

Subject ID



Provider Data Collection Form

36 Weeks

Final Version 1.0, 1/17/2020

Please answer the following questions to the best of your ability and return the completed form to the study coordinator when you are done.

GENERAL INFORMATION

Date form completed: |_|_| / |_|_| / |_|_|_|_|

Month Day Year

EXPERIENCES PROVIDING CARE TO PATIENTS WITH SICKLE CELL DISEASE (SCD)

1. How many patients with SCD (all sickle genotypes) would you estimate currently receive regular care from you?

_____ # of patients

2. Do you have any specific training for SCD? (Check all that apply)

Fellowship training

Residency training

Attended special course

Attended online training

Learned "on the job"

Other, specify _____

3. Please estimate the percentage of your patients with SCD you are currently managing with hydroxyurea.

<25%

25-50%

51-75%

76-100%

I do not manage any patients with hydroxyurea therapy for SCD

I don't know

4. Are you aware that the National Heart, Lung, and Blood Institute (NHLBI) published guidelines on Primary Care Management for SCD?

Yes

No

5. Have you read the NHLBI guidelines for care of SCD patients?

Yes

No

6. Indicate the number of episodes of acute chest syndrome required to initiate treatment with hydroxyurea:

- 0
- 1
- 2
- 3
- 4
- 5+
- I don't know

7. Please indicate your level of agreement with the following statements regarding taking care of persons with SCD.

		Strongly disagree	Disagree	Agree	Strongly agree	Don't know	Rather not provide
a.	I have the knowledge to provide care for a person with SCD.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	I have the training to deliver care to a person with SCD.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	I have the administrative support I need to treat patients with SCD.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	I have access to medications I need to treat individuals with SCD.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. What do you consider to be the best sources of information about SCD and SCD treatment, including hydroxyurea? Rank the items below in order of importance:

		Most important 1	2	3	4	5	Least important 6
a.	Textbooks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	Peers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	Scientific articles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	Online videos (e.g., YouTube)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e.	NHLBI guidelines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f.	Other society guidelines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

HYDROXYUREA SELF EFFICACY

9. Which of the following CRITERIA do you use to place patients with SCD on hydroxyurea therapy? (Check all that apply)

- Episodes of acute chest syndrome

- At least three painful episodes/year requiring hospitalization
- At least three painful episodes/year at home
- Chronic pain requiring excessive or frequent opioid use
- Stroke history
- Renal failure
- Priapism
- Low hemoglobin F levels
- Pulmonary hypertension
- Symptomatic severe anemia
- Elevated white cell count without evidence of infection
- Leg ulcers
- Patient or family request
- Presence of hypoxemia
- I rely on recommendations from a specialist
- I do not prescribe hydroxyurea
- Other, specify _____

10. What is your comfort level in managing hydroxyurea as a disease modifying therapy for SCD?

- Very uncomfortable
- Somewhat uncomfortable
- Neither comfortable or uncomfortable
- Somewhat comfortable
- Very comfortable
- I don't know

11. How effective do you think hydroxyurea is for preventing painful events in people with SCD?

- Very effective
- Somewhat effective
- Effective
- Not effective
- I don't know

12. How many hours of CME have you completed related to hydroxyurea prescribing for patients with SCD in the past 3 years?

_____ # of hours or I don't know

13. How often should hydroxyurea be taken by individuals with SCD?

- Once daily
- Twice daily
- Three times daily
- Every other day
- Once a week
- I don't know

14. What is the NHLBI recommended initial daily dosing of hydroxyurea for individuals with SCD?

- 0.5 mg/kg/day
- 1 mg/kg/day
- 20 mg/kg/day
- 50 mg/kg/day
- 100 mg/kg/day
- I don't know

