healthcare professionals, who are passionate about improving the lives of patients with disabilities. BSPRM is thankful to NICE for providing us with an opportunity to review draft of new NICE guidelines on transition. The rehabilitation medicine has a separate training programme with a set of competencies and curriculum. The specific roles of a rehabilitation medicine doctor relate to the process of rehabilitation, and management of specific issues related to impairments such as spasticity, weakness, cognitive problems, communication and behavioural issues. No other profession has this kind of specific, focussed training on rehabilitation. We note with concern that the speciality of rehabilitation medicine was not consulted . A significant proportion of young adults do have neurological disabilities. The NCEPOD enquiry also has highlighted the issues faced by this cohort. However, We, BSPRM was not invited to join the quality standard advisory committee and our specility is only peripherally mentioned once in these draft guidelines. This will deprive opportunities for patients, especially for those with more complex needs, from gaining from inputs from doctors trained specifically to address their complex needs. These young adults with disabling conditions , assessments, interventions and ongoing oversight by a consultant in rehabilitation medicine. BSPRM urge NICE to review and rectify this glaring omission which is detrimental to the long-term management of young people with complex needs.
2. Lack of accountability: Currently the actual care is delivered through multiple agencies and is not co-ordinated. A named adult service provider should be responsible for co-ordinating the person’s care after transition. There should be a named NHS trust (or in some cases the ICB may wish to take that role) of taking the overall responsibility of the transition service, especially for those young adults with complex disabilities.
3. Focus of Children services: Current transition programmes are devised by, and for Children services to get young adults out of the service. The focus should shift to getting the young adults on into the adult services.
 | Thank you for your feedback which we will pass on to the Implementation Support team at NICE.Please note that this was a partial update of this quality standard based on stakeholder feedback from the rare diseases community. As such, we have varied our process and did not recruit to a quality standards advisory committee for the partial update. We have, however, consulted with all stakeholders as usual. The scope of this quality standard covers transition from children’s to adult’s services across all health and care services. With such a broad scope it has not been possible to focus on the needs of specific populations. |
| 363 | Brittle Bone Society | Question 8 | A major gap in Quality standards is embedding active quality improvement as part of the service model including co-production with patients with lived experience, without this the potential of local services to improve their transition will be blunted. This will require template questionnaires for patient satisfaction and experience. A major gap in the quality standards is the lack of specific measures to measure and reduce inequity of care. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE.Please note that we have highlighted the template questionnaires for young people and parent carers from NCEPOD in the quality standard data sources where appropriate. |
| 364 | Child Growth Foundation | Question 8 | Challenges: Having access to the data, obtaining the data, professionals putting transition routinely on their agenda during a consultation, having the resources to be able to monitor transition within a service/ speciality (eg nominated keyworker), having documentation that makes it easy to record when transition plans have been discussed and put into practiceSuggestions: NCEPOD transition from child into adult healthcare (2023) contains some examples of good practice, Locally a dedicated transition team have been employed (a nurse, paediatric Consultant and Adult Consultant) to provide guidance and information in the Trust to ensure that transition is managed appropriately | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 365 | Children with Exceptional Healthcare Needs networkNSS CEN – NHS Scotland National Services | Question 8 | A major challenge is the variation in age criteria for entering and leaving different elements of healthcare. This includes inpatient hospital care,, mental health services, specialist medical services in both paediatrics and adult medicine where outpatient reviews may still be held by a paediatric specialist team when the associated inpatient care is in an adult ward.Young People who move away from their parents/childhood carers’ place of residence require additional transition planning with the challenge to any transition coordinator to identify and interact with both the original local services and referral centres and those in the new area of residence for the young person. This may include unfamiliar third sector organisations in each locality.Transfer to adult service care may involve charges to equipment that the young person and their carers have been trained to use and feel confident to do so. The move to unfamiliar technology, additional training and service agreements adds further stress to an already challenging time. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 366 | Clinical Genetics Society | Question 8 | Provision of additional funding to support transition genetics clinics, for example that could be delivered by genetic counsellors for those with confirmed genetic diagnoses could improve care in this area, and provide a more standardised national approach. Typically, funding for transition genetics clinics only currently exists within highly specialised or supra regional specialist services, where there is bespoke funding available for such clinics.Development of additional supporting practical resources eg patient information leaflet ior educational videos could be helpful. