



Transition from children's to adults' services

Quality standard

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This standard is based on NG43 and NG213.

This standard should be read in conjunction with QS152, QS41, QS39, QS168, QS175, QS25, QS182, QS81, QS48, QS188, QS191 and QS194.

Quality statements

<u>Statement 1</u> 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. **[2016]**

<u>Statement 2</u>Young people who will move from children's to adults' services have a coordinated transition plan. [new 2023]

<u>Statement 3</u> Young people who will move from children's to adults' services have an annual meeting to review transition planning. [2016]

<u>Statement 4</u> 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. [2016]

<u>Statement 5</u> 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. [2016, updated 2023]

<u>Statement 6</u> 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]

In 2023 this quality standard was updated and some statements prioritised in [2016] were updated [2016, updated 2023]. A new statement was also added [new 2023]. For more information, see <u>update information</u>.

The previous version of the quality standard for transition from children's to adults' services is available as a pdf.

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. [2016]

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 and carers, losing confidence and to stop using services. Early planning, led by the health and social care practitioners but with full involvement from the young person and their family or carers, allows them 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.

Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Process

a) Proportion of young people in school year 9 (aged 13 to 14 years) who will move from children's to adults' services who have started planning their transition.

Numerator – the number in the denominator who have started planning their transition.

Denominator – the number of young people in school year 9 (aged 13 to 14 years) who will move from children's to adults' services.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, for example from patient or client records.

b) Proportion of young people entering children's services after school year 9 and who will move to adults' services who started planning their transition immediately.

Numerator – the number in the denominator who started planning their transition immediately.

Denominator – the number of young people entering children's services after school year 9 and who will move to adults' services.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, for example from patient or client records.

Outcome

a) Proportion of young people (and their families and carers), who have transferred from children's to adults' services, who were satisfied with planning for transition and transfer (including their involvement).

Numerator – the number in the denominator who were satisfied with planning for transition and transfer (including their involvement).

Denominator – the number of young people (and their families and carers) who have transferred from children's to adults' services.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, for example from a patient or client survey. Resources to support this could include the TIER Ready, Steady, Go programme which includes feedback on transition planning in its questionnaires for young people and their families and carers. Also, the <a href="National Confidential Enquiry into Patient Outcome and Death transition from child into adult healthcare young person and parent carer survey includes questions on transition planning."

b) 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.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, for example from patient or client records. For example, NHS Digital's hospital episode statistics (HES) includes data on hospital outpatient appointments and attendances.

c) Proportion of young people attending adults' services after transfer from children's services who continue to engage with services.

Numerator – the number in the denominator who continue to engage with services.

Denominator – the number of young people attending adults' services after transfer from children's services.

Data source: Data can be collected from information recorded locally by health and care practitioners and provider organisations, for example from patient or client records. For measurement purposes 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.

What the quality statement means for different audiences

Service providers (children's and adults' health, mental health and social care providers) ensure that systems are in place to identify young people who will move from children's to adults' services and to start involving them and their families or carers in planning their transition by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.

Health and social care practitioners (such as hospital consultants, nurses, GPs, social workers, mental health workers, care coordinators or named workers) involve children and young people, and their families or carers, in planning their transition from children's to adults' services by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.

Commissioners ensure that they commission services that identify young people who will move from children's to adults' services and start planning their transition by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.

Commissioners should ensure that the planning involves the young person and their family or carers, as well as the practitioners.

Young people who will move from children's to adults' services work with their health or social care practitioners to start planning for the move by school year 9 (aged 13 to 14 years). For young people who enter children's services after year 9, planning for the move should start immediately. Early planning gives young people time to be involved in decisions and to understand and adapt to changes in their future care.

Families and carers of young peoplewho will move from children's to adults' services are involved from the start in planning for the move. This gives them time to understand and to adapt to changes in the young person's future care. Their level of involvement will depend on the needs and preferences of the young person.

