



Child Health and
Wellbeing Network
North East and North Cumbria

TRANSITIONS: Defining and Facilitating Developmentally Appropriate Healthcare for Young People

Findings and Recommendations Paper

June 2022

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Version Control

Information below is provided to enable the changes to the document to be recorded and monitored as part of the governance around the agreed processes.

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Background

Adolescence is the transitional phase of growth and development between childhood and adulthood. There are three discrete phases of adolescence: early adolescence (10 to 13 years), middle adolescence (14 to 17 years) and late adolescence (18 years onwards) during which adolescents and young adults (AYA) move from concrete to abstract thinking and from dependency to autonomy. The many physical, sexual, cognitive, social, and emotional changes that happen during this time combine with the challenges of school to work transitioning to ensure that adolescence and young adulthood is a challenging and important phase of life, presenting distinct and highly specific developmental and emotional challenges(1). In countries such as the UK, where adolescent medicine is not a recognised medical specialty, the transition from paediatric to adult services presents a further challenge to AYA with chronic or lifelong conditions.

Developmentally appropriate healthcare

Developmentally appropriate healthcare (DAH), with a particular focus on preventative medicine and effective transitions, and responsive to the evolving developmental status of AYA, is integral to the provision of high-quality, young-person centred healthcare.

DAH encompasses five interrelated dimensions (2):

1. Biopsychosocial development and holistic care (informing the dynamic nature of DAH)
2. Acknowledgement of young people as a distinct group (in paediatric and adult healthcare settings)
3. Adjustment of care as the young person develops
4. Empowerment of the young person through health education and health promotion
5. Effective interdisciplinary and interorganisational work.

Health inequalities

The transition from childhood to adulthood is a time of great change, both emotionally and physically, for any young person and is known to be particularly challenging for those living in poverty and / or those with a long-term condition.

Social determinants, also known as wider determinants, are a diverse range of social, economic, and environmental factors which impact on population health. These factors, influenced by local, national, and international distribution of resources, shape the conditions of daily life and the extent to which individuals of all ages have the physical, social, and personal resources to identify and achieve goals, and respond to changes in their circumstances. The NENC region has a higher proportion (29.4%) living in the 20% most

deprived areas of England than the national average (20.2%) Recent data demonstrate that our region houses a large and expanding number of young people and families facing multiple disadvantages, including poverty, poor mental health, and family breakdown.

The Marmot review emphasised the strong and persistent link between social inequalities and disparities in health outcomes and the importance of tackling the wider determinants of health to improve health outcomes and reduce health inequalities. Evidence suggests that these 'wider determinants of health' are more important than health care in ensuring a healthy population and reducing health inequality.

The requirement to move from paediatric to adult services is an additional challenge for AYA living with a chronic health condition and a poorly planned or ineffective transition is known to be associated with increased morbidity and/or mortality (3). AYA living in poverty are at higher risk from incoherent or inconsistent transition pathways. Providing accessible and effective DAH and well-planned and executed transition and transfer of care for vulnerable AYA living in poverty with a chronic illness should therefore be a priority across our region.

Long term conditions

Despite detailed 2020 figures it is hard to quantify the number of CYP with long term conditions who are currently in Transition between acute paediatric services and adult services. [Figure 1]

Table 1: NENC local population demographic by age (2020)

	Period	England	Region	Lower tier local authorities															
				North Cumbria				North of Tyne and Gateshead				Durham, South Tyneside and Sunderland				Tees Valley			
				Allerdale	Carlisle	Copeland	Eden	Gateshead	Newcastle upon Tyne	Northumbria	North Tyneside	County Durham	South Tyneside	Sunderland	Darlington	Hartlepool	Middlesbrough	Redcar and Cleveland	Stockton-on-Tees
Population aged 0-4 (Count and % of total population)	2020	3,239,447 5.7%	154,194 5.1%	4,395 4.5%	5,614 5.2%	3,260 4.8%	2,147 4.0%	10,174 5.0%	16,383 5.3%	14,506 4.5%	11,256 5.4%	25,658 4.8%	8,130 5.4%	14,370 5.2%	5,692 5.3%	5,147 5.5%	9,431 6.7%	6,954 5.1%	11,077 5.6%
Population aged 5-9 (Count and % of total population)	2020	3,539,458 6.3%	173,222 5.8%	5,175 5.3%	6,329 5.8%	3,752 5.5%	2,589 4.8%	11,378 5.6%	17,375 5.7%	16,606 5.1%	11,928 5.7%	29,949 5.6%	8,728 5.8%	16,080 5.8%	6,509 6.1%	5,774 6.2%	9,840 7.0%	8,289 6.0%	12,921 6.5%
Population aged 10-14 (Count and % of total population)	2020	3,435,579 6.1%	172,737 5.7%	5,459 5.6%	6,151 5.7%	3,748 5.5%	2,776 5.2%	11,327 5.6%	16,469 5.4%	17,580 5.4%	12,162 5.8%	30,024 5.6%	8,594 5.7%	15,738 5.7%	6,674 6.2%	5,982 6.4%	9,031 6.4%	7,990 5.8%	13,032 6.6%
Population aged 15-19 (Count and % of total population)	2020	3,115,871 5.5%	162,601 5.4%	4,741 4.8%	5,525 5.1%	3,285 4.8%	2,459 4.6%	10,917 5.4%	21,041 6.9%	15,920 4.9%	10,471 5.0%	29,348 5.5%	7,681 5.1%	14,390 5.2%	5,729 5.3%	5,126 5.5%	8,267 5.9%	6,952 5.1%	10,749 5.4%
Population aged 20-24 (Count and % of total population)	2020	4,197,633 7.4%	228,977 7.6%	5,614 5.7%	6,495 6.0%	3,957 5.8%	2,691 5.0%	14,631 7.2%	46,881 15.3%	17,444 5.4%	12,042 5.8%	43,516 8.2%	9,823 6.5%	20,071 7.2%	6,538 6.1%	6,339 6.8%	12,861 9.1%	8,575 6.2%	11,499 5.8%

The Northumbria Healthcare Toolkit indicates that in any single NHS Provider Acute Trust (serving a combined population of 270,000) there could be as many as 700 young people who are in transition at any one time.

Anecdotal communications from specialty leads across NENC suggest that the maturity of transitional care services varies between specialities. This communication is gravely concerning; inequity of access to transitional care, dependent upon disease or geographic location, predicts further, system dependent, health inequalities.

National context

In 2016, the National Institute for Clinical Excellence (NICE) used existing evidence to synthesise and publish a Transition from Children's to Adults services Quality Standard, covering the period before, during and after a young person moves from children's to adults' services in all settings where transitions from children's to adults' health or social care services take place [<https://www.nice.org.uk/guidance/qs140>] (4). The Quality Standards includes guidance relating to five key areas:

1. Identify early and start planning – Year 9
2. Annual review of transition plan
3. Key worker to support young person through process
4. Meet adult team before transfer
5. Specific YP DNA policy in adult services

In 2019, the NHS Long Term Plan highlighted the need to improve pathways, experiences and outcomes for children, young people, and their families as they approach adulthood and beyond [<https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>] (5). DAH has the potential to enable system-wide adolescent-responsive healthcare delivery. There is significant national commitment to and financial resourcing of DAH, as evidenced by the conception and recruitment of Regional Nurse Advisors. The North of England Regional Nurse Advisor (Emma Powell) advised and supported this project.

