Journal of Patient-Centered Research and Reviews

Volume 10 | Issue 2 Article 3

4-18-2023

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Recommended Citation

Baines R, Stevens S, Garba-Sani Z, Chatterjee A, Austin D, Leigh S. Attitudes toward personal health data sharing among people living with sickle cell disorder, exemplar for study of rare disease populations. J Patient Cent Res Rev. 2023;10:68-76. doi: 10.17294/2330-0698.2006

Published quarterly by Midwest-based health system Advocate Aurora Health and indexed in PubMed Central, the Journal of Patient-Centered Research and Reviews (JPCRR) is an open access, peer-reviewed medical journal focused on disseminating scholarly works devoted to improving patient-centered care practices, health outcomes, and the patient experience.

Attitudes Toward Personal Health Data Sharing Among People Living With Sickle Cell Disorder, Exemplar for Study of Rare Disease Populations

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Purpose Rare conditions are often poorly understood, creating barriers in determining the value treatments can provide. This study explored barriers and facilitators to personal health data sharing among those with one particular group of rare hematologic disorders, ie, sickle cell disorder (SCD) and its variants.

Methods A single online focus group among those >18 years of age and living with SCD was conducted. Participants (N=25) were recruited through a United Kingdom-based SCD charity. Discussions were transcribed verbatim, with data therein analyzed using inductive thematic analysis.

Results Five primary motivators for sharing health data were identified: improving awareness; knowing this would help others; evidencing impact; financial incentives; and being recognized as "experts with lived experience" rather than "specimens to be studied." Barriers included lack of clarity regarding "why" data was sought and "who" benefited. Participants stated that electronic health record (EHR) and genetic data were often "too detailed" and therefore "off limits" for sharing. However, experiences, mindset, and well-being data, often hidden from the EHR, were acceptable to share and considered a better barometer of how rare conditions treat patients day-to-day.

Conclusions Utilizing patient experience data obtained under real-world conditions is key to painting the most accurate picture of needs and understanding how SCD impacts patients' day-to-day lives. Study findings suggest that patients with SCD are not merely passive providers of health data, but rather experts by experience. To appreciate the value that patient perspectives bring, we must revisit this status quo, amending our approach to patient centricity and reframing patients as high-value managers of their condition and personal health data who crucially decide what, how, and when they share it. (*J Patient Cent Res Rev.* 2023;10:68-76)

Keywords real-world data; patient-reported outcomes; sickle cell; rare diseases; data sharing; qualitative research

Approximately 7000 rare diseases affect almost 350,000,000 people worldwide.[1] Despite the immense personal, societal and economic burden of rare diseases, only 5% of rare diseases have an approved treatment.[2] Designing a clinical program that will result in regulatory approval is particularly challenging for rare disease treatments,[2,3] with trials often hampered by poorly developed study endpoints,[4,5] insufficient patient data, and an incomplete or inaccurate picture of unmet needs.[6-8] Additionally, because the patient populations affected by rare diseases are typically small and highly heterogeneous, this often complicates understanding of disease pathophysiology, with a rare disease patient (on average) visiting several specialists[9] and correct diagnoses taking as long as 5 to 8 years.[10]

It is therefore clear that creative approaches are required to overcome existing barriers to capturing the patient perspective in rare diseases and the potential value of treatment, with a more focused appreciation of patients' most critical needs, their experiences, natural history, and how their condition affects them day to day.[4,11] Because the spectrum of all rare diseases is too broad and varied to address in a single study, we focused the

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qualitative research presented herein on one group of rare hematologic conditions — sickle cell disorder (SCD) and its variants — in an attempt to generate hypotheses that can then be tested in other rare disease populations. SCD was chosen to serve as an exemplar due to its high unmet need for treatment breakthroughs and need for supporting data, with no new treatments approved in the United Kingdom in the 20 years prior to this study's focus group session taking place. Putting a greater emphasis on patient empowerment and real-world data sharing is an essential first step in generating interpretable and clinically meaningful data for treatment approval.[12]