Source guidance

<u>Transition from children's to adults' services for young people using health or social care services. NICE guideline NG43</u> (2016), recommendation 1.2.1

Equality and diversity considerations

It will be important to adapt the timing and approach to transition to reflect the needs of young people with a learning disability or neurodevelopmental needs or both. Health and social care practitioners should ensure that the starting point for 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. [NICE's guideline on transition from children's to adults' services for young people using health or social care services, recommendations 1.1.2 and 1.2.3, terms used in this guideline and expert opinion]

Quality statement 2: Coordinated transition plan

Quality statement

Young people who will move from children's to adults' services have a coordinated transition plan. [new 2023]

Rationale

Having a transition plan that is coordinated across all services will make it clear when the care and support provided to a young person will move from children's to adults' services and how it will be delivered. Children's and adults' services should work together and with the young person and their family or carers to develop a coordinated transition plan that meets the young person's individual needs, 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. It is recognised that for young people covered by health and social care or education legislation this will be part of a broader plan.

Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Process

Proportion of young people from school year 9 (aged 13 to 14 years) and above, who will move from children's to adults' services, who have a coordinated transition plan.

Numerator – the number in the denominator who have a coordinated transition plan.

Denominator – the number of young people from school year 9 (aged 13 to 14 years) and

above, who will move from children's to adults' services.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, for example from patient or client records. From school year 9 (aged 13 to 14 years) and above is included for measurement purposes, although it is recognised that the starting time may vary in different services. Data on a personalised transition plan and coordination of age of start of transition is included in the National Confidential Enquiry into Patient Outcome and Death transition from child into adult healthcare audit toolkit, which can be implemented locally.

Outcome

a) Proportion of young people (and their families and carers) who have transferred from children's to adults' services, who were satisfied with planning for transition and transfer (including their involvement).

Numerator – the number in the denominator who were satisfied with planning for transition and transfer (including their involvement).

Denominator – the number of young people (and their families and carers) who have transferred from children's to adults' services.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, for example from a patient or client survey. Resources to support this could include the TIER Ready, Steady, Go programme which includes feedback on transition planning in its questionnaires for young people and their families and carers. Also, the <a href="National Confidential Enquiry into Patient Outcome and Death transition from child into adult healthcare young person and parent carer survey includes questions on transition planning."

b) 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.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, for example from patient or client records. For example, MHS Digital's hospital episode statistics (HES) includes data on hospital outpatient appointments and attendances.

c) Proportion of young people attending adults' services after transfer from children's services who continue to engage with services.

Numerator – the number in the denominator who continue to engage with services.

Denominator – the number of young people attending adults' services after transfer from children's services.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, for example from patient or client records. For measurement purposes, 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.

What the quality statement means for different audiences

Service providers (children's and adults' health, mental health and social care providers) work together to develop and agree a coordinated transition plan with young people who will transition from children's to adults' services, and their families and carers.

Health and social care practitioners (such as hospital consultants, nurses, GPs, social workers, mental health workers, care coordinators or named workers) work with young people, and their families or carers, to develop a transition plan for the move to adults' services. They read the sections of the plan produced by other practitioners, to make sure the plan works as a whole. Where a named worker is in place, they will coordinate the transition plan.

Commissioners ensure they commission services that work together, and with young people, and their families and carers, to develop and agree a coordinated transition plan for the move to adults' services.

Young people who will move from children's to adults' services work with health and care practitioners to develop and agree a plan for moving that covers all the services they use. This will set out what changes there will be, as well as when and how those changes will happen.

Families and carers of young people who will move from children'sto adults' services work with health and care practitioners to develop and agree a plan for the move. This will set out future changes to services and care that the young person will receive.