There is a growing body of evidence highlighting the importance of effective and well-coordinated transition to young people and their families. Recent qualitative research led by the Royal College of Paediatrics and Child Health (RCPCH) identified that young people believe:

- Transition should be personal:
 - Decisions should be made by the YP and healthcare team together
 - 'No decision about us without us'
 - The medical team should consider more than healthcare:
 - Adult services should get to know the YP before they move.

- Local services and resources should be used.
- Mental health support should be provided.

[<https://www.rcpch.ac.uk/resources/young-peoples-experiences-health-transition>]

Local context

The Northumbria Transition Network, working together with the Healthcare Trust and Newcastle University, has developed and published a transition toolkit and resources to guide healthcare teams working with AYA populations (6). They identified six key priority areas:

- 1) Commissioners and providers regard transition as the responsibility of children's services. This is inappropriate, given that transition extends to approximately the age of 24 years. Our findings indicate an important role for commissioners of adults' services to commission transitional health care, in addition to commissioners of children's services with whom responsibility for transitional health care currently lies.
- 2) DAH is a crucial aspect of transitional health care. Our findings indicate the importance of health services being commissioned to ensure that providers deliver DAH across all health-care services, and that this will be facilitated by commitment from senior provider and commissioner leaders.
- 3) Good practice led by enthusiasts rarely generalised to other specialties or to adults' services. This indicates the importance of NHS Trusts adopting a trust-wide approach to implementation of transitional health care.
- 4) Adults' and children's services are often not joined up. This indicates the importance of adults' clinicians, children's clinicians and general practitioners planning transition procedures together.
- 5) Young people adopt one of four broad interaction styles during transition: 'laid back', 'anxious', 'wanting autonomy' or 'socially oriented'. Identifying a young person's style would help personalise communication with them.
- 6) Three performance-based financing (PBFs) of transitional health care are significantly associated with better outcomes: -
 - 'Parental involvement, suiting parent and young person'
 - 'Promotion of a young person's confidence in managing their health' and
 - 'Meeting the adult team before transfer'.

It is presently unclear how effectively local healthcare teams are using the Transition Network priorities to engage with national transitional care guidance and facilitate DAH across their services.

Aims and Objectives

Recognising that DAH is a small but integral piece of the jigsaw when considering the wider context of transition to adulthood for YP. The aim of this project was to champion developmentally appropriate healthcare and seamless transitions for adolescents and young adults aged 11 to 25 years living across the North-East and North Cumbria, specifically focussing on:

- experiences of young people and their families
- health outcomes for young people
- choice, control, and independence
- ease of navigation for families and professionals
- consistency of access to services
- improved access and appropriate use of primary care and other community services
- reduced avoidable emergency admission for long term conditions.

Short-term objectives (within 6 month project)

1. Summarise the current situation (scoping exercise across health specialities and relevant executive teams)
2. Identify gaps and share best practice (analyse, summarise, and share survey data)

Long-term objectives (>6 month project)

Collaborate with relevant specialist health advisors / leads to:

1. Embed equitable transitional care across our region
2. Support the roll-out of the new NHS competency framework
3. Develop a regional educational package
4. Share relevant information on the Healthier Together website

Methodology

The project was undertaken between October 21 and April 22. Stages of the work plan were as follows:

1 – Establishment of core steering group and key roles and responsibilities, identification of resources

To facilitate service improvement and champion developmentally appropriate healthcare and seamless healthcare transitions for adolescents and young adults aged 11 to 25 years living across the North East and North Cumbria, we identified the need for a Transitions Leadership Group with key roles and clear Terms of Reference.

2 – Identification of groups/services for inclusion

This stage of the project took place at the outset and resulted in the preparation and refinement of three lists of identified colleagues - paediatricians, young adult service leads or adult specialty leads, and NHS Foundation Trust Chief Officers and Directors of Nursing. These groups were identified as the appropriate representatives to support an initial exploration of Developmentally Appropriate Healthcare.

The first stage was to identify the NHS Foundation Provider Trusts that deliver healthcare services to children and adults across the NENC ICS footprint. From this point the various DGHs and main service centres were identified across the ICS. Chief Executive Officers and Directors of Nursing and subsequent contact details for each setting were gathered and compiled. Lists of paediatric and adult specialties and clinical leads were identified via personal communication and liaison with Trust Management Teams.

Further work was undertaken to identify appropriate mechanisms for liaison with young people and parent / carers to allow us to collate views from young people and families with lived experiences of transitional care. We worked with the relatively new GNCH Youth Forum as well as the Regional and Local Parent Carer Forum(s).

3 – Map and Understand current practice and compare across a range of disciplines

We worked with Emma Powell (Regional Nurse Advisor for Young People's Healthcare Transition) to develop a series of questionnaires appropriate for the three groups of health professionals and Trust Senior Managers. The questionnaires were based around known models of good practice and relevant NICE Standards and Clinical Guidelines.

Lines of enquiry within questionnaires ranged from organisational commitment and approach, training and development opportunities for frontline staff, clinic provision and arrangements, to young people's involvement in service improvement and planning. The questionnaires were designed to allow triangulation of responses relating to a single issue.

Cover letters were shared with the CHWN Systems Engagement Group prior to distribution. The group commented that, although important, Developmentally Appropriate Healthcare is just one aspect of the Transitions and Preparing for Adulthood agenda and that wider system engagement will be required as the programme progresses.

Questionnaires were distributed directly via the Child Health and Wellbeing Network generic inbox to these nominated individuals with the covering letter on 23rd December 2021 with a return date of 31st January 2022. The email was followed up via the CHWN on 17th January 2022 and through personal phone calls, email and other correspondence from the Transitions Clinical Leads.

Responses were uploaded to MS Forms for analysis.

4 – Understand need and aspirations of YP and families

The YPAG-NE Young Person's Group have recently completed a big piece of work around the experience of transitional care at GNCH. The work has been presented at the RCPCH Annual Conference and is being written up for publication. Working closely with the YPAG-NE team, we identified that the relatively new GNCH Youth Forum would be well placed to comment on our survey findings. We used facilitated discussion with five young people (Jam Board) to prioritise our recommendations in order of impact on young people and their families.

Further work was undertaken with the support and guidance of Joanne Gilliland, Chair of North Tyneside Parent Carer Forum/Chair for the Regional Parent Carer Forum. Initial intelligence indicated that an online survey would be the most appropriate mechanism for engagement given the timescales and impact of the COVID pandemic and other pressures within the system on busy families. A survey aligning with the healthcare professionals survey was developed, circulated and promoted via the Parent Carer Forums.

Responses were uploaded to MS Forms for analysis.

5 – Identify/share good practice

This part of the programme remains underway.

Results

1 – Establishment of core steering group and key roles and responsibilities, identification of resources

A Transitions Leadership Group was identified and set up with key roles (clinical leadership and project management and responsibilities articulated) and ToR developed and agreed 08/11/21.

The Transitions workstream and project outline (PID and Logic Models) for NENC Child Health and Wellbeing Network was presented and approved at OOG on 13th December 2021.

