Sickle Cell Transitions
Policy Lab

Charter for optimal transitions from paediatric to adult care in sickle cell disease

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The Sickle Cell Policy Lab chairs

- **Jenica Leah,** President, European Sickle Cell Federation (ESCF), UK
- **Lora Ruth Wogu,** Chief Executive Officer, European Sickle Cell Federation (ESCF), Ireland
- **Dr Mariangela Pellegrini,** Educational & Patients Program Manager, European Reference Network on Rare Hematological Diseases, European Reference Network on Rare Hematological Diseases, ERN-EuroBloodNet, France

The Sickle Cell Policy Lab

- **Dr Anna Collado Gimbert,** Consultant Paediatric Haematologist, SCD transition expert, Vall d'Hebron University Hospital, Barcelona, Spain and European Reference Network on Rare Hematological Diseases, European Reference Network on Rare Hematological Diseases, ERN-EuroBloodNet
- **Prof. Antonis Kattamis,** Professor of Paediatric Hematology-Oncology, National and Kapodistrian University of Athens, Greece and European Reference Network on Rare Hematological Diseases, European Reference Network on Rare Hematological Diseases, ERN-EuroBloodNet
- **Prof. Caterina Minniti,** Consultant Paediatric Haematologist, Albert Einstein College of Medicine, New York, USA
- **Dr Gabriela Medin,** Paediatric Psychologist, Hospital General Universitario Gregorio Marañón, Madrid, Spain and European Reference Network on Rare Hematological Diseases, European Reference Network on Rare Hematological Diseases, ERN-EuroBloodNet
- **Hannah Jerman,** SCD Nurse Specialist, Guys and St Thomas' NHS Foundation Trust, London, UK
- **Hayley King,** Founder, Cianna's Smile, UK
- **John James OBE,** Chief Executive, Sickle Cell Society, UK
- **Dr. Kofi Anie,** Consultant Psychologist, London North West University Healthcare NHS Trust, London, UK
- **Dr María del Mar Mañú Pereira,** Head of the Rare Anemia Disorders Research Laboratory, Vall d'Hebron Research Institute & University Hospital, Barcelona, Spain and European Reference Network on Rare Hematological Diseases, ERN-EuroBloodNet, Scientific Coordinator & ENROL/RADeep Coordinator
- **Miriam Santos Freire,** SCD Patient and Patient representative, ESCF, UK/Portugal, and European Reference Network on Rare Hematological Diseases, ERN-EuroBloodNet, Portugal
- **Nedda Al-Ammar,** SCD Patient and Patient Representative, Sweden
- **Nowell Ngwenya,** SCD Nurse Specialist, St. James's Hospital, Dublin, Ireland
- **Dr. Samah Babiker,** Consultant Paediatric Haematologist, Guys & St Thomas' NHS Foundation Trust, London, UK
- **Dr Sara Stuart-Smith,** Consultant Adult Haematologist, King's College Hospital NHS Foundation Trust, London, UK
- **Dr. Valentine Brousse,** Centre de Référence MCGRE, Service d'Hémato Immunologie, Hôpital Universitaire Robert-Debré, APHP, Paris, France and European Reference Network on Rare Hematological Diseases, ERN-EuroBloodNet

The Lived Experience Council

- **Aghate Wakunga,** Patient Representative, ESCF, Italy
- **Alonso Soto,** Patient Representative, ESCF, Spain
- **Awa-Edwige Kekeh,** Patient Representative, France
- **Awa Touré,** Patient Representative, France
- **Bintou Kanté,** Patient Representative, France
- **Cianna Bent,** Patient Representative, UK
- **Daniels Afekhai,** Patient Representative, Ireland
- **David-Zacharie Issom,** Patient Representative, ESCF, Switzerland
- **Divine Osumbu,** Patient Representative, Germany
- **Elvie Ingoli,** Patient Representative, ESCF, Germany
- **Grace Luau,** Patient Representative, Sweden
- **Hawa Diakite,** Patient Representative, France
- **Janet Idowu,** Patient Representative, ESCF, Ireland
- **John Lawal,** Patient Representative, ESCF, Ireland
- **Joseph Ajayi,** Patient Representative, ESCF, Ireland
- **Mary Shaniqua,** Patient Representative, ESCF, UK
- **Mélissa Compere,** Patient Representative, France
- **Mimie Minsiemi Maboloko,** Patient Representative, ESCF, Belgium
- **N'Dita Okouma Leboussi,** Parent Representative, France
- **Nell Tsang-Sam Moi,** Patient Representative, France
- **Olu Loremikan,** Patient Representative, UK

Foreword

Across Europe, thousands of young people living with Sickle Cell Disease (SCD) face preventable threats to their health and independence during the critical transition from paediatric to adult care. This period is meant to be a step forward in autonomy. However, it is too often characterised by systemic fragmentation, inadequate preparation, and avoidable clinical risks.

Many young adults feel isolated, unprepared, or even unsafe during the transition, as adult systems lack specialist knowledge and cohesive care pathways.[1,2] Poorly managed transitions lead to higher rates of hospitalisations, disease complications, and disengagement from care; outcomes that are particularly concerning for a population already facing stigma, socioeconomic barriers and systemic health inequities.[1,3]

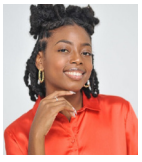
Disparities in the transition experience across Europe are stark. While some centres offer comprehensive, structured programmes, others leave families to navigate this complex shift alone, creating inequalities in care.[2] And SCD is not alone in this challenge. Young people with chronic and rare diseases face similar barriers, making this a pressing, cross-cutting issue in health policy.[4]

For policymakers, the case for investment is clear: early, structured, and person-centred transitions not only improve health outcomes, but they also readuce emergency care use, and protect years of prior investment in paediatric services.[2,4]

The SCD Transitions Policy Lab was launched to find practical solutions to this urgent issue. Bringing together patient representatives, advocates, clinicians and system experts from across Europe, we co-developed solutions grounded in the lived experience of SCD and the operational realities of health systems. The resulting Charter clearly defines an optimal transition that all people with SCD should experience, wherever they live, and outlines essential steps to deliver holistic, coordinated, and continuous care.

We now call on decision-makers at all levels to act. The tools and knowledge already exist, but sustained leadership and targeted action are needed to scale effective models and reduce variation. By embedding structured transitions into national plans, specialist pathways, and workforce training, we can improve outcomes for thousands of young people and set a new benchmark in chronic and rare disease care.

Chairs, Sickle Cell Transitions Policy Lab

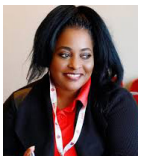


Jenica Leah

President, European Sickle Cell Federation (ESCF), UK

Dr Mariangela Pellegrini

Educational & Patients Program Manager, ERNEuroBloodNet, France



Lora Ruth Wogu

Chief Executive Officer, European Sickle Cell Federation (ESCF), Ireland

Section 1

Why is the transition from paediatric to adult care important in sickle cell disease?

1.1 What is sickle cell disease?

Sickle cell disease (SCD) is a life-threatening inherited blood condition that has been designated as a public health priority by the World Health Organization (WHO).[1] It affects haemoglobin, the protein in red blood cells that is responsible for carrying oxygen around the body. SCD is caused by a genetic mutation in the haemoglobin gene, and results in the production of abnormal haemoglobin. The abnormal haemoglobin causes the red blood cells to become crescent or sickle shaped and rigid, instead of being round and flexible like normal red blood cells.[5,6] These sickle shaped red blood cells can obstruct blood flow, leading to painful episodes called vaso-occlusive crises (VOCs), chronic haemolytic anaemia, organ damage, and an increased risk of infections.[7-9] SCD is most common in individuals of African and Caribbean descent, it can also occur in other populations with a history of malaria exposure, such as Middle East, parts of India, the eastern Mediterranean, and South and Central America.[10]

While SCD is considered a rare disease in Europe, the number of people living with the condition is steadily growing.[10] The number of people living with SCD globally has increased by 41·4%, from 5·46 million in 2000 to 7·74 million in 2021.[11] Owing to recent decades of increased population movements, the number of people living with SCD is also steadily increasing in Europe.[10] With a European prevalence of approximately 30 cases per 100,000 people, SCD is the most prevalent genetic disease in France and the UK.[10]

Advances in newborn screening, preventative measures and disease-modifying therapies have significantly improved survival for children with SCD in many high-resource countries. Comprehensive measures such as prophylactic penicillin, vaccinations and stroke prevention have further reduced mortality and morbidity.[10] In the past decade, the widespread use of hydroxycarbamide and red cell exchange has led to substantial improvements in life expectancy in many European countries.[10,12] As a result, an increasing number of people with SCD will transition from paediatric to adult care, where the disease continues to carry significant complications.

1.2 What is the transition?

What do we mean by transfer?

A transfer refers to the switch from paediatric to adult care.[13]

What do we mean by the transition into adult health and social care services?