Source guidance

- <u>Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education. NICE guideline NG213</u> (2022, updated 2023), recommendations 1.8.6 and 1.8.7
- Transition from children's to adults' services for young people using health or social care services. NICE guideline NG43 (2016), recommendations 1.1.6 and 1.2.4

Definitions of terms used in this quality statement

Coordinated transition plan

Children's and adults' services should work together and with the young person and their family or carers to develop a transition plan that meets the young person's individual needs. 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; 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 transition plan should:

- coordinate the age of non-statutory transitions to adults' services, to ensure a consistent approach
- include the services that are available locally to support transition
- be agreed with the young person and their family or carers (for example, by including a section for their comments and views)
- link to other plans the young person has in respect of their care and support.

[NICE's guideline on disabled children and young people up to 25 with severe complex needs, recommendations 1.8.5, 1.8.6 and 1.8.7 and NICE's guideline on transition from children's to adults' services for young people using health or social care services, recommendations 1.2.4 and 1.3.9 and expert opinion]

Equality and diversity considerations

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.

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 plan should ensure that the point of transfer is not based on a rigid age threshold and takes place at a time of relative stability for the young person. [NICE's guideline on transition from children's to adults' services for young people using health or social care services, recommendations 1.1.2 and 1.2.3 and terms used in this guideline]

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. [NICE's guideline on transition from children's to adults' services for young people using health or social care services, recommendations 1.2.11 and 1.2.12]. 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 or the equivalent standards for the devolved nations.

Service managers should ensure practitioners can respond to the specific needs of care leavers including the option to continue access to services beyond age 18 until care has been transferred to adults' services. Practitioners should ensure that the transition plan for care leavers is included within their pathway plan for leaving care. [NICE's guideline on looked-after children and young people, recommendations 1.8.4 and 1.8.10]

Quality statement 3: Annual meeting

Quality statement

Young people who will move from children's to adults' services have an annual meeting to review transition planning. [2016]

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, and their families or carers, the meetings may need to be more frequent, depending on their individual needs.

Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Process

Proportion of young people older than school year 9 (aged 13 to 14 years), who will move from children's to adults' services, who have had a meeting in the previous 12 months to review transition planning.

Numerator – the number in the denominator who have had a meeting in the previous 12 months to review transition planning.

Denominator – the number of young people older than school year 9 (aged 13 to 14 years) who will move from children's to adults' services.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, for example from patient or client records.

Outcome

a) Proportion of young people (and their families and carers) who have transferred from children's to adults' services, who were satisfied with planning for transition and transfer (including their involvement).

Numerator – the number in the denominator who were satisfied with planning for transition and transfer (including their involvement).

Denominator – the number of young people (and their families and carers) who have transferred from children's to adults' services.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, for example from a patient or client survey. Resources to support this could include the IER Ready, Steady, Go programme which includes feedback on transition planning in its questionnaires for young people and their families and carers. Also, the <a href="National Confidential Enquiry into Patient Outcome and Death transition from child into adult healthcare young person and parent carer survey includes questions on transition planning."

b) 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.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, for example from patient or client records. For example, NHS Digital's hospital episode statistics (HES) includes data on hospital outpatient appointments and attendances.

c) Proportion of young people attending adults' services after transfer from children's services who continue to engage with services.

Numerator – the number in the denominator who continue to engage with services.

Denominator – the number of young people attending adults' services after transfer from children's services.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, for example from patient or client records. For

measurement purposes, 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.

What the quality statement means for different audiences

Service providers (children's and adults' health, mental health and social care providers) ensure that systems are in place for young people who will move from children's to adults' services, and their families or carers, to have an annual meeting to review transition planning with all practitioners providing support.

Health and social care practitioners supporting transition (such as hospital consultants, nurses, social workers, mental health workers, GPs, care coordinators or named workers) take part in an annual meeting to review transition planning for young people who will move from children's to adults' services. They ensure that they share the updated plan with young people and their families or carers after the meeting.

Commissioners ensure that they commission services that arrange an annual meeting with all practitioners to review transition planning for young people who will move from children's to adults' services.

Young people who will move from children'sto adults' services have a meeting each year to talk about planning for the move and check that the plans are still suitable for them. The meeting should involve all practitioners supporting the young person, and their family or carers.

