Charter for optimal care transitions between paediatric and adult care in sickle cell disease

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#SCDTransitionCharter

European Reference Network | Hematological Diseases (ERN EuroBloodNet)

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Sickle cell disease is a life-threatening inherited blood condition.[1]

Despite being a rare disease, sickle cell is:[1,2]

- The most common genetic disorder in the UK and France.
- Increasingly prevalent across Europe.

Increased survival due to advances in newborn screening, preventative measures and disease modifying therapies.[3]

1 Manu Pereira, M et al.,(2023). Sickle cell disease landscape and challenges in the EU: the ERNEuroBloodNet perspective. Lancet Haematol, 10(8). **2** Colombatti, R., and Sainati, L. (2016). Management of children with sickle cell disease in Europe: current situation and future perspectives. EMJ Hematol, 4(1). 3. Colombatti R and Sainati, L. (2016). MANAGEMENT OF CHILDREN WITH SICKLE CELL DISEASE IN EUROPE: CURRENT SITUATION AND FUTURE PERSPECTIVES.EMJ Hematol., 1, 129–135.

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The transition from paediatric to adult care is a critical risk point and a moment of vulnerability

Rise in preventable mortality and worsening health outcomes among young people aged 18 to 26 years[1]

Missed or delayed follow-up appointment after leaving paediatric services[2]

Increased numbers of avoidable emergency room visits[2] and prolonged hospitalisations[3]

Increased risk for depression and anxiety, delays in social functioning, and impairments in quality of life [4]

1. Kayle, M., et al. (2019). Transition to adult care in sickle cell disease: A longitudinal study of clinical characteristics and disease severity. Pediatric Blood & Cancer, 66(1), e27463. https://doi.org/10.1002/pbc.27463. 2. Manu Pereira M,. et al Sickle cell disease landscape and challenges in the EU: the ERN-EuroBloodNet perspective. Lancet Haematol. 2023;10(8):e620–e628. 3. 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). 4. Crosby, L. E., Hood, A., Kidwell, K., Nwankwo, C., Peugh, J., Strong, H., Quinn, C., & Britto, M. T. (2020). Improving self-management in adolescents with sickle cell disease. Pediatric Blood & Cancer, 67(10), e28492. https://doi.org/10.1002/

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There is a lack of prioritisation of transition at all levels

Some countries have well-established protocols and specialised programmes:[1]

Specific SCD guidelines for transition[2,3,4]

Incorporate transition into existing chronic disease or other health policies[5,6,7]

While others lack formal plans:[1]

However, implementation and quality are not guaranteed.[8]

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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. Sickle Cell Society and PHE Sickle cell disease in childhood: Standards and recommendations for clinical care. (2019). Sickle Cell Society and Public Health England. **3.** 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). **4.** Data on file. **5.** 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). **6.** 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. **7.** Pape, L., & Ernst, G. (2022). Health care transition from pediatric to adult care: An evidence-based guideline. Eur J Pediatr, 181(5), 1951–1958. 8. 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).

The real life impact is significant

🇬🇧 *“There’s a **lack of support** or the support has been **non existent**, [the patient] had a video call with her nurse from the clinical side but there was no support during secondary school.”*

🇩🇪 *“There are still not many physicians who know about SCD, which means that **adult patients are still treated in paediatric clinics**.”*

🇫🇷 *“[We need to] **educate and advocate for better care** outside of Paris, in small towns”*

🇮🇪 *“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**. ... it might be **confusing** for a lot of people.”*

