

Transition from child to adult services study

Study protocol - July 2021

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Introduction

The transition of a young person aged 10 – 24 years old, to 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.¹ There is evidence that for many young people with complex conditions and their families, this can be an apprehensive time as it is often associated with a dislocation of care and a deterioration in health and wellbeing.²

Parallel adult specialties and the role of the GP

Due to increasing survival rates into adulthood, the number of young people with complex conditions accessing adult services has increased.^{3,4} Continuity of care can be a major concern especially where there are significant differences between the provision of specialisms available in child health and those found in adult care.⁵ Children's services can end at age 16, and the adult pathways may not start until age 18, and there can be a lack of clarity about where young people are cared for and who takes clinical responsibility between these ages.⁶ When continuity of care between children's and adult health specialties is poor, young people's care can default to a primary care professional. Where parallel adult services do exist, paediatric services have reported that they are sometimes uncertain whether to refer young people as they are unsure if there is a pathway set up, or if parallel adult services will meet the young person's needs.⁶ This uncertainty about the adult pathway was again demonstrated in the same focus groups where young people who had experience with transition explained that in adult services there was "no clear path of who to talk to"⁷.

In addition to care provided by the specialist teams all children should be registered with a GP, who as the key record holder can provide continuity for the young person before, during and after transition as well as manage other concerns such as mental or sexual health. However, there is evidence to suggest that young people with complex conditions often do not have a relationship with their GP⁸, or have little meaningful contact, which can result in them only seeking contact when in crisis.⁹ Parent carers who participated in a focus group session run by NCEPOD in 2020 underscored this, commenting that they were unclear on the GP's role in bridging the gap between paediatric and adult services.⁷

Effective handover to adult services

The Care Quality Commission's (CQC) report 'From the Pond into the Sea' published in 2014, reported that health and social care professionals felt that there was a lack of clarity for the process of handover to adult services and the availability of appropriate services to effectively map the care that they provide to young people after the age of 18.⁶ In the same report, young people identified that deficiencies in the handover process had a negative impact on planning for their eventual transition to adult services.⁶ NICE guidelines, published in 2016, recommended that a named worker must be assigned to a young person who is transitioning to adult services and that this named worker is responsible for the coordination and proper handover of the young person's care needs to adult services.¹⁰ While a number of hospitals have adopted this guideline in their own transition policies¹¹, young people and parent carers participating in the NCEPOD focus groups voiced their concern that the coordination of effective handover to adult services is still an area of transitional care that requires improvement, as illustrated in this comment:

"It's about proper handover. It's got to be handed over properly. Because you go to adults and they haven't got a clue because nothing's been passed to them."⁷

Developmentally appropriate healthcare (DAH)

The World Health Organisation has stated that ‘adolescent-responsive health systems are required’ and that developmentally appropriate healthcare (DAH) in clinical practice can help underpin this.¹² Tools to implement this model, such as HEADSSS can be used to structure the assessment of a young person, encompassing home, education/employment, drugs, sexual health and relationships, mental health and the potential risk factors that accompany adolescence.¹³ However, a systematic review of the application of these assessments published in 2012, indicated that whilst healthcare professionals do tend to use such tools, there were still occasions when clinicians failed to discuss with the young person some of the most serious risks they had identified through these assessments. This was particularly apparent in community health centres and general practices where time constraints were an issue, and, anecdotally, it is likely that these time constraints are present in adult secondary care.¹⁴

There are also issues around the application of the DAH model when young people are cared for in acute settings. There is evidence to suggest that young people can benefit from being treated on adolescent wards specifically designed for their stage of development and staffed by health care professionals who are trained in adolescent health care.¹⁵ Studies stretching back to the 1990s have concluded that it is inappropriate for young people to be treated on adult wards as they may feel intimidated or witness distressing scenes that they are not mature enough to handle.¹⁶ Participants in the NCEPOD focus group work suggested that, if admitted for long periods, young people with complex conditions are sometimes unable to access vital educational services that usually reside in paediatrics.⁷ While some young people feel comfortable on paediatric wards that they may be familiar with,¹⁷ these wards can be inappropriate for the range of conditions that are predominant in older adolescents with complex needs.¹⁸

Communication and training

Young people experience systemic and cultural changes during adolescence.¹⁹ This is a natural part of their development and one of the reasons why they need to be viewed as a distinct group and approached in a way that is adapted to their age range.²⁰ In a 2018 mixed-method systematic review that looked into a range of health, social care, social science and psychology studies on young people with chronic kidney disease who were transitioning to adult services, it was reported that many young people saw this period as a ‘zone of conflict between independence and dependency with [them] feeling powerless on the one hand and overwhelmed on the other’²¹. As young people with complex conditions move away from paediatric services, there is a risk of disengaging with healthcare which can lead to poorer outcomes.²² In 2019 Coyne et al found that ‘little effort’ was made by a group of surveyed healthcare professionals to follow-up young adults, as making contact was seen to be the responsibility of the young adults.²³ Young people participating in the NCEPOD focus groups highlighted increased independence as a positive aspect of transitioning to adult services. However, it was also commented that while, as an adolescent they are no longer a child, they are also not yet an adult.⁷ This is supported by neuroimaging techniques that show between the ages of 11 and 25 years there are significant changes that occur in the dynamics of an adolescent’s brain,²⁴ which suggests that healthcare professionals should be assessing, and approaching, adolescents as a distinct group.²⁵ However, there is evidence to show that healthcare professionals can lack training around assessing capacity and consent for young people.²⁶

