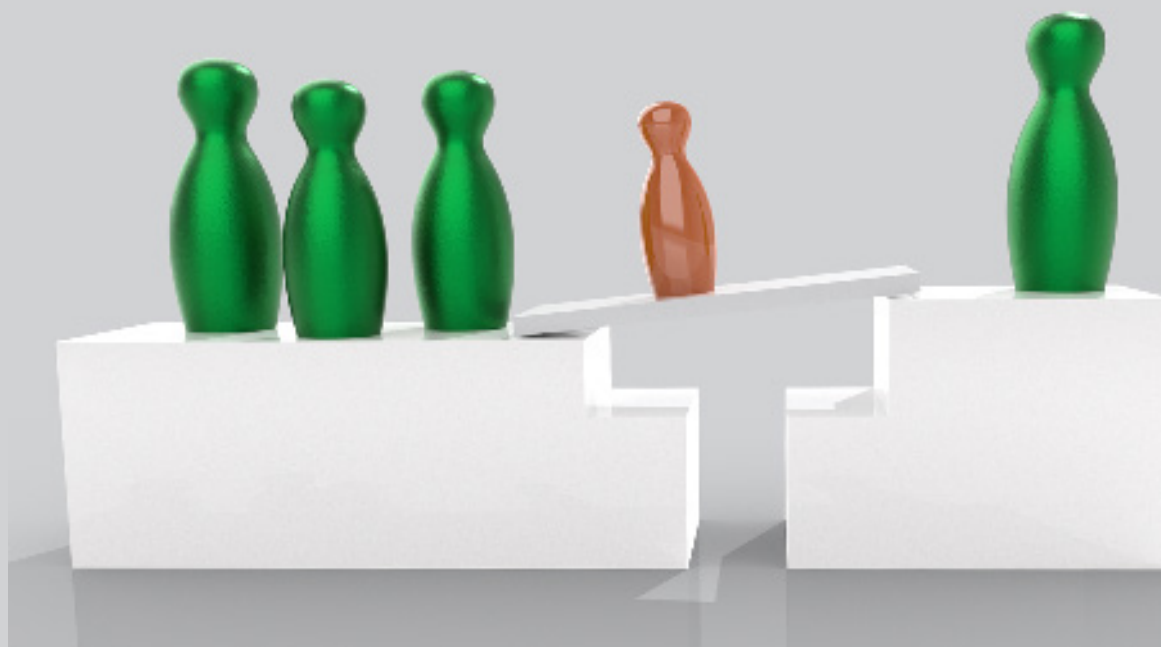


# The Inbetweeners

A review of the barriers and facilitators in the process of the transition of children and young people with complex chronic health conditions moving into adult health services

## SUMMARY



# THE INBETWEENERS

*A review of the barriers and facilitators in the process of the transition of children and young people with complex chronic health conditions into adult health services*

A report published by the National Confidential Enquiry into Patient Outcome and Death (2023)

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*Cohort: 1st October 2019 and 31st March 2021*

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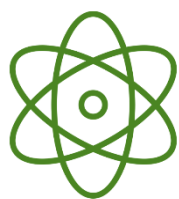
# EXECUTIVE SUMMARY

To assess the barriers and facilitators for young people receiving a good transition to adult healthcare services, data were collected on children and young people with one of 12 complex conditions identified from a sample period between 1st October 2019 and 31st March 2021. Analysis was undertaken on questionnaires from 829 community/secondary/tertiary care clinicians, 167 primary care clinicians, 483 sets of case notes, 192 secondary/tertiary organisational questionnaires and 152 primary care organisational questionnaires, supported by qualitative data from young people, parent/carers, and health and social care professionals.

## CONCLUSION

There is no clear pathway for the transition from healthcare services for children and young people to adult healthcare services. Moreover, the process of transition and the subsequent transfer is often fragmented, both within and across specialties. Often the adult services sit only with primary care. Developmentally appropriate healthcare needs to be everyone's responsibility and adequate resources need to be made available to allow this to happen.

### 1. MAKE DEVELOPMENTALLY APPROPRIATE HEALTHCARE CORE BUSINESS FOR ALL INVOLVED



**This would ensure that transition and transfer planning is embedded into everyday healthcare by all the teams involved.**

Only 16/167 (9.6%) organisations had transition included in the job descriptions of all healthcare staff involved in transition.

Mandatory training for staff in transition was found to be lacking, with only 37/169 (21.9%) organisations having such training in place.

### 2. INVOLVE YOUNG PEOPLE AND PARENT/CARERS IN TRANSITION PLANNING AND TRANSFER TO ADULT SERVICES

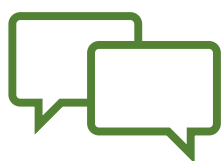


**This would put young people at the centre of their own care, and they could support improvements in the transition service.**

118/178 (66.3%) organisations had a policy stating that young people should be offered the opportunity to be involved in their own transition process.

