Sickle Cell Transitions
Policy Lab

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

Advocacy Toolkit

Version 2: Pre- and Post-Launch Charter promotion

June 2025

Novo Nordisk and Pfizer commissioned and funded the production of the Charter associated Pledge. 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.

Toolkit Contents

About this toolkit

- This toolkit has been developed for sickle cell community advocates to successfully launch and disseminate the *Charter for optimal care transitions in sickle cell disease.*
- This is the second iteration of the Charter toolkit. It provides an overview of the charter and guidance to prepare for the charter launch on 12 June 2025, and to promote the Charter directly after the launch.
- There will be further iterations of this toolkit to support advocates to activate the Charter across 2025.

If you have any questions, feedback or require further information, please contact sicklecell@mhpgroup.com

Introduction

This Advocacy Toolkit has been developed to support the launch and implementation of the *Charter for optimal transitions from paediatric to adult care in sickle cell disease*. The Charter has been co-developed by a multidisciplinary Policy Lab which is chaired by Lora Ruth Wogu and Jenica Leah (ESCF) and Mariangela Pellegrini (ERN-EuroBloodNet). It represents an evidence- and consensus-based call to action for improving the transition from paediatric to adult care for people living with sickle cell disease.

Transition is a critical period that too often results in young people falling through the cracks of fragmented healthcare systems. The Charter sets out clear recommendations to ensure that every young person has access to a safe, person-centred, and supported transition — regardless of where they live.

This toolkit provides practical resources to raise awareness, engage stakeholders, and drive meaningful advocacy. Whether you're a clinician, advocate, young person, or policymaker, these materials are designed to help you champion better transition care in your community, your clinic, and beyond.

Together, we can close the gap in sickle cell transition care.

Section 1

Charter Overview

1.1 Charter Overview

How we developed the Charter

Sickle Cell Transitions
Policy Lab

The Sickle Cell Transitions Policy Lab was established in 2024 to drive health system change and improve outcomes for people living with Sickle Cell Disease (SCD) during the transition from paediatric to adult care. Our vision is to seamlessly bridge this gap, ensuring a continuous, coordinated, compassionate healthcare journey, optimising mental and physical well-being during this critical time.

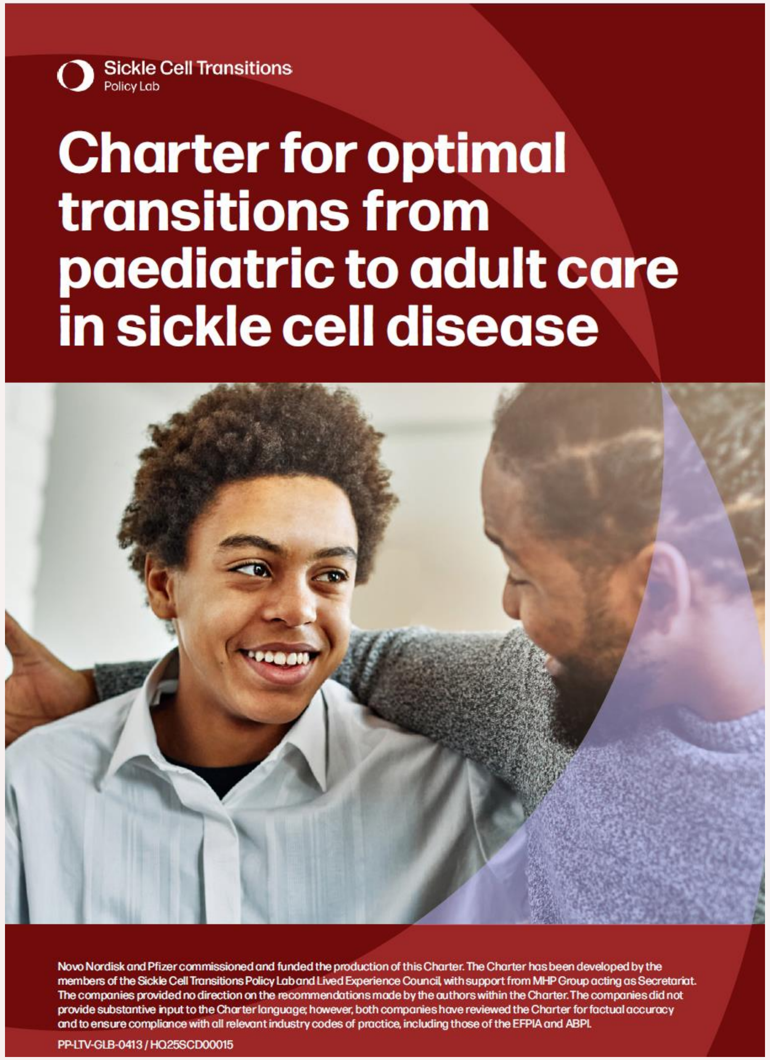
Bringing together patient representatives, advocates, clinicians and system experts from across Europe, we co-developed solutions grounded in the lived experience of SCD and the operational realities of health systems. The resulting Charter clearly defines an optimal transition that all people with SCD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

1.1 Charter Overview

The Charter looks to answer the following questions:

1. Why is the transition from paediatric to adult care important in sickle cell disease? What is the transition and what is the current transition landscape in Europe?
2. What are the components of an optimal transition?
3. How can we make optimal transitions a reality?
4. What prevents people from experiencing an optimal transition?
5. What is the cost of inaction?
6. What is the way forward? What can policymakers at different levels do to drive change and improve transition care?

