



Default Question Block

What is the study about?

We are exploring the process of the transition of young people with complex chronic conditions from children's to adult health services across all healthcare settings.

As part of the study we are asking young people and parent carers about their experiences of transition. The aim of the study will be to produce a report for clinicians and other professionals about how to improve the care they deliver, and guidance for young people and families on what care you should expect to receive.

“Transition” is defined as the purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of a young person as they move from child-centred to adult-centred healthcare. (Blum R. W. et al, Transition from child-centred to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine, J Adolesc Health, 1993 Nov;14(7):570-6.)

As an example, we will be looking at young people and young adults with chronic conditions such as cerebral palsy or epilepsy who have experience transferring of their care from a paediatrician or child health professional to a doctor in adult medicine, GP or other adult health professional.

Who should complete this questionnaire?

Please complete this survey if you:

- Are a young person, or the carer of a young person, aged 13 - 24 years old
- You, or the young person you care for, has had experience of moving ongoing healthcare needs from child to adult services

Definitions

'Transition': *The process of preparation for moving from child to adult health services.*

'Move from childhood to adult services': *The actual transfer from childhood to adult services.*

'Key worker': *Someone who is in charge of supporting the process transition*

If you are a parent carer, throughout the survey, the young person you provide care for will be referred to as 'the young person'.

If you have any questions or you need this survey in another language or braille, or have any queries about this study in general, please contact us at transition@ncepod.org.uk or ring us on 020 7251 9060.

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

ALL RESPONSES GIVEN AS PART OF THIS SURVEY ARE CONFIDENTIAL

Information about you

2. Are you a:

- young person
 parent carer

3. How old are you?

Years old

7. How old is the young person you care for?

Years old

5. Are you:

Male Female

-

Other (Optional: specify below)

-

8. Is the young person you care for:

Male Female

Other (please describe)

6. Which of the following health condition(s) do you have? (please tick all that apply)

Epilepsy

Duchenne muscular dystrophy

Type 2 diabetes and obesity

Sickle cell anaemia

Post transplant patient (kidney, heart and liver)

Chronic kidney disease

Juvenile idiopathic Arthritis

Autism

Other (please specify)

Cerebral palsy

Brain tumour (medulloblastoma)

Unknown

Spina bifida

10. What health condition(s) does the young person have that require ongoing healthcare?(please tick all that apply)

Epilepsy

Duchenne muscular dystrophy

Type 2 diabetes and obesity

Sickle cell anaemia

Post transplant patient (kidney, heart and liver)

Chronic kidney disease

Juvenile idiopathic Arthritis

Autism

Other (please describe)

Cerebral palsy

Brain tumour (medulloblastoma)

Unknown

Spina bifida

11. Do you have a learning disability?

Yes - mild

No

Yes - moderate

Unknown

Yes - profound

12. Does the young person have a learning disability?

- | | |
|--------------------------------------|-------------------------------|
| <input type="radio"/> Yes - mild | <input type="radio"/> No |
| <input type="radio"/> Yes - moderate | <input type="radio"/> Unknown |
| <input type="radio"/> Yes - profound | |

13. How many different healthcare teams look after you? (including primary care/GP and community care if applicable)

- | | |
|-------------------------|-----------------------------------|
| <input type="radio"/> 1 | <input type="radio"/> 5 |
| <input type="radio"/> 2 | <input type="radio"/> More than 5 |
| <input type="radio"/> 3 | <input type="radio"/> Unknown |
| <input type="radio"/> 4 | |

14. How many different healthcare teams look after the young person? (including primary care/GP and community care if applicable)

- | | |
|-------------------------|-----------------------------------|
| <input type="radio"/> 1 | <input type="radio"/> 5 |
| <input type="radio"/> 2 | <input type="radio"/> More than 5 |
| <input type="radio"/> 3 | <input type="radio"/> Unknown |
| <input type="radio"/> 4 | |