The transition, however, is much more than transferring a young person's care from children's to adults' services, and is defined as "the purposeful, gradual, planned process of transferring a young person's healthcare from a child-centred to an adult orientated care setting that comprehensively addresses the medical, psychosocial, educational and vocational needs of that young person."[14] Transition is not specific to SCD and presents a key period of care for young people living with chronic and life-long conditions as they move to adulthood.

When should the transition occur?

The transition process should ideally start well in advance of the designated age of transfer as outlined in individual hospital or national policies. This approach ensures that young people receive timely and personalised transition support as they move between different care settings. This transition framework recommends beginning **at least two years** before transfer. However, transition planning and initiation should also consider factors such as disease severity, the young person's development, self-management skills and psychosocial needs. skills, and psychosocial needs.

During the critical period of transition from paediatric to adult care, there is a concerning rise in mortality among young people with SCD who are aged 18 to 26 years. This is partly due to the accumulation of organ damage, complications related to disease progression, inadequate access to care, differing models of care in adult settings, reduced medication adherence, and numerous other contributing factors.

However, the issue is poorly understood in Europe. The rise in mortality in this age group has been seen in the US over the past 50 years *(see Figure 1)*,[3] but data on these shifting mortality patterns in Europe remain sparse. The limited availability of data means that medical and patient communities are only now beginning to understand the full extent of this issue and the many systemic factors that contribute to it.

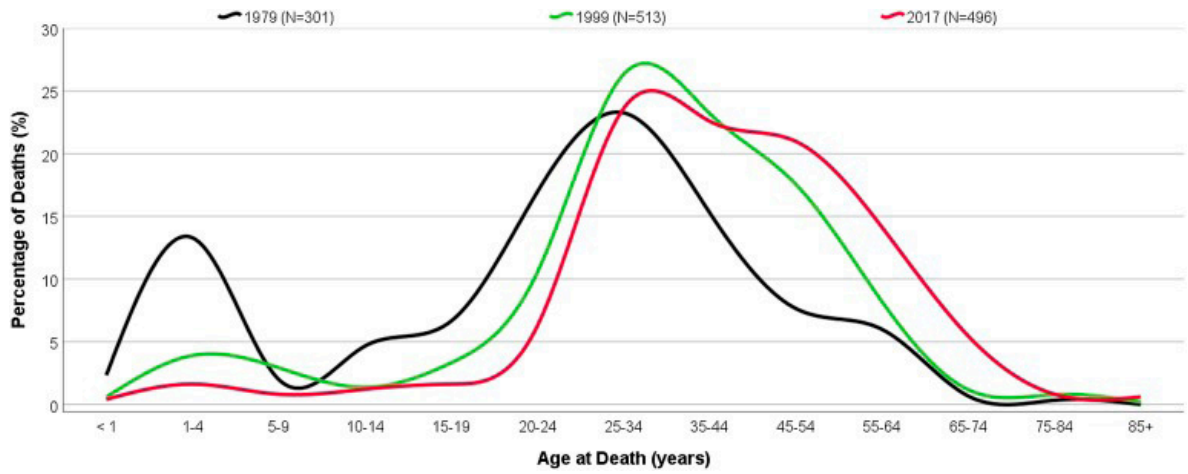


Figure 1: Proportion of deaths among individuals with SCD by age group in the US.
Source: Saulsberry et al., 2019

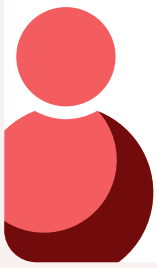
The transition from paediatric to adult care is a gradual process, and preparations should begin early. This process aims to empower young people by helping them understand their condition, know the standard of care they should receive, and be aware of the support available to them. It also ensures that young people can advocate for themselves within the adult health system.[15]

Across Europe, the process generally occurs between the ages of 14 and 25, but preparations for transition can begin when the person is as young as 11 or 12, as recommended in the UK, Germany, Spain and Ireland *(see Table 1)*. The age of transition preparation and transfer varies widely across Europe, reflecting differences in health systems, policies, resources and each young person's individual readiness to transition effectively.

1.3 What is the current transition landscape in Europe?

Some countries have well-established protocols and specialised transition programmes, but implementation and quality of the transition is not guaranteed. Some countries have specific SCD guidelines for transition. In contrast, others incorporate transition into existing chronic disease or other health policies (also see Best practices - Develop clear policies and guidelines), and others have no plans *(see Table 1)*.

Overall, there remains a significant variation in how SCD transition is included in official guidelines, what is included in these guidelines, and whether they are nationally endorsed.[1] Even if formal policies are in place nationally, their implementation and effectiveness 'on the ground' is not guaranteed.[16] This is exemplified by the testimony below from the UK, which has produced SCD-specific clinical guidelines for transition, but their application remains uncertain.



"There's been very much a lack of support or the support has been non-existent, she [the patient] had a video call with her nurse from the clinical side but there was no support during secondary school."

Hayley King, Parent of a SCD Patient, UK

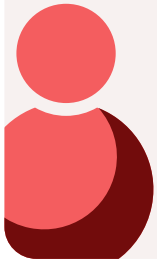
Moving from general transition guidelines to SCD-specific guidelines

In Germany, a general guideline for the transition from paediatric to adult care has been developed by the German Society for Transition Medicine (GSTM). This guideline contains general recommendations covering all aspects of transition that should be considered in all patients, regardless of the underlying disorder.[17] This general guideline was reviewed and endorsed by all major German medical societies in 2021.

However, further work in Germany has focused on transition in rare diseases,[17] and specifically transition for people with SCD. A consensus statement was developed and endorsed by a multidisciplinary panel of experts as a first step.[18] It is hoped that this initiative will eventually provide a foundation for a dedicated transition programme for people with SCD in Germany.[19,20]

Variations in transition policies, systems and infrastructure contribute to the lack of consensus on an optimal, formalised SCD transition process across Europe. The boundaries between paediatric and adult care, particularly the age of transfer, vary widely between countries and regions; therefore, guidelines that can be adapted nationally are needed.[7] The adult health system is poorly equipped for the new and growing population of adults with SCD. Whilst paediatric care for SCD is typically well-coordinated, comprehensive and specialist-driven, adult care can sometimes be less integrated without the same level of specialised SCD knowledge. Therefore, the onus of care coordination can often fall upon the young person with SCD, resulting in suboptimal and poorly coordinated care with an increased risk of death.[3]

Poor transitions lead to poor clinical outcomes. People with SCD describe drastically different experiences of care, including transitioning at inappropriate times and often too late, for example, when they leave for university or college. This leaves them without much-needed support during periods of change, and leads to deepening potential disparities in health outcomes and quality of life.[19]



> "With the children's clinic, you get a bit more support and a lot of people are a bit more interested in what's going on with you. But when you are transitioned into the adult clinic, you are expected to know every single thing about what's going on with your health. Which, of course, you should, but during that transition, it might be a bit confusing for a lot of people that have been dependent on other people for a long time."
>
> **Joseph Ajayi, Patient Representative, Ireland**

"My experience with the transition was a bit better [than other peoples']. I think we had a few meetings from the paediatric hospital and were introduced to adult services, where we met a few of the staff on the sickle cell team. We also got to go to the adult hospital to visit."

Daniels Afekhai
Patient Representative, Ireland

"For Germany, the national awareness about sickle cell disease is not really there. There are still not many physicians who know about SCD, which means that adult patients are still treated in paediatric clinics."

Elvie Ngoli
Patient Representative, Germany

"In my case, I never had a real transition. In Switzerland, I think we had the worst practice because there was no transition. It was about being transferred from paediatric care to trying to find an adult specialist by yourself, which was not easy. It took a lot of time to find a good one, which I still have for now."