Families and carers of young people who will move from children'sto adults' services are involved in a meeting each year to review planning for the move. The meeting ensures that families and carers feel involved and know about future changes to services and care that the young person will receive.

Source guidance

Transition from children's to adults' services for young people using health or social care services. NICE guideline NG43 (2016), recommendation 1.2.4

Definitions of terms used in this quality statement

Annual meeting

The annual meeting should involve the young person, their family or carers and input from all practitioners providing support.

The meeting can take place either in person or via teleconferencing or video.

The meeting should identify what is working well in the transition planning and what can be improved. The young person should be treated as an equal partner and their views taken into account. They should be supported to make decisions and build their confidence to direct their own care and support over time. At the meeting there should be a review of the young person's current:

- clinical needs
- psychological status
- social and personal circumstances
- · caring responsibilities
- · educational and vocational needs
- · cognitive abilities, and
- · communication needs.

[NICE's guideline on transition from children's to adults' services for young people using health or social care services, recommendations 1.1.2, 1.1.4, 1.2.4 and expert opinion]

Equality and diversity considerations

Health and social care practitioners should consider the young person's travel and communication needs when deciding whether the annual meeting should take place in person or virtually.

Service managers should ensure a range of support is available, and used, to help young

people communicate effectively at the annual meeting. 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. [NICE's guideline on transition from children's to adults' services for young people using health or social care services, recommendations 1.2.11 and 1.2.12]. 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 or the equivalent standards for the devolved nations.

Service providers should consider the best way to ensure that young people, especially those with complex needs, do not have to re-tell their story at each transition meeting. This could include making sure the same practitioners attend each meeting and/or developing and sharing a personal folder that includes key information about the young person. [NICE's guideline on transition from children's to adults' services for young people using health or social care services, recommendation 1.3.3]

Quality statement 4: 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. [2016]

Rationale

Transition can be a difficult time for young people and their families or carers, because it is a lengthy process and involves various practitioners and sometimes, several services with different timescales. 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 adults' services and lead to a better experience of care and better outcomes.

Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Process

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

Numerator – the number in the denominator who have a named worker to coordinate care and support before, during and after transfer.

Denominator – the number of young people who are moving from children's to adults' services.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, for example from patient or client records. Data

on having a key worker before, during and after transition is included in the <u>National</u> <u>Confidential Enquiry into Patient Outcome and Death transition from child into adult</u> healthcare audit toolkit which can be implemented locally.

Outcome

a) Proportion of young people (and their families and carers) who have transferred from children's to adults' services, who were satisfied with planning for transition and transfer (including their involvement).

Numerator – the number in the denominator who were satisfied with planning for transition and transfer (including their involvement).

Denominator – the number of young people (and their families and carers) who have transferred from children's to adults' services.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, for example from a patient or client survey. Resources to support this could include the TIER Ready, Steady, Go programme which includes feedback on transition planning in its questionnaires for young people and their families and carers. Also, the <a href="National Confidential Enquiry into Patient Outcome and Death transition from child into adult healthcare young person and parent carer survey includes questions on transition planning."

b) 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.

Data source: Data can be collected from information recorded locally by health and care practitioners and provider organisations, for example from patient or client records. For example, NHS Digital's hospital episode statistics (HES) includes data on hospital outpatient appointments and attendances.

c) Proportion of young people attending adults' services after transfer from children's services who continue to engage with services.

Numerator – the number in the denominator who continue to engage with services.

Denominator – the number of young people attending adults' services after transfer from

children's services.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, for example from patient or client records. For measurement purposes, 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.

What the quality statement means for different audiences

Service providers (children's and adults' health, mental health and social care providers) ensure that systems are in place for young people who are moving from children's to adults' services to have a named worker to coordinate care and support before, during and after transfer. To support this, service providers could consider joining up services for young people involved with multiple medical specialities, for example, by having a single physician, such as a rehabilitation consultant, taking a coordinating role. [NICE's guideline on transition from children's to adults' services for young people using health or social care services, recommendation 1.5.10]

Health and social care practitioners (such as hospital consultants, nurses, GPs, youth workers, social workers, mental health workers and care coordinators) work with the young person who is moving from children's to adults' services to identify a named worker and then work with this practitioner to coordinate care and support before, during and after transfer.