2 – Identification of groups / services for inclusion

Surveys were sent to 21 CEOs and Directors of Nursing from nine NHS Foundation Trusts. Response rates were 43% (9/21) for organisational leadership teams which included seven of eight acute foundation trusts and one mental health trust. Nine responses were received, two of these were from the same trust. As this was a scoping exercise and not an assessment exercise trusts were not asked to identify the organisational name on completion of the survey. However, on reviewing the responses we are fairly confident that we have feedback from the majority of trusts across the region.

The analysis from clinical teams in paediatric and adult care only included those providing acute physical health services and we did not request feedback from mental health services. 35 medical specialties were identified, and 102 paediatric specialty leads and 110 adult specialty leads invited to participate in the survey. There was a 43% (44/102) response rate from paediatric clinical leads with at least one response from each acute trust. Response rates were 33% (36/110) from adult clinical leads from acute trusts across the region. All of these responses were from clinicians who identified themselves as running some form of transition service. Services were split between secondary care (46%) and tertiary care (52%).

Table 2. Specialities represented in transition surveys

Specialty	Paediatrics	Adult
Asthma / respiratory	3	4
Cleft lip/palate	1	0
Cong heart disease	1	1
Dermatology	2	1
Ophthalmology	1	0
Cystic fibrosis	2	1
Diabetes / endocrinology	5	6
Epilepsy	4	1
Gastroenterology	6	7
Neurodisability	3	1
Haem/oncology	2	1
Surgery	3	3
Renal	2	0
Rheumatology	1	4

3 – Map and Understand current practice and compare across a range of disciplines

Trust management feedback

Although seven of eight trusts confirmed that management recognised the transition from children’s to adult services as a priority, just three of eight trusts have a trust-wide transition policy in place and two have an overarching transition steering group. The core members of the groups do not have designated time in job plans. Two of eight trusts have a transitions clinical lead post. In two organisations these transition posts are new and on short term charity funding from their own trust charity funds. Three of eight organisations have a senior executive member accountable for implementing transition strategy.

Four of eight organisations provide training on adolescent and young adult healthcare (AYA). No hospital provides mandatory training on AYA healthcare for all staff members. Two of these four trusts provide mandatory training to certain groups.

Just two of eight organisations routinely audit transition services as part of trust-wide audit cycles.

A quarter of the organisations employ youth workers, but they are only accessible to certain groups of young people.

Three quarters of the organisational leads were aware of the “You’re Welcome” criteria but only three of eight organisations have “You’re Welcome” accreditation in some or all areas (paediatric inpatients or outpatients.)

No organisation has a separate DNA policy for 18–25-year-olds.

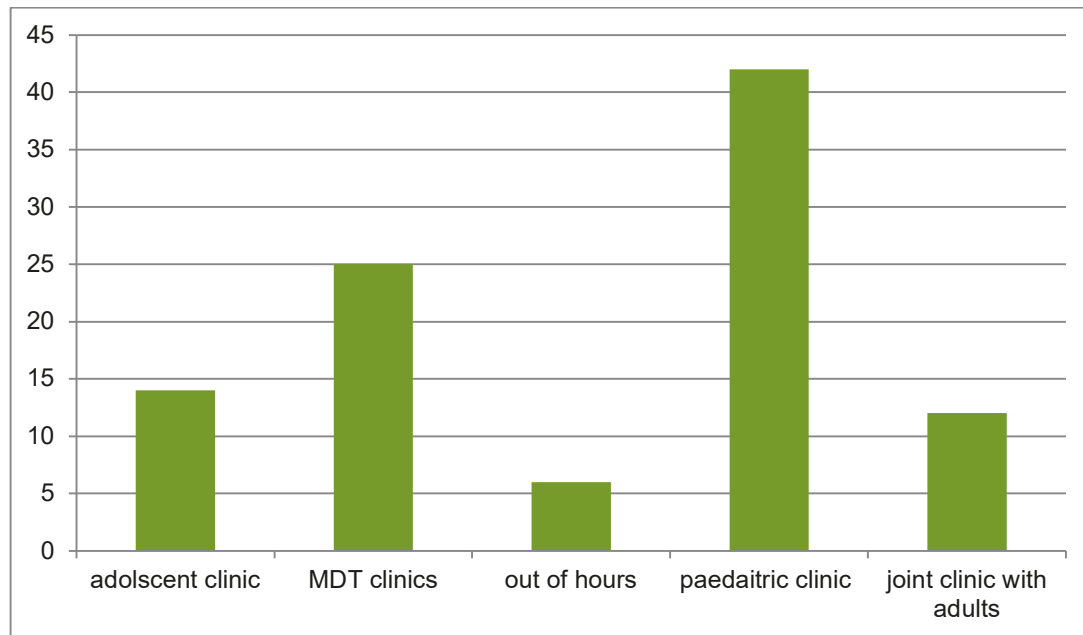
Two of eight organisations routinely involve young people in the development of services: Both have a Youth Forum, and involve young people in recruiting and interviewing, and designing new services. All trusts capture generic patient experience feedback but not none highlight 16–25-year-olds or experience of transition. One trust has recently changed its patient experience datasets to capture voice of young people aged 16-25 years in all specialty questionnaires. However, no organisation is routinely capturing the experience of YP as they move from paediatrics to adult services. Some organisations have designed questionnaires to capture experience and are starting to roll these out. Another trust designed pre and post transfer questionnaire but response rates by young people was persistently low.

Paediatric clinical leads results

The 43% response rate captured responses from specialities in each of the acute trusts in our region. Most responses were from medical specialities with only three surgical specialities represented.

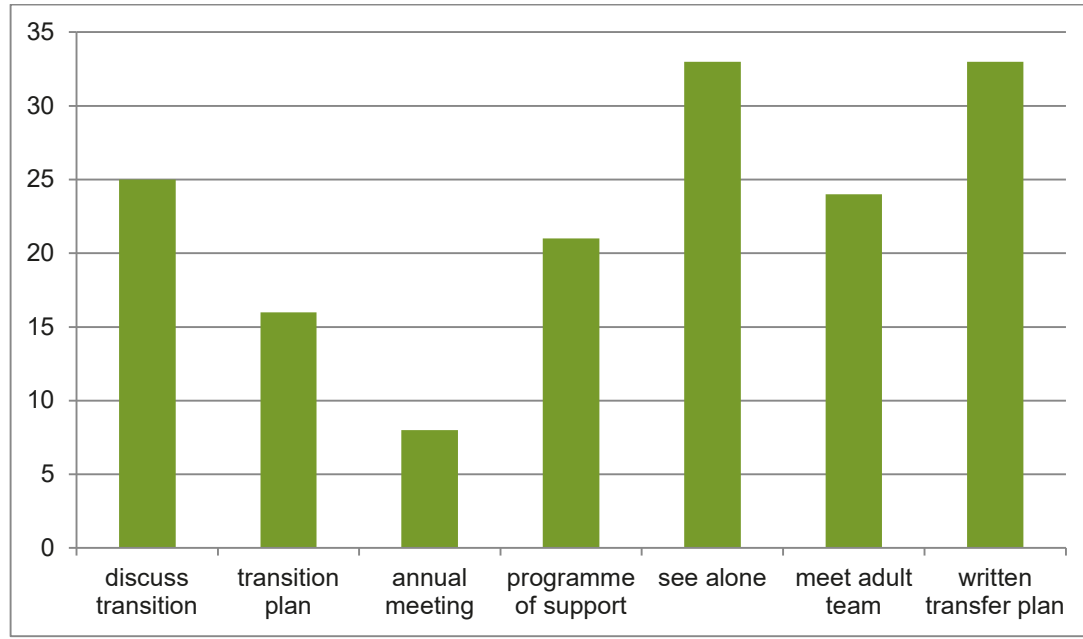
There was an equal distribution between tertiary and secondary care services, 32/44 services in paediatrics continue to care for patients up to the age of 18 years. There were some exceptions to this; paediatric solid tumours take new patients up to the age of 20 years and then link in with the TYA (18-25 years) service. Those with neurodisability stay within paediatrics until 19 years of age. Three of the specialist services looked after adults and paediatric patients. (Cleft lip and palate, orthopaedic, dermatology)

