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PS2168 – Establishing consensus on the key components of optimal transition from paediatric to adult care in sickle cell disease across Europe

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Background

European countries have improved survival rates for children with sickle cell disease (SCD) due to newborn screening and therapies like hydroxyurea and red cell exchange.[1] However, transition from paediatric to adult care remains marked by care gaps, high hospitalisation rates, poor treatment adherence and mortality rates.

Local variation in the availability and application of SCD-specific clinical guidelines for transition and a lack of consensus on what constitutes an optimal and formalised transition, lead to poor clinical outcomes.

A coordinated Europe-wide approach is vital to promote health equity and ensure consistent, high-quality care for young adults with SCD.

Objectives

- Find a multidisciplinary consensus on the core components of holistic transition services, adapted to European health systems.
- Advocate for policy change and improve outcomes for young adults with SCD.

Methods

The Policy Lab methodology[2] was used to find consensus on optimal transition components through collaboration with healthcare professionals (HCPs), policymakers, public health professionals, patient advocates and patients as equal partners. Participants had in-person and virtual discussions, a council meeting and world-café style sessions.[3] Existing guidelines, frameworks and case studies were reviewed to identify service gaps and generate recommendations applicable to diverse European healthcare settings. The iterative process prioritised patient co-creation, integrating insights from experts and a lived experience council enabling a comprehensive, collaborative and scalable transition model for addressing complex healthcare challenges.

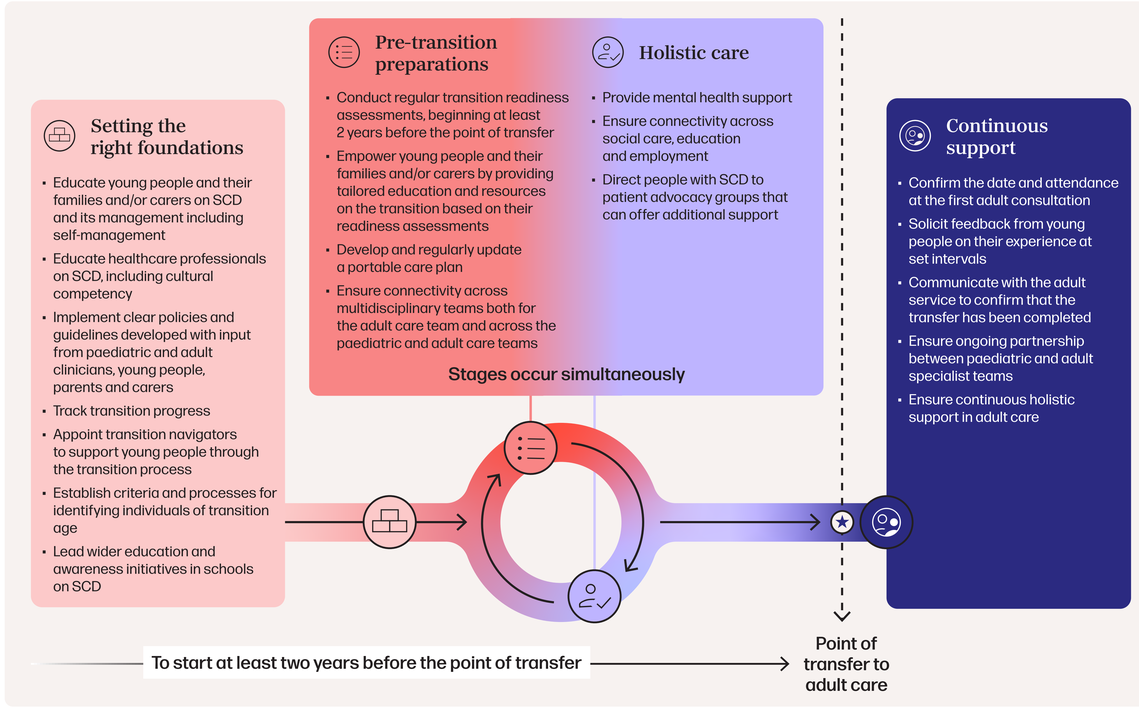
Results: Key barriers to successful SCD transitions

- Wide variation in transition policies and guidelines across countries and healthcare centres.
- Societal and cultural challenges e.g. social marginalisation, stigma, misconceptions and institutional racism.
- Low SCD awareness among HCPs.
- Limited resources and funding for SCD specialists and effective care coordination.
- Poor care coordination.
- Misalignment in transition expectation and experience between patients and HCPs.
- Variable patient and caregiver transition knowledge and limited opportunity for self-advocacy and engagement.
- Gaps in transition advocacy efforts from stakeholders, especially on transition.

Results: Our implementation framework

Our implementation framework (Figure 1) includes early planning, pre-transition preparations, person-centred transition and ongoing monitoring, emphasising different stakeholder roles.

Figure 1. Sickle cell care transition implementation framework.



Five key health system components of a successful transition

- National frameworks with early planning, person-centred approaches, suitable resources and accountability.
- Dedicated, sustainably funded transition trained staff, supported by SCD-specific transition assessment tools.
- Comprehensive SCD-specific training for relevant adult care providers.
- Carer and patient education and support systems beyond the clinic.
- Creation of multilingual, culturally-sensitive education resources.

Conclusion

This is the first multidisciplinary European effort to find consensus on essential SCD transition components. By addressing existing gaps and barriers, this framework offers actionable recommendations to improve transition services and health outcomes for young adults with SCD.

Sickle Cell Transitions Policy Lab

European Reference Network for rare or low prevalence complex diseases
Network Hematological Diseases (ERN EuroBloodNet)

ESCF European Sickle Cell Federation

References

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