

Transition from child to adult health services: Reviewer assessment form

A. A. Study inclusion and reviewer details

What is this study about?

The aim of this study is to explore the barriers and facilitators in the process of the transition of young people with complex chronic conditions from child to adult health services

Inclusions

Data is being collected on young people between 13 years and their 25th birthday, with a chronic complex condition, transitioning from child to adult health services.

The twelve conditions for inclusion are:

Epilepsy
Sickle cell anaemia
Juvenile idiopathic arthritis
Cerebral palsy
Spina bifida
Duchenne muscular dystrophy
Post-transplant patients - kidney, heart and liver
Autism spectrum disorder
Rett Syndrome
Brain tumours (medulloblastoma)
Type 2 diabetes and obesity
Chronic kidney disease

2. Name of reviewer

3. Date of the meeting

4. Site ID

6 digit number beginning with 3

Value should be between 300,000 and 399,999

Unknown

5. Trust ID

6 digit number beginning with 2

Value should be between 200,000 and 299,999

Unknown

6. Matching NCEPOD numbers

If multiple matching files, please separate the NCEPOD numbers with a comma

B. B. The young person's details

1. What was the age of the young person on 31/03/2021

Unknown

Value should be between 13 and 25

2. Sex

Male

Female

Other

Unable to answer

3. Ethnicity

White British/White - other

Black/ African/ Caribbean/ Black British

Asian/ Asian British (Indian, Pakistani, Bangladeshi, Chinese, other Asian)

Mixed/ Multiple ethnic groups

Unable to answer

If not listed above, please specify here...

4. What underlying condition(s) does the young person have? (Please tick all that apply)

Epilepsy

Sickle cell anaemia

Juvenile idiopathic arthritis

Cerebral palsy

Spina bifida

Duchenne muscular dystrophy

Post transplant patient (kidney, heart and liver)

Autism

Rett syndrome

Brain tumour (medulloblastoma)

Type 2 diabetes and obesity

Chronic kidney disease

Unable to answer

Please specify any additional options here...

5a. What stage of transition was the young person in on the 31/03/2021? (Please tick all that apply)

Transition not started

Preparing for adulthood

Peri-transfer from child to adult health services

Fully transferred from child to adult health services

No evidence of transition in the case notes but the young person has transferred to adult services

Not applicable - diagnosed when already under adult health services

Unable to answer

If transition has not started or the young person was diagnosed when already under adult health services, please let a member of the NCEPOD team know

5b. If answered "Preparing for adulthood" to [15a] then:

If preparing for adulthood, what specialties are involved with the care of the young person at this stage of transition?

5c. If answered "Peri-transfer from child to adult health services" to [15a] then:

If peri-transfer, what specialties are involved with the care of the young person at this stage of transition?

**5d. If answered "Fully transferred from child to adult health services" to [15a] then:
If fully transferred, what specialties are involved with the care of the young person at
this stage of transition?**

**5e. Please give any further details regarding the stage(s) of transition (e.g. further details
where the stage of transition varies across specialties)**

1a. Is there evidence in the case notes of any barriers to accessing the transition service for this young person?

- Yes No
 Unable to answer No mention of transition in the case notes

1b. Please give further details:

2a. Would you consider this case to demonstrate good practice in terms of accessing the transition service?

- Yes No
 Unable to answer No mention of transition in the case notes

2b. Please give further details:

Please save the questionnaire as you work through this section

1a. Is transition from child to adult health services explicitly mentioned in these case notes?

- Yes No

If transition has not been explicitly mentioned, we are aware that parts of the transition pathway could still been delivered, and we would like to capture this where possible.

1b. In your opinion, did the transition process start at a developmentally appropriate age for this young person?

- Yes - for all services Yes - for some services No
 Unable to answer

1c. Please give further information

2a. Is there evidence in the case notes that the young person has/had a transition plan in place?

- Yes - for all services Yes - for some services No
 Unable to answer

2b. If answered "Yes - for all services" or "Yes - for some services" to [2a] then:
If YES, is there evidence that the transition plan was 'individualised' to the needs of the young person?

- Yes No Unable to answer

3a. Is there evidence in the case notes that the young person has a learning disability?

