

# Improving Transition from **Paediatric to Adult Care** for Young People Living with a Rare Disease

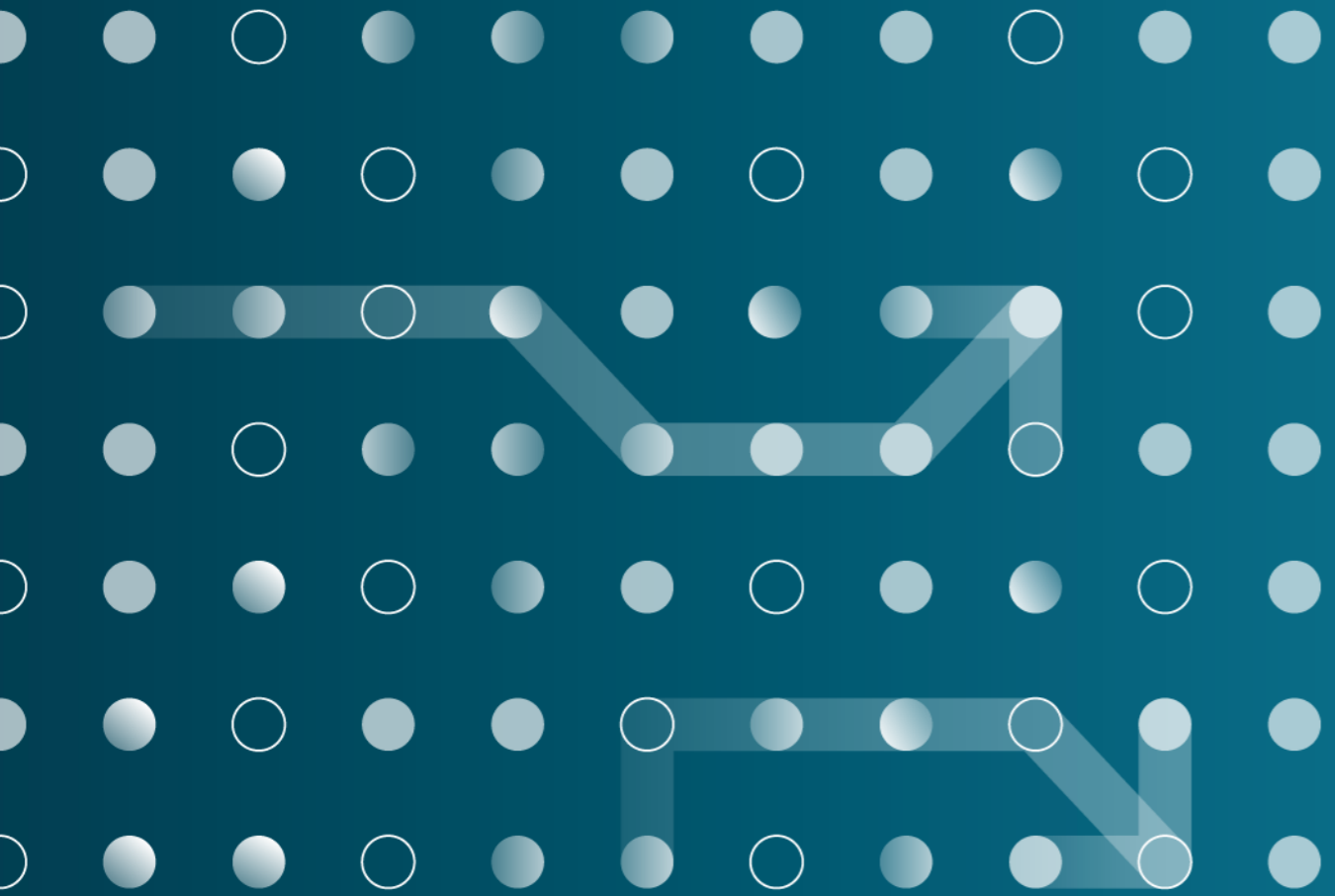
A roundtable discussion

MARCH 2022



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# Executive Summary

In recent years, advances in the diagnosis and treatment of rare diseases have led to improved life expectancy and quality of life for many patients.<sup>1</sup> Consequently, children with complex and chronic rare diseases, who previously may not have survived past infancy, are now expected to live well into adulthood. The increasing number of patients transitioning from paediatric to adult care has placed growing pressure on healthcare systems to develop age-appropriate services that ensure continuity of quality care. While improving transition pathways is an area of increasing focus, the rare diseases community continues to face substantial challenges when it comes to transitioning from paediatric to adult services. As such, there is a need to identify and characterise key challenges, as well as potential solutions, in order to inform further policy change and improve the transition processes for patients with rare diseases.

On the 15<sup>th</sup> October 2021, Costello Medical, in collaboration with Cambridge Rare Disease Network (CRDN) and Beacon, hosted a roundtable meeting to discuss the current challenges associated with the transition of young adults with rare diseases into adult healthcare services, as well as identify potential solutions and recommendations for action. Fourteen participants including healthcare professionals (HCPs), patients and caregivers, patient advocates, and policy experts shared their insights and experiences of transition services at different hospitals and clinics in Cambridgeshire and the surrounding region.

Roundtable discussions identified multiple challenges associated with transition from paediatric to adult care. Key themes included the lack of communication, continuity of care and guidance throughout the transition process, highlighting the unmet need for these patients.

Participants also proposed a number of solutions to improve the transition process for patients and their families; grouped into eight overarching themes, and underpinned by a need for better coordinated, age-appropriate care, with a greater emphasis on wellbeing.

