Sickle Cell Transitions
Policy Lab

Bridging the gap: The Charter for optimal transitions from paediatric to adult care in sickle cell disease

The transition from paediatric to adult care

Sickle cell disease is a life-threatening inherited blood condition.[1] It is the most common genetic disorder in the UK and France, despite being a rare disease.[1,2] The number of people living with sickle cell disease is steadily rising due to advances in newborn screening, preventative measures and disease modifying therapies improving survival.[2] As a result, more people living with sickle cell disease will move from paediatric care to adult care - a process known as a transfer.[3]

Alongside the transfer, young people with rare conditions such as sickle cell disease undergo a transition from paediatric to adult care – a critical period 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."[4]

While people with sickle cell disease are living for longer, the number of deaths occurring in young people aged 18 to 26 is rising, coinciding with the transition period. Poor transitions can lead to long-term health complications, poor quality of life and increased risk of mortality.[5,6]

Across Europe, young people's transition experiences vary. While some countries have well-established protocols and specialised programmes, others lack formal plans.[1] Even in countries with national policies, implementation and quality are not guaranteed.[1,7]

Some countries, like the UK,[8] Spain[9] and Ireland,[10] have specific guidelines for transition.

Others, like France[11,12] and Germany,[13] incorporate transition into existing chronic disease or other health policies.

Italy, Portugal, Greece and Sweden have no formal policies or guidelines.

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1 Manu Pereira, M., Colombatti, R., Alvarez, F., Bartolucci, P., Bento, C., & Brunetta, A. (2023). Sickle cell disease landscape and challenges in the EU: the ERNEuroBloodNet perspective. Lancet Haematol, 10(8). **2** Colombatti, R., & Sainati, L. (2016). Management of children with sickle cell disease in Europe: current situation and future perspectives. EMJ Hematol, 4(1). **3** National Institute for Health and Care Excellence (NICE). (2016). Transition from children's to adults' services for young people using health or social care services. NICE guideline NG43. https://www.nice.org.uk/guidance/ng43/chapter/Recommendations#transition-planning. **4** National Confidential Enquiry into Patient Outcome and Death (NCEPOD). (2023). The Inbetweeners: Transitioning young people with long-term conditions. NCEPOD. https://www.ncepod.org.uk/2023transition/The%20Inbetweeners_summary%20report.pdf. **5** Saulsberry, A. C., Porter, J. S., & Hankins, J. S. (2019). A program of transition to adult care for sickle cell disease. Hematology Am Soc Hematol Educ Program, 2019(1), 496–504. **6** Bemrich-Stolz, C. J., Halancych, J. H., Howard, T. H., Hilliard, L. M., & Lebensburger, J. D. (2015). Exploring Adult Care Experiences and Barriers to Transition in Adult Patients with Sickle Cell Disease. Int J Hematol Ther, 1(1). **7** Samarasinghe, S. C., Medlow, S., Ho, J., & Steinbeck, K. (2020). Chronic illness and transition from paediatric to adult care: A systematic review of illness specific clinical guidelines for transition in chronic illnesses that require specialist to specialist transfer. Journal of Transition Medicine, 2(1). **8** Sickle Cell Society and PHE Sickle cell disease in childhood: Standards and recommendations for clinical care. (2019). Sickle Cell Society and Public Health England. https://www.sicklecellsociety.org. **9** López Rubio M., M., Ricard Andrés, M., & VM, A. (2021). Guías y recomendaciones: Guía de enfermedad de células falciformes. Grupo de Eritropatología de la Sociedad Española de Hematología y Hemoterapia (SEHH). https://share.google/yZvnqyUk4VeTixanP. **10** Data on file. **11** Hoegy, D., Bleyzac, N., Gauthier-Vasserot, A., Cannas, G., Denis, A., & Hot, A. (2020). Impact of a paediatricadult care transition programme on the health status of patients with sickle cell disease: Study protocol for a randomised controlled trial (the DREPADO trial. Trials, 21(1). **12** Haute Autorité de Santé. (2024). Syndromes drépanocytaires majeurs de l'enfant et de l'adolescent: Protocole national de diagnostic et de soins (PNDS). Haute Autorité de Santé. https://www.sfpediatrie.com/sites/www.sfpediatrie.com/files/medias/documents/PNDS_Syndromes_drepanocytaires_majeurs_enfant_adolescent.pdf. **13** Pape, L., & Ernst, G. (2022). Health care transition from pediatric to adult care: An evidence-based guideline. Eur J Pediatr, 181(5), 1951–1958.

