

Transition from child to adult health services: Clinician questionnaire

A. Introduction

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 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 condition, transitioning from child to adult health services. Data is being collected on the services provided to young people identified to us over an 18-month period, from 1st October 2019 - 31st March 2021.

Sampling

Eligible cases were identified from the hospital central record system (using ICD10 codes). Up to 15 cases per hospital have been selected for review

Who should complete this questionnaire?

This questionnaire should be completed by a member of the clinical team providing care to this young person. This may be in a community, secondary or tertiary, or mental health care setting.

The questions should be answered in relation to the care provided by your team to the young person, and should be completed in relation to the status of the patient/transition care received up to the 31/03/2021.

One questionnaire should be completed by each clinical team providing care to the young person.

Please do not include any patient identifiers in the free text boxes.

Definitions

A list of definitions can be found here:

<https://www.ncepod.org.uk/pdf/current/Transition/Definitions%20Transition%20%20finalised.pdf>

Questions or help

If you have any queries about this study or this questionnaire, please contact: transition@ncepod.org.uk or telephone 020 7251 9060.

CPD accreditation

Consultants who complete NCEPOD questionnaires make a valuable contribution to the investigation of patient care. Completion of questionnaires also provides an opportunity for consultants to review their clinical management and undertake a period of personal reflection. These activities have a continuing medical and professional development value for individual consultants. Consequently, NCEPOD recommends that consultants who complete NCEPOD questionnaires keep a record of this activity which can be included as evidence of internal/self directed Continuous Professional Development in their appraisal portfolio.

About NCEPOD

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) reviews healthcare practice by undertaking confidential studies, and makes recommendations to improve the quality of the delivery of care, for healthcare professionals and policymakers to implement. Data to inform the studies are collected from NHS hospitals and Independent sector hospitals across England, Wales, Northern Ireland and the Offshore Islands. NCEPOD are supported by a wide range of bodies and the Steering Group consists of members from the Medical Royal Colleges and Specialist Associations, as well as observers from The Coroners Society of England and Wales, and the Healthcare Quality Improvement Partnership (HQIP).

Impact of NCEPOD

Recommendations from NCEPOD reports have had an impact on many areas of healthcare including: Development of the NICE 'Acutely ill patients in hospital guideline' (CG50) – 'An Acute Problem' (2005). Appointment of a National Clinical Director for Trauma Care – 'Trauma: Who Cares?' (2007). Development of NICE Clinical Guidelines for Acute Kidney Injury, published 2013 – 'Adding Insult to Injury' (2009). Development of ICS Standards for the care of adult patients with a temporary Tracheostomy, published 2014 – 'On the right trach?' (2014). Development of guidelines from the British Society of Gastroenterology: diagnosis and management of acute lower gastrointestinal bleeding, published 2019 – 'Time to Get Control' (2015).

Development of the British Thoracic Society's Quality Standards for NIV, published 2018 - 'Inspiring Change' (2017).

This study was commissioned by The Healthcare Quality Improvement Partnership (HQIP) as part of the Clinical Outcome Review Programme into Child Health.

B. Organisation details

1a. Are you part of a clinical team providing regular healthcare to this young person?

Please see definitions

Yes

No

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

Please provide the details of the organisations where the young person's regular clinical team(s) are based. Please include the Trust/Health Board name(s) and the specialty of the team(s). This may be both within and outside of this organisation.

Please do not provide clinician names

If you are not part of a clinical team who provides regular healthcare to this young person, please return this questionnaire to your Local Reporter (hand your assignment back) who will notify NCEPOD

1c. If answered "Yes" to [1a] then:

Are there any other specialty teams regularly involved in the care of this young person?

Yes - within this organisation (physical, mental or community healthcare)

Yes - physical healthcare outside this organisation

Yes - mental healthcare outside this organisation

Yes - community healthcare outside this organisation

No

Unknown

Please specify any additional options here...

