

Transition from child to adult health services: Organisational questionnaire

A. Introduction

What is this study about?

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

Inclusions

Organisations providing healthcare to young people aged between 13 years and their 25th birthday with a complex 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.

Who should complete this questionnaire?

This questionnaire has been designed to collect data on the organisational structures surrounding the process of transition from child to adult health services.

One questionnaire should be completed for each Trust/Health Board/Organisation providing care to young people transitioning from child to adult health services

This questionnaire should be completed by a member of the transition team where available, or by a health care professional responsible for the transition of young people (from child to adult health services) in this organisation

Definitions

This questionnaire is to be completed at Trust, Health board or overarching organisation level. Throughout the questionnaire, the Trust or Health Board will be referred to as the organisation.

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

Please answer the questions in relation to services provided by your organisation up to the 31/03/2021

Please save the questionnaire as you work through this section

1. Does this organisation provide: (Please tick all that apply)

- Physical healthcare Community healthcare Mental healthcare
 Primary care

Please specify any additional options here...

2. Does this organisation provide: (Please tick all that apply)

- Paediatric services Adolescent services Adult services

Please specify any additional options here...

3a. If answered "Paediatric services" to [2] then:
In general, up to what age do paediatric services commonly care for young people?

years Not Applicable Unknown

3b. If answered "Paediatric services" to [2] then:
Does this vary by specialty?

- Yes No Unknown

4a. If answered "Adult services" to [2] then:
What age do adult services commonly start in this organisation?

years Not Applicable Unknown

4b. If answered "Adult services" to [2] then:
Does this vary by specialty?

- Yes No Unknown

5. If answered "Paediatric services" or "Adult services" to [2] then:
Are paediatric and adult services on the same site?

- Yes - for all sites Yes - for some sites No
 Unknown Not applicable

6a. Does this organisation have an adolescent inpatient unit/ward?

- Yes No Unknown

6b. If answered "Yes" to [6a] then:
What is the age range of patients seen in this unit/ward?
If not known, please type unknown

**6c. If answered "Yes" to [6a] then:
When is this unit/ward open?**

- 24/7
- Normal working hours (e.g. 8am-6pm) 7 days/week
- Normal working hours (e.g. 8am-6pm) Monday-Friday
- Unknown

If not listed above, please specify here...

**6d. If answered "Yes" to [6a] then:
How many beds does this unit/ward have?**

 beds Unknown

**6e. If answered "Yes" to [6a] then:
Which specialties can use this unit/ward?**

- Medical and surgical
- Medical only
- Surgical only
- Unknown

If not listed above, please specify here...

**6f. If answered "Yes" to [6a] then:
How many whole time equivalent nurses does the unit/ward have? (role solely for adolescent medicine)**

 Not Applicable Unknown

**6g. If answered "Yes" to [6a] then:
Are nursing staff:**

- Separate from paediatric or adult services
- Shared with paediatric and adult services
- Unknown

If not listed above, please specify here...

7a. Does this organisation have an adolescent outpatient clinic?

- Yes
- No
- Unknown

**7b. If answered "Yes" to [7a] then:
What is the age range of patients seen in this clinic?**

If not known, please type unknown

**7c. If answered "Yes" to [7a] then:
Which specialties can use this clinic?**

- Medical and surgical
- Medical only
- Surgical only
- Unknown

If not listed above, please specify here...

8a. Is there a policy to schedule adolescent outpatient appointments to be longer than paediatric and adult appointments?

- Yes
- No
- Unknown

**8b. If answered "Yes" or "No" to [8a] then:
Please give any further details about the scheduling of adolescent outpatient
appointments**

Please answer the questions in relation to services provided by your organisation up to the 31/03/2021

Please save the questionnaire as you work through this section

This next set of questions aims to find out if there is a team that oversees transition across the whole organisation, and whether there are teams that organise transition services at a specialty level

1a. Does this organisation have one overarching transition team that supports transition across every specialty?

Please see definitions: <https://www.ncepod.org.uk/transition.html>

- Yes No Unknown

**1b. If answered "Yes" to [1a] then:
Which division is the primary focus of the transition team?**

- Paediatric services Adult services
 Combined (paediatric and adult) services Unknown

If not listed above, please specify here...