20/136 (14.7%) organisations had a transition service that involved young people in the design of the service for all specialties.

### 3. IMPROVE COMMUNICATION AND CO-ORDINATION BETWEEN ALL SPECIALTIES



**Clear communication between all specialties across multiple teams will stop the young person falling into a gap between services.**

For 72/119 (60.5%) young people who were under the care of multiple teams the transition process was considered to be co-ordinated across the different teams.

Reviewers were unable to find evidence of co-ordination between teams in 165/242 (68.2%) cases reviewed.

### 4. ORGANISE HEALTHCARE SERVICES TO ENABLE YOUNG PEOPLE TO TRANSFER TO ADULT SERVICES EFFECTIVELY



**This would ensure there is a direction for every young person moving to adult services and ensure receiving services/GPs are prepared.**

Where the organisation had an overarching transition policy, that policy covered all young people with long-term conditions in just 76/98 organisations.

98/175 (56.0%) organisations had separate transition policies for different specialties.

### 5. PROVIDE STRONG LEADERSHIP AT BOARD AND SPECIALTY LEVEL AT ALL STAGES OF TRANSITION AND TRANSFER



**Strong leadership is needed to implement a transition service that ensures every young person receives the care they should expect.**

Only 74/157 (47.1%) organisations had a senior executive responsible for supporting the development and publication of transition strategies and policies.

Only 60/167 (35.9%) organisations had a member of the transition service supporting the executive board.

## RECOMMENDATIONS

These recommendations have been formed by a consensus exercise involving all those listed in the acknowledgements. The recommendations have been independently edited by medical editors experienced in developing recommendations for healthcare audiences to act on.

The recommendations highlight areas that are suitable for regular local clinical audit and quality improvement initiatives by those providing care to this group of patients. The results of such work should be presented at quality or governance meetings and action plans to improve care should be shared with executive boards.

Executive boards are ultimately responsible for supporting the implementation of these recommendations. Suggested target audiences to action recommendations are listed in italics under each recommendation. At a local level the recommendations are aimed at all members of the multidisciplinary team involved in the care of a young person who will move from healthcare services for children and young people into adult services including doctors, nurses, occupational therapists, physiotherapists and speech and language therapists.

The recommendations in this report heavily support those that have been made previously by other organisations, and for added value should be read alongside:

- [NICE: Transition from children's to adults' services for young people using health or social care services \(NG43\)](#)
- [NICE: Transition from children's to adults' services \(QS140\)](#)
- [CQC: From the pond into the sea](#)
- [RCPCH: Facing the Future: Standards for children with ongoing health needs](#)
- [DHSC: Quality criteria for young people friendly health services](#)
- [Together for Short Lives: Stepping Up. Transition to Adult Services Pathway](#)
- [Welsh Government: Transition and handover from children's to adult health services](#)
- [Intensive Care Society: Paediatric to adult critical care transition](#)
- [WellChild: 8 Principles for Transition](#)

LOCAL LEVEL	
1.	<p>Develop a personalised transition plan with each young person who will need to move from child into adult healthcare service. Give the young person and their parent/carer access to this plan.*</p> <p><i>*This should be developmentally appropriate and encourage independence in the transition process wherever possible. Language should be clear and understandable by all and accessible formats should be used.</i></p> <p><b>Target audience:</b> <i>All members of the multidisciplinary team caring for the young person in child health services and the adult health services that the young person will move to, supported by the trust/health board transition team</i></p>