Discussions on the day culminated in the development of **four key recommended actions** to help improve the transition from paediatric to adult care for people living with rare diseases:

- 1 Strengthen the coordination of transition processes for young adults with rare diseases
- 2 Ensure that the transition process begins early and allows flexibility for individuals with complex rare diseases
- 3 Invest in the development of age-appropriate services for teenagers and young adults
- 4 Hold services accountable for their approach to transition

# Meeting Participants

## MEETING CHAIRS

**RICK THOMPSON**  
CEO, Beacon

**JO BALFOUR**  
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## ATTENDEES

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Lead Nurse for Discharge and Transitions,  
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**TARA LLEWELLYN**  
Divisional Head of Nursing,  
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**KATIE CALLAGHAN**  
Founder of Cards for Bravery;  
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Lead Nurse, Transition Team,  
Colchester Hospital

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Support Services Manager,  
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Consultant Medical and Teenage and Young Adult  
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**LAURENCE WOOLLARD**  
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## MEETING ORGANISERS

**DEBBIE NIXON**  
Head of Health Policy, Costello Medical

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# Introduction

There are currently around 3.5 million people in the UK living with a rare disease, with 1 in 17 people likely to be affected by a rare disease at some point during their lifetime.<sup>1,2</sup> The burden of rare diseases is often significant and can have a substantial impact on the quality of life of patients and caregivers. Advances in genetic testing and the availability of treatments have led to a better understanding of the spectrum of rare diseases, resulting in improved management, life expectancy and quality of life for many patients.<sup>3</sup> As such, children with complex and chronic rare diseases, who previously may not have survived past infancy, are now expected to live well into adulthood. Data suggest that 70% of rare diseases traditionally viewed as childhood conditions have now also become adult diseases.<sup>3</sup> With increasing numbers of rare disease patients transitioning from paediatric to adult care, healthcare systems are under growing pressure to develop age-appropriate services that ensure continuity of quality care.

Transition has been described as **“the purposeful and planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult orientated healthcare systems”**.<sup>4</sup>

This definition highlights that paediatric and adult care differ greatly in their approach to issues of growth, development, patient agency and family involvement.<sup>5</sup> For transition to be successful, it is necessary to adopt an appropriately guided, educational and therapeutic approach, through which young people are encouraged to take responsibility for their care and foster positive health-related behaviours in the long-term.<sup>4</sup> A poorly managed transition can increase the burden of care on family members, and even result in severe health outcomes and a greater risk of emergency admissions and hospitalisations due to acute complications. This is particularly salient for people living with rare conditions, which are often complex and require care coordination across multiple sectors and healthcare professionals.<sup>6</sup> Indeed, reports have identified instances of poor communication and fragmentation in the management of transition for young adults with rare diseases across the UK.<sup>7</sup>

The importance of successful transitions from paediatric to adult care has been recognised for decades, yet only in recent years has it resulted in the development of guidelines and policy frameworks. For example, guidance from the National Institute for Health and Care Excellence (NICE) provides recommendations aimed at health and social care providers on the overarching principles of good transition for all patients.<sup>8</sup> The importance of successful transitions specifically for patients with rare diseases was also acknowledged in the recent UK Rare Diseases Framework published on the 9<sup>th</sup> January 2021.<sup>1</sup> The framework highlights the importance of transition and improving the coordination of care for those living with rare diseases, recognising **“the challenges in ensuring continuity of care across paediatric and adult services”** to reduce the burden of care on patients and their families.<sup>1</sup>

However, the impact of this recent guidance remains unclear, and the rare diseases community in particular continues to face substantial and consistent challenges when it comes to transitioning from paediatric to adult services. As such, there is a need to clearly identify and characterise key challenges, as well as potential solutions, in order to inform further policy change and improve the transition of care for patients with rare diseases across the UK.

This report summarises the discussions of a multistakeholder roundtable meeting on the topic of improving transition from paediatric to adult care for young people living with a rare disease in Cambridgeshire and the surrounding region. Stakeholders within the rare diseases space are encouraged to leverage the findings reported here and prioritise improvements to transition processes, particularly as we enter an era of Rare Diseases National Action Plan development.

# Background

On the 15<sup>th</sup> of October 2021, Costello Medical, in collaboration with Cambridge Rare Disease Network (CRDN) and Beacon, hosted a multistakeholder roundtable meeting to discuss the current challenges associated with the transition of teenagers and young adults with rare diseases into to adult healthcare services, as well as identify potential solutions and recommendations for action. In total, fourteen participants from Cambridgeshire and the surrounding region attended the roundtable and offered their experiences and insights; these included HCPs, patients and caregivers, patient advocates, and policy experts.

The outcomes from the roundtable discussions are captured in this report. Specific case studies have also been incorporated to illustrate some of the discussions on the day. Although the outcomes reported here focus on transition from paediatric to adult care at the local level, many of the issues and themes raised are likely to be relevant to the transition process at a national level.

## Meeting Preparation

Prior to the roundtable event, a number of informal discussions and focus groups with local patients and families living with rare diseases, and a local HCP, were conducted to identify key topics for discussion in relation to the transition process from paediatric to adult care. These activities highlighted huge variability in the transition process between patients and services, and identified a number of key challenges that were further discussed at the roundtable event.

## Meeting Attendees



The roundtable consisted of three group discussion topics. Firstly, discussion was focused on the key challenges to achieving successful transition for patients with rare diseases. Next, participants were asked to reflect on their own experiences and learnings, to identify solutions which may address current challenges. Finally, participants agreed on a list of key recommendations and actions which could help to realise the potential of proposed solutions and improve the transition pathway for patients with rare diseases.

## PART 1:

# Challenges

The first session of the roundtable focused on the challenges that patients and families living with rare diseases face during the transition from paediatric to adult care. Participants were asked about the areas of greatest unmet need for transition pathways and where existing pathways are failing. However, one of the first challenges to emerge from the roundtable discussion was in defining transition itself, and the important distinction between transition and transfer of care (see **Box 1**).

Other key challenges discussed amongst participants are grouped into seven overarching and interconnected themes: a lack of coordinated care; insufficient transparency and communication; timing of transition; the changing role of parents; limited consideration of wellbeing; fear of moving to adult care and lack of age-appropriate care. Although all interlinked, participants noted that communication and coordination were especially important.

## BOX 1

## Defining Transition: An Underlying Barrier to Successful Transitions

Transition refers to the managed and coordinated process of transfer from paediatric to adult care; transfer of care, often mistaken as transition, refers to the shift in care from paediatric to adult services. Most patients will transfer from paediatric to adult care, but few will experience a well-managed transition, a process that typically takes a number of years.