Joint working

Joint working across care settings and specialties has been highlighted by NICE and Special needs and educational disabilities (SEND) as fundamental to ensuring effective coordination of a young person’s care from paediatric to adult services.¹⁰ The inclusion of the young

person in multidisciplinary and multi-service discussions also presents an opportunity for any decisions made to be person-centred and coordinated with the full consent and knowledge of the person who will be affected.¹⁰ However, evidence from young people and their carers in a series of NCEPOD focus groups suggests that neither person-centred, nor joint working between care settings and specialties, is the norm.⁷ In a one-on-one interview, a young person who had experience transitioning their care across multiple specialities said that they were not invited to any planning for transition meetings, and that when they entered adult care there was a lack of joint working which presented avoidable issues for the management of their complex condition.⁷ Parent carers who have had negative experiences also highlighted the lack of person-centred and joined up care as one of the barriers they face, with one commenting that “...we have a paediatrician until they’re 16, we need an adultiatrician”⁷. However, other parent carers cited joint clinics and regular multidisciplinary team (MDT) meetings that involved both paediatric and adult physicians, as well as themselves and their young person, as being one of the main drivers behind their positive experience with transition⁷. These contrasting experiences illustrate that while good practice does exist and can have a meaningful impact on young people’s care, not all young people and their families are able to access and benefit from it.

Commissioning

The commissioning of services and care packages for young people transitioning to adult services varies considerably according to a young person’s underlying condition and where they live.²⁷ NCEPOD focus group data demonstrates young people and parent carers feel like they are in a ‘postcode lottery’ in terms of services and care packages they receive when transitioning.⁷ These perceptions are supported by a study published in 2018 that collected qualitative data from commissioners on the state of commissioning arrangements for transitional care. The study found that there are no national guidelines for commissioners to follow regarding the integrated commissioning of transitional care and that ‘commissioning organisations responsible for transition have different cultures, funding arrangements and related practices which make inter- and intra-agency co-ordination and cross-boundary continuity of care difficult to achieve’.²⁸ The CQC’s report in 2014 also identified that complexities involved in allocating funding for care packages can cause significant anxiety for young people and their families.⁶

Named transition key worker

Having a named key worker for transition has been identified by service users as a particular area of concern. The CQC’s ‘From Pond to Sea’ document highlighted that only 50% of young people and their families reported that they received support from a named lead professional leading up to the transition of their care to adult services.⁶ Recently, NICE guidelines have stressed the importance of a named transition key worker in coordinating transitional care.¹⁰ However, there was a consensus among most of the young people and parent carers who participated in a focus group session held in 2020 that they lacked a named key worker with clearly defined responsibilities for helping them manage their transition.⁷

Examples of good practice and transition tools

While there is much scope to improve the quality of transitional care, there are also a number of initiatives, tools, guidelines and services which act as examples of good practice.

Many of these tools have been developed by local authorities, charities, Trusts/Health Boards and individual clinicians and provide guides on what service users should expect from the pathway to adult services and how healthcare professionals can care for young people in a developmentally appropriate way.^{29, 30}

The HEADSS assessment is a tool that healthcare professionals can use to ensure that they approach adolescents in a developmentally appropriate way when practicing.³¹ While, Together for Short Lives' 'Stepping Up' provides a framework for the process of transition for young people with life limiting conditions which can be adapted on a local level to help plan more detailed service provision³².

Another example of good practice on an organisational level can be found in Adolescent services.³³ These services encompass both inpatient and outpatient settings and ensure that young people are cared for among other adolescents and are treated by clinicians who have specific adolescence healthcare training. This is particularly important in an inpatient environment as young people have reported that adult wards can be intimidating,³⁴ while paediatric wards can lack the facilities adolescents require, especially while inpatients for an extended period of time.³⁵ In a cross-sectional study conducted across a paediatric and adult hospital in the UK in 2013, it was also reported by young people that they were more satisfied with the outpatient care they received when they attended clinics that adhered to national guidance on transitional care and were holistic and youth-friendly in their approach.³⁶