1d. If answered "Yes" to [1a] and "Yes - within this organisation (physical, mental or community healthcare)" to [1c] then:

Please provide the specialty of any other healthcare teams providing regular care to this young person in this organisation

Please do not provide any clinician names

1e. If answered "Yes" to [1a] and "Yes - physical healthcare outside this organisation" to [1c] then:

Please provide the details of the physical healthcare teams outside this organisation providing care to this young person (Trust/Health Board name(s) and specialty of the clinical team(s))

Please do not provide any clinician names

1f. If answered "Yes" to [1a] and "Yes - mental healthcare outside this organisation" to [1c] then:

Please provide the details of the mental healthcare teams outside this organisation providing care to this young person (Trust/Health Board name(s) and specialty of the clinical team(s))

Please do not provide any clinician names

1g. If answered "Yes" to [1a] and "Yes - community healthcare outside this organisation" to [1c] then:

Please provide the details of the community healthcare teams outside this organisation providing care to this young person (Trust/Health Board name(s) and specialty of the clinical team(s))

Please do not provide any clinician names

1h. If answered "Yes" to [1a] then:

Please provide the name of the young person's GP practice

Please do not provide any clinician names

Please answer the remainder of the questions in this questionnaire in relation to the care provided by your organisation (i.e. if under multiple teams, complete based on the care you provide from this team)

1a. Grade of person completing the questionnaire

1b. Specialty of person completing the questionnaire

1c. Role within the young person's care/transition team

1d. Specialty of the team providing care to the young person

1e. Which service does this team sit under?

- Paediatric service Adult service Adolescent service Unknown

If not listed above, please specify here...

2. Please use the box below to provide a brief summary of this patient's major medical conditions, adding any additional comments or information you feel relevant. You should be assured that this information is confidential. NCEPOD attaches great importance to this summary. Please give as much information as possible about the transitional care of this young person.

D. The young person's details

Please answer the questions in relation to the care provided up to the 31/03/2021

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

 Years

Value should be between 13 and 24

Not Applicable Unknown

2. Sex

Male Female Other Unknown

3. Ethnicity

- White British/White - other
- Black/African/Caribbean/Black British
- Asian/Asian British (Indian, Pakistani, Bangladeshi, Chinese, other Asian)
- Mixed/Multiple ethnic groups
- Unknown

If not listed above, please specify here...

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

- | | |
|--|--|
| <input type="checkbox"/> Epilepsy | <input type="checkbox"/> Sickle cell anaemia |
| <input type="checkbox"/> Juvenile idiopathic arthritis | <input type="checkbox"/> Cerebral palsy |
| <input type="checkbox"/> Spina bifida | <input type="checkbox"/> Duchenne muscular dystrophy |
| <input type="checkbox"/> Post transplant patient (kidney, heart and liver) | |
| <input type="checkbox"/> Autism spectrum disorder | <input type="checkbox"/> Rett syndrome |
| <input type="checkbox"/> Brain tumour (medulloblastoma) | <input type="checkbox"/> Type 2 diabetes and obesity |
| <input type="checkbox"/> Chronic kidney disease | <input type="checkbox"/> Unknown |

Please specify any additional options here...

This question is repeated at the start of each section throughout the remainder of the questionnaire. It is acting as a filter to bring up the relevant questions in each section based on whether the young person is pre-/peri- or fully transferred. If you change the answer to this question at any point, your answers in the previous sections will be lost and you will need to go back and recomplete them before the questionnaire can be submitted.

5a. What is the current stage of transition?

Please see definitions

- Transition not started
- Preparing for adulthood
- Peri-transfer from child to adult health services
- Fully transferred from child to adult health services
- Not applicable - diagnosed when already under adult health services
- Unknown

**5b. If answered "Transition not started" to [1a] then:
If transition has not started, why not?**

Please see definitions

- No transition service at this hospital
- Young person won't engage with the transition process
- Parent carers won't engage with the transition process
- Life limiting condition
- Unknown

If not listed above, please specify here...

**5c. If answered "Transition not started" to [1a] then:
Please give further details**

If transition has not yet started for this young person, the diagnosis was made when already under adult health services or the stage of transition is unknown, please press the next button, and then submit the questionnaire.