**1c. If answered "Yes" to [1a] then:
Who are regular members of the transition team responsible for transition? (Please tick all that apply)**

- | | | |
|--|--|---|
| <input type="checkbox"/> Paediatric clinicians | <input type="checkbox"/> Adult clinicians | <input type="checkbox"/> Clinical nurse specialists |
| <input type="checkbox"/> Nurses | <input type="checkbox"/> Physiotherapists | <input type="checkbox"/> Occupational therapists |
| <input type="checkbox"/> Management | <input type="checkbox"/> Key workers | <input type="checkbox"/> Youth workers |
| <input type="checkbox"/> Peer support | <input type="checkbox"/> Community team clinicians | <input type="checkbox"/> Community team nurses |
| <input type="checkbox"/> GPs/Primary care | <input type="checkbox"/> Young people | <input type="checkbox"/> Parent carers |
| <input type="checkbox"/> Unknown | | |

Please specify any additional options here...

**1d. If answered "Yes" to [1a] then:
Do core members of the transition team have dedicated time in their job plan for transition?**

- Yes No Unknown

**1e. If answered "Yes" to [1a] then:
Are any members of this transition team on short term funding**

- Yes No Unknown

**1f. If answered "Yes" to [1a] and "Yes" to [1e] then:
Which funding is provided? (Please tick all that apply)**

- Roald Dahl funding Burdett Nursing Trust funding Other charity funding
 Unknown

Please specify any additional options here...

**1g. If answered "Yes" to [1a] and "Yes" to [1e] then:
Has there been an organisational commitment to continue the role long term?**

- Yes No Unknown

**1h. If answered "Yes" to [1a] then:
Are other colleagues invited to transition team meetings as needed?**

- Yes No Unknown

**1i. If answered "Yes" to [1a] and "Yes" to [1h] then:
If virtual meetings are held, do:**

- More colleagues attend than an in-person meeting
- Less people attend than an in-person meeting
- There is no difference in attendance between in-person and virtual meetings
- Unknown
- NA - virtual meetings not held

If not listed above, please specify here...

**1j. If answered "Yes" to [1a] then:
Please give any further details regarding transition team meetings:**

2a. Does this organisation have more than one service that supports transition (i.e. specialty led transition)?

- Yes No Unknown

**2b. If answered "Yes" to [2a] then:
Is this:**

- Single site Trust/Health Board - by specialty
- Multi-site Trust/Health Board - by hospital across all specialties (one transition service within in each h
- Multi-site Trust/Health Board - by specialty across all hospitals (one transition service for each specialt
- Multi-site Trust/Health Board - by specialty and by hospital (one transition service for each specialty w
- Unknown

If not listed above, please specify here...

**2c. If answered "Yes" to [2a] then:
Is there one person coordinating this across services?**

- Yes No Unknown

**2d. If answered "Yes" to [2a] then:
Are other colleagues invited to transition team meetings as needed?**

- Yes - for all specialties Yes - for some specialties No
 Unknown

2e. If answered "Yes - for all specialties" or "Yes - for some specialties" to [2d] and "Yes" to [2a] then:

If YES, does this include those caring for the young person?

- Yes - for all specialties Yes - for some specialties No
 Unknown

2f. If answered "Yes - for all specialties" or "Yes - for some specialties" to [2d] and "Yes" to [2a] then:

If virtual meetings are held, do:

- More colleagues attend than an in-person meeting
- Less people attend than an in-person meeting
- There is no difference in attendance between in-person and virtual meetings
- Unknown
- NA - virtual meetings not held

If not listed above, please specify here...

2g. If answered "Yes" to [2a] then:

Please give any further details regarding transition team meetings:

3a. If answered "No" to [1a] and "No" to [2a] then:

If there is not more than one team, service or person overseeing transition, is there one person who oversees transition in the organisation?

- Yes No Unknown

3b. If answered "No" to [1a] and "Yes" to [3a] and "No" to [2a] then:

Please give further details:

Do not include any names

4. Please give any further details regarding this organisations transition service:

From this point on, questions about the 'transition team or service' refer to the model of transition service used in this organisation, i.e. one team that support transition across the organisation, multiple teams across the organisation or one person.

5a. Do all young people transitioning from child to adult services have a key worker/named worker? (someone who coordinates their care)

Please see definitions: <https://www.ncepod.org.uk/transition.html>

Yes No Unknown

**5b. If answered "Yes" to [5a] then:
Is there a job description of their role?**

Yes No Unknown

**5c. If answered "Yes" to [5a] then:
How are key workers/named workers funded? (Please tick all that apply)**

Core NHS activity Roald Dahl funding Burdett Nursing Trust funding
 Other charity funding Unknown

Please specify any additional options here...