Figure 1. Clinic set-up for transition



25/44 offered MDT clinics, only 18% (8/44) had access to psychology and no service had regular access to youth worker in clinics. Most patients seen in paediatric clinic setting and only 14% (6/44) saw patients after school/college hours.

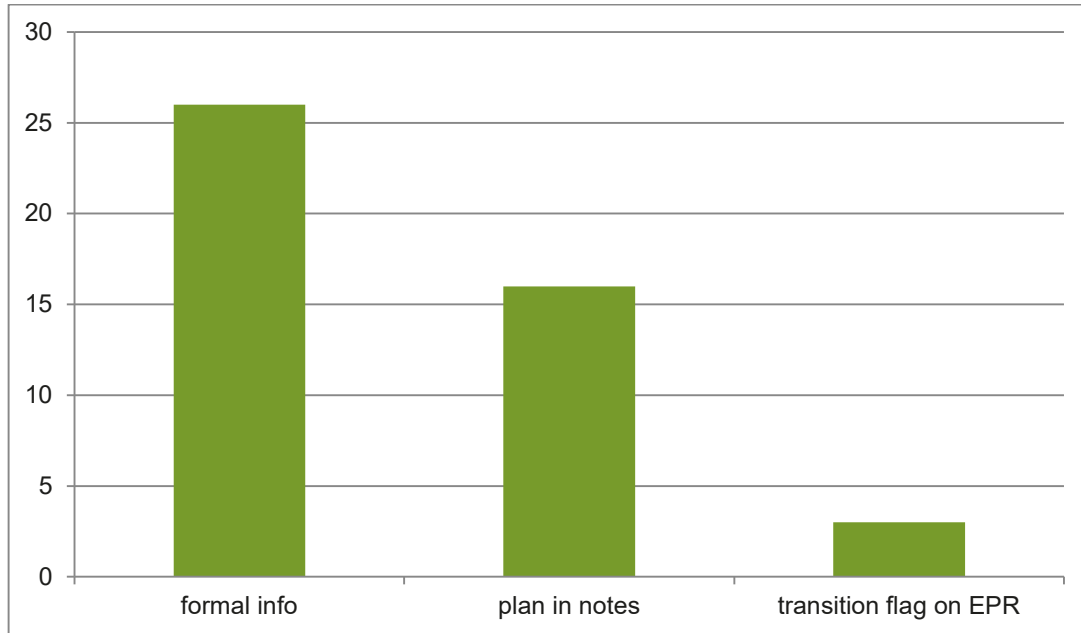
Figure 2. Preparation and support for transition and ultimate transfer



Most specialities started transition discussions around age 14 (11+) in a few cases it would depend on age of diagnosis and development of young person. (E.g., if diagnosis after 14th birthday). Only 16/44 had a transition plan and only 8/44 documented an annual review of transition. 50% of specialities offered a programme of education or support, this was usually Ready, Steady, Go or specialty specific programme (e.g. diabetes tools of education). 33/44 offered young person to be seen in clinic on their own. 22/44 offered young person to meet adult team before transfer. 33/44 wrote a transfer plan or summary at point of discharge.

A keyworker was identified in 14/44 services, in most cases this was role of nurse specialist, this was only specified in job plan in some services (diabetes, renal, gastroenterology). There was a dedicated specialty specific transitions nurse role in two specialities. Five of seven teams that identified nurse specialists with transition in their job plan had attended some form of training on adolescent healthcare and transition; this was mostly external training.

Figure 3. Transition planning and documentation

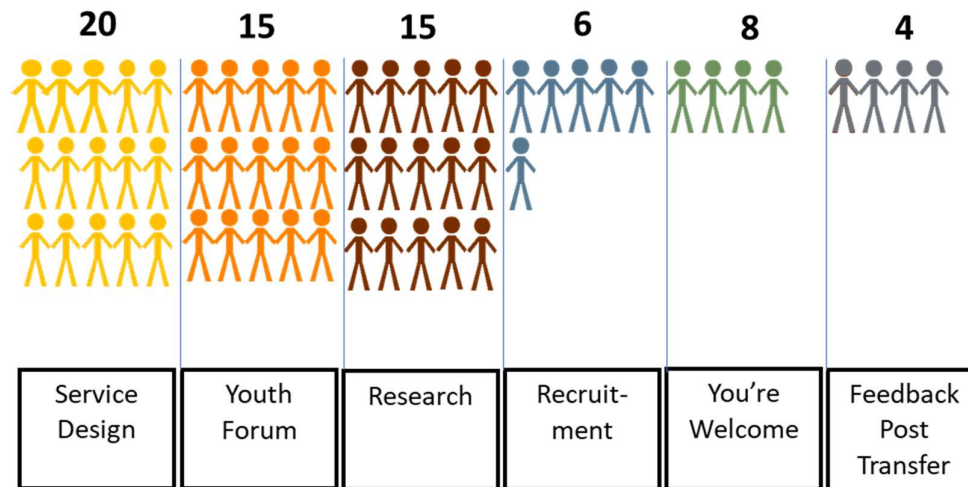


Most specialties do not have established documentation for transition or standard plans. Only three specialties had a transition flag on electronic patient record.

Post transfer engagement was varied, 13/44 specialties had ongoing contact for 3-6 months post transfer to adult services, however, most didn't offer follow up once seen by adult service. Five services had young adult or adolescent clinics and so ongoing joint involvement was longer and up to 25 years in some services. (e.g. diabetes, oncology)

Although 35/44 professionals were aware of the NICE quality standards only a quarter had received any formal training on their use.

Figure 4. Engaging young people in healthcare (paediatrics)



Most specialities involved young people in some aspect of service design and research. 15/44 give young people opportunity to take part in youth forum but not all these were in house some were national, e.g. Diabetes UK. Only one trust has a trust wide youth forum. A few specialities also involve young people in paediatric staff recruitment.

