Sickle Cell Transitions
Policy Lab

Sickle Cell Transitions Policy Lab

Charter for optimal care transitions in sickle cell disease

From framework to action: Using the Charter to amplify your advocacy work

The Charter and activities related to the Sickle Cell Policy Lab are supported with funding from Novo Nordisk and Pfizer. All activities are strictly non-promotional. Specific medicines should not be discussed or referred to either directly or indirectly.

This slide deck covers:

1. **The care transition: What it is and why it matters**
2. **Introducing the Charter for optimal care transitions in sickle cell disease**
3. **From framework to action**
4. **What you can do to take the issue of poor care transitions forward**

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The care transition: What is it and why it matters

What is transition?

Transfer

The ‘handover’
from paediatric to adult care.[1]

vs

Transition

“The purposeful, gradual, planned process of transferring a young person’s healthcare from a child-centred to an adult-oriented care setting that comprehensively addresses the medical, psychosocial, educational and vocational needs of that young person.”[2]

1.Vassilev, D., Boulle, A., & Thompson, C. (2021). The global burden of cardiovascular disease: Impact of heart failure. Eur Heart J, 42(41), 4213–4221. Https://doi.org/10.1093/eurheartj/ehab478. (n.d.). 2. 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. (n.d.).

Why does the transition matter?

Sickle cell disease is a life-threatening inherited blood condition, recognised as a public health priority by the World Health Organization.[1]

The condition affects haemoglobin, the protein inside red blood cells that carry oxygen around the body.[2] For people affected, the red blood cells become hard, sticky and become crescent/sickle shaped.[2]

Despite being a rare disease, sickle cell is:[1,3]

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

While people living 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 are reported to lead to:[4,5]

- Poor quality of life
- Long-term health complications
- Increased risk of death

1 Manu Pereira, M et al.,(2023). Sickle cell disease landscape and challenges in the EU: the ERNEuroBloodNet perspective. Lancet Haematol, 10(8). 2. Sickle Cell Society, What is sickle cell disorder? Available at: https://www.sicklecellsociety.org/what-is-sickle-cell-disorder/. 3. Colombatti, R., and Sainati, L. (2016). Management of children with sickle cell disease in Europe: current situation and future perspectives. EMJ Hematol, 4(1). 4. 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. 5. 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).

Experiences of the transition

"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 about being **transferred from paediatric care and trying to find an adult specialist by yourself**, which was not easy."

Why do people experience a poor transition?

People with sickle cell disease often experience poor transitions in care for many different reasons.

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 guidelines
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

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Introducing the Charter for optimal care transitions in sickle cell disease

How we developed the Charter

Our vision

To seamlessly bridge the gap between paediatric and adult care for people living with Sickle Cell Disease, ensuring a continuous, coordinated, and compassionate healthcare journey that optimises their mental and physical well-being during this critical time.

Our process

We convened a multidisciplinary Policy Lab and Lived Experience Council made up of:

20+ Patients

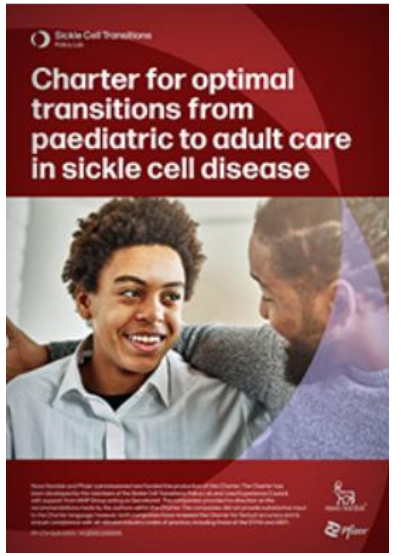
5 patient advocacy organisations

12 adult and paedatric clinicians

from

UK
Germany
Switzerland
Spain
France
Portugal
Greece
Sweden
Ireland
Italy
Belgium

Our Charter



Available in English, French, Italian and Spanish here

Our Policy Lab process

Multi-stakeholder co-creation

Convened a Policy Lab of experts from across Europe including physicians, patient organisations, public health representatives.

Literature review and evidence mapping

Systematic review of EU and national policies on transition care, care pathways and models of service organisation, case studies across the EU.

Co-creating the Charter

Six consensus meetings to agree priorities, identify barriers and develop evidence-based policy recommendations.

Integrating the lived experience

Four Lived Experience Council meetings with adult patients, adolescents and young adults and caregivers

Finalising the Charter

Refine and finalise Charter recommendations

The Policy Lab was co-chaired by the European Sickle Cell Federation and ERN-EuroBloodNet