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 367 | Communication Matters (ISAAC UK Ltd) | Question 8 | Provision of Augmentative and Alternative Communication (AAC) remains a post code lottery in England. The NHS specialist assessment centres only see around 10% of those who need AAC with the more complex needs. There are strict eligibility criteria for assessment so for instance once a young person has literacy, they are unlikely to be seen by specialists unless they have complex access needs. Even then once their assessment is completed their ongoing support is down to the local AAC team, and their reassessment as they grow/develop, or their needs change has to then meet the eligibility criteria again. The remaining 90% of those who need AAC are assessed and supported locally. Some will use classroom provided resources, others may be assessed as able to use direct access resources with text and these groups become less likely to be judged to need ongoing support. In both cases some young people are ‘signed off’ as needing communication support once an effective intervention is in place, yet technology becomes obsolete, individual needs change and what is right at 15 may not be right at 25 years of age. We welcome the recommendation below, highlighted in yellow, in the Equality Impact Assessment for this consultation. If this could be a standardised section in every Education, Health and Care Plan (EHCP) this would be hugely beneficial in capturing information around individual communication needs, that could then be assessed by adults’ services for a transitional appointment and ongoing support.**Equality Impact Assessment2.1 Have any potential equality issues been identified during the development of the quality standard (including those identified during the topic engagement process)? How have they been addressed?***Stakeholders highlighted the importance of recognising the young person’s communication needs. Equality considerations have therefore been added to statements 3 to 6 so that service managers ensure a range of support is available, and used, to help young people communicate effectively. This could include having a written record of how a young person communicates, such as a communication passport or 1-page profile, and different ways to help the young person communicate, such as communication boards and digital communication tools. An equality consideration has also been added to statement 5 to ensure that health and social care practitioners consider the young person’s communication needs and preferences when deciding on the format for the introductory meeting with adults’ services.* | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 368 | Derby and Derbyshire Integrated Care Board | Question 8 | **Paediatric consultant feedback –** * Funding and job planning are big ones. Ideally there should be a lead for paediatrics and adults in both medical, nursing and social care fields. If there isn't the time or the funding to organise transition clinics, MDT meetings etc, then it won't happen. When I first started, the diabetes transition clinics are sometimes not attended by anyone from the adult teams as they were expected to do this on their own times. Now that it is starting to be job planned for, there is always someone attending, and more clinics can be done.
* I appreciate the guidance that transition guidance says start transition planning from 11 years of age. However I don't think this is realistic. Many 11-year-olds I see are relatively immature still and need so much parental guidance. Most won't even want to sign their name on anything and often do not pay attention in clinic. I think 14+ is a better age to start transition planning. IMO, it should not take transition to teach them about their condition and medications so maybe 11+ for patient education on self-management and 14+ on transition planning.
* One of the things we realise here is that there are a lot of admin involved in transition planning and it doesn't just depend on healthcare team. Hence need to ensure there is adequate admin support.
 | Thank you for your feedback which we will pass on to the Implementation Support team at NICE.To clarify, statement 1 in the quality standard indicates that planning for transition should start by school year 9 (13 to 14 years). |
| 369 | Derby and Derbyshire Integrated Care Board | Question 8 | **Transition Nurse feedback*** Identifying young people in transition organisationally and regionally – young people are in various clinics and some may or may not transition a code assigned to a young person in transition for an EPR system would enable many areas of the guidance to be better tracked and implemented, Such as tracking number of YP in transition, Numbers of YP expected into adults for capacity planning, DNA’s in adult, tracking numbers of patients with transition plans if electronic. If the code could be the same for GP’s that would also help to plan numbers and target improvements.
* Challenge to have transition clinics or extra time to complete plans as transition not in job plans for any professionals – doctors, nurses, admin etc, no extra time allocated for admin and additional time in appointments to transition plan unless have a transition clinic which is not unified for all specialities. A national guidance that this needs to happen would help.
* Implementing guidance throughout a trust or region is a challenge for staff and ICBS as there is inequity in provision in all specialties, There is also inequity between services that are provided at a tertiary level in paediatrics which then need to be taken over by adult services that don’t exist. Organisational transition leads  need to be an expectation in all trusts to help support improvements in all areas not just speciality specific and to identify and manage risk trust wide in relation to transition.
* It is a challenge to work together in health, education and social care as systems do not match and there is a large time commitment for professionals to attend ECHP meetings. There is also no standard way to share EHCP’s with all professionals. A national standardisation of sharing EHCP’s may help.
 | Thank you for your feedback which we will pass on to the Implementation Support team at NICE.We understand that NHS England may be developing new SNOMED codes that can be used for transition that will improve identification of young people in future. |
| 370 | Derby and Derbyshire Integrated Care Board | Question 8 | **ICB feedback*** Identifying the young people who may need transition to either adult health/social care team is currently a challenge.
* Lack of funding and resources will prove a challenge to fully implement a transition pathway.
