

Patient Advocacy-led Educational Sessions for Payer Professionals Yields Increased Confidence and Planned Change in Sickle Cell Disease (SCD)



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Background:

SCD is a rare, genetic, life-shortening blood disorder that affects every organ in the body, and the most common inherited blood disorder in the U.S. In 2022 and 2023, Sick Cells collaborated with Impact Education, LLC support their Annual Coverage for SCD Summit. Sick Cells is a patient advocacy organization focused on amplifying the voices of the SCD community. Each educational session was designed to meet the unique needs of managed care professionals, focusing on efficacy and safety data of treatments and novel treatment strategies, including gene therapies. It is important for managed care professionals to understand SCD treatments to fulfill their responsibilities in managing costs, improving the quality of care, ensuring access to effective treatments for patients with SCD.

Objective:

Describe educational outcomes following two managed care professional-focused accredited sessions in SCD.

Methods:

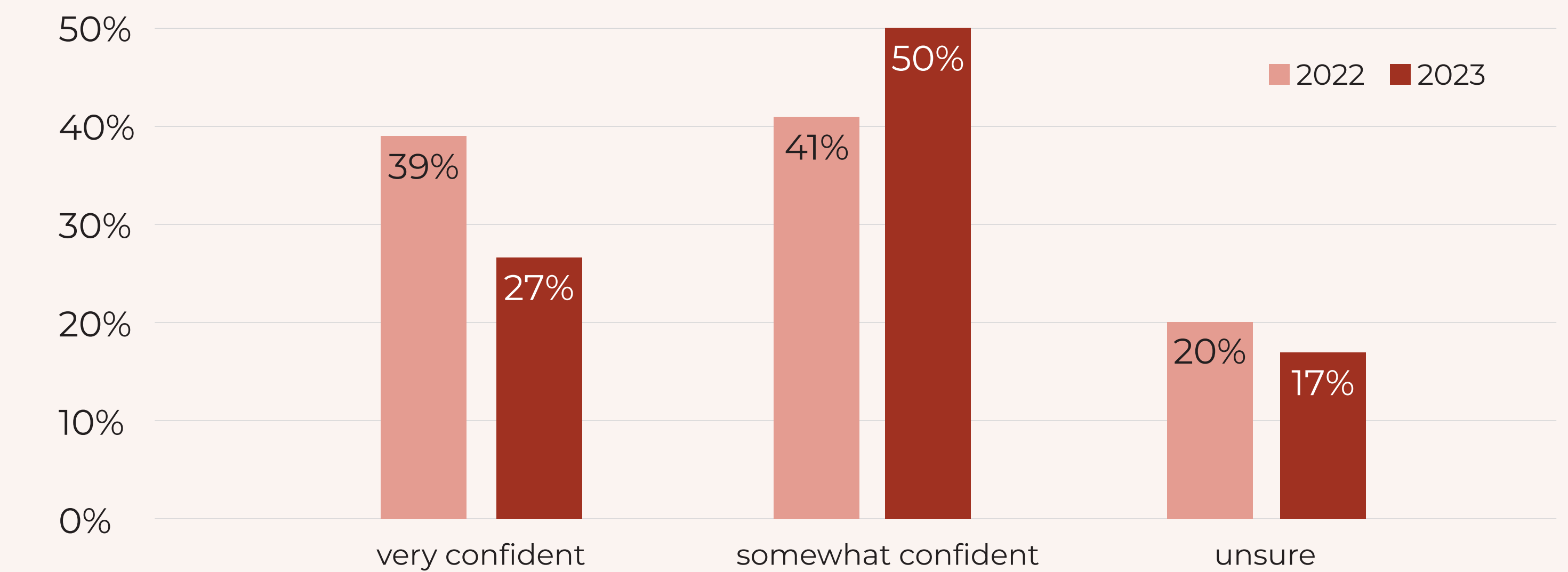
In 2022, a panel consisting of four key opinion leaders from the SCD community, payer sector, and hematology fields led an accredited session focused on enhancing equity and affordability of SCD therapies. In 2023, a subsequent panel comprising four key opinion leaders with expertise in the same areas presented on avenues for enhancing equity, affordability, and ensuring appropriate treatment access for SCD patients. Pre- and post-assessments were conducted to gauge participants' knowledge and intentions to change behavior.

Results:

Over the two years in which these payer-focused sessions were conducted, a total of 214 learners participated, with 79 completing both the pre- and post-program surveys to obtain credit (2022, N=30; 2023, N=49). In an analysis of data from both programs (N=79), a total of 86% of completers plan to implement changes in their practice based on the information presented or had current practices reinforced. Confidence of completers to implement changes was high for each program. In 2022, 80% of completers indicated that they were "somewhat confident" to "very confident" in their ability to implement and/or recommend patient-centered care and services that support appropriate treatment, coverage, and access for patients with SCD. Likewise, in 2023, 77% in the post-survey indicated that they were "somewhat confident" to "very confident" in their ability to implement and/or recommend evidence-based formulary management strategies for SCD.



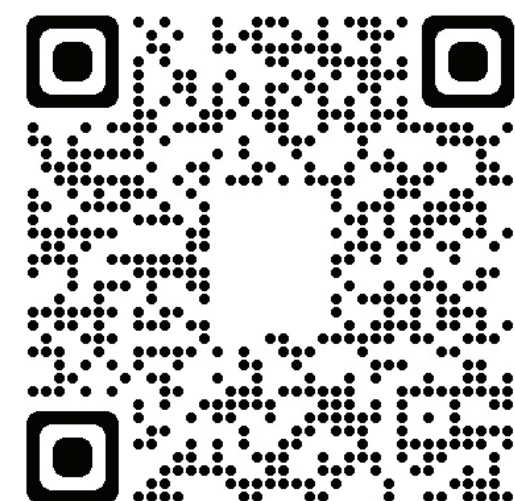
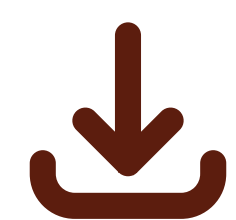
2022 and 2023 Educational Sessions Percent of Completers Confidence in Changing Behavior Post Session



Conclusions:

Patient advocacy-driven educational sessions for managed care professionals resulted in heightened confidence and a plan to change the management of SCD. The implementation of comprehensive focused education over time has shown to be an effective approach for bolstering the confidence of managed care professionals in the management of rare diseases, as exemplified by the results achieved in SCD.

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