

Folia Health Canopy Series

Summer 2023

Sickle Cell Disease



General Overview

What inspired canopy series

You have the power to change the way you advocate for your health. Through Canopy Series, we aim to show you that not only do your tracking habits matter to you, but have the ability to help others like you. Having symptoms or a condition can be scary and isolating, and we can learn how others are handling their care, and use this knowledge to better advocate for ourselves.

Moving forward with community driven research

As the Folia Community continues to grow, we hope to continue holding space for the sharing of knowledge. Contributing to research is a common desire amongst the Folia community, but participating in a clinical trial does not allow you to see some of the details of what others are doing. This provides the opportunity to contribute to research, while also seeing results in real time.

Sickle Cell Community Snapshot

number of participants

63

number of data points

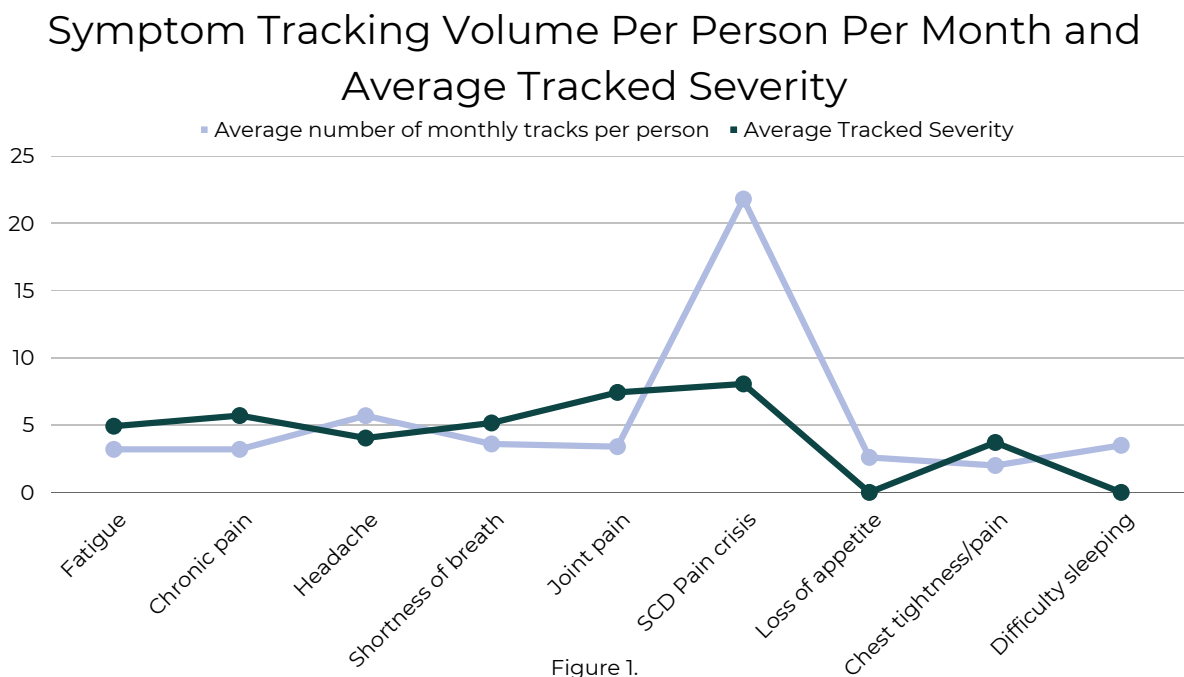
2128

More about SCD

On average, individuals reported a chronic pain severity of

5.71

on a scale of 1-10.



Additional Yes/No Questions

Are you experiencing difficulty sleeping?

90.0% of respondents reported Yes

Are you experiencing loss of appetite?

45.6% of respondents reported Yes

Analysis of Symptomatology

In figure 1 above, participants tracked SCD Pain Crisis at the highest rate, with 21.88 average number of monthly tracks per person. This symptom also had the highest reported average severity at 8.06.

Joint pain had the next highest average tracked severity at 7.43, but was only tracked an average 3.4 times per month by each individual participant.

Treatment Use

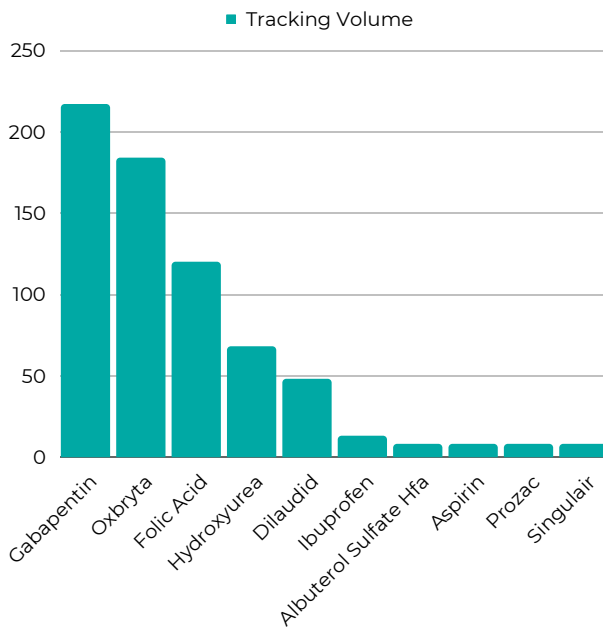


Figure 2.

Analysis of treatments and comorbid conditions

Figure 2 shows Gabapentin was tracked most often with 217 total tracks. Oxbryta was the next most common treatment with 184 total tracks.

Between the population of 63 individuals, 40 total comorbid conditions were reported. 9 individuals reported having a mental health condition, and 11 individuals reported having a cardiovascular or respiratory related condition.

Canopy Series wouldn't be possible without you

Thank you so much for your participation

You matter and your health experiences matter. Conditions often are heterogeneous meaning they can present themselves differently in each individual. While your specific experience is unique to you, we also know you may encounter situations similar to others.

This project was inspired by a theme of a Maya Angelou poem - that we are more alike than we are unlike. In the healthcare world, why don't we take more time to learn from others? This is our first step towards making this possible.

Your participation in research helps to inform others as they embark on or manage their Sickle Cell Journey. As you continue to track more, we will be able to answer more of your questions. We are so grateful you are part of the Folia Community, and we look forward to future research projects.

Happy Tracking!

We are more alike, my friends,
Than we are unlike.
-Maya Angelou