Making the optimal transition from paediatric to adult care a reality

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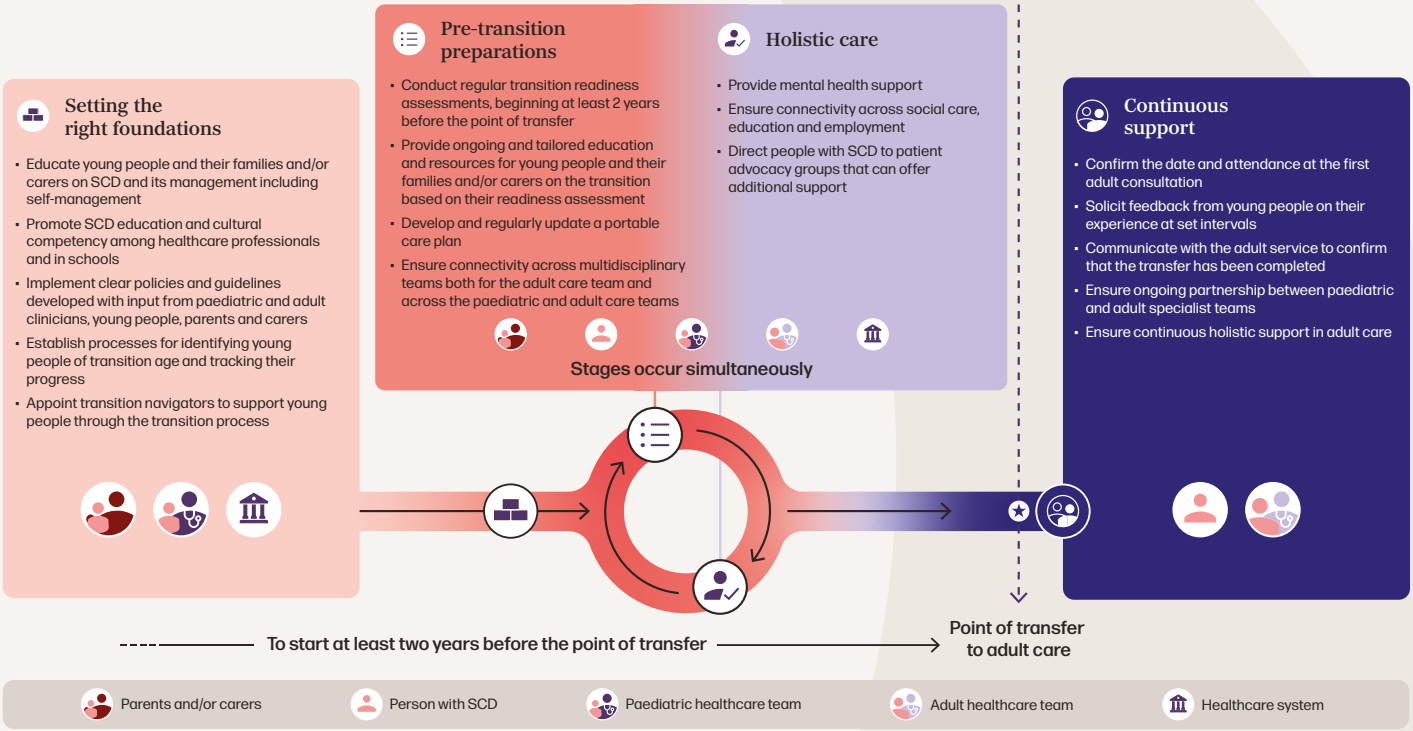
An optimal transition should ensure that young people experience a seamless, coordinated and compassionate healthcare journey that enhances both their physical and mental well-being.[14,15]



All young people living with sickle cell disease deserve to experience a smooth, person-centred transition. Health systems, regardless of geographical location, should be well-equipped to provide a transition that is tailored to each individual's needs.

Robust policies at the EU and national levels should support an optimal transition from paediatric to adult care for people living with sickle cell disease and:

1. **Recognise sickle cell disease transition within wider rare or chronic disease policies, ensuring that policies** and guidelines are developed with input from young people and their families and/or carers.
2. **Mandate early, tailored and holistic transition planning,** starting at least two years before the transfer to adult care, supported by dedicated funding and resources.
3. **Embed evidence-based best practice** to support healthcare teams, ensuring clear, consistent and high-quality care across Europe.

A full list of recommendations can be found in the Charter for optimal transitions from paediatric to adult care in sickle cell disease. Please scan the QR code below to access the Charter and its recommendations.

How the Charter and components of the optimal transition were developed
This Charter has been developed to support people with sickle cell disease across Europe making the transition between paediatric and adult care. It represents the collective work of the Sickle Cell Transition Policy Lab, a multidisciplinary group of 18 experts from across Europe and the Lived Experience Council, a group of 21 patient and patient representatives from across Europe.

Novo Nordisk and Pfizer commissioned and funded the production of this Charter. The Charter has been developed by the members of the Sickle Cell Transitions Policy Lab and Lived Experience Council, with support from MHP Group acting as Secretariat. The companies provided no direction on the recommendations made by the authors within the Charter. The companies did not provide substantive input to the Charter language; however, both companies have reviewed the Charter for factual accuracy and to ensure compliance with all relevant industry codes of practice, including those of the EFPIA and ABPI.

Read the Charter to understand how to make an optimal transition a reality.

The Policy Lab is funded by Novo Nordisk and Pfizer.

14 GotTransition.org. (n.d.). Got transitionR – Six core elements of Health Care TransitionTM. https://www.gottransition.org/six-core-elements/. **15** National Institute for Health and Care Excellence (NICE). (2023). Transition from children's to adult's services. Quality Standard QS140. https://www.nice.org.uk/guidance/qs140/chapter/Quality-statement-2-Coordinated-transition-plan.