Please answer the questions in relation to the care provided up to the 31/03/2021

1. What is the current stage of transition?

Please see definitions

- Transition not started
- Preparing for adulthood
- Peri-transfer from child to adult health services
- Fully transferred from child to adult health services
- Not applicable - diagnosed when already under adult health services
- Unknown

For patients who are fully transferred, please continue to section F

Approaching transfer (including preparing for transfer and peri-transfer)

2a. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Is the transition of this young person managed under this specialty?

- Yes No Unknown

2b. If answered "Yes" to [2a] and "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Who is (typically) involved in this young persons transition? (Please tick all that apply)

- Hospital based paediatric specialist lead(s)
- Community based paediatric specialist lead(s)
- Hospital based adult physician(s) from receiving team(s)
- Community based adult physician(s) from receiving team(s)
- Clinical nurse specialist(s)
- General practitioner
- Occupational therapist(s)
- Physiotherapist(s)
- Dietitian(s)
- Psychologist(s)
- Key worker(s)
- Youth worker(s)
- Social worker(s)
- Unknown

Please specify any additional options here...

2c. If answered "Yes" to [2a] and "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

If the GP is not typically involved, how do those involved in this young persons transition communicate with primary care?

If the GP is involved, please mark as 'NA - GP involved'

2d. If answered "Yes" to [2a] and "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Are other people involved in the care of the young person invited to attend transition meetings as required?

- Yes No Unknown

2e. If answered "Yes" to [2a] and "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Has the transition pathway for this young person been discussed within this specialty?

- Yes No Unknown

**2f. If answered "Yes" to [2a] and "No" to [2e] and "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:
Why not?**

2g. If answered "Yes" to [2a] and "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Please give any further information about the management of transition within your specialty (i.e. what the team does, how often the team meets etc.)

2h. If answered "No" to [2a] and "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

If the transition of this young person is not managed under this specialty, why not?

3a. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Does this young person have access to: (Please tick all that apply)

Please see definitions

- | | | |
|---|---|--|
| <input type="checkbox"/> A key/named worker | <input type="checkbox"/> A youth worker | <input type="checkbox"/> A peer support worker |
| <input type="checkbox"/> A social worker | <input type="checkbox"/> None of these | <input type="checkbox"/> Unknown |

Please specify any additional options here...

3b. If answered "A key/named worker" to [3a] and "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

What is the key/named workers role?

- | | | |
|--------------------------------------|---|------------------------------------|
| <input type="radio"/> Lead clinician | <input type="radio"/> Clinical Nurse Specialist | <input type="radio"/> Youth worker |
| <input type="radio"/> Unknown | | |

If not listed above, please specify here...

3c. If answered "A key/named worker" to [3a] and "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Where is the key/named worker based?

- | | |
|--|---|
| <input type="radio"/> Within children's services | <input type="radio"/> Within adult services |
| <input type="radio"/> Within both children's and adults services | <input type="radio"/> Unknown |

If not listed above, please specify here...

3d. If answered "A key/named worker" to [3a] and "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

How many young people are they a key/named worker for?

3e. If answered "A key/named worker" to [3a] and "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

How is the key/named worker role funded?

- | | | |
|---|--|--|
| <input type="checkbox"/> Roald Dahl funding | <input type="checkbox"/> Burdett Nursing Trust funding | <input type="checkbox"/> Other charity funding |
| <input type="checkbox"/> Unknown | | |

Please specify any additional options here...

Please answer the questions in relation to the care provided up to the 31/03/2021

Please save the questionnaire as you work through this section

1. What is the current stage of transition?

Please see definitions

- Transition not started
- Preparing for adulthood
- Peri-transfer from child to adult health services
- Fully transferred from child to adult health services
- Not applicable - diagnosed when already under adult health services
- Unknown

For questions on patients who are fully transferred, please scroll towards the end of the page

Approaching transfer (including preparing for transfer and peri-transfer)

2. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

What age was the young person when transition was first discussed?

If unknown, please write 'Unknown'. If not discussed, please write 'Not discussed'

3a. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Was the young person involved with choosing when transfer to adult services should start?

- Yes No Unknown

3b. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [3a] then:

Please give further details:

4a. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Does the young person have a transition plan in place? (e.g. Ready Steady Go?)