Patients hold the key to better research, better health care, and better outcomes. Therefore, involving patients (and patient advocacy groups that often coordinate the large-scale collaboration of patients) as equal partners in the discovery, development, and approval of pharmacological treatments as early as possible can provide a more accurate picture of what it is like to live with a specific condition and represents a 21st century approach to addressing the challenge of slow approval of rare disease treatments. Yet, while the structured and coordinated sharing of real-world personal health data offers a theoretical solution to the problem of poor understanding of condition impact, unmet needs, and potential value of treatment, in practice, the factors likely to limit or encourage success have not been subject to significant research.

The aim of this study was to explore factors which may facilitate or act as barriers to the sharing of personal health data among a focus group comprised of people from the United Kingdom living with SCD. In doing so we examined the types of data most likely to be shared, explored reasons for concern, and presented a roadmap for the sharing of patient experience data based on the barriers and facilitators identified. Our aim was to generate testable hypotheses that may be applicable to a broad array of rare diseases.

METHODS

Design, Recruitment, and Sampling

Utilizing a qualitative study design, a semi-structured focus group format was developed involving participants with SCD. Individuals 18 years of age or over with lived experience of SCD were purposefully recruited on a voluntary basis. An advertisement poster, co-designed by those living with SCD, was disseminated on relevant social media sites and the social media pages of a U.K.-based national sickle cell charity (the Sickle Cell Society). Participants were incentivized with vouchers or could request a charitable donation in recognition of their time and expertise. While remunerating participants for their time may have biased their motivations for taking part, recognizing peoples' time and expertise is best practice in co-designed research with patient and public involvement.[13-15]

Setting

Due to ongoing COVID-19 concerns and restrictions, the focus group was held online via Zoom. Guided by the patient research partner, the focus group was held on a weekday evening to maximize participation opportunities for those in employment or with child care responsibilities. During the focus group, respondents were given the choice to turn on their video cameras or not, allowing a wider inclusion of those who may be uncomfortable with being seen[16,17] as well as preventing respondent's awareness of their online presence becoming a distraction, as shown in previous studies.[18] In addition to allowing cameras to be turned off during the focus group, participants were informed in advance of the focus group how to change their Zoom screen name to an anonymous identifier should they wish to do so; upon admittance to the focus group, users were reminded that if they wished to change their screen name, they could do so by following instructions provided in the chat box. In the event that video cameras were not turned on, a researcher verification check was performed whereby respondents were asked to use the chat function and to send (privately) their registered contact details and preferences for payment to the focus group moderator.

As demonstrated in previous studies,[19] participants also were encouraged to post comments in the chat box for all respondents to see and comment on, with the facilitator reading these aloud,[20] allowing for later download and addition to the focus group transcript. This alleviated the common barrier with larger focus groups or workshops of struggling to know when to enter a conversation and potentially feeling uncomfortable.

Data Collection

A semi-structured topic guide was co-designed with the patient research partner and informed by existing literature.[21] The topic guide design aimed to answer one primary question: What would motivate or inhibit people with SCD to share their personal health data, with sharing including but not limited to, research organizations, academic institutions, registries, third parties, friends or online communities, their personal or family physician, and pharmaceutical or life science companies? For the purpose of this study, personal health data was defined as any health-related data that either objectively or subjectively characterized the symptomology, progression, or management of SCD. Thus, specific measures under consideration included lab-based data within respondent's electronic health records (EHR), genomic data, personally collected real-world data

concerning mental health, sociability, symptoms and the use of medicines, and quality-of-life data. Topic guide questions were purposefully open-ended to facilitate in-depth discussions, with suggested prompts provided to further facilitate discussion/clarification if required.