15. In which scenario below should hydroxyurea be held due to drug toxicity?

- Hb 5 mg/dL, Absolute neutrophil count 4500/mm³, Absolute reticulocyte count 20 x10⁶/mm³, and platelets 250 x10³/mm³
- Hb 7 mg/dL, Absolute neutrophil count 4500/mm³, Absolute reticulocyte count 200 x10⁶/mm³, and platelets 250 x10³/mm³
- Hb 9 mg/dL, Absolute neutrophil count 4000/mm³, Absolute reticulocyte count 130 x10⁶/mm³, and platelets 250 x10³/mm³
- Hb 9 mg/dL, Absolute neutrophil count 4500/mm³, Absolute reticulocyte count 120 x10⁶/mm³, and platelets 250 x10³/mm³
- Hb 9 mg/dL, Absolute neutrophil count 4500/mm³, Absolute reticulocyte count 120 x10⁶/mm³, and platelets 150 x10³/mm³
- I don't know

16. In which scenario below should hydroxyurea be held due to drug toxicity?

- Platelets 70 x10³/mm³
- Platelets 150 x10³/mm³

- Platelets $250 \times 10^3/\text{mm}^3$
- Platelets $350 \times 10^3/\text{mm}^3$
- Platelets $450 \times 10^3/\text{mm}^3$
- I don't know

17. In which scenario below should hydroxyurea be held due to toxicity?

- Absolute neutrophil count $800/\text{mm}^3$
- Absolute neutrophil count $3000/\text{mm}^3$
- Absolute neutrophil count $3500/\text{mm}^3$
- Absolute neutrophil count $4000/\text{mm}^3$
- Absolute neutrophil count $4500/\text{mm}^3$
- I don't know

MOBILE APPLICATION RATING SCALE

HU TOOLBOX APP QUALITY RATINGS

The Rating scale assesses the *HU Toolbox App* quality on four dimensions. All items are rated on a 5-point scale from "1. Inadequate" to "5. Excellent". Circle the number that most accurately represents the quality of the app component you are rating. Please use the descriptors provided for each response category.

Engagement – fun, interesting, customizable, interactive (e.g., sends alerts, messages, reminders, feedback, enables sharing), well-targeted to audience

1. Entertainment: Is the app fun/entertaining to use? Does it use any strategies to increase engagement through entertainment (e.g., through gamification)?

- 1 Dull, not fun or entertaining at all
- 2 Mostly boring
- 3 OK, fun enough to entertain user for a brief time (<5 minutes)
- 4 Moderately fun and entertaining, would entertain user for some time (5-10 minutes total)
- 5 Highly entertaining and fun, would stimulate repeat user

2. Interest: Is the app interesting to use? Does it use any strategies to increase engagement by presenting its content in an interesting way?

- 1 Not interesting at all
- 2 Mostly uninteresting
- 3 OK, neither interesting nor uninteresting, would engage user for a brief time (<5 minutes)

- 4 Moderately fun and entertaining, would entertain user for some time (5-10 minutes total)
 - 5 Very interesting, would engage user in repeat time
3. Customization: Does it provide/retain all necessary settings/preferences for app features (e.g., sound, content, notifications, etc.)?
- 1 Does not allow any customization or requires setting to be input every time
 - 2 Allows insufficient customization limiting functions
 - 3 Allows basic customization to function adequately
 - 4 Allows numerous options for customization
 - 5 Allows complete tailoring to the individual's characteristics/preferences, retains all settings
4. Interactivity: Does it allow user input, provide feedback, contain prompts (reminders, sharing options, notifications, etc.)?
- 1 No interactive features and/or no response to user interaction
 - 2 Insufficient interactivity, or feedback, or user input options, limiting functions
 - 3 Basic interactive features to function adequately
 - 4 Offers a variety of interactive features/feedback/user input options
 - 5 Very high level of responsiveness through interactive features/feedback/user input options
5. Target group: Is the app content (visual information, language, design) appropriate for your target audience?
- 1 Completely inappropriate/unclear/confusing
 - 2 Mostly inappropriate/unclear/confusing
 - 3 Acceptable but not targeted. May be inappropriate/unclear/confusing
 - 4 Well-targeted, with negligible issues
 - 5 Perfectly targeted, no issues found

