Novel data capture method for the identification of potential flare events in chronic diseases via patient self-tracking: insights from use case in Sickle Cell Disease (SCD)

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OBJECTIVE

To describe and test the feasibility of a new method for identification and characterization of flare events.

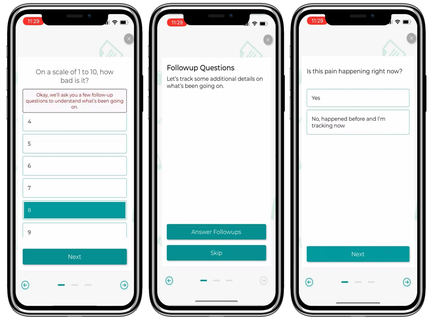
METHODS

Within the Folia home-reported outcomes platform for self-tracking of chronic diseases, a flare tracking system was developed on the basis of 5 years of participant and researcher feedback.

The flare tracking system identifies potential events by flagging changes in symptom burden as they are reported, resulting in a prompt to enter additional information. The flag-enabled symptom names, flag thresholds, and follow-up questions are developed via an iterative development process with patients and experts.

This method was implemented in SCD for identification of potential pain crises, with three flag-enabled symptoms: “chronic pain”, “acute pain”, and “pain crisis”. The thresholds were set for change in severity of 2+ points (out of 10) over patient-identified baseline severity for each symptom, or any tracking of these symptoms utilizing the “lightning bolt” feature on the app. When the threshold was met, users received a prompt to answer 5 additional questions about the potential event.

PARTICIPANT FLOW



Shown above is a typical participant experience of the “lighting bolt” feature. In the example above, the participant is experiencing severe chronic pain. After choosing the severity level, they have the option to continue with answering follow up questions regarding this potential flare event.

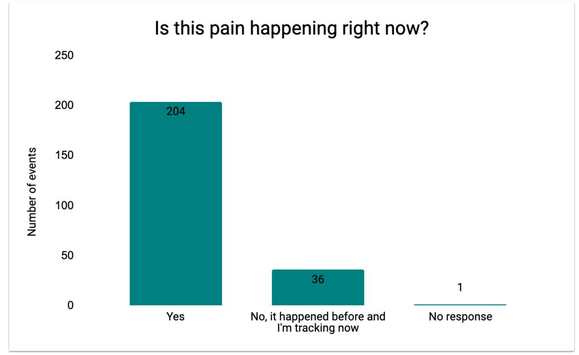
RESULTS

Data in this analysis was collected from 73 participants in Sept-Nov 2022. During this time, the cohort recorded 20,317 symptom tracks. Of these, there were 2954 tracks for chronic pain, 250 for pain crisis, and 95 for acute pain.

Tiered tracking symptoms	Total tracks
Chronic pain	2954
Pain crisis	250
Acute pain	95

RESULTS (CONTINUED)

A total of 241 (7.3%) of these tracks were flagged as potential flare events and triggered follow-up questions. On average, there were 80 unique potential flare events per month. When users were asked when the potential event happened, 85% indicated they were tracking in real-time.



CONCLUSION

This novel framework promotes patient self-identified, real-time or short-recall flare tracking, which expands upon current data capture methods used for pain crisis. Further studies should be conducted to increase sensitivity of flare tracking and eventual early intervention for potential flare events in chronic disease.

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