15. What stage of transition to adult services are you currently in*?

- | | |
|---|---|
| <input type="radio"/> Planning for transition | <input type="radio"/> Previously transitioned more than 2 years ago |
| <input type="radio"/> Currently transitioning | <input type="radio"/> Unknown |
| <input type="radio"/> Recently transitioned in the last 2 years | |

16. What stage of transition to adult services is the young person currently in*?

- | | |
|---|---|
| <input type="radio"/> Planning for transition | <input type="radio"/> Previously transitioned more than 2 years ago |
| <input type="radio"/> Currently transitioning | <input type="radio"/> Unknown |
| <input type="radio"/> Recently transitioned in the last 2 years | |

B. What went well/not so well

Please think about healthcare services you are receiving or have received in relation to moving from child to adult services, and tell us:

18. Up to three things that have worked well during this period?

a)

b)

c)

83. Up to three things that have not worked well during this period?

a)

b)

c)

Please think about healthcare services the young person is receiving or has received in relation to moving from childhood to adult services, and tell us:

20. Up to three things that have worked well during this period?

a)

b)

c)

84. Up to three things that have not worked well during this period?

a)

b)

c)

C. Transition planning/process

We would now like to ask a few more specific questions about the transition process.

22. Were you made aware of the process of moving from children's to adult services by a healthcare professional (for example, a doctor or nurse)?

Yes No Unknown

23. How were you made aware of this?

Conversation

Leaflet

Digital source
(i.e. website)

Other (please
describe)

Unknown

24. What age were you when a healthcare professional (for example, a doctor or nurse) first spoke to you about the move from childhood to adult services?

- | | |
|------------------------------------|--|
| <input type="radio"/> 13 years old | <input type="radio"/> 20 years old |
| <input type="radio"/> 14 years old | <input type="radio"/> 21 years old |
| <input type="radio"/> 15 years old | <input type="radio"/> 22 years old |
| <input type="radio"/> 16 years old | <input type="radio"/> 23 years old |
| <input type="radio"/> 17 years old | <input type="radio"/> 24 years old |
| <input type="radio"/> 18 years old | <input type="radio"/> No discussion took place |
| <input type="radio"/> 19 years old | <input type="radio"/> Unknown |

25. What age was the young person when the clinical team(s) first started to talk about the move from childhood to adult services? (if the age discussions started varied across clinical teams, please give the youngest age bracket)

- | | |
|---------------------------------------|--|
| <input type="radio"/> 13-15 years old | <input type="radio"/> 22-25 years old |
| <input type="radio"/> 16-18 years old | <input type="radio"/> No discussion took place |
| <input type="radio"/> 19-21 years old | <input type="radio"/> Unknown |

26. Do you think:

- | | |
|--|---|
| <input type="radio"/> This was the right age to start planning | <input type="radio"/> It was too late to start planning |
| <input type="radio"/> It was too early to start planning | <input type="radio"/> Unknown |

26. On a scale of 1 to 5, how involved are/were you in transition planning?

No
involvement

2 3

4

Fully
involved

Unknown

45. On a scale of 1 to 5, how involved you are/were in making decisions about your move from childhood to adult services?

No
involvement

2 3

4

Fully
involved

Unknown

28. On a scale of 1 to 5, how involved you are/were in making decisions about the young person's move from childhood to adult services?

No
involvement

2

3

4

Fully
involved

Unknown

29. Is/was your General Practitioner (GP) involved in the transition process?

Yes

No

Unknown

30. Is/was the young person's General Practitioner (GP) involved in the transition process?

Yes

No

Unknown

31. Are/were you invited to attend any specific meetings regarding your move from childhood to adult services?

- Yes No Unknown
-

34. Are/were you aware if the clinical teams are using/used a plan, such as 'Ready Steady Go', to plan the move from paediatric to adult services?

