National Institute for Health and Care Excellence

Transition from children's to adults' services

Consultation on draft quality standard – deadline for comments 5pm on 26/10/23

Please email your completed form to: QualityStandards@nice.org.uk

Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly.

Please only comment on the specific questions below.

Organisation details

Organisation name (if you are responding as an individual rather than a registered stakeholder please leave blank)	**The Royal College of Physicians of Edinburgh (RCPE)** We are grateful to Dr Una Macfadyen FRCPE, Lead Clinician at NSS CEN (NHS Scotland National Services Children with Exceptional Healthcare Needs network) who has supported the development of these comments.
Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.	The RCPE has no links, either direct or indirect to the tobacco or any linked industry.
Name of person completing form	**Douglas Pattullo, Policy Officer.**
Supporting the quality standard Would your organisation like to express an interest in formally supporting this quality standard? More information.	
Type	**[Office use only]**

Comments on the updated quality standard

Question /comment number	Question Or 'general' for other comments	Comments Insert each comment in a new row. Do not paste other tables into this table because your comments could get lost – type directly into this table.
1	**For draft quality statement 2:** Does this quality statement accurately reflect a key area for quality improvement?	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.
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.	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,
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	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.

	any resource requirements that you think would be necessary for this statement. Please describe any potential cost savings or opportunities for disinvestment.	
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.	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?
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.	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.

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?	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.
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.	
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).	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.

Insert more rows as needed

Checklist for submitting comments

- Use this form and submit it as a Word document (not a PDF).
- Complete the disclosure about links with, or funding from, the tobacco industry.
- Combine all comments from your organisation into 1 response. We cannot accept more than 1 response from each organisation.
- Do not paste other tables into this table – type directly into the table.
- **Clearly mark any confidential information or other material that you do not wish to be made public. Also, ensure you state in your email to NICE that your submission includes confidential comments.**
- Do not include medical information about yourself or another person from which you or the person could be identified.
- Spell out any abbreviations you use

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Comments received from registered stakeholders and respondents during our stakeholder engagements are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.