A. A. Study inclusion and reviewer details

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 complex 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 complex condition, transitioning from child to adult health services.

The twelve conditions for inclusion are:
Epilepsy
Sickle cell anaemia
Juvenile idiopathic arthritis
Cerebral palsy
Spina bifida
Duchenne muscular dystrophy
Post-transplant patients - kidney, heart and liver
Autism spectrum disorder
Rett Syndrome
Brain tumours (medulloblastoma)
Type 2 diabetes and obesity
Chronic kidney disease

2. Name of reviewer

Date of the meeting	
Site ID 6 digit number beginning with 3	
	🔲 Unknown
Value should be between 300,000 and 399,999	
. Trust ID 6 digit number beginning with 2	
	🔲 Unknown
<i>Value should be between 200,000 and 299,999</i>	

If multiple matching files, please separate the NCEPOD numbers with a comma

	B. B. The	young person's details	
What was the ag	e of the young person		
		Unkr	iown
Value should be betwee	en 13 and 25		
Sex			
O Male	O Female	O Other	O Unable to answer
Ethnicity			
O White British/V	Vhite - other		
O Black/ African/	Caribbean/ Black British		
O Asian/ Asian B	ritish (Indian, Pakistani, B	angladeshi, Chinese, oth	ner Asian)
O Mixed/ Multiple	e ethnic groups		
O Unable to answ	ver		
If not listed above,	please specify here		
What underlying	condition(s) does the	young person have?	(Please tick all that apply)
Epilepsy	-	☐ Sickle cell an	
Juvenile idiopa	thic arthritis	Cerebral pals	
Spina bifida		-	uscular dystrophy
—	t patient (kidney, heart a		
Autism		Rett syndrom	ne
Brain tumour (medulloblastoma)	_	tes and obesity
Chronic kidney	v disease	Unable to an	swer
Please specify any	additional options here		
apply) Transition not Preparing for a Peri-transfer fr Fully transferre No evidence o	started idulthood om child to adult health s ed from child to adult hea f transition in the case no - diagnosed when alread	services Ith services tes but the young perso	/03/2021? (Please tick all that n has transferred to adult services vices
	t started or the young ase let a member of tl		d when already under adult v
If preparing for a	paring for adulthood" adulthood, what specia age of transition?		h the care of the young
If answered "Pei If peri-transfer,	ri-transfer from child to	o adult health service	

5d. If answered "Fully transferred from child to adult health services" to [15a] then: If fully transferred, what specialties are involved with the care of the young person at this stage of transition?

5e. Please give any further details regarding the stage(s) of transition (e.g. further details where the stage of transition varies across specialties)

	C. C. The transition service*			
a. Is there evidence in the case notes of any barriers to accessing the transition service for this young person?				
 Yes Unable to answer 	igodoldoldoldoldoldoldoldoldoldoldoldoldol			
1b. Please give further details:				
2a. Would you consider this case to transition service?	o demonstrate good practice in terms of accessing the			
O Yes	O No			
O Unable to answer	igodown No mention of transition in the case notes			
2b. Please give further details:				

Please save the questionnaire as you work through this section

1a. Is transition from child to adult health services explicitly mentioned in these case notes?

O Yes O No

If transition has not been explicitly mentioned, we are aware that parts of the transition pathway could still been delivered, and we would like to capture this where possible.

1b. In your opinion, did	the transition process	s start at a developi	nentally appropriate ag	je for
this young person?				

O Yes - for all services

Г

O Yes - for some services

O No

- O Unable to answer
- **1c. Please give further information**

2a	. Is there evidence i place?	in the case notes	that the young person has/had a transition plan in
	\bigcirc Yes - for all service \bigcirc Unable to answe	-	es - for some services O No
2b	If YES, is there evi		or "Yes - for some services" to [2a] then: ransition plan was 'individualised' to the needs of the
	young person?		•
	young person?	O No	O Unable to answer
3a	O Yes	O No	
3a	O Yes	O No	O Unable to answer
	 Yes Is there evidence i Yes If answered "Yes" 	○ No in the case notes ○ No to [3a] then:	O Unable to answer that the young person has a learning disability?
	 Yes Is there evidence i Yes If answered "Yes" If YES, is there evidence is the interval of the interval of	○ No in the case notes ○ No to [3a] then:	 Unable to answer that the young person has a learning disability? Unable to answer
3b	 Yes Is there evidence i Yes If answered "Yes" If YES, is there evi parent carers? Yes 	No in the case notes No to [3a] then: dence in the case No	 Unable to answer that the young person has a learning disability? Unable to answer unable to answer e notes that mental capacity has been discussed with