- Yes No Unknown
-

35. How is/was this plan shared with you?

- Mentioned in letters It's not shared with me
- Given a paper copy Unknown
- Referred to a digital source (i.e. website)

36. Do/did you feel ready to move from childhood to adult services?

- Yes - for all teams Unknown
- Yes - for some teams NA - too early in the process
- No

37. Do/did you feel ready for the young person to move from childhood to adult services?

- Yes - for all teams Unknown
- Yes - for some teams NA - too early in the process
- No

38. Please give further information:

39. Do adult services now provide your care?

- Yes No Unknown
-

47. Do adult services now provide care for the young person?

- Yes No Unknown
-

41. In general, what age did the adult healthcare team take responsibility for your care?

- | | |
|------------------------------------|---|
| <input type="radio"/> 13 years old | <input type="radio"/> 20 years old |
| <input type="radio"/> 14 years old | <input type="radio"/> 21 years old |
| <input type="radio"/> 15 years old | <input type="radio"/> 22 years old |
| <input type="radio"/> 16 years old | <input type="radio"/> 23 years old |
| <input type="radio"/> 17 years old | <input type="radio"/> 24 years old |
| <input type="radio"/> 18 years old | <input type="radio"/> No one has taken responsibility for my care |
| <input type="radio"/> 19 years old | <input type="radio"/> Unknown |

94. In general, what age did the adult healthcare team take responsibility for the young person's care?

- | | |
|------------------------------------|---|
| <input type="radio"/> 13 years old | <input type="radio"/> 20 years old |
| <input type="radio"/> 14 years old | <input type="radio"/> 21 years old |
| <input type="radio"/> 15 years old | <input type="radio"/> 22 years old |
| <input type="radio"/> 16 years old | <input type="radio"/> 23 years old |
| <input type="radio"/> 17 years old | <input type="radio"/> 24 years old |
| <input type="radio"/> 18 years old | <input type="radio"/> No one has taken responsibility for the young person's care |
| <input type="radio"/> 19 years old | <input type="radio"/> Unknown |

42. How old were you when you first met the adult team?

- | | |
|------------------------------------|------------------------------------|
| <input type="radio"/> 13 years old | <input type="radio"/> 20 years old |
| <input type="radio"/> 14 years old | <input type="radio"/> 21 years old |
| <input type="radio"/> 15 years old | <input type="radio"/> 22 years old |

- 16 years old
- 17 years old
- 18 years old
- 19 years old
- 23 years old
- 24 years old
- I haven't met the adult team
- Unknown

46. How old was the young person when you first met the adult team?

- 13 years old
- 14 years old
- 15 years old
- 16 years old
- 17 years old
- 18 years old
- 19 years old
- 20 years old
- 21 years old
- 22 years old
- 23 years old
- 24 years old
- I haven't met the adult team
- Unknown

43. Did you meet members of the adult team whilst care was still provided by children's services?

- Yes No Unknown
- -
 -

44. Were you shown around the adult department/services before the transfer to adult services?

- Yes No Unknown
- -
 -

50. On a scale of 1 to 5, how prepared did you feel to take more responsibility for your care?

- Not prepared at all
- - 2 3
 -
 -

4

Fully prepared

Unknown

65. How prepared do you feel the young person was to take more responsibility for their care?

Not prepared at all

2

3

4

Fully prepared

Unknown

52. Were you taking medication whilst under children's services for your condition(s)?

Yes No Unknown

53. Was the young person taking medication whilst under children's services for their condition(s)?

Yes No Unknown

67. How prepared did you feel to manage your medication prescription?

Not
prepared at
all

2

3

4

Fully
prepared

Unknown

68. How prepared did you feel the young person was to manage their medication prescription?

Not
prepared at
all

2

3

4

Fully
prepared

Unknown

56. Has/did anyone from the children's team check with you that the move to adult services went well?

Yes No Unknown

D. Communication/Support

57. Do/did you have an assigned key worker/named worker*: (please tick all that apply) *Definition: a 'key worker' is someone who is in charge of supporting the process transition*

- | | |
|--|--|
| <input type="checkbox"/> Before transition | <input type="checkbox"/> No key worker involvement |
| <input type="checkbox"/> During transition | <input type="checkbox"/> Unknown |
| <input type="checkbox"/> After transition | |