Commissioners ensure that they commission services that work with young people who are moving from children's to adults' services to identify a named worker to coordinate care and support before, during and after transfer.

Young peoplewho are moving from children's to adults' services should be helped to choose a single worker – preferably someone that they know and trust – to act as a named worker who coordinates care before, during and after transfer. The named worker acts as a link with staff providing support, including the young person's GP. The named worker should arrange appointments, as well as providing support to the young person and their family or carers.

Families and carers of young peoplewho are moving from children's to adults' services can contact the named worker for information and support for themselves. If appropriate, they can also ask the named worker for extra support for the young person to help with the move.

Source guidance

<u>Transition from children's to adults' services for young people using health or social care</u> services. NICE guideline NG43 (2016), recommendations 1.2.5 and 1.2.9

Definitions of terms used in this quality statement

Named worker

The named worker is a role rather than a job title. This should be one of the people from among the group of workers providing care and support to the young person, who has been designated to take a coordinating role. The young person should help decide who this person should be. It could be, for example, a support planner, a nurse, a youth worker, an allied health professional or another health or social care practitioner. It could also be someone who already has the title keyworker, transition worker or personal adviser. The transition process is lengthy and it would be expected that the named worker may change over time.

A named worker should oversee, coordinate and deliver transition support, including the transition plan. They should be the main link with other practitioners, particularly if a young person receives care from more than one service. They should arrange appointments for the young person, act as their representative, direct them to other services and sources of support, and support the young person's family or carers if appropriate.

The named worker should be involved throughout transition, supporting the young person before and after transfer until a time agreed with the young person and their family or carers. The named worker should hand over responsibilities to a practitioner in adults' services (if the named worker is based in children's services) and give the practitioner's details to the young person and their family or carers.

The named worker should ensure that support with education and employment is offered. For disabled young people in education, the named worker should liaise with education

practitioners to ensure comprehensive student-focused transition planning is provided.

[NICE's guideline on transition from children's to adults' services for young people using health or social care services, recommendations 1.2.5 to 1.2.10 and NICE's guideline on disabled children and young people up to 25 with severe complex needs, recommendation 1.8.12]

Equality and diversity considerations

Service managers should ensure a range of support is available, and used, to help young people communicate effectively with the named worker. 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. [NICE's guideline on transition from children's to adults' services for young people using health or social care services, recommendations 1.2.11 and 1.2.12]. 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 or the equivalent standards for the devolved nations.

Quality statement 5: Meeting a practitioner in adults' services

Quality statement

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. [2016, updated 2023]

Rationale

Young people, and their families and carers, 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.

Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Process

Proportion of young people who moved from children's to adults' services who met a practitioner from each adults' service they moved to before they transferred.

Numerator – the number in the denominator who met a practitioner from each adults' service they moved to before they transferred.

Denominator – the number of young people who moved from children's to adults' services.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, for example from patient or client records. Data on attendance at a joint transition clinic is included in the National Confidential Enquiry into Patient Outcome and Death transition from child into adult healthcare audit toolkit which can be implemented locally.

Outcome

a) Proportion of young people (and their families and carers) who have transferred from children's to adults' services, who were satisfied with planning for transition and transfer (including their involvement).

Numerator – the number in the denominator who were satisfied with planning for transition and transfer (including their involvement).

Denominator – the number of young people (and their families and carers) who have transferred from children's to adults' services.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, for example from patient or client survey. Resources to support this could include the TIER Ready, Steady, Go programme which includes feedback on transition planning in its questionnaires for young people and their families and carers. Also, the <a href="National Confidential Enquiry into Patient Outcome and Death transition from child into adult healthcare young person and parent carer survey includes questions on transition planning."

b) 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.