QR code to read the Charter.
Please note this will not be live until the Launch on12 June



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.

PP-LTV-GLB-0413 / HQ25SCD00015

1.2 About the Policy Lab

This 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 its Secretariat. We warmly thank the following participants for their considerable contributions and insights, which have driven the development of this Charter at every stage.

The Sickle Cell Policy Lab

Dr Anna Collado Gimbert, Consultant Paediatric Haematologist, SCD transition expert, Vall d'Hebron University Hospital, Barcelona, Spain

Prof. Antonis Kattamis, Professor of Paediatric Hematology-Oncology, National and Kapodistrian University of Athens, Greece

Prof. Caterina Minniti, Consultant Paediatric Haematologist, Albert Einstein College of Medicine, New York

Dr Gabriela Medin, Paediatric Psychologist, Gregorio Marañón Hospital, Madrid, Spain

Hannah Jerman, SCD Nurse Specialist**,** Guys and St Thomas NHS Trust, London, UK

Hayley King, Founder, Cianna's Smile, UK

Jenica Leah, President, ESCF, UK

John James OBE, Chief Executive, Sickle Cell Society, UK

Dr. Kofi Anie, Consultant Psychologist, London North West University Healthcare NHS Trust, London, UK

Lora Ruth Wogu, Chief Executive Officer, ESCF, Ireland

Dr María del Mar Mañú Pereira, Head of Research Lab in rare anaemia, EuroBlood-Net, France

Mariangela Pelligrini, Educational & Patients Program Manager, ERN-EuroBloodNet, France

Miriam Santos Freire, SCD patient and Patient representative, ESCF, UK/Portugal, and 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 Trust, London, UK

Dr Sara Stuart-Smith, Consultant Adult Haematologist, King's College Hospital, London, UK

Dr. Valentine Brousse, Centre de Référence MCGRE, Service d'Hémato-Immunologie, Hôpital Universitaire Robert Debré, APHP, Paris, France

1.3 About the Lived Experience Council

This 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 its Secretariat. We warmly thank the following participants for their considerable contributions and insights, which have driven the development of this Charter at every stage.

The Sickle Cell 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 Luwau, 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

1.4 About The Launch

Launch of the *Charter for optimal care transitions in sickle cell disease*

Hybrid launch event

10:15-11:15 CEST

12 June 2025

During the launch of the Charter, you will be able to:
- Gain insights on the key care transition issues and opportunities from people with sickle cell disease, clinicians and policy experts
- Discuss how the Charter supports broader rare disease and youth health policy priorities
- Pledge your support for its recommendations.

As a hybrid event, there are two ways to participate:

In person participation in Milan

Copernico Centrale, Via Copernico, 38, Milan, Italy
Please register using this link

Online participation

Meeting will be hosted via Zoom
Please register using this link

1.4 About The Launch

Duration	Activity	Lead
10:15-10:20 **5 mins**	**Welcome and Opening Remarks** • Opening with a showcase of the Policy Lab video • Overview of the Charter's development and the significance of the programme.	Mario Ottiglio (World Coalition on Sickle Cell Disease)
10:20-10:30 **10 mins**	**Highlighting the challenges with transition and the need for systemic change.** • Presentation on the challenges and unmet need during the transition from paediatric to adult care	Jenica Leah (ESCF)
10:30-10:40 **10 mins**	**Presenting the Charter for optimal transitions** • Overview of the contents of the Charter, including key objectives and recommendations	Mariangela Pellegrini (ERN-EuroBloodNet) Jenica Leah (ESCF)
10:40-11:00 **20 mins**	**Moderated Panel Discussion : Advocating for Best Practices in Transition Care** • Explore key strategies and emerging best practices for supporting patients through transitions in care from different perspectives and different settings.	Aghate Wakunga, Patient, Italy Samah Babiker (Guys & St Thomas NHS Trust) Valentine Brousse (Hôpital Universitaire Robert Debré, APHP) Facilitator: Mario Ottiglio (World Coalition on Sickle Cell Disease)
11:00-11:10 **10 mins**	**Q&A session** • Questions submitted in person and virtually posed to the panellists	
11:10 – 11:15 **5 mins**	**Thank you and closing remarks**	Lora Ruth Wogu (ESCF)