- Yes No Unknown

**4b. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [4a] then:
Which plan is being used?**

- Ready Steady Go
- HEADSSS
- Together for short lives - Stepping Up
- 10 step programme - Alder Hey
- Making healthcare work for young people - Northumbria Healthcare Foundation Trust
- Education Health Care Plan model - Council for Disabled Children
- Local transition plan
- Unknown

If not listed above, please specify here...

**4c. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [4a] then:
Has the developmental stage of the young person been considered as part of this plan?**

- Yes No Unknown

**5. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:
Have there been annual (or more frequent) transition reviews?**

- Yes No Unknown
 Not applicable - too soon

**6a. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:
Has the young person attended a joint transition clinic with their paediatric and adult service counterparts?**

- Yes No Unknown

**6b. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [6a] then:
How frequently does/will the young person attend such clinics?**

- Four times a year Twice a year Once a year
 Once every 18 months Once every two years As needed
 Unknown

If not listed above, please specify here...

**7a. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:
If able to be seen at appointments alone, is this offered routinely at every attendance?**

- Yes No Unknown Not appropriate

**7b. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [7a] then:
Is the young person:**

- Seen first on their own, then with their parent carer
 Seen first with their parent carer, then on their own
 Unknown

If not listed above, please specify here...

8. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Has the young person attended all appointments with adult services?

- Yes No Unknown
 Not applicable - too soon

9. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Does the young person have:

Please see definitions

- A physical disability A learning disability
 Both a physical and learning disability No disability
 Unknown

10. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "A learning disability" or "Both a physical and learning disability" to [9] then:

If the young person has a learning disability, has the ability to make independent decisions regarding their health care been considered as part of transition planning? (i.e. discussion regarding mental capacity)

- Yes No Unknown

11a. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Has there been any liaison with education as part of the planning for transition process?

- Yes No Unknown

11b. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" or "No" to [11a] then:

Please give details (we are especially interested in how this has gone well or barriers to this process)

12a. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Has the young person received any support regarding education or careers?

- Yes No Unknown

12b. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [12a] then:

How was this support provided?

- In person Careers advisor Signposting to other services
 Sharing resources Unknown

Please specify any additional options here...

**12c. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" or "No" to [12a] then:
Please give details (we are especially interested in how this has gone well or barriers to this process)**

**12d. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:
Does the young person have an Education and Health Care Plan?**

- Yes No Unknown Not applicable
-

13. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Is the young person 'looked after'?

Please see definitions

- Yes No Unknown
-

14a. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Has there been any liaison with social care as part of the transition process?

- Yes No Unknown

14b. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [14a] then:

Does the young person have a social worker?

- Yes No Unknown

**14c. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" or "No" to [14a] then:
Please give details (we are especially interested in how this has gone well or barriers to this process)**

15a. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Is the young person routinely signposted to holistic services when they attend for appointments?

Please see definitions

- Yes No Unknown

**15b.If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [15a] then:
What services? (Please tick all that apply)**

- Sexual health Mental health Drug and alcohol support
 Education and careers advice Nutrition Unknown

Please specify any additional options here...

**16a.If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:
During appointments, has the young person been given the opportunity or encouraged to develop the skills for the self-management of their health needs?**

- Yes No Unknown

**16b.If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [16a] then:
Please give further information:**

**17a.If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:
Have there been any problems with this young person engaging with this service?**

- Yes No Unknown

**17b.If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [17a] then:
Please give further details:**

**18a.If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:
Is there a plan for when the YP will be discharged from paediatric services?**

- Yes No
 Unknown Not applicable - too soon to plan

**18b.If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [18a] then:
At what age will this take place?**

 years

Not Applicable Unknown

Value should be no more than 24

**18c.If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" or "No" to [18a] then:
Please give further details:**

**18d.If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [18a] then:
If YES, is there an equivalent specialty for the young person to transfer to?**

Yes No Unknown

**18e.If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [18a] and "No" to [18d] then:
If NO, where will the young person transfer to?**

Primary care Unknown

If not listed above, please specify here...