2.	<p>Copy young people and, where appropriate, their parent/carer into all correspondence regarding ongoing healthcare needs. The correspondence should:</p> <ol style="list-style-type: none"> <li>Be developmentally appropriate, allowing for a learning disability, autism or both, and mental capacity (e.g. easy read);</li> <li>Respect the young person's preferences (they may not want to receive it);</li> <li>Comply with the young person's consent for their parent/carer to be copied in;</li> <li>Be in a spoken language understood by those receiving it (e.g. in different languages);</li> <li>Be in an accessible format for those receiving it (e.g. Braille).</li> </ol> <p><b>Target audience:</b> All members of the multidisciplinary team caring for the young person in child health services and the adult health services that the young person will move to, supported by the trust/health board transition team</p>
3.	<p>Hold joint transition clinics for young people moving from child into adult healthcare services, involving healthcare staff from the young person's paediatric team and the adult service(s) they will move to.</p> <p><b>Target audience:</b> All members of the multidisciplinary team caring for the young person in child health services and the adult health services that the young person will move to, supported by the trust/health board transition team and primary care</p>
4.	<p>Request input into the multidisciplinary team (MDT) for young people with ongoing healthcare needs as needed from:</p> <ol style="list-style-type: none"> <li>Relevant healthcare professionals from physical, community and mental healthcare services, in the same or other locations</li> <li>Educational services, e.g. to share education and healthcare plans (EHCPs), subject to the young person's consent</li> <li>A representative of the social care team should always be included for looked after, or accommodated children or young people, and for care leavers. This is particularly important if the child and/or family are known to social care, have unmet social care needs and/or there are safeguarding or child protection concerns.</li> </ol> <p><b>Target audience:</b> All members of the multidisciplinary team caring for the young person in child health services and the adult health services that the young person will move to, supported by the trust/health board transition team</p>
5.	<p>Involve primary care throughout the transition process from child into adult healthcare services to:</p> <ol style="list-style-type: none"> <li>Provide continuity of care for young people who are discharged to primary care if there is no equivalent healthcare professional in adult services</li> <li>Address any wider health concerns unrelated to the young person's long-term condition.</li> </ol> <p><b>Target audience:</b> Primary care and all members of the multidisciplinary team caring for the young person in child health services and the adult health services that the young person will move to, supported by the trust/health board transition team</p>
<b>TRUST/HEALTH BOARD LEVEL</b>	
6.	<p>Convene an overarching trust/health board transition team to provide a 'one stop shop' model of holistic care for young people moving from child into adult healthcare services. The team should:</p> <ol style="list-style-type: none"> <li>Include a senior executive responsible for developing a transition policy and strategies</li> <li>Include a senior manager responsible for the implementation of the transition policy and strategies (see recommendation 7)</li> <li>Engage with young people and their parents/carers to be involved in the design of services</li> <li>Co-ordinate the age when transition starts</li> </ol>

	<ul style="list-style-type: none"> <li>e. Co-ordinate the transition if multiple specialties are involved within and across different provider organisations (<i>see recommendations 3, 4 and 5</i>)</li> <li>f. Provide access to a key worker before, during and after transfer into adult services</li> <li>g. Ensure each young person is transferred into adult services during a time of relative stability and that their readiness for transfer is assessed holistically. The young person should be supported in a developmentally appropriate way by the teams providing healthcare in both children's and adult services</li> <li>h. Ensure adherence to best practice guidance.</li> </ul> <p><b>Target audience:</b> <i>Executive boards and clinical leads of all trusts/health boards</i></p>
7.	<p>Implement an overarching trust/health board transition policy for all young people with ongoing healthcare needs. This should ensure that:</p> <ul style="list-style-type: none"> <li>a. The young person is at the centre of their care and empowered to be involved in managing their own condition, including being copied into correspondence (<i>see recommendation 2</i>)</li> <li>b. Where possible, young people are seen during hours that are appropriate for them (e.g. after school)</li> <li>c. Where possible, young people are seen in an age-appropriate environment</li> <li>d. Appointments are of adequate duration to give sufficient time for detailed discussion, e.g. a double appointment</li> <li>e. Young people and their parents or carers have opportunities to be seen independently</li> <li>f. Wider conversations are undertaken with young people to address needs beyond their medical conditions.</li> </ul> <p><b>Target audience:</b> <i>Executive boards and clinical leads of all trusts/health boards, with support from the transition team</i></p>
8.	<p>Ensure transition from child into adult healthcare services is in the job plan for all members of the multidisciplinary team working in all child and adult specialties delivering clinical care to children and young people with ongoing healthcare needs.</p> <p><b>Target audience:</b> <i>Executive boards and clinical leads of all trusts/health boards, with support from the transition team</i></p>
9.	<p>Ensure staff in all organisations complete training in developmentally appropriate healthcare and the transition from child into adult healthcare services. The content should be tailored to the job role and the degree of involvement with children and young people.</p> <p><b>Target audience:</b> <i>Executive boards and clinical leads of all trusts/health boards, with support from the transition team</i></p>
<b>NATIONAL LEVEL</b>	
10.	<p>Ensure that all young people who may need to move from child into adult healthcare services can be identified as such on electronic patient systems, across all healthcare sectors*.</p> <p><i>*A standardised set of codes would support this.</i></p> <p><b>Target audience:</b> <i>NHS England, Digital Health and Care Wales and Northern Ireland Statistics and Research Agency with support from trust/health board executive committees and commissioners</i></p>
11.	<p>Ensure that transition from child into adult services is specified in the service outcome measures and that the financial support for this reflects the additional clinical and administrative time needed. Appropriate quality and outcome measures should be included in both child and adult service specifications.</p> <p><b>Target audience:</b> <i>Commissioners, Integrated Care Boards</i></p>

## INTRODUCTION

The transition of a young person into adult health and social care services is defined as *‘The purposeful, planned process of transferring a young person’s healthcare from a child-centred to an adult-orientated care setting that comprehensively addresses the medical, psychosocial, educational and vocational needs of that young person.’*<sup>[1]</sup> It is widely recognised that this process does not always work well, numerous documents support this and have recommended where improvements are needed, e.g. the Royal College of Nursing in 2013, the Care Quality Commission in 2014, NICE in 2016, and the Royal College of Paediatrics and Child Health in 2018.<sup>[2-7]</sup> In fact, NCEPOD has also published three reports looking at the care of young people within very different clinical settings (chronic neurodisability, mental health, and long-term ventilation),<sup>[8-10]</sup> all of which highlighted issues with the transition planning and transfer into adult healthcare.

