Rare Horizons:

Empowering Young People and Transforming Transition in Rare Disease

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Acknowledgements and Funding

Steering committee

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Intent Health has been commissioned by Novo Nordisk to facilitate the project and acts as Secretariat to the Rare Horizons Steering Committee. Intent Health works to help bridge the gap between underserved communities and health systems by translating insight into action through strategic communications. Through extensive experience working with communities around the world, they are experienced in recognising barriers, navigating mistrust and facilitating effective relationships.

Sprout Health Solutions

Sprout Health Solutions led the foundational research to uncover existing models and frameworks and identify critical gaps in transition of care, shaping strategic discussions with the Steering Committee. Guided by a science-led approach and a deep commitment to amplifying the patient voice, Sprout's expertise lies in translating evidence into innovative, actionable strategies that create meaningful change for patients, their families as well as healthcare providers.

Empowering Young People and Transforming Transition in Rare Disease

Executive Summary

Rare Horizons represents a first-of-its-kind collaboration, bringing together rare disease youth advocates, patient organisation representatives, clinicians, nurse specialists and expert psychologists, with a **mission to empower adolescents and young adults to feel in control and confident throughout the transition of care process. Transition of care is defined as the purposeful and planned movement of adolescents and young adults from paediatric to adult care.**

This pivotal moment in rare disease care is too often fragmented, inconsistent, or even neglected, leaving young adults and their caregivers to navigate an unfamiliar system at a time of major life change, putting them at risk of poorer health outcomes.[1]

> *I found out in my appointment that it was my last with my paediatric doctor. It was overwhelming to know that would be my last appointment with the doctor I'd been to for years.*
>
> *To then suddenly having to go to a completely different hospital, trying to be independent and going by myself. It was awful. That first appointment I got so lost, I didn't know where I was going.*
>
> ***Zoe Glasgow, Teen Co-ordinator, Turner Syndrome Support Society - UK***

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Globally, there is a lack of national consensus regarding transition models in rare disease; however, some progress is being made. Across rare diseases, many clinical specialties have published guidelines outlining what a "good" transition of care should include such as assessing readiness, coordinated planning, tailored communication, psychological support, and shared decision-making. In Ireland, the National Clinical Programme for Rare Diseases has published a *Model of Care for Transition from Paediatric to Adult Healthcare providers in Rare Disease.*[2] In addition, organisations such as the American Academy of Paediatrics and the US-based Got Transition initiative have published detailed, structured recommendations for transition processes across chronic conditions, although these are not specific to rare diseases.[3,4] Evidence from population-based registry data further highlight the scale of transition and the growing need for high-quality structured approaches. In a longitudinal study of rare disease patients in the Veneto Region Rare Disease Registry, the number of patients moving from paediatric to adult care steadily increased between 2006 and 2016, corresponding to a three-fold rise over the 10-year period.[5] Patients who went through a structured transition process from paediatric to adult care during this time represented nearly 9.2% of all the adult patients enrolled in the registry, highlighting the growing number of patients with specific transition needs and the ongoing need to improve the quality of transition of care.[5]

What remains largely missing is practical guidance on **how** to meet guideline goals: the implementation models, operational steps, and real-world examples that show rare disease ecosystem partners how good transition can be achieved in practice. Across Europe, clinical teams, patient organisations and translational cross-border initiatives such as European Reference Networks (ERNs) for rare diseases are developing their own solutions to bridge the gap and explore new ways of engaging with and supporting young people living with a rare disease during the transition process.

Rare Horizons' aim is to identify and scale best practices in empowering adolescents and young adults throughout the transition of care process across Europe to share learnings and accelerate implementation.