- Yes No Unable to answer

3b. If answered "Yes" to [3a] then:
If YES, is there evidence in the case notes that mental capacity has been discussed with parent carers?

- Yes No Unable to answer

4a. Is there evidence in the case notes of any barriers in transition planning for this young person?

- Yes No Unable to answer

4b. Please give further details:

5a. Please grade the overall process of transition planning for this young person:

- Good Adequate Poor Unacceptable
 Unable to answer

5b. Please give further information

6. Prior to transfer to adult services is there evidence in the case notes that there have been/were annual (or more frequent) transition reviews?

- Yes - for all services
 Yes - for some services
 No
 Unable to answer
 Not Applicable - too early in the transition process

7. Prior to transfer to adult services is there evidence in the case notes that the young person has attended/did attend a joint transition clinic with their paediatric and adult service counterparts?

- Yes - for all services
 Yes - for some services
 No
 Unable to answer
 Not applicable - too early in the transition process

8. Prior to transfer to adult services is there evidence in the case notes of any liaison with educational services or institutions as part of the planning for transition process?

- Yes No Unable to answer Not applicable

9a. Is there evidence in the casenote that the young person has/had social care involvement?

- Yes No Unable to answer

9b. If answered "Yes" to [9a] then:

If YES, is there evidence in the case notes that this is/was included in the transition plan?

- Yes No Unable to answer
 NA - no transition plan

9c. If answered "Yes" to [9a] then:

Please give further details

10. Prior to transfer to adult services is there evidence in the case notes of any liaison with social care as part of the transition process?

- Yes - associated with transition Yes - not associated with transition
 No Unable to answer
 Not applicable

11. Prior to transfer to adult services is there evidence in the case notes that the young person has/had an Education and Health Care Plan?

- Yes No Unable to answer Not applicable

12a. Is there evidence in the case notes that the young person was given the opportunity or encouraged to develop the skills for the self-management of their health needs?

- Yes No Unable to answer

12b. Please give further information:

13a. Is there evidence in the case notes of a plan for when the young person will be/was transferred to adult services?

- Yes - for all services
 Yes - for some services
 Yes - for primary care
 No
 Unable to answer
 Not applicable - too early in the transition process

13b.If answered "Yes - for all services", "Yes - for some services" or "Yes - for primary care" to [13a] then:

In your opinion, is/was this appropriate for the needs of the young person?

- Yes No Unable to answer

13c. Please give any further information

14. Is there evidence in the case notes that the young person knew who to contact if transition was not going well?

- Yes No Unable to answer

Following transfer to adult services

This question is pre-populated following completion in an earlier section, and is here in order to bring up the relevant questions for young people post transfer to adult services. If you change the answer to this question here, it will also change it earlier in the questionnaire.

15a.What stage of transition was the young person in on the 31/03/2021? (Please tick all that apply)

- Transition not started
- Preparing for adulthood
- Peri-transfer from child to adult health services
- Fully transferred from child to adult health services
- No evidence of transition in the case notes but the young person has transferred to adult services
- Not applicable - diagnosed when already under adult health services
- Unable to answer

15b.If answered "Fully transferred from child to adult health services" to [15a] then: What age was the young person transferred to adult services?

years Not Applicable Unknown

16. If answered "Fully transferred from child to adult health services" to [15a] then: Is there evidence in the case notes that medications were managed appropriately when transferring from paediatric to adult services?

- Yes No
 Unable to answer Not applicable - no medications
 Not applicable - not transferred

17. If answered "Fully transferred from child to adult health services" to [15a] then: Is there evidence in the case notes that the young person was offered an appointment to review the process of transition and identify any ongoing concerns post-transfer?

- Yes No
 Unable to answer Not applicable - not transferred

**18. If answered "Fully transferred from child to adult health services" to [15a] then:
Is there evidence in the case notes that the young person has remained engaged with their healthcare?**

- Yes
- No
- Unable to answer
- NA - Young person wasn't engaged prior to transfer
- NA - young person has not transferred to adult services yet

All patients

19a. If there is no evidence of transition in the case notes, in your opinion were there any missed opportunities for engagement in transition?

- Yes
- No
- Not applicable - evidence of transition in the case notes

19b. If answered "Yes" to [19a] then:

If YES, please give further information regarding these missed opportunities

20a. Is there evidence in the case notes of any barriers in the transition pathway for this young person?

