ASCAT

2026

7-10 October 2026 | London, UK
Central Hall Westminster

Mental Health and Quality of Life in Sickle Cell Disease

ERN-EuroBloodNet & RADeep: patients' session

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ERN-EuroBloodNet & RADeep: patients' sessions

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Since 2019, **ERN-EuroBloodNet** has partnered with **ASCAT (Academy for Sickle Cell and Thalassemia)** to organize dedicated educational sessions for individuals living with **SCD** within the framework of the Congress.

2019

Topic: The SCD Research Prioritization Workshop: Top 10 SCD Patient Priorities

Participants: 28

2020

Topics: Living with SCD and coping with COVID19; Patients' role in research & peer reviewing; Meet-the-experts & patient panel discussions.

Participants: 48

2021

Topics: Racism in healthcare; Mental health; Pregnancy & Bone marrow transplant.

Participants: 54

2022

Topics: Tips for transition; Aging well; Embryonal selection, Prenatal Diagnosis & Preimplantation; Patient-doctor dynamics & assertiveness training; Understanding PROMs; how to share knowledge at local level.

Participants: 89

2023

Topics: Discrepancies in disease perception Adult patients mentoring teenagers; Global SCD strategy with the Lancet Commission; AI applications in SCD; Patient-doctor dynamics through role-playing.

Participants: 15

2024

Topic: Spotlight **on Transition Care**: from Pediatric to Adult

Participants: 27

2025

Topic: Sexual Health and Sickle Cell Disease.

Participants: 33

2026

Topic: Mental Health and Quality of Life in Sickle Cell Disease

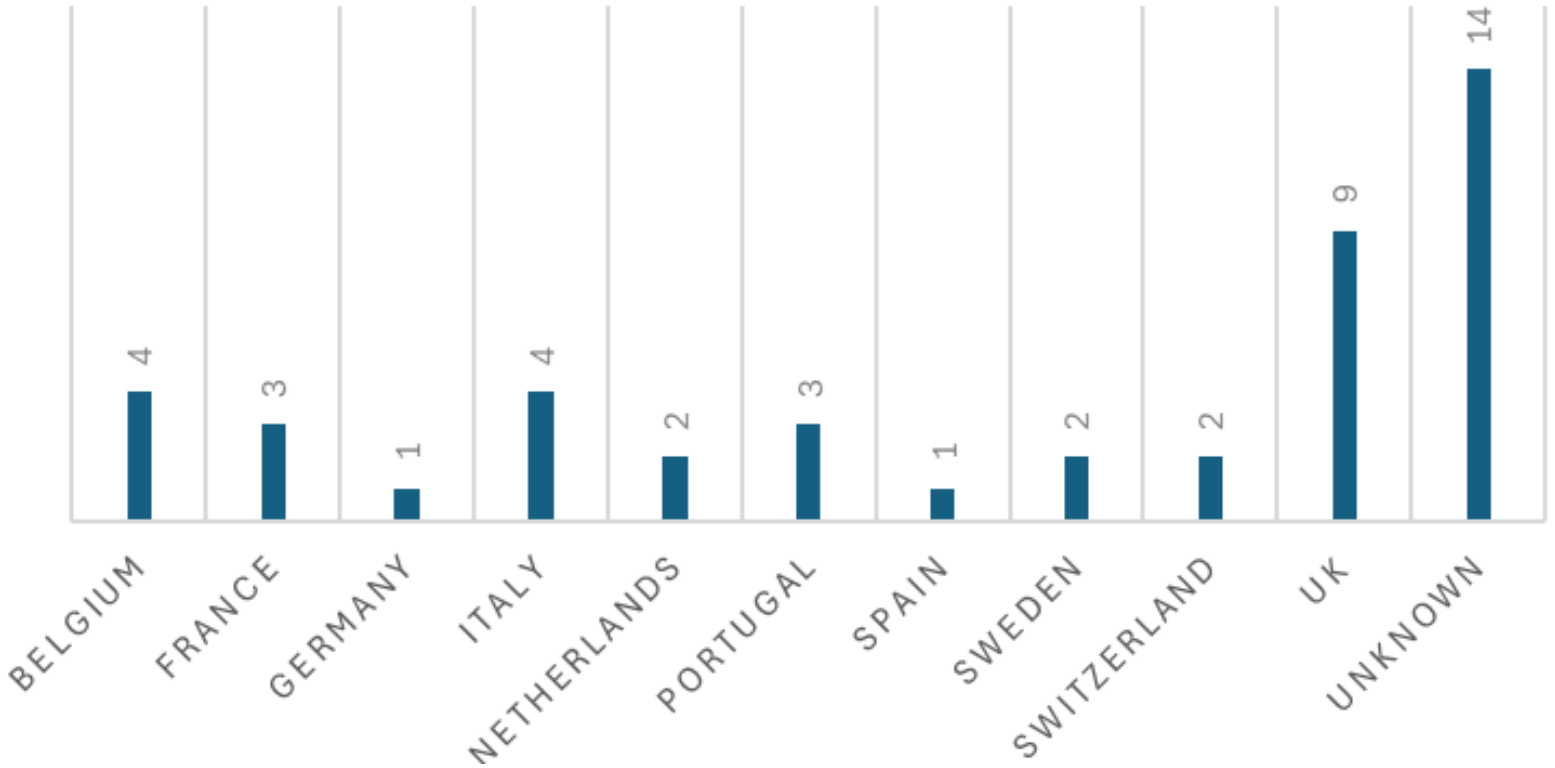
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Total assistance: 45