The process of transition is complex as the needs of each young person are not identical.<sup>[11]</sup> It is more challenging when a young person has multiple complex conditions, in settings where there may not be an adult team to transfer to.<sup>[12]</sup> or where children and young people’s services end at age 16 and the adult service does not start until age 18.<sup>[3]</sup> In these cases the care often defaults to primary care. While all young people should be registered with a general practice (GP), there is evidence to suggest that young people with complex conditions often do not have an existing relationship with their GP.<sup>[13]</sup> This may result in them only seeking contact when in crisis,<sup>[14]</sup> or not at all. This could particularly impact on young people with a learning disability, autism or both, or poor mental health, who may find it more of a challenge to access primary care.

This NCEPOD report highlights a fundamental issue: transition from child into adult services is often perceived as the responsibility of the team the young person is leaving, instead of it being in the job plans of all healthcare professionals involved, including those in adult healthcare services. Good, developmentally appropriate care should not be an exception, it should be part of core business.

This report focuses on five main issues to highlight the barriers and facilitators to good developmentally appropriate healthcare:

1. *Developmentally appropriate healthcare*
2. *Involvement of children and young people and their parents/carers in their transition planning*
3. *Communication and co-ordination of care between all involved in the transfer into adult services*
4. *The organisation of transition services*
5. *Leadership*

As would be expected, the recommendations in this report support previous recommendations in this area, particularly the NICE guidelines which should be read in conjunction with this report.

This report highlights examples of good care as learning aids to support the existing initiatives, tools and guidelines, developed by local authorities, charities, trusts/health boards and individual clinicians to provide guidance on what service users should expect and how healthcare professionals can care for young people in a developmentally appropriate way.



## WHAT ONE THING WOULD HAVE IMPROVED YOUR TRANSITION EXPERIENCE?

Young people and parent carers were asked what one thing would have improved their experience of the transition process into adult health services. The responses fell into broad categories:

**THE AGE OF TRANSFER AND WHETHER IT IS DEVELOPMENTALLY APPROPRIATE**

**HAVING A TRANSPARENT TRANSITION**

**HAVING A KEY WORKER**

**BETTER COMMUNICATION**

**HAVING EQUIVALENT ADULT HEALTHCARE SERVICES**

**HELP AND SUPPORT FOR YOUNG PEOPLE**

**HELP AND SUPPORT FOR PARENT/CARERS**

*"A well thought out transition process which was person centred (not just age triggered at 16) with true involvement from young person and parent."*

*"Services working together instead of against each other, to work with and support the children and their families, not treating us like an inconvenience."*

*"My daughter had more than 30 specialist health professionals supporting her through childhood and very few of them knew who or how to transition us to the adult equivalent."*

*"A key worker to support the family through the process and to co-ordinate care, as no one took the lead and communication between teams was poor."*

*"Informed of what will happen by the healthcare provider and not having to do own research."*

*"Meeting new consultants beforehand and making sure all care in each speciality is carried on. We found some areas like respiratory just stopped."*

*"Adult care actually being provided."*

*"Parents being informed and advised what help there is out there for young adults 18+ and not for services to completely disappear with parents/carers not knowing where to turn for help."*

*"Make it more gradual, it's frustrating when I can't take telephone consultations because of school but I know my mum would be available to, this isn't an option anymore and it results in missed telephone consultations which slows down my healthcare."*

*"I was over 18 when I transitioned to adult services and the process was extremely quick. I was lost in communication between the two hospitals, so the adult services were unaware I was coming."*

More detail can be found in a summary of the focus groups [here](#).

## METHOD

### Study Advisory Group

A multidisciplinary group was convened to define the objectives of the study and advise on the key questions to ask. The Study Advisory Group (SAG) comprised healthcare professionals, lay and patient representatives, and commissioners with a specialist interest in transition. This group steered the study from design to completion.

### Focus groups and interviews

Young person and parent/carer focus groups and interviews were conducted to inform the direction of the study.

### Study aim

To explore the barriers and facilitators in the process of the transition of children and young people with chronic health conditions into adult health services.

