NATIONAL INSTITUTE FOR HEALTH AND
CARE EXCELLENCE

Quality standards

Briefing paper: Transition from children’s to adults’ services (QS140)

Listening event: 29th June 2023

1. Introduction

The Department of Health and Social Care has asked NICE to undertake a review of [NICE's quality standard on transition from children’s to adult’s services](https://www.nice.org.uk/guidance/qs140) (QS140) to ensure it reflects the needs of young people with rare diseases. The first stage of the review will be a listening event with key stakeholders to understand the priorities for updating the quality standard.

This paper sets out information about the quality standard, together with what we know about how the NICE guideline and quality standard on transition from children’s to adults’ services have been implemented. The listening event will consider the quality standard in detail to agree if any changes are needed to existing quality statements to better reflect the needs of young people with rare diseases and if there are any new areas that should be included in the quality standard.

1. About NICE quality standards

NICE quality standards set out priority areas for quality improvement in health, public health and social care. They highlight areas with identified variations in current practice. Each quality standard includes:

* a set of statements to help improve quality
* information on how to measure progress.

Our quality standards are developed independently in collaboration with health and social care professionals, practitioners and service users. They're based on our guidance and other NICE-accredited sources. Areas prioritised for inclusion in the quality standard must be specific, measurable, and focussed on one concept.

Our quality standards are not mandatory. But they do support the government's vision for a health and care system focused on delivering the best possible health outcomes. Our quality standards can be used for:

* Quality improvement
	+ identifying areas for quality improvement
	+ designing and conducting audits
	+ writing improvement and action plans
	+ demonstrating the level at which services should be provided/setting goals
	+ training and education.
* Quality assurance and monitoring
	+ developing frameworks for quality assurance
	+ identifying gaps in services, benchmarking and monitoring/tracking changes
	+ setting key performance indicators (KPIs) and monitoring performance
	+ evidence of service quality for regulators.
* Influencing commissioning
	+ identifying support or changes needed to improve services
	+ supporting business cases along with requests for funding and resources.
1. Initial feedback on the quality standard

Those attending the listening event were asked to provide initial feedback on the current quality standard by responding to the following questions:

* Do you agree or disagree that the areas included in the current NICE quality standard on transition from children’s to adult’s services reflect the key priorities for improvement for people with rare diseases?
* Are there any changes that could be made to the current quality standard to better reflect the needs of people with rare diseases? If so, please specify.
* Are there any additional key areas for quality improvement that you would like to be included in this quality standard to reflect the needs of people with rare diseases?

2 responses were received. This feedback is summarised within the paper.

1. NICE quality standard: Transition from children’s to adults’ services (QS140)

The quality standard covers the period before, during and after a young person moves from children's to adults' services in all settings where transitions from children’s to adults’ health or social care services take place. It 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. This includes young people with mental health problems, disabilities and long-term, life-limiting or complex needs, and those in secure settings or under the care of local authorities. It describes high-quality care in priority areas for improvement. It does not cover areas of national policy, such as funding for health or social care.

This quality standard is based on the [NICE guideline on transition from children’s to adults’ services for young people using health or care services](https://www.nice.org.uk/guidance/ng43) (NG43). The guideline and quality standard were published in 2016 together with implementation support.

In 2019 NICE and the Social Care Institute for Excellence (SCIE) produced a [video on 5 key points to help young people succeed in moving from child to adult services](https://www.youtube.com/watch?v=RiHq9YihaLo&list=PLRbwbc3dfXUNefausjPRrYYDvvkKvfFeP&index=6) and a [podcast on improving mental health transitions for young people](https://www.youtube.com/watch?v=fHg7kkX-r1o&list=PLRbwbc3dfXUNefausjPRrYYDvvkKvfFeP&index=6&t=0s). In 2020 NICE produced a [quick guide for practitioners on building independence through planning for transition](https://www.nice.org.uk/about/nice-communities/social-care/quick-guides/building-independence-through-planning-for-transition?utm_medium=webpage&utm_source=toolsr&utm_campaign=quickguides&utm_content=qg3) based on the guideline and quality standard.