Moderators	
UK	Hematologist
Spain	Pediatrician
UK	Psychologist (x2)
Italy	Specialist Nurse

2026 program:

- **Day 1: Understanding the mental health burden of SCD**
    - Mental health Impact on daily life and functioning
    - Practical Strategies to Improve Well-being
- **Day 2: Assessing Mental Health in Sickle Cell Disease: Patient-Reported Outcomes (PROMs) and Access to Care**
    - Access to Mental Health Care for the SCD community
    - Patient-Reported Outcomes and Quality of Life
- **Day 3: Patient Perspectives in Practice. Workshop**

How SCD affects our mental health and lifestyle

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Why a psychologist belongs on the team

- Work and education
- Relationships and dating
- Self-esteem and confidence
- Unpredictability and insecurity
- Watching family suffer too
- Burnout from constant coping

"Parity of esteem: mental health and physical health, you can't have one without the other."

"There can be a struggle to value life when constantly in and out of hospital."

"Living with sickle cell directly defines the way a patient lives, even after being treated with a transplant."

"Help needed to cope with low self-esteem... not being identified solely by the condition."

Sickle cell reaches into work, relationships and learning

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Work and independence

What gets harder

- Accessibility and travel
- Working with pain
- Stressful jobs, deadlines and targets
- Constantly explaining yourself
- Absences and fear of losing the job
- Keeping up concentration and energy

What helps

- Understanding employers
- Adjustments such as flexible hours
- Disability legislation reflecting SCD
- Talking to your manager

Relationships and social life

What gets harder

- Being an equal partner in decisions
- Loneliness
- Being active: beach, sport
- Caregivers who understand
- Parenting duties
- Showing up

What helps

- Others making an effort to understand
- Resilience and staying hopeful
- Being open and explaining