A transition process is necessary to help ensure that patients and parents are prepared for the transfer of care; however, in reality, many patients do not receive a transition process at all, instead they experience an uncoordinated transfer of care at different times across hospitals.



**There is a difference between transition, which is a process and should start early, and transfer of care which is when someone becomes the responsibility of adult services.**

**Liz Morris** Lead Specialist Nurse in Lysosomal Storage Disorders, Addenbrooke's Hospital

## A Lack of Coordinated Care

For complex rare diseases, patient care frequently spans clinical sub-specialities and requires increased coordination compared with more common chronic diseases. With the transition to adult services, patients and their families often manage uncoordinated periods of transition across sub-specialities, with different transition processes and timings at each.



**It is risky to have a system that relies on individuals.**

**Liz Morris** Lead Specialist Nurse in Lysosomal Storage Disorders, Addenbrooke's Hospital

Meeting attendees noted a general lack of coordination between paediatric and adult healthcare teams, as well as a disconnect between medical and social care teams, contributing towards a loss of continuity of care during transition. One roundtable attendee reported that during their period of transition, they were in a position where neither team (adult or paediatric) could decide who should take responsibility for their immediate care, and as a result the quality of care worsened and the patient's condition and wellbeing deteriorated (see **Transition in Practice: Katie's Story**). Another participant noted that, once in adult care, the whole care plan that had been agreed upon whilst in paediatrics was discarded and had to be reorganised, which was frustrating and stressful and resulted in more work for the HCPs and the family. Both examples demonstrate the detrimental impacts of a lack of coordination between paediatric and adult care teams.

For the minority of patients and families who experience a well-managed transition, participants suggested that this is often due to an individual HCP being engaged, supportive and willing to take on a coordinator role to help navigate the transition process. One participant shared their experience of a well-managed transition process due to the support of their paediatric consultant who took responsibility for

coordinating with HCPs in adult care.

Conversely, another attendee reported having a poorly managed transition as a result of their trusted consultant retiring shortly before their transition to adult care. In the absence of an engaged and supportive HCP, the coordination responsibilities often fall solely to parents or other family members. This places a huge strain on these individuals who have to take on the role of central coordinator and advocate, alongside their parental responsibilities. Furthermore, patients without parents or family members able to take on the role of coordinator may be left in a situation where nobody is able to help navigate them through the process.

Attendees agreed that the reliance on individuals to facilitate coordination is not sustainable; it places extreme burden on those individuals and, when those individuals are not present, patients are left without anyone to help navigate the transition from paediatric to adult care.

## Insufficient Transparency and Communication

The transition from paediatric to adult care is a process involving substantial change, which can be daunting and stressful for patients and their families. To feel prepared and have confidence in this process, patients and their families should be informed of the changes that are occurring, when they will occur, and what the consequences will be.

Patients and parents reported an absence of engagement and information, with no forewarning about who would be taking over their care from paediatric teams and how their care would change as they move into less integrated and/or specialist adult services which often require greater patient autonomy. Such limited communication and transparency between HCPs and patients has a substantial negative impact on wellbeing, leading to undue stress, confusion and anxiety for patients and their families at an already difficult time. All participants felt that there was a considerable need to improve transparency and communication between healthcare teams (both paediatric and adult) and the individuals that they care for, throughout the entirety of the transition process.



## TRANSITION IN PRACTICE

## Katie's Story

**Katie Callaghan** Founder of Cards for Bravery; Member of Rare Youth Revolution Team



Despite attempting to initiate conversations about transition as a teenager, my transfer into adult care came about abruptly, when I was admitted to the A&E department as a young adult. This was shortly after my primary paediatric doctor retired.

The healthcare team within the A&E department failed to communicate effectively with me, or each other. Despite being cared for by paediatric healthcare teams previously, the paediatric and adult healthcare teams debated about which team was responsible for overseeing my condition in A&E. Nobody was actually focusing on or caring for my needs, which ultimately resulted in me becoming seriously ill and being transferred to the paediatric intensive care unit (PICU). During my time in PICU, I stayed within paediatric wards but was refused to be seen by any paediatric clinicians, which was confusing and frightening. Then when I left PICU (aged 16), I was informed that my care would fall under the responsibility of adult healthcare teams. To this day, I am still unsure which individual or team to go to for what issue. The situation has been made more confusing by different hospitals and departments transitioning my care to adult teams at different ages.



**I still don't know who I'm really supposed to go to for what issue.**

**Katie Callaghan** Founder of Cards for Bravery; Member of Rare Youth Revolution Team

Unfortunately, I have not enjoyed my experiences of adult wards at hospitals to date and would describe my admission to an adult ward at age 16 as a horrible experience. Clinicians within adult healthcare teams do not appear to have been properly trained on how to talk to young adults. This is exacerbated by the fact that, although I had previously had direct access to the relevant specialist care when under paediatric care, I had to be admitted to the relevant specialty via the A&E department when I moved to adult care, making the process longer and more stressful. The restricted visiting hours in adult wards also meant that my parents were unable to stay with me.

In contrast, I had a **very positive experience of age-appropriate care at University College London Hospital (UCLH)**, where there is a dedicated adolescent ward for patients up to 25 years old. The environment catered towards the needs of adolescents, without feeling like a paediatric ward, and I felt comfortable talking directly to clinicians and nurses without my parents being present. Many young people do not have this confidence or ability to communicate freely with their adult healthcare team, especially if they have had a negative experience of transition to adult care. It is, therefore, important for young people to feel as though they have an advocate throughout the transition process.

As a member of Youth Revolution, I am currently creating a document about transition that is written by young people, for young people, collating opinions, case studies, statistics and policies that young people would like to see in place when it comes to the transition of care.

## Timing of Transition

As noted in **Box 1**, the process of moving from paediatric to adult care should go beyond simple transfer of care responsibilities. There should be early conversations to prepare the patient and their family for transition. The transition process itself should then be gradual, starting at an appropriate time and progressing at a comfortable speed until all healthcare responsibilities have been transferred to the adult healthcare teams.