The focus group was jointly facilitated by an experienced qualitative researcher and the patient research partner. Following registration for the focus group, which included the provision of a participant information leaflet, the facilitators explained the aims of the project to participants and then continued to ask participants questions regarding their personal experiences and beliefs concerning health data sharing. The focus group was audio-recorded, conducted with informed consent, and transcribed verbatim independently by two members of the research team.

Data Analysis and Synthesis

All data were analyzed using inductive thematic analysis as per best practice guidelines.[22] Adopting an inductive approach helped ensure themes arose from the data generated, as opposed to predefined ideas or concepts. This was felt to be particularly important given the relatively unexplored area of attitudes toward data sharing in the SCD community. Each respondent was subsequently invited to review and comment on the findings and groupings of themes prior to publication, ensuring accuracy and sufficient coverage of themes expressed during the focus-group. This method also gave participants the opportunity to share their opinions on themes for which they may have not had the opportunity to provide input during the focus group.

Data saturation was defined as the point at which no new generic themes or variations of a given theme emerged. This is in line with existing best practice for discontinuing data collection and/or analysis.[23]

Ethical Approval

The study obtained ethical approval (No. 2826) from the University of Plymouth Faculty Research Ethics and Integrity Committee. Funding was provided in the form of a small business innovation grant as part of eHealth Productivity and Innovation in Cornwall and The Isles of Scilly (EPIC), a European Union Regional Development program led by the University of Plymouth.

RESULTS

A total of 25 participants from across the United Kingdom took part in the focus group. Through the process of inductive thematic analysis, 3 key themes were identified: 1) barriers to sharing data; 2) motivations and enablers for sharing data; and 3) aspirations for sharing data. Each key theme and related subthemes are discussed in turn, beginning with barriers to data sharing. Quotations subjectively deemed by authors to be most reflective of identified themes are noted throughout this section to provide additional context or examples.

Barriers to Sharing Data

Participants described 7 key factors that affect people's willingness to share sickle cell data (Table 1).

Trust and Understanding. A lack of trust and understanding was repeatedly identified as the biggest barrier to sharing health data. However, during the discussion, several participants acknowledged that they had previously been sharing their data without their full awareness or understanding. For example: *"It just dawned on me that I've actually given my data away for free"* [participant 4]; *"To be quite honest, ever since I've come on the chat, I've realized that I share my data a hell of a lot … I share my data left, right, and center, and I'm saying that I'm very wary about it, but actually I'm sharing my data all the time"* [participant 3].

Despite this apparent lack of understanding and awareness, participants expressed a clear appetite to *"know more about it* [data sharing]" [participant 14]. However, this desire was often underpinned by a need for choice, honesty, and understanding.

Company Values. Hesitancies to sharing data were often linked to the perceived motivations, values, and intent of companies looking to obtain health care data. For example, *"I guess the thing is you don't want people to think, oh who are they selling my data to? Like what company is going to get hold of it?"* [participant 5]. This theme was often linked to feelings of mistrust toward the health care system and society in general, with respondents highlighting that such data may be *"used against"* [participant 3] them in the future, for example, by health insurance companies.

Perceived Risk and Data Type/Sensitivity. Perceived risk and data type were felt to *"determine whether"* participants *"do or don't share"* [participant 4] the data. Data collected through products such as *"an apple watch"* were perceived as low risk by the majority of participants, whereas more sensitive or personal information such as *"genomics"* were described as *"really sensitive"* [participant 2].

Differences and concerns around sharing genomic data were repeatedly described, accentuating its commonality across participant views. *"It just feels different, like you're giving a specimen of yourself in comparison to words. It's just two different things. Like, I'm literally just talking to*