> *"It felt like I was just parachuted one day from paediatrics to adult care. Going from having a sickle cell crisis and going straight up to the ward as a child, to then having to go through A&E first [after transition to adult care] - which can be challenging when care plans and NICE guidelines are not consistently followed. This can have real physical and psychological impacts on the individual including delays to pain relief and treatment, anxiety and stress. We need to help people be better prepared for this transition and supported in how to navigate adult services"*
>
> ***Patrish Zituboh-Zeabie - Founder, Sickle Teller & Lead Mentor, Sickle Cell Society (UK)***

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Rare Horizons Principles & Areas of Focus

In September 2025, drawing on existing evidence of unmet needs and gaps in current transition models, the Steering Committee convened to identify the challenges in rare disease transition of care and areas where Rare Horizons can achieve impact.

Committee members agreed on principles to guide the work of Rare Horizons to meet the need they see in their experiences of rare disease transition of care:

- Human-centred & holistic – considering the full human experience during adolescence and young adulthood (not just what's happening in the clinic).
- Patient-led – inclusive, representative co-creation by patients, for patients.
- Flexible to individual patient needs – to meet young people where they are in their transition journey.
- Recognising expertise in all stakeholders – patients as experts in their lived experience of disease; caregivers as experts in the child's and adolescent's healthcare to date; healthcare providers (HCPs) as clinical experts.
- Building trust – with patients, caregivers, rare disease communities and HCPs.
- Pragmatic & scalable – recognising system limitations with a focus on catalysing change where you can across different settings.
- Adaptable & equitable – relevant across rare diseases and equitable in approach.

> *We have to be pragmatic about what resources are available in services and systems. Guidance on the principles of what should be present in different aspects of transition and a 'building block' approach where you can start to implement what you can with the resource available, working in partnership with patients, caregivers, patient organisations and the clinical teams.*
>
> ***Tenna Toft Sylvest, President, XLH, arvelig rakitis - Denmark***

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Putting the lived experience of young people at the centre, the Rare Horizons Steering Committee identified three priority areas for action:

1. Psychological Support

The “red thread” through every challenge, transition support must include mental health, identity development, peer connections, and emotional safety. There is a need to identify and scale holistic, peer-developed approaches which can be adapted depending on available resource.

2. System Navigation

Young people need practical, intuitive tools to help them navigate adult pathways with confidence. There is a need to identify and scale best practice approaches to support rare disease patient organisations and clinical teams to accelerate developing bespoke resources.

3. Data and Evaluation

Systems need evidence on the impact of well-planned and executed, holistic transition processes to inform and prioritise investment. There is a need to identify and scale best-practice frameworks that help providers to measure outcomes, demonstrate impact and make the case for addressing persistent gaps.

These priorities will be underpinned by a commitment to identifying and spreading best practice – collecting and critically appraising transition initiatives and tools across rare diseases and health systems to scale innovation and equip rare disease communities to develop and implement their own effective approaches at pace.

What’s Next and How You Can Be Involved

We call on patient organisations, clinicians, healthcare providers, researchers, and partners to join us in shaping a more holistic and empowering transition experience for every young person living with a rare disease.

In 2026, Rare Horizons will open new channels for young people across Europe to share their experiences and will create new opportunities for the community to bring forward their ideas, experiences, and examples of what effective transition can look like.

Together, we can turn best practice into standard practice and ensure adolescents and young adults feel supported and confident as they prepare to move into adult care.

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Literature Review to Understand the Unmet Need in Rare Disease Transition of Care

To support the initiation of Rare Horizons, a focused literature review was undertaken to identify: the unmet needs of young people living with a rare disease and their caregivers in transition of care; factors indicating readiness for transition and drivers of successful transition; and interventions or behaviour change techniques that can facilitate this process.