**19. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:
If the young person has an acute deterioration of their condition within approximately 6 months either side of transfer to adult services, is there a plan of who they should contact?**

Yes No Unknown

Fully transferred

**20. If answered "Fully transferred from child to adult health services" to [1a] then:
What age was the young person discharged from paediatric services?**

 years

Unknown

Value should be no more than 24

**21. If answered "Fully transferred from child to adult health services" to [1a] then:
Was the young person offered an appointment to review the process of transition and identify any ongoing concerns?**

Yes No Unknown

**22a.If answered "Fully transferred from child to adult health services" to [1a] then:
Are you aware of any issues in the planning of transition from child to adult health services for this young person?**

Yes No Unknown

**22b.If answered "Fully transferred from child to adult health services" to [1a] then:
Please give any further details regarding the planning of transition for this young person:**

**23a.If answered "Fully transferred from child to adult health services" to [1a] then:
Are you aware of any other issues in the transition pathway for this young person?**

Yes No Unknown

**23b.If answered "Fully transferred from child to adult health services" to [1a] then:
Please give any further details regarding the transition pathway for this young person:**

Please answer the questions in relation to the care provided up to the 31/03/2021

1. What is the current stage of transition?

Please see definitions

- Transition not started
- Preparing for adulthood
- Peri-transfer from child to adult health services
- Fully transferred from child to adult health services
- Not applicable - diagnosed when already under adult health services
- Unknown

For questions on patients who are fully transferred, please scroll towards the end of the page

Approaching transfer (including preparing for transfer and peri-transfer)

2a. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Has the young person been copied into any correspondence you have sent regarding their care?

- Yes No Unknown

2b. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "No" to [2a] then:

Please give further details:

2c. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Have the young person's parent carers been copied into any correspondence you have sent regarding their young person's care?

- Yes No Unknown Not applicable

3a. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Has the young person been involved in the transition process?

- Yes
- No
- Unknown
- Not applicable - too soon in the transition process

**3b. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [3a] then:
How was this done? (Please tick all that apply)**

- Jointly developed care plans
- Deciding how they would like a parent carer to be involved
- Unknown

Please specify any additional options here...

**4a. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:
Were the young people's parent carers involved in the transition process?**

- Yes
- No
- Unknown
- Not applicable - too soon in the transition process

**4b. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [4a] then:
How was this done? (Please tick all that apply)**

- Involved in completing transition documentation
- Attended parent groups
- Attended transition appointments with the young person - always
- Attended transition appointments with the young person - sometimes
- Attended transition appointments with the young person - occasionally
- Attended transition appointments without their young person
- Unknown

Please specify any additional options here...

Fully transferred

**5a. If answered "Fully transferred from child to adult health services" to [1a] then:
Are you aware of any issues with communication during the process of transition from child to adult health services for this young person?**

- Yes
- No
- Unknown

**5b. If answered "Fully transferred from child to adult health services" to [1a] and "Yes" to [5a] then:
Please give any further details:**

Please answer the questions in relation to the care provided up to the 31/03/2021

Please save the questionnaire as you work through this section

1. What is the current stage of transition?

Please see definitions

- Transition not started
- Preparing for adulthood
- Peri-transfer from child to adult health services
- Fully transferred from child to adult health services
- Not applicable - diagnosed when already under adult health services
- Unknown

For questions on patients who are fully transferred, please scroll towards the end of the page

Approaching transfer (including preparing for transfer and peri-transfer)

2a. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Is the young person under the care of multiple hospital based clinical teams?

- Yes
- No
- Unknown

**2b. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [2a] then:
How many teams?**

teams Unknown

2c. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [2a] then:

Is the transition process coordinated across the different teams?

- Yes
- No
- Unknown

**2d. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [2a] and "Yes" to [2c] then:
Please give details as to how this is undertaken?**

3a. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Is the young person under the care of a community based services? (not primary care)

- Yes
- No
- Unknown

3b. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [3a] then:

Who is responsible for providing community based care for this young person?

- | | |
|--|---|
| <input type="checkbox"/> Registered healthcare staff (NHS) | <input type="checkbox"/> Registered healthcare staff (other provider) |
| <input type="checkbox"/> Carers (NHS) | <input type="checkbox"/> Carers (other provider) |
| <input type="checkbox"/> Family/parent carers | <input type="checkbox"/> Self care |
| <input type="checkbox"/> Unknown | |

Please specify any additional options here...