Guidelines and standards

- RCN Lost in Transition (2013) <https://www.swswchd.co.uk/image/Clinical%20information/Transition/Lost%20in%20Transition%202013.pdf>
- CQC From the pond to the sea (2014) https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf
- Acute Care Toolkit (RCP) (2015) <https://www.rcplondon.ac.uk/projects/acute-care-toolkits>
- Campbell F et al: Transition of care for adolescents from paediatric services to adult health services Review) (2016) <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD009794.pub2/epdf/full>
- NICE Transition from children's to adults' services for young people using health or social care services (2016) <https://www.nice.org.uk/guidance/ng43> reviewed in May 2020
- NICE Transition from children's to adults' services. Quality Standard [QS140] (2016) <https://www.nice.org.uk/guidance/qs140>
- British Youth Council, the Association for Young People's Health, & Youth Focus North West You're welcome pilot (2017) https://www.youngpeopleshealth.org.uk/yourewelcome/wp-content/uploads/2017/02/YoureWelcome_RefreshedsStandards.pdf
- Colver A et al: (2020) Facilitating transition of young people with long-term health conditions from child to adult health services. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6964170/pdf/clinmed-20-1-74.pdf>
- YPHSIG HEADSSS app: <https://www.yphsig.org.uk/>
<https://apps.apple.com/us/app/heedsss/id1418543003>
<https://www.health.nsw.gov.au/kidsfamilies/youth/Pages/heedsss-videos.aspx#plan>
- Ready, Steady, Go, transition programme: <https://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx>
- Growing up, gaining independence: <https://www.gosh.nhs.uk/your-hospital-visit/growing-gaining-independence/>
- 10 Steps. Transition to Adult Services: <https://10stepstransition.org.uk/>

- The transition research programme: <https://research.ncl.ac.uk/transition/>
- [E-Learning for Healthcare: https://www.e-lfh.org.uk/](https://www.e-lfh.org.uk/)
- Queens Nursing Institute. Transition of Care Programme. Managing the transition from children's to adult's community services. <https://www.qni.org.uk/nursing-in-the-community/from-child-to-adult/>
- [RCPCH: https://www.rcpch.ac.uk/resources/transition-adult-services](https://www.rcpch.ac.uk/resources/transition-adult-services)

Definitions

Throughout the protocol the following definitions have been used.

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

Transfer: The formal event of moving a young person and transferring responsibility of their care from child to adult health services.

While our method allows us to look at the process of transition from child to adult services in healthcare, we are aware the process of transition involves more than just healthcare staff and services. We are aiming to collect data on education and social care provision from the clinical questionnaires, the review of the case notes, the health and social care professional survey, and from the patient and parent carer survey and focus groups, however we recognise this will not be a complete picture.

Aims and objectives

Overall aim:

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.

Objectives

Organisational

To review:

- The use of policies and protocols for transition
- The organisation of, and access to, transition services where the young person transfers to an equivalent service in the adult healthcare setting
- The organisation of, and access to, transition services where there is no equivalent adult specialty for the young person to transfer to in the adult health setting
- The commissioning and funding of transition services
- Communication both within and between organisations and healthcare professionals (including the coordination of care)
- The delivery of staff training and education in adolescent and young adult health practice (10-24 years) (and including in transition)
- The use of benchmarks (including 'You're Welcome' standards)
- The role of executive and organisational leads (including the role of the hospital board, transition coordinators, key workers and youth workers)
- The use of formal networks of care both within and outside the organisation
- MDT working including the use of virtual platforms for communication between MDT members and between the MDT and the young person
- The availability and use of peer support, mentoring or access to an integrated youth forum
- Access to support groups for parent carers during the transition process
- The delivery of holistic developmentally appropriate care
- Quality improvement methodology and audit in transition
- Examples of good practice

Clinical

To review:

- The transition process (including developmentally appropriate care, the age at which preparation started)
- The use of transition documentation for young people and parent carers, e.g. 'Ready Steady Go'

- The presence and funding of named key workers responsible for transition and support, before during and after transfer to adult services
- The role of the young person and parent carers in the process of transition (including assessment of capacity, decision making and whether the process of transition was person centered)
- The role of primary care in transition
- The delivery of developmentally appropriate holistic care
- The follow up process (including support offered) once transfer to adult services has occurred (Including the involvement of primary care)
- Communication between clinical teams, and between teams and the young person/parent carers (including the coordination of care)
- Clinicians' experiences of the process of transition
- Young people and parent carers' experiences of transition
- Examples of good practice

Methods

Early patient and parent carer involvement

As part of the early scoping of this study, we have worked with young people and parent carers to identify the areas of care important to review, and to ensure a patient-centred study. Two methods were used to do this:

- i. A young people and parent carer online anonymous survey was disseminated
- ii. A series of four focus groups were undertaken

The results of these have fed into the development of the study aims and objectives, and a summary is included in Appendix 1.

Inclusion criteria

Young people aged between 13 years and their 25th birthday with a complex chronic condition, transitioning from child to adult health services. Whilst it is recognised transition can or should start from as young as 10 years old, 13 years has been chosen as the starting point for this study as a means of ensuring the young people sampled for inclusion in the study/participating in the study have had some experience of transition.