Across the literature, several themes are apparent:

Poorly planned transition has been associated with increased risk of treatment non-adherence and poor follow-up, which may result in poor outcomes.[1]

For example, young people with sickle cell disease who experienced a transfer gap of 6 months or more between paediatric and adult care are approximately twice as likely to be hospitalised.[6] In haemophilia, treatment adherence decreased from 90% in children under the age of 12 to 36% in young people aged 19-28, resulting in bleeds and reduced quality of life.[7] In addition to contributing to poor clinical outcomes, poorly planned transition carries a substantial economic burden. It is linked to higher healthcare costs driven by increased emergency department visits, hospitalisations, and intensive care admissions.[8]

Globally, there is a lack of consensus regarding transition models and guidelines in rare diseases, however, progress is being made.[9]

For example, in the UK, the *Ready Steady Go program* outlines a tailored transition approach[10], while in the United States, Got Transition identifies core elements of transition.[11]

- Canada has published national guidelines to inform transition for young people with special needs,12 and the National Clinical Programme for Rare Diseases in Ireland has published the *Model of Care for Transition from Paediatric to Adult Healthcare Providers in Rare Diseases*.[3] A Dutch diabetes controlled evaluation study highlighted that future transitional care models and investments should extend beyond transfer, with a focus on education for young adults, caregivers and parents.[13]

Transition readiness measures are reported as a critical tool to gauge preparedness.[14-16]

One example is the Transition readiness assessment (TRAQ), which uses age-dependent percentile scores to identify inadequate readiness for transition.[17] However, there is still a lack of evidence and validation in patients with rare disease to suggest the best readiness measures for each disease. Readiness measures may need to be selected and adapted according to the specific disease and care setting.

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Behavioural factors can influence successful transition.

Self-efficacy (an individual's belief in their capacity to achieve something) has become a critical component of transition programmes.[18] Enhancing self-efficacy helps patients feel ready for transition, navigate complex healthcare systems, manage their condition effectively, and maintain continuity of care during transitions.[19-21] However, while self-efficacy is an important component, successful transition cannot be predicted by high self-efficacy alone.[22]

Broadly, ongoing barriers and unmet needs in rare disease transition fall into four categories:

1. Communication and coordination gaps between care teams, as well as a disconnect between patients and providers

Misaligned beliefs and expectations regarding adult care among patients, families, and healthcare providers represent significant challenge.[9] A lack of information transfer between paediatric and adult care teams can also be problematic for a smooth transition. In addition, limited continuity and coordination between healthcare professionals may reduce opportunities for trust building and person-centred transition planning.[23]

2. Lack of sufficient disease education and transition information

A multinational literature review identified that many patients do not engage in transition conversations, indicating a gap in preparatory education. Further compounding this issue, the review revealed a significant gap in understanding adolescent needs among adult care providers.[9] Young people in Europe and the USA often noticed a lack of information and preparation about the transition process whilst in paediatric care, leaving them feeling unprepared for transition.[15,23] Additionally, young people report limited access to disease experts during the transition process.[9]

3. Psychological barriers

Young patients experience reluctancy around leaving their paediatric care team and they can be slow to build new relationships with adult care providers.[9] Without sufficient support, caregivers can be hesitant to transfer more autonomy to their child, especially when information and guidance throughout transition is missing.[9,23] A European study found that when young people report a lack of information and preparation regarding the transition process while still in paediatric care, this can result in fears and worries about the transition, notably related to having a new care team, not being noticed by the healthcare providers, worries about infections and quality of care. The study reported that young people feel less supported in adult care settings, which in turn can have substantial psychological impacts.[23]

4. Healthcare system and structural barriers are prevalent across the transition journey

Across EU countries, there is an absence of sufficient financial support for rare disease transition programmes and lack of qualified care structures close to home.[24] Young people going through transition of care in Europe receive less support in adult care settings compared to paediatric care.[23] Reasons for this could be due to lack of time, physician shortage and insufficient funding for adult rare disease services.[24] Issues such as the loss of ancillary staff, healthcare culture differences between paediatric and adult care teams, the administrative burden of the transition process, and the transfer of insurance coverage can be significant barriers to a "good" transition.[9]

What emerges from the literature is a picture of young people living with a rare disease encountering a critical stage of their healthcare journey often without the clarity, support, or continuity needed to ensure the best outcomes. These gaps are consistent across rare diseases and countries, and their consequences can be significant - ranging from loss of confidence and disengagement from care to poorer clinical outcomes and increased healthcare utilisation, with a resulting economic burden.