6a. Does this organisation have a youth worker?

Yes - for all specialties Yes - for some specialties No
 Unknown

**6b. If answered "Yes - for all specialties" or "Yes - for some specialties" to [6a] then:
How many?**

**6c. If answered "Yes - for all specialties" or "Yes - for some specialties" to [6a] then:
How are these roles funded? (Please tick all that apply)**

Core NHS activity Roald Dahl funding Burdett Nursing Trust funding
 Other charity funding Unknown

Please specify any additional options here...

7a. Does the transition team or service involve young people in the design of the transition service?

Yes - for all specialties Yes - for some specialties
 No Unknown
 NA - no transition team or service

**7b. If answered "Yes - for all specialties" or "Yes - for some specialties" to [7a] then:
How is this undertaken? (Please tick all that apply)**

Suggestions box Informal discussion Group meetings Not involved
 Unknown

Please specify any additional options here...

8. Generally when does the transition team or service stop being involved with the care of the young person?

- At transfer
- Varies by transition team
- Unknown
- After review in adult services
- NA - no transition team or service

If not listed above, please specify here...

9. Is transition care included in funding arrangements/contracts?

- Yes - for all specialties
- Yes - for some specialties
- No
- Unknown

10. Is there separate commissioning for transition care?

- Yes - for all specialties
- Yes - for some specialties
- No
- Unknown

Please answer the questions in relation to services provided by your organisation up to the 31/03/2021

1a. Does this organisation have at least one clinical lead for transition? (i.e. consultant/CNS/lead nurse)

- Yes No Unknown

**1b. If answered "Yes" to [1a] then:
Please give further details**

2a. Does this organisation have a senior executive accountable for developing and publishing transition strategies and policies?

- Yes No Unknown

**2b. If answered "Yes" to [2a] then:
Please give further details (e.g. around the reviewing, auditing and updating of policies)**

3a. Does this organisation have a member of the transition team or service who supports the executive board in developing and publishing transition strategies and policies?

- Yes No Unknown

**3b. If answered "Yes" to [3a] then:
Please give any further details**

4a. Does this organisation have a senior manager accountable for implementing transition strategies and policies?

Yes

No

Unknown

**4b. If answered "Yes" to [4a] then:
Please give any further details**

Please answer the questions in relation to services provided by your organisation up to the 31/03/2021

1. Is transitional care included in the job descriptions of healthcare staff involved in transition?

- Yes - for all specialties Yes - for some specialties No
 Unknown

2a. Does this organisation hold transition clinics where both children's and adult services attend the appointment?

- Yes - for all specialties Yes - for some specialties No
 Unknown

2b. If answered "Yes - for all specialties" or "Yes - for some specialties" to [2a] then: Are these formally commissioned/funded?

- Yes - for all specialties Yes - for some specialties No
 Unknown

2c. If answered "Yes - for all specialties" or "Yes - for some specialties" to [2a] then: How are these run? (Please tick all that apply)

- Jointly between paediatric and adult services (within the same organisation)
 Jointly between organisations (between paediatric and adult services)
 From paediatric services only
 From adult services only
 Unknown

Please specify any additional options here...

2d. If answered "Yes - for all specialties", "Yes - for some specialties" or "No" to [2a] then: Please give any further details/examples of what is done in this organisation (we would like to share examples of where this works well or barriers to this process)

3a. Does this organisation hold joint appointments staffed by both children's and adult services?

- Yes - for all specialties Yes - for some specialties No
 Unknown

**3b. If answered "Yes - for all specialties", "Yes - for some specialties" or "No" to [3a] then:
Please give any further details regarding this (we would like to share examples of where
this works well or barriers to this process)**

4a. Does this organisation have resources to specifically develop young people's self-management of their health needs?

- Yes No Unknown

**4b. If answered "Yes" to [4a] then:
Please give any further details about these resources (we would like to share examples
of where this works well or barriers to this process)**

5a. Does this organisation have a policy to encourage young patients to access primary care for their other health needs?