David-Zacharie Issom,
Patient Representative, Switzerland

"[We need to] educate and advocate for better care outside of Paris, in small towns'

Ousmane Camara,
Patient Representative, France

Table 1: Comparison of epidemiology and clinical SCD transition protocols across selected European countries

Country	Epidemiology	Clinical transition protocols							
	Number of people living with SCD	Is there a SCD-specific clinical guideline for transition? (Y/N)	Are there other guidelines that could cover SCD transition? (Y/N)	When do guidelines recommend transition preparation begin? (Age in years)	Timeline for transition within the guidelines (Age in years)	Is primary care involved? (Y/N)	Is specialist care involved? (Y/N)	Are health records updated and transferred appropriately? (Y/N)	Is monitoring post-transfer included? (Y/N)
United Kingdom [i]	17,000	Yes	Yes - chronic disease	11-13	16+ (review at 15-16; some centres may require 16)	Y	Y	Y	Y
France [ii]	21,668	None found	Yes - rare diseases	14-16	18	Y	Y	Y	Y
Germany [iii]	2,000	None found	Yes - chronic disease	11-16	18	Y	Y	Y	Y
Italy [iv]	7,977	None found	None found	Unknown	16-18	-	-	-	-
Spain [v]	1,300	Yes	Yes - chronic disease	12	16-21	Varies across different autonomous communities	Y	Y	Y
Portugal [vi]	2,000	No – however hospitals may have their own guidelines	Yes	Unknown	18-20	N	Y	Y	Y
Greece [vii]	1,032	None found	None found	Unknown	-	-	-	-	-
Ireland [viii]	600	Yes	Yes	12	18-20	Y	Y	Y	Y
Sweden [xi]	584	None found	None found	Unknown	-	-	-	-	-

Sources for different countries: [i] United Kingdom: Sickle Cell Disease in Childhood: Standards and Recommendations for Clinical Care.[21] [ii] France: Guidance based on the DREPADO study. Hoegy et al., not an official guideline HCT/HCT specific to SCD.[22,23] SCD-specific guideline mentioned in the French General Paediatric Guidelines, PNDS, page 25.[23] [iii] Germany: Does not have SCD-specific CPG only German Society for Transition Medicine for chronic disease.[19] [iv] Italy: Guidance based on Study by Elli et al., Italy does not have a SCD-specific or chronic disease HCT CPG.[24] [v] Spain: Guía de Enfermedad de Células Falciformes (SCD Guide).[25] [vi] Portugal: Epidemiology data[3] [vii] Greece: Epidemiology data 26 [viii] Ireland[27] [xi] Sweden: Epidemiology data[28]

Section 2

What are the components of an optimal transition?

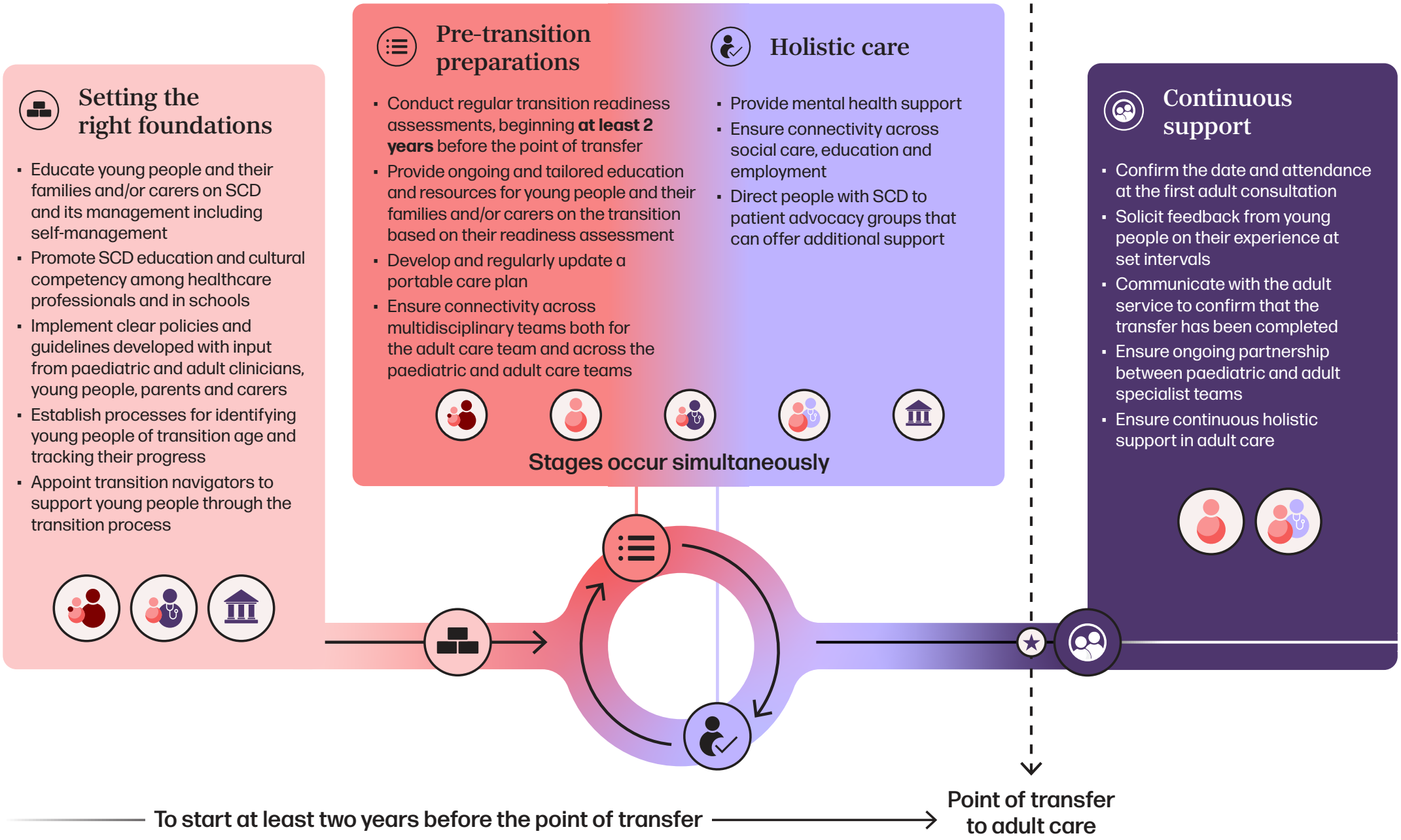
An optimal transition should ensure a seamless, coordinated and compassionate healthcare journey that enhances both mental and physical well-being.[29] It should feel smooth and adaptable to the patient's evolving needs while providing support during potential crises across all healthcare settings and stages of the journey, ensuring consistency and continuity of care.

These components aim to enable healthcare decision-makers to shape health systems to better provide quality care and support for people with SCD as they transition from paediatric to adult care. The components outline an evidence-based and consensus-driven vision to bridge the gap between paediatric and adult care for young people living with SCD. While it may be challenging to achieve all components in every country, our recommendations are designed to provide a 'gold standard' to work towards to improve the standards of care across Europe. The following sections outline how this approach can become a reality, together with a *'bank of case studies'*, which provide useful resources and examples of best practice from around the world *(see the section on Best practices)*.

The Policy Lab and Lived Experience Council call for all European health systems to commit to the fundamental components of the transition, and to improve transition for all people with SCD.

Charter for optimal care transitions in sickle cell disease

Components of a quality transition from paediatric to adult care for people with sickle cell disease



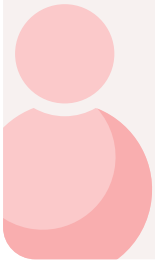
Section 3

How can we make optimal transition a reality?

3.1. Setting the right foundations

"Transition is a product of a process that starts during childhood, paying attention to inform the children in a proper way, that allows them to find a way to deal with their chronic condition and care. Talking to them, avoiding overprotection, noticing their behaviours, leads to developing autonomy seamlessly."

Gabriella Medin, Paediatric Psychologist, Spain



"Many of our members are afraid of the transition because there's a lack of information, communication and education. That's why we focus on therapeutic education for patients, parents and caregivers. It's crucial to provide accurate information to patients from a young age, so they are prepared when it's time to transition to adult care and to help them manage the change."

Mimie Minsiemi Maboloko, Patient Representative, Belgium

Establishing strong foundations for the transition from paediatric to adult care creates a structured, consistent and proactive approach, which ensures that the right systems and policies are in place before pre-transition preparations begin.

At a minimum, every system should:

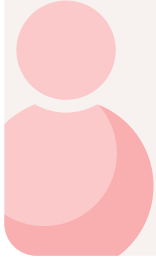
- Educate young people and their families and/or carers on SCD and its management, including self-management
- Promote SCD education and cultural competency among healthcare professionals and in schools
- Implement clear policies and guidelines developed with input from paediatric and adult clinicians, young people, parents and carers
- Establish processes for identifying young people of transition age and tracking their progress
- Appoint transition navigators to support young people through the transition process

These essential components lay the groundwork for a smooth, coordinated and person-centred transition experience for young adults, their families and/or carers, and their healthcare teams.

Early SCD education is central to transition success. Insights from the Lived Experience Council highlighted that young people with SCD require early, structured education about SCD, including their baseline health indicators, navigating health systems, managing their condition independently, family planning, nutrition and physical health, and understanding what to expect in adult care and during the transition from paediatric care. This knowledge must be reinforced and increased in complexity over time to help young people develop independence, autonomy and confidence in their care at a developmentally appropriate rate.[1] Therapeutic educational programmes for young people with SCD, for example, Drépéduc, demonstrate best practices in therapeutic education by providing tailored, multidisciplinary support to help young people understand and manage their condition effectively. Through individual consultations and group workshops led by healthcare professionals, participants receive structured guidance on self-management strategies, treatment options and navigating the healthcare system.[30]

Education should also extend to families and/or carers and schools to reduce stigma and ensure that young people have a supportive home environment that encourages self-management.[31] Integrating structured therapeutic education into transition pathways can empower young people with SCD, improving long-term health outcomes and fostering smoother transitions to adult care *(also see Best practices – Educate young people and their families and/or carers on SCD and its management)*.