**If a young person asks about transition aged 14/15 they are often told it's too early; don't worry yet.**

**Karen Harrison** Lead Support Services Manager, Alex, The Leukodystrophy Charity

However, participants from the roundtable explained that this is not the typical experience for patients living with rare diseases. For many patients, there are no early conversations to help prepare them and their families for transition. In fact, the transition process itself is often completely absent or begins late, and is therefore rushed. Most patients simply receive a transfer of care from their paediatric to adult healthcare teams as soon as the patient is considered eligible for adult care, neglecting other measures of readiness such as developmental age (in both the mental and physical sense). This varies between departments or clinics but usually occurs between the ages of 16–18 years.

Patients and their families reported a lack of consultation regarding decisions about the timing. Some described the transfer as happening “virtually overnight”, resulting in substantial distress to patients and families who are left uninformed and uninvolved. To add further confusion and anxiety, the patient care is transferred by paediatric healthcare teams in some departments or hospitals but not others.

Participants agreed that decisions on when transition processes begin must be tailored to ensure that the patients are developmentally ready to transition to adult healthcare services. Importantly, it was

noted that some rare diseases lead to early onset of symptoms or complications most commonly associated with adult conditions (for instance, rare forms of juvenile dementia). In these circumstances, care responsibilities may be transferred to adult healthcare teams before the patient reaches adulthood. However, despite being initiated at an earlier age, the timing of transition for these patients is still not communicated or coordinated effectively in current pathways.

## The Changing Role of Parents

The role of parents in their child's healthcare changes considerably during the transition to adult care. While parents are expected to join consultations and play an active role in paediatric care, this expectation often ends abruptly after the transition to adult care, where the expectation is that the patient should take responsibility for their own care. Parents reported being asked to leave consultations by adult healthcare teams and feeling as though their expertise surrounding their child's rare condition was disregarded or ignored. Moreover, adult services do not always have appropriate facilities to support parents who do need to be involved in their child's care. For example, some adult wards do not have beds for parents should they wish to stay overnight with their child.

Such changes in the perception and role of parents in their child's care can cause distress to both the parents and the young people involved. This is especially pertinent in cases where a patient lives with physical impairments or learning difficulties and relies more heavily on the support of their parents in managing their care and coordinating transition. While it is important that the wellbeing of patients is prioritised during the process of transition to adult care, the participants agreed that transition is also a very challenging and anxious time for parents, who often need time and support to adapt to their changing role.

## Limited Consideration of Wellbeing

Regardless of any underlying health condition, adolescence is itself a period of transition associated with substantial physical, psychological and social changes. Having a rare disease and undergoing the transition from paediatric to adult healthcare services adds to this already challenging period of life. Attendees reported that current transition pathways

often neglect the wellbeing of the young adult, focusing only on the aspects involved in transferring the patient's healthcare with very limited, if any, consideration of how the patient is feeling or coping, emotionally.

Attendees noted that in rare diseases, there is sometimes a lack of understanding regarding the complexity and nuances of certain conditions that may affect patients' needs during transition. For example, those affected by anxiety disorders or learning difficulties may find the change in healthcare teams and settings particularly challenging to adapt to.

Participants agreed that the psychological and social changes associated with the timing of transition need to be addressed. For example, it was noted that conversations regarding sexual health and relationships need to be openly discussed with young adults when they are ready. However, it was also acknowledged that young adults might not feel comfortable asking such questions to family members or HCPs who have treated them their whole life, highlighting the importance of having a trusted adult to initiate these conversations.

### Fear of Moving to Adult Care

Leaving paediatric care teams can be a difficult process for patients and families, who are often concerned, anxious and hesitant to move to adult care. This creates a fearful and negative perception of adult care, which hinders the development of relationships with HCPs who may be responsible for the patient's care for the rest of their life.

Participants noted that there is often no preparation for young adults being moved into adult care, both in terms of preparing them for the changes they can expect and in introducing them to their new healthcare team(s). This creates fear among patients and their family members about leaving paediatric care, where they may have formed long, trusted relationships with the team of HCPs. As a result, some parents and patients referred to leaving paediatric care as a type of bereavement process; with the lack of continuity of care coupled with poor communication creating substantial anxiety about the transfer of care.

### Lack of Age-Appropriate Care

Participants noted that a lack of appropriate intermediary care settings can contribute towards feelings of fear,

anxiety and disruption, with the need for an environment suited to teenagers and young adults with rare diseases who are transitioning between paediatric and adult care.

Paediatric and adult wards are often very different in their structure, atmosphere and layout. Paediatric wards are usually bright and colourful with paintings and activities targeted towards children, and specially-designed spaces for families; providing a more welcoming environment. By comparison, adult wards are typically less inviting with a more 'clinical' atmosphere. Part of this comes down to a lack of age-appropriate décor in adult wards, making the space feel hostile and intimidating. In addition, adult wards often lack the other facilities needed to support young adults; for example, one participant noted that there is no educational capacity within adult wards for young adults still in school. There is also a general lack of consideration for parents in adult wards, with no facilities for those who wished to stay overnight with their child, and more restricted visiting hours. Roundtable participants also noted the issue of safety and safeguarding young adults during and immediately after the transfer of care; specifically, how to ensure the safety of a child or young person once they need to attend an adult clinic. One attendee noted that paediatric care was much more prepared to engage with safeguarding issues than adult services.

Finally, a lack of age-appropriate communication prior to transition prevents young adults from engaging with their care plan and the transition process. Training of HCPs seems to be focused either on adult or paediatric care, leaving a gap for young adults and contributing towards anxiety about the transition. In some cases, the lack of age-appropriate communication ultimately leaves young adults feeling disengaged from their healthcare services.



**If you're not engaging young adults as though they are a young adult (either too mature or immature) then they are likely to disengage with the services.**

**Katie Callaghan** Founder of Cards for Bravery; Member of Rare Youth Revolution Team

## PART 2:

# Solutions

The second section of the roundtable focused on the discussion of possible solutions to overcome the current challenges that patients living with rare diseases face during the transition to adult care. Participants were asked to propose possible ways to achieve improved transition processes for these patients and their families; the solutions could be based on participants' knowledge of existing facilitators of well-managed transitions, or could be hypothetical.

