

Tab 1

Privacy Policy

SickleCellPedia / Drepanopedia – Chatbot Privacy Policy

Last updated: Dec 2, 2025

1. What We Collect

When you use **SickleCellPedia / Drepanopedia**, we may receive:

- **Your messages** and questions, including health-related information you choose to share.
- **Technical data** such as your messaging ID/phone number on the Platform, IP address, device type, language, and time of interaction.
- **Usage logs** (e.g., how often and when you use the Chatbot, errors).

We encourage you **not** to share more personal details than necessary.

2. How We Use Your Information

We use your information to:

- Run and improve **SickleCellPedia / Drepanopedia**.
- Understand what users ask and what information is most helpful.
- Train, test, and refine our AI tools.
- Conduct **research** and produce **de-identified or aggregated insights** about sickle cell information needs and Chatbot use.
- Publish these insights in reports, articles, or presentations, **without identifying you**.
- In the future, **license or sell de-identified and aggregated data, models, or insights**.

We **do not sell personally identifying information**, such as your name, phone number, or direct contact details.

3. Who We Share With

We may share information with:

- **Service providers** (e.g., hosting, AI model providers, analytics) who process data on our behalf under contracts that require them to protect it.
- **Research partners, in de-identified or aggregated form.**
- **Other organizations**, if we license or sell **de-identified or aggregated datasets or models.**
- **Authorities**, if required by law or to protect people's safety or our rights.

4. Where Your Data Is Processed

- SCKIN is based in the **United States.**
- Your information may be processed in the US and other countries where our providers operate.
- We use legal and technical measures to protect your data, but no system is 100% secure.

5. How Long We Keep Data

- We keep personal data as long as needed to run **SickleCellPedia / Drepanopedia**, improve it, and meet legal obligations.
- We may keep **de-identified or aggregated data** for research and analytics **for a long time or indefinitely.**

6. Your Rights

Depending on where you live, you may have rights to:

- Access, correct, or delete your personal data;

- Object to or restrict some types of processing;
- Withdraw consent where we rely on consent;
- Complain to a data-protection authority.

Because we see only limited identifiers (e.g., your messaging handle/phone number on the Platform), we may need you to contact us and provide enough detail to find your data.

You can reach us at: contact@sckin.org

7. Children

SickleCellPedia / Drepanopedia is **not directed at children under 13**.

If we learn we collected personal data from a child unlawfully, we will take reasonable steps to delete it.

8. Third-Party Platforms

- WhatsApp, Facebook Messenger, and other Platforms have their **own** privacy policies and data practices.
- We do **not control** their handling of your data.
- Please review their policies directly.

9. Changes

We may update this Privacy Notice from time to time. We will update the “Last updated” date. Continued use of **SickleCellPedia / Drepanopedia** means you accept the updated Notice.

Résumé en FR – Vie privée (Drepanopedia)

Comment Drepanopedia utilise vos données – version courte

- Nous voyons les **questions que vous envoyez** et quelques infos techniques (par ex. type d'appareil, heure d'utilisation).
- Nous utilisons ces données pour **faire fonctionner le chatbot**, corriger les problèmes et **améliorer Drepanopedia**.
- Nous utilisons vos questions, sous forme **agrégée et/ou dé-identifiée**, pour la **recherche** et des **publications** sur les besoins d'information en drépanocytose et les outils numériques.
- À l'avenir, nous pourrions **concéder sous licence ou vendre des données ou modèles agrégés et dé-identifiés**.
- Nous **ne vendons pas d'informations qui vous identifient directement** (nom, numéro de téléphone, etc.).
- Drepanopedia fonctionne via des applications tierces (WhatsApp, Facebook Messenger, etc.) qui ont leurs **propres politiques de confidentialité** que nous ne contrôlons pas.

Pour toute question ou demande concernant vos données, contactez-nous à **contact@sckin.org**.