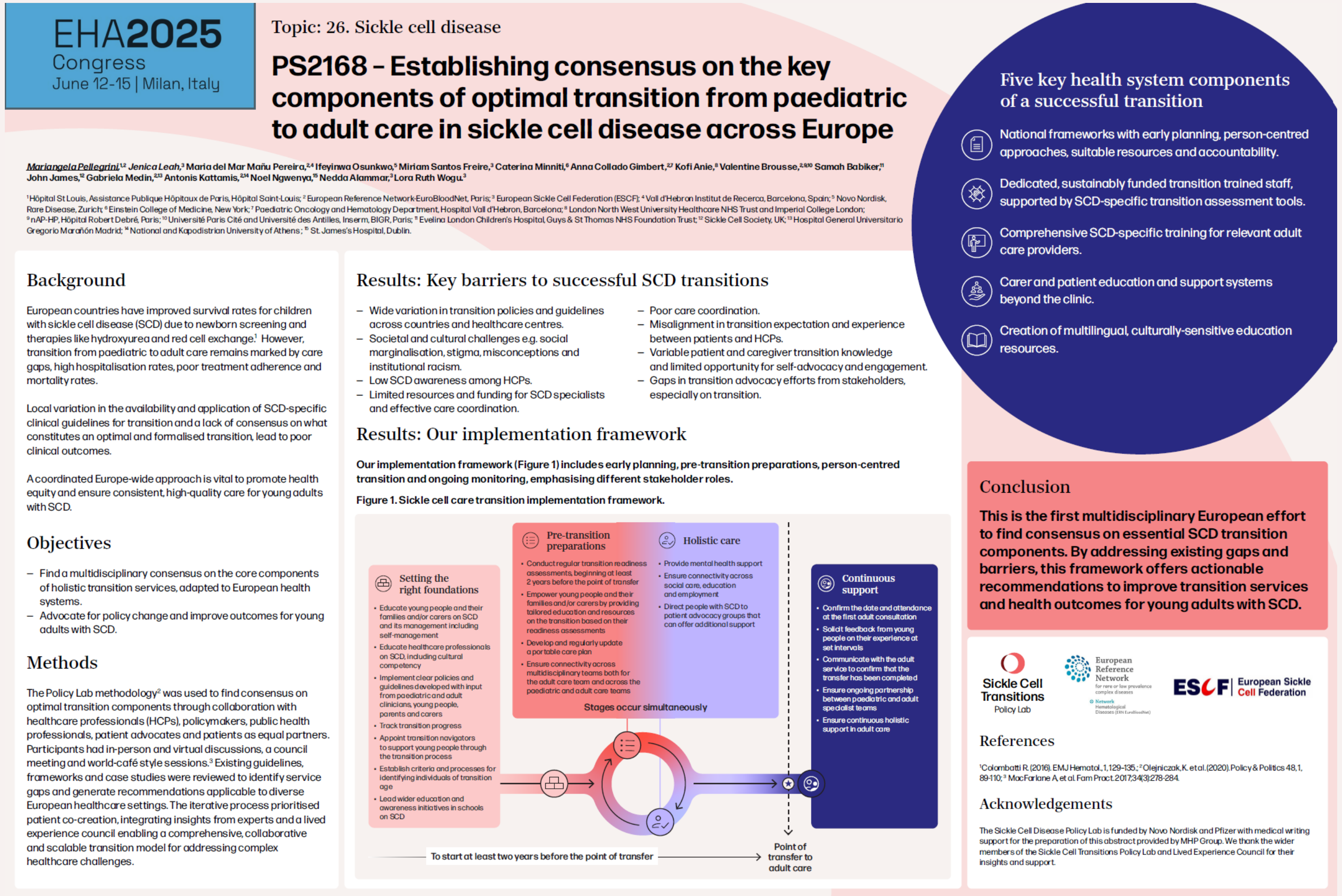
1.4 About the Launch

Poster to be presented at EHA

Alongside the Launch event for the Charter, a poster will also be presented at EHA on the key components of optimal transition from paediatric to adult care in sickle cell disease across Europe.

We are excited by this recognition, which is a strong indication of the importance and relevance of the work we are doing. It is also a great start to our launch cadence and a testament to the hard work of the Policy Lab so far.

If you are at EHA and available during Poster Session 2 on Saturday, 14 June (18:30 – 19:30 CEST) we encourage you to attend to see the poster presentation.



EHA2025
Congress
June 12-15 | Milan, Italy

Topic: 26. Sickle cell disease

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

Mariangela Pellegrini,[1,2] *Jenica Leah*,[3] Maria del Mar Mañu Pereira,[2,4] Ifeyinwa Osunkwo,[5] Miriam Santos Freire,[3] Caterina Minniti,[6] Anna Collado Gimbert,[2,7] Kofi Anie,[8] Valentine Brousse,[2,9,10] Samah Babiker,[11] John James,[12] Gabriela Medin,[2,13] Antonis Kattamis,[2,14] Noel Ngwenya,[15] Nedda Alammar,[3] Lora Ruth Wogu.[3]

[1]Hôpital St Louis, Assistance Publique Hôpitaux de Paris, Hôpital Saint-Louis; [2] European Reference Network-EuroBloodNet, Paris; [3] European Sickle Cell Federation (ESCF); [4] Vall d'Hebron Institut de Recerca, Barcelona, Spain; [5] Novo Nordisk, Rare Disease, Zurich; [6] Einstein College of Medicine, New York; [7] Paediatric Oncology and Hematology Department, Hospital Vall d'Hebron, Barcelona; [8] London North West University Healthcare NHS Trust and Imperial College London; [9] nAP-HP, Hôpital Robert Debré, Paris; [10] Université Paris Cité and Université des Antilles, Inserm, BIGR, Paris; [11] Evelina London Children's Hospital, Guys & St Thomas NHS Foundation Trust; [12] Sickle Cell Society, UK; [13] Hospital General Universitario Gregorio Marañón Madrid; [14] National and Kapodistrian University of Athens ; [15] St. James's Hospital, Dublin.

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.

