

Incorporating the Patient Voice in Rare Disease Education: Multi-stakeholder Collaborations to Improve Diagnosis, Quality of Care, and Outcomes

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INTRODUCTION

Persistent clinician and public education on rare diseases is critical to raise the index of suspicion for rare diseases, decrease the time to diagnosis, and provide optimal management for patients (1 in 10 Americans have a rare disease). In 2019, the National Organization for Rare Disorders (NORD) launched a partnership with PlatformQ Health, a healthcare education provider, to develop continuing medical education (CME) curricula that focus on a wide variety of rare-disease topics, truly represent rare-disease patients and advocates, and enable clinicians to better recognize, diagnose, and treat rare conditions. Through this multi-stakeholder collaboration, we have developed a library of rare-disease education designed to improve clinical practice and patient outcomes.



METHODS

Since 2019, **93 educational sessions** have been developed for clinicians, patients, and caregivers.

Education: Sessions were designed in partnership with NORD's advocacy member organizations, providing a platform to share the patient voice in CME. The education was provided online via live and on-demand clinician and patient/caregiver learning channels and promoted via social media and partner websites. Learners were invited to submit questions in advance of the live events. Programs featured interactive panel discussions, patient-story vignettes, polling, and live Q&A sessions.

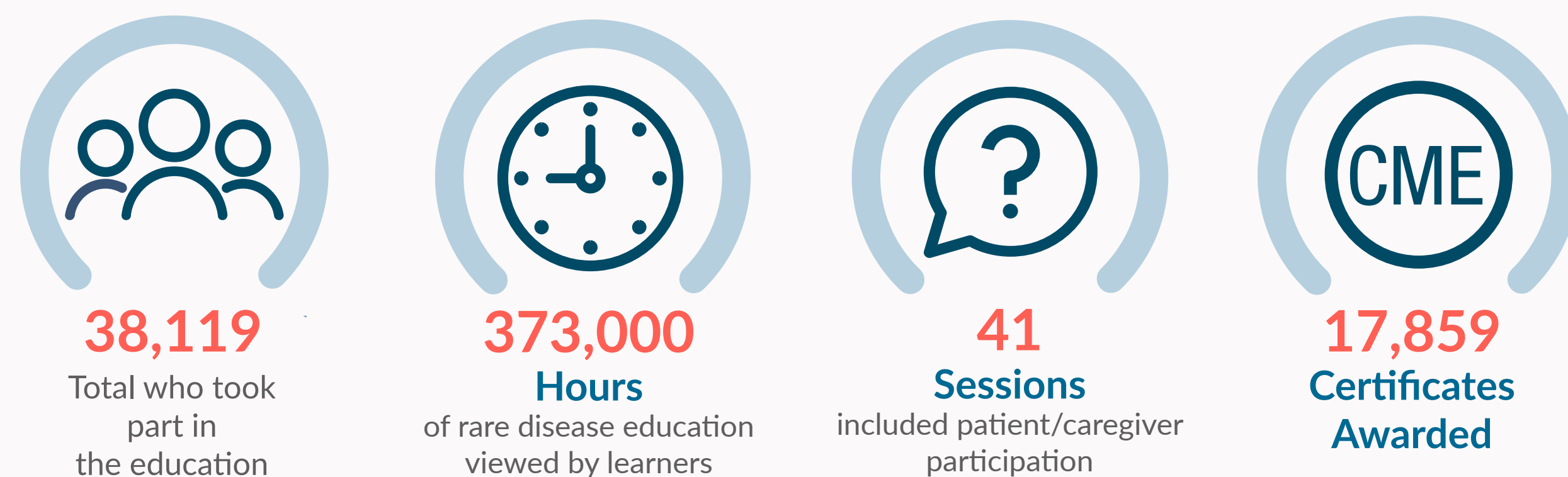
Panelists included key stakeholders from NORD, advocates from NORD member organizations, healthcare professionals (HCPs), and patients and caregivers. Unique program formats included "joint" or "tethered" CME and patient/caregiver education, and CME programming that emphasized the patient voice. Programs incorporating the patient voice share compelling patient experiences with providers and increase clinician engagement. NORD member organizations provided key insights into the needs of their patient, caregiver, and provider communities.