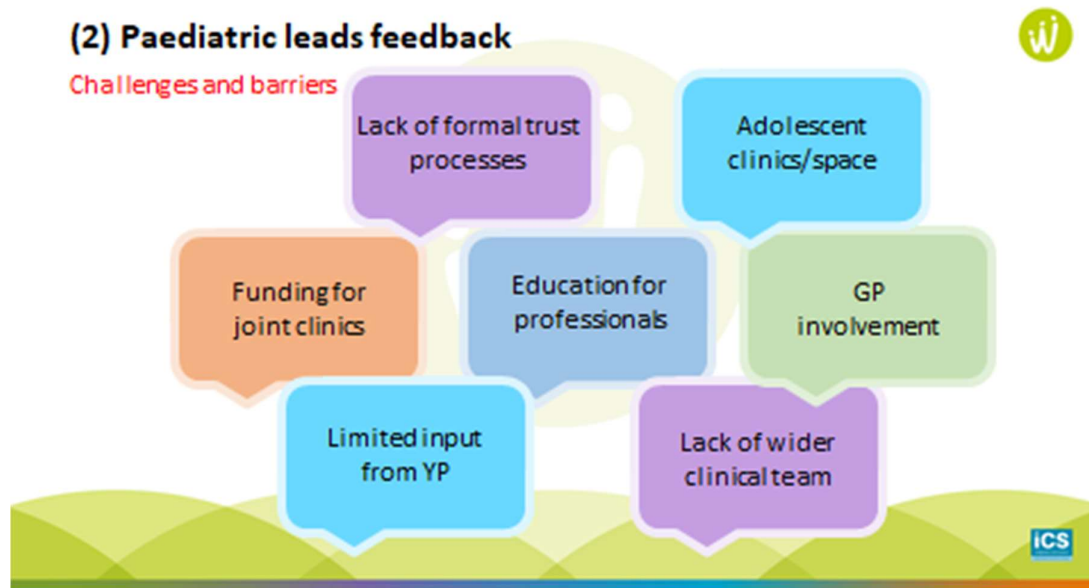
Formal feedback on the transition process and transfer was documented by four specialities and is not being routinely collated by any trust. Three specialities in one trust were piloting a post transfer survey.

Health professionals were asked to feedback on their transition service and experiences of what is working well and what are the challenges/changes needed. They were asked to score their service from 0-10, with 10 being an exemplar transition service. The average score was 5.5/10.

Clinicians highlighted the following levers to good transition: formal transition process, early education and preparation of families, importance of establishing good working relationships with adult colleagues, ability to have joint clinics in adult settings and the provision of clinical nurse specialist in the service. Patients having access to support groups and transition nurses was also considered positive where available.

Barriers to good transition included: lack of formal transition pathway or process, no access to nurse specialists, lack of funding for joint clinics with adult services. Other reported challenges included limited education for professionals, limited designated adolescent clinics, lack of clinic space, and lack of access to wider clinical and non-clinical team members, limited input from young people in the design, delivery, and evaluation of services.

Figure 5. Challenges and barriers defined by paediatric leads



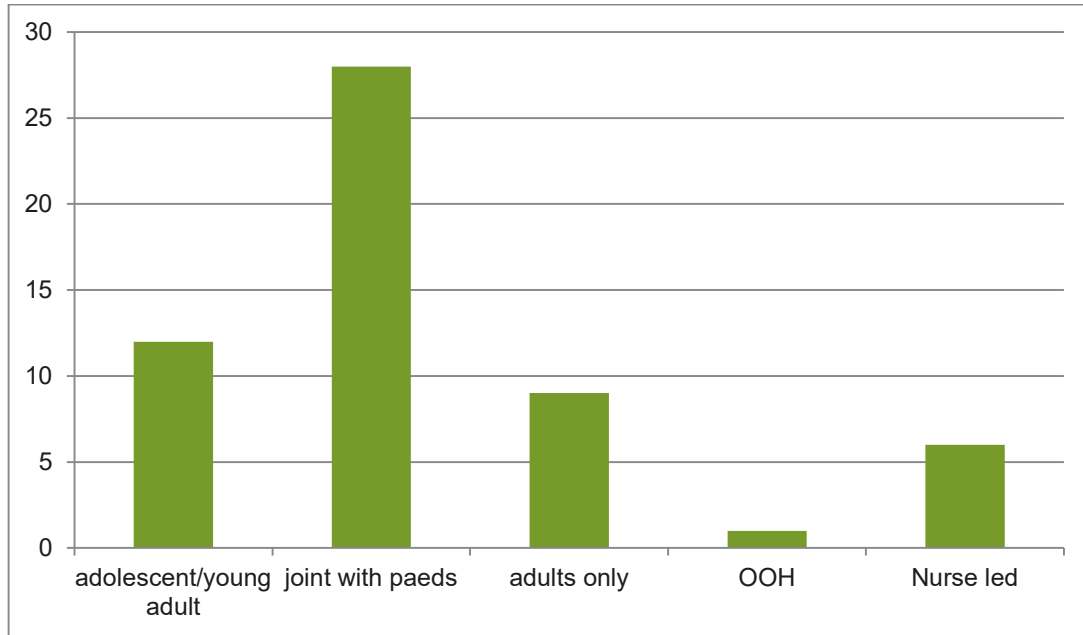
For patients with neurodisability, clinicians highlighted engagement with GP and encouraging patients to attend annual review at GP from 14 years had a positive impact on transition process but absence of any pathways or paperwork for learning disability and complex patients was raised as an issue. One of services in the region for patients with neurodisability and LD is working with regional transition nurse to develop pathways for learning disability patients.

Paediatric teams were aware of consequences of poor transition and implications on poorer disease outcomes. 38/44 said they would like to be involved regional transitions forum with access to pathways and documentation.

Adult clinic leads feedback

There was a 32% response rate; all these responses were from clinicians who were already running some form of transitions service. One can assume that a number of the non-responders may represent services that do not have any transition service in place or are not aware of transition as a concept within their service. Most offered services from 16 years upwards, although one third only saw from 18 years. Eight specialities offered clinics specifically for adolescents and young adults, mainly 16-25 years. 25/36 said they had a formal process for transition to adult services.

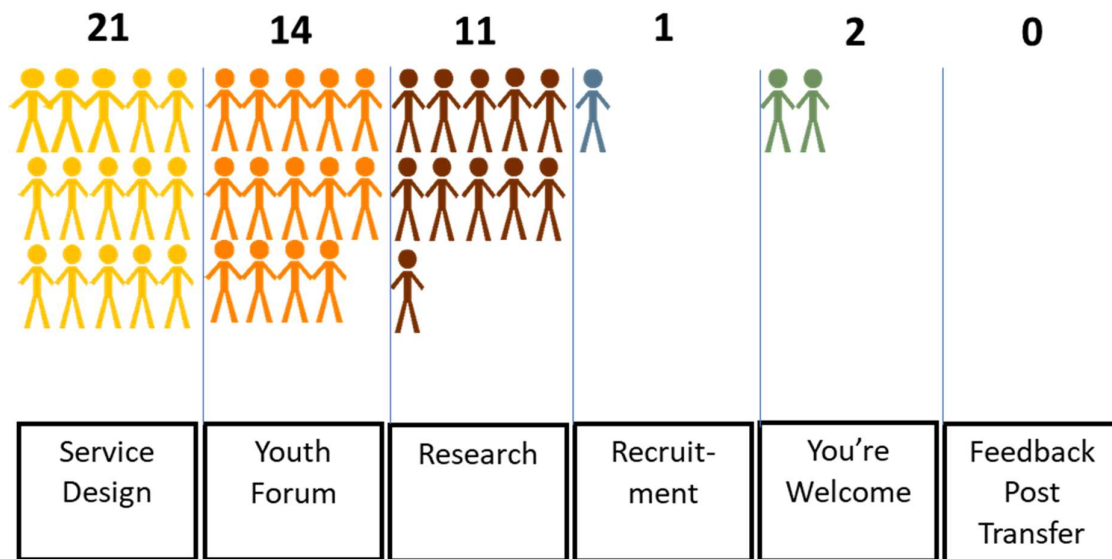
Figure 6. Clinic set-up in adult services



The majority of respondents offered either young adult clinics or joint clinics with paediatricians. Only 1 service offered clinics after college or work.