Γ

Good Unable to answer	O Adequate	ansition planning for this	s young person: O Unacceptable
GoodUnable to answer	O Adequate	_	
GoodUnable to answer	O Adequate	_	
Please grade the ov Good Unable to answer Please give further	O Adequate	_	
O Good O Unable to answer	O Adequate	_	
O Unable to answer	•	O Poor	O Unacceptable
•	information		
Prior to transfer to been/were annual (ere evidence in the case	e notes that there have
\bigcirc Yes - for all service	-		
O Yes - for some ser			
🔘 No			
O Unable to answer			
O Not Applicable - to	o early in the transiti	on process	
	d/did attend a joint	ere evidence in the case t transition clinic with th	
Yes - for all service	es		
Yes - for some ser			
O No			
O Unable to answer			
O Not applicable - to	o early in the transition	on process	
		ere evidence in the case part of the planning for	e notes of any liaison with transition process?
O Yes	O No	O Unable to answe	er O Not applicable
la thora ovidance in	the exercise that	the young percenter the	
is there evidence in	the casenote that	Unable to answe	ad social care involvement?

) Yes	O No	igcolumbda Unable to answer
🔵 NA - no tra	nsition plan	
	'Yes" to [9a] then: urther details	
		ere evidence in the case notes of any liaison with
	s part of the transition pro	
O Yes - assoc	tiated with transition	\bigcirc Yes - not associated with transition \bigcirc Unable to answer
O Not applica	able	
	sfer to adult services is the addition and Healthead	ere evidence in the case notes that the young th Care Plan?
O Yes	() No	O Unable to answer O Not applicable
		It the young person was given the opportunity or le self-management of their health needs?
O Yes	O No	O Unable to answer
.Please give f	urther information:	
.Is there evid	ence in the case notes of a	a plan for when the young person will be/was
O Yes - for al	o adult services?	
O Yes - for so		
~		
O Yes - for pr		
O No		
O No O Unable to a	answer able - too early in the transitio	

O Yes	O No	O Unable to answer
. Please give an	y further information	
	nce in the case notes not going well?	that the young person knew who to contact if
		O Unable to answer
O Yes	O No	
ollowing transfe	r to adult services	
his question is n	we negulated following	
	pre-bobulated lollowir	ng completion in an earlier section, and is here in orde
		ng completion in an earlier section, and is here in orde young people post transfer to adult services. If you
bring up the re	elevant questions for	
b bring up the re nange the answe	elevant questions for er to this question he	young people post transfer to adult services. If you re, it will also change it earlier in the questionnaire.
b bring up the re nange the answe	elevant questions for er to this question he	young people post transfer to adult services. If you
b bring up the re hange the answe a.What stage of	elevant questions for er to this question he transition was the yo	young people post transfer to adult services. If you re, it will also change it earlier in the questionnaire.
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 bring up the repained of the answere the answere the answere of apply) Transition no Preparing fo Preparing fo Peri-transfer Fully transfe No evidence Not applicab Unable to an b. If answered "F Is there evider transferring fr Yes Unable to an Not applicab 	elevant questions for er to this question her transition was the yo of started r adulthood from child to adult heal rred from child to adult heal of transition in the case ole - diagnosed when alread swer fully transferred from the young person transferred from nation paediatric to adult hiswer ole - not transferred from for paediatric to adult aswer	young people post transfer to adult services. If you re, it will also change it earlier in the questionnaire. oung person in on the 31/03/2021? (Please tick all that the services health services e notes but the young person has transferred to adult services e notes but the young person has transferred to adult services eady under adult health services child to adult health services to [15a] then: msferred to adult services? years Not Applicable Unknown child to adult health services to [15a] then: that medications were managed appropriately when it services? Not applicable - no medications child to adult health services to [15a] then: that the young person was offered an appointment to

18. If answered "Fully transferred from child to adult health services" to [15a] then: Is there evidence in the case notes that the young person has remained engaged with their healthcare?

- O Yes
- O No
- O Unable to answer
- O NA Young person wasn't engaged prior to transfer
- O NA young person has not transferred to adult services yet

All patients

19a.If there is no evidence of transition in the case notes, in your opinion were there any missed opportunities for engagement in transition?