Here, identified solutions are grouped into eight overarching themes: designated transition coordinators; multidisciplinary team meetings; more tailored timing of transition; providing age-appropriate care; having a trusted point of contact; patient empowerment; use of existing guidelines and benchmarks; and raising awareness of rare disease among adult healthcare teams. Underpinning all of these solutions was a focus on better coordination, wellbeing and ensuring age-appropriate care.

### Allocating Designated Transition Coordinators

Attendees agreed that to achieve a well-coordinated transition process which reduces the need for individual HCPs and parents to take on a coordinator role, a designated transition coordinator role could be introduced (for example, a dedicated transition nurse). The transition coordinator would be responsible for overseeing the transition from paediatric to adult care for patients with rare diseases, facilitating a cohesive and well-communicated transition across specialities by liaising with both paediatric and adult healthcare teams as well as the patient and their family. They could help to assess when the patient is ready to begin learning about and preparing for transition to adult care and coordinate the timing of each stage of transition, using tailored transition plans, to ensure an appropriate speed and consistency across sub-specialities.

Transition coordinators could also take an active role in preparing patients and their families for each stage of transition, informing them of upcoming changes to healthcare teams, settings or processes. They could, for instance, facilitate meetings between patients and adult healthcare teams and arrange visits to adult wards where they will receive their future care.

Finally, transition coordinators would ensure that patients, families and HCPs are aware of their transition-related rights and responsibilities and help to advocate for patients, reducing the burden on parents and facilitating their new, less-involved role where appropriate.

Two participants, working at Colchester Hospital, discussed the role of dedicated transition nurses, acting as transition coordinators, in aiding young people through the transition process (see [Transition in Practice: Colchester Hospital](#)).

## TRANSITION IN PRACTICE

## Colchester Hospital

**Elizabeth Thomas** Lead Nurse, Transition Team  
**Rachel Fletcher** Hospital Youth Worker



## Transition Tools

*Ready Steady Go*<sup>9</sup> is a transition programme designed to support young adults through their transition to adult healthcare services and encourage them to become involved in the process. The transition team at Colchester Hospital utilises an adapted version of *Ready Steady Go*<sup>9</sup>, which is based on developmental signposts. The tool acts as a prompt for clinicians to initiate conversations about transition with young people from an early age, prior to the transition process beginning, ensuring they are fully prepared for their transition into adult care. Once transition is underway, the transition team at Colchester Hospital use *Ready Steady Go*<sup>9</sup> to continue to remind clinicians to have certain conversations with patients at specific milestones, providing a global overview of each young person's progress throughout transition. The team ensures that a transition plan is completed for each individual patient. This plan is then embedded into a clinical letter which is sent to the young person to keep as part of their portfolio, as well as to the various professionals involved in their care in order to facilitate alignment and coordination across multidisciplinary teams.

## The Role of Youth Workers

At Colchester, youth workers have been fundamental in supporting young people through their transition period, particularly from a developmental point of view. The support provided by youth workers at Colchester Hospital might include anything from working with a patient who is struggling to manage their condition in the school setting, to discussing life aspirations with a young adult going through transition. By taking a holistic view, youth workers communicate with patients in a way that ensures they fully understand their transition plan and help to empower them to feel comfortable sharing their experiences with clinicians. Youth workers are also involved in initiating discussions with parents and carers around future plans for the care of the young adult. In this way, youth workers are crucial in the coordination of care and play a crucial role to recognising that the transition process, as well as care more broadly, should focus on more than just the patient's condition.



## Multidisciplinary Team Meetings

Participants suggested that pre-arranged and regular meetings before and throughout the transition process would facilitate improved transparency, communication and coordination. It was agreed that early in the transition process, prior to the transfer of care, a joint meeting between patients and their families, the paediatric healthcare team and the adult healthcare team should be held. This would provide an important opportunity for patients and their families to meet the adult healthcare team and begin to develop a relationship with them before the transfer of care occurs, reducing the anxiety and fear associated with the process.

In addition, participants suggested that multidisciplinary team (MDT) meetings, involving HCPs across adult and paediatric healthcare specialities, and individuals involved in patients social and psychological wellbeing, should be held from early in the transition process and at regular intervals throughout transition. Dedicated transition coordinators would be key participants, and the meetings would ensure a higher level of coordination across all aspects of a patient's life, and place greater emphasis on patient wellbeing.

## Starting Transition Early, Tailoring the Specific Timing and Speed to Individual Patients

Participants agreed that to create a well-managed transition process, transition should start as early as possible, with initial conversations about transition with paediatric care teams in early teenage years and visits and meetings involving the adult healthcare teams before the transfer of care occurs. Such activities would help patients and their families feel prepared for and involved in the transition process.

As well as beginning the process early, participants agreed that the timing of the transfer of care should be more flexible and be tailored to the individual patient's wishes and needs. These decisions should consider the patient's level of confidence to take ownership of their care and engage in conversations with adult healthcare teams, as well as the mental and physical developmental stage of the patient.

Participants from the roundtable provided examples of transition tools such as *Ready Steady Go*<sup>9</sup> and

*10 Steps*<sup>10</sup> to help HCPs and patients determine the appropriate time for transition to begin, as well as the speed of the transition process and when it is right for the transfer of care to adult healthcare teams to occur. It was suggested that these tools could be utilised more frequently by many HCPs during the transition process, but that these would be particularly important for designated transition coordinators. Such tools also provide a valuable means of communicating the timing and speed of transition to patients and their families.



**If the timing of transition is right, everything else should fall into line.**

**Katie Ashley-Burke** Lead Nurse for Discharge and Transitions, Children's Community Specialist Nursing Service, Cambridgeshire and Peterborough

## Providing Age-Appropriate Care

To achieve a smooth transition and prevent families and patients resisting care, age-appropriate care and services need to be available to patients. Participants proposed practical solutions to create more age-appropriate environments, such as painting the walls and including art works. These practical changes to the interior would help to make the space feel more welcoming and reduce the abrupt contrast between paediatric and adult care.