- Yes No Unknown

**5b. If answered "Yes" or "No" to [5a] then:
Please give any further details/examples of what is done in this organisation (we would
like to share examples of where this works well or barriers to this process)**

Please answer the questions in relation to services provided by your organisation up to the 31/03/2021

Please save the questionnaire as you work through this section

1. Does this organisations electronic medical record have a flagging system to identify young people going through transition?

- Yes No Unknown

2a. Does this organisation have an overarching transition policy?

- Yes No Unknown

2b. If answered "Yes" to [2a] then:
Does this cover young people with:

- All long-term conditions Specific long-term conditions Unknown

2c. If answered "Yes" to [2a] then:
Does it state: (please tick all that apply)

- At what age transition planning should generally start
- That there is an option for young people to choose the time to transfer to adult services
- In general how long before planned transfer to adult services, young people should be involved in disc
- That every patient transitioning to adult care has a personal folder/passport of relevant information ab
- That all young people transitioning have a transition plan in place from early adolescence (e.g. Ready,
- That all young people who are transitioning meet the adult team before moving to adult services
- That young people should be given support to learn how to self-manage their condition(s)
- That care should be given in a developmentally appropriate setting
- Steps to assess the developmentally and clinically appropriate age for transfer to adult services?
- Unknown

Please specify any additional options here...

2d. If answered "Yes" to [2a] and "At what age transition planning should generally start" to [2c] then:

If YES to age at which transition planning should generally start, what age is this?

- Years Unknown

2e. If answered "Yes" to [2a] and "That all young people transitioning have a transition plan in place from early adolescence (e.g. Ready, Steady, Go?)" to [2c] then:
If YES to transition plans, which plans are used: (Please tick all that apply)

- Ready Steady Go
- HEADSS
- 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

Please specify any additional options here...

2f. If answered "Yes" to [2a] and "That all young people transitioning have a transition plan in place from early adolescence (e.g. Ready, Steady, Go?)" to [2c] then:
If YES to transition plans, is this audited to confirm transition plans are in place?

- Yes No Unknown

**2g. If answered "Yes" to [2a] and "That all young people who are transitioning meet the adult team before moving to adult services" to [2c] then:
If YES to meeting with the adult team, is this audited to confirm this has taken place?**

- Yes No Unknown

**2h. If answered "Yes" to [2a] then:
Is there flexibility within the policy to allow for the young person to be transferred at a time that is developmentally and clinically appropriate?**

- Yes No Unknown

**2i. If answered "Yes" to [2a] then:
Please give any further details/examples of this organisations transition policy (we would like to share examples of where this works well or barriers to this process)**

**3a. If answered "No" or "Unknown" to [2a] then:
Does this organisation have separate policies which state: (please tick all that apply)**

- At what age transition planning should generally start
- That there is an option for young people to choose the time to transfer to adult services
- In general how long before planned transfer to adult services, young people should be involved in disc
- That every patient transitioning to adult care has a personal folder/passport of relevant information ab
- That all young people transitioning have a transition plan in place from early adolescence (e.g. Ready,
- That all young people who are transitioning meet the adult team before moving to adult services
- That young people should be given support to learn how to self-manage their condition(s)
- That care should be given in a developmentally appropriate setting
- Steps to assess the developmentally and clinically appropriate age for transfer to adult services?
- No separate policies
- Unknown

Please specify any additional options here...

**3b. If answered "That all young people transitioning have a transition plan in place from early adolescence (e.g. Ready, Steady, Go?)" to [3a] and "No" or "Unknown" to [2a] then:
If YES to transition plans, which plans are used: (Please tick all that apply)**

- Ready Steady Go
- HEADSS
- 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

Please specify any additional options here...

3c. If answered "That all young people transitioning have a transition plan in place from early adolescence (e.g. Ready, Steady, Go?)" to [3a] and "No" or "Unknown" to [2a] then: If YES to transition plans, is this audited to confirm transition plans are in place?

- Yes No Unknown

3d. If answered "That all young people who are transitioning meet the adult team before moving to adult services" to [3a] and "No" or "Unknown" to [2a] then: If YES to meeting with the adult team, is this audited to confirm this has taken place?

- Yes No Unknown

3e. If answered "No" or "Unknown" to [2a] then: Is there flexibility within the policies to allow for the young person to be transferred at a time that is developmentally and clinically appropriate?