Data source: Data can be collected from information recorded locally by health and care practitioners and provider organisations, for example from patient or client records. For example, NHS Digital's hospital episode statistics (HES) includes data on outpatient appointments and attendances.

c) Proportion of young people attending adults' services after transfer from children's services who continue to engage with services.

Numerator – the number in the denominator who continue to engage with services.

Denominator – the number of young people attending adults' services after transfer from children's services.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, for example from patient or client records. For measurement purposes, 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.

What the quality statement means for different audiences

Service providers (children's and adults' service managers) ensure there are systems in place for young people to meet a practitioner from each adults' service they will move to before they transfer from children's to adults' services. These may include joint appointments, joint clinics, virtual meetings, and pairing of a practitioner from adults' services with one from children's services. Children's services should consider ensuring that practitioners work with the young person to create a personal folder with key information to help with their introduction to adult's services.

Health and social care practitioners from adults' services (such as hospital consultants, nurses, GPs, social workers and mental health workers) meet the young people who will move into their service before they transfer. This meeting should help them to identify the support the young person will need to prepare for adult life and maximise their independence.

Commissioners ensure that they commission adults' services in which practitioners meet young people before they transfer from children's services.

Young peoplewho will move from children'sto adults' services meet someone from each of their new adults' services before they transfer, to help them feel more confident about the move.

Source guidance

<u>Transition from children's to adults' services for young people using health or social care services. NICE guideline NG43</u> (2016), recommendation 1.3.1

Equality and diversity considerations

Health and social care practitioners should consider the young person's travel and communication needs and preferences when deciding on the format for the introductory meeting with adults' services.

Service managers should ensure a range of support is available, and used, to help young people communicate effectively when they meet practitioners from adults' services. 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. [NICE's guideline on transition from children's to adults' services for young people using health or social care services, recommendations 1.2.11 and 1.2.12]. 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 or the equivalent standards for the devolved nations.

Quality statement 6: Missed initial appointments after transfer to adults' services

Quality statement

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

Adults' services need to engage with young people following transfer so that they continue to receive the care and support they need. If young people stop attending meetings or appointments or engaging with services during transition it can affect their future health, mental health and social care needs.

Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Structure

a) Evidence of local arrangements to monitor and assure transitions from children's to adults' services.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, such as local policy and audit, data sharing platforms and patient or client surveys.

b) Evidence of local processes in adults' services for follow-up arrangements for young

people who have moved from children's to adults' services but do not attend their initial meetings or appointments.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, for example from service protocols.

Process

Proportion of young people who have moved from children's to adults' services but did not attend their initial meetings or appointments who were contacted by adults' services and given further opportunities to engage.

Numerator – the number in the denominator who were contacted by adults' services and given further opportunities to engage.

Denominator – the number of young people who have moved from children's to adults' services but did not attend their initial meetings or appointments.

Data source: Data can be collected from information recorded locally by health and care practitioners and provider organisations, for example from patient or client records. For measurement purposes, this could be defined as 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.

Outcome

a) Proportion of young people who transferred from children's to adults' services who are discharged from each adults' service without attending a meeting or appointment.

Numerator – the number in the denominator who are discharged from each adults' service without attending a meeting or appointment.

Denominator – the number of young people who transferred from children's to adults' services.

Data source: Data can be collected from information recorded by health and care practitioners and provider organisations, for example from patient or client records.

b) Proportion of young people attending adults' services after transfer from children's services who continue to engage with services.

Numerator – the number in the denominator who continue to engage with services.

Denominator – the number of young people attending adults' services after transfer from children's services.

Data source: Data can be collected from information recorded locally by health and care practitioners and provider organisations, for example from patient or client records. For measurement purposes, 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.