- O Yes
- O No

O Not applicable - evidence of transition in the case notes

19b.If answered "Yes" to [19a] then:

If YES, please give further information regarding these missed opportunities

20a.Is there evidence in the case notes of any barriers in the transition pathway for t	his
young person?	

- O Yes
- O Unable to answer

O No

O No mention of transition in the case notes

20b.Please give further details:

Please grade the o	overall transition path	way for this young p	Derson:

	E. E. MDT working & t	the coordination of care			
Ple	ease save the questionnaire as you work thro	ough this section			
1a.	a. Is/Was the young person under the care of multiple specialties? (e.g. haematology and rheumatology)				
	 Yes - all within the same Trust Yes - all across different Trusts Unable to answer 	 Yes - within and across Trusts No 			
lf	YES				
1b.	If answered "Yes - all within the same Trust" across different Trusts" to [1a] then: If YES, is there evidence in the case notes th coordinated across the different teams?	', "Yes - within and across Trusts" or "Yes - all nat the transition process has been/was			
	O Yes O Unable to answer	$igodoldsymbol{O}$ No $igodoldsymbol{O}$ NA - too early in the transition process			
1c.	Lc. If answered "Yes - all within the same Trust", "Yes - within and across Trusts" or "Yes - al across different Trusts" to [1a] then: If YES, is there evidence in the case notes that there is/was one person or team identified as point of contact for any queries regarding transition?				
	YesUnable to answer	\bigcirc No \bigcirc NA - too soon in the transition process			
1d.	across different Trusts" to [1a] then:	', "Yes - within and across Trusts" or "Yes - all nat there have been/were any issues with the ne process of transition?			
	O Yes O No	O Unable to answer			
1e.	If answered "Yes - all within the same Trust" across different Trusts" to [1a] then: If YES, is there evidence in the case notes th transition between these teams during the p				
	O Yes - between all teams O Yes - between O Unable to answer	en some teams O No			
1f.	If answered "Yes - all within the same Trust" across different Trusts" to [1a] and "Yes - be teams" to [1e] then: If YES, how would you grade the quality of t				
	O Good	O Adequate			
	O Poor	O Unacceptable			
	O Unable to answer	igodown NA - too early in the transition process			
1g.	If answered "Yes - all within the same Trust" across different Trusts" to [1a] then: Please give any further details:	', "Yes - within and across Trusts" or "Yes - all			

If NO

1h.	. If answered "No" to [1a] then:	
	If NO to 1a (under the care of a single speci transition been well managed within this te	
	() Yes	∩ No
	O Unable to answer	\bigcirc NA - too early in the transition process
11.	. If answered "No" to [1a] then: If NO, is there evidence in the case notes th coordinated within the team?	
	O Yes	O No
	O Unable to answer	${igodot}$ NA - too early in the transition process
1j.	. If answered "No" to [1a] then: If NO, is there evidence in the case notes th as point of contact for any queries regardin	at there is/was one person or team identified g transition?
	O Yes	O No
	O Unable to answer	${igodot}$ NA - too soon in the transition process
1k.	. If answered "No" to [1a] then: If NO, is there evidence in the case notes th engagement within this team during the pro	
	O Yes	O No
	O Unable to answer	igodown NA - too soon in the transition process
11.	. If answered "No" to [1a] then: If NO, is there evidence in the case notes th transition within this team during the proce	
	O Yes - between all teams O Yes - between O Unable to answer	en some teams O No
1m	. If answered "No" to [1a] and "Yes - between [1l] then: If YES, how would you grade the quality of t	all teams" or "Yes - between some teams" to his communication?
	() Good	O Adequate
	O Poor	O Unacceptable
	O Unable to answer	\bigcirc NA - too early in the transition process
-	•	
1n.	. If answered "No" to [1a] then: Please give any further details:	
2a.	 Is there evidence in the case notes of comm healthcare setting and the GP about transit Yes - for all services Yes - for some services Yes - for some services No Unable to answer NA - no specialty team involvement in the physical healthcare notes not available 	