The layout of the wards was also discussed; it was suggested that spaces that catered to parents needs should be incorporated, where they could remain involved if needed, but also support the independence of patients. The inclusion of social spaces for patients was also discussed; an attendee shared their success in creating age-appropriate environments at the TYA ward at Addenbrooke's Hospital in Cambridge (see **Transition in Practice: Addenbrooke's Hospital**). Another example of a successful age-appropriate service is the Well Centre in London, which is a health and wellbeing clinic supporting young people aged 13 to 21 years old. The clinic provides these young people easy access to GPs, youth workers and mental health nurses all in one place.<sup>11</sup>



## TRANSITION IN PRACTICE

## Addenbrooke's Hospital

**Helen Hatcher** Consultant Medical and Teenage and Young Adult Oncologist

### Age-Appropriate Environment

The Teenage and Young Adult (TYA) ward at Addenbrooke's Hospital offers an age-appropriate space for the treatment of patients aged 14 to 24 years. Focus groups with young people held prior to opening the TYA ward meant that they were directly involved in its design. Based on these discussions, brightly coloured walls, comfortable armchairs and mood lighting all contribute to creating a home-away-from-home for young people, providing a less daunting stepping-stone in the transition from paediatric to adult wards. Indeed, feedback from visitors has suggested that this environment makes the ward feel "very calm", despite being at full capacity.



Young people raised that they value having areas where they can socialise with others, as well as areas where they can have some space to be alone. As such, a social zone was included in the design of the ward, featuring a pool table, jukebox and kitchen, with regular activities organised by youth workers taking place. In addition, side rooms and bays offer young people a private space, should they wish to have some time to themselves. Patients also have access to televisions and games consoles in their bedrooms, adding to the homely feel of the ward. Helen Hatcher, a Consultant Oncologist on the ward, explained, "... it's like heaven for some young people...you're trapped in hospital, but you're given permission to do 12 hours of Xbox!". There is also a separate kitchen designed for parents where they can relax whilst visiting.

### Multidisciplinary Care Teams

At Addenbrooke's, the TYA ward provides a focal point for young adult care, bringing together a multidisciplinary team (MDT) of clinicians, youth workers, social workers and mental health support workers. This MDT structure is important in determining the right time to initiate transition for each individual, based on factors such as developmental age and family structures. Everyone who works in the ward engages with the young adults and communicates with them about their future aspirations and goals, rather than just their illness. This environment has been invaluable in providing patients and their families with the necessary support throughout the transition from paediatric to adult care.



**Young people sometimes prefer to ask questions in a different way, such as email or text. Eventually they build up the confidence to ask questions outright.**

**Helen Hatcher** Consultant Medical and Teenage and Young Adult Oncologist, Addenbrooke's Hospital

Roundtable attendees also highlighted the importance of age-appropriate communication, and suggested that improvements could be made to help ensure that patients understand their healthcare plan and feel comfortable to ask questions and raise concerns; skills which are required for the patient to take ownership of their care throughout adulthood. To improve awareness among HCPs of the importance of age-appropriate communication, it was suggested that HCPs working with teenagers and young adults with rare diseases could undergo training in age-appropriate communication. In particular, it was proposed that HCPs should be encouraged to have an open and two-way conversation with patients going through transition, whereby they regularly ask if the patient understands what they are saying. Further, it was suggested that methods of communication should be flexible; recognising that some patients may be anxious or shy when communicating with their healthcare team (particularly if the healthcare team is new), one participant suggested that patients may find it easier to text or write about questions or concerns as opposed to speaking directly to an HCP.

### Trusted Point of Contact

To ensure that patients feel supported and confident throughout the process of transition and into adult care, participants agreed that there should be a designated point of contact, chosen by the individual patient, who they can reach out to at any point with questions about their transition (or healthcare more generally) which they may not feel comfortable raising with other HCPs or family members.

The point of contact may also be available to discuss wider concerns that the patient has, for instance those

relating to social or psychological wellbeing, and help to direct queries or concerns to relevant individuals and teams. This trusted point of contact would be an important facilitator to an improved, patient-centred approach to transition and could be any individual involved in the transition pathway or adult healthcare team that the patient felt a particular connection to.

Participants noted that at Colchester Hospital, some patients' have a designated social worker who can address questions, support the individual and consider safeguarding issues (see **Transition in Process: Colchester Hospital**).

### Empowering Patients with Rare Diseases to Understand and Question Their Transition

Teenage and young adult patients should be supported and encouraged to take ownership of their care as they transition into adulthood. To achieve this, participants agreed that more emphasis needs to be placed on empowering patients throughout the transition pathway, allowing them to understand and ask questions about these changes and hold their healthcare teams accountable for any loss of quality or continuity of care.



**Encouraging young people to share their experience with their doctors can be powerful, and have a bigger impact.**

**Rachel Fletcher** Hospital Youth Worker, Colchester Hospital

Participants agreed that empowering patients, as well as their families and caregivers, to understand and challenge their transition would be hugely beneficial to the transition process; although it should not be the responsibility of these individuals alone to advocate for high quality transition pathways, it was felt that ensuring that patients are aware of their rights to a well-coordinated transition would be a central part of overcoming current challenges. System-wide encouragement of patient empowerment and

advocacy could also be important to confront the stereotypes of ‘spoilt children’ and ‘demanding, over-involved parents’ which currently exist in some practices.

A number of actors within the transition process could play a role in encouraging patient empowerment and self-advocacy; key actors would be the transition coordinator, the patient-chosen trusted point of contact and youth workers. However, it was felt that it should be the responsibility of all healthcare teams working with teenage and young adult individuals living with rare diseases to empower these patients. Age-appropriate communication was raised as an important tool for this change.