* Any quality standards need to be inclusive of the wider health/social care system inclusive of education, social care teams and health

Sharing of information across multiple providers who have different systems that do not talk to each other! | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 371 | Duchenne UK | Question 8 | Patients with rare and complex conditions, such as Duchenne muscular dystrophy (DMD), particularly face challenges when it comes to transition from children’s to adult’s services. They will often have a multidisciplinary care team, each part of which will treat transition differently, and do so at different ages. In addition, their health and mobility are declining right at the point they are meant to be making this move towards independence: for example, many patients with DMD will lose ambulation in their mid-teens.Transition is done best when there is a named individual who is responsible for co-ordinating that process. Youth and social workers, or DMD specialists (such as Neuromuscular Nurse Specialists) are ideally placed, but not every locality will have access to such individuals. Without that well-placed individual, who knows the condition, much of the implementation is missed or ignored. This is unfortunately too common in general, but exacerbated in rare disease communities where there aren’t the resources for staffing. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 372 | Faculty of Pain Medicine of the Royal College of Anaesthetists | Question 8 | Supportive tools (E.g. “Ready, steady, go”) already in place in some paediatric services but no additional clinical or administrative capacity to input or capture the data and not all adult services have been introduced to them.Liaison between adult and paediatric services within the same institution still requires an uplift in allocated time and resource for both teamsWhere one service (often paediatric) is supra-regional, how are the systems to link with local adult services in different areas to be funded or manned? In some areas, paediatric services end at 16 years but local adult services may not start until 18 years – how do both services support the young person outside their remit?Ideally a tool to facilitate identification of children as they progress through stages, which can be used by both children’s and adult services. This could be incorporated into the hospital electronic notes, via MDT list which shares info into individual patient notes, and children are not dropped off the list until 1 year following transition, for active review by both teams, allowing time for the young person to embed fully into adult services | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 373 | Faculty of Pharmaceutical Medicine | Question 8 | The low numbers of children with rare disease by geographic region, making national coordination a must. There should be a linking to the national registries of rare diseases. More thought needs to be given to the cross discipline linkages of healthcare professionals when dealing with rare diseases. Also many rare diseases are undergoing active research, how does active research integrate with the transition strategy. The document also makes no consideration of the autonomy of the individual | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 374 | Great Ormond Street Hospital (GOSH) | Question 8 | More services are required nationwide including youth support workers who can continue to support the young person into adult settings which have been proven effective in hospitals that have this service well established. Introduce peer support workers structure (similar to the mental health systems) where patients who have previously transitioned can support young people and their families. We developed an away day with one service where transitioned patients could come and talk about their experiences which allowed young people and families to ask questions and think about transition in a new way outside of the clinical setting. Interested in thinking about children where there are safeguarding concerns; where there are concerns about them not engaging with adults services – how can social care be brought into this process and be part of the standards? Vulnerable young adults? Different tools and approaches used by services to support with transition – is there a central repository?Thinking about linking with Research in Practice about transitional safeguarding and how is this captured in health? Do we need to think about children in care Do we need to think about children choosing who should be part of transition planning? Non statutory services? How do we support those with capacity issues in this guidance, consideration of guardian and how teams can notify of appointment etcResource is not available so this can be challenging and time consuming with more patients entering adolescent than ever before, increases pressure on resource and skillTimes have changed in health over the past 10 years, and this has not been reflected in the provision set aside by govThe locality of the patient is key in the community of their health care – e.g., gosh becomes their community but when they go to adult this may transfer completely out of London and back to services locally where they are not connected to their health community. Ensuring community teams are involved sooner is key and support the younger age for transition.Different hospital adolescent clinics vary -some up to 25, some 18 – impacting which hospital can offer this bridging suggestion. Also, variation in services around accepting age into adult services 16 or 18, which is also impacted by complexity of transition and whether patient has Learning disabilities, which causes challenges for A&E and inpatient settings. How does this doc consider the children that have complex health needs as children and then discharge but this reoccurs in adulthood – how will this info transfer to the adult services, but also to ensure the young person has the information to be prepared for adulthood– simple e.g. gastrostomy inserted as child – adults often wont then manage these going in to adulthood – so how do these adolescents receive support for this. More complex diagnosis too e.g. childhood cancers | Thank you for your feedback which we will pass on to the Implementation Support team at NICE.Please note that the scope of this quality standard does not include children who are discharged from paediatric services but then go on to need support from adult services later on. |
| 375 | Kent and Medway NHS and Social Care Partnership Trust | Question 8 | * The quality statements and guidance can be ambiguous and open to different interpretation, which means there is fluctuating standardisation in implementation.
* Current resources limit the implementation of the NICE guidelines/ quality standards; for example, workforce issues and lacking other resources.

Some of the standards are not applicable in some localities due to NHS/ICB Commissioning arrangements. For example, in Kent and Medway, there are two different NHS organisations in partnership trying to manage transition pathway – North East London Foundation Trust for Children and Young People’s Services and Kent and Medway NHS and Social Care Trust for Adult Services. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 376 | Metabolic Support UK | Question 8 | **The main challenges faced will be:*** A lack of appropriate adult services to transition to.
* A lack of adequate staffing to ensure the statements are adhered to.
* A lack of resourcing to ensure these statements are carried out.
