World Sickle Cell Day 2026: Young Voices Rising

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1. What?

World Sickle Cell Day 2026 focuses on **Young Voices Rising**, with the call to action: "**Own your health now. Live well with sickle cell.**" [1]

Around 18,500 people
in the UK live with sickle cell disease (SCD)

Sickle cell disease is the most common inherited blood disorder in the UK.

2. Why?

In 2025, NICE recommended **exagamglogene autotemcel (exa-cel)** for managed access on the NHS in England for some people aged 12 and over with severe sickle cell disease.[2]

Exa-cel is a one-off gene therapy using **CRISPR-Cas9 editing** on a person's own blood stem cells to increase fetal haemoglobin and reduce sickling

3. Clinical evidence for exa-cel[3]

CLIMB SCD-121
Single-arm trial

29 people
with sufficient follow-up

Aged 12–35
Severe SCD

96.6% Had **no severe vaso-occlusive crises** for at least 12 months after infusion

100% Had **no hospitalisations** for severe vaso-occlusive crises over the same period

Results are promising, but the trial was small and longer-term evidence is needed

4. Who may benefit – and what may limit access?

Exa-cel offers a new option for some people aged 12 and over with **severe sickle cell disease**, recurrent **vaso-occlusive crises** and **specific genotypes**, for whom stem cell transplant is suitable but no matched related donor is available.

Real world impact will depend on eligibility, referral pathways, specialist capacity, trust in the service and long-term follow-up

5. Author's commentary

"Exa-cel is a scientific milestone, but its real-world value will depend on more than clinical trial results. It will depend on equitable access, careful long-term monitoring, and whether young people with sickle cell disease are properly supported to understand their choices, voice their concerns and shape what better care looks like".

Sources

1. https://www.sicklecellsociety.org/wscd26/ 2. NHS England » Revolutionary gene-editing therapy for sickle cell 'offers hope of a cure' for NHS patients 3. Exagamglogene Autotemcel for Severe Sickle Cell Disease | New England Journal of Medicine