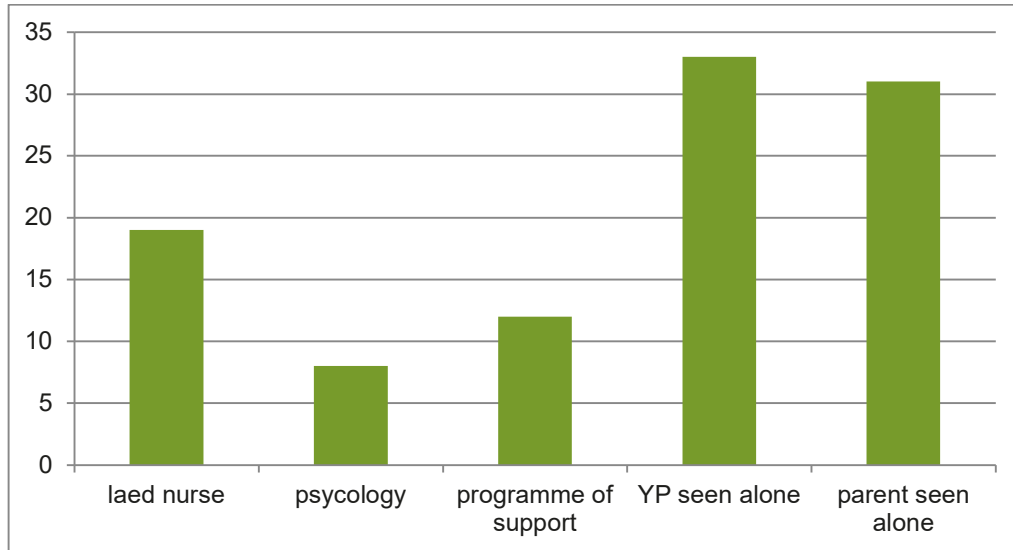
Most clinics 31/36 were made up of other MDT members, only 8/36 had access to psychology. Only one clinic had access to youth worker and sexual health worker. 27/36 had a lead clinician and 19/36 had a lead nurse for adolescent and young adults within their speciality.

Figure 7. Engaging young people in healthcare (adult specialities)



As in paediatrics most specialities gave young people opportunity to be involved in service design and research.

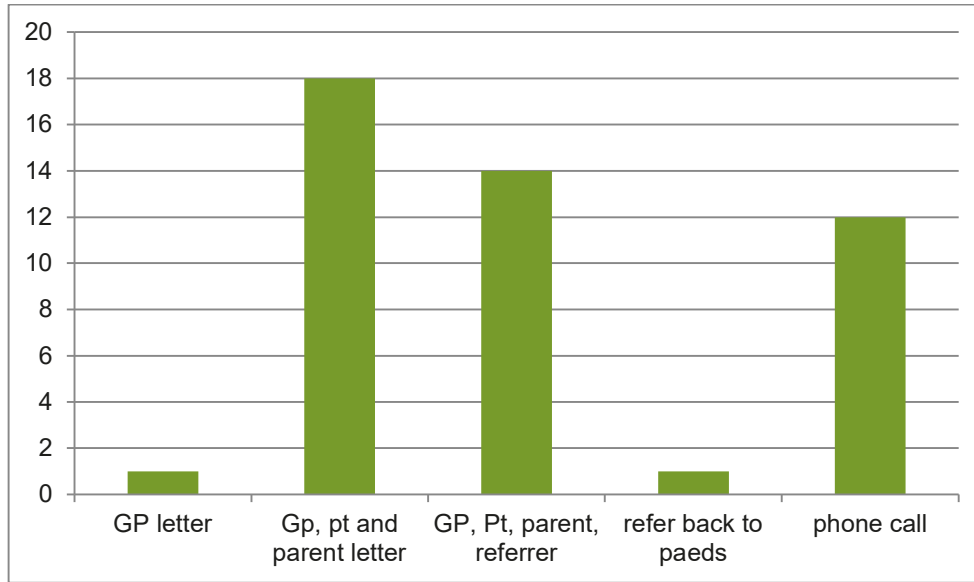
Figure 8. Preparation and support during and after transfer



In most clinics parents and young person were given opportunity to speak to healthcare professionals alone, with 19/36 having a lead nurse supporting young people in clinic. Of the 12 clinics that used a programme of support this was either Ready Steady Go, a specialty specific or a trust specific programme.

The response to non-attendance at an adult clinic was inconsistent across the specialities. The majority of young people were contacted post non-attendance but not all were actively followed up. Only 6/36 adult services had specific policy for young adults who did not attend after transfer to adult services.

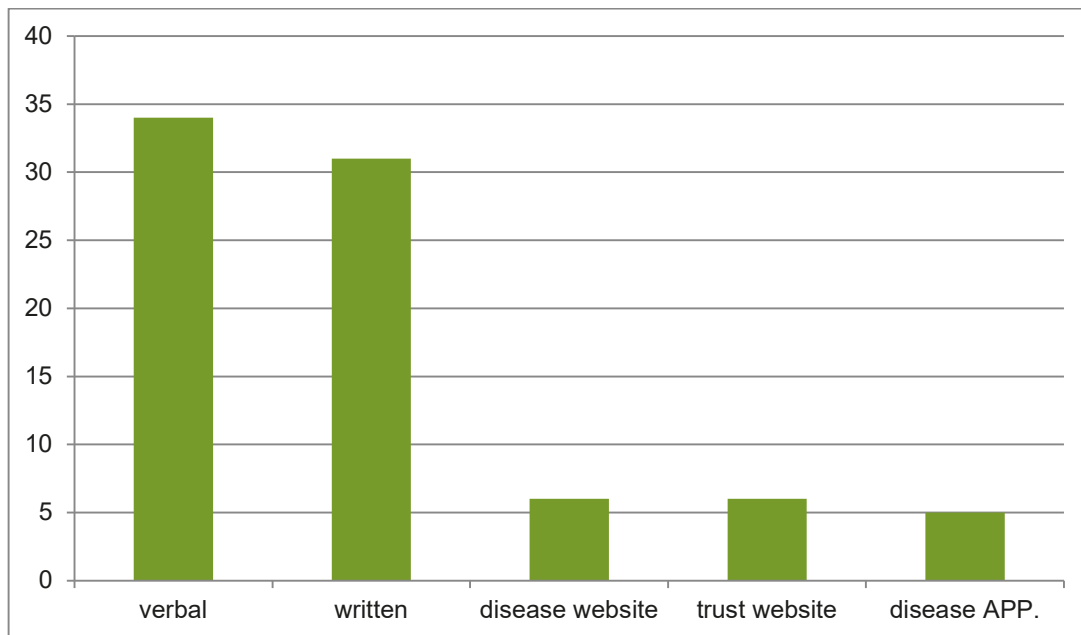
Figure 9. Action following non-attendance at adult clinic



Sources of information for young people

34/36 specialties give information to young people about their condition and contact details for the team, usually written or verbal information.