Both paediatric and adult healthcare professionals must play an active role in transition planning. This requires adult healthcare professionals to be equipped with the necessary medical knowledge and cultural competency to care for adults with SCD effectively.[7] Beyond clinical expertise, targeted training in effective communication, culturally sensitive care and implicit bias is essential to improve patients' experiences and outcomes. However, many adult care providers in Europe have limited experience of SCD, and may lack the cultural and linguistic competence needed to deliver appropriate, person-centred care.[32,33] There is an urgent need for comprehensive education programmes that train adult haematologists, primary care practitioners and emergency department specialists in both the clinical complexities of SCD and the socio cultural factors that influence care. These programmes should emphasise improving communication skills, addressing health disparities and fostering trust, to ensure that young people feel heard, respected and supported throughout the transition process. Additionally, education should extend beyond the clinical setting to include people with SCD, their families and/or carers and school staff, supporting broader awareness and understanding within educational environments to create a more informed and supportive ecosystem during this critical period.[34] *(Also see Best practices – Educate healthcare professionals on SCD, including cultural competency.)*



"In Sweden, it feels like [the doctors] don't really care, and they don't help much with the pain. But when I was in Zimbabwe, I didn't need to say much because the nurses and doctors already knew exactly what to do. Sickle cell is more common there, so they are more specialised in treating it. The doctors already knew what kind of treatment to put me on, and I didn't have to ask or keep explaining my condition. But here in Sweden, I have to constantly ask and call for help all the time. It feels like they neglect me sometimes."

Grace Luau, Patient Representative, Sweden

Implementing policies and guidelines for the SCD transition provides clarity for both healthcare teams and people with SCD.[31] Clear policies should formalise key milestones, roles and responsibilities in the transition process. They may be developed at a hospital or health system level. They should be developed with input from young people with SCD and their families and/or carers and members of the multidisciplinary team (MDT), and based on evidence and international best practice.[3,35] In a UK report, only 14.7% of organisations (which included primary, secondary, community and mental health providers) had a transition service that actively involved young people in shaping their care, compounding disengagement from services.[14] The policies and guidelines should be written concisely at an appropriate reading level, and available in languages commonly spoken in each SCD clinic population.[3] Making these policies accessible by displaying them in clinics or providing written guides reinforces a shared commitment to a successful transition. Transition policies or guidelines should be shared with young people and their families and/or carers early in adolescence, and revisited periodically.[3] *(Also see Best practices – Develop clear policies and guidelines.)*

A systematic process for tracking transition progress is essential to ensure that key activities such as patient education, readiness assessments and care transfers are completed.[3,29] Structured documentation within medical records or patient registries enables proactive follow-up and allows health systems to measure and refine their transition programmes over time. Establishing standardised criteria and tracking mechanisms to monitor transition progress facilitates timely identification of young people approaching transition age, ensuring proactive and consistent planning across services.[3] The transition tracking and monitoring component of the Got Transition's Six Core Elements of Health Care Transition™, a widely adopted approach that defines the basic components of a structured transition process, highlights the importance of this structured approach in improving long-term patient outcomes.[29] Ideally, tracking should be digitally integrated and interoperable, allowing for continuity if a young person moves within countries, such as to a university or college, as well as to new countries *(also see Best practices – Track transition progress)*.

The appointment of transition navigators or coordinators has been shown to facilitate a smooth transition.[36] These roles act as a single point of contact and a familiar face to facilitate young people with SCD to engage with their new adult healthcare team, organise appointments and provide tools to support treatment adherence. They also help support communication across the adult and paediatric teams and provide all-important continuity and stability across their transition.[7,22] Qualified healthcare professionals and practitioners, including nurses, social workers, physicians and physician assistants, can serve as patient navigators. Trained lay people, such as community workers and patients, can also take on this role. They are often recruited from the target communities, as they better understand local needs and can build trust. Lay workers typically collaborate closely with trained professionals as part of an MDT.[37] When it is challenging to provide in-person transition navigators, remote support, digital health tools, and patient advocacy groups can help meet some of these needs. *(Also see Best practices – Appoint transition navigators.)*

Once these components are in place, health systems can focus on the next phase: pre-transition preparations.

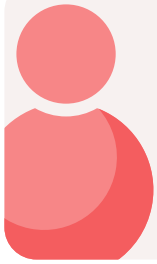
"Learn to listen to the patients. Invisible disability is a real thing, do not minimise it."

Hawa Diakite, Patient Representative, France

3.2. Pre-transition preparations

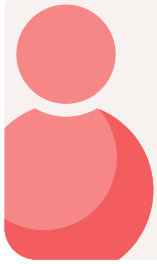
"Early transition planning is critical and serves many benefits. It allows early empowerment by instilling new skills needed to create independence, which will, in turn, improve adherence to medications, therapeutic interventions and monitoring. It can take years to build new skills and habits, therefore early preparation reduces the stress of this difficult period, and consequently leads to better health outcomes."

Dr Samah Babiker, Paediatric Consultant Haematologist, UK



"I had to sit there for hours, in pain, because they didn't know what to do with me. They kept asking me the same questions over and over, and I was too tired to keep explaining."

Nedda Al Ammar, Patient Advocate, Sweden



"Transition is not a [transfer], a sudden and brutal change. It's a process that should be slow, progressive and gradual."

Waly Okouma Leboussi, Patient Representative, France

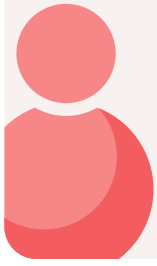
Pre-transition preparations and planning should start as early as possible, and at least 2 years before the point of transfer. This allows for flexibility, tailoring of approaches, considerations around cultural sensitivities, and the use of assessment tools to support young people with SCD and their families and/or carers to best understand how to manage their health and navigate the complexities of the adult health system.

At a minimum, every system should:

- Conduct regular transition readiness assessments, beginning at least 2 years before the point of transfer
- Provide ongoing and tailored education and resources for young people and their families and/or carers on the transition based on their readiness assessment
- Develop and regularly update portable care plans
- Ensure connectivity across MDTs, both for the adult care team and across the paediatric and adult care teams

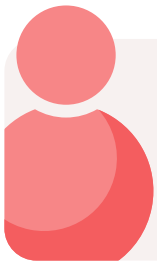
A transition readiness assessment is a critical first step in preparing young people for adult healthcare. Transition readiness assessments should be conducted regularly, beginning with a baseline assessment **at least 2 years before the point of transfer.** This periodic evaluation of key self-management and health system navigation skills alongside clinical and socioeconomic factors will help to identify young people who are at risk of poor transition outcomes and require more intensive transition support.[38] The results of these assessments are used to develop tailored educational interventions to tackle specific areas of need, including knowledge-building, confidence and self-advocacy training. The timing of the assessments depends on the person's age and local healthcare policies or guidelines. There are different questionnaires currently used globally to assess readiness for transition in young people with SCD *(also see Best practices – Conduct regular transition readiness assessments, beginning at least 2 years before the point of transfer).*[38]

Empowerment and self-advocacy skills will increase as education is provided and tailored to the needs of the developing young adult. Individualised education supports increasing involvement in healthcare decision-making.[39] However, as readiness improves with age,[36,38] education must be continuous, adapting to different developmental stages, educational levels and phases of transition. Regular transition readiness reassessments and tailoring education around the outcomes of the assessments help to address evolving needs, reduce anxieties and build confidence for increasingly independent disease management *(also see Best practices – Empower patients and their families and/or carers by providing tailored education and resources).* Providing tailored information and support for families and/or carers is also vital.[40] Information on the transition process, their evolving role from managing their child's care to supporting their child's independence, and key disease-related knowledge, including treatments, side effects and emergency signs, can be hugely beneficial.[40] Families and/or carers should also be informed about available adult care centres, social services and emergency protocols. To ensure effectiveness, education and support must take into account the health literacy, socio-cultural factors and language needs of the young person and their families and/or carers *(also see Best practices – Educate young people and their families and/or carers on SCD and its management).*



"I wonder if there's a guide for parents on how to deal with this before they have to face it. Like, when should I start talking to my child? That question alone causes so much anxiety. When is the right time to tell them they have an illness if they haven't realised it yet? And then later, when they're older, how will that transition to adult care unfold? It would be so helpful to have experiences exchanged between parents or family group meetings where this kind of information is shared."

Alonso Soto, Parent of Child with SCD, Spain



"Parents should be allowed to stay with their kids at the ER and in the hospital [during this process], even if they are over 18."

