

### **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.

#### **Qualtrics Survey Software**

**'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:
  - O young person
  - O parent carer
- 3. How old are you?

0 Years old

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

0 Years old

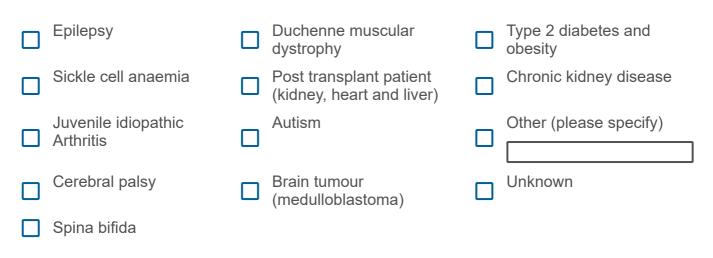
5. Are you:

Male	Female	
0	0	
Oth	er (Optional: spec below)	if
	0	

8. Is the young person you care for:

	0	
Oth	er (please describe)	
0	0	
Male	Female	

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



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	<ul> <li>Post transplant patient (kidney, heart and liver)</li> </ul>	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?

0	Yes - mild	0	No
0	Yes - moderate	0	Unknown
Ο	Yes - profound		

- 12. Does the young person have a learning disability?
  - Yes mild
    Yes moderate
    Unknown
  - O Yes profound

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

0	1	0	5
0	2	0	More than 5
0	3	0	Unknown
0	4		

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

0 1	<b>O</b> 5
O 2	O More than 5
O 3	O Unknown
<b>O</b> 4	

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

0	Planning for transition		Previously transitioned more than 2 years ago
Ο	Currently transitioning	0	Unknown

O Recently transitioned in the last 2 years

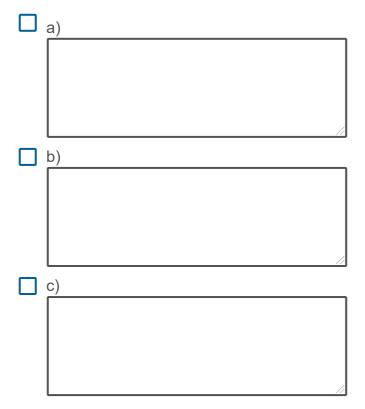
16. What stage of transition to adult services is the young person currently in\*?

0	Planning for transition	0	Previously transitioned more than 2 years ago
0	Currently transitioning	0	Unknown
0	Recently transitioned in the last 2 years		

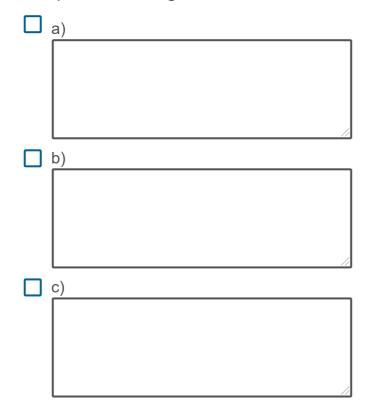
#### B. What went well/not so well

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?

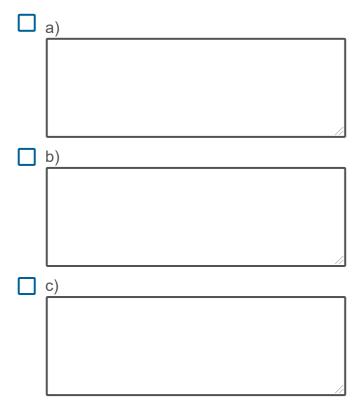


83. Up to three things that have not worked well during this period?

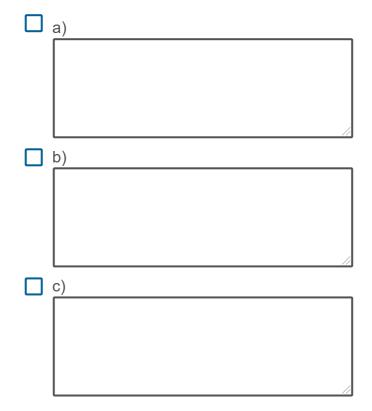


Please think about healthcare services the young person is receiving or has received in relation to moving from childhood to adult services, and tell us:

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



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



# 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

0 0 0

23. How were you made aware of this?

Conversation

Leaflet

Ο

Digital source (i.e. website)

Ο

Other (please describe)

O

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?

O 13 years old	20 years old
O 14 years old	O 21 years old
O 15 years old	O 22 years old
O 16 years old	O 23 years old
O 17 years old	O 24 years old
O 18 years old	O No discussion took place
O 19 years old	O Unknown

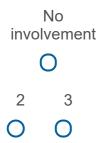
25. What age was the young person when the clinical team(s) first started to talk about the move from childhood to adult services? (if the age discussions started varied across clinical teams, please give the youngest age bracket)

13-15 years old	O 22-25 years old
O 16-18 years old	O No discussion took place
O 19-21 years old	O Unknown
26 Do you think:	
26. Do you think:	
O This was the right age to start planning	O It was too late to start planning
It was too early to start planning	O Unknown

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



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



Ο

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?