### Objectives

The SAG identified organisational and clinical objectives that would address the primary aim of the study, including examples of good practice. These included:

#### Organisational review

- The use of policies and protocols for transition
- The organisation of, and access to, transition services where there is transfer to an equivalent service in the adult healthcare setting and where there is no equivalent adult specialty
- The commissioning and funding of transition services
- Communication both within and between organisations and healthcare professionals
- The delivery of staff training and education in adolescent and young adult health practice
- The use of benchmarks (including [You're Welcome](#) <sup>[15]</sup> standards)
- The role of executive and organisational leads (including members of the hospital board, transition co-ordinators, key workers, and youth workers)
- The use of formal networks of care both within and outside the organisation
- Multidisciplinary team (MDT) working including the use of virtual platforms for communication between MDT members and the young person/parent/carer
- The availability and use of peer support, mentoring or access to an integrated youth forum
- Access to support groups for parents/carers during the transition process
- The delivery of holistic developmentally appropriate care
- Quality improvement methodology and audit in transition

## **Clinical review**

- The transition process (including developmentally appropriate care and the age at which preparation started)
- The use of transition documentation for young people and parents/carers, e.g. [Ready Steady Go](#) <sup>[16]</sup>
- The presence and funding of named key workers responsible for transition and support, before during and after transfer into adult services
- The role of the young person and parents/carers in the process of transition (including assessment of mental capacity, decision making and whether the process of transition was person centred)
- The role of primary care in transition
- The delivery of developmentally appropriate holistic care
- The follow up process (including support offered) once transfer into adult services has occurred (including the involvement of primary care)
- Communication between clinical teams, and between teams and the young person/parents/carers (including the co-ordination of care)
- Young people and parents/carers' experiences of transition
- Clinicians' experiences of the process of transition

## **Study population and case ascertainment**

### **Inclusion criteria**

This enquiry is about transition from health services for children and young people into adult health services. It does not investigate any single medical condition. The SAG decided that cases for review would be drawn from several conditions in order to encompass a breadth of health issues experienced by young people. The criteria were to include the following: a complex medical condition, a disabling condition, a condition that necessitated the involvement of both medical and surgical specialties, a condition resulting in significant cognitive impairment, a condition arising in adolescence, and finally, a condition requiring significant technological support. The SAG used online voting software to select 12 medical conditions that would encompass these issues. Young people aged between 13 and 25 years with one or more of the following 12 conditions were identified for a sample period between 1st October 2019 and 31st March 2021:

- Epilepsy • sickle cell disease • juvenile idiopathic arthritis • cerebral palsy • spina bifida • muscular dystrophy • solid organ post-transplant (heart, liver, or kidney) • a brain tumour • autism • Rett syndrome • type 2 diabetes in young people with obesity • chronic kidney disease.

### **Hospital participation**

Data were included from providers of primary, community, physical and mental healthcare in England, Wales, and Northern Ireland.

### **Data collection - peer review**

#### **Identification of a sample population**

A pre-set spreadsheet was sent to providers of community and physical healthcare to identify all young people who met the study criteria during the defined period. From this initial cohort up to five young people were sampled per organisation for inclusion in the study.

### **Questionnaires**

#### **Organisational questionnaires**

Questionnaires were sent to all primary, community, physical and mental healthcare organisations, to collect data on the organisation of services, networks of care, MDT working, the commissioning of services, and the use of guidelines and protocols and training.

### ***Clinician questionnaires***

Questionnaires were sent to all teams identified as providing ongoing care to a young person included in the sample, across primary, community, physical and mental healthcare settings. Information was requested on the transition service, the transition pathway, communication with the young person and parents/carers, and MDT working and the co-ordination of care.

### **Case notes**

To allow for the assessment of the pre, peri and post transition period, both electronic and paper case notes were requested from the age of 13 years (or the point of diagnosis) to the young person's 25th birthday or to the 31st March 2021. If a young person was identified and tracked across a number of care settings, case notes were requested from all organisations. If a young person was seen in multiple clinics, or by multiple specialties within the same organisation, case notes were requested from all services. Notes requested included:

- Clinic letters
- Discharge summaries
- Transition documentation (including [\*Ready Steady Go\*](#) <sup>[16]</sup> and transition plans)
- All MDT notes
- Education, health, and care plans (EHCPs)
- Moving on passport/transition passport
- Care plans
- Treatment escalation plans
- Any relevant primary care records as determined by the GP.

### **Peer review of the case notes and questionnaire data**

A multidisciplinary group of case reviewers comprising transition co-ordinators, paediatricians, physicians and surgeons, nurses, general practitioners, physiotherapists, speech and language therapists, occupational therapists, and hospital-based youth workers working in primary, community, physical healthcare, and social care, were recruited to peer review the case notes and associated clinician questionnaires.

### **Data collection - young person and parent/carer surveys and focus groups**

An open-access anonymous online survey collected the views of young people and parents/carers on the process of transition. The data were not linked to any other aspect of clinical data collection. Smaller focus groups were undertaken to gather more in-depth information.

### **Data collection - health and social care professional survey**

An open-access anonymous online survey asked health and social care professionals for their views on the transition services available to them. The data were not linked to any other aspect of clinical data collection.

### **Information governance**

All data received and handled by NCEPOD complied with relevant national requirements, including the General Data Protection Regulation 2016 (Z5442652), Section 251 of the NHS Act 2006 (21/CAG/0085, App No 1019), and the Code of Practice on Confidential Information.