Learning and growth

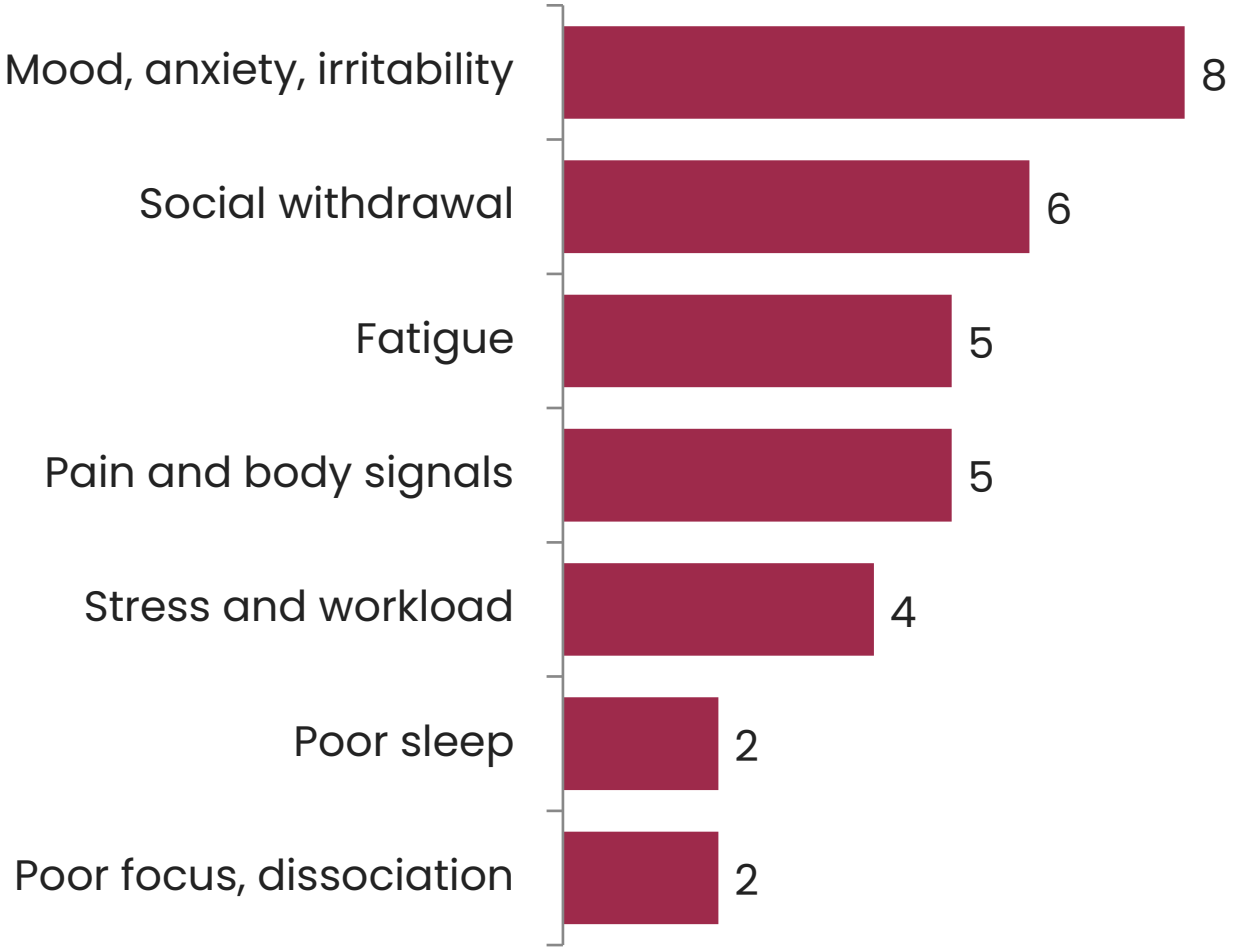
What gets harder

- Completing training and courses
- Fear of falling behind
- Getting a job according to your level of education/qualifications
- Getting a job due to our diagnosis

What helps

- Adjusted schedules
- Flexibility

Early signs of struggle are mostly emotional, not physical



In our words

"I'm a very joyful person, so when I don't smile anymore, that means something is very, very off."

"Not replying to my messages. Disappear. Less desire of being around people."

"The surroundings don't understand how stress affects you, so they keep stressing you out."

How pain affects mental health

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Pain is not only felt in the body: in your own words, it is **“physical and mental damage”**.

It drains sleep, focus and energy

“Too uncomfortable to sleep, think and function at all.”

It brings helplessness and distress

“It makes you cry… knowing you can’t do anything unless they help you.”

It is unpredictable, so you live on alert

“It hurts and it keeps happening.”
“Different from one crisis to another.”

It is hard to explain, which isolates

“A pain with no emotional word.”

How mental health shapes pain

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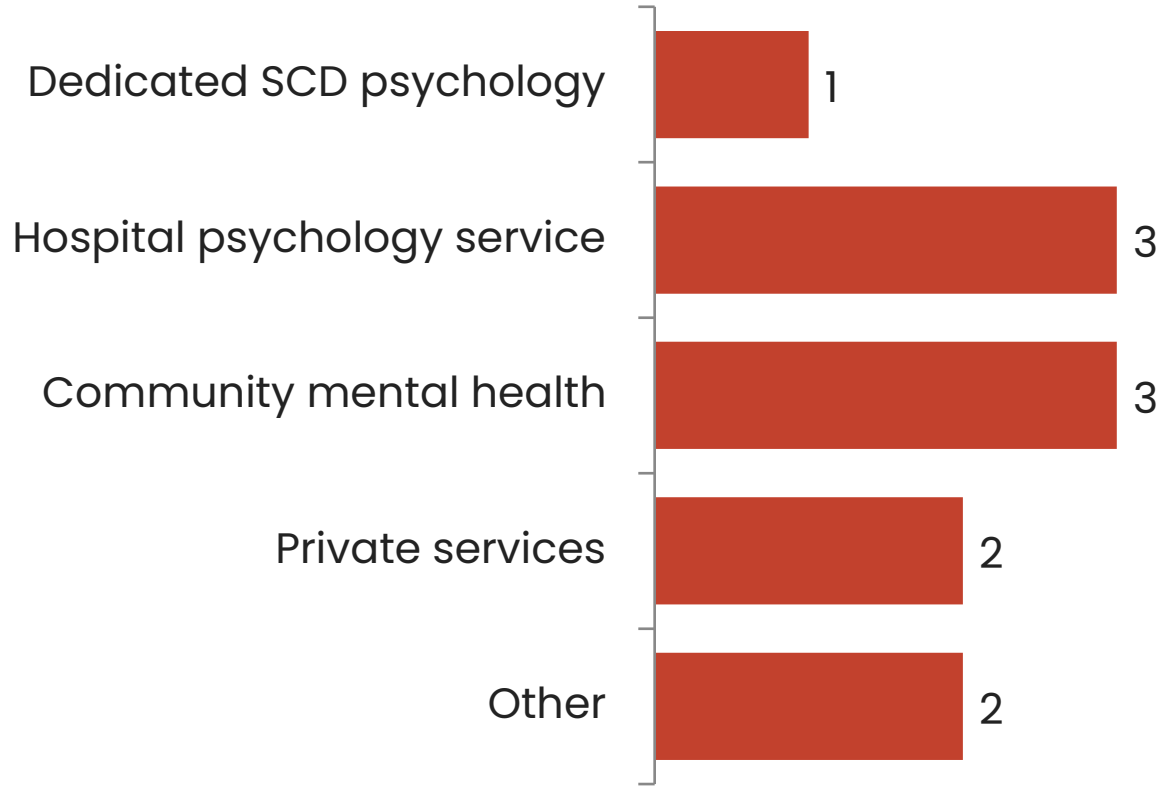
Pain is real and physical, but the brain decides how loud the alarm rings.