58. Does/did the young person have an assigned key worker/named worker*: (Please tick all that apply)

- | | |
|--|--|
| <input type="checkbox"/> Before transition | <input type="checkbox"/> No key worker involvement |
| <input type="checkbox"/> During transition | <input type="checkbox"/> Unknown |
| <input type="checkbox"/> After transition | |

60. Which of the following areas have been/were discussed with you by a healthcare professional during the transition period (please tick all that apply):

- | | |
|--|--|
| <input type="checkbox"/> Education | <input type="checkbox"/> Relationships |
| <input type="checkbox"/> Employment | <input type="checkbox"/> Mental health |
| <input type="checkbox"/> Drugs and alcohol | <input type="checkbox"/> None |
| <input type="checkbox"/> Sexual health | <input type="checkbox"/> Unknown |

95. Which of the following areas have been/were discussed with the young person by a healthcare professional during the transition period (Please tick all that apply):

- | | |
|--|--|
| <input type="checkbox"/> Education | <input type="checkbox"/> Relationships |
| <input type="checkbox"/> Employment | <input type="checkbox"/> Mental health |
| <input type="checkbox"/> Drugs and alcohol | <input type="checkbox"/> None |
| <input type="checkbox"/> Sexual health | <input type="checkbox"/> Unknown |

During the transition process, on a scale of 1 to 5:

61. How well do you feel you have been/were supported by healthcare professionals in children's services?

Not
supported
at all

2

3

4

Extremely
supported

Unknown

N/A

70. How well do you feel you have been/were supported by healthcare professionals in adult services?

Not
supported
at all

2

3

4

Extremely
supported

Unknown

N/A - not transferred

71. How well do you feel you have been/were communicated with by healthcare professionals in children's services?

Poorly 2

3 4

Extremely well

Unknown

72. How well do you feel you have been/were communicated with by healthcare professionals in adult services?

Poorly 2

3 4

Extremely well

Unknown

73. How well do you feel the difference between children's and adult services was/has been communicated to you?

Poorly 2

3 4

Extremely well

Unknown

The difference
has not been
communicated

74. How well do you feel the teams providing healthcare to you, communicated with each other?

Poorly

2 3

4

Extremely
well

Unknown

N/A

75. How well do you feel the teams providing healthcare to the young person have communicated with each other?

Poorly

2

3

4

Extremely
well

Unknown

N/A

77. How well do you feel you understand/understood the process of transition?

Poorly

2

3

4

Extremely
well

Unknown

N/A

78. Have you used any technology platforms to help you through the process of transition?

Yes No Unknown

79. Please give further details:

E. Funding

80. Have there been/were there any issues with funding during the transition period?

Yes No

Unknown

N/A - funding not
applied for

81. Please expand on this:

82. Please expand on what has worked well:

F. Social care

83. Have you received social care at any point during your move from childhood to adult services?

Yes No Unknown

84. Has the young person received social care at any point during the move from childhood to adult services?

Yes No Unknown

85. On a scale of 1 to 5, how well do you feel you have been supported by social care during this period?

Not
supported at
all

2

3

4

Fully
supported

Unknown

96. On a scale of 1 to 5, how well do you feel the young person has been supported by social care during this period?

Not
supported at
all

2 3

4

Fully
supported

Unknown

86. Would you liked to have had a social worker?

Yes No Unknown

89. Please give any further details:

87. Do you feel the young person could have benefited from having a social worker?

Yes No Unknown

88. Please give any further details:

G. Overall

90. What one thing do you think could change to make the move from childhood to adult health services easier for other young people and their parent carers?

H. Future involvement in the study

We may be running focus group meetings to collect further more detailed information. Would you like to be contacted about being involved in this meeting?

- Yes - I am interested
- No - I am not interested

Please enter your email address here:

If you are happy to be contacted, your email address will be held securely until the end of the study and then deleted. You can change your mind at any point and have the right to-opt out of us holding you email address. If you decide that you would prefer that your information is not used in this way please let us know by contacting us in writing at the postal address or email address below, or by telephoning:

Email - transition@ncepod.org.uk

Number - 0207 251 9060

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