- Yes
- No
- Unable to answer
- No mention of transition in the case notes

20b. Please give further details:

21a. Please grade the overall transition pathway for this young person:

- Good
- Adequate
- Poor
- Unacceptable
- Unable to answer

21b. Please give further information

1h. If answered "No" to [1a] then:

If NO to 1a (under the care of a single specialty), in your opinion, is/was the process of transition been well managed within this team?

- Yes No
 Unable to answer NA - too early in the transition process

1i. If answered "No" to [1a] then:

If NO, is there evidence in the case notes that the transition process has been/was coordinated within the team?

- Yes No
 Unable to answer NA - too early in the transition process

1j. If answered "No" to [1a] then:

If NO, is there evidence in the case notes that there is/was one person or team identified as point of contact for any queries regarding transition?

- Yes No
 Unable to answer NA - too soon in the transition process

1k. If answered "No" to [1a] then:

If NO, is there evidence in the case notes that there have been/were any issues with engagement within this team during the process of transition?

- Yes No
 Unable to answer NA - too soon in the transition process

1l. If answered "No" to [1a] then:

If NO, is there evidence in the case notes that there has been communication about transition within this team during the process of transition?

- Yes - between all teams Yes - between some teams No
 Unable to answer

1m. If answered "No" to [1a] and "Yes - between all teams" or "Yes - between some teams" to [1l] then:

If YES, how would you grade the quality of this communication?

- Good Adequate
 Poor Unacceptable
 Unable to answer NA - too early in the transition process

1n. If answered "No" to [1a] then:

Please give any further details:

2a. Is there evidence in the case notes of communication between the team(s) in the physical healthcare setting and the GP about transition?

- Yes - for all services
 Yes - for some services
 No
 Unable to answer
 NA - no specialty team involvement in the physical healthcare setting
 Physical healthcare notes not available

2b. Is there evidence in the case notes of communication between the team(s) in the community healthcare setting and the GP about transition?

- Yes - for all services
- Yes - for some services
- No
- Unable to answer
- NA - no specialty team involvement in the community healthcare setting
- Community healthcare notes not available

2c. Is there evidence in the case notes of communication between the team(s) in the mental healthcare setting and the GP about transition?

- Yes - for all services
- Yes - for some services
- No
- Unable to answer
- NA - no specialty team involvement in the mental healthcare setting
- Mental healthcare notes not available

3a. Is there evidence in the case notes that the young person is/was known to multiple other services in the community, including CAMHs, social care and education?

- Yes No Unable to answer

3b. If answered "Yes" to [3a] then:

If YES, is there evidence in the case notes that there has been/was transition planning which involves all parties?

- Yes
- No
- Unable to answer
- Not applicable - too early in the transition process
- No mention of transition in the case notes

**3c. If answered "Yes" to [3a] and "Yes" to [3b] then:
If YES, please give further details:**

3d. If answered "Yes" to [3a] and "No" to [3b] then:

If NO, please give further details (including which parties were not involved in transition planning):

4a. Is there evidence in the case notes that the young person has/had access to a key worker/named worker in the physical healthcare setting?

- Yes
- No
- Unable to answer
- NA - care not provided in the physical healthcare setting
- Physical healthcare notes not available

4b. Is there evidence in the case notes that the young person has/had access to a key worker/named worker in the community healthcare setting?

- Yes
- No
- Unable to answer
- NA - care not provided in the community healthcare setting
- Community healthcare notes not available

4c. Is there evidence in the case notes that the young person has/had access to a key worker/named worker in the mental healthcare setting?

- Yes
- No
- Unable to answer
- Mental healthcare notes not available
- NA - care not provided in the mental healthcare setting

5a. Is there evidence in the case notes of any barriers in the coordination of MDT transition care for this young person?

- Yes
- No
- Unable to answer
- No mention of transition in the case notes

5b. Please give further details:

6a. Based on the evidence in the case notes, how would you grade the coordination of MDT care during the transition process?

- Good
- Adequate
- Poor
- Unacceptable
- Unable to answer

**6b. If answered "Good", "Adequate", "Poor" or "Unacceptable" to [6a] then:
Please give further details:**

Please save the questionnaire as you work through this section

Communication

1a. Is there evidence in the case notes that (in general) the young person was copied into correspondence sent regarding their care?