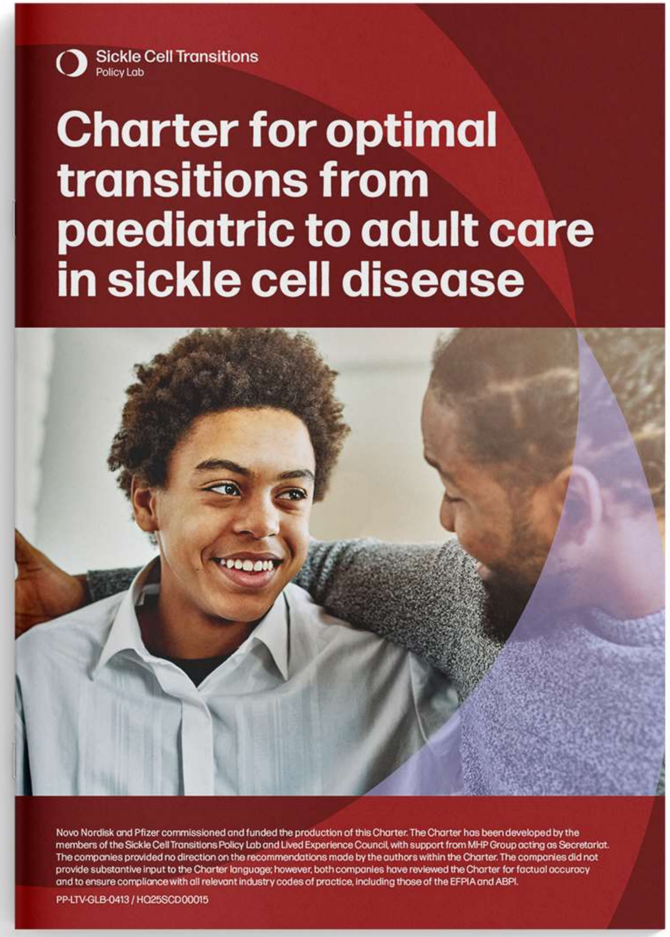
🇨🇭 *“In my case, **I never had a real transition**.... It was abou being **transferred from paediatric care and trying to find an adult specialist by yourself**, which was not easy.”*

There are many barriers to an optimal transition

Fragmented health and care systems	Social and cultural barriers	Lack of education and support	Structural and policy barriers
Siloed adult and paediatric services with poor coordination	Disadvantaged groups face limited access, support, and resources	Inadequate patient and parent/carer education on self-management and navigating adult care	No or limited national/centre-level guidelines or structured processes
Limited access to specialist adult providers and continuity of care	Lack of culturally competent care and support tailored to diverse needs	Poor patient engagement, low autonomy, and fear around transition	Lack of data, monitoring, and interoperability between care systems
Geographical, financial, and coverage-related barriers to smooth transition	Stigma, discrimination, and low trust in healthcare providers	Emotional burden, isolation, and lack of psychosocial support	Inadequate reimbursement and undervaluing of multidisciplinary working

The Charter is
a collective call to
action for Europe

We need to work together
to change
minds and drive change



Sickle Cell Transitions
Policy Lab

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

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.

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Who developed the Charter and how?

The Charter is grounded in lived experience and clinical expertise, co-developed through months of dialogue and collaboration

20+ Patients

5 Patient advocacy organisations

12 Clinicians from paediatric and adult care systems

Ongoing consultation with experts outside of the Policy Lab

11 European Countries Represented

- UK
- France
- Ireland
- Spain
- Sweden
- Germany
- Portugal
- Italy
- Switzerland
- Greece
- Belgium

Methods (1/2): Stakeholder creation and evidence review

Step 1: Stakeholder creation

- 2 co-chairs led the Charter development process
- Identified and engaged with:
  - Expert physicians (paediatric and adult care)
  - Patient organisations and communities
  - Public health representatives
  - Industry partners*

**Industry partners provided no direction on the recommendations and nor did they provide substantive input into the Charter language. However, they did review the Charter for factual accuracy and to ensure compliance will all relevant industry codes of practice*

Step 2: Literature review and evidence mapping

- Systematic review of:
  - EU and national policies on transition care
  - Care pathways and models of service organisation
  - Case studies from different EU Member States
- Identified transition as a journey with several steps – clinical, psychosocial and systemic

Methods (2/2): Co-creation and consensus building

Step 3: Co-creation process

- Consensus meetings with stakeholders to agree priorities and recommendations
- Brainstorming sessions to map barriers and proposed solutions

Step 4: Integrating the lived experience

- Series of Lived Experience Council meetings with:
    - Adult patients
    - Adolescents and young adults
    - Caregivers

Step 5: Workshop on transition

- Transition workshop with adult, adolescent and young adult patients and caregivers
- Captured experiential evidence to refine Charter recommendations