Functionality – app functioning, easy to learn, navigation, flow logic, and gestural design of app

6. Performance: How accurately/fast do the app features (functions) and components (buttons/menus) work?
- 1 App is broken; no/insufficient/inaccurate response (e.g., crashes/bugs/broken features, etc.)
 - 2 Some functions work, but lagging or contains major technical problems
 - 3 App works overall. Some technical problems need fixing/Slow at times

- 4 Mostly functional with minor/negligible problems
- 5 Perfect/timely response; no technical bugs found/contains a 'loading time left' indicator
7. Ease of use: How easy is it to learn how to use the app; how clear are the menu labels/icons and instructions?
 - 1 No/limited instructions; menu labels/icons are confusing; complicated
 - 2 Useable after a lot of time/effort
 - 3 Useable after some time/effort
 - 4 Easy to learn how to use the app (or has clear instructions)
 - 5 Able to use app immediately; intuitive; simple
8. Navigation: Is moving between screens logical/accurate/appropriate/uninterrupted; are all necessary screen links present?
 - 1 Different sections within the app seem logically disconnected and random/confusing/navigation is difficult
 - 2 Usable after a lot of time/effort
 - 3 Usable after some time/effort
 - 4 Easy to use or missing a negligible link
 - 5 Perfectly logical, easy, clear and intuitive screen flow throughout, or offers shortcuts
9. Gestural design: Are interactions (taps/swipes/pinches/scrolls) consistent and intuitive across all components/screens?
 - 1 Completely inconsistent/confusing
 - 2 Often inconsistent/confusing
 - 3 OK with some inconsistencies/confusing elements
 - 4 Mostly consistent/intuitive with negligible problems
 - 5 Perfectly consistent and intuitive

Aesthetics – graphic design, overall visual appeal, color scheme, and stylistic consistency

10. Layout: Is arrangement and size of buttons/icons/menus/content on the screen appropriate or zoomable if needed?
 - 1 Very bad design, cluttered, some options impossible to select/locate/see/read device display not optimized
 - 2 Bad design, random, unclear, some options difficult to select/locate/see/read

- 3 Satisfactory, few problems with selecting/locating/seeing/reading items or with minor screen-size problems
- 4 Mostly clear, able to select/locate/see/read items
- 5 Professional, simple, clear, orderly, logically organized, device display optimized. Every design component has a purpose

11. Graphics: How high is the quality/resolution of graphics used for buttons/icons/menus/content?

- 1 Graphics appear amateur, very poor visual design-disproportionate, completely stylistically inconsistent
- 2 Low quality/low resolution graphics; low quality visual design-disproportionate, stylistically inconsistent
- 3 Moderate quality graphics and visual design (generally consistent in style)
- 4 High quality/resolution graphics and visual design-mostly proportionate, stylistically consistent
- 5 Very high quality/resolution graphics and visual design-proportionate, stylistically consistent throughout

12. Visual appeal: How good does the app look?

- 1 No visual appeal, unpleasant to look at, poorly designed, clashing/mismatched colors
- 2 Little visual appeal-poorly designed, bad use of color, visually boring
- 3 Some visual appeal-average, neither pleasant, nor unpleasant
- 4 High level of visual appeal-seamless graphics-consistent and professionally
- 5 As above + very attractive, memorable, stands out; use of color enhances app features/menus

Information – Contains high quality information (e.g., text, feedback, measures, references) from a credible source. Select N/A if the app component is irrelevant.

13. Accuracy of app description (in app store): Does app contain what is described?

- 1 Misleading. App does not contain the described components/functions. Or has no description
- 2 Inaccurate. App contains very few of the described components/functions
- 3 OK. App contains some of the described components/functions
- 4 Accurate. App contains most of the described components/functions
- 5 Highly accurate description of the app components/functions

14. Goals: Does app have specific, measurable and achievable goals (specified in app store description or within the app itself)?

