

What do people ask SickleCellPedia, an AI assistant for sickle cell disease?

A sample of 1,925 messages from 434 users in 33 countries, June 2025 to October 2026

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**SCKIN**

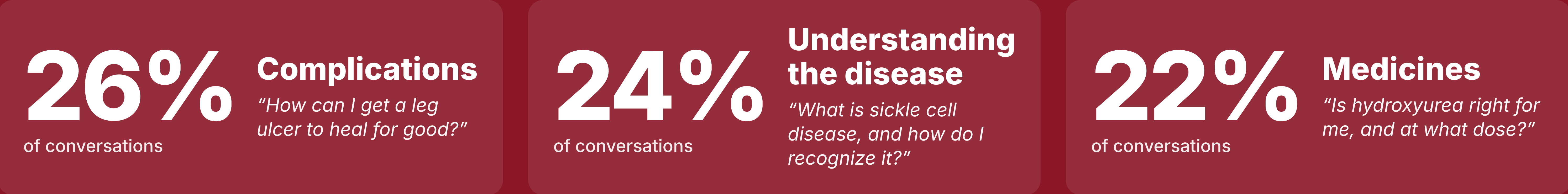
Sickle Cell Knowledge and Information Network

www.sckin.org

SCDAA 54th Annual National Convention · October 2026

The top three needs

What users most often came to SickleCellPedia for



THE NEXT FIVE Pain and crisis management **22%** · Inheritance and testing **15%** · Daily living **13%** · Cures: transplant and gene therapy **11%** · Mental health, relationships and work **10%**

Share of the 415 conversations that contained a relevant question. One conversation can raise several needs. Example questions are paraphrased.

Methods

- 1 A sample of real use.** 1,925 messages sent by 434 users on WhatsApp and the web, June 2025 to October 2026. SCKIN's own test conversations were excluded.
- 2 Analyzed with AI tools.** An AI language model sorted every message by type and tagged each conversation with the needs it raised.
- 3 Privacy respected.** Users accept a privacy policy that covers research use. Data were anonymized before analysis.

About SCKIN

Our mission: make useful and reliable information about sickle cell disease universally accessible.

People live with sickle cell disease every day, yet most see a specialist rarely, and many never do. Reliable information, in their own language and at the moment they need it, helps them recognize danger signs, use treatments well and arrive in clinic with better questions.

How SickleCellPedia works

- Free
- WhatsApp and web
- Multilingual

An AI assistant that answers questions about sickle cell disease from a curated library of trusted sources, and says where its answers come from.

EXAMPLES FROM OUR SOURCE LIBRARY

Articles, e.g. *Role of gene therapy in sickle cell disease* (Raghuraman et al., 2024) and *The nephropathy of sickle cell trait and sickle cell disease* (Ataga et al., 2022)

Books, e.g. *Sickle Cell and the Social Sciences* (Dyson, 2019) and *Sickle Cell Disease* (Gladwin, Kato and Novelli, 2021)