- Yes No Unknown
 NA - no separate policies

3f. If answered "No" or "Unknown" to [2a] then: Please give any further details/examples of these policies: (we would like to share examples of where this works well or barriers to this process)

4a. In general, do different specialties have separate policies for transition?

- Yes - for all specialties Yes - for some specialties No
 Unknown

4b. If answered "Yes - for all specialties", "Yes - for some specialties" or "No" to [4a] then: Please give any further details/examples of what is done in this organisation (we would like to share examples of where this works well or barriers to this process)

5a. Does this organisation have a mechanism for the coordination of a single transfer date for patients under multiple clinical teams?

- Yes No Unknown

5b. If answered "Yes" to [5a] then:

Please give any further details/examples of what is done in this organisation (we would like to share examples of where this works well or barriers to this process)

6a. What happens where there is no equivalent adult specialty for the young person to transfer to? (Please tick all that apply)

- Young person is seen in a general adult clinic
- The young person is discharged to the GP
- Young person is seen in a specialty clinic for main subspecialty only
- Unknown
- Not applicable

Please specify any additional options here...

6b. If answered "Young person is seen in a general adult clinic", "The young person is discharged to the GP" or "Young person is seen in a specialty clinic for main subspecialty only" to [6a] then:

Please give any further details/examples of what is done in this organisation if there is no equivalent adult specialty for the young person to transfer to (we would like to share examples of where this works well or barriers to this process)

7a. Does this organisation have a pathway to liaise with social care for young people transitioning?

- Yes No Unknown

7b. If answered "No" to [7a] then:

If NO, how are the transition needs of looked after children addressed?

Please see definitions: <https://www.ncepod.org.uk/transition.html>

8a. Does this organisation have a pathway to liaise with education for young people transitioning?

Yes

No

Unknown

8b. If answered "Yes" or "No" to [8a] then:

Please give any further details/examples of what is done in this organisation (we would like to share examples of where this works well or barriers to this process)

9a. Does the organisation have a policy to check that all young people under the care of their services are registered with a GP?

Yes

No

Unknown

9b. Does the organisation have information for patients on how to contact their GP?

Yes

No

Unknown

9c. Does this organisation have a pathway to liaise with primary care for young people transitioning?

Yes

No

Unknown

9d. Please give any further details/examples of what is done in this organisation (we would like to share examples of where this works well or barriers to this process)

10a. Is this organisation a member of a network of care for transition?

Please see definitions:

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

- Yes - formal Yes - informal No Unknown

**10b. If answered "Yes - formal" or "Yes - informal" to [10a] then:
Is this**

- Trust/Health Board based Specialty based Unknown

If not listed above, please specify here...

**10c. If answered "Yes - formal" or "Yes - informal" to [10a] then:
Please give any further details/examples of what is done in this organisation (we would like to share examples of where this works well or barriers to this process)**

**10d. If answered "No" to [10a] then:
If NO, how does this organisation link with other organisations to address the needs of young people transitioning from child to adult health services?**

Please answer the questions in relation to services provided by your organisation up to the 31/03/2021

Please save the questionnaire as you work through this section

1. Does this organisation have a policy giving the opportunity for young people to routinely attend appointments on their own?

- Yes - for all specialties Yes - for some specialties No
 Unknown

2a. If a young person attends appointments with parent carers are they given the opportunity to be seen alone?

- Yes - for all specialties Yes - for some specialties No
 Unknown

2b. If answered "Yes - for all specialties" or "Yes - for some specialties" to [2a] then: Is this information (that they are able to be seen alone) made clear in appointment letters, posters in waiting areas, and informational resources?

- Yes No Unknown

2c. If answered "Yes - for all specialties" or "Yes - for some specialties" to [2a] then: Please give any further information as to how this is undertaken:

3. Are parent carers given the opportunity to be seen alone?

- Yes - for all specialties Yes - for some specialties No
 Unknown

4a. Does this organisation have a policy which states that all young people from the age of 13 transitioning have an annual (or more frequent) transition review pre-transfer?

- Yes No Unknown

4b. Does this organisation have a policy which states that all young people who have transferred to adult services are offered an annual (or more frequent) transition review post-transfer to ensure engagement?

- Yes No Unknown

5a. Does this organisation have a policy which states that all young people transitioning receive any support regarding education or careers?