Table 1. Barriers to Sharing Health Data

Identified barrier	Verbatim examples
Lack of trust and understanding	*"The idea of sharing my data, I don't really feel comfortable. It doesn't sound like a very trustworthy process."* [participant 1] *"I don't really understand how it works."* [participant 2]
Company values and motivations	*"It depends on who you're working with and how the people are operating."* [participant 9] *"I'd want to do my research and do my own due diligence, just to make sure that I'm happy with what they stand for."* [participant 4]
Type, or source of data collector	*"It depends what company and who is asking me."* [participant 5] *"Say I'm talking to a friend or family member or partner, that sometimes can be a bit daunting to share that piece of information, but if I'm speaking to someone like you per se, doing the research, I honestly don't mind."* [participant 3]
Perceived risk and data type/sensitivity	*"Actually the risk is not that high. If you know how many steps I take in a day, I don't really care to be honest. Whereas I did the 23andme genome thing, and I was really conscious because I was like, 'oh, this data is really, really sensitive.'"* [participant 2] *"I think, for me personally, it's literally the type of data you want from me. That kind of determines whether I do or don't share, or whether I get involved or don't get involved."* [participant 4]
Lack of control	*"So it's about control ... If I can't control it or I feel not too sure about that, I just won't do it."* [participant 5]
Perceived benefits	*"Sharing your data with healthcare companies, where actually the benefit is for them rather than you."* [participant 2]
Lack of evidence of change	*"I feel like that's sometimes a waste of time because nothing ever comes from it."* [participant 6]

you right now. So whether you take my word verbatim or not, I'm never gonna know. Whereas, like, that's DNA. It's gonna be with you for God knows how long and what are you doing with it? So it's, it's all dependent on the type of data that you want from me" [participant 5].

Other differences in willingness to share applied to data in the EHR. Despite EHR data being described as not covering all relevant aspects of care and condition management, respondents were generally cautious in sharing. Specifically: *"I don't mind sharing, like, how I'm feeling and lived experience, that kind of stuff. But I think really granular levels of data I'm a little bit more cautious about. So for example, my electronic health care record data, if you want all of that and being able to see exactly what my health history is, and every conversation I've had with my GP, I feel like that's quite personal and really, really detailed"* [participant 2].

The subtheme of data type or sensitivity connected strongly to the participant's definition of *"how your sickle cell is treating you"* [participant 4], and the assertion that things often change on a day-to-day basis. Participants described the importance of *"measuring sickle cell on that day-to-day basis of my life ... because you can go to bed feeling one type of way and then wake up the next morning and it's like 'whoa, what happened?'"* [participant 3]. This was contrasted with the rather fixed and one-off nature of the EHR, which tended to collect data usually at predetermined snapshots of time and often may not cover outcomes that those living with SCD believed were associated with feeling well.

Perceived Lack of Change. Finally, previous experience and/or a lack of evidence of change also were considered to be highly influential when deciding whether to share health data or not. As explained by one participant, *"I feel like commercial research is often a waste of time because nothing ever comes from it"* [participant 6]. Evidence of change appeared to be of paramount importance in facilitating data sharing behavior and linked to those living with SCD being *"experts with lived experience"* in their condition. Participants raised parallels to other experts, such as the likelihood of health care professionals giving up their time, effort, and personal data if it was believed that the reason for sharing would ultimately result in no benefit to those involved.

Motivations and Enablers for Sharing Health Data

For purposes of consistency and transparency, all

motivations and enablers for sharing health data as described by participants are outlined in Table 2. Motivations most frequently described by participants included improving awareness and understanding of rare diseases, altruistic motivations of helping others, and seeing evidence of change. Furthermore, incentives were felt to be of considerable importance in helping individuals avoid feeling like a *"specimen to be studied"* [participant 5]. A personalized approach to incentives (not just personal financial gain) appeared particularly desirable to participants.

Factors believed to facilitate the process of sharing health data by participants included regular reminders, automated/ease of use processes, realistic data collection frequency, and provision of anonymity (Table 2).