* A lack of data harmonisation between sites.
 | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 377 | Midlands Partnership University NHS Foundation Trust | Question 8 | Inconsistencies in commissioning create gaps where there are no similar services for CYP in adult services or no available services. This creates fragmented care for CYP and navigation to services outside children’s services can be daunting for them.Improving relationships with GP’s could help – the annual reviews for CYP with long-term/complex conditions appear inconsistent in quality and availability.Improve engagement of CYP with their own health needs where appropriate – role of school nurses and youth workers who have high level skills to support with this should not be underestimated. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 378 | National Confidential Enquiry int Patient Outcome and Death (NCEPOD) | Question 8 | Organisations seem to think of transition as an ‘extra’ to health care rather than being embedded and part of good developmentally appropriate health care. With around half of all organisations having no input into transition at executive and senior managerial level there is not the visibility of the problem. Commissioning of transition services is not overt but bundled in with other health care and there are few audits of practice to enable commissioners to analyse the quality of the services they are commissioning.In order for effective transition and transfer to adult services to happen, transition needs to be job planned in both child and adult services. The NCEPOD report found this to be severely lacking. Without the role being dedicated and without targeted resource (transition CNS/Youth workers as key workers) proper, robust transition with adherence to NICE standards is not feasible. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 379 | National Deaf CAMHS (North) | Question 8 | Services for the deaf community are low and access to mainstream services can be challenging. Similarly, the location of services are geographically distant and could contribute to challenges developing coordinated transition plans. Establishing key links between specialist services and mainstream services would hopefully increase feasibility of this.For high risk deaf CYP (who would sit within mainstream CAMHS), crisis planning should form part of transition planning. There are a number of barriers facing deaf community when needing access to crisis services. Highlighting specific services that are accessible would support the development of a comprehensive transition plan. Highlighting the Accessible Information standard and BSL Act. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE.We confirm that we have added NHS England’s Accessible Information Standard to the equality considerations. |
| 380 | National Network of Designated Healthcare Professionals for Children | Question 8 | Lack of engagement with local authority colleagues is a concern as is the large number of partners who may need to provide transition support. To fix that, it would be worth engaging with safeguarding partnerships more broadly on this issue because they will have oversight of the more complex young people we are trying to help with this guidance.  | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 381 | National Rheumatoid Arthritis Society | Question 8 | With the current state of the NHS we believe that it is likely to be challenging for many units to ensure implementation of NICE Quality Standards. We know from the British Society for Rheumatology Workforce report: A Crisis in Numbers, that many rheumatology units cannot currently meet NICE Quality Standards in adult care. This is due to shortages in the multidisciplinary team workforce and long backlogs of patients waiting to be seen, in large part, caused by the pandemic. However, both of these scenarios existed, in part, pre-pandemic.As a National patient organisation, we provide wide ranging resources, services and programmes for children and young people with juvenile idiopathic arthritis, young adults with adult Juvenile Idiopathic Arthritis and young adults with Rheumatoid Arthritis. These educate, inform and advocate for children and young adults and health professionals in rheumatology, should refer and signpost their patients to such resources which can help to support the young people through the transition process. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 382 | NHS England | Question 8 | We suggest some of the challenges include: * The knowledge and understanding of statutory frameworks (including mental capacity act) around children’s services including transition and preparing for adulthood (including SEND legislation).
* It will be good to know of any evidence around whether where the transition workers sits affects the engagement of different services
* Referral thresholds are often significantly different for children’s and adult services so this needs to be factored into transition planning.
* Strategic partnership working between adults and children.
* Lack of resource in both health and social care to enable co-ordination and early planning.
* Greater awareness of the quality standard among service users might help push it forward, eg. parent carer forums, Healthwatch and other organisations could use it as a lever for improving transition.
* It would be helpful if those working in SEND were aware of the quality standard, since many of the relevant young people will have special educational needs and disabilities. Linking it closely to this legal framework (while also identifying cohorts who don’t fit within SEND) could help co-ordinated improvements to transition.
* How commissioners for children's services and adult services collaborate during transition so that both have clear responsibilities for the care pathway
* There could be a data challenge as some of the data may not be able to be retrieved from electronic systems and localised audits based on NICE guidance will be required.