- Yes No Unknown

5b. If answered "Yes" to [5a] then:

Does it state how this should be provided? (Please tick all that apply)

- | | |
|--|--|
| <input type="checkbox"/> Yes - In person careers advisor | <input type="checkbox"/> Yes - Signposting to other services |
| <input type="checkbox"/> Yes - Sharing resources | <input type="checkbox"/> No |
| <input type="checkbox"/> Unknown | |

Please specify any additional options here...

6a. Does this organisation have a policy which states that young people should be offered the opportunity to be actively involved in transition?

- Yes No Unknown

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

Does this state how this should be undertaken? (Please tick all that apply)

- | |
|---|
| <input type="checkbox"/> Yes - Jointly develop care plans |
| <input type="checkbox"/> Yes - Deciding how they would like a parent carer to be involved |
| <input type="checkbox"/> No |
| <input type="checkbox"/> Unknown |

Please specify any additional options here...

7a. Does this organisation have a policy which states that parent carers should be offered the opportunity to be actively involved in transition?

- Yes No Unknown

7b. If answered "Yes" to [7a] then:

Does this state how this should be undertaken?

- Yes No Unknown

**7c. If answered "Yes" to [7a] and "Yes" to [7b] then:
How is this undertaken?**

8a. Does this organisation have a youth forum?

- Yes No Unknown

8b. If answered "Yes" to [8a] then:

Does this include young people with: (Please tick all that apply)

- | | | |
|--|--|--|
| <input type="checkbox"/> Physical health needs | <input type="checkbox"/> Mental health needs | <input type="checkbox"/> Social care needs |
| <input type="checkbox"/> No health care needs | <input type="checkbox"/> Lay representatives | <input type="checkbox"/> Unknown |

Please specify any additional options here...

**8c. If answered "Yes" to [8a] then:
How often does this group meet?**

- Once a month Four times a year Twice a year Once a year
 Unknown

If not listed above, please specify here...

**8d. If answered "Yes" to [8a] then:
How often does the group give feedback?**

- Once a month Four times a year Twice a year Once a year
 Unknown

If not listed above, please specify here...

**8e. If answered "Yes" to [8a] then:
Who does the group give feedback to?**

9a. Are parent carers signposted to support groups during the transition process?

- Yes No Unknown

**9b. If answered "No" to [9a] then:
If NO, how are parent carers supported?**

Please answer the questions in relation to services provided by your organisation up to the 31/03/2021

Please save the questionnaire as you work through this section

1. Does this organisation have a transition page on its website?

- Yes No Unknown

2. Does this organisation have a policy that appointments for young people are made at times more convenient for them (i.e. after school hours)?

- Yes No Unknown

3. Does this organisation offer a service of holistic care to young people? (e.g. a 'one-stop-shop' model - with access to other services such as sexual health, mental health, nutrition etc)

Please see definitions: <https://www.ncepod.org.uk/transition.html>

- Yes No Unknown

4. Does the organisation have a policy that young people are routinely copied into correspondence regarding their care:

- Both pre- and post transfer Pre-transfer only Post transfer only
 Unknown

If not listed above, please specify here...

5. Does this organisation have a policy that parent carers are routinely copied into correspondence where appropriate regarding their young person's care:

- Both pre- and post transfer Pre-transfer only Post transfer only
 Unknown

If not listed above, please specify here...

6a. Who else is routinely copied into correspondence regarding young people's care pre-transfer? (Please tick all that apply)

- Primary care Community care Social care Education
 Unknown

Please specify any additional options here...

6b. Who else is routinely copied into correspondence regarding young people's care post-transfer? (Please tick all that apply)

- Primary care Community care Social care Education
 Unknown

Please specify any additional options here...

7a. Does this organisation have an appropriate environmental space for young people? (i.e. a young person friendly environment appropriate for age)

- Yes - for all specialties Yes - for some specialties No
 Unknown

7b. If answered "Yes - for all specialties" or "Yes - for some specialties" to [7a] then: What resources are available for young people within this environment? (Please tick all that apply)

- Sexual health resources Resources regarding drugs Educational resources
 Unknown

Please specify any additional options here...

8a. Does this organisation have resources specifically designed for young people? (i.e. One stop-shop model)

- Yes - for all specialties Yes - for some specialties No
 Unknown

8b. If answered "Yes - for all specialties" or "Yes - for some specialties" to [8a] then: Please give further information about these resources, including where they are provided (e.g. intranet, leaflets, websites, apps, shared care records etc.):

9a. Does this organisation have a policy to provide young people and their families with information about the process of transition in this organisation?