In 2020 the [NICE impact report on children and young people’s healthcare](https://www.nice.org.uk/about/what-we-do/into-practice/measuring-the-use-of-nice-guidance/impact-of-our-guidance/niceimpact-children-and-young-peoples-healthcare) highlighted some progress in transition from child to adult services in some areas including epilepsy, cancer, mental health and autism but overall concluded that there is still room to improve the provision of child to adult transition services. The report highlighted [shared learning examples](https://www.nice.org.uk/about/what-we-do/into-practice/shared-learning-case-studies) showing how services in [Southampton](https://www.nice.org.uk/sharedlearning/implementing-transition-care-locally-and-nationally-using-the-ready-steady-go-programme) and [Liverpool](https://www.nice.org.uk/sharedlearning/young-adult-diabetes-engaging-to-improve-outcomes-of-the-young-adult-clinic-restructure) have implemented our recommendations.

We are aware that the NICE quality standard (QS140) has been used to assess services and to support [quality improvement](https://adc.bmj.com/content/107/Suppl_2/A459.1) in a variety of paediatric services. A [study of transition from child and adolescent services to adult intellectual disability services](https://www.ingentaconnect.com/content/mcb/amhid/2022/00000016/00000004/art00001) highlighted poor recording of data and poor compliance with the quality standard.

The NICE field team supports service providers and commissioners to implement our guidance and have highlighted several examples of how our guideline and quality standard on transition from children’s to adults’ services have been incorporated into local resources and used to support baseline assessments. They noted that some providers have suggested that it can be difficult to plan transitions for children with complex disabilities when there is no adult equivalent service.

#### Initial feedback- general

Initial feedback suggests that the areas included in the current quality standard do reflect the key areas for improvement for people with rare diseases. There was concern however that few hospitals and healthcare services are following the recommendations. It was noted that the quality standard should refer to moving ‘into’ rather than ‘to’ adult services to ensure supports continues until the person is settled and engaged in the adult service.

The sections that follow focus on each quality statement included within the current quality standard.

* 1. Quality statement 1: Planning transition

#### Quality statement

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.

#### Rationale

Starting to plan their transition as early as possible can lead to a better experience for young people moving from children's to adults' services. Early planning allows a more gradual process. A sudden move to adults' services with no time for preparation or support can lead to young people and their families losing confidence and disengaging with services. Early planning, led by the health and social care practitioners but with full involvement from the young person, allows young people more time to be involved in decisions and to adjust to changes to their future care. It is recognised that for some young people, those covered by health and social care or education legislation, early transition planning is already a legal requirement.

#### Current practice

A [UK study of transition services for paediatric inflammatory bowel disease](https://journals.lww.com/jpgn/Fulltext/2021/08000/Transition_Services_for_Paediatric_Inflammatory.23.aspx) found that the average age of starting transition was 15.4 years in standalone children’s hospitals and 15.3 years in those centres co-located with adult hospitals.

#### Initial feedback

It was suggested that the statement should emphasise that planning should start at the latest by year 9 as services transfer at different ages and it may be as early as year 7 for transfer at age 16.

It was suggested that is important to ensure that the needs of people whose condition affects their development or maturity are considered. The transition process and when it starts should be considered carefully and will be more complex due to their developmental or learning disabilities.

#### For discussion

* Do we need to make any changes to this quality statement to better reflect the needs of young people with rare diseases?
* Are there any equality considerations that we should add to this statement?
	1. Quality statement 2: Annual meeting

#### Quality statement

Young people who will move from children's to adults' services have an annual meeting to review transition planning.

#### Rationale

Transition is a lengthy process that starts early, by school year 9 (aged 13 to 14 years) and continues past the point of transfer. Regular review of transition planning ensures that a young person's changing needs are taken into account. Transition planning should be reviewed at least annually, but for some young people the meetings may need to be more frequent, depending on their individual needs.

#### Initial feedback

As people with rare diseases may be seen by a number of hospitals and healthcare teams it was suggested that is important to emphasise that the annual meeting should include all the different healthcare providers.

#### For discussion

* Do we need to make any changes to this quality statement to better reflect the needs of young people with rare diseases?
* Are there any equality considerations that we should add to this statement?
	1. Quality statement 3: Named worker

#### Quality statement

Young people who are moving from children's to adults' services have a named worker to coordinate care and support before, during and after transfer.

#### Rationale

Transition can be a difficult time for young people and their families, because it is a lengthy process and involves various professionals and services. A single point of contact – preferably a person that the young person knows and trusts – can coordinate care and signpost to appropriate support. This can increase attendance in adult services and lead to a better experience of care and better outcomes.

#### Current practice

The [British Association of Community Child Health review of transition practice in community child health](https://adc.bmj.com/content/107/Suppl_2/A87.3) was an audit of 53 young people attending a specialist education provision and those with a diagnosis of attention deficit hyperactivity disorder in 2019 and 2020. They found that none of the young people had a named transition worker to coordinate care and provide support.