Setting the right foundations
- Educate young people and their families and/or carers on SCD and its management including self-management
- Educate healthcare professionals on SCD, including cultural competency
- Implement clear policies and guidelines developed with input from paediatric and adult clinicians, young people, parents and carers
- Track transition progress
- Appoint transition navigators to support young people through the transition process
- Establish criteria and processes for identifying individuals of transition age
- Lead wider education and awareness initiatives in schools on SCD

Pre-transition preparations
- Conduct regular transition readiness assessments, beginning at least 2 years before the point of transfer
- Empower young people and their families and/or carers by providing tailored education and resources on the transition based on their readiness assessments
- 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

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

[1]Colombatti R. (2016). EMJ Hematol., 1, 129-135.; [2] Olejniczak, K. et al. (2020). Policy & Politics 48, 1, 89-110; [3] MacFarlane A, et al. Fam Pract. 2017;34(3):278-284.

Acknowledgements

The Sickle Cell Disease Policy Lab is funded by Novo Nordisk and Pfizer with medical writing support for the preparation of this abstract provided by MHP Group. We thank the wider members of the Sickle Cell Transitions Policy Lab and Lived Experience Council for their insights and support.

1.5 Information on Dissemination Activities and Other Key Dates

Grey boxes are events led by the Secretariat and white boxes indicate other wider activities for potential engagement by members of the Policy Lab and advocates.

June

July

August

September

October

November

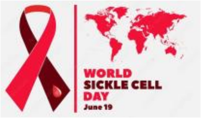
December

12 June

Launch of the Charter at EHA

19 June

World Sickle Cell Day



Communications campaign to build towards autumn launches supported by version 2 of this Toolkit

Ongoing 1:1 dissemination of the Charter via email and meetings

ASCAT session to launch to a wider patient audience

Eurordis meetings to engage with the wider rare disease community

Policy launch in Brussels to engage with EU policymakers

Preparations for 2026

Section 2

Awareness Materials

2.1 Social Media Toolkit

- Sample posts for X, LinkedIn
- Suggested Hashtag
- Social Cards

2.2 Email/Comms Templates

2.3 Visual Assets

Suggested hashtag:

#SCDTransitionCharter

2.1 Social Media Toolkit

Sample posts for X & LinkedIn – please feel free to personalise the content with your own perspective or reason for supporting the Charter.

	From Wednesday 28 May	From Wednesday 4 June	Thursday 12 June	Friday 13 June and beyond
	Problem Statement/Teaser Post	Problem Statement/Teaser Post	Launch Day Post with Link to Charter	Post-Launch Day Thank you with Link to Charter
X	Too many young people with #SickleCell fall through the cracks during healthcare transition. It doesn't have to be this way. The #SCDTransitionCharter sets out a clear path to change. Launching 12 June.	The #SCDTransitionCharter was developed by patients, caregivers, clinicians & system experts. We're proud to support this work and share in its vision for a more connected, compassionate future for young people with #SickleCell.	The #SCDTransitionCharter launches today at EHA – defining what good transition care should look like for young people with #SickleCell. We're honoured to support this collaborative work and share its vision https://www.mhpgroup.com/the-charter-for-optimal-care-transitions-in-sickle-cell-disease-eng/	Thank you to everyone who supported the launch of the #SCDTransitionCharter yesterday. We're proud to stand behind this work – and we'll continue driving forward action to improve transitions for people with #SickleCell. https://www.mhpgroup.com/the-charter-for-optimal-care-transitions-in-sickle-cell-disease-eng [Insert photo from event]
in	Transition from paediatric to adult care is a critical moment for young people with Sickle Cell Disease – but systems often fail them. The #SCDTransitionCharter defines what good should look like and what health systems can do to get there. We're supporting this initiative as part of our broader commitment to improving care across the life course. Launches **12 June**.	No one organisation can improve care alone. We've joined a broad coalition of patients, advocates, clinicians and policy experts to co-create the #SCDTransitionCharter – a blueprint for better transitions in Sickle Cell Disease. Proud to be part of this movement ahead of the Charter's launch on **12 June.**	We are proud to support the launch of the #SCDTransitionCharter – unveiled today. This new Charter defines what every young person with Sickle Cell Disease should experience when transitioning from paediatric to adult care. Developed in collaboration with patients, caregivers and health system experts, it offers both a vision and a roadmap for health systems across Europe. This is a significant milestone – and just the beginning of further work to come throughout 2025. Read more: https://www.mhpgroup.com/the-charter-for-optimal-care-transitions-in-sickle-cell-disease-eng	Thank you to all who joined us for the launch of the #SCDTransitionCharter today. This Charter reflects a shared vision – shaped by lived experience and built through collaboration. We're proud to support this initiative and look forward to building on this work over the months ahead, as we continue to advocate for stronger, more equitable care for young people living with Sickle Cell Disease. Learn more about the Charter and what comes next: https://www.mhpgroup.com/the-charter-for-optimal-care-transitions-in-sickle-cell-disease-eng [Insert photo from event]

Suggested hashtag:

#SCDTransitionCharter

2.1 Social Media Toolkit

If you wish to share the invitation with your networks, please use these posts. The links in the posts are for online participation, if you wish to share in-person invitations, please let the Secretariat team know as there are limited seats.

The #SCDTransitionCharter launches on 12 June – a vital step towards improving care for young people with #SickleCell as they transition from paediatric to adult services.