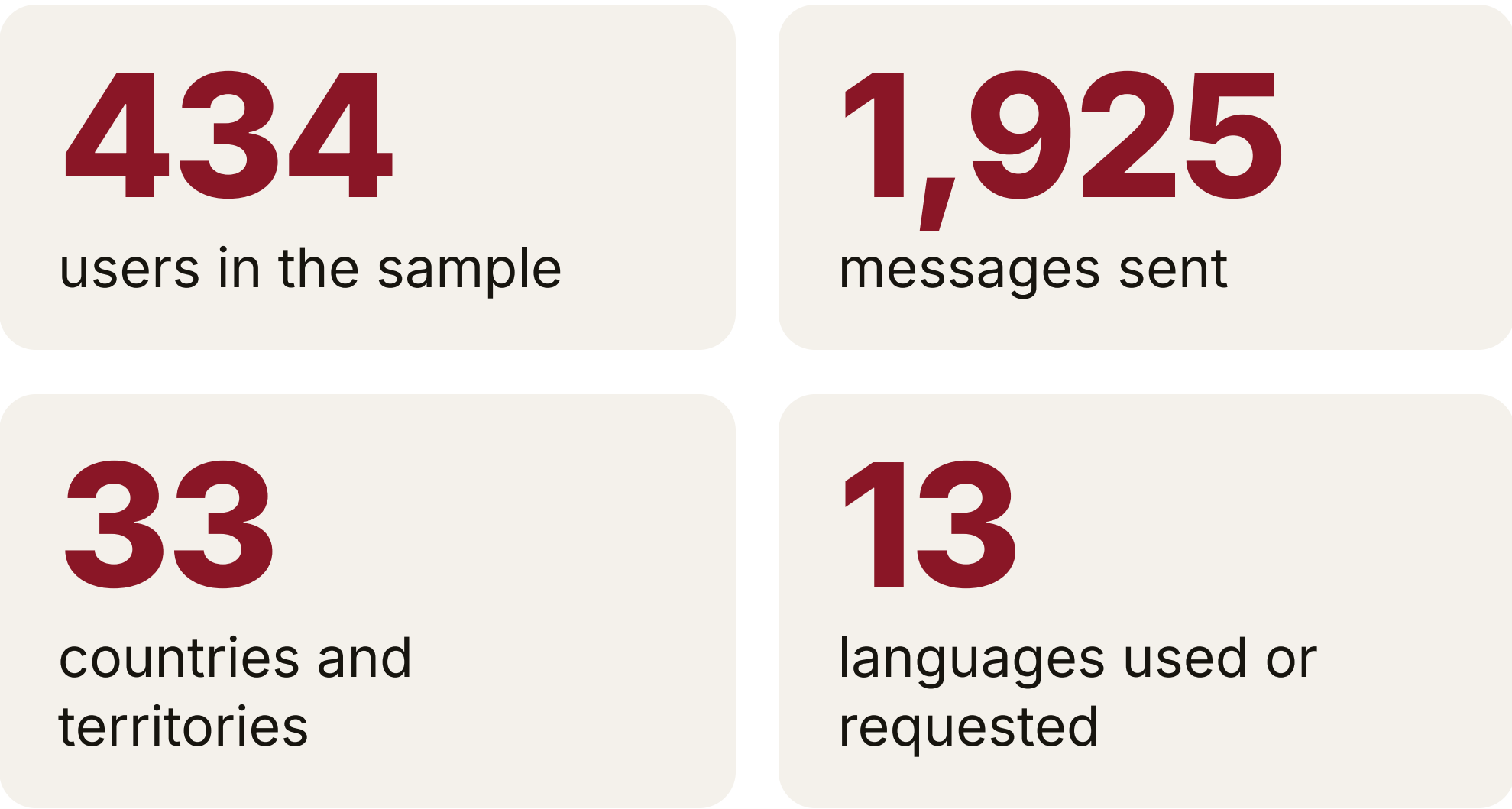
Websites, e.g. NIH (NHLBI), CDC and SCDAA (sicklecelldisease.org)

Sickle cell specialists are evaluating the accuracy of its answers: Liman-Tingui Z, Thomas L, et al. *A specialized AI agent for sickle cell patient education in low-resource settings: a benchmarking evaluation*. Br J Haematol 2026, abstract O18. doi:10.1111/bjh.70838

Discussion

- What users ask shows where reliable information is missing. Across countries and languages, people most need help with complications, with understanding the disease and with medicines.
- People ask an AI assistant what they may not ask in clinic: sometimes out of shame, often because no expert is available when the question comes up. No patient can reach their doctor at any hour.

Who uses it

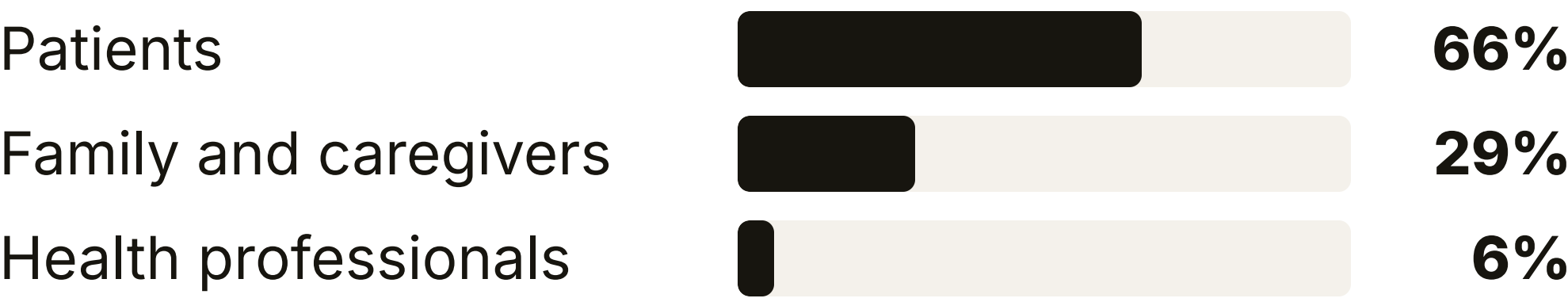


Where users are



Number of users in the five largest countries. Country is derived from the phone code of the 333 WhatsApp users with a valid number.

Who is asking



Among the 143 conversations in which the person said who they were. In the other 272 the asker could not be identified.