### Increasing the Use of Guidelines and Benchmarks

Participants agreed that many HCPs may believe that they are delivering a “good” transition when, in reality, this is not the case. This lack of awareness and understanding of what is needed to ensure a successful transition is worrying, and highlights the need for more frequent and dedicated use of guidelines and benchmarks. Healthcare teams (both paediatric and adult) should be encouraged to refer to existing guidelines and benchmarks for transition (such as those provided by NICE and NHS England Improvement Standards) more frequently, and held accountable for the quality of transition pathways, with penalties for services failing to provide adequate transition.

It was suggested that additional guidelines for transition, specific to the transition of patients with rare diseases, could also be developed; these could be informed by input from stakeholders across the transition pathway to ensure high-quality, coordinated transitions which take into account patient preference and wellbeing.

Roundtable participants noted the important caveat that patients with rare diseases often have complex and unique needs and so, while guidelines can be helpful at setting a minimum standard of care, there has to be room for flexibility to avoid a one-size-fits-all approach. It was suggested that the designated transition coordinator, trusted point of contact and members of MDT meetings should ensure that guidelines are being applied appropriately at the level of individual patients.

### Improving Awareness of Rare Diseases Among Adult Healthcare Teams

An awareness and knowledge of rare diseases, and the unique needs of those patients living with these conditions, is crucial to ensure a high quality of care is maintained when patients transition to adult healthcare services. However, due to the increased number of patients with rare diseases surviving into adulthood and the fact that adult healthcare is typically divided by specialities relating to processes within specific body systems, the awareness of rare diseases among adult healthcare teams remains relatively limited. This has been recognised as a policy priority within the UK Rare Diseases Framework,<sup>1</sup> and stems from a lack of education about rare diseases for HCPs and medical students.

Participants suggested that to improve the awareness of rare diseases among HCPs, training could be provided to adult healthcare teams which see patients with rare diseases. Similar training could be given to medical students who are at an earlier stage of their career. Improved training would introduce adult healthcare teams to the unique challenges that patients with rare diseases face and the increased need for coordinated approaches to ensure that these patients are receiving consistent high quality care. Medics4RareDiseases is an example of an organisation providing such training to doctors and medical students in the UK.<sup>12</sup>

### The Role of Charities

Charities and patient groups play a vital role in supporting patients and families with rare diseases. Participants agreed that this role can be applicable to transition processes, whereby these organisation can help to facilitate and support well-managed transitions from paediatric to adult care. Some of the ways in which charities and patient groups can support improved transition processes are outlined in **Box 2**. However, many charities are working on a purely voluntary basis and may need additional support and resources to achieve this.

### BOX 2

## The Role of Charities in Supporting Transition

### 1. Educate Patients and Families About Their Rights to a Coordinated Transition

Breakdown jargon and disseminate information so patients and their families are equipped with the knowledge they need about what transition services exist and what they are entitled to ask for and receive. By raising awareness of the services and support that should be offered, they can empower patients and families to create accountability within the healthcare system.

### 2. Facilitating Communication Between HCPs and Families

Having a simple, formal process in place to engage with HCPs and specialist teams to advocate on behalf of a patient or family and explain their needs; helping families and patients communicate their concerns. Charities could help organise video consultations between families and HCPs from paediatric and adult care throughout the transition period.

### 3. Working Directly with Healthcare Teams as Part of MDTs

There is currently a disconnect as clinics act as a gateway for holistic support services. If there is no initial engagement between caregivers and young people upon leaving home, charities need to step in and provide information on where to look for extra levels of support.

### 4. Advocating for System-Wide Change

Advocating for more support for patients, charities should play a role in setting expectations for the transition process and in supporting families and patients in challenging the current approach to transition.

### 5. Supporting the Development of Age-Appropriate Care

Support making areas more suitable for young people; for example through providing artwork, small investments to the hospital to improve adult services, making them more suitable environments for young people.



**Many stakeholders hold an ethical and moral responsibility for young people; this goes for charities as well as clinicians. Should charities be playing a larger role?**

**Laurence Woollard** Director,  
On The Pulse Consultancy

PART 3:

# Summary and Recommendations

The roundtable discussions identified multiple challenges faced by young people living with rare diseases during the transition to adult care and key learnings from successful case studies in the local region. Key themes such as a lack of communication, continuity of care and guidance throughout the transition process highlight the unmet need for these patients at a key developmental stage in their lives. Moving forwards, these challenges must be addressed. Four key recommendations were compiled, based on the solutions proposed by roundtable participants. It is hoped that these recommendations will help to improve the transition from paediatric to adult care for young people living with rare diseases in the Cambridgeshire region.

## 1 Strengthen the coordination of transition processes for young adults with rare diseases

Better communication and collaboration across paediatric and adult services is necessary in order to build an aligned, system-wide transition process that prioritises the wellbeing of young adults living with rare conditions. Roundtable discussions emphasised the need for a designated transition coordinator, who would be responsible for overseeing the whole transition process of an individual. A trusted point of contact would also add value, acting as a sounding board for patients and empowering them to take ownership of their own care. Services should also focus on utilising MDT meetings to ensure the wellbeing of patients with rare diseases is considered across all aspects of care.

## 2 Ensure that the transition process begins early and allows flexibility for individuals with complex rare diseases

The transition process should be initiated as early as possible, with transition coordinators helping to fully prepare patients and their families for the transfer of care. Services should recognise that certain elements of transition will be more acute and bespoke for some patients with rare diseases. However, the timing and speed of transition itself should be flexible, accounting for developmental progress and the patient's wishes. Decisions on the appropriate timing of transition should be based upon MDT meetings with input from HCPs and social workers.