N'dita Okouma Leboussi, Parent of child with SCD, France

The development of an individual, portable healthcare plan that would be held by the young person, including readiness assessment findings, the young person's goals and prioritised actions, medical summary and emergency care plan, and a fact sheet about SCD is essential for ensuring continuity of care and successful integration into adult care for young people with SCD.[8,41]

These plans provide continuous and coordinated care across health and social care systems, aiming to address each person's unique needs *(also see Best practices – Pre transition preparations).*

An effective healthcare plan should:

- **Be portable:** This allows providers in any health or social care setting to easily access comprehensive patient data, which will increase professional accountability and quick tailoring of care approaches.[41,42] It also allows much better ownership of the information and care plan by the person with SCD, further enhancing the overall experience and health outcomes.[8,41,42]

- **Include emergency scenario planning:** Detailed protocols for managing emergencies specific to SCD, including personalised pain plans, can ensure rapid and effective responses from healthcare professionals unfamiliar with the person with SCD.[42]

- **Include health system considerations:** Realistic assessments of available resources within the person's local health system can identify services and teams that are equipped to care for people with SCD, and outline referral processes to specialist care.[42]

- **Have a framework for evaluation:** A structured framework to evaluate progress and outcomes at various stages of the transition (regular transition readiness assessments) should build upon the baseline transition readiness assessment, capturing metrics for both clinical care outcomes and the psychosocial aspects of the transition.[42]

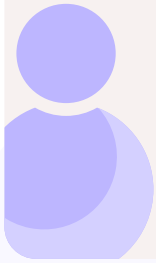
Effective communication between the paediatric and adult MDTs, as well as within the adult MDT, is crucial. Collaborating with the various individuals involved in SCD care necessitates regular and active communication and data sharing.[36] This communication can be enhanced through the implementation of tools such as integrated health records or electronic medical records. In addition, there should be a period of overlap between paediatric and adult care providers, with the roles and responsibilities of the paediatric team decreasing in tandem with the increasing responsibilities of the adult team and regular paediatric-adult multidisciplinary meetings across the transition process. Many young people with SCD and their families and/or carers value a 'joint handover approach', which includes multiple in-person interactions with both clinical teams in a positive and friendly environment.[36] Clear shared-care arrangements are crucial, with a named key contact for emergency and routine advice. The adult MDT must address both medical and psychosocial needs, and include haematologists, specialist nurses, pain specialists, psychologists, neuropsychologists, social workers, physiotherapists, dietitians and transition navigators. Strong collaboration with emergency care providers, GPs, community health services and patient advocacy groups further improves continuity and outcomes.[43] *(Also see Best practices – Ensure connectivity across MDTs both for the adult MDT care team and across the paediatric and adult care team.)*

Once these components are in place, health systems can focus on the next phase: A Person-centred transition.

3.3. Holistic care

"Each individual will develop at different speeds and may need differing levels of support at different stages of transition. It is important to monitor each individual throughout and not use a one size fits all approach."

Hannah Jerman, SCD Nurse Specialist, UK



"During the transition, our studies and in general, in our lives, we have support to treat the consequences of the disease, but not the long-term impact. [We] lack daily support."

Trésor Ntchamba, Patient Representative, France

A holistic approach to transition is essential in managing the move from paediatric to adult care for people with SCD. Multidisciplinary care, coordination and an approach that provides connectivity between all aspects of the lives of young people with SCD can enhance quality of life and other outcomes.

To achieve this, every system should:

- Providing mental health support
- Ensuring connectivity across social care, education and employment
- Direct people with SCD to patient advocacy groups that can offer additional support

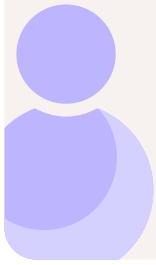
These components will ensure that the transition genuinely meets and adapts to the changing needs of the young person with SCD.

Mental health support provides valuable psychosocial support for young people with SCD and their families and/or carers, and can facilitate a positive transition experience.[36] Support can include healthcare provider-led education, psychological services, and peer interactions facilitated by experienced patient educators.[44] An international survey of adolescents with SCD in the US and UK found worsening physical and psychological symptoms with age and educational level,[45] highlighting the need for tailored psychological care. At a minimum, young people should have access to mental health providers, with psychosocial information shared between paediatric and adult teams. Ideally, mental health professionals should be integrated into SCD care teams, ensuring coordinated, interdisciplinary support that addresses both physical andpsychological needs *(also see Best practices – Provide mental health support)*. However, in contexts where access to mental health providers is challenging, telehealth providers could provide valuable support.

Ensuring connectivity across social work, education and employment is important to address the broader challenges faced by young people with SCD.[10] Collaboration with social workers can help mitigate social determinants of health, such as housing, financial stability and access to essential resources. Education and employment support should focus on ensuring that young adults with SCD have the necessary adaptations and guidance to navigate their career and academic paths successfully[44,46] Both healthcare teams and community organisations can play a crucial role in connecting between these different bodies *(also see Best practices – Ensure connectivity across social care, education and employment).*

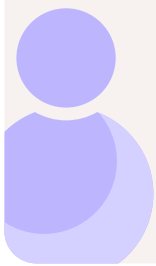
Directing young people and their families and/or carers to patient advocacy groups to receive peer-to-peer and other additional support is integral to facilitating an optimal transition. Community organisations can play a crucial role in providing peer support, advocacy and additional resources to assist young people and their families and/or carers during the transition process. In particular, peer-to-peer interactions can provide valuable social opportunities and psychosocial and educational support for young people with SCD.[36,38] It is vital that peer mentors are equipped with appropriate training and support to ensure that they can offer safe, informed and empathetic guidance, rather than assuming that anyone with lived experience is automatically suited to the role. Such engagement might offer much-needed support when people are navigating some of the psychosocial and socio-economic challenges experienced during the transition and teenage years *(also see Best practices – Ensure peer-to-peer support).*

Once these components are in place, health systems can focus on the next phase: Completion.



"Movement from a paediatric service into an adult service is also how do we equip the child to be a fully functioning adult in control of their diagnosis. In a way that it doesn't limit their life goals, their ability to achieve, their ability to get further education, build a career, build a family."

Mary Shaniqua, Patient Representative, United Kingdom



"Don't hesitate to educate your close ones. Educate yourself and advocate about SCD. Reach out to other patients."

Awa Touré, Patient Representative, France

3.4. Continuous support

"Follow-up in adult services is just as important as the thorough preparation. Having a familiar face and someone they know to go to with concerns helps to increase engagement of young people in their own health and helps improve outcomes."

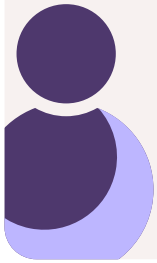
Hannah Jerman, SCD Nurse Specialist, UK

A structured and proactive follow-up approach is essential to ensuring a smooth transition from paediatric to adult care for young people with SCD. The Got Transition™ framework highlights the importance of ongoing communication, feedback and collaboration between paediatric and adult teams to improve continuity of care and patient outcomes.[29]

At a minimum, every system should:

- Confirm the date and attendance at the first adult consultation
- Solicit feedback from young people on their experience at set intervals
- Communicate with the adult service to confirm that the transfer has been completed
- Ensure ongoing partnership between paediatric and adult specialist teams
- Ensure continuous holistic support in adult care

By implementing these structured follow-up steps, healthcare teams can reduce missed follow-ups, address challenges early, and improve long-term success for transition to adult services *(also see Best practices – Continuous support).*



"[HCPs should] know that we are different from others, be careful and educate [themselves] about SCD. SCD can be seen as a strength in [patients'] lives."

Zainab Khoma, Patient Representative, France

Section 4

What prevents people from experiencing an optimal transition?

"Adult services are completely different to paediatrics, and even with the best preparation in the world, patients often struggle. The reasons for this are multifactorial, not only because of the system itself, but experiences of patients and clinicians in key clinical areas often create negativity and worsen outcomes."

Hannah Jerman, SCD Nurse Specialist, UK

4.1 Systemic, cultural and socio-behavioural barriers to an optimal transition

The stigma and racism that underpins the overall patient experience in SCD extends, and can be exacerbated, during transition.[47] People with SCD often belong to groups that generally experience sub-standard care, with racism frequently interacting with other sources of health-related stigma in SCD, including disease, associated pain and opioid-based stigma.[29,48,49] Racial and ethnic biases in pain management have been well-documented, with many young people in the Lived Experience Council reporting that their pain is often dismissed or undertreated, further reinforcing barriers to seeking timely medical attention.[39,50,51] The 'No One is Listening' report by the UK's Sickle Cell Society highlighted frequent reports of negative attitudes towards people with SCD, noting that such attitudes are often underpinned by racism.[52] The report also found that concerns about poor experiences have led to fear and avoidance of hospitals for many people living with SCD, which can lead to worse outcomes.[52] Associated with this are feelings of isolation, anxiety, psychological distress and a belief that their adult healthcare team does not provide high quality, sensitive care,[48,53–55] as well as strained patient-provider relationships.[52]

Cultural perceptions of SCD also play a role, as stigma and misinformation within some communities may discourage proactive disease management and engagement with healthcare providers. Members of the Lived Experience Council shared that, in some communities, SCD is associated with shame and social exclusion, which discourages families from openly discussing the condition or seeking appropriate care. In certain regions, people with SCD may also face marital discrimination, employment challenges and social isolation due to misconceptions about their health and life expectancy.