Together, the findings also point to opportunities for change: approaches that build readiness, strengthen communication, enhance confidence, and support mental wellbeing. These findings align closely with the lived experience shared by the Rare Horizons Steering Committee and shape the recommendations that follow.

Exploring the Rare Horizons Areas of Focus

In September 2025, the Rare Horizons Steering Committee convened to examine the challenges facing young people in rare disease transition and to identify where Rare Horizons can contribute most effectively. Guided by its mission and principles, the Committee prioritised the following focus areas:

Psychosocial Support: Taking a Holistic Approach to Transition

Across the Steering Committee's discussions, there was a powerful shared understanding that transition is not simply a clinical handover - it is an important psychosocial milestone. For adolescents and young adults living with a rare disease, this period brings a complex mix of emotional, social, developmental, and identity-related changes such as becoming capable in their own care that traditional healthcare structures and transition processes are not always designed to support.

> *At this time, they are navigating how they can be accepted as a young person living with a disease. They need support on how to present that information, how to express openly how they feel so they don't feel like they have to mask pain or their experience.*
>
> ***Sine Lyons, Psychotherapist specialising in children with chronic disease - Denmark***

The Committee emphasised that adolescence is a time of transformation beyond the clinic. In the context of the initial adult-service appointment, the Committee advised avoiding in-depth medical discussions or introducing additional stressors. This approach allows healthcare professionals to focus on getting to know the patient, building trust and rapport, and establishing a strong foundation to support the individual's transition process. Young people are navigating shifts in education, employment, relationships, housing, independence, identity, and social belonging, all while adapting to new expectations within adult healthcare. Members described psychosocial support as the "red thread" running through nearly every challenge raised, and that it should be an essential foundation rather than a supplementary feature.

Yet across Europe, psychosocial support for young people in transition remains variable, underfunded, and insufficiently integrated. The Steering Committee highlighted shortages of trained therapist, psychotherapists and transition patient navigators with experience supporting adolescents and young adults with complex, long-term conditions. Even where psychological services are available, capacity constraints often leave young people without timely or consistent support at the moments when it is most needed. Therefore, it is important to consider video consultations, regular check-ins every 3–6 months, and the rescheduling of missed appointments, as these measures help build trust and continuity between healthcare providers and patients. As transition is a process that varies in duration and complexity depending on the individual characteristics and context, continuity of support is essential to the psychosocial sustainability of any intervention.[25]

In this context, peer-to-peer support emerged as a valuable and effective strategy. Approaches such as transition buddies, youth mentoring schemes, and peer-led workshops offer young people emotional validation, shared understanding, practical advice, and a sense of belonging that clinical environments alone cannot always provide.

However, patient organisations - who frequently lead or facilitate this type of support - face significant capacity challenges. Many are run by small teams or volunteers, with limited time, resources and funding.

There is an opportunity to provide guidance and case studies of pragmatic, scalable approaches that outline an ambition for the kind of psychosocial support that should be provided during the transition process, whilst acknowledging resource limitations and designing a collaborative approach with roles played by clinical and patient group partners.

> *Guidance and tools need to be adaptable: from low resource settings to high resource settings. Practical tools that rare disease partners who are often rich in ideas but limited in time - can readily pick up and implement.*
>
> ***Fiona Brennan Psychologist & Independent consultant to European Haemophilia Consortium & the Institute of Policy Advancement Ltd -Ireland***

The Essential Role of Caregivers

The Steering Committee also acknowledged that caregivers experience their own psychosocial transition. Moving from a hands-on caregiving role to a more supportive, advisory one can be emotionally challenging, particularly when the transition process lacks clarity or structure and sufficient communication to caregivers.