2b.	Is there evidence in community healthca		ommunication between the team(s) in GP about transition?	n the
	 Yes - for all services Yes - for some services No Unable to answer NA - no specialty tes Community healthout 	ices eam involvement in th	e community healthcare setting le	
2c.	Is there evidence in healthcare setting a		ommunication between the team(s) in ansition?	n the mental
	 Yes - for all services Yes - for some services No Unable to answer NA - no specialty te Mental healthcare restricts 	ices eam involvement in th	e mental healthcare setting	
3a.			t the young person is/was known to m AMHs, social care and education?	nultiple other
	O Yes	O No	igcolumbda Unable to answer	
3b.	If answered "Yes" to If YES, is there evide which involves all pa O Yes O No O Unable to answer O Not applicable - too O No mention of trans	ence in the case not arties?	-	n planning
3c.	If answered "Yes" to If YES, please give fu	[3a] and "Yes" to [
3d.	If answered "Yes" to If NO, please give fu planning):		Bb] then: ding which parties were not involved	in transition

4a.	Is there evidence in the worker/named worker		he young person has/h hthcare setting?	ad access to a key
	 Yes No Unable to answer NA - care not provide Physical healthcare 		thcare setting	
4b.	Is there evidence in the worker/named worker		he young person has/h healthcare setting?	ad access to a key
	 Yes No Unable to answer NA - care not provide Community healthcare 			
4c.	Is there evidence in t worker/named worker		he young person has/h thcare setting?	ad access to a key
	 Yes No Unable to answer Mental healthcare no NA - care not provide 		hcare setting	
5a.	Is there evidence in the care for this young pe		y barriers in the coordi	nation of MDT transition
5a.	care for this young pe O Yes		O No	
	care for this young pe	erson?	O No	nation of MDT transition
	care for this young per O Yes O Unable to answer	erson?	O No	
5b.	care for this young per Yes Unable to answer Please give further de	erson? etails: e in the case notes,	O No O No mention of tra	

6b. If answered "Good", "Adequate", "Poor" or "Unacceptable" to [6a] then: Please give further details:

Please save the questionnaire as you work through this section

Communication

1a.	a. Is there evidence in the case notes that (in gene	eral) the young person was copied ir	to
	correspondence sent regarding their care?		

	O Yes - for all services			
	O Yes - for some servi	ices		
	NoUnable to answer			
	O Not applicable - too	early in the trans	ition process	
1b.			hat (in general) the young person's parent carers nt regarding their care (whilst under paediatric	
	O Yes - for all services	5		
	O Yes - for some servi	ices		
	NoUnable to answer			
	O Not applicable - too	early in the trans	ition process	
2.		oung person to	rices, is there evidence in the case notes of a check that they understand their condition (e.g.	
2.	discussion with the y	oung person to		
	discussion with the y completion of Ready O Yes	voung person to Steady Go)? O No the case notes o	check that they understand their condition (e.g. Unable to answer of any barriers in communication with the young	
	discussion with the y completion of Ready O Yes Is there evidence in the person during the pr O Yes	voung person to Steady Go)? O No the case notes o	check that they understand their condition (e.g. Unable to answer of any barriers in communication with the young	
	discussion with the y completion of Ready O Yes Is there evidence in the person during the pr O Yes O No	voung person to Steady Go)? O No the case notes o	check that they understand their condition (e.g. Unable to answer of any barriers in communication with the young	
	discussion with the y completion of Ready () Yes Is there evidence in the person during the pr () Yes () No () Unable to answer	voung person to Steady Go)? No the case notes of ocess of transiti	check that they understand their condition (e.g. Unable to answer of any barriers in communication with the young ion?	
За.	discussion with the y completion of Ready O Yes Is there evidence in the person during the pr O Yes O No O Unable to answer O Not applicable - too	voung person to Steady Go)? No the case notes of ocess of transition early in the trans	check that they understand their condition (e.g. Unable to answer of any barriers in communication with the young ion?	
За.	discussion with the y completion of Ready () Yes Is there evidence in the person during the pr () Yes () No () Unable to answer	voung person to Steady Go)? No the case notes of ocess of transition early in the trans	check that they understand their condition (e.g. Unable to answer of any barriers in communication with the young ion?	
За.	discussion with the y completion of Ready O Yes Is there evidence in the person during the pr O Yes O No O Unable to answer O Not applicable - too	voung person to Steady Go)? No the case notes of ocess of transition early in the trans	check that they understand their condition (e.g. Unable to answer of any barriers in communication with the young ion?	

4a. Is there evidence in the case notes of any barriers in communication with the parent carer during the process of transition?