Twelve conditions have been chosen as a means of identifying a broad sample of young people with a complex chronic condition for inclusion in the study. We want to capture broad experience of transition rather than focusing on condition. Looking at complex young people should lead to a better understanding of barriers and good practice.

- Epilepsy
- Sickle cell
- Juvenile idiopathic arthritis
- Cerebral palsy
- Spina bifida
- Muscular dystrophy
- Post-transplant patients (heart, liver or kidney)
- Brain Tumour (Medulloblastoma)
- Autism spectrum disorder
- Rett syndrome
- Type 2 diabetes in obese young people
- Chronic kidney disease

Young people will be identified using one of the included conditions, ICD10 or SNOMED codes, via:

- Primary care (all young people under the care of the practice with one of the included conditions/SNOMED codes)
- Community healthcare (all young people referred with an included condition/ICD10 code)
- Physical healthcare (all young people admitted with an included condition/ICD10 code)

Data sampling timeframe

Data will be collected over an 18-month period from 1st October 2019 – 31st March 2021.

Participating providers of healthcare

Identifiable information – Providers of primary, community, physical and mental healthcare.
 Non-identifiable information – Voluntary sector organisations, commissioning organisations, local authorities and hospices.

Incidence and prevalence of the exemplar conditions

It is not possible to identify the number of young people under the care or a particular service or seen in an outpatient clinic using nationally collated data, however we are able to identify the number of admissions (Table 1).

Table 1. Nationally collated hospital admission data (Hospital Episodes Statistics data 2019/20 – hospital admissions in patients aged 15-24 years; Patient Episode Database for Wales (PEDW) data 2019/20 – hospital admissions in patients aged 13-24 years; Department of Health Hospital activity statistics 2019/20 – hospital admissions to HSC Hospitals in Northern Ireland in patients aged 13-24 years)

Condition	ICD10 code	13-15 years (PEDW & DH Northern Ireland)	15 years (HES data)	16-18 years	(19-24 years)	Total
Epilepsy	G40; G41	289	4,434	6,932	18,857	30,512
Sickle cell anaemia	D57.0; D57.1	28	826	2,511	5,791	9,156
Juvenile idiopathic arthritis	M08	28	933	1,968	2,132	5,061
Cerebral palsy	G80- G83	118	1,312	3,344	4,902	9,676
Spina bifida	Q05	42	609	351	592	1,594
Duchenne muscular dystrophy	G71.0	11	176	591	773	1,551
Post-transplant patients – kidney, heart and liver	Z94.0; Z94.1; Z94.4	34	302	1,183	1,789	3,308
Autism spectrum disorder and Rett syndrome	F84.0; F84.1; F84.2	124	2,716	6,915	2,008	11,763
Type 2 diabetes and obesity ¹	E11 + E66	4	114	439	230	787

Brain tumours (medulloblastoma)	C71	8	271	600	804	1,683
Chronic kidney disease	N18	157	614	2,398	4,116	7,285

¹Numbers only included for diabetes

Study promotion

Prior to data collection, NCEPOD will contact all primary, community, physical and mental healthcare organisations involved in providing healthcare. The study will also be promoted to young people and parent/carers via patient groups, third sector organisations, NCEPOD Local Reporters (sending the study poster on to the relevant departments), via any study contacts recruited, and via the relevant Colleges and Associations.

Study method test

The data collection methods and data collection tools will be tested to ensure they are robust before the full study is run.

Methods of data collection

There will be five main ways of collecting data for the study:

1. Young person/parent carer views will be collected by NCEPOD through focus groups and an on-line anonymous survey. We will work with Local Reporters, and relevant charities (e.g. Together for Short Lives, WellChild, Roald Dahl's Marvellous Children's Charity and specialist charities relevant to the conditions included) to encourage involvement.
2. Healthcare professional (including clinicians, nursing staff and allied health professionals), social care and commissioner views will be collected through interviews and an on-line anonymous survey. We will work with Local Reporters and study contacts to encourage involvement from clinicians and commissioners.
3. An organisational questionnaire will be sent to all hospitals and services in which care to young people transitioning from child to adult health services, with one of the included conditions, is provided.
4. Clinical data collection: A questionnaire will be sent to all clinicians who were responsible for the care of the young person during the transition process. These will include clinicians working in primary care, community care, physical and mental healthcare.
5. Case note review: Copies of selected extracts of case notes will be collected for peer review, mainly focusing on communication.

Further details on the methods of each method of data collection are given below.

1. Anonymous on-line young person and parent carer survey and focus group interviews

The survey and focus group interviews will gather data on the young person and parent carer views of the services available to them. The data will not be linked to any other aspects of data collection.

2. Anonymous on-line health and social care professional survey and interviews

The survey and interviews will gather data on health & social care professional views of the services available for them to provide. The data will not be linked to any other aspects of data collection.