3c. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [3a] then:

Is transition planning coordinated across the hospital and community teams

- Yes No Unknown

3d. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [3a] and "Yes" to [3c] then:

Please give details as to how this is undertaken?

4a. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Is the young person registered with a GP?

- Yes No Unknown

4b. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [4a] then:

Are the young person's GP details recorded in the hospital records?

- Yes No Unknown

4c. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [4a] then:

If the young person is at college or university, are they registered with a GP there?

- Yes No Unknown Not applicable

4d. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [4a] then:

Have primary care been involved with the transition process for this young person? (E.g. attending MDT meetings)

- Yes No Unknown Not applicable

4e. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [4a] and "Yes" to [4d] then:

How have they been involved? (Please tick all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Inclusion in all correspondence | <input type="checkbox"/> Invitation to attend transition meetings |
| <input type="checkbox"/> Contribution to the transition plan | <input type="checkbox"/> Unknown |

Please specify any additional options here...

**4f. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [4a] then:
At clinic appointments, is the young patient encouraged to access primary care for their other health needs?**

- Yes No Unknown

**4g. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [4a] then:
Please give any further details regarding the involvement of primary care (we are especially interested in how this has gone well or barriers to this process)**

**5a. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:
If the young person is known to multiple services in the community (including social care and education), is there transition planning which involves all parties?**

- Yes No Unknown Not applicable

**5b. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [5a] then:
Please give details as to how this is undertaken?**

**6. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:
Does the young person have a treatment escalation plan (e.g. change in medication for worsening condition)?**

- Yes No Unknown Not applicable

**7a. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:
Does the young person have a life limiting condition?**

Please see definitions

- Yes No Unknown

7b. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] and "Yes" to [7a] then:

Does/did the young person have an advanced care plan (ReSPECT form/ceiling of care) for their life limiting condition (including palliative care and admission to ICU)?

Please see definitions

- Yes No Unknown
-

8. If answered "Preparing for adulthood" or "Peri-transfer from child to adult health services" to [1a] then:

Please give any further information about how the transition process is joined up across services providing healthcare to this young person

Fully transferred

9a. If answered "Fully transferred from child to adult health services" to [1a] then:

Has the young person transferred to adult health services across all clinical teams?

- Yes No Unknown

9b. If answered "Fully transferred from child to adult health services" to [1a] and "No" to [9a] then:

Why not?

10a. If answered "Fully transferred from child to adult health services" to [1a] then:

At the point of transition, was the young person under the care of multiple clinical teams?

- Yes No Unknown

**10b.If answered "Fully transferred from child to adult health services" to [1a] and "Yes" to [10a] then:
Which teams were involved with the care of this young person at the point of transition?
(Please tick all that apply)**

- | | |
|--|---|
| <input type="checkbox"/> Hospital-based paediatric team - secondary care | <input type="checkbox"/> Hospital-based paediatric team - tertiary care |
| <input type="checkbox"/> Hospital-based adult team - secondary care | <input type="checkbox"/> Community team - paediatrics |
| <input type="checkbox"/> Hospital-based adult team - tertiary care | <input type="checkbox"/> Primary care |
| <input type="checkbox"/> Community team - adults | <input type="checkbox"/> Unknown |
| <input type="checkbox"/> Social care | |

Please specify any additional options here...

**10c.If answered "Fully transferred from child to adult health services" to [1a] and "Yes" to [10a] and "Hospital-based paediatric team - secondary care", "Hospital-based paediatric team - tertiary care" or "Community team - paediatrics" to [10b] then:
If hospital-based paediatric team or community team - paediatrics, did this team stay involved with the care of the young person once they had transferred to adult services?**

- Yes No Unknown

**10d.If answered "Fully transferred from child to adult health services" to [1a] and "Yes" to [10a] and "Hospital-based paediatric team - secondary care", "Hospital-based paediatric team - tertiary care" or "Community team - paediatrics" to [10b] and "Yes" to [10c] then:
If hospital-based paediatric team or community team - paediatrics, how long did they stay involved?**