#### Initial feedback

It was suggested that it should be clearer if the coordination of care is in one service or all services that the person is transitioning through. It was suggested that it would be helpful to have a named worker in each service and a transition coordinator to help them navigate services if they are transitioning through 3 or more services.

#### For discussion

* Do we need to make any changes to this quality statement to better reflect the needs of young people with rare diseases?
* Are there any equality considerations that we should add to this statement?
	1. Quality statement 4: Introduction to adults' services

#### Quality statement

Young people who will move from children's to adults' services meet a practitioner from each adults' service they will move to before they transfer.

#### Rationale

Young people may feel unsure about moving to adults' services, especially if they have been with children's services for a while. Meeting a practitioner who will take a lead role in their future care, at least once, from each of the adults' services they will move to can help build a young person's confidence, reduce their concerns and increase their willingness to have new practitioners involved in their care. This can lead to a smoother transition for the young person and more regular attendance at appointments in adults' services, with better outcomes.

#### Current practice

The [British Association of Community Child Health review of transition practice in community child health](https://adc.bmj.com/content/107/Suppl_2/A87.3) found that 68% of 53 young people attending a specialist education provision and those with a diagnosis of attention deficit hyperactivity disorder in 2019 and 2020 had not met the adult team prior to transition.

A [UK study of transition services for paediatric inflammatory bowel disease](https://journals.lww.com/jpgn/Fulltext/2021/08000/Transition_Services_for_Paediatric_Inflammatory.23.aspx) found that the transition process involved a visit to adult only clinics in 50% of centres. Joint transition clinics were held in every centre however with adult and paediatric gastroenterologists, but more patchy availability of other team members.

#### Initial feedback

It was suggested that young people with rare diseases may have to transfer to a new hospital for their adult care as it can be difficult to find a team that understands the rare disease. This can make it more difficult to meet the new team but also makes it even more important in order to reduce anxiety about the change.

#### For discussion

* Do we need to make any changes to this quality statement to better reflect the needs of young people with rare diseases?
* Are there any equality considerations that we should add to this statement?
	1. Quality statement 5: Missed first appointments after transfer to adults' services

#### Quality statement

Young people who have moved from children's to adults' services but do not attend their first meeting or appointment are contacted by adults' services and given further opportunities to engage.

#### 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.

#### Initial feedback

It was suggested that the wording should be changed to reflect that young people may attend the first but not the second appointment if they do not like it. It was felt that it is important to ensure that young people who do not attend any of their appointments in adult services are contacted and that the GP should be notified of any disengagement.

#### For discussion

* Do we need to make any changes to this quality statement to better reflect the needs of young people with rare diseases?
* Are there any equality considerations that we should add to this statement?
1. Areas not covered in the current quality standard

Since 2016 NICE has published additional guidelines which are not currently used in the quality standard on transition. These, along with the [NICE guideline on transition](https://www.nice.org.uk/guidance/ng43), could be used to support development of any additional statements.

* [Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education](https://www.nice.org.uk/guidance/ng213) (NG213, published 2022). This guideline includes a section on transition from children’s to adults’ services.
* [Babies, children and young people's experience of healthcare](https://www.nice.org.uk/guidance/ng204) (NG204, published 2021)

The following is a summary of suggestions made so far for additional statements:

#### Transition when there is not an adult service and/or a clear diagnosis

It was suggested that it needs to be clear what services who are supporting young people with rare diseases should do if there is not an equivalent adult service that they can transition to or if there is not a clear diagnosis.

This area is not included the [NICE guideline on transition from children’s to adults’ services](https://www.nice.org.uk/guidance/ng43) or the [NICE guideline on disabled children and young people up to 25 with severe complex needs](https://www.nice.org.uk/guidance/ng213).

#### Involving parents and carers

It was suggested that young people should be able to consider how involved they would like their parents or carers to be in their care during and after transition to adult services. It is important to ensure that young people are supported to gradually build up their confidence to communicate with healthcare professionals during and after transition.

These issues are supported by recommendations in the [NICE guideline on transition from children’s to adults’ services](https://www.nice.org.uk/guidance/ng43) in sections on building independence (recommendations 1.2.13 to 1.2.18) and involving parents and carers (recommendations 1.2.19 to 1.2.22). This area was discussed during development of the quality standard but not prioritised.

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