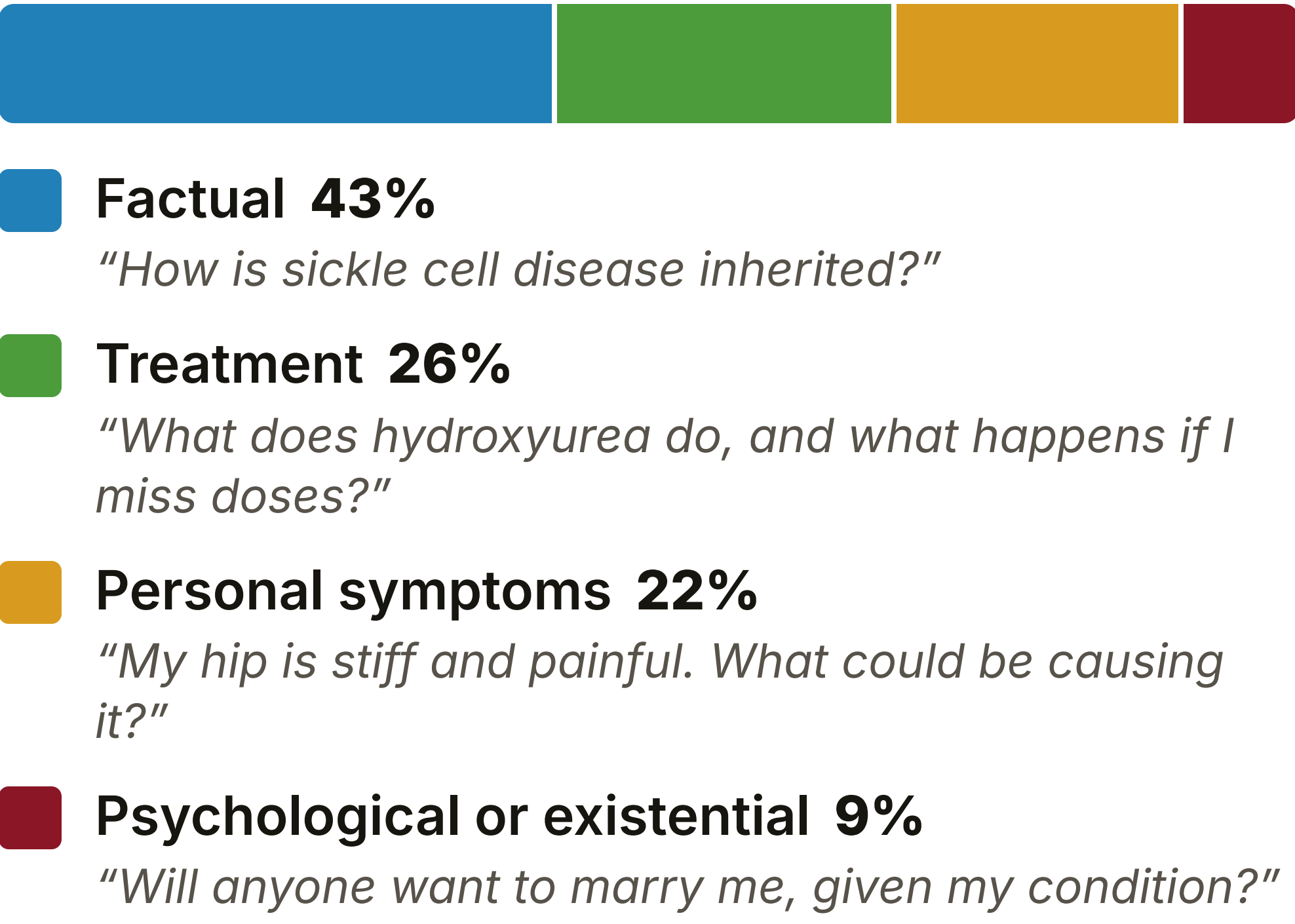
Languages

Users wrote in English, French, Hindi, Marathi, Assamese, Dutch, Swahili and Haitian Creole, and asked for answers in Hausa, Arabic, Urdu, Tamil and Spanish.

Further research

- Know who is asking, and where.** With consent, record role, country and language at the first message, so needs can be mapped by community.
- Measure whether answers help.** With consent, follow up to learn whether an answer led someone to seek care, talk to their doctor or manage a crisis.
- Turn questions into local action.** Share anonymized, country-level reports of unmet needs with patient organizations and clinicians.

What they ask



Share of the 1,136 substantive questions. Greetings, thanks and off-topic messages (41% of all messages) were excluded.

Questions evolve with use

Facts and medicine → Psychological and existential

As people kept using the tool, their questions moved from facts and medicine toward psychological and existential concerns.



Share of questions at each point in a conversation that were psychological or existential.

Community organizations

Bring SickleCellPedia to your members, or try it yourself on the web and WhatsApp.

sckin.org/scdaa