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> *Teens don't always want to be bothered by their disease; they just want to live their life. But there can be little "red flags" you may not have experienced before that can indicate progression of the disease and which need to be addressed. Young people need help knowing what they should be looking out for.*
>
> *That's where patient organisations can help – working on a shared approach with the hospital team to help build that awareness and proactivity. Which acknowledges the reality that the adult service may only be able to provide thirty minutes a year with a consultant."*
>
> ***Tenna Toft Sylvest, – President, XLH, arvelig rakitis - Denmark***

Committee members underlined three caregiver-related needs:

1. Support to "step back" safely and gradually
Caregivers can struggle with "letting go" - not out of reluctance, but out of concern for their child's wellbeing and the uncertainty of adult services and the support available to empower the young person to engage proactively.

2. Confidence that the young person is ready and engaged
Caregivers need reassurance that their child has the skills, self-efficacy, and support network to manage treatment, attend appointments, and advocate for themselves. Committee members highlighted the importance of providing additional support to parents, including walking them through what to expect during the first clinic appointment and offering reassurance to help them feel confident and comfortable in "letting go" as their child transitions to adult care.

3. Flexible involvement
Families need approaches that allow for varying levels of caregiver involvement depending on the young person's readiness, confidence, health status, and preference. This approach requires clear and ongoing communication with caregivers about changing responsibilities, ensuring involvement is responsive to the young person's readiness. Transition should not force premature independence nor perpetuate dependence; instead, it should support a graduated shift in roles tailored to each patient's needs with appropriate communications to the caregiver on the approach.

Across all discussions, the Committee consistently returned to a central insight: effective transition must recognise and respond to the whole person. Psychosocial needs cannot be separated from clinical needs, because transition is not just a healthcare event - it is an emotional, social and developmental one.

Supporting young people to build identity, self-efficacy, resilience, and emotional safety is essential to ensuring that they enter adult care empowered to proactively manage their health and participate in shared decision-making. How young people understand their condition, whether as an integrated part of their identity or separate, shapes how they manage their health and engage with care. This concept influences how confidently they present themselves to an adult healthcare team, how they articulate their needs, and how actively they participate in decision-making.

> *One adolescent patient will say 'I'm not a child anymore, and they talk to me like I'm a child'. And another will say 'they were using a lot of difficult words and I'm not an adult just yet.'*
>
> *You do your best but it's not perfect for everyone. We need tools to help clinicians approach that, working alongside caregivers.*
>
> ***Greta Mulders, Nurse Practitioner, Haemophilia Treatment Centre, Erasmus University Medical Centre. Board Member, Dutch Association of Haemophilia Nurses - Netherlands***

System Navigation Tools: Guiding Young People Through Adult Care Pathways

The Steering Committee emphasised that young people living with a rare disease face a healthcare landscape that becomes more fragmented, less coordinated and can feel less personal as they move into adult services. The Committee agreed that clear, practical, and intuitive navigation tools are essential to help young people build the confidence needed to navigate adult care. Together, these tools can support a shared understanding of transition readiness, helping to align young people, clinical teams, and care systems before, during, and after transfer to adult services.

> *Teens have questions and they need a safe space: to say that they don't feel ready, or they want to meet the adult doctors one more time before transfer.*
>
> *It's a big change; in paediatrics you can have one doctor for everything. Then all of a sudden, you're thrown into a new world with all these "-ologists" and it can be very daunting and confusing.*
>
> *We need spaces and processes to check in with young people to make sure they are OK. I hear a lot from teens that they don't feel listened to and they don't feel heard. They need support to voice their opinions.*
>
> ***Zoe Glasgow, Teen Co-ordinator, Turner Syndrome Support Society - UK***

A core theme across discussions was the need to strengthen paediatric-to-adult handovers - not as a single event, but as a gradual and structured process that promotes trust, understanding, and continuity. Members stressed that a warm handover is ideally not simply a transfer of information between clinicians; it is a relational bridge to support young people and helps prevent emotional stress, anxiety and psychological trauma.