- Yes - for all services
- Yes - for some services
- No
- Unable to answer
- Not applicable - too early in the transition process

1b. Is there evidence in the case notes that (in general) the young person's parent carers were copied into correspondence sent regarding their care (whilst under paediatric services)?

- Yes - for all services
- Yes - for some services
- No
- Unable to answer
- Not applicable - too early in the transition process

2. At the point of transfer to adult services, is there evidence in the case notes of a discussion with the young person to check that they understand their condition (e.g. completion of Ready Steady Go)?

- Yes
- No
- Unable to answer

3a. Is there evidence in the case notes of any barriers in communication with the young person during the process of transition?

- Yes
- No
- Unable to answer
- Not applicable - too early in the transition process

3b. Please give further details:

4a. Is there evidence in the case notes of any barriers in communication with the parent carer during the process of transition?

- Yes
- No
- Unable to answer
- Not applicable - too early in the transition process

4b. Please give further details:

5a. Based on the evidence in the case notes, how would you grade communication with the young person during the transition process?

- Good Adequate Poor Unacceptable
 Unable to answer

5b. Please give further details:

6a. Based on the evidence in the case notes, how would you grade communication with parent carers during the transition process?

- Good Adequate Poor Unacceptable
 Unable to answer

6b. Please give further details:

Involvement

7a. Is there evidence in the case notes that (in general) the young person has been involved in the transition process?

- Yes - for all services
- Yes - for some services
- No
- Unable to answer
- Not applicable - too early in the transition process

7b. Is there evidence in the case notes that (in general) the the young person's parent carers were involved in the transition process?

- Yes - for all services
- Yes - for some services
- No
- Unable to answer
- Not applicable - too early in the transition process

8a. Is there evidence in the case notes of any barriers in the involvement of the young person in the process of transition?

- Yes
- No
- Unable to answer
- Not applicable - too early in the transition process

8b. Please give further details:

9a. Is there evidence in the case notes of any barriers in the involvement of the parent carer in the process of transition?

- Yes
- No
- Unable to answer
- Not applicable - too early in the transition process

9b. Please give further details:

10a. Based on the case notes, how would you grade the involvement of the young person in the transition process?

- Good
- Adequate
- Poor
- Unacceptable
- Unable to answer
- Not applicable - too early in the transition process

10b. Please give further details:

11a. Based on the case notes, how would you grade the involvement of the young person's parent carers in the transition process?

- Good
- Adequate
- Poor
- Unacceptable
- Unable to answer
- Not applicable - too early in the transition process

11b. Please give further details:

1a. Please grade the overall process of transition from child to adult health services for this young person.

- Good Adequate Poor Unacceptable
 Unable to answer

**1b. If answered "Good", "Adequate", "Poor" or "Unacceptable" to [1a] then:
Please provide reasons for this grade**

2a. Is there an example of good transition practice demonstrated in this case?

- Yes No

**2b. If answered "Yes" to [2a] then:
If YES, please give details**

**2c. If answered "Yes" to [2a] then:
If YES, do you think this should be highlighted in the report?**

- Yes No

3a. What is the biggest barrier to transition demonstrated in this case?

3b. Do you think this should be highlighted in the report?

- Yes No

4. Do you think we should consider this case as a vignette/case study in the report?

Yes

No

5. Please provide details of what was missing from these case notes (if anything):

6a. Please share any further details about this case not already documented

Cause for concern

Occasionally NCEPOD will refer cases that have been identified as 'UNACCEPTABLE' when it is felt that further feedback to the Trust/ Health Board is warranted. This is usually due to an area of concern to the hospital or clinician involved, and not for issues highlighted across the body of case notes. This process has been agreed by the NCEPOD Steering Group and the GMC. The medical director of the Trust/ Health Board is written to by the Chief Executive of NCEPOD explaining our concerns. This process had been in operation for 10 years and the responses received have always been positive in that they feel we are dealing with the concerns in the most appropriate manner.

6b. If answered "Unacceptable" to [1a] then:

Do you feel that this case should be considered for such action?

Yes

No