Join us here: https://rb.gy/n7yshm

#SCDTransitionCharter #SickleCellAwareness #HealthEquity

Too many young people with #SickleCell are let down during the critical transition to adult care. The #SCDTransitionCharter is a bold step to change this.

Join us on 12 June to launch this vision for better care: https://rb.gy/n7yshm

#SickleCellAwareness #HealthEquity

Join Us for the Launch of the #SCDTransitionCharter

Too many young people with Sickle Cell Disease face unnecessary challenges when transitioning from paediatric to adult care. The #SCDTransitionCharter is a bold step forward, offering a clear vision for improving these critical transitions at all levels.

Join us on 12 June for the official launch event, where we'll unveil this exciting new vision for change. Together with patients, advocates, clinicians, and policymakers, we'll explore how we can ensure no young person falls through the cracks.

📅 Date: 12 June 2025
⏰ Time: 10:15-11:15 CEST
📍 Please register for online participation here: https://rb.gy/n7yshm

Let's work together to transform care for young people with Sickle Cell Disease.

#SickleCell #SCDTransitionCharter #HealthcareInnovation

Improving Sickle Cell Transitions: Be Part of the Solution

The transition from paediatric to adult care is a critical moment for young people with Sickle Cell Disease – but too often, the system lets them down.

On 12 June, we're launching the #SCDTransitionCharter, a collaborative vision for change co-created by leading patients, advocates and clinicians. I've been involved in developing the Charter, and I truly believe it defines what good care should look like and how we can work together to make it a reality.

📅 Date: 12 June 2025
⏰ Time: 10:15-11:15 CEST
📍 Please register for online participation here: https://rb.gy/n7yshm

Join us for this important event and help shape a future where no young person with Sickle Cell Disease experiences a poor transition. Together, we can drive meaningful change.

#SickleCell #SCDTransitionCharter #HealthEquity #HealthcareInnovation

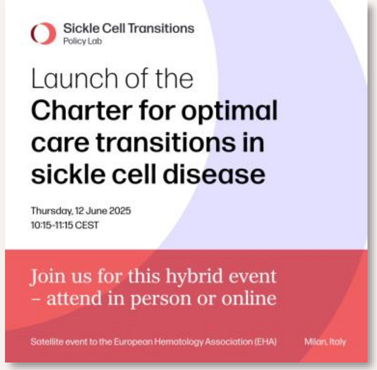
2.1 Social Media Toolkit

Suggested hashtag:

#SCDTransitionCharter

Social cards

Each social media platform has its own image requirements for posts. We have provided the full range of image sizes for whichever platform you decide to post on.



Sickle Cell Transitions
Policy Lab

Launch of the
Charter for optimal care transitions in sickle cell disease

Thursday, 12 June 2025
10:15-11:15 CEST

Join us for this hybrid event – attend in person or online

Satellite event to the European Hematology Association (EHA) Milan, Italy

Instagram (1080x1080)*

Sickle Cell Transitions
Policy Lab

Launch of the Charter for optimal care transitions in sickle cell disease

Thursday, 12 June 2025
10:15-11:15 CEST

Join us for this hybrid event – attend in person or online

Satellite event to the European Hematology Association (EHA) Milan, Italy

X aka Twitter
(1600x900)

Sickle Cell Transitions
Policy Lab

Launch of the Charter for optimal care transitions in sickle cell disease

Thursday, 12 June 2025
10:15-11:15 CEST

Join us for this hybrid event – attend in person or online

Satellite event to the European Hematology Association (EHA) Milan, Italy

LinkedIn or Facebook
(1200x627)

Sickle Cell Transitions
Policy Lab

Launch of the
Charter for optimal care transitions in sickle cell disease

Thursday, 12 June 2025
10:15-11:15 CEST

Join us for this hybrid event – attend in person or online

Satellite event to the European Hematology Association (EHA) Milan, Italy

Instagram stories or
TikTok (1080x1920)

The social cards are included as attachments in the same email as the advocacy toolkit.

*Please note that Instagram does not allow including links in the text of a post.

2.2 Email/Comms Template – Pre-Launch

Please use this email template to promote the launch of the Charter to networks, mailing lists, colleagues or other stakeholders.

It highlights the purpose of the Charter, the launch event, and includes a call to action.

As an alternative, please forward on your invite!

To:

Subject:

Dear [Name / Colleagues / Friends],

I'm pleased to share that on **Thursday 12 June**, the new **Charter for optimal care transitions in sickle cell disease** will be officially launched.

This Charter is the result of a collaborative effort across Europe, bringing together patient representatives, advocates, clinicians, and system experts. Together, we've co-developed a shared vision for what transition from paediatric to adult care should look like for young people living with **Sickle Cell Disease (SCD)**.

Transition is a critical moment in the care journey, yet many young people with SCD experience disruptions, delays, and disconnection between services. The Charter outlines what good, coordinated, compassionate transition should look like – and the practical steps health systems can take to achieve it.

As a proud supporter of this work, [we/I] invite you to participate in the Charter launch and join the movement to improve outcomes for the SCD community.

Date: 12 June 2025
Time: 10:15-11:15 CEST
Please register for online participation here: https://rb.gy/n7yshm

This is just the beginning. Over the coming months, we'll continue working with the SCD community to drive awareness and implementation of the Charter's principles across Europe. We'd welcome your support, visibility, and engagement in this next phase.