To achieve this, the Committee highlighted the importance of creating safe spaces where paediatric and adult teams can connect meaningfully with young patients. These spaces allow adult clinicians to observe how paediatric teams communicate with adolescents, understand their developmental needs, and build rapport before transfer of care.

> *"Transition is rarely a one-way street. There must be the flexibility to go back and repeat a step of the process. And you need a point person to help navigate that. A care co-ordinator or care navigator that the patient can easily access and talk to who helps assess their needs and experience of the process.*
>
> *Even after the handover to the adult team – some patients may need additional care in paediatrics so that communication is so important."*
>
> ***Dr. Sebastian Neggers, Consultant in Medicine and Endocrinology, Erasmus University Medical Centre - Netherlands***

The Steering Committee also noted the need for practical examples of how warm handovers can be designed and implemented across different settings and resource levels. "Transition days," held in non-clinical environments such as youth centres or community spaces, were cited as effective models. These events can combine informal activities, introductions to adult teams, peer support, and practical demonstrations of what adult care will involve. Beyond structured transition activities, it is important that patients have clear and reliable means of contacting their healthcare team in the event of an emergency. Where patients are unable to attend a scheduled clinic appointment, they should not be removed from care immediately, as there may be mitigating circumstances. Together, these measures help to promote continuity of care and ensure consistent, well-coordinated handovers between paediatric and adult services.

Furthermore, the Steering Committee emphasised that transition and adolescence should be understood as ongoing processes, grounded in authentic communication over time. Through this process, young people learn to navigate adult care pathways while developing core skills such as negotiating personal space and boundaries, participating in decision-making, and building health self-efficacy. Navigation tools, open questions, and supported conversations were identified as key enablers in preparing young people for transition, as they create the conditions for exploring questions of identity, independence, and responsibility. These conversations can be initiated by care coordinators, parents, clinicians, and other healthcare providers.

Importantly, members emphasised that transition is rarely linear. Young people may progress through transition at different paces, encounter setbacks, or require varying levels of support depending on life circumstances, mental health, education, or work commitments. A flexible approach is essential - one that includes post-handover check-ins to ensure continuity, catch emerging issues early, and re-engage young people who feel lost or overwhelmed.

Across all discussions, the Committee identified a common need: scalable best-practice approaches to help patient organisations and clinical teams develop bespoke navigation tools that empower young people to proactively engage with their new adult services and clinicians. Sharing adaptable templates, case studies and models can reduce duplication and help time-poor patient organisations bring their ideas to life at pace, as well as drawing on best practices or proven approaches implemented elsewhere.[26]

> *"It's a vital role of the paediatric team to give a holistic view of the patient. The medical transfer of knowledge but also insight into social and psychological aspects of that young person. Adult teams can lack the time to build that understanding. Also to manage expectations of how much autonomy that young person is ready to take on. Sometimes there can be an expectation that they will immediately attend appointments on their own, but not everyone is ready to do that.*
>
> *Then ongoing communication between paediatric and adult teams post-transfer is critical so the patient feels that continuity of care. Care co-ordinators can be amazing in this role, but it's not always possible to fund them for every service. So, we need a collaborative approach."*
>
> ***Dr. Sonata Šaulytė Trakymienė, Paediatric Haematologist/ Oncologist, Vilnius University - Lithuania***

Data and Evaluation: Building the Evidence Base for Transition Funding

In the Steering Committee's discussions, a clear theme emerged: transition cannot improve without data that demonstrates the impact of "good" transitions on the broader health system. Members agreed that while psychosocial support and navigation tools are essential, these elements cannot be sustainably resourced unless services can demonstrate their impact.

Committee members described the current state of transition data collection as fragmented and inconsistent. There is no shared view of what should be measured, no agreed minimum dataset, and no reliable way to compare experiences or outcomes across hospitals or regions. As a result, services can struggle to evidence the value of structured transition, identify gaps, or make a strong case for investment.