Poor service provision in secondary care adult services owing to long waits. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 383 | NHSE Sheffield response | Question 8 | Resources – time for transition clinics and related admin work for the multidisciplinary team in all specialities. Administration support. Interest and knowledge – training. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 384 | NHSE specialised commissioning | Question 8 | Q8 response:It would be good if there could be a pilot of an online shared data system which pulls information for named patients from named data sources in all services that the patient has contact with and collates this information in a package for the patient, rather than a more manual approach where information from emails is received in to a series of local transition co-ordinators. In highly specialised services which offer care for people with rare diseases, this would draw information from services in quaternary, tertiary, secondary and primary care. In this example, new transition co-ordinators in primary care could see on a dashboard screen for each patient who they are being seen by and where they are up to with their transition management planning and when they will be transferred over to adult care for each care issue that they have.There are such apps in development.  | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 385 | Nottinghamshire Healthcare NHS Foundation Trust | Question 8 | Digital record keeping systems – Different organisations use different systems - A regional digital “hub” to share information.A system wide approach to Transition -  | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 386 | NSA for PCC NHSE | Question 8 | Not sure. From a PCC standpoint, CYP who do transition but then have a higher risk if needing critical care support (eg. Technology dependent) – may need joint consultation with local critical care services, especially in light of the recent work taking place in DGHs regarding escalation and critical care outreach. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 387 | Paediatric Continence Forum | Question 8 | A major challenge to implementing the NICE guidance underpinning this quality standard is the variation in the quality and resourcing of paediatric continence (bladder and bowel) service provision across the UK. A Freedom of Information project undertaken by the PCF in 2021 and published in 2022 identified continued disparities in service provision, with only 37.89% of NHS organisations providing integrated services for constipation and soiling, difficulties with toilet training, daytime bladder issues, and bedwetting as well as product provision. This is particularly significant for the transition from children’s to adults’ services, given that paediatric continence conditions can have long-term negative effects on all aspects of children and young people’s lives, with research increasingly identifying the impact felt through to adulthood. Supporting all local services, ICBs, health boards and health and social care boards across the UK to use the PCF’s Children’s Continence Commissioning Guide (CCCG) as a key resource in commissioning paediatric continence services would be an effective route to standardise excellent service provision across the UK and to ease the resource demand on services during transition of those young people who continue to need support with their bladder and bowel health from adults’ services. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 388 | RCPCH | Question 8 | #Advancements in medical treatment and technology have increased the life expectancy of children with special health care needs, the majority of whom are now living into adulthood. This means, a greater number of youth with special health care needs, are transferring to adult care, placing more demand on adult specialists, to treat individuals with childhood onset conditions, despite minimal knowledge and training with respect to these conditions. (10). # Youth and families, also find themselves coordinating care, in a new and more fragmented system, often lacking the skills and support required to navigate the system.# Adult specialists and primary care providers identify the lack of knowledge and/or training they receive regarding childhood onset conditions, their long-term complications, and the surveillance requirements, as contributing to these poor outcomes in patients (10). # Further, adult care providers report concern with the inadequate transfer of information and medical documentation. Hence, increase in stress and anxiety is reported, by all parties involved in the transition, from a paediatric to adult care setting. Additionally, a growing pool of quantitative data reflects poor clinical outcomes post transfer. For example, prior to initiating a transition program in Manitoba, 40% of young adults with type 1 diabetes dropped out of adult health care (11) resulting in an increased risk of amputation, blindness and even death. Another study found that prior to initiating a transition program in British Columbia kidney transplant patients had worse health outcomes, including a 24 percent incidence of graft loss and/or death within two years of transfer (12) Youth with chronic health conditions may also experience gaps in care during the years immediately following transfer. Data show, transitioning from paediatric to adult care, is associated with decreased clinic attendance ,impeding the management of a chronic health condition and leading to an increased risk that young adults will not receive care, until after complications arise When youth and their families face barriers and challenges as they transfer from paediatric to adult services, care can be disrupted, and financial costs can be incurred not only by the patient and family but also by the health care system. For example, patients may use health care resources like emergency departments more frequently, and experience increased hospitalizations and longer inpatient stays. The lack of preparation for and awareness of the differences between paediatric and adult care, are identified as common barriers to successful transition (13). The paediatric model of care is usually multidisciplinary and holistic in nature, with attention to psychosocial functioning, development, and navigational support. Paediatric care is also family centred, and parents or caregivers are actively involved in making medical decisions and delivering care. In contrast, in adult health care, the patient, is seen as responsible and self-reliant, and expected to advocate for themselves, manage their own health and make informed, independent treatment decisions (14). This often leads to decreased opportunities for youth who transferred to meet with health care providers on their own or practice self-directing their care as they approach the age of transfer (14). Fear of the unknown and uncertainty about the future are also commonly experienced by youth and their families during this time (15). Transition (which includes transfer) is more complex and generally more difficult for youth with medical complexity or who have multi-system issues, co-morbidities and physical and/or cognitive challenges. (16).  | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 389 | Research in Practice | Question 8 | Constrained resources of course pose some challenge. However, equally important is the culture and value base of services and professionals. Where young people are seen as passive, this impedes meaningful co-production. Where young people are seen as ‘disengaging’ there is little drive to ensure adult services are better at engaging young people. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 390 | Royal College of General Practitioners  | Question 8 | Within current NHS practice, primary care can offer a comprehensive register of children and young people with long-term illness or disability.Community Paediatric teams offer community-based registers of children and young people with learning disability and the transition of medical care of these patients is most complex given that much of their care is undertaken by Community Paediatrics and there is no direct pathway of transition to adult agencies e.g. incontinence, behaviour, mental health.It will be important to consider the following:* Health informatics challenges including how and where data is recorded and analysed
* NICE could recommend for each denominator and numerator,
	+ Specific SNOMED codes
	+ Where these SNOMED codes should be located, for example, identification of appropriate Data Sets
* Ideally, there should be a standardised Care and Support Plan pro-forma to which all interested parties can contribute. This would be an ideal role for the Professional Record Standards Body (PRSB) to oversee. One possibility would be to use or adapt PRSB’s Personalised Care and Support Plan Standard V2.0, which meets modern information standards and generates appropriate SNOMED codes to enable good quality data collection.
 | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. We confirm that we have added details of any national data sources that may be helpful for the measures suggested in the quality standard. We understand that NHS England may be developing new SNOMED codes that can be used for transition that will improve data collection in future. |
| 391 | Royal College of Nursing | Question 8 | Resources to establish why young people ‘have not engaged’ could be needed. Could this possibly fall within a role of a youth worker to support and promote developmentally appropriate healthcare who could explore any issues around non-engagement that could be overcome? | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 392 | Royal College of Occupational Therapists (RCOT) | Question 8 | Key challenges to implementation include the following: * Waiting lists for some children’s services, meaning limited time to develop and implement transition plans - impact on young people and service providers
* Patchy availability of adult services to transition to, especially for young people with physical health needs but without a learning disability – impact on young people & quality measures
* Increased demand for children’s health services and workforce challenges affecting capacity of service providers to develop timely, personalised transition plans with young people – impact on development and monitoring of transition plans

Poor integration of health/care/third sector IT systems and lack of consistency in recording is likely to affect efficiency of data collection and validity of findings – impact on evaluation of quality standards. Development of standardised IT and recording systems is crucial.   | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 393 | Somerset Foundation Trust | Question 8 | Until Transition activity is included in the job plans of relevant adult services this will be a challenge to achieve. In some clinical areas where there is a critical mass eg epilepsy this may be possible. We need to promote the importance of young people with long term medical conditions engaging in adult services and give incentives for doing so. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 394 | Spinal Muscular Atrophy UK | Question 8 | Challenges:* Workforce capacity, time for professionals and also buy-in from professionals
* Waiting lists
* Staff turnover resulting in inconsistency of staff involved
* Time, lack of specialist teams- lots of areas don’t have transition workers
* Parents unsure of process, fearful of change
* Reduced services and change in provision in different areas
* Engagement of teenagers and young adults in the transition process- what are the benefits for them? (making this clear to them)

 What would help:* Clear info sharing
* Specialist workers with knowledge of children and adults' services and workshops.
* Consider using the T-KASH model (discussed in box above)
 | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 395 | The Neurological Alliance | Question 8 | There are many reasons why a person, including a young person, might not attend an appointment. As noted in NHS England guidance on [reducing Did Not Attends (DNAs) in outpatient services](https://www.england.nhs.uk/long-read/reducing-did-not-attends-dnas-in-outpatient-services/#causes-of-dnas), a significant majority of reasons for DNAs are outside of a patient’s control. It is vital to better understand why people miss an appointment and action is taken within services to address identified reasons that are outside of a patient’s control. Ensuring communications with patients are personalised and accessible (including meeting any specific communication needs) is critical to improving patient experience of their care and to reducing DNAs. Signposting to guidance on good communications, such as the NHSE [Good Communication with Patients Wating for Care](https://www.england.nhs.uk/coronavirus/publication/good-communication-with-patients/) would help to strengthen this quality statement.People who may experience health inequalities, including people living in areas of higher socioeconomic deprivation, may also face additional challenges with attending appointments. In our 2021/22 children and young peoples national neurological patient experience survey, My Neuro Survey, we asked how difficult respondents found it to travel to the majority of appointments for their neurological condition. 31% of respondents in England whose postcodes were within quintile 1 (according to deprivation quintiles) and 43% of respondents within quintile 2 reported they found it difficult or very difficult. In comparison 24% of respondents within quintile 5 reported finding It difficult or very difficult.Specific actions to better support people who may experience health inequalities to attend appointments, including during the transition to adult services, should be considered as part of this quality standard. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE.We confirm that we have added information to the equality considerations following consultation. |
| 396 | The Royal College of Physicians of Edinburgh (RCPE) | Question 8 | A major challenge is the variation in age criteria for entering and leaving different elements of healthcare. This includes inpatient hospital care, mental health services, specialist medical services in both paediatrics and adult medicine where outpatient reviews may still be held by a paediatric specialist team when the associated inpatient care is in an adult ward.Young people who move away from their parents/childhood carers’ place of residence require additional transition planning with the challenge to any transition coordinator to identify and interact with both the original local services and referral centres and those in the new area of residence for the young person. This may include unfamiliar third sector organisations in each locality.Transfer to adult service care may involve charges to equipment that the young person and their carers have been trained to use and feel confident to do so. The move to unfamiliar technology, additional training and service agreements adds further stress to an already challenging time.Information to those transitioning is critical and the use of technology key to engage them. Also key information such as availability of services and treatments, for example after the age of 18 years any patients on kidney replacement therapy no longer receives priority of the UK transplant waiting list. What is clear speaking to this cohort is the need for flexibility in the system for them – in terms of follow-up, its nature – e.g. face to face, virtual etc and empowerment in their care through use of patient knows best and other systems. | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 397 | Together for Short Lives | Question 8 | As we set out in our response to question 3, we believe that the main challenges are:* a lack of professionals with the skills and experience needed to care for young people with life-limiting or life-threatening conditions
* inequitable and unsustainable NHS funding for palliative care services needed by children and young people
* the extent to which local NHS organisations plan and fund service which are consistent with this quality standard – and the extent to which the UK’s governments and bodies such as NHS England hold them to account in doing so.