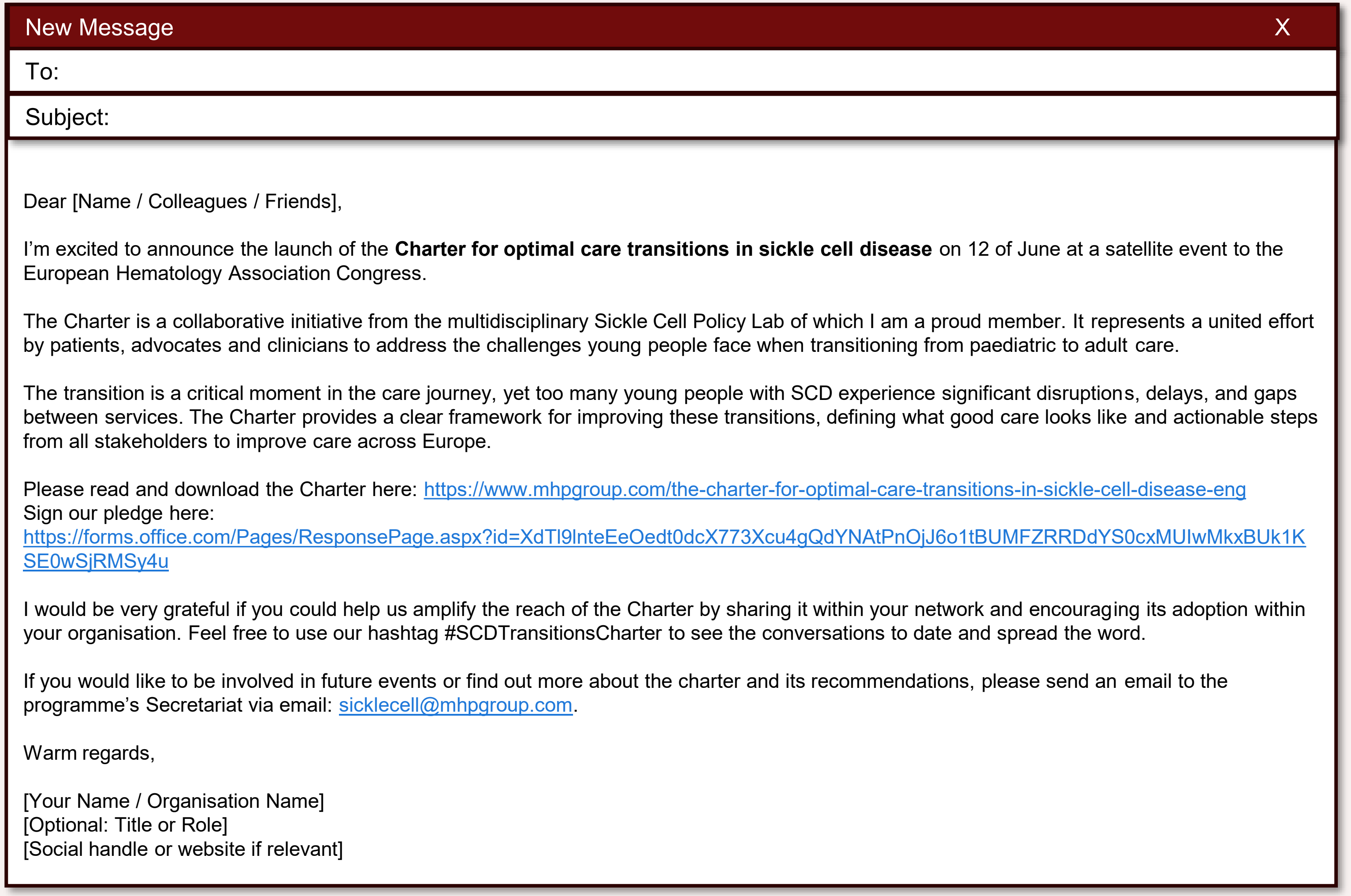
Warm regards,

[Your Name / Organisation Name]
[Optional: Title or Role]
[Social handle or website if relevant]

2.2 Email/Comms Template – Post-Launch

Please use this email template to promote the launch of the Charter to networks, mailing lists, colleagues or other stakeholders.

It highlights the purpose of the Charter, the launch event, and includes a call to action.



To:

Subject:

Dear [Name / Colleagues / Friends],

I'm excited to announce the launch of the **Charter for optimal care transitions in sickle cell disease** on 12 of June at a satellite event to the European Hematology Association Congress.

The Charter is a collaborative initiative from the multidisciplinary Sickle Cell Policy Lab of which I am a proud member. It represents a united effort by patients, advocates and clinicians to address the challenges young people face when transitioning from paediatric to adult care.

The transition is a critical moment in the care journey, yet too many young people with SCD experience significant disruptions, delays, and gaps between services. The Charter provides a clear framework for improving these transitions, defining what good care looks like and actionable steps from all stakeholders to improve care across Europe.