3. Organisational questionnaire

Data collected will include information around the organisation of services, networks of care and multidisciplinary team working, the commissioning of services, the use of guidelines and protocols and training. Questionnaires will be sent to all primary, community, physical and mental healthcare organisations via the online questionnaire system.

4. Clinical data collection

Patient identification

Primary Care

Where contact details are available, primary care practices will be sent a patient identification spreadsheet for completion. They will be asked to return this with the details of all young people receiving care in their practice with one of the included conditions/ICD10/ SNOMED codes. The data fields requested will include NHS number, hospital number, date of birth, sex, and details of the included condition. From this up to 15 young people will be sampled for inclusion in the study. At this point we will request additional details from the local reporter regarding the conditions the young person has, the teams providing care in this setting, and the details of any previous admissions or outpatient attendances. We will also ask for the details of other settings where care is provided so we are able to track the young person across organisations

Community Healthcare

The Local Reporter will be asked to complete the patient identification spreadsheet with the details of all young people who have been referred to their organisation with one of the included conditions/ICD10/ SNOMED codes. The data fields requested will include NHS number, hospital number, date of birth, sex, and details of the included condition. From this up to 15 young people will be sampled for inclusion in the study. At this point we will request additional details from the local reporter regarding the conditions the young person has, the teams providing care in this setting, and the details of any previous admissions or outpatient attendances. We will also ask for the details of other settings where care is provided so we are able to track the young person across organisations

Physical Healthcare

The Local Reporter will be asked to complete the patient identification spreadsheet with the details of all young people admitted to their organisation during the study time period, with one of the included ICD10/SNOMED codes. The data fields requested will include NHS number, hospital number, date of birth, sex, and details of the included condition. From this up to 15 young people will be sampled for inclusion in the study. At this point we will request additional details from the local reporter regarding the conditions the young person has, the teams providing care in this setting, and the details of any previous admissions or outpatient attendances. We will also ask for the details of other settings where care is provided so we are able to track the young person across organisations

Mental Healthcare

The patient identification spreadsheet will not be sent for mental healthcare providers for completion. If a young person is identified via a primary, community, or physical healthcare organisation and they also have a mental health condition, the relevant mental healthcare team will be sent the clinician questionnaire to complete, and they will be asked to return this alongside copied extracts of the case notes.

Tracking young people across multiple organisations

The NHS number and date of birth will be used to track young people across multiple organisations. The details of providers of care outside the organisation submitting the data will be requested on the patient identification spreadsheet, and in the clinician questionnaires. If a young person is identified as receiving care from an organisation, but was not included on their initial data spreadsheet, the local reporter of that organisation will be contacted, before questionnaires are sent out, and asked to confirm whether the young person is known to them based on the available NHS number.

Clinician questionnaires

Two questionnaires will be used to collect clinical data for this study:

- 1) Primary clinician care questionnaire
- 2) Clinician questionnaire (Community, physical, and mental healthcare)

Primary care clinician questionnaire

The primary care clinician questionnaire will be sent directly to the GP for completion via the online questionnaire system or hard copy if the online system cannot be used (the system requires a user email). Reminder letters will be sent at six weeks and ten weeks where the data is outstanding. Up to 15 patients per practice will be sampled for inclusion in the study. In addition to this, questionnaires will also be sent if the GP is identified as providing care to a young person identified for inclusion in the study via another organisation.

Clinician questionnaires

The clinician questionnaires will be sent to the NCEPOD Local Reporter for dissemination via the online questionnaire system. Reminder letters will be sent at six weeks and ten weeks where the data is outstanding. Up to 15 patients per hospital will be sampled for inclusion in the study. Where the patient is under the care of multiple specialties within the same organisation, the clinician questionnaire will be sent for each of the individual teams. In addition to this, questionnaires will also be sent if the hospital is identified as providing care to a young person identified for inclusion in the study via another organisation.

5. Case note review

The case note review will focus on what is going or went well, and what is not going or did not go well during the transition process and will focus on two groups of young people:

- i. A sample of young people who are currently going through the process of transition
- ii. A sample of young people who have transferred from child to adult health services

For both groups notes will be requested from the person's 13th birthday until the end date of the study period. Case notes will be requested from primary, community, physical and mental healthcare services. If a young person is identified and tracked across a number of care settings, case notes will be requested from all organisations. If a young person is seen in multiple clinics/by multiple specialties within the same organisation, case notes will be requested from all services.

It is proposed up to four sets of case notes will initially be requested from each participating organisation. This selection will be based on responses in the clinical questionnaire. We will ask for two sets of notes where the clinician completing the questionnaire indicated the transition process is working/worked well, and two sets of notes where the clinician completing the questionnaire indicated the transition process is not/did not work well.

In addition to this, additional case note requests will be sent if an organisation is identified as providing care to a young person in the study via another organisation.