We call for the following action:* Local NHS organisations and local authorities across the UK should plan services which make sure that young people experience smooth transitions between children’s and adult palliative care services – and receive care which is appropriate for their age and developmental status.
* We recommend that our ‘Stepping Up’ Transition Pathway is used as a framework to support this process.
* The UK’s governments should hold them to account to make sure they do this.
* Local NHS organisations and local authorities should, in particular, take into account the fact that life-limiting and life-threatening conditions are more prevalent in young people from minority ethnic backgrounds (in particular from Pakistani backgrounds) and those living in more deprived areas.
* NHS England should make sure that data about the population of young people in England who need to transition from children’s to adult palliative care services are made available to palliative care networks, NHS commissioners and provider organisations.
* The UK governments should make sure that local NHS organisations and local authorities work together so that transitions for young people with life-limiting or life-threatening conditions are joined up across education, health and social care services.

In *Being curious and confident* (which we refer to in our answer to question 1), Susanna Shouls, MSc states that there is a mixed picture of UK hospice service provision for the growing number of young adults with life-limiting conditions. The challenges have been identified as:* lack of adult respite services including developmentally appropriate services
* lack of funding and capacity
* need for a skilled and confident workforce in adult hospices for young adults with complex life-limiting illness
* need for more integrated provision between children’s and adults’ hospices.

She states that expectations of young people and their families are being dashed when young people do not meet eligibility criteria for adult hospice care. Overall, there is a lot of information and research describing the need for improvement, that some of the challenges are around:* having the right services, co-coordination and planning
* having the right skills and confidence
* engaging and working with young people and their parent carers throughout transition.

In *Being curious and confident* Susanna Shouls, MSc makes the following recommendations from the three-year Hospice UK Transitions ECHO programme to inform the next steps that need to be taken to improve care outcomes for young people and their families: 1. Harness the expert voice of experience to improve transitional care.
2. Encourage and support adult hospices to do more to support young people through transition.
3. Discover more about who is missing out on care so that we can tackle unequal access.
4. Continue the Transition ECHO hubs and National Transition Network to realise their full potential.
5. Make sure that local health and care systems consider the needs of young people in transition to adult services.

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report *The Inbetweeners: a review of the barriers and facilitators in the process of the transition of children and young people with complex chronic health conditions into adult health services* (<https://www.ncepod.org.uk/2023transition/The%20Inbetweeners_full%20report.pdf>) identifies a series of challenges. NCEPOD states that:* there is no clear pathway for the transition from healthcare services for children and young people to adult healthcare services
* the process of transition and the subsequent transfer is often fragmented, both within and across specialties
* often the adult services sit only with primary care.

NCEPOD recommends the following action:1. Make developmentally appropriate healthcare core business for all involved.