**10e.If answered "Fully transferred from child to adult health services" to [1a] and "Yes" to [10a] and "Hospital-based paediatric team - secondary care", "Hospital-based paediatric team - tertiary care" or "Community team - paediatrics" to [10b] and "Yes" to [10c] then:
If hospital-based paediatric team or community team - paediatrics, how did they stay involved?**

**10f. If answered "Fully transferred from child to adult health services" to [1a] and "Yes" to [10a] then:
Are you aware of any issues with the engagement of any of these teams during the process of transition from child to adult health services for this young person?**

- Yes No Unknown

**10g.If answered "Fully transferred from child to adult health services" to [1a] and "Yes" to [10a] and "Yes" to [10f] then:
Please indicate for which teams there were problems with engagement: (Please tick all that apply)**

- | | |
|--|---|
| <input type="checkbox"/> Hospital-based paediatric team - secondary care | <input type="checkbox"/> Hospital-based paediatric team - tertiary care |
| <input type="checkbox"/> Hospital-based adult team - secondary care | <input type="checkbox"/> Community team - paediatrics |
| <input type="checkbox"/> Hospital-based adult team - tertiary care | <input type="checkbox"/> Primary care |
| <input type="checkbox"/> Community team - adults | <input type="checkbox"/> Unknown |
| <input type="checkbox"/> Social care | |

Please specify any additional options here...

**10h.If answered "Fully transferred from child to adult health services" to [1a] and "Yes" to [10a] and "Yes" to [10f] then:
Please give any further details:**

**11. If answered "Fully transferred from child to adult health services" to [1a] then:
Following transfer do you see the young person: (Please tick all that apply)**

- In an adult clinic In an adolescent clinic In a young adult clinic
 Unknown

If not listed above, please specify here...

**12. If answered "Fully transferred from child to adult health services" to [1a] then:
Is there evidence of engagement with adult services? (e.g. the young person is attending appointments)**

- Yes No Unknown
 Not applicable - too soon

**13. If answered "Fully transferred from child to adult health services" to [1a] then:
Has the young person missed three or more appointments in adult care (DNA)?**

- Yes No Unknown
 Not applicable - too soon

**14. If answered "Fully transferred from child to adult health services" to [1a] then:
Has the young person had any emergency hospital admissions following transfer to adult services?**

- Yes No Unknown

**15a.If answered "Fully transferred from child to adult health services" to [1a] then:
Are you aware of any issues with the coordination of care during the process of transition from child to adult health services for this young person?**

- Yes No Unknown

**15b.If answered "Fully transferred from child to adult health services" to [1a] and "Yes" to [15a] then:
Were these:**

- | | |
|--|--|
| <input type="checkbox"/> Between hospitals | <input type="checkbox"/> Between hospital and community care |
| <input type="checkbox"/> Between hospital and primary care | <input type="checkbox"/> Between community and primary care |
| <input type="checkbox"/> Between community care teams | <input type="checkbox"/> Unknown |

Please specify any additional options here...

**15c. If answered "Fully transferred from child to adult health services" to [1a] and "Yes" to [15a] then:
Please give any further details:**

Please answer the questions in relation to the care provided up to the 31/03/2021

1a. What is the current stage of transition?

Please see definitions

- Transition not started
- Preparing for adulthood
- Peri-transfer from child to adult health services
- Fully transferred from child to adult health services
- Not applicable - diagnosed when already under adult health services
- Unknown

**1b. If answered "Preparing for adulthood", "Peri-transfer from child to adult health services" or "Fully transferred from child to adult health services" to [1a] then:
In your opinion, is/has the process of transition working/worked well for this young person?**

- Yes No Unknown

**1c. If answered "Preparing for adulthood", "Peri-transfer from child to adult health services" or "Fully transferred from child to adult health services" to [1a] then:
Please give further details**

**2. If answered "Preparing for adulthood", "Peri-transfer from child to adult health services" or "Fully transferred from child to adult health services" to [1a] then:
In your opinion, what one thing would improve the process of transition from child to adult health services?**

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE

By doing so you have contributed to the dataset that will form the report and recommendations due for release in March 2023