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

Yes	No	Unknown
0	0	0

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

Yes No Unknown
O O O

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

Yes No Unknown O O O

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?

es	No	Unknown				
)	0	0				
	Ŭ	•				
How	/ is/wa	s this plan	shared with you?			
Me	entione	d in letters		0	It's not shared with me	
Giv	ven a p	aper copy		0	Unknown	
			ource (i.e. website)	Ŭ		
T\C	lencu	to a digital s				
	tid vo	, fool roady	, to move from chil	dha	ad to adult convisoe?	
J0/0	lia you	lieerreauy		uno	ou to adult services?	
Ye	s - for a	all teams		0	Unknown	
Ye	s - for s	some teams		$\bigcirc$	NA - too early in the process	
				Ŭ	5	
UNI	,					
	How Me Giv Re Do/c Ye Ye	Do/did you Yes - for a	OOO How is/was this plan Mentioned in letters Given a paper copy Referred to a digital s Do/did you feel ready Yes - for all teams Yes - for some teams	<ul> <li>O O</li> <li>How is/was this plan shared with you?</li> <li>Mentioned in letters</li> <li>Given a paper copy</li> <li>Referred to a digital source (i.e. website)</li> <li>Do/did you feel ready to move from chil</li> <li>Yes - for all teams</li> <li>Yes - for some teams</li> </ul>	<ul> <li>O O</li> <li>How is/was this plan shared with you?</li> <li>Mentioned in letters</li> <li>Given a paper copy</li> <li>Referred to a digital source (i.e. website)</li> <li>Do/did you feel ready to move from childhood</li> <li>Yes - for all teams</li> <li>Yes - for some teams</li> </ul>	<ul> <li>O</li> <li>O</li> <li>How is/was this plan shared with you?</li> <li>Mentioned in letters</li> <li>Given a paper copy</li> <li>It's not shared with me</li> <li>Unknown</li> <li>C</li> <li>Co/did you feel ready to move from childhood to adult services?</li> <li>Yes - for all teams</li> <li>Yes - for some teams</li> <li>C</li> <li>Unknown</li> <li>NA - too early in the process</li> </ul>

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

- Yes for all teams
  - Yes for some teams
- ) No

- ) Unknown
- O NA too early in the process
- 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
0	0	0

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

0	13 years old	0	20 years old
0	14 years old	0	21 years old
0	15 years old	0	22 years old
0	16 years old	0	23 years old
0	17 years old	0	24 years old
0	18 years old	0	No one has taken responsibility for my care
0	19 years old	0	Unknown

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

0	13 years old	0	20 years old
0	14 years old	0	21 years old
0	15 years old	0	22 years old
0	16 years old	0	23 years old
0	17 years old	0	24 years old
0	18 years old	0	No one has taken responsibility for the young person's care
0	19 years old	0	Unknown

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

0	13 years old	0	20 years old
0	14 years old	0	21 years old
0	15 years old	0	22 years old
ttps://ncer	ood.gualtrics.com/Q/EditSection/Blocks/Aiax/GetSurvevPrintPrev	view?C	ontextSurvevID=SV

13/12/2021, 12:45

- 16 years old
- O 17 years old
- O 18 years old
- O 19 years old

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- 23 years old
- O 24 years old
- I haven't met the adult team
- O Unknown

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

0	13 years old	0	20 years old
0	14 years old	0	21 years old
0	15 years old	0	22 years old
0	16 years old	0	23 years old
0	17 years old	0	24 years old
0	18 years old	0	I haven't met the adult team
0	19 years old	0	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?



Unknown

0

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



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

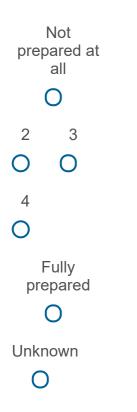
Yes	No	Unknown
0	0	0

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

Yes No Unknown O O O 67. How prepared did you feel to manage your medication prescription?



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



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* 

Before transition	No key worker involvement
During transition	Unknown
After transition	

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

Before transition	No key worker involvement
During transition	Unknown
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):

Education	Relationships
Employment	Mental health
Drugs and alcohol	None
Sexual health	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):

Education	Relationships
Employment	Mental health
Drugs and alcohol	None None
Sexual health	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?



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



Unknown

Ο

N/A - not transferred

Ο

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

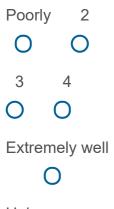


72. How well do you feel you have been/were communicated with by healthcare professionals in adult services?



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

13/12/2021, 12:45



Unknown

0

The difference has not been communicated

Ο

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

Poorly



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

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Poor O	y	
2 O	3 O	
4 O		
	emely ell	
Unkn	iown	
N/A O		

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



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?



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
O O O

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

Yes No Unknown O O O

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



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	
0	0	
4		
0		
	Fully oported	
	0	
Unk	nown	
C	)	

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

Yes	No	Unknown
0	0	0

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?

- O Yes I am interested
- O 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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