Please read and download the Charter here: https://www.mhpgroup.com/the-charter-for-optimal-care-transitions-in-sickle-cell-disease-eng
Sign our pledge here:
https://forms.office.com/Pages/ResponsePage.aspx?id=XdTl9lnteEeOedt0dcX773Xcu4gQdYNAtPnOjJ6o1tBUMFZRRDdYS0cxMUlwMkxBUk1KSE0wSjRMSy4u

I would be very grateful if you could help us amplify the reach of the Charter by sharing it within your network and encouraging its adoption within your organisation. Feel free to use our hashtag #SCDTransitionsCharter to see the conversations to date and spread the word.

If you would like to be involved in future events or find out more about the charter and its recommendations, please send an email to the programme's Secretariat via email: sicklecell@mhpgroup.com.

Warm regards,

[Your Name / Organisation Name]
[Optional: Title or Role]
[Social handle or website if relevant]

2.3 Visual Assets

Teams/Zoom background

To use this background on Teams, please follow the following instructions:

1. Download image to your computer
2. Open Teams and select the drop down menu under ‘Camera’ and select ‘More video effects and settings’
3. Under ‘Backgrounds’, select ‘Add new’ and upload image from your computer
4. If image does not appear right away, click on ‘Show all’ and it should appear
5. Select the image and click ‘Apply’
6. The image should appear behind you.

Please note that the logo will appear mirrored to you, but it will be flipped the correct way around for the other people on the call.

To use this background on Zoom, please follow the following instructions:

1. Download image to your computer
2. Open Zoom and select the drop down menu under ‘Video’ and select ‘Video settings…’
3. Select the menu item ‘Background & effects’ and select ‘Virtual Backgrounds’.
4. Click on the blue plus sign on the righthand side and select ‘Add image’.
5. Upload image from your computer, and it should appear behind you right away

Please note that the logo will appear mirrored to you, but it will be flipped the correct way around for the other people on the call.

The Teams/Zoom background is included as an attachment in the same email as the advocacy toolkit.

2.3 Visual Assets

Teams background, email banner

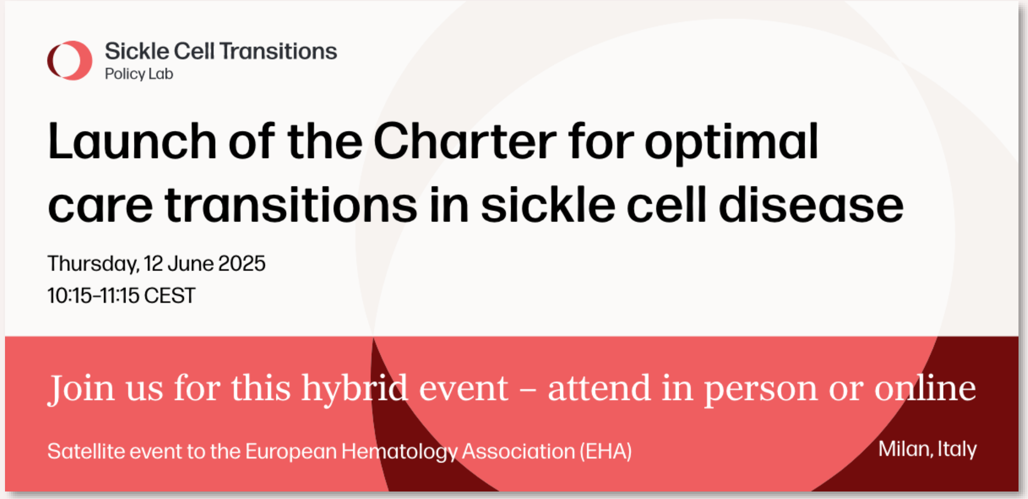
Please feel free to add this email banner to your email signature to visually support your communication about the event.

To use this email banner on Outlook, please follow the following instructions:

- Open Outlook and go to **File** > **Options** > **Mail** > **Signatures**.
- Select your existing signature or create a new one.
- Place your cursor where you'd like the banner to appear (typically at the bottom).
- Click the **image icon** and upload the banner image file.
- (Optional) Highlight the image and click the **link icon** to make it clickable, linking to the online event registration link.
- Click **OK** to save.

To use this email banner on Gmail, please follow the following instructions:

- Go to **Settings** (gear icon) > **See all settings** > **General** tab.
- Scroll down to the **Signature** section and either edit your existing signature or create a new one.
- Click the **Insert image** icon and upload or paste the banner image URL.
- (Optional) Select the image, click the **Link** icon, and add the online event registration link as a hyperlink.
- Scroll down and click **Save Changes**.



Sickle Cell Transitions
Policy Lab

Launch of the Charter for optimal care transitions in sickle cell disease

Thursday, 12 June 2025
10:15–11:15 CEST

Join us for this hybrid event – attend in person or online

Satellite event to the European Hematology Association (EHA)

Milan, Italy

The email banner is included as an attachment in the same email as the advocacy toolkit.