The period of adolescence and early adulthood is a time of significant socio-behavioural and lifestyle changes that can affect how young people with SCD manage their health. During this period, some young people may struggle to prioritise their condition,[47] leading to attempts to self manage complications at home rather than seeking medical attention.[3] This disengagement can result from negative healthcare experiences and mistrust in adult healthcare services. Factors such as problems with cognitive ability, insufficient education and information about SCD and mental health challenges such as depression or anxiety can further complicate the transition process.[3,56]

There is also a prevailing perception that SCD is not significantly prevalent in Europe. This means there has been little effort to track the SCD population and improve services, despite the fact that SCD is increasing in prevalence, being the fastest growing genetic disease in the UK and France[10] due to factors such as migration from high prevalence countries. There is a need to challenge these perceptions and assist policymakers with evidence-based decision-making on how to allocate funding and resources to address the unmet needs of people with SCD.[57]

4.2 Health system barriers to optimal transition

The availability and implementation of SCD policies and guidelines for transition across Europe is inconsistent. While some countries have made progress by incorporating transitional care into other types of national policies, there is no European framework for SCD. Existing guidelines and policies are often centre- or region-specific, leading to geographical inequalities in access to transition care,[21,22] unclear implementation and differences in accountability. Even where guidelines and policies exist, implementation is not guaranteed, and care does not always adhere to best practices.[16] Greater clarity on implementation responsibility and mechanisms for accountability is urgently needed to improve outcomes.[16,21,22,39]

Many countries lack dedicated transition SCD programmes and resources, making it difficult for young people to receive structured, continuous support. Multidisciplinary working practices that are essential for coordinated care across adult and paediatric systems[22] are often poorly reimbursed and therefore difficult to organise.[58]

"The adult health system is not ready to receive this onslaught of paediatric SCD patients, it lacks specialists and infrastructure."

Professor Caterina Minniti,
Consultant Paediatric Haematologist, Italy/USA

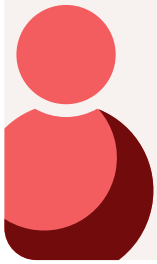
The approach to care and resourcing in the adult system is different than that in the paediatric system, requiring investment so that young people who transition to adult care have somewhere to go to. Care in the adult system is typically reactive rather than pro-active and preventative. This can often result in limited access to specialists, limited knowledge of and expertise in SCD, poor understanding of the needs of young people with SCD, long waiting times and ineffective care coordination.[16,59,60] These issues contribute to healthcare inequalities, non adherence to guidelines, inconsistent treatment and mistrust.[3,44] Many adult MDTs do not have sufficient connectivity with GPs, support in the community, social workers or psychologists to provide the comprehensive support needed for people with SCD. This, in turn, results in unplanned visits to emergency healthcare settings and care being provided by healthcare teams and professionals who do not have the knowledge, skills or expertise to care for people with SCD,[3,61] which perpetuates the cycle of inadequate care.

Many young adults with SCD also face financial and insurance-related challenges during transition.[32] Even in countries with universal healthcare, associated healthcare costs can be felt acutely during the transition,[33] and limited access to care coverage or adequate insurance can be a challenge. For example, in the UK, SCD is not a qualifying condition for a medical exemption from prescription charges, meaning that young adults suddenly face having to pay expenses in the form of prescription charges for essential medications once they turn 18, when they may be on a limited young adult budget.[46]

Additionally, the high cost of travel to access appropriate specialists creates further barriers to accessing necessary care.[62]

Insights from the Lived Experience Council show that awareness of available support programmes such as financial assistance, support to navigate insurance systems, workplace accommodations and mental health services is low among young people with SCD, limiting their ability to access essential resources. Even when support is available, it is often burdened by bureaucracy and healthcare bias, which forces many people with SCD into economic hardship, job insecurity and social isolation, exacerbating mental health challenges such as depression and anxiety.

In France, for example, the MDPH (Maison Départementale des Personnes Handicapées) provides essential recognition and support for people living with chronic illnesses like SCD, including disability cards, allowances, and educational or workplace accommodations. However, young people from the French LEC shared that the application process is complex and often requires proactive support from healthcare providers, many of whom are not equipped or willing to assist. As a result, patient groups frequently play a critical role in helping individuals navigate and access these services.



"My first job, I remember I was in hospital and my mum called my boss to tell her I was in hospital and she said, 'Well, when is she going to be back then?' Not even, 'I hope she's OK' … It's very tiring to [keep] having to explain yourself all the time."

Cianna Bent, Patient Representative, UK

Section 5

The cost of inaction

The transition from paediatric to adult care remains a dangerously weak link in the health system for young people with SCD. As they transition between services, young people experience an increased risk of complications,[1] gaps in specialist care, poor coordination of care, and a lack of proactive disease management, with many important downstream effects:

- **Young people are being failed by the health system as they experience worsening health outcomes and, in too many cases, preventable mortality.**[63] The impact can be wide ranging, including impairing young people's ability to engage with employment and educational systems.[46] Young people with SCD may end up having poorer educational attainment compared to those without SCD due to missed days, which can impact earning potential later in life.[46] In particular, due to the debilitating nature of the disease, school absenteeism is a significant problem for young people with SCD.[64] Complications from SCD can also affect young people's mental health, putting them at risk of depression and anxiety.[1,8,16,65]

- **Young people also experience increased numbers of avoidable emergency room visits**[1,16] **and prolonged hospitalisations, placing a significant and avoidable burden on health systems.** This leads to long-term disability costs and strains national health budgets, diverting resources from preventative care.[66]

  In a retrospective open cohort study conducted in the US, it was observed that patients with high emergency department reliance (EDR) experienced significantly higher total quarterly healthcare costs compared to those with low EDR ($14,715 vs. $7,339, respectively). These higher costs were driven by inpatient costs ($10,971 vs. $3,543, respectively) and emergency department costs ($499 vs. $57, respectively).[67] Improving the transition from paediatric to adult care would not only improve wellbeing and outcomes for people with SCD, but would also reduce the overall disease burden, resulting in a reduction of healthcare costs.[68]

- **A failure to invest in proactive, integrated transition care results in repeated emergency admissions, extended hospital stays and long-term disability costs.** In France, a study found that out of 604 VOC-associated hospitalisations, the frequency of VOC was highest in the 15–25 year age group (the transitioning period). There were 320 hospitalisations lasting one night or more, and 89.9% followed an emergency visit.[69]

Addressing these systemic barriers demands more than minor adjustments, it demands significant policy transformation. Without urgent reform and investment for SCD transition programmes, health systems in Europe will continue to neglect this vulnerable population, leading to reduced life expectancy not due to SCD itself, but because the systems designed to support young people are failing them.

Section 6

The way forward

All adolescents and young adults living with SCD deserve to have a smooth, person-centred transition with appropriate planning, pre-transition preparation, and teams that stretch beyond clinical care with ongoing progress monitoring and tailoring of the transition plan.

All health systems should be able to provide this transition, regardless of geographic location.

To ensure that everyone with SCD has the opportunity to have a transition that is tailored to their needs, the members of the Sickle Cell Policy Lab and Lived Experience Council recommend the following priority actions.

To work towards achieving the optimal transition...

	People with SCD and their families and/or carers should have the opportunity to...	Patient advocacy groups and community-based organisations need to...	Healthcare providers need to...	Health systems need to...	National and/or Euro-pean policymakers need to...
Setting the right foundations	— Receive education and resources about SCD and its optimal management including self-management. — Be supported by a transition navigator. — Provide input into developing clear SCD policies and guidelines. — Feed back on their experience of the transition process at set intervals.	— Provide education and increase awareness about SCD and transition, particularly in schools and in the community. — Offer patient education and support about SCD.	— Start preparing young people and their families and/or carers for transition as early as possible, depending on the maturity of the person. — Educate young people and their families and/or carers about SCD and its management, care expectations and transition. — Take responsibility for tracking and adjusting transition plans at the healthcare provider level.	— Provide dedicated staff and funding specific to SCD and transition. — Educate all staff about transition policies and the distinct roles of all stakeholders. — Establish a monitoring system to track progress and quality of the transition in digital health records. — Ensure that all data collection tools are interoperable across different settings and used as part of ongoing quality improvement initiatives. — Explore the use of digital tools, telemedicine and other forms of remote support to improve access to specialists and care in under-resourced settings.	— Recognise SCD transition within wider chronic disease or rare disease policies as appropriate, and ensure that policies and guidelines are developed with input from young people and their families and/or carers. — Dedicate funding to ensure that all policies are sustainably implemented via appropriate mechanisms within government departments responsible for health and finance. — Establish policies to tackle wider social determinants of health, and tackle inequalities in access to care.

