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

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| --- | --- |
| **Organisation name**(if you are responding as an individual rather than a registered stakeholder please leave blank) | **Faculty of Pharmaceutical Medicine** |
| **Disclosure**Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry. | **None** |
| **Name of person completing form** | **Dr Anthony E Lockett**  |
| **Supporting the quality standard**Would your organisation like to express an interest in formally supporting this quality standard? [More information.](https://www.nice.org.uk/standards-and-indicators/get-involved/support-a-quality-standard) | **Yes** |
| **Type** | **[Office use only]** |

# Comments on the updated quality standard

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| --- | --- | --- |
| **Question****/comment number** | QuestionOr ‘general’ for other comments | CommentsInsert 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? | Yes the standard does reflect a key area for quality improvement |
| 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. | 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  |
| 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. | 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 |
| 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. | 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  |
| 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. | 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 |
| 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? | No please see answer to question 5  |
| 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. | no |
| 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). | 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  |
|  | Other considerations  | Much of the care given during the day involves schools, there appears to be no consideration of the involvement of schools in the strategyMany 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  |
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# 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

Please return to QualityStandards@nice.org.uk

NICE reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of NICE, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.

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.