Section 3

Sign and Support

3.1 Signing the Pledge Online

3.1 Signing The Pledge Online

Join us in transforming the future of young people living with Sickle Cell disease

Why Your Commitment Matters

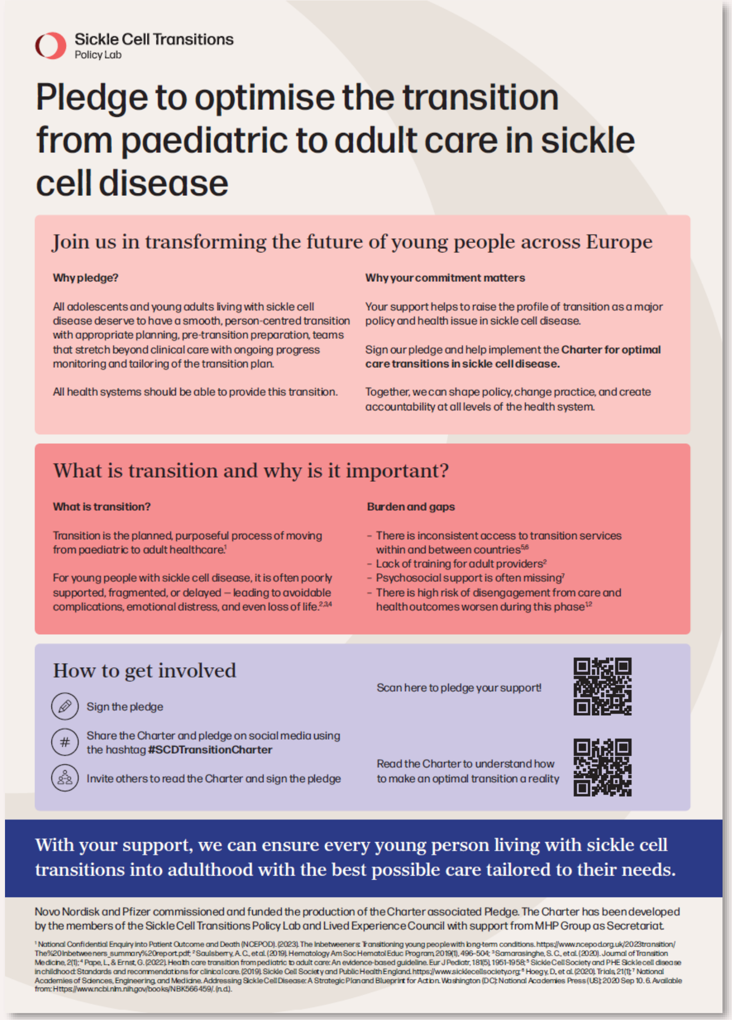
Your support helps to raise the profile of transition as a major policy and health issue in sickle cell disease.

Pledge your support to help implement the **Charter for optimal care transitions in sickle cell disease.**

Together, we can shape policy, change practice, and create accountability at all levels of the health system.

How to contribute

- Sign the pledge here or on the QR code on this page.
- Share the Charter and pledge online using the hashtag **#SCDTransitionCharter**
- Invite your organisation, colleagues and friends to read the Charter and sign the pledge online.



Sickle Cell Transitions
Policy Lab

Pledge to optimise the transition from paediatric to adult care in sickle cell disease

Join us in transforming the future of young people across Europe

Why pledge?

All adolescents and young adults living with sickle cell disease deserve to have a smooth, person-centred transition with appropriate planning, pre-transition preparation, 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.

Why your commitment matters

Your support helps to raise the profile of transition as a major policy and health issue in sickle cell disease.

Sign our pledge and help implement the **Charter for optimal care transitions in sickle cell disease.**

Together, we can shape policy, change practice, and create accountability at all levels of the health system.

What is transition and why is it important?

What is transition?

Transition is the planned, purposeful process of moving from paediatric to adult healthcare.[1]

For young people with sickle cell disease, it is often poorly supported, fragmented, or delayed – leading to avoidable complications, emotional distress, and even loss of life.[2,3,4]

Burden and gaps

- There is inconsistent access to transition services within and between countries[5,6]
- Lack of training for adult providers[2]
- Psychosocial support is often missing[7]
- There is high risk of disengagement from care and health outcomes worsen during this phase[1,2]

How to get involved

- Sign the pledge
- Share the Charter and pledge on social media using the hashtag **#SCDTransitionCharter**
- Invite others to read the Charter and sign the pledge

Scan here to pledge your support!

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

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.

Novo Nordisk and Pfizer commissioned and funded the production of the Charter associated Pledge. The Charter has been developed by the members of the Sickle Cell Transitions Policy Lab and Lived Experience Council with support from MHP Group as Secretariat.

[1] National Confidential Enquiry into Patient Outcome and Death (NCEPOD). (2023). The Inbetweeners: Transitioning young people with long-term conditions. https://www.ncepod.org.uk/2023transition/The%20Inbetweeners_summary%20report.pdf; [2] Saulsberry, A. C., et al. (2019). Hematology Am Soc Hematol Educ Program, 2019(1), 496-504; [3] Samarasinghe, S. C., et al. (2020). Journal of Transition Medicine, 2(1); [4] Pape, L., & Ernst, G. (2022). Health care transition from pediatric to adult care: An evidence-based guideline. Eur J Pediatr, 181(5), 1951-1958; [5] 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; [6] Hoegy, D., et al. (2020). Trials, 21(1); [7] National Academies of Sciences, Engineering, and Medicine. Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action. Washington (DC): National Academies Press (US); 2020 Sep 10. 6. Available from: Https://www.ncbi.nlm.nih.gov/books/NBK566459/. (n.d.).

Thank you

If you have any questions or require any support, please contact:

sicklecell@mhpgroup.com