> *Currently, the definition of a 'good' transition is not very clear. And there's no consistent tool to measure this. There is work to be done in evaluation post-transition.*
>
> ***Dr. Sebastian Neggers, Consultant in Medicine and Endocrinology, Erasmus University Medical Centre -Netherlands***

The Steering Committee emphasised that meaningful measurement requires a combination of quantitative and qualitative information, capturing not only whether transition processes occurred are aligned to best practice guidelines, but whether they improved young people's experience, confidence and ultimately health outcomes. It's necessary to build a baseline with typical data from the transition process to subsequently measure the impact of improvement initiatives implemented across every aspect of the transition, justifying greater investments and identifying the most widely shared impact points. These drivers become crucial in decision-making processes regarding regulations, funds, investments, and implementation plans that are as widely shared as possible across different contexts internationally, because we must also consider the ever-increasing mobility of people.[27]

> *While clinic attendance is often used as a marker of successful transition, it overlooks many critical elements of the young person's experience. Attendance alone does not tell us whether the young person understood the role of the clinician they met, how they experienced arranging and attending the appointment independently, or whether they felt comfortable raising any concerns they may have.*
>
> *Similarly, medication adherence is important, but it does not indicate whether young people are meaningfully engaged in shared decision-making. These are less tangible, harder-to-measure aspects of transition but are key to evaluating its success and in empowering young people to take an active role in their healthcare going forward.*
>
> ***Fiona Brennan, Psychologist & Independent consultant to European Haemophilia Consortium & the Institute of Policy Advancement Ltd - Ireland***

Quantitative indicators such as attendance at the first adult appointment, drop-out rates, treatment adherence, and acute care utilisation provide insight into continuity and outcomes. Qualitative insights - including young people's sense of readiness, confidence, decision-making capabilities emotional safety, and engagement – can reveal aspects of transition that numbers alone cannot capture. Together, these measures help define what "good" transition looks like in practice and ongoing gaps that may need a new approach.

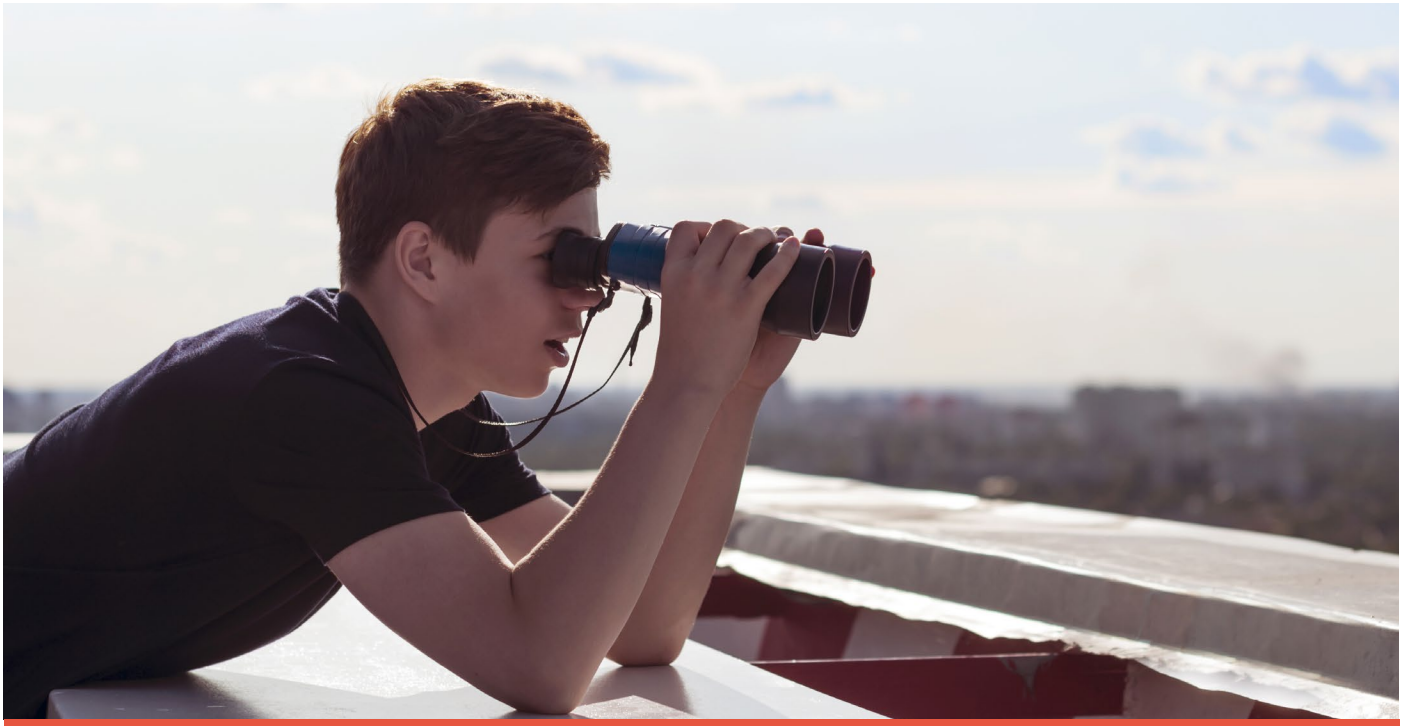
Members noted that many services do not routinely collect these data because they lack practical tools, clear expectations, and examples of what effective measurement looks like in rare disease. Patient organisations may gather valuable qualitative insight but can lack the capacity to structure or report it in ways that influence service improvement or funding decisions.