Aspirations for Data Sharing in Sickle Cell

When asked, "What if anything would you like to see happen in data sharing and sickle cell?" participants suggested *"more of a community, a conversation"* [participant 4] as *"It doesn't seem so daunting, if you're just talking you can actually gather a lot more information; it's a friendlier approach. You know, it's nice to study sickle cell, but sometimes [a reliance on study-like approaches only] makes us feel like 'oh species, let's study them'"* [participant 3]. Similarly, *"Communication with words and seeing faces, learning about other people's experiences, you can't beat that"* [participant 6]. Ultimately, all participants acknowledged that it was *"really important for the sickle cell communities' voice to be heard"* [participant 2], a notion that underpinned many of the barriers, enablers, and motivations identified in this section — voice and choice.

DISCUSSION

Responding to identified gaps in existing literature, this research identifies the barriers, enablers, and aspirations of sharing personal health data from the perspective of individuals living with SCD. Barriers to sharing included a lack of trust and understanding as to "why" data were being sought, "who" benefited from these data, and concerns regarding the types of data willing to be shared. Motivations for sharing primarily centered around improving awareness and understanding of rare diseases, helping others, being recognized and rewarded as an expert, and being able to see evidence of change. Evidence of change also was found to be a strong motivator and barrier, depending on its presence or absence within a data-sharing process.

Factors found to facilitate the decision and or process of sharing data included reminders, provision of anonymity, a clear and responsive route for withdrawing consent, and a reciprocal relationship that exceeded a transactional exchange. Importantly, underpinning many of the barriers and enablers identified was the importance of voice and choice in what, how, and when data is both shared and withdrawn. The value attributed to patient voice (arguably something that has historically remained silenced) and choice has perhaps been overlooked in previous explorations of data-sharing preferences.[24x] However, given its repeated discussion by participants in this research, such behavior can no longer be justified. Ignoring patient voice and choice may be to the detriment of future data-sharing opportunities and developments.

Interpretation in Light of Other Evidence

An interesting study finding, similar to much published evidence concerning the sharing of patient-level health data,[25,26] was that with the right societal, personal, and financial incentives, patients are happy to share their personal health data. Many participants acknowledged a current lack of awareness and understanding of rare diseases as a significant motivation for sharing health data, partly given the direct link between this and slower processes for both drug approvals and identification of unmet needs.

One key example of where patients were prepared to share their story was if it resulted in evidence of change, specifically in the form of research or approval of new treatments, a theme observed in prior studies.[27] Many respondents commented on how they often felt prior engagements with the pharmaceutical industry and other market research agencies had left them with a feeling of *"OK, what next, how does this benefit me or others?"* These themes highlight the importance of public responsibility, transparency, and a broader aspiration to reconceptualize patients as active high-value managers of health data as opposed to passive providers.[14]

Additionally, the feeling of altruism and helping others in a similar position was considered as one of the primary motivators for the sharing of personal health data, a theme central to patient advocacy and the role of patient advocacy groups. Many respondents remarked along the lines that *"doing something to help younger people so they don't need to experience what I have"* was a key driver of willingness to share experiences. Additionally, and perhaps unsurprisingly, financial incentives as well as being recognized as an *"expert with lived experience in a condition"* rather than a *"specimen to be studied"* were significant considerations. Respondents believed that being recognized with financial or other incentives would be a longer-term facilitator of structured exchange of personal health data, which has been as observed elsewhere,[28] with one respondent remarking that *"Incentives are always*

