



## 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.*



















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

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

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

Poorly

2 3

4

Extremely  
well

Unknown

N/A

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

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

Poorly

2      3

4

Extremely  
well

Unknown

N/A

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

Yes   No   Unknown  
     

Please give further details:

## E. Funding

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

Yes   No  
  

Unknown

N/A - funding not  
applied for

Please expand on this:

Please expand on what has worked well:

## F. Social care

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

Yes   No   Unknown  
     

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

Yes   No   Unknown  
     

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

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

Would you liked to have had a social worker?

Yes    No    Unknown  
     

Please give any further details:

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

Yes    No    Unknown  
     

Please give any further details:

**G. Overall**

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](mailto:transition@ncepod.org.uk)

Number - 0207 251 9060

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