Figure 10. Information resources available for young people in adult services



Adult clinicians were asked to rate their transition service on a scale of 0-10, the average score was 6.3.

Elements of the service clinicians felt contributed to a good service included having an established transition process, joint clinics with the paediatric team, good working relationships with paediatricians, MDT clinics and role of key worker in place.

Clinicians also highlighted the importance of working at the young person's own pace and providing a bespoke transition service.

Challenges to providing a transition service included a lack of resources and time, lack of recognition of work and time involved. Services without MDT members and nurse specialists were also challenged to provide a good service.

Clinicians clearly recognised the importance of transition and the consequences of poor transition leading to increased morbidity and mortality. A number of clinicians were concerned about loss of faith in adult services if the transition did not run smoothly and that it was sometimes difficult to then gain trust back from young people within a new service. 33/36 said they would like to link in with regional transitions forum with access to approved documentation and pathways.

4 – Understand needs and aspirations of YP and families

On 15th March 2022 we presented our findings to the GNCH Youth Forum and solicited their opinion regarding priorities for improvements in transitional care. The session was facilitated by Ms Jo Ball, Mr Jack Courtney, Ms Victoria Harbottle, Dr Emma Lim and Dr Flora McErlane. There were five young people in attendance and all five were actively engaged with healthcare services. Three of five YP felt nervous about transitioning to adult healthcare and the group made several suggestions intended to improve the experience of transition:

'Going on a sort of trial experience in adults'

'Transition is not good for people who have recently got their diagnosis'

'Meet adult consultant and current team together'

'I like the idea of a joint meeting with the adult team and the children's team both being there'

The young people prioritised the recommendations as follows:

- 1) Teach all hospital staff about YP friendly services and good transition
- 2) Work with YP groups to understand what they consider to be YP friendly services
- 3) Encourage all hospitals to have a Youth Forum to inform patient-led improvements in services

- 4) Develop a regional Transition Forum to lead improvements in YP services
- 5) Work with hospital management teams to ensure that they understand the importance of good transitional care.

5 – Identify/share good practice

This part of the programme remains underway.

The project has been highlighted in several forums, including the CHWN Operational Oversight Group and the Systems Engagement Group. This project was showcased at the South Tees Transitions Event on 11th March and the findings and recommendations were well received. Further to this information has been cascaded within NEY regional reporting as an area of progression and one that we are seeking to further develop.

There have been several Paediatricians and Adult Physicians who, following receipt and completion of the questionnaires, have expressed an interest in becoming engaged with the wider work as this programme develops.

An abstract has been submitted to RCPCH in February 2022 outlining the project and the preliminary findings, it has yet to be confirmed whether more information will be shared and potentially published in the future in relation to the findings and the proposed next steps.

We have been made aware of some positive practice and have been able to make links into some already established (and some more developing) working groups.

Plans are underway to deliver a CHWN Huddle event in June 2022 where we will seek to engage the wider system, to share our findings and recommendations and to seek buy in and engagement for a Regional Transitions Group that can become established and seek to bring consistency and continue the development and sharing of good practice. Over 150 individuals from across the system who have registered their attendance at the Huddle have expressed interest in remaining engaged in this work to varying degrees.

Implications of the survey results

Our survey is the first to explore transitional care across the North-East and North Cumbria, highlighting pockets of excellent practice and willingness amongst both paediatric and adult professionals to further develop their transition services to improve the quality of care for young people with chronic health conditions moving across to adult services. Trust management teams recognise that transition from paediatric to adult services is a priority but very few have trust-wide transitional care pathways or jointly agreed and shared transitional care policies. No organisation has sufficient systems in place to fulfil the 2006 NICE Transitions guidance [NG43]. There is a lack of consistent involvement of young people in the development of services for adolescent and young adults.

An important body of evidence underpins the understanding that structured transition pathways improve patient and family experience, clinical outcomes, and engagement in adult services. In 2011, Crowley et al undertook a systematic review including 10 studies documenting patient education and transition clinics as central to improving clinical outcomes for young people (7). Many studies in different specialities have documented poorer outcomes in young people with no transition or improved outcomes with a structured transition (8,9). National transition guidance, including the Northumbria University NIHR 5-year transition project (6) and NICE Quality Standard NG43, recommend patient education and empowerment, appropriate parent involvement and meeting the adult team before transfer.

NHS E/I have committed to developing a 0–25-year service model where appropriate to enhance young people's experiences of health, continuity of care and outcomes. This model will include access to mental health and physical health services for children, young people, and adults. The anticipated publication of a national framework for transition will enable ICS and ICBs to develop and improve services within their regions and trusts.

Areas of good practice in our survey

- In both adult and paediatric services there is clear recognition that involvement of young person in their healthcare is important. Most services provide opportunities for young people to be seen alone. In adult services there was a reassuring recognition that parents may need to voice their concerns with opportunities provided for the parent / carer to be seen alone.
- There are a significant number of services across the region who are providing joint clinics.
- Young people are involved in service development and design in some services but not all, some trusts have young person representatives on consultant paediatrician interview panels.
- Most adult specialities have a lead for adolescents and young adults within their service.
- There are several very specialist services where clinicians are providing bespoke services to improve transition, although this is not always recognised within their job

plans or given adequate clinical time and this is a barrier to development of services further.

Areas for development

- There is inconsistent access to transitional care services across the region; access varies by disease area as well as geographic area.
- Just 50% of services are using a structured transition or education programme to support young people.
- There is inconsistent access to healthcare psychology and youth workers across the region, depending on where a young person's care is delivered and the clinical condition of the young person.
- Just 50% of paediatric services have a named key worker for all young people preparing to move to adulthood, in most cases a specialist nurse. This role is usually undertaken in addition to their recognised job plan.
- Half of paediatric services are offering an opportunity to meet the adult team before transfer. Barriers include lack of time, appropriate clinics, and services. In cases of complex patients with learning disability there is often not a single service to refer to. The role of GP is paramount in these patients.
- Feedback on the transition process and support given to families and young people is not routinely captured. It is essential that feedback is obtained so that healthcare professionals and managers can review and adapt their services to meet needs.
- Audit and benchmarking against standards of healthcare transition is not universally part of trust audit agenda. Data collection on outcomes for 16-25 years is not routinely collected at any acute trust.

In summary, there is a pressing need for improved education and support at trust management and clinical team levels, to ensure that clinical teams are able and supported to engage more effectively with their young people and deliver equitable and higher quality transitional care. The planning and commissioning of adult services must include consideration of the additional support needed by young people around the time of transfer to adult services.