Each young person was given a unique NCEPOD number. All electronic questionnaires were submitted through a dedicated online application. Prior to any analysis taking place, the data were cleaned to ensure that there were no duplicate records and that erroneous data had not been entered. Any fields that contained data that could not be validated were removed.

## **Data analysis**

Following cleaning of the quantitative data, descriptive data summaries were produced.

Qualitative data collected from the case reviewers' opinions and free text answers in the clinician questionnaires were coded, where applicable, according to content to allow quantitative analysis.

As the methodology provides a snapshot of care over a set point in time, with data collected from several sources to build a picture, denominators will change depending on the data source, but each source is referenced throughout the document. This deep dive uses a qualitative method of peer review, and anonymised case studies, have been used throughout this report to illustrate themes. The sampling method of this enquiry, unlike an audit, means that data cannot be displayed at a hospital/trust/health board/regional level.

### **Data analysis rules**

- Small numbers have been suppressed if they risked identifying an individual
- Any percentage under 1% has been presented in the report as <1%
- Percentages were not calculated if the denominator was less than 100
- There is variation in the denominator for different data sources and for each individual question as it is based on the number of answers given.

The findings of the report were reviewed by the SAG, case reviewers and the NCEPOD Steering Group which included clinical co-ordinators, trustees, and lay representatives prior to publication.

## DATA RETURNED AND STUDY SAMPLE

### Data returns

#### Clinical data

In total 46,645 young people were identified as meeting the study inclusion criteria (Figure 2.1). Sampling was weighted to ensure that young people with a range of conditions were chosen, resulting in 1,076 young people being included in the initial sample.

Figure 2.1 summarises the data included. The clinician questionnaires were completed by a wide range of healthcare professionals, including doctors, nurses, occupational therapists, physiotherapists and speech and language therapists across all organisations identified as being involved in the ongoing care of the young person, including primary care, community care, physical and mental healthcare. The most common reason for cancelling a questionnaire was because no ongoing care could be identified by the team.

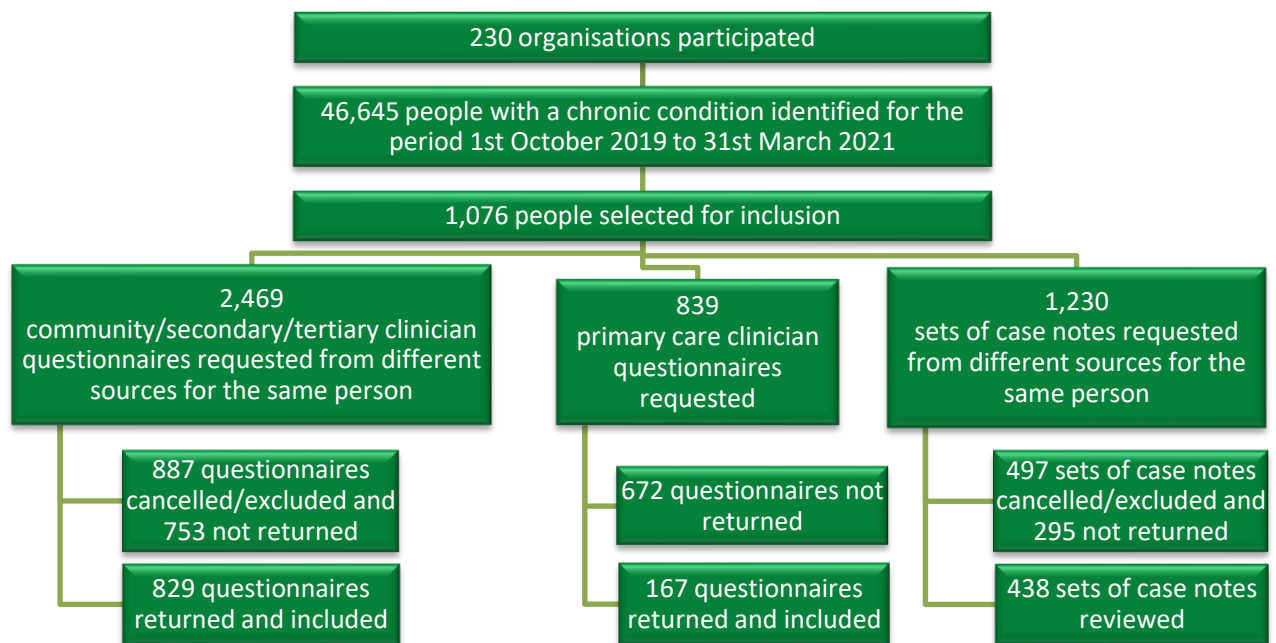


Figure 2.1 Clinical data returned

#### Organisational data

Organisational questionnaires were also received from 192/230 (83.5%) hospitals participating in the clinical data collection and a further 152 organisational questionnaires were received after contacting 6,786 primary care practices.