A strong message from the Steering Committee was that transition should be viewed as a system responsibility. When hospitals and commissioners take ownership of transition through defined objectives, monitoring processes, and budgeted roles, services are better able to reduce drop-out, support adherence, and provide continuity of care.

Across the discussion, members identified an important opportunity for Rare Horizons: to surface, share, and elevate examples of best practice in transition measurement. These might include simple minimum datasets used successfully by individual centres, creative methods for capturing youth experience, or quality-improvement approaches that link transition processes to outcomes.

> *We stopped looking at transition through the lens of individual diseases and took a system-wide approach. When you see transition as a hospital responsibility rather than a fragmented set of practices you find commonality of need across different diseases and how resources can be shared.*
>
> *By counting how many young people were transitioning, how many appointments they needed, and what support they required, we had the evidence to propose dedicated funding.*
>
> *Taking a system approach made it a system priority. A unified transition pathway and the support of hospital leadership enabled us to make changes to hospital-wide processes, such as how we reimburse clinician attendance at handover meetings, changes to discharge records, even how we incentivise colleagues to be part of this project.*
>
> *A system response can be complicated, but it's possible and we have learned so much on how to make it work. There are many learnings to share across diseases and systems.*
>
> ***Dr. Raffaella Colombatti, Paediatric Haematologist-Oncologist, University of Padova - Italy***

By highlighting what works and how it has been implemented, Rare Horizons can help services adopt practical approaches without needing to build measurement systems from scratch.



What's Next?

Rare Horizons is at the beginning of a multi-year journey. The evidence from the literature and insights from the Steering Committee highlight the need to address unmet needs, for better psychological support, improved navigation tools and shared measures of success.

Over the coming years, Rare Horizons will work together in partnership with adolescents, caregivers, clinicians, patient and health organisations and wider health system stakeholders to translate these priorities into practical frameworks and adaptable tools. The next phase will further explore transition approaches that support system readiness for care through evidence-based models, while ensuring sustainability and efficient use of resources, thereby enabling long-term adoption within health systems and funding frameworks.

This position paper establishes the foundation for the collaborative work and marks the starting point for co-creating a new shared standard of transition across the rare disease ecosystem.

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