- Yes No Unknown

9b. If answered "Yes" to [9a] then: Does it state how this information should be provided? (please tick all that apply)

- Yes - verbally Yes - written Yes - digitally No
 Unknown

Please specify any additional options here...

10. Does this organisation have a policy regarding reasonable adjustments (such as accessible information) for young people with a learning disability?

- Yes No Unknown

Please answer the questions in relation to services provided by your organisation up to the 31/03/2021

1a. Does this organisation have training for staff regarding developmentally appropriate healthcare/adolescent healthcare/caring for young people? (Please tick all that apply)

- Yes - mandatory training Yes - non-mandatory training No
 Unknown

**1b. If answered "No" to [1a] then:
If NO, why not?**

2a. Does this organisation have a policy which explains consent for young people?

- Yes No Unknown

2b. Do staff in this organisation receive training in consent for young people?

- Yes No Unknown

3a. Does this organisation have a policy which describes how confidentiality should be explained to young people?

- Yes No Unknown

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

Does it include information for parents about the young persons rights to confidentiality?

- Yes No Unknown

3c. Do staff in this organisation receive training in confidentiality for young people?

- Yes No Unknown

4a. Does this organisation have a policy to review mental capacity and the ability to make decisions regarding their healthcare, for young people before they reach adulthood?

- Yes No Unknown

4b. Does this organisation provide training in the use of the Mental Capacity Act in relation to Young People?

- Yes No Unknown

5. Are there are clear policies and procedures for safeguarding young people including those involved in youth participation

- Yes No Unknown

6a. Does this organisation provide training for staff in transition from child to adult health services?

- Yes No Unknown

**6b. If answered "No" to [6a] then:
If NO, why not?**

7. Please give any further information around training programmes for transition: (we would like to share examples of where this works well or barriers to this process)

Please answer the questions in relation to services provided by your organisation up to the 31/03/2021

1a. Does this organisation have a register/registers of how many young people aged 13 years and over with chronic disease are currently in the process of transitioning to adult services?

- Yes - for all specialties Yes - for some specialties No
 Unknown

1b. If answered "Yes - for all specialties" or "Yes - for some specialties" to [1a] then: How many young people are currently on the register(s)?

1c. If answered "Yes - for all specialties" or "Yes - for some specialties" to [1a] then: Is there a method of assessing where young people are on the pathway?

- Yes No Unknown

1d. If answered "Yes - for all specialties" or "Yes - for some specialties" to [1a] then: Please give any further details:

2a. Is the effectiveness of transition strategies and policies regularly reviewed/audited?

- Yes - for all specialties Yes - for some specialties No
 Unknown

2b. If answered "Yes - for all specialties" or "Yes - for some specialties" to [2a] then: How often does this occur?

- Quarterly Six-monthly Annually Unknown

If not listed above, please specify here...

2c. If answered "No" to [2a] then: If NO, why not?

3a. Is an organisational gap analysis undertaken to identify young people who were under children's services but could not access support from adult services?

- Yes - for all specialties Yes - for some specialties No
 Unknown

3b. If answered "Yes - for all specialties" or "Yes - for some specialties" to [3a] then: Is this analysis been used to inform local planning and commissioning of services?

- Yes No Unknown

3c. If answered "Yes - for all specialties" or "Yes - for some specialties" to [3a] then: Please give any further details:

4a. Is an organisational gap analysis undertaken to assess compliance with NICE guidelines on transition?

- Yes - for all specialties Yes - for some specialties No
 Unknown

4b. Is an organisational gap analysis undertaken to assess compliance with the 'You're Welcome' standards?

- Yes - for all specialties Yes - for some specialties No
 Unknown

5. Does this organisation audit the attendance of staff: (Please tick all that apply)

- At joint clinics At transition team meetings Not undertaken
 Unknown

6a. Is there joint evaluation of the transfer process by the child and adult teams to review ongoing engagement?

- Yes - for all specialties Yes - for some specialties No
 Unknown

6b. If answered "Yes - for all specialties" or "Yes - for some specialties" to [6a] then: If YES, do these meetings take place on a regular basis?

- Yes - for all specialties Yes - for some specialties No
 Unknown

**6c. If answered "No" to [6a] then:
If NO, why not?**

1. Please give any information on the impact of the pandemic on young people going through transition:

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