What the quality statement means for different audiences

Service providers (adult health, mental health and social care services) ensure that systems are in place, so they know who is transferring from children's services, and that a young person is contacted and given further opportunities to engage promptly if they do not attend (or were not brought to) any one of their initial meetings or appointments in adults' services. Providers ensure 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.

Health and social care practitioners from adults' services (such as hospital consultants, social workers, mental health workers, GPs) ensure that they work with children's services to identify young people who have moved to adults' services but did not attend (or were not brought to) any one of their initial meetings or appointments. They ensure that the young people are contacted and given further opportunities to engage as quickly as possible. If a young person does not respond practitioners should not discharge them from the service but should refer them back to the named worker or children's service.

Commissioners ensure that they commission adults' services that contact young people who have moved to their services but do not attend (or were not brought to) any one of the initial meetings or appointments and quickly give them further opportunities to engage (for example, other appointments). Commissioners ensure that the adults' services they

commission do not discharge young people if they do not attend their initial meetings or appointments but refer them back to the named worker or children's service.

Young peoplewho have moved from children'sto adults' services but do not attend (or were not brought to) their initial meetings or appointments are contacted by someone from adults' services as soon as possible. They will check if the young person's care and support plan is still right and whether they need any other help to get back in touch with the service.

Families and carers of young peoplewho have moved from children'sto adults' services but do not attend (or were not brought to) their initial meetings or appointments are contacted by someone from adults' services as soon as possible to try to help the young person keep in touch with adults' services.

Source guidance

<u>Transition from children's to adults' services for young people using health or social care services. NICE guideline NG43</u> (2016), recommendations 1.4.1 and 1.4.2

Definitions of terms used in this quality statement

Further opportunities to engage

If a young person does not attend meetings and appointments in adults' services, the adults' service should try to contact them and their family or carers and follow up with the young person, then involve other relevant practitioners (including children's services and their GP) if necessary. They should try to understand the reasons for not attending and identify any changes that could be made to encourage attendance in future. If there is still no contact then the relevant provider should refer back to the named worker or the children's service with clear guidance on re-referral, if applicable. The named worker should review the person-centred care and support plan with the young person to identify how to help them use the service. If the young person does not want to engage in adults' services, they should be offered alternative ways to meet their support needs by the named worker. [NICE's guideline on transition from children's to adults' services for young people using health or social care services, recommendations 1.4.1 to 1.4.3 and expert opinion].

Equality and diversity considerations

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.

Service managers should 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. [NICE's guideline on transition from children's to adults' services for young people using health or social care services, recommendations 1.2.11 and 1.2.12]. 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 or the equivalent standards for the devolved nations.

Update information

December 2023: This quality standard was updated following feedback from stakeholders.

Statements are marked as:

- [2016] if the statement remains unchanged
- [new 2023] if the statement covers a new area for quality improvement
- [2016, updated 2023] if the statement has been amended.

About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about <u>how NICE quality standards are developed</u> is available from the NICE website.

See our <u>webpage on quality standard advisory committees</u> for details about our standing committees. Information about the topic experts invited to join the standing members is available from the webpage for this quality standard.

NICE has produced a <u>quality standard service improvement template</u> to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Diversity, equality and language

Equality issues were considered during development and <u>equality assessments for this</u> <u>quality standard</u> are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

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Endorsing organisation

This quality standard has been endorsed by Department of Health and Social Care, as required by the Health and Social Care Act (2012)

Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- Together for Short Lives
- Association of Paediatric Chartered Physiotherapists
- Association of Respiratory Nurse Specialists
- Brittle Bone Society
- British Society of Physical and Rehabilitation Medicine
- National Confidential Enquiry into Patient Outcome and Death
- National Rheumatoid Arthritis Society
- Spinal Muscular Atrophy UK
- British Association of Teachers of Deaf Children and Young People (BATOD)
- UK Cystic Fibrosis Medical Association
- Child Growth Foundation

- Faculty of Pain Medicine of the Royal College of Anaesthetists
- Royal College of Physicians (RCP)
- Royal College of Paediatrics and Child Health