## Survey data and focus groups

The health and social care professional survey was completed by 454 respondents. The young person and parent/carer survey was completed by 50 young people and 79 parent/carers. Four small focus groups were undertaken with two groups of four parent/carers and two groups of three. In addition, three young people were interviewed, representing a mix of physical and mental health conditions, and stages of transition.

## Sample population

### Underlying conditions

Young people were randomly selected for inclusion in the study based on the presence of at least one of the 12 identified conditions (Table 2.1).

Table 2.1 Underlying health condition

	Number of young people	%
Epilepsy	300	27.9
Cerebral palsy	187	17.4
Autism spectrum disorder and Rett syndrome	178	16.5
Type 2 diabetes and obesity	89	8.3
Juvenile idiopathic arthritis	87	8.1
Post-transplant - kidney, heart, or liver	86	8.0
Chronic kidney disease	81	7.5
Sickle cell anaemia	80	7.4
Duchenne muscular dystrophy	75	7.0
Brain tumours (medulloblastoma)	63	5.9
Spina bifida	49	4.6
Rett syndrome	16	1.5

*Patient identification spreadsheet data; Answers may be multiple; n=1,076*

Clinicians completing the clinician questionnaire considered that 462/829 (55.7%) young people had multiple conditions and that 105/254 (41.3%) young people who were preparing for, or transferring to, adult services had a life-limiting condition.<sup>[17]</sup> In addition, 191/254 (75.2%) young people approaching transfer or transferring into adult services were considered by the clinicians to have a disability which could add additional complexity to their care (Table 2.2 and Table 2.3).

Table 2.2 Concurrent disabilities in young people approaching transfer or transferring into adult services

	Number of young people	%
Both a physical and learning disability	121	48.4
No disability	59	23.6
A physical disability	54	21.6
A learning disability, autism or both	16	6.4
<b>Subtotal</b>	<b>250</b>	
Unknown	4	
<b>Total</b>	<b>254</b>	

*Clinician questionnaire data*

### Stage of transition

Where transition had started, 112/542 (20.7%) young people were preparing to transfer; 142/542 (26.2%) were peri-transfer and 288/542 (53.1%) had fully transferred from health services for children and young

people into adult health services. Transition had not started for 179/829 (21.6%) young people (Table 2.3). A total of 114/173 (65.9%) of these young people were under the age of 15; however, 36/173 (20.8%) were 16 years of age (Table 2.4).

Table 2.3 Stage of transition

	Number of young people	%
Fully transferred into adult health services	288	53.1
Peri-transfer into adult health services	142	26.2
Preparing for transfer	112	20.7
<b>Subtotal</b>	<b>542</b>	
Transition not started	179	
Not applicable - diagnosed when under adult health services	64	
Unknown	44	
<b>Total</b>	<b>829</b>	

*Clinician questionnaire data*

Table 2.4 Age of young person where transition not started

	Number of young people	%
13	16	9.2
14	43	24.9
15	55	31.8
16 -17	56	32.4
18 - 20	3	1.7
<b>Subtotal</b>	<b>173</b>	
Unknown	6	
<b>Total</b>	<b>179</b>	

*Clinician questionnaire data*

The main reasons given for transition not starting were the structure of the transition service and the absence of a transition service at the organisation (Table 2.5). For 8/145 (5.5%) young people transition was not started because they had a life-limiting condition. However, as the date of death in people with life-limiting conditions is anticipated rather than known it may be beneficial to start transition in young people who could live beyond 16 -19 years of age, as adult-based end of life care input may be required.

Table 2.5 Reason transition had not started

	Number of young people	%
Structure of service/too early to transition	38	26.2
No transition service at this hospital	26	17.9
Life-limiting condition	8	5.5
Severity of condition	4	2.8
Care to be transferred to the general practitioner	4	2.8
Young person would not engage with the transition process	2	1.4
Parents/carers would not engage with the transition process	2	1.4
Other	61	42.1
<b>Subtotal</b>	<b>145</b>	
Unknown	34	
<b>Total</b>	<b>179</b>	

*Clinician questionnaire data*



## GOOD PRACTICE EXAMPLES

### LEARNING EXAMPLE

#### TRANSITION AS CORE BUSINESS

- A 19-year-old patient with sickle cell disease, a learning disability, arteriovenous malformation and one total hip replacement had regular appointments to discuss transition and plan the transfer into adult services.
- A transition lead was identified for the patient's care, who acted as an overarching co-ordinator and made arrangements for the patient to visit the adult services site.
- The patient had a transition plan, which was vital at times of crisis during emergency department attendance.
- The patient was seen in the paediatric emergency department until transfer to adult services had taken place at the age of 17, at which point they were seen in the adult emergency department.
- The patient was fully informed of this process, as were the parents, so expectations were appropriately managed.