Case notes

Notes requested relating to transition will include:

- Clinic letters
- Discharge summaries
- Transition documentation (including 'Ready Steady Go' and Transition plans)
- General MDT notes (all relevant health care professional MDT notes including those from allied health professionals)
- Education, Health and Care Plans (where available)
- Moving on Passport/Transition passport
- Care plans
- Treatment escalation plans
- Any relevant primary care records as determined by the GP

Upon receipt at NCEPOD the case notes will be redacted if not already done so prior to sending.

Reviewer assessment form

A multidisciplinary group of reviewers (detailed below) will be recruited to assess the case notes and questionnaires and provide their opinion on what went well and what did not go well during the process of transition via the reviewer assessment form.

Table 2 summarises the data sources for significant points along the pathway.

Area of enquiry	Method of data collection	Confidentiality
Primary care	Case notes (communications with the GP included in the main case note data collection)	Identifiable
	Online surveys and focus groups/interviews	Anonymous
Community care	Case notes, clinician questionnaire, organisational questionnaires	Identifiable
	Online surveys and focus groups/interviews	Anonymous
Physical and mental healthcare (including outpatient appointments and transition clinics)	Case notes, clinician questionnaire, organisational questionnaires	Identifiable
	Online surveys and focus groups/interviews	Anonymous

Sample Size

Data source	Target number
Young person online survey	50
Parent/carer online survey	50
General clinician transition online survey (non-identifiable)	300
Organisational questionnaire (primary, community, physical and mental healthcare providers)	~250
Clinician questionnaires (primary, community and physical healthcare providers)	Up to 15 young people per hospital*
Case note review	Up to 4 young people per organisation*

* In addition to this, questionnaires and case note requests will also be sent if a hospital is identified as providing care to a young person identified for inclusion in the study via another organisation.

Analysis and Review of Data

Reviewers

A multidisciplinary group of reviewers will be recruited to assess the case notes and questionnaires and provide their opinion on what went well and what did not go well during the process of transition. The reviewer group will comprise transition coordinators, paediatricians; physicians and surgeons; nurses; general practitioners; physiotherapists; speech & language therapists; occupational therapists; hospital-based youth workers; working in primary, community, physical healthcare and social care, with an interest in transition.

An advert will be sent to Local Reporters to disseminate throughout the relevant departments. It will also be placed on the NCEPOD website. Successful applicants will be asked to attend a training day where they will each assess the same two cases to ensure consistent assessment. A number of meeting dates will be arranged, and each reviewer will then be asked to attend a minimum of a further 4 meetings. NCEPOD staff will ensure there is a mix of specialties at each meeting from across the UK. Each meeting will be chaired by an NCEPOD clinical coordinator who will lead discussion around the cases under review. The meetings will either be held in person in the NCEPOD office, or over Microsoft Teams with secure and temporary access to the case notes for review (not downloadable or printable by the case reviewer). Towards the end of the study the reviewers will be invited to attend a meeting where the data will be presented to and discussed with them. The reviewers will also be sent two copies of the draft report for their comment as this is developed.

Confidentiality and data protection

All electronic data are held in password protected files and all paper documents in locked filing cabinets. As soon as possible after receipt of data NCEPOD will encrypt electronic identifiers and anonymise paper documents. Section 251 approval has been obtained to perform this study without the use of patient consent in England and Wales.

Study outputs

On completion of the study a report will be published and widely disseminated to all stakeholders to encourage local quality improvement (QI) (further details available in the communication plan). In addition to the report, supporting tools will be made available including:

- A summary report and summary sheet
- Infographics
- The recommendation checklist
- An audit tool
- A slide set
- A guide for commissioners
- Fishbone diagrams
- Useful links for young people and parent carers

Examples of good practice will be shared, and additional QI tools will be developed where appropriate. Key messages from the report will be shared via social media.

Following publication, the report findings will be shared at national and local conferences, study days and other events; and papers submitted to journal for consideration for publication.

Data sharing

Post publication of the study there is the potential to share anonymised data sets with interested parties working in the same field. This will be undertaken following a strict process and will ensure the data does not become identifiable in their nature due to small numbers.

Timescale

	Jan 20	Feb 20	Mar – Aug 20	Aug 20	Sept 20	Oct 20	Nov 20	Dec 20	Jan – Mar 21	Apr 21	May 21	June 21	July 21	Aug 21	Sept 21	Oct 21	Nov 21	Dec 21	Jan – Mar 22	Apr 22	May 22	Jun 22	Jul 22	Aug 22	Sep 22	Oct 22	Nov 22	Dec 22	Jan 23	Feb 23	Mar 23	Apr 23	May 23	Jun 23		
Form the Study Advisory Group (SAG)																																				
Preliminary focus groups/online survey																																				
First SAG meeting																																				
Second SAG meeting																																				
Write the protocol																																				
Design the questionnaires																																				
Write strategy of analysis																																				
Design study database																																				
Advertise the study																																				
Test the data collection method																																				
Third SAG meeting																																				
Submit final protocol for approvals																																				
Advertise for reviewers																																				
Start data collection																																				
Run case reviewer meetings																																				
Data analysis																																				
Presentation to SAG and Reviewers																																				
Presentation to Steering Group																																				
Start writing the report																																				
First draft to reviewers																																				
Second draft to reviewers																																				
Third draft to reviewers																																				
Submit report to HQIP																																				
Report design																																				
Publish the report																																				
Disseminate the findings																																				