The valuable role of the transition nurse should be recognised across all chronic illness specialities and trusts with transitional care highlighted within job plans. The role of the GP is paramount in a significant proportion of patients, particularly those with complex neurodevelopmental needs, and this needs to be recognised in service development and aligned with annual health check and school transition annual reviews.

Recommendations

There is a region wide need for improvements in the quality and equity of transitional care. CYP with long-term conditions are presently offered very variable support around the time of transition, transitional services vary between hospital and, perhaps more concerning, between disease areas. Critical gaps identified are limited knowledge of national standards, limited time, and lack of formal processes. No service is fulfilling all the quality standards set out by NICE guidance on transition services.

The regional survey has informed development of three groups of recommendations: trust management, paediatric service, and adult service recommendations. A regional transition support network will inform an ongoing programme of education and support, recognised and enabled by senior leadership teams. We are working with YP to understand their experience and priorities relating to transitional care.

1. Trust management recommendations

A. All organisations should have an overarching transition policy

The policy should include:

- A pathway for transition and ultimate transfer of patients between specialist paediatric services in adult services or primary care.
- A pathway for management of non – attendance in the 16-25 year age group
- Pathway for the transition and ultimately transfer of patients with special educational needs and learning disability

B. All organisations should offer training to relevant healthcare professionals who will care for adolescent and young adults.

This training should include:

- How to engage with young people
- Safeguarding of adolescents and young adults
- Developmentally appropriate healthcare
- Transition processes including evidence for and suggested pathway
- Legal processes related to adolescents and young adults
- Supporting adolescent and young adults and their family with special educational needs and learning disability through the transition process

C. All organisations to consider developing a Youth Forum

The Youth Forum should be actively involved in and advising on

- Design of services
- Patient experience and feedback
- Innovations for engaging young people
- Interviewing and recruitment of the clinical staff
- Peer support

D. All organisations to review patient experience questionnaires and family and friends' feedback, collating feedback from adolescent and young adults (16-25 years) as a separate group

This is particularly relevant to those with chronic illness transitioning and ultimately transferring between paediatric and adult services.

E. Healthcare transition services should be part of an organisation's annual audit cycle.

Questions pertaining to the care of adolescent and young adults should be included in all specialities both adult and paediatric.

F. All organisations to consider recruiting to the role of trust-wide lead professional for healthcare transition.

This role should support clinical teams in adult and paediatrics to implement services that are developmentally appropriate and provide seamless transition between paediatric and adult care.

2. Paediatric service recommendations

All paediatric specialty services to identify transitions lead within their service responsible for:

- Promoting early identification of patients eligible for transition
- Developing with their team and adult services and using a transition education programme
- Liaising with adult clinical lead/CD to develop joint clinics/transition pathway.
- Paediatric services across region to involve YP in review of and design of clinical settings

- Ensure young people given information regarding their condition and contact details for their team in a format that is user friendly and readily available to them. i.e. digital/social media

Research and evidence highlight that young people prefer the use of digital and social media to communicate and receive health information rather than written and verbal information. Numerous reports (reference TYA) highlight digital media as a preference for adolescent and young people.

3. Adult services recommendations

Adult services to nominate a clinical lead for young adults for their specialty who should:

- Champion adolescent and young adult healthcare
- work with the relevant paediatric team to develop transition to promote developmentally appropriate healthcare model
- Work with each specialty to Develop use of “Hello to adult” and 16+ pathway or similar disease specific education and support programmes for young people referred directly to adult care at 16 years
- Ensure young people given information regarding their condition and contact details for their team in a format that is user friendly and readily available to them. i.e. digital/social media
- Develop their service with input from YP service users’ feedback.
- Standardise follow up of non-attendance in clinic of young people within first two years after transfer to adult services.

Risks and Issues

A key role of the Transitions Leadership Group has been to manage, mitigate, respond to, and resolve risks and issues presenting during the project. Relevant issues and actions have been captured, recorded and reviewed in the risks and issues log. Updates about progress and potential for delays have been reported appropriately through CHWN Governance Procedures.

Staff capacity and skillset were identified as key risks early in the project. Resources and support were identified to fund clinical leads for the project. Subsequent modifiable risks including limitations of future funding opportunities have been addressed where possible and included in the recommendations for future activity. The additional demand to complete the survey, in the context of a highly pressured work environment, was recognised as a further key risk to the project. In response, the survey was designed to be as concise as possible.

Non-modifiable risks included limitations to data and ability to quantify impact/measurable change in the absence of common measurement systems. Furthermore, the COVID 19 pandemic and systemwide focus on recovery impacted on the prioritisation of this work. Another issue that we were required to accommodate and mitigate where problem were the requirements around GDPR and enabling participant anonymity presented further challenges to the reporting of survey data. Current regulatory arrangements cannot completely identify key gaps suggesting scrutiny could be enhanced.

The most significant risk to the success of this project is the longer-term requirement to ensure that Developmentally Appropriate Healthcare provision is able to operate cohesively with other parts of the wider transitions system(s). Initial mitigations have focused specifically on Developmentally Appropriate Healthcare to limit the potential risks of duplication, mixed or confused messaging, reputational risk and participant fatigue. Actions have been taken in relation to sharing of information about the project and to prepare the system for the subsequent report and findings. This has been done via the Parent Carer Forums and various meeting forums as well as the South Tees Transitions conference on 11th March 2022. The next phase of the project will seek to develop multi agency regional steering group that will enable the cross fertilisation and the connections to be made across the system, especially with secondary school/education settings and public health colleagues.

Conclusion

The importance of good transitional care is recognised across our region, and we have identified pockets of excellent practice with clear willingness amongst both paediatric and adult professionals to improve the quality of care they provide to young people with chronic health conditions moving across to adult services.

Trust management teams recognise that transition from paediatric to adult services is a priority, but no organisation has sufficient systems in place to fulfil the 2006 NICE Transitions guidance [NG43]. Paediatric and adult healthcare professionals caring for the 16 to 25-year age group need improved education, resources and time within job plans to deliver a consistent and equitable transition service mapped to national standards.

Improved accountability for transitional care across our region will transform the care of young people. This will require senior management and commissioning support to enable development of a robust transition pathways. Young people must be involved in service design, delivery and asked for regular feedback to ensure trusts provide developmentally appropriate services. The NHSE/I have committed to transition and development of 0-to-25-year services in the long-term plan and we are hopeful that the imminent publication of the Transitions Capability Framework will empower organisations to deliver trust-wide improvements in developmentally appropriate healthcare.

Next steps

The Child Health and Wellbeing Network transitions project team plan to develop the following actions over the next 6 months to support colleagues in developing the recommendations highlighted in this report.

1. Present findings and recommendations to trust management teams across the region.
2. Raise awareness of importance of transition, patient empowerment (using validated tools) and the impact of poorly planned transition for healthcare professionals.
3. Develop a regionwide transition steering group to develop pathways and share good practice and raise awareness.
4. Facilitate a regionwide steering group to review current pathways and share practice for patients with complex health needs and disability.
5. Champion the roll out of NHSE/I competency package when published later in the autumn.
6. Develop a transition platform on the Healthier Together website to include information for young people, families and professionals.

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