### LEARNING EXAMPLE

#### GOOD YOUNG PERSON INVOLVEMENT

- An 18-year-old patient with beta thalassaemia attended the hospital for regular transfusions.
- The young person attended a teenage clinic where there were specialists for children and young people and adults.
- There were regular mixed multidisciplinary meetings to discuss different aspects of the patient's medical care, but also to talk about their general wellbeing and developmental stage.
- During the COVID-19 pandemic the patient had to attend appointments on their own, allowed them to gain further independence and to manage the disease, which was empowering, and gave them more confidence.

### GOOD CO-ORDINATED PATIENT-CENTRED CARE

- A 22-year-old patient with diabetes and obesity who required non-invasive ventilation was under the care of numerous teams at a regional centre.
- Much of the patient's care was provided in an adolescent endocrine clinic and transition was regularly discussed.
- The patient was asked if they would prefer to have ongoing care delivered at the regional centre or at the local district general hospital.
- Once the patient and their family had decided what worked best for them, direct introductions were made to the adult teams.
- One of the consultants wrote to the patient to welcome them to the adult services while also checking where they would want to be cared for if they were to become acutely unwell.
- The GP was involved throughout, enabling any wider health issues to be addressed.

### GOOD COMMUNICATION

- A 19-year-old patient with muscular dystrophy was initially under the care of paediatric neurology and cardiology but lived a long way from a tertiary centre
- Once fully transferred into adult care, the patient benefited from excellent communication over a 4-year period and very good interaction between tertiary children and young people's and adult services.
- Local adult secondary care services were involved and acted as a local back-up for their care.
- The patient's GP was very involved and ensured any broader healthcare needs were being met.

### GOOD TRANSITION ARRANGEMENTS

- An 18-year-old patient had received a kidney transplant for end stage kidney failure.
- The patient had a complex medical history with a learning disability and motor problems.
- An excellent transition into adult services was made with use of Ready Steady Go documentation.
- There was good evidence of ongoing involvement of parents and patient in their care.
- The trust had developed the role of a 'complex care' specialist nurse who knew all the relevant services in the local area and ensured that appropriate transition arrangements were in place for all aspects of the patient's care.
- Letters from adult specialists were copied to the children and young person's team for a year afterwards to ensure that no aspects of care had been missed or misinterpreted.
- The unit routinely sent out a survey to young people and their parents/carers after transfer to provide a rolling audit of quality of care.

### A GOOD QUALITY TRANSFER INTO ADULT HEALTH SERVICES

- A 19-year-old patient with a complex metabolic condition requiring a liver transplant, was under the care of multiple specialists.
- The gastro-hepatology team started discussing transfer into adult services when the patient was 14 years old.
- They liaised with the child and adolescent mental health services team. The clinic letters addressed wider issues of the patient's healthcare needs, including diet and exercise as well as sexual health.
- The patient was signposted to other resources including various apps to help them self-manage their care.
- At the age of 16 years the patient was transferred to the adult hepatology team where they were seen in an adolescent and young adult clinic in evening hours.
- At the appointment, they could meet with the wider multidisciplinary team to discuss education and mental health, as well as exercise and general wellbeing.

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## USEFUL LINKS

 <b>NICE</b> National Institute for Health and Care Excellence	<a href="#">NICE Guideline 43</a> <a href="#">NICE Quality Standard 140</a>
 Royal College of Nursing The voice of nursing	<a href="#">Lost in Transition</a>
 Care Quality Commission	<a href="#">From the Pond into the Sea</a>
 Ready Steady Go programme	<a href="#">Transition programme</a>
 <b>RCPCH</b> Royal College of Paediatrics and Child Health Leading the way in Children's Health	<a href="#">Transition resources</a>
 together for short lives	<a href="#">Family resources</a> <a href="#">Transition pathway</a>
 TRANSITION	<a href="#">The Transition Research Programme, Newcastle</a>
 <b>yphsig</b> young peoples health special interest group	<a href="#">HEEADSSS app</a>

	<a href="#"><u>Association for Young People's Health</u></a>
 Royal College of Physicians	<a href="#"><u>Young Adults and Adolescents Steering Group (YAASG)</u></a>
 elfh elearning for healthcare	<a href="#"><u>Adolescent health programme</u></a>
	<a href="#"><u>Transition programme</u></a>
 COUNCIL FOR DISABLED CHILDREN	<a href="#"><u>Developmentally appropriate healthcare</u></a>
 NHS Great Ormond Street Hospital for Children NHS Foundation Trust	<a href="#"><u>Great Ormond Street Hospital for Children</u></a>
 NHS Nottinghamshire Healthcare NHS Foundation Trust	<a href="#"><u>Preparing for adulthood</u></a>
	<a href="#"><u>Scottish Transitions Forum</u></a>
	<a href="#"><u>Paediatric to adult critical care transition</u></a>
 WellChild the national charity for sick children	<a href="#"><u>8 Principles for Transition</u></a>