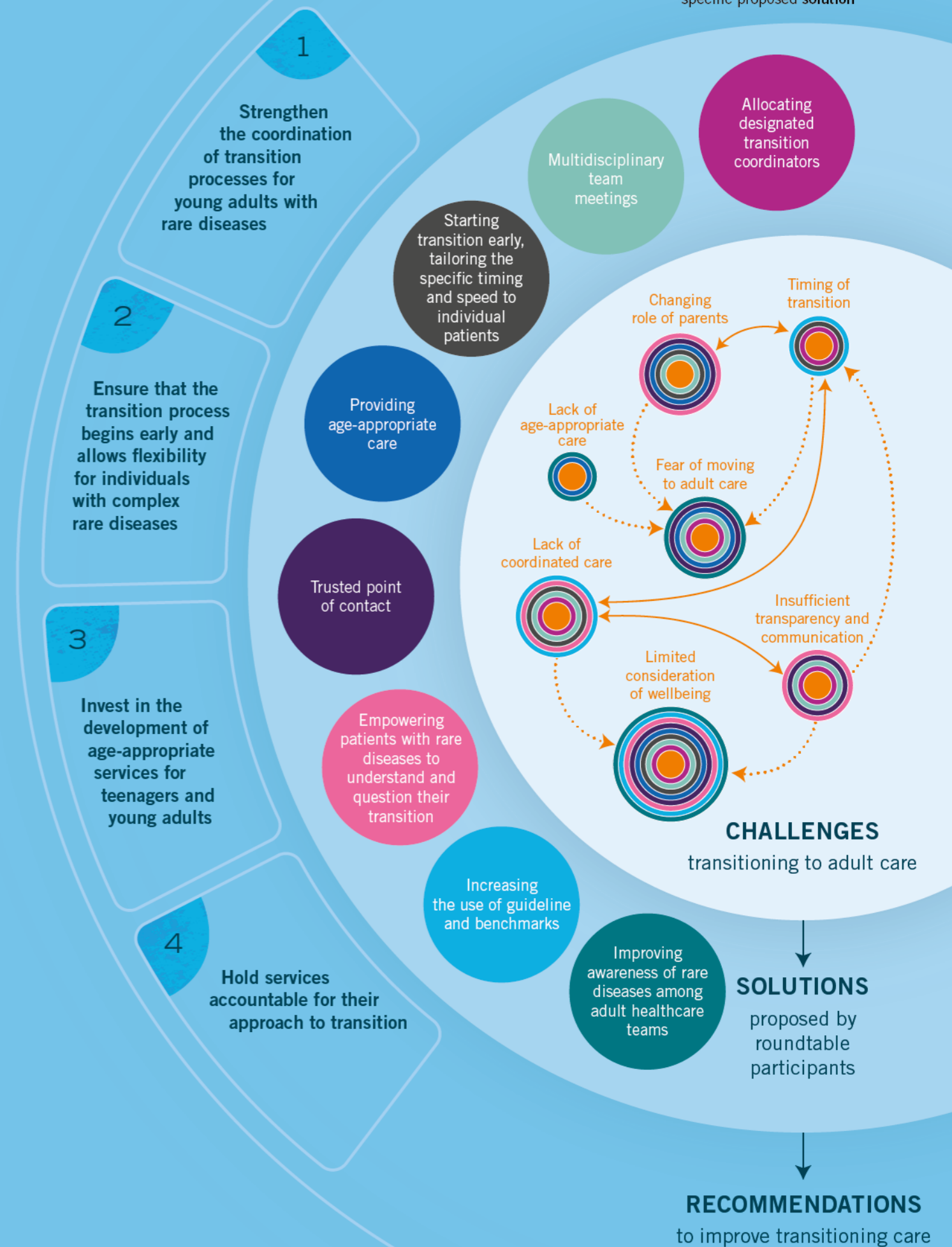
## 3 Invest in the development of age-appropriate services for teenagers and young adults

Adult services should work with young people and their families to co-design age-appropriate environments for people transitioning from paediatric care, to help foster positive experiences for young adults throughout transition and beyond. This might involve cosmetic interventions to make the design of adult wards less intimidating and more relaxed, organised activities and games to create a less clinical atmosphere, or introducing wards that cater specifically for young adults between paediatric and adult care. HCPs should also be trained in how to communicate appropriately and effectively with young adults and their families.

## 4 Hold services accountable for their approach to transition

Services must be held accountable for their approach to transition, particularly for patients with complex rare diseases. In addition, raising awareness of existing guidelines, benchmarks and frameworks, and holding trusts to account if they are failing to align, should improve national standards and expectations when it comes to transition. This could be achieved by highlighting examples of services and transition pathways that have been successful through local community networks.

The colours used to depict challenges, indicate a link with a specific proposed solution





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# Acknowledgements

Costello Medical, Cambridge Rare Disease Network and Beacon would like to thank roundtable attendees for their valuable contributions to discussions, as well as all participants of the focus groups and interviews undertaken to inform the roundtable content and structure. In addition, we would like to thank Jo Balfour and Rick Thompson for helping to coordinate the event and for keeping discussions on track through their expert chairing.

Writing and editorial support for this report was provided by Saoirse Moriarty, Noa Chapman, Kerris Chappell-Smith and Debbie Nixon, Costello Medical, UK. Graphic design support was provided by Evelyn Adams and Charlotte Bright, Costello Medical, UK.



Costello Medical provides scientific support in the analysis, interpretation and communication of clinical and health economic data. We enjoy building lasting partnerships in the healthcare sector by providing an exceptional service. Our vision is to be a community of the very best people, constantly challenging ourselves to make meaningful and outstanding contributions to improving healthcare. We have experience with a variety of leading pharmaceutical and device companies across an extensive range of therapy areas and geographies, including Europe, Asia Pacific, and North America.

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Cambridge Rare Disease Network is a platform for change. It is the infrastructure that unites patients, advocates, experts and leaders to address the challenges faced by people affected by rare diseases. By sharing knowledge and experience, and working together, the journey towards better diagnosis, treatment and support for patients and their families is smoother and more certain.

[WWW.CAMRAREDISEASE.ORG](http://WWW.CAMRAREDISEASE.ORG)



Beacon is a UK charity building the rare disease community to drive research and develop treatments. Our vision is a world in which all rare diseases have treatments - made together with patients, for patients. We look to achieve our vision by focusing our work around two main aims: empowering patient groups to build their patient communities, develop as a charity, and drive treatment development and promoting collaboration between rare disease stakeholders to facilitate treatment development for all.

[WWW.RAREBEACON.ORG](http://WWW.RAREBEACON.ORG)

## FURTHER INFORMATION

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