Pre-transition preparations		— Offer culturally appropriate resources to young people with SCD and their families and/or carers.	— Start preparing young people and their families and/or carers for transition as early as possible, depending on the maturity of the person. — Educate young people and their families and/or carers about SCD and its management, care expectations and transition. — Take responsibility for tracking and adjusting transition plans at the healthcare provider level. — Conduct regular transition readiness assessments, be-ginning at least 2 years before the point of transfer. — Provide ongoing education on SCD based on readiness assessments. — Develop and regu-larly update a port-able care plan. — Take cultural pref-erences into ac-count throughout transition planning.	— Ensure that care plans and medical records are portable and adaptable across different centres/countries. — Ensure transparency and accountability for transition information across healthcare providers. — Ensure that all programmes have a transition navigator or other support role that is fully funded.

Person-centred transition	— Be empowered to take a more active role in their healthcare. — Have mental health support if they need it.	— Offer ongoing support to young people with SCD in the community across their journey.	— Implement and continuously adapt the portable care plan. — Engage patients and their carers at every stage of the transition to ensure it is personalised to their unique needs and requirements. — Ensure access to a comprehensive MDT who are fully trained in caring for people with SCD. — Involve GPs, social workers, schools and other non healthcare roles as part of the extended MDT. — Direct young people and their families and/or carers to patient advocacy groups and community education programmes. — Provide mental health support if required.	— Ensure connectivity within and across MDTs. — Ensure that there is a holistic approach to transition including mental health support. — Ensure access to peer-to-peer support that is sustainably funded. — Ensure information and resource-sharing links between schools and other non-health settings.
Completion			— Confirm the date of the first adult consultation and ensure connectivity with the adult healthcare team.	

Glossary

Below is a list of key terms related to SCD and the transition from paediatric to adult care.

A

- **Adherence** – The extent to which a person follows their prescribed medical treatment, including medications, lifestyle changes and clinic visits.
- **Adult care** – Healthcare services designed to meet the needs of adults, typically with different care models and responsibilities compared to paediatric care.
- **Advocacy** – The act of supporting and empowering people with SCD to navigate the health system, access resources and influence policies.

C

- **Care coordination** – The deliberate organisation of healthcare services between providers to ensure smooth, continuous and efficient care.
- **Chronic disease** – A long-term condition that requires ongoing medical care and management, such as SCD.
- **Comprehensive care** – A multidisciplinary approach to managing SCD that includes medical, psychological and social support.
- **Cultural and linguistic competence** – The ability of healthcare providers to effectively communicate and provide care that respects and accommodates the cultural and linguistic backgrounds of patients, particularly in diverse or relocating populations.

E

- **Empowerment** – The process of enabling people with SCD to take control of their health, make informed decisions and self-advocate.
- **Epidemiology** – The study of the distribution, causes and effects of health conditions, such as SCD, in different populations.
- **Emergency protocols** – A predefined set of guidelines designed to ensure effective and timely management of emergency situations, specifically related to SCD.
- **Emergency scenario planning** – The process of creating protocols and plans that detail how to handle emergency situations related to SCD, ensuring rapid, effective care from healthcare providers.
- **Evaluation framework** – A structured system used to assess and track progress, outcomes and improvements during the transition from paediatric to adult care.

G

- **Guidelines** – Official recommendations that outline best practices for caring for and transitioning young people with SCD from paediatric to adult care

H

- **Health disparities** – Differences in health outcomes and access to care among different populations due to social, economic, or geographic factors.
- **Health literacy** – The ability to obtain, process and understand health information to make informed decisions.
- **Health system considerations** – Assessing and understanding the available resources within a local health system, including identifying specialised facilities and the referral process for people with SCD.
- **Holistic care** – An approach to healthcare that addresses not only the physical aspects of a person's condition but also their emotional, psychological, social and cultural needs.

I

- **Integrated health records** – A system that combines and centralises patient data from various healthcare providers, ensuring continuity of care and easy access for all involved parties.

M

- **Morbidity** – The presence of illness or disease-related complications, such as organ damage in SCD.
- **Mortality** – The rate or risk of death associated with a condition like SCD.
- **Multidisciplinary team (MDT)** – A team of healthcare professionals, including doctors, nurses, psychologists and social workers, working together to manage SCD.

P

- **Paediatric care** – Healthcare services focused on infants, children, and adolescents, often offering more structured and coordinated support than adult care.
- **Person-centred transition** – An approach to transition that focuses on the unique needs of each person, incorporating tailored support, education and empowerment throughout the transition process.
- **Peer-to-peer support** – A support model where people with similar conditions or experiences help each other, offering emotional, educational and psychosocial support during the transition process.
- **Plan-Do-Study-Act (PDSA) Cycle** – A quality improvement process used to test and implement changes in healthcare practices by planning, executing, studying results and adjusting based on findings.
- **Portable healthcare plan** – A healthcare plan that is easily transferable between different healthcare providers, allowing them to access comprehensive patient data, ensuring continuity of care across settings.
- **Prophylactic treatment** – Preventative measures, such as vaccinations or medications like penicillin, to reduce the risk of infections in people with SCD.

Q

- **Quality improvement tools** – Methods and strategies used to continuously assess and improve the quality of care provided in transition programmes, including process mapping, data tracking, and the Plan Do-Study-Act (PDSA) cycle.

R

- **Readiness assessment** – A tool used to evaluate a young person's ability to manage their healthcare independently before transitioning to adult care.
- **Rare disease** – A condition affecting a small percentage of the population (fewer than 50 per 100,000 people in the EU), such as SCD in some European countries.

S

- **Self-management skills** – The ability of people to manage their own healthcare, make informed decisions and navigate the medical system independently, which is essential during the transition to adult care.
- **Sickle cell crisis** – Painful episodes caused by blocked blood flow due to sickle-shaped red blood cells.
- **Specialist care** – Healthcare provided by professionals with expertise in managing complex conditions like SCD.
- **Stroke prevention programme** – A medical strategy, including screening and treatment, to reduce the risk of stroke in people with SCD.
- **Support services** – Non-medical resources, such as counselling and peer support groups, that assist people with SCD and their families and/or carers.

T

- **Transition** – The process of moving from paediatric to adult healthcare, involving education, empowerment and gradual responsibility transfer.
- **Transition planning** – The structured approach to preparing young people with SCD for independent management of their health in adult care settings.
- **Transition readiness assessment** – A tool or process used to assess how prepared a person is for transitioning from paediatric to adult care, including the person's knowledge, skills, and support needs.
- **Transition navigator** – A healthcare professional who acts as a point of contact, guiding patients through their transition from paediatric to adult healthcare services, ensuring communication and providing support.

V

- **Vaso-occlusive crisis (VOC)** – A painful complication of sickle cell disease where sickled red blood cells block small blood vessels, restricting blood flow to tissues and causing severe pain, usually in the extremities, back or abdomen.

Y

- **Young adult** – An young person between adolescence and full adulthood, typically in the process of transitioning from paediatric to adult healthcare. Young people are defined by the EU as being between 15 and 29 years old.[70]

Best practices

This section provides real-world examples of how the principles outlined in this charter have been successfully applied. These serve as a reference for best practices, challenges encountered and solutions implemented.

Component	Best practice example description	Country
	Setting the right foundations	
Educate young people and their families and/or carers on SCD and its management, including self-management	— The Sickle Cell Society's parent guide to managing the disease attempts to provide answers to questions raised by parents and seeks to dispel many of the myths and misconceptions about SCD.[55] While it does not specifically mention transition, it is a useful resource that informs parents and carers about management and treatment, as well as providing information on various resources to support with emotional wellbeing, social care, educational support and other aspects to support optimal care. — The Sickle Cell Society created the Self Over Sickle (SOS) programme, including events, challenges and a podcast, which aims to support transitions for young people with sickle cell disease and their families. — Therapeutic education for adult sickle cell patients (Drépéduc) offers therapeutic education to people with SCD, aiming to enhance self-management and improve quality of life. Through personalised consultations, individual and group workshops, and ongoing support, an MDT comprising doctors, nurses, physiotherapists, dietitians, and psychologists equips patients with the essential knowledge and skills to manage their condition effectively.	UK France
Promote SCD education and cultural competency among healthcare professionals and in schools	— As of June 2024, The North Central London Integrated Care System created the first training in sickle cell management accredited by the Royal College of Nursing. It has free training information (videos and quizzes) that aim to the tackle lack of awareness of SCD, in providing support to staff in community and hospital settings. — A consultation-mediation in Paris was set up for medical teams that have difficulty setting up a care plan for people living with a chronic illness that bridges cultural gaps between the healthcare team and the person and their family. The mediation works by fostering an active partnership to avoid miscommunications or misunderstandings. There are two types of interventions offered: — A consultation takes place at the premises of the requesting department with the person (and their loved ones if they so wish), a cultural mediator, and a doctor trained in the intercultural approach. — A consultation takes place at the person's home with the cultural mediator — They do also offer indirect consultations in the form of situation studies.	UK France