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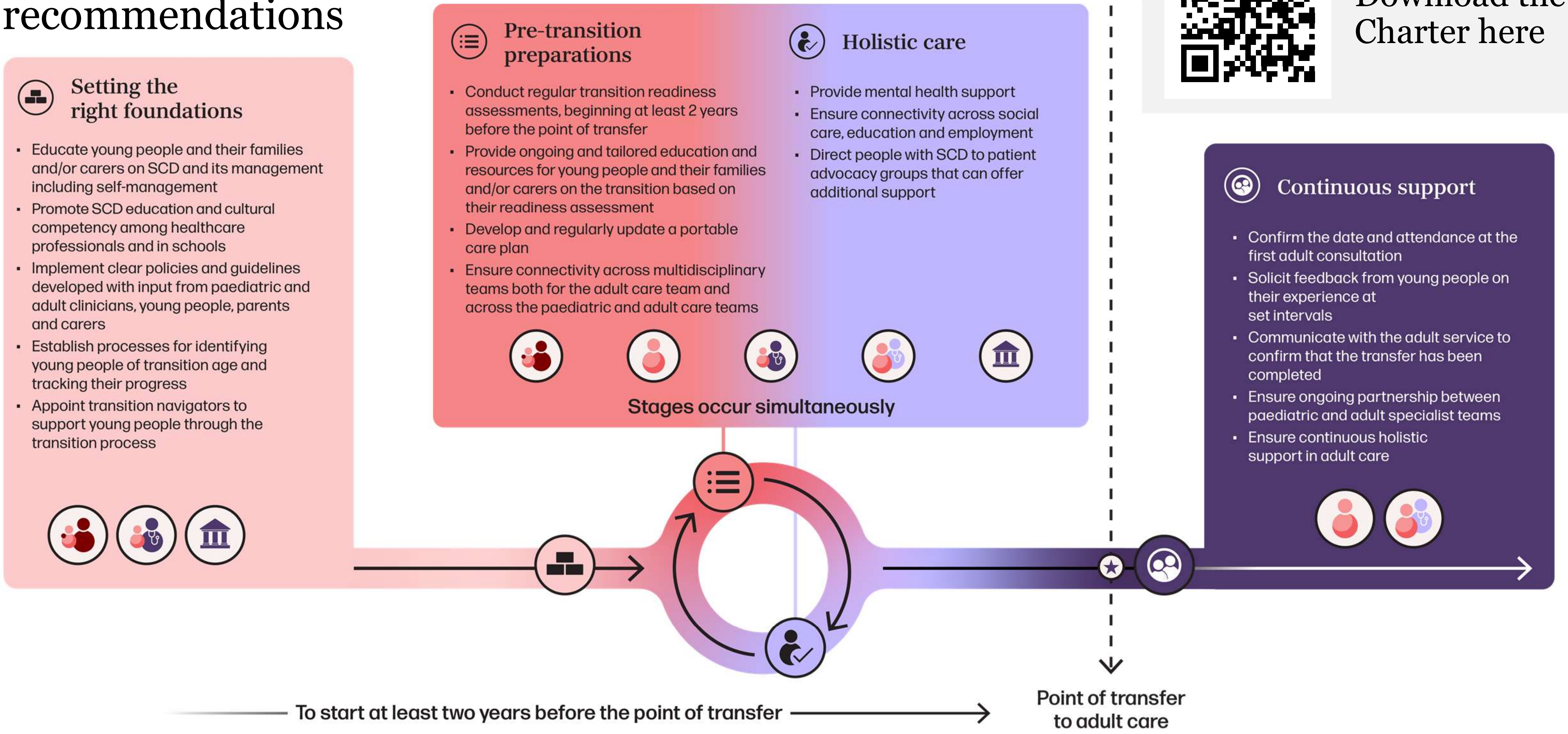
Our framework and recommendations

Download the Charter here



Setting the right foundations

- 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

Pre-transition preparations

- 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 a portable care plan
- Ensure connectivity across multidisciplinary teams both for the adult care team and across the paediatric and adult care teams

Holistic care

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

Stages occur simultaneously

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
- Ensure ongoing partnership between paediatric and adult specialist teams
- Ensure continuous holistic support in adult care

To start at least two years before the point of transfer →

Point of transfer to adult care

Parents and/or carers | Person with SCD | Paediatric healthcare team | Adult healthcare team | Healthcare system

The need for action at the European level

All young people living with sickle cell disease deserve to experience a smooth, person-centred transition.

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:

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.

Mandate early, tailored and holistic transition planning, starting at least two years before the transfer to adult care, supported by dedicated funding and resources.

Embed evidence-based best practice to support healthcare teams, ensuring clear, consistent and high-quality care across Europe.

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The Charter was official launched at the European Hematology Association Congress

Presentation at the European Parliament

Thank you!

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