References

1. Colver A, Rapley T, Parr JR et al. 2020. Facilitating transition of young people with long-term health conditions from children's to adults' healthcare services – implications of a 5-year research programme. *Clinical Medicine (London)*. 20(1): 74–80.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6964170/> Accessed May 2021
2. Campbell F, Biggs K, Aldiss SK et al. 2016. Transition of care for adolescents from paediatric services to adult health services. *Cochrane Database of Systematic Reviews*. 29(4): 1-56.
<https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD009794.pub2/epdf/full> Accessed May 2021
3. Rosen D. 1995. Between two worlds: Bridging the cultures of child and adult medicine. *Journal of Adolescent Health*. 17(1): 10-6.
4. Gibson-Smith D, Jarvis S, Normal P et al. 2021. Making every young person count: Estimating current and future prevalence of young people with life-limiting and life-threatening conditions in England. <https://www.togetherforshortlives.org.uk/resource/making-every-young-adult-count/> Accessed May 2021.
5. Beresford B, Cavet J. 2009, *Transitions to Adult Services by Disabled Young People Leaving Out of Authority Residential Schools*. Social Policy Research Unit, University of York.
<https://www.york.ac.uk/inst/spru/pubs/pdf/resident.pdf> Accessed May 2021.
6. Care Quality Commission (CQC). 2014. *From the pond into the sea: Children's transition to adult health services*. https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf Accessed May 2021.
7. The National Confidential Enquiry into Patient Outcome and Death. 2020. Scoping focus group session.
8. Kelly A. 1995. The primary care provider's role in caring for young people with chronic illness. *Journal of Adolescent Health*. 17(1): 32–36.
9. David TJ. 2001. Transition from paediatric clinic to the adult service. *Journal of the Royal Society of Medicine*. 94(8): 373–374.
10. National Institute for Health & Clinical Excellence. 2016. *Transition from children's to adults' services for young people using health or social care services*. NICE Guideline [NG43].
<https://www.nice.org.uk/guidance/ng43> Accessed May 2021.
11. Manchester University Foundation Trust. 2021. *Transition of Care for Young People Strategy*.
<https://mft.nhs.uk/withington/patients-visitors/transition-of-care-for-young-people-strategy/> Accessed May 2021.
12. Rapley T, Farre A, Parr JR et al. 2019. Can we normalise developmentally appropriate health care for young people in UK hospital settings? An ethnographic study. *BMJ Open*. 9:e029107.
<https://pubmed.ncbi.nlm.nih.gov/31501109/> Accessed May 2021.
13. Teach Me Paediatrics. 2021. *HEADSSS assessment*. TeachMe Series.
<https://teachmepaediatrics.com/community/holistic-care/headsss-assessment/> Accessed May 2021.
14. Bradford S, Rickwood D. 2012. Psychological assessments for young people: a systematic review examining acceptability, disclosure and engagement, and predictive utility. *Adolescent Health, Medicine and Therapeutics*. 21(3): 111-25.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3915791/> Accessed May 2021.
15. Viner R. 2007. Do adolescent inpatient wards make a difference? Findings from a national young patient survey. *Paediatrics*. 120(4): 749-55.