Our framework and recommendations

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

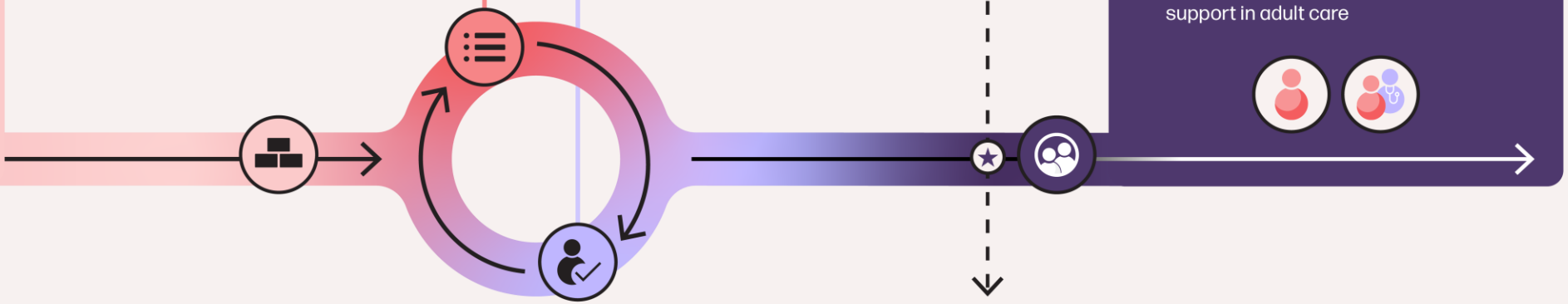
Holistic care

- 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



Download the Charter here

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 are needed and should:

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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From framework to action

The tools we have developed

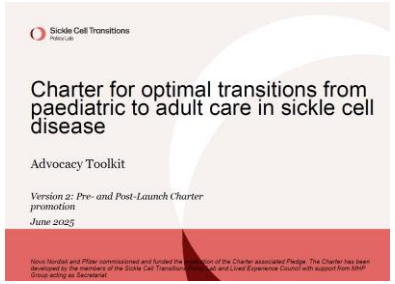
Read them. Share them. Use them.

[The Sickle Cell Policy Lab website](#)

hosts a range of materials to support your advocacy work, including the Charter, Charter summary, an advocacy toolkit, short videos, conference posters and event materials.

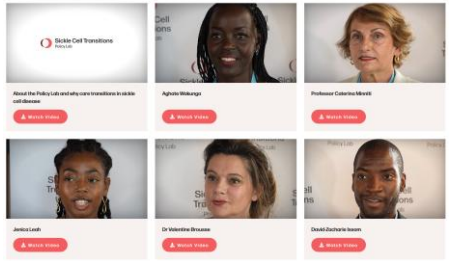
The evidence-based and clear call to action to policy and decision-makers at all levels

Available in English, French, Spanish and Italian. 1-page summary also available in English



A practical guide to help advocates make the case for better transition care

Includes key messages, policy asks, social media assets and more



Short videos to bring the Charter to light

Includes patient stories, expert perspectives and the ‘why’ behind the Charter

Everything is free to access. Scan the QR code to find all resources in one place

Taking the Charter across Europe

The Charter was launched at the European Hematology Association Congress in June 2025

The Charter was subsequently launched at a multistakeholder roundtable at the European Parliament in October 2025

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What you can do to take the issue of poor care transitions forward

Sign our pledge to optimise the transition from paediatric to adult care in sickle cell disease

To ensure that all adolescents and young adults living with sickle cell disease benefit from a smooth and person-centred transition from paediatric to adult care with:

- appropriate planning and pre-transition preparation
- teams that stretch beyond clinical care
- ongoing progress monitoring and a tailored health plan

We commit to driving health system change at all levels to ensure that health systems deliver an optimal transition for every young person with sickle cell disease, regardless of where they live.

With your support, we can ensure every young person living with sickle cell transitions into adulthood with the best possible care tailored to their needs.

Use the Charter to support your advocacy work

Read the Charter and identify what recommendations would have the biggest impact on improving transition care experiences in your country

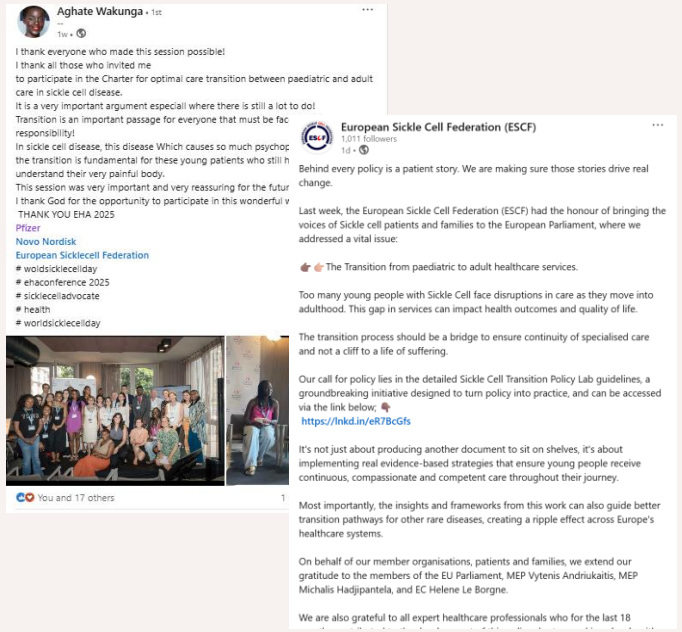
Connect with other advocates and patients to understand centres of best practice for transition care in your country, to use as a case study in engagement

Engage with your local health system policymakers, using the Charter to highlight the gaps in transition care and the need for urgent action

Sustain engagement through campaigning (e.g. writing letters to local stakeholders, social media, engaging in meetings, organise local events)

Use your voice – examples of advocacy in action

Share the Charter and videos with your care team, child's school, employer or wider community



Post about care transitions on social media using our ready-made assets

Write to, or meet with, a local politician or hospital lead to share the Charter and discuss why care transitions must improve

Your experience is evidence. Every conversation matters.

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Thank you

For any questions, please email
sicklecell@mhpgroup.com

https://www.sicklecellpolicylab.com/