- O Yes
- O No
- O Unable to answer
- O Not applicable too early in the transition process

Based on the eviden young person during	ce in the case note y the transition prod	s, how would you gra cess?	ade communication with the
O Good O Unable to answer	O Adequate	O Poor	O Uncceptable
. Please give further o	details:		
parent carers during	the transition pro	cess?	ade communication with
			ade communication with
parent carers during O Good O Unable to answer	the transition proc O Adequate	cess?	
parent carers during O Good	the transition proc O Adequate	cess?	
parent carers during O Good O Unable to answer	the transition proc O Adequate	cess?	
parent carers during O Good O Unable to answer	the transition proc O Adequate	cess?	
parent carers during O Good O Unable to answer	the transition proc O Adequate	cess?	

Involvement

7a. Is there evidence in the case	notes that (in general)) the young person b	as been involved
in the transition process?			

- O Yes for all services
- O Yes for some services
- Õ No
- O Unable to answer
- O Not applicable too early in the transition process

7b. Is there evidence in the case notes that (in general) the the young person's parent carers were involved in the transition process?

- O Yes for all services
- O Yes for some services
- O No
- O Unable to answer
- O Not applicable too early in the transition process

8a. Is there evidence in the case notes of any barriers in the involvement of the young person in the process of transition?

- O Yes
- O No
- O Unable to answer
- O Not applicable too early in the transition process

8b. Please give further details:

9a. Is there evidence in the case notes of any barriers in the involvement of the parent carer in the process of transition?

- O Yes
- O No
- O Unable to answer
- O Not applicable too early in the transition process

9b. Please give further details:

10a.Based on the case notes, how would you grade the involvement of the young person in the transition process?

- O Good
- O Adequate
- Õ Poor
- O Unacceptable
- O Unable to answer
- ${igcolumna O}$ Not applicable too early in the transition process

10b.Please give further details:

11a.Based on the case notes, how would you grade the involvement of the young person's parent carers in the transition process?

- O Good
- O Adequate
- O Poor
- O Unacceptable
- O Unable to answer
- O Not applicable too early in the transition process

11b.Please give further details:

		of the transition proce	
Plazco grado tk	he overall process of trai	sition from child to	adult health services for th
young person.	ne overall process of trai		adult health services for th
O Good O Unable to ans	O Adequate swer	O Poor	O Unacceptable
	ood", "Adequate", "Poor reasons for this grade	' or "Unacceptable"	to [1a] then:
. Is there an exa	mple of good transition	practice demonstrat	ed in this case?
O Yes	O No		
. If answered "Ye	es" to [2a] then:		
If YES, please g			
If YES, please g			
. If answered "Ye		lighted in the report	
. If answered "Ye	give details es" to [2a] then:	lighted in the report	:?
. If answered "Ye If YES, do you t O Yes	give details es" to [2a] then: think this should be high		
. If answered "Ye If YES, do you t O Yes	es" to [2a] then: think this should be high		
. If answered "Ye If YES, do you t O Yes	es" to [2a] then: think this should be high		
. If answered "Ye If YES, do you t O Yes	es" to [2a] then: think this should be high		
. If answered "Ye If YES, do you t O Yes	es" to [2a] then: think this should be high		
. If answered "Ye If YES, do you t O Yes	es" to [2a] then: think this should be high		
. If answered "Ye If YES, do you t O Yes	es" to [2a] then: think this should be high		
. If answered "Ye If YES, do you t O Yes . What is the big	give details es" to [2a] then: think this should be high O No gest barrier to transition	n demonstrated in th	
. If answered "Ye If YES, do you t O Yes . What is the big	es" to [2a] then: think this should be high	n demonstrated in th	

4. Do you think we should consider this case as a vignette/case study in the report?

O Yes O No

5. Please provide details of what was missing from these case notes (if anything):

6a. Please share any further details about this case not already documented

Cause for concern

Occasionally NCEPOD will refer cases that have been identified as 'UNACCEPTABLE' when it is felt that further feedback to the Trust/ Health Board is warranted. This is usually due to an area of concern to the hospital or clinician involved, and not for issues highlighted across the body of case notes. This process has been agreed by the NCEPOD Steering Group and the GMC. The medical director of the Trust/ Health Board is written to by the Chief Executive of NCEPOD explaining our concerns. This process had been in operation for 10 years and the responses received have always been positive in that they feel we are dealing with the concerns in the most appropriate manner.

6b. If answered "Unacceptable" to [1a] then: Do you feel that this case should be considered for such action?

O Yes O No