- <https://pubmed.ncbi.nlm.nih.gov/17908761/> Accessed May 2021.
16. Gillies ML et al. 1992 Suitability of the paediatric setting for hospitalised adolescents. *Archives of Disease in Childhood*. 67: 1506 -1509.
<https://adc.bmj.com/content/archdischild/67/12/1506.full.pdf> Accessed May 2021.
17. Clift L, Dampier S, Timmons S. 2007. Adolescents' experiences of emergency admission to children's wards. *Journal of Child Health Care*. 11(3): 195-207.
<https://pubmed.ncbi.nlm.nih.gov/17709355/> Accessed May 2021.
18. Heaton P, Routley C, Siba P. 2013. Caring for young adults on a paediatric ward. *British Journal of Nursing*. 22(19): 1129 – 34.
<https://www.researchgate.net/publication/258115785> Caring for young adults on a paediatric ward Accessed May 2021.
19. Viner R. 1999. Transition from paediatric to adult care: Bridging the gaps or passing the buck? *Arch Dis Child*. ;81(3):271-5.
<https://pubmed.ncbi.nlm.nih.gov/10451404/> Accessed May 2021.
20. Farre A, Wood V, McDonagh JE et al. 2016. Health professionals' managers' definitions of developmentally appropriate healthcare for young people: conceptual dimensions and embedded controversies. *Archives of Disease in Childhood*; 101(7): 628–633.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5245734/> Accessed May 2021.
21. Dallimore DJ. 2018. Why is transition between child and adult services a dangerous time for young people with chronic kidney disease? A mixed-method systematic review. *PLoS ONE* 13(8): e0201098.1-2.
22. Campagna B, Weatherly K, Shemesh E et al. 2020. Adherence to Medication During Transition to Adult Services. *Pediatric Drugs*. 22: 501–509.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7474320/> Accessed May 2021.
23. Coyne I, Sheehan A, Heery E et al. 2019. Healthcare transition for adolescents and young adults with long-term conditions: Qualitative study of patients, parents and healthcare professionals' experiences. *Journal of Clinical Nursing*. 28(21-22): 4062-4076.
24. Colver A & Longwell S. 2013. New understanding of adolescent brain development: relevance to transitional healthcare for young people with long term conditions. *Archives of Disease in Childhood*. 98(11): 902-907
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4096849/> Accessed May 2021
25. Royal College of Physicians. 2015. *On the margins of healthcare: Why young adults and adolescents need better healthcare*. Royal College of Physicians London.
26. Wright RJ, Howard EJ, Newbery N et al. 2017. Training gap – the present state of higher specialty training in adolescent and young adult health in medical specialties in the UK. *Future Healthcare Journal*. 4: 80-5.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6502624/> Accessed May 2021
27. Humphries R & Wenzel L. 2015. *Options for integrated commissioning: beyond barker*. The King's Fund.
28. Maniatopoulos G, Le Couture A, Vale L et al. 2018. Falling through the gaps: exploring the role of integrated commissioning in improving transition from children's to adults' services for young people with long-term health conditions in England. *Journal of Health Services Research & Policy*. 23(2):107-115.
29. Great Ormond Street Hospital for Children. *Transition to Adult Services*.
<https://www.gosh.nhs.uk/your-hospital-visit/transition-adult-services>. Accessed February 2021.

30. Southampton Children's Hospital. *Ready Steady Go: Transition programme*.
<https://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx> Accessed February 2021.
31. Young People's Health & Specialist Interest Group. *YPHSIG HEEADSSS app*.
<https://apps.apple.com/us/app/heedsss/id1418543003> Accessed February 2021.
32. Together for Short Lives. 2015. *Stepping Up. A guide to enabling a good transition to adulthood for young people with life-limiting and life-threatening conditions*.
<https://www.togetherforshortlives.org.uk/resource/transition-adult-services-pathway/> Accessed May 2021.
33. University College London Hospitals. *Children and young people adolescent services*.
<https://www.uclh.nhs.uk/our-services/find-service/children-and-young-peoples-services> Accessed February 2021.
34. Dean L & Black S. 2015. Exploring the experiences of young people nursed on adult wards. *British Journal of Nursing*. 24(4): 229-236.
35. Lundgren J, Norell-Clarke A, Hellstrom I et al. 2020. Adolescents' Experiences of Staying Overnight at Family-Centred Pediatric Wards. *SAGE Open Nursing*. 2020: 1-10.
<https://journals.sagepub.com/doi/full/10.1177/2377960819900690> Accessed May 2021.
36. Shaw KL, Watanabe A, Rankin E et al. 2014. Walking the talk. Implementation of transitional care guidance in a UK paediatric and a neighbouring adult facility. *Child: Care Health and Development*. 40(5): 663-7
<https://onlinelibrary.wiley.com/doi/abs/10.1111/cch.12110> Accessed May 2021.

Appendix 1

Scoping focus group summary

At the outset of the NCEPOD Transition study, one interview and two focus groups were undertaken to gather the views of young people and parent carers on what went well, and what did not go well during the process of transition from child to adult health services to inform the direction of the study.

Participants were recruited through an online survey and social media. Seven parent carers and one young person participated in these sessions, with representation from across the UK.

All of the parent carers' young people had gone through the process of transition and were over the age of 16 years. They had a mix of physical and mental health conditions with autism and learning difficulties being predominant and all of the parent carers' children, commonly, required a high level of care. The young person who was interviewed had a chronic physical health condition that required input from a number of specialties.

The areas the focus group participants indicated it was important to include in the study are listed below. These have fed into the development of the study aims and objectives.

Areas to review

- Commissioning/funding/healthcare budgets
- Transition process
- Leads for transition
- Policies and pathways
- Communication
- Continuity of care – between paediatric and adult services, and between adult to adult services
- The use of emergency healthcare plans
- (Young) Person centred care
- Access to services (including adult and adolescent services, and missing services (no adult equivalent))
- The role of primary care
- The role of social care
- Support services/advocacy
- Education – good at transition - lessons to be learnt from this
- Audit – availability of a national database