- **Stress turns the volume up:** Worry, tension and low mood make the same pain feel stronger.
- **The body learns to expect pain:** After many painful experiences, just thinking about it can trigger it.
- **Being believed changes pain:** Expecting to be treated properly can modulate the pain you perceive.
- **So can we turn it down?** Calm, trust and support can help, alongside medical treatment, never instead of it.

A cycle: pain → stress, fear, poor sleep → more pain. **If you feel it, you've got it.**

Only one in eleven have access to dedicated sickle cell psychology

“Where can you personally get mental health support?” (11 respondents)



1 in 11

has a psychology service designed around sickle cell

Most rely on general hospital or community services, and some pay privately.

Responses come from several countries, so this reflects a mix of health systems.

Barriers to mental health care are structural, cultural and personal

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Structural

- Limited funding
- Time and bureaucracy of referrals
- Few professionals who know SCD
- Structural racism; little diversity among professionals
- Overwhelming initial assessment
- Sessions limited by funding, not by need
- Inconsistency and hospital organisation
- Cognitive Behavioral Therapy used generally as the only approach
- Focus only on emergencies such as suicide risk

Cultural

- Not seen as a “real” health problem
- Family and peers questioning it
- Taboo within the family
- Seen as lack of faith: “you need to pray”
- Spiritual explanations: demons, witchcraft
- Disbelief in diagnosis or in therapy
- Clashes with family faith or beliefs

Stigma

- Being labelled crazy or mad
- Seen as dangerous or unpredictable
- Labelled as not able to having children
- Seen as weak for seeking therapy
- Feeling embarrassed, a failure, or scared

Patients' blueprint for a psychology service

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Make it easy to get in - Access

- Psychological support as a standard of care
- Simpler referrals and shorter waits
- A 24/7 helpline and online consultations

Led by need, not funding/quota

- Number of sessions set by need, not budget
- Group sessions
- Self-management tools people can use themselves

The right people

- Listen to patients; be kind and compassionate
- Train mental health sickle cell specialists
- Employ a multicultural/diverse workforce

Build it into the system

- Part of the multidisciplinary team
- Co-design care pathways with patients and carers

Participation in Patient Reported Outcome (PRO) studies

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9 in 14

had never heard of a PRO, or didn't know what one was

13 in 21

had never taken part in a PRO studies

What do you think happens to it after you hand in a questionnaire?

"Nothing." "Not used." "Sell it." "I don't know."

"They use it for their research, but it doesn't help us. So it's for them, not for us."

"They take it… to understand us better, that's what I wish, but there is never feedback about that."

What would make you trust the process more?

- Feedback on results, and acknowledgement of receipt
- Transparency about how data and decisions are used
- Visible action and changes to care
- Shorter questionnaires
- Fair compensation

"Knowing that my voice is genuinely heard and leads to real changes in my care"

Final remarks

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1. **Mental health is part of SCD care:** make psychological support a standard of care, throughout the life cycle /lifespan.
2. **Listen and believe the patients. Co-design with patients:**
   - A psychology service that meets our needs
   - PROMS tools and studies. Tell patients what happens to our answers, and act on them.

Being understood, make change happen

With the support of

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