N/A Description does not list goals, or app goals are irrelevant to research goal (e.g., using a game for educational purposes)

1 App has no chance of achieving its stated goals

2 Description lists some goals, but app has very little chance of achieving them

3 OK. App has clear goals, which may be achievable

4 App has clearly specified goals, which are measurable and achievable

5 App has specific and measurable goals, which are highly likely to be achieved

15. Quality of information: Is app content correct, well written, and relevant to the goal/topic of the app?

N/A There is no information within the app

1 Irrelevant/inappropriate/incoherent/incorrect

2 Poor. Barely relevant/appropriate/coherent/may be incorrect

3 Moderately relevant/appropriate/coherent/and appears correct

4 Relevant/appropriate/coherent/correct

5 Highly relevant, appropriate, coherent, and correct

16. Quantity of information: Is the extent coverage within the scope of the app; and comprehensive but concise?

N/A There is no information within the app

1 Minimal or overwhelming

2 Insufficient or possibly overwhelming

3 OK but not comprehensive or concise

4 Offers a broad range of information, has some gaps or unnecessary detail; or has no links to more information and resources

5 Comprehensive and concise; contains links to more information and resources

17. Visual information: Is visual explanation of concepts-through charts/graphs/images/videos, etc. – clear, logical, correct?

N/A There is no visual information within the app (e.g., it only contains audio, or text)

1 Completely unclear/confusing/wrong or necessary but missing

2 Mostly unclear/confusing/wrong

3 OK but often unclear/confusing/wrong

4 Mostly clear/logical/correct with negligible issues

5 Perfectly clear/logical/correct

18. Credibility: Does the app come from a legitimate source (specified in app store description or within the app itself)?

1 Source identified but legitimacy/trustworthiness of source is questionable (e.g., commercial business with vested interest)

2 Appears to come from a legitimate source, but it cannot be verified (e.g., has no webpage)

3 Developed by small NGO/institution (hospital/center, etc.) specialized commercial business, funding body

4 Developed by government, university or as above but larger in scale

5 Developed using nationally competitive government or research funding (e.g., Australian Research Council, NHMRC)

19. Evidence base: Has the app been trialed/tested; must be verified by evidence (in published scientific literature)?

N/A The app has not been trialed/tested

1 The evidence suggests the app does not work

2 App has been trialed (e.g., acceptability, usability, satisfaction ratings) and has partially positive outcomes in studies that are not randomized controlled trials (RCTs), or there is little or no contradictory evidence.

3 App has been trialed (e.g., acceptability, usability, satisfaction ratings) and has positive outcomes in studies that are not RCTs, and there is no contradictory evidence.

4 App has been trialed and outcome tested in 1-2 RCTs indicating positive results

5 App has been trialed and outcome tested in ≥ 3 high quality RCTs indicating positive results

APP SUBJECTIVE QUALITY

20. Would you recommend this app to providers who might benefit from it?

- 1 **Not at all** I would not recommend this app to anyone
- 2 There are very few providers I would recommend this app to
- 3 **Maybe** There are several providers whom I would recommend it to
- 4 There are many providers I would recommend this app to
- 5 **Definitely** I would recommend this app to everyone

21. How many times do you think you would use this app in the next 12 months if it was relevant to you?

- None
- 1-2
- 3-10
- 10-50
- >50

22. Would you pay for this app?

- No
- Maybe
- Yes

23. What is your overall star rating of the app?

- 1 ★ One of the worst apps I've used
- 2 ★★
- 3 ★★★ Average
- 4 ★★★★
- 5 ★★★★★ One of the best apps I've used

	Strongly disagree				Strongly agree
	1	2	3	4	5
24. Awareness: This app is likely to increase awareness of the importance of the importance addressing provider lack of knowledge of hydroxyurea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Knowledge: This app is likely to increase knowledge/understanding of hydroxyurea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Attitudes: This app is likely to change attitudes toward prescribing hydroxyurea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Intention to change: This app is likely to increase prescribing of hydroxyurea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Behavior change: Use of this app is likely to increase prescribing of hydroxyurea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

This is the END of the survey. Please return it to the study coordinator.

Thank you for your participation.