Figure S1 Advertisement for survey.

Appendix 1: Survey instrument

Background

1. How would you describe your gender?
- Female
- Male
- Transgender
- Gender neutral
- Non-binary
- Other
- Prefer not to say

2. What is your age?
- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75-84
- 85+
- Prefer not to say

3. Please choose one option that best describes your ethnic group or background

Black/African/Caribbean/Black British
- African
- Caribbean
- Any other Black/African/Caribbean background, please describe

Asian/Asian British
- Bangladeshi
- Chinese
- Indian
- Pakistani
- Any other Asian background, please describe

Mixed/multiple ethnic groups
- White and Asian
- White and Black African
- White and Black Caribbean
- Any other Mixed/Multiple ethnic background, please describe

White
- English/Welsh/Scottish/Northern Irish/British
- Irish
- Gypsy or Irish Traveller
- Any other White background, please describe

Other ethnic groups
- Arab
- Any other ethnic group, please describe

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4. In addition to your sickle cell disease, do you have another healthcare condition or disability linked to your sickle cell disease?

- Yes (please specify)
- No
- Not sure

5. In addition to your sickle cell disease, do you consider that you have another healthcare condition or disability not linked to your sickle cell disease?

- Yes (please specify)
- No
- Not sure

6. How many sickle cell crises have you experienced in the past 12 months?

- 0
- 1-2
- 3-5
- 6-10
- 11+

7. How many times have you gone to hospital because of a sickle cell crisis in the past 12 months?

- 0
- 1-2
- 3-5
- 6-10
- 11+

8. How many times have you seen a sickle cell disease specialist [e.g., consultant haematologist, clinical nurse specialist (CNS), etc.] in past 12 months

- 0
- 1-2
- 3-5
- 6+

9. Have you previously shared your health data, and if so with who?

- Yes (please specify)
- No
- Not sure

If you have, please specify:

- Charitable research institutions (e.g., the Sickle Cell Society)
- Academic Institutions (e.g., universities)
- Commercial Research Organisations (e.g., pharmaceutical companies like Novartis)
- Digital Health Companies (e.g., eleven)
- Health Insurance Companies
- Via social media

Main questions

1. How willing are you to share health data? (Scale Not at all willing 1 to 10 Very willing)

2. Which of the following factors may influence your likelihood of sharing your health data (multiple answer) (Yes/No)
- How much I trust the organisation collecting/using my data
- How much I trust the company
- Whether it is clear how my data will be used
- Whether I have the ability to remove/withdraw consent of using my data at any point
- Whether my data is stored in a secure facility
- Whether organisations that misuse my data will be subjected to large fines or penalties

3. Which types of organisations would you most likely share your health data with in the future?
- Charitable research institutions (e.g., the Sickle Cell Society)
- Academic Institutions (e.g., universities)
- Commercial Research Organisations (e.g., pharmaceutical companies like Novartis)
- Digital Health Companies
- Health Insurance Companies

4. Which types of health data would you be willing to share? (Scale Not at all willing 1 to 10 Very willing)
- Health record data (e.g., tests and data collected by your GP or hospital doctor)
- How I'm feeling mentally, emotionally or physically
- Symptoms related to my sickle cell disease
- Details about how often I have been to the GP or hospital
- Details about my use of medications, including whether I have taken them
- Demographic data (e.g., my age, my gender, my ethnicity, etc.)
- Genomic data (e.g., my DNA or genetic make-up)

5. How much do you agree with the following statement (1-Strongly disagree – 10-Strongly agree):
"Sharing my health data may benefit other people with sickle cell disease"

6. Do you feel that healthcare professionals should pay more attention to any of the following when supporting you in managing your sickle cell disease? (Yes/No)
- How you are feeling mentally
- Your lifestyle (diet and exercise)
- How regularly you take your medications
- Your fluid intake
- Daily fluctuations and changes in how you feel both mentally and physically
- Other (please specify)

7. Which of the following would motivate or incentivise you to collect and share your health data?
- Financial benefits (e.g., cash payments, shopping or Amazon vouchers, etc.)
- Financial donations to charities (including the Sickle Cell Society)
- Personalised guidance and insights about your symptoms
- Being made aware of new treatments or trials which you may be eligible for
- Knowing how your data has helped other people with sickle cell disease
- Being made aware of your contribution to sickle cell disease research

- Knowing precisely how your data is going to be used
- Knowing that my friends/peers are also sharing their health data

8. Is there anything else you would like to tell us about sharing your health data?

Table S1 Demographics and baseline characteristics of survey respondents

Items	Frequency (% of sample) (n=47)
Age (years)	
18–24	17 (36.2)
25–34	21 (44.7)
35–44	5 (10.6)
45–54	2 (4.3)
55–64	1 (2.1)
65 and over	1 (2.1)
Sex	
Male	10 (21.3)
Female	35 (74.5)
Non-binary	2 (4.3)
Ethnicity	
Black, Black British or Caribbean—African	17 (36.2)
Black, Black British or Caribbean—Caribbean	6 (12.8)
Mixed or multiple ethnic groups—White and Asian	3 (6.4)
Mixed or multiple ethnic groups—White and Black African	11 (23.4)
Mixed or multiple ethnic groups—White and Black Caribbean	1 (2.1)
White (includes any White background)	1 (2.1)
Prefer not to say	8 (17.0)
Previously shared health data	
Yes	21 (44.7)
No	26 (55.3)