Table 2. Motivations and Enablers for Sharing Health Data

Motivations	Verbatim examples
Improving awareness and understanding of rare diseases	*"There's not enough data available for people with sickle cell."* [participant 1]
Helping others	*"If it helps someone out there, I'd share."* [participant 9] *"I'm 100% about helping other people with sickle cell."* [participant 3]
Evidence of change	*"Ensure that what you're saying is being put to use, that you can see it. Not that you're giving your data and you don't know what the hell is being done with your data. And you feel like you've just given it away."* [participant 4]
Research opportunities	*"The chance to be more involved in the research."* [participant 10]
Ability to control and personalize individual data-sharing practices	*"I control what I enter and join and where my information goes to."* [participant 7] *"…actually, if I had the choice to pick and choose which parts of it I can share, I think I'd be more happy to."* [participant 2] *"It's all dependent on the type of data or collection that you want from me."* [participant 5]
A choice of personalized incentives (not always financial)	*"Incentives are always great motivators."* [participant 12] *"I think it's quite nice actually, like, you could either take the voucher or donate to a sickle cell charity. That's a new thing I thought that was quite nice actually and was an incentive for me."* [participant 4] *"I did one of the clinical trials where you had to enter things every single day for I think it was 95 days. And I did every single day because I'm going to be honest, I was earning a bit of money for that one."* [participant 3]
Enablers	**Verbatim examples**
Reminders	*"It's literally making sure you remember, that's the key word there, remember."* [participant 8]
Automated/easy to use	*"Don't mind sharing as long as it's automated/not too much hassle."* [participant 11]
Realistic frequency of data entry	*"And I get a reminder every Friday that I haven't entered it in, and I happen to do it on a Friday, but the everyday thing, I actually am so bad."* [participant 3]
Provision of anonymity	*"Just that anonymity."* [participant 10]
A clear and responsive route for withdrawing consent	*"Sometimes it feels really hard to withdraw consent … There's been times that I've sent an email saying take me off this list, stop sending me emails, they still send you emails. So you just wonder whether that's the case with my health data as well. Would you actually listen to me? Where's the accountability? Who can I talk to about this?"* [participant 5]
Reciprocal relationships, not a transactional exchange	*"If Prometheus were to ask me to share my data with them, I'm probably more likely to because I feel like it's a joint relationship. I have a say in how, the process, the approach ... whereas, actually, I think sometimes researchers ask you for your data, but it's more like you're giving us something and that's about it. It's very transactional."* [participant 2]
Minimal risk	*"If I understand the benefit and I've been able to analyze the risk, and I don't think it's actually that risky for me — it's just helping other people — I don't mind."* [participant 6]

great motivators." This linked specifically to choice, not just in terms of choice of how to be thanked for taking part in data-sharing exercises but also choice around the precise type and frequency of data shared.

The notion of choice links to a further theme identified in this research — that the data those living with SCD were prepared to share may differ person to person. This finding also has been seen in maternity care, with novel measures of patient-reported outcomes including the Mother-Generated Index.[29] In the Mother-Generated Index, pregnant women are asked to list the facets of their life that currently bring them most satisfaction and, subsequently, determine how the process of childbirth affected each facet, whether positively or negatively. Because the variables the user can define are

not prespecified, this enables creation of a completely personalized and highly sensitive estimation of real-world impact, which does not detract from the collection of key clinical endpoints but instead adds to our understanding of how the process impacts those involved and what this means from the patient's perspective.

As such, it may be that existing, clinically tailored measures (eg, vaso-occlusive crises and hospitalizations, which are of value to payers and health systems) provide a skewed view of condition severity and only provide information regarding the tip of the iceberg when it comes to condition management. This highlights an opportunity for traditional markers of "illness" that are of relevance to other stakeholders to be augmented with lived experience data and insights, reflecting the day-to-day fluctuations in symptomology and providing a more holistic understanding of factors also relevant to "experts by experience," those living with said conditions. The ability to collect data that matters to patients at far more regular intervals, including lifestyle choices and healthy habits, sociability, mindset, feelings, and associated complications, as reported by respondents, would likely add significant value to our understanding of the true day-to-day impact of SCD, as would choice and control around which data get shared.

Again pertaining to a theme of control, respondents often mentioned the conundrum of refusing to donate personal health data, which may help others, because they felt they were being asked for "too much," or that they did not agree with sharing such large amounts of data without adequate explanation of, firstly, why it is necessary and, secondly, how they might request to have the data deleted at a later date. Respondents were clear that genetic data represent a significant issue, with reservations around having a part of oneself documented and replicable somewhere — a step too far — particularly among a patient whose trust in the health system was already reported as being lower than ideal.[30] This feeling extended to their EHR, with many highlighting a strong aversion to sharing EHR data on the belief that this is too personal and detailed. Therefore, our findings suggest that by allowing patients to personalize and choose which data to provide information on, it is more likely that gaps in our understanding of rare diseases, including SCD, can be filled.