Implement clear policies and guidelines developed with input from paediatric and adult clinicians, young people, parents and carers	In France, the Haute Autorité de Santé (HAS) published clinical practice recommendations for children and adolescents with SCD in which they mention that, when transitioning to adult services, it is necessary to consider certain elements: — Time – there is no ideal age as it depends on the state of health of the person and their pubertal development. Transition should begin when the person is in a stabilised clinical situation and has stopped growing. — Degree of autonomy – transition to adult services is only effective if the person acquires the ability to manage their illness outside of their primary carer and team – this emphasises the importance of preparation well before transition. — Coordination of transfer – the person should visit an adult centre prior to full transition and should have an established paediatric-adult care for a few months, at most.	France
Establish processes for identifying young people of transition age and tracking their progress	The US's Got Transition™ plan includes tracking and monitoring. The process involves tracking exactly when each element of the transition programme is delivered. This information is critical for understanding at a system level how transition services are provided, and ensuring that all people undergoing transition experience a smooth transition and are supported with care tailored to their specific needs.	USA
Appoint transition navigators to support young people through the transition process	— A protocolised transition navigator intervention was developed in 2022 and has been found to be acceptable in the short term to adolescent young adults with SCD. — In Germany, an Onkolotse is an individual contact provided for people who have cancer. It is the role of the Onkolotse to guide, advise, and inform people and their families and/or carers through the health system. The Onkolotse will also consolidate life plans, and provide independent information on patient rights and social issues. They are provided as an option from the initial cancer diagnosis and act as a permanent contact person/liaison.	USA Germany
Pre-transition preparations		
Conduct regular transition readiness assessments, beginning at least 2 years before the point of transfer	— TIP-RFT is a tool to assess transition readiness in young people with SCD. According to a study, "The TIP-RFT assessment can guide interventions to improve transition readiness and can provide a foundation for future research on other variables that might be associated with transition readiness".[35] — Ready Steady Go is a programme in the UK for children aged 11 or older who have long-term health conditions, designed to help them with their transition to adult age services. — The STARx questionnaire (Self-Management and Transition Readiness) has 18 questions across three domains of communication with medical provider, disease knowledge, and self-management.[47,71] It has versions for parents and children and is available in English, Spanish, Danish, Arabic and Thai.[47,71] — Got Transition™ uses a self-assessment form looking at 26 questions across four domains of transition – importance and confidence, my health and healthcare, my medicines, and desired skills. This is also available in Spanish.[72]	USA UK

Provide ongoing and tailored education and resources for young people and their families and/or carers on the transition based on their readiness assessment	— An ASAFE initiative supported by ERN- EuroBloodNet. Online conversation groups are held for patients and families. These are conversation groups around the concerns and topics that the participants of each meeting raise. The conversation is coordinated by an hematologist and a psychologist. During them experiences, resources that had been useful as well as doubts and concerns are shared.[73] — In the UK, The Sickle Cell Society provides numerous ongoing resources for both young people with SCD and their families. 'A parent's guide to managing sickle cell disease' is a comprehensive resource containing all relevant information, support and further sign-posts to additional services and resources. [55] Additionally, they hold a host of parent sessions, including family well-being workshops and family retreats providing management education.	Spain UK
Develop and regularly update portable care plans	— The digital health passport for SCD is an NIHR funded project. The DHP team, in collaboration with the Caribbean and African Health Network and interoperability experts from the OpenEHR community, received funding that will enable the swift design, prototype, and development of a platform for people with SCD that will be initially operable as a standalone service that will eventually be integrated into other care planning systems. — The Universal Care Plan on the NHS App allows patients to personalise their future care by registering preferences about their treatment. It ensures that medical teams can access vital health information immediately. Other digital tools are also used – for example, MyChart. Unfortunately, the tools are not interoperable, and more awareness is needed to ensure young people know how to use them.	UK
Ensure connectivity across MDTs, both for the adult MDT care team and across the paediatric and adult care team	Project ECHO (Extension for Community Healthcare Outcomes) is an innovative telementoring approach linking multidisciplinary specialists with other healthcare professionals via videoconference, where they engage in case-based learning and didactic presentations regularly created by the Sickle Treatment and Outcomes Research in the Midwest (STORM) Network. The participants in this project were primarily paediatric and adult haematologists, MDT sickle cell healthcare providers, and a small number of primary care providers, despite targeted recruitment efforts.	USA
Holistic Care		
Provide mental health support	— In the UK, paediatric and adult psychologists are built into transition MDTs. There are also support groups for transition-age young adults and a separate support group for families and/or carers in the paediatric service. People with known mental health concerns are highlighted and followed up closely in the adult service. All young adults are offered the opportunity to have a private conversation with the paediatric and adult psychologist in the MDT clinic. Contact details for the psychologist, adult nurse and other healthcare professionals are given to ensure relationship continuity. A 1–2 year grace period is permitted after transition, in which young adults can contact either paediatric or adult providers, until they are well incorporated into the adult service.[74] — In Spain, at the Hospital General Universitario Gregorio Marañón, the mental health support model is as follows: a psychologist is presented as a member of the MDT team from the first visit at diagnosis. Parents have a telephone number and are also able to write to them if they have a specific need between routine visits. Following this, they are present in some medical visits throughout the follow-up if a mental health risk has been detected. When the patient is admitted, the psychologist assesses the situation and decides whether an intervention is needed. If a person presents with psychological symptoms, individual follow-up is carried out on a weekly or bi-weekly basis. This model facilitates a reduction in the barrier to access mental health help, and reduces prejudices regarding mental healthcare.[75]	UK Spain

Ensure connectivity across social care, education and employment	The South East London Sickle Cell Improvement Programme is a two-year pilot programme aiming to improve services across all care settings for better care and health outcomes for people with SCD. As part of this programme, community services across six boroughs in South East London (Bexley, Bromley, Greenwich, Lambeth, Lewisham, and Southwark) are being enhanced, which will include access to more specialist nurses (who will work with local NHS Trusts), a wider support team, help with everyday life (welfare advice and support on benefits and legal advice – engaging with social workers), peer support (through the Sickle Cell Society mentoring programme) and developing educational resources to help schools, workplaces, and healthcare professionals learn more about SCD.	UK
Direct people with SCD to patient advocacy groups that can offer additional support for young people	Whittington Health NHS Trust – NCL Red Cell Community Service have a Sickle Cell Support Group (est. 1989) that meets on the first Friday of the month at the Sickle Cell and Thalassemia Centre. The group offers formalised peer support, a forum to share coping strategies, and organises educational talks on health and care services for people with SCD and their families and/or carers in the Camden/Islington area (London). Similar groups are available across the country. Following a successful pilot programme in East London and Essex, the Sickle Cell Society Mentoring Scheme for children and young people aged 10–24 living with SCD has been extended to all of London. Members of the scheme have access to free support and advice in one-to-one mentoring sessions led by trained peer mentors who are also living with SCD.	UK
 **Continuous support**		
Confirm the date and attendance at the first adult consultation **Solicit feedback from young people on their experience at set intervals** **Communicate with the adult service to confirm that the transfer has been completed** **Ongoing partnership between paediatric and adult specialist teams**	An integral component of the Got Transition® plan is tracking and monitoring.[29,72] The process involves tracking exactly when each element of the transition programme is delivered. This information is critical for understanding how transition services are provided at a system level and ensuring that all people undergoing the transition experience a smoother transition and are supported with care tailored to their specific needs. The guide includes recommendations on various quality improvement tools to continually improve tracking and programme effectiveness. It also includes how to develop clear goals for the tracking system, process mapping, and recommendations for 'Plan-Do-Study-Act' cycles.	USA

Methodology

The Sickle Cell Transitions Policy Lab was established to drive health system change and improve outcomes for people living with Sickle Cell Disease (SCD) during the transition from paediatric to adult care. Its vision is to seamlessly bridge this gap, ensuring a continuous, coordinated, compassionate healthcare journey that optimises mental and physical well-being during this critical time.

Using the Policy Lab methodology,[76] the initiative brought together healthcare professionals, policymakers, patient advocacy groups, patients and public health experts as equal partners. Members engaged in virtual and in-person discussions, lived experience councils, and a world café-style session[4] to review existing guidelines, identify service gaps, and develop evidence-based recommendations for diverse European healthcare settings. Two virtual and one in-person lived experience councils ensured authentic representation by involving patients, caregivers and representatives from across Europe. This collaborative process identified key enablers and challenges, shaping a comprehensive, scalable transition model. This report outlines the significant barriers to a successful SCD transition from paediatric to adult care, and presents an implementation framework to drive policy change and optimise services across European health systems.

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Sickle Cell Transitions
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For any questions please contact the secretariat of the Policy Lab at sicklecell@mhpgroup.com