2. Involve young people and parent/carers in transition planning and transfer to adult services.
3. Improve communication and co-ordination between all specialties.
4. Organise healthcare services to enable young people to transfer to adult services effectively.
5. Provide strong leadership at board and specialty level at all stages of transition and transfer.
 | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 398 | UK Cystic Fibrosis Medical Association | Question 8 | We think it is good to have a quality standard, but sometimes it can be hard to implement this, as the resources available can vary across the country. It may be difficult to follow on from one service to another (childrens to adults) – they often work quite separately, so would need to make an effort to improve this. We (CFMA) could run a workshop to help inform clinicians about this and advertise the standard.  | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 399 | University Hospitals Birmingham NHS Foundation Trust | Question 8 | As the lead for Transition in my opinion the NICE guidance is long and repetitive and within a large organisation compliance needs to be viewed in different ways, locally at an individual pathway level, organisationally from a strategic and assurance perspective and then at a system level given that many of the elements will require a system wide approach to succeed. The Quality standards have been a useful framework to initially audit individual pathways against broadly, to then be able to create an overarching picture for reporting into Quality and Board meetings. Utilising a RAG rating system does create a visual method to articulate the scale, challenges and needs around Transition services within the organisation.Transition is all about seeing a cohort of patients that need something different and providing a quality, holistic service. This is exceptionally difficult to lead and advocate for in amongst NHS priorities and demands, where the front door, waiting lists and workforce take understandable priority. The Transition agenda remains driven by passionate individuals championing a wealth of evidence both historic and contemporary, with no real carrot or stick to empower change within organisations and providers. The NCEPOD report has been very powerful with quality and compliance agendas in many organisations and provided a tool for discussion and escalation. However, until young people are ‘seen’, care modelled and delivered for 0-25 year olds as per the Long Term Plan and resources are in place, compliance will remain low. Resources and initiatives such as a National Framework with minimum standards, a CQC inspection framework for transition in adult services, SNOMED codes and associated currencies and the Core capabilities for staff would support this.In reference to the briefing paper, I would share my concerns around healthcare services following the recommendations. I fully support the initial feedback outlined on page 5 referring to a language change from ‘to’ to ‘into’ adult services.  | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |
| 400 | Versus Arthritis | Question 8 | The main challenge to implementing the guidance is a lack of oversight or enforcement at a local level which effectively means the guidance is at risk of becoming a tick box exercise. There are also discrepancies in approaches and views of paediatric and adult HCPs that underlines the importance of cross disciplinary and service teams as recommended in - [Developmentally-appropriate-care-top-tips.pdf (rheumatology.org.uk)](https://rheumatology.org.uk/Portals/0/Documents/Policy/Developmentally-appropriate-care-top-tips.pdf?ver=2022-06-29-134707-550) and in NCEPOD Inbetweeners in terms of transition leads in adult care. **Resources** * Ready, Steady, Go [Ready Steady Go - TIER Network](https://www.readysteadygo.net/rsg.html)
* NCEPOD report - [The Inbetweeners\_full report.pdf (ncepod.org.uk)](https://www.ncepod.org.uk/2023transition/The%20Inbetweeners_full%20report.pdf)
* AYPH report - [Improving access to secondary care for young people - ayph](https://ayph.org.uk/improving-access-to-secondary-care-for-young-people/)
 | Thank you for your feedback which we will pass on to the Implementation Support team at NICE. |

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2. [‘The current mental health status of children and young people with JIA, and their wider family’: a charity partner collaboration survey | Pediatric Rheumatology (springer.com)](https://link.springer.com/article/10.1186/s12969-023-00898-5) [↑](#endnote-ref-2)
3. [versus-arthritis-state-msk-musculoskeletal-health-2023.pdf (versusarthritis.org)](https://www.versusarthritis.org/media/25649/versus-arthritis-state-msk-musculoskeletal-health-2023.pdf) [↑](#endnote-ref-3)
4. [versus-arthritis-state-msk-musculoskeletal-health-2023.pdf (versusarthritis.org)](https://www.versusarthritis.org/media/25649/versus-arthritis-state-msk-musculoskeletal-health-2023.pdf) [↑](#endnote-ref-4)
5. [“They Make Heavy Stuff Lighter.” Youth Workers in the Hospital Setting: A Service Evaluation (brighterfuturestogether.org.uk)](https://brighterfuturestogether.org.uk/app/uploads/2022/09/They-Make-Heavy-Stuff-Lighter-Youth-Workers-in-the-Hospital-setting.pdf) [↑](#endnote-ref-5)
6. [Improving access to secondary care for young people - ayph](https://ayph.org.uk/improving-access-to-secondary-care-for-young-people/) [↑](#endnote-ref-6)
7. [Continuing specialist care into adulthood in young people with juvenile idiopathic arthritis: a retrospective cohort study using electronic health records in England | Rheumatology | Oxford Academic (oup.com)](https://academic.oup.com/rheumatology/advance-article/doi/10.1093/rheumatology/keac497/6711385) [↑](#endnote-ref-7)
8. [Research priority setting for paediatric rheumatology in the UK - The Lancet Rheumatology](https://www.thelancet.com/journals/lanrhe/article/PIIS2665-9913%2822%2900106-0/fulltext) [↑](#endnote-ref-8)
9. [JIA Register | British Society for Rheumatology](https://www.rheumatology.org.uk/improving-care/registers/juvenile-idiopathic-arthritis) [↑](#endnote-ref-9)
10. [The Inbetweeners\_full report.pdf (ncepod.org.uk)](https://www.ncepod.org.uk/2023transition/The%20Inbetweeners_full%20report.pdf) [↑](#endnote-ref-10)
11. [The Inbetweeners\_full report.pdf (ncepod.org.uk)](https://www.ncepod.org.uk/2023transition/The%20Inbetweeners_full%20report.pdf) [↑](#endnote-ref-11)
12. [RHEUmatic and musculoskeletal conditions: geographical MApping of Prevalence and outcomeS | The Institute of Applied Health Sciences | The University of Aberdeen (abdn.ac.uk)](https://www.abdn.ac.uk/iahs/research/epidemiology/mapping-rmd-study-1688.php) [↑](#endnote-ref-12)