Strengths and Limitations

While several prior studies have focused on approaches to genetic data pooling[31,32] and registries sharing data,[12,33,34] there has until now been a dearth of published evidence regarding attitudes to patient-level data sharing in rare diseases.[35] This study represents a novel addition to what we know about rare disease data sharing by being the first to consider not just the sharing of EHR data but also real-world symptom data. It is our hope that having the study co-designed and coordinated by those living with a rare disease served to maximize relevance of results.

Still, several limitations to this analysis may impact the generalizability of findings. The first and most obvious limitation is that this analysis concerned only a small group of people living with one specific rare disorder, sickle cell. While the views of this group may in fact be representative of the U.K. sickle cell community, they are unlikely to speak to the concerns or beliefs of the 300 million patients globally who are living with one of thousands of other rare diseases. As such, it would be beneficial to repeat this exercise with more diverse and representative groups of people living with a variety of rare diseases, including family members and caregivers whose views were absent from this study, in order to confirm the applicability of these findings beyond SCD.

A similar study limitation relates to the size of the focus group. Given the number of participants (N=25), it is entirely likely that the ability to participate was reduced and that some opinions were not, or could not be, expressed. If attempting to validate or test the findings of this study in alternative cohorts, a number of smaller focus groups to maximize the opportunity for involvement may be preferable. Furthermore, the nature of recruitment meant that it is likely only those with a specific position for or against data sharing were likely to attend, therefore disproportionately attracting more fixed or even extreme views. While recruitment in rare diseases is generally more problematic than other condition areas,[36] a larger sample would have enabled the attitudes of the "median" person with SCD to be highlighted and the findings more likely to be generalizable to wider populations. Additionally, those with SCD — a condition that mainly affects Black people — have often reported not being listened to by health care staff in the United Kingdom, as well as a continual lack of investment in services.[29] This general perception may provide increased incentives for those with SCD to share their data as compared to those with other rare diseases. Further research should mirror this work in other rare disease cohorts to determine if the findings are generalizable.

CONCLUSIONS

Rare conditions are often poorly understood by those who do not live with them day to day. This research highlights how we may gain a more focused appreciation of the needs and experiences of those living with sickle cell disorder to fill gaps in our understanding. Under the right conditions, participants were prepared to share their health data and experiences in a more systematic

and frequent manner, but crucial to this, was reframing patients not just as experts in their condition but as high-value managers of their health care data, who decide what they share and when they share it.

Patient-Friendly Recap

- Hundreds of millions of people worldwide live with one of about 7000 rare diseases, yet just 5% benefit from approved treatments. Understanding patients' needs, goals, and burden of illness is essential for highlighting the potential value of treatments, but such information in the context of a rare disease like sickle cell can be scarce.
- Authors asked 25 people with sickle cell disorder, living in the United Kingdom, what would encourage or act as a barrier to sharing personal experiences or health care data to paint a clearer picture of unmet needs among this patient population.
- Knowing that the data shared would have a demonstrable impact on others was an oft-cited motivator, as were financial incentives. Barriers to sharing included lack of clarity as to "why" the data were being sought and "who" might benefit.

Acknowledgments

We unreservedly thank everyone who participated in this study, for kindly providing their time and expertise, and making this research possible.

Author Contributions

Study design: Baines, Stevens, Garba-Sani, Chatterjee, Leigh. Data acquisition or analysis: all authors. Manuscript drafting: Baines, Leigh. Critical revisions: all authors.

Conflicts of Interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Funding Sources

The research was funded by a small business innovation grant as part of eHealth Productivity and Innovation in Cornwall and The Isles of Scilly (EPIC), a European Union Regional Development program led by the University of Plymouth.

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