For individual sessions, pre- and immediate post-activity testing, real-time in-activity polling, and 2-month post-activity follow-up responses were analyzed for engagement, knowledge/competence change, and remaining needs. Aggregate data show the impact of overall educational initiatives.



RESULTS

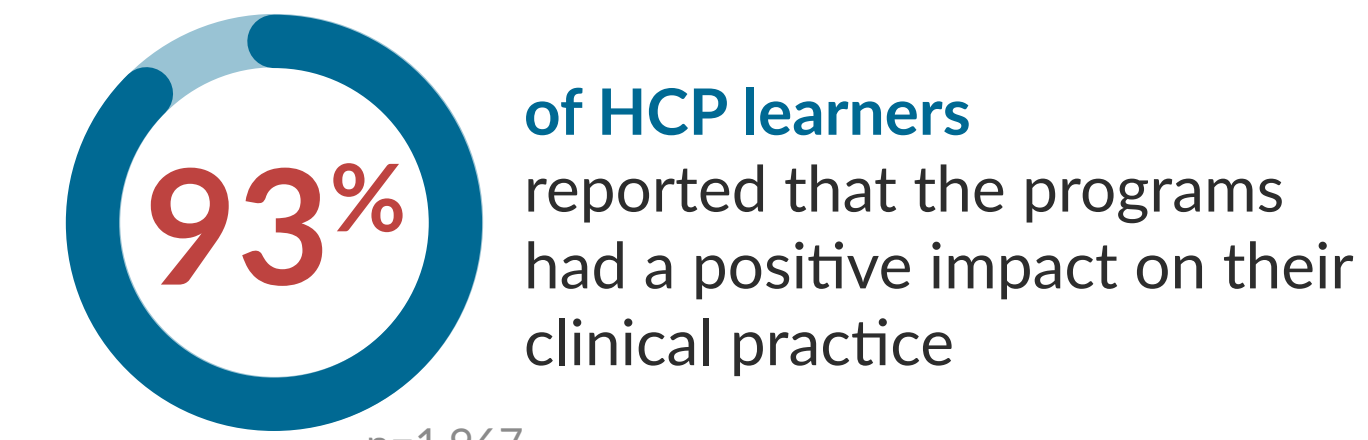
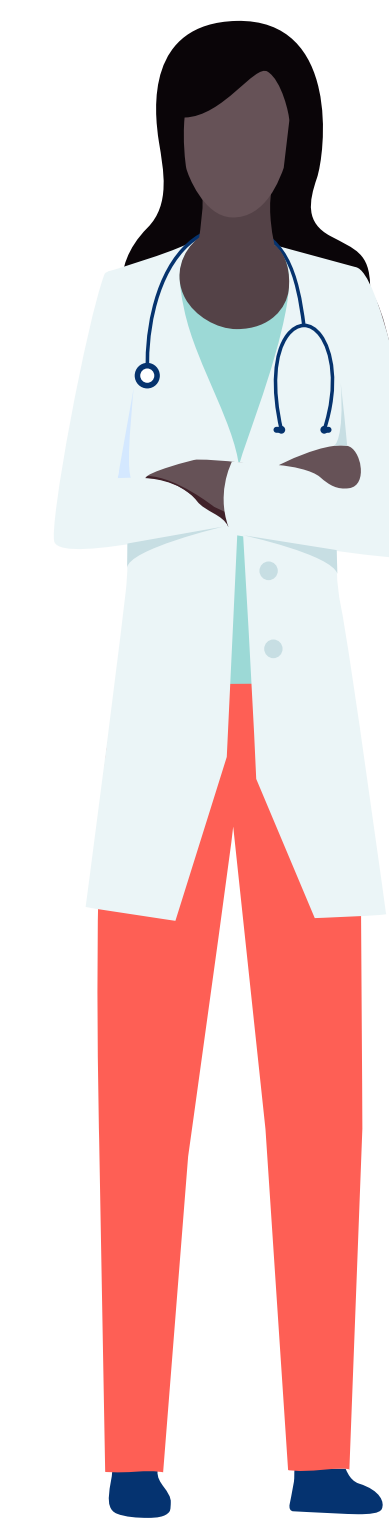
As of July 2023:



IMPACT

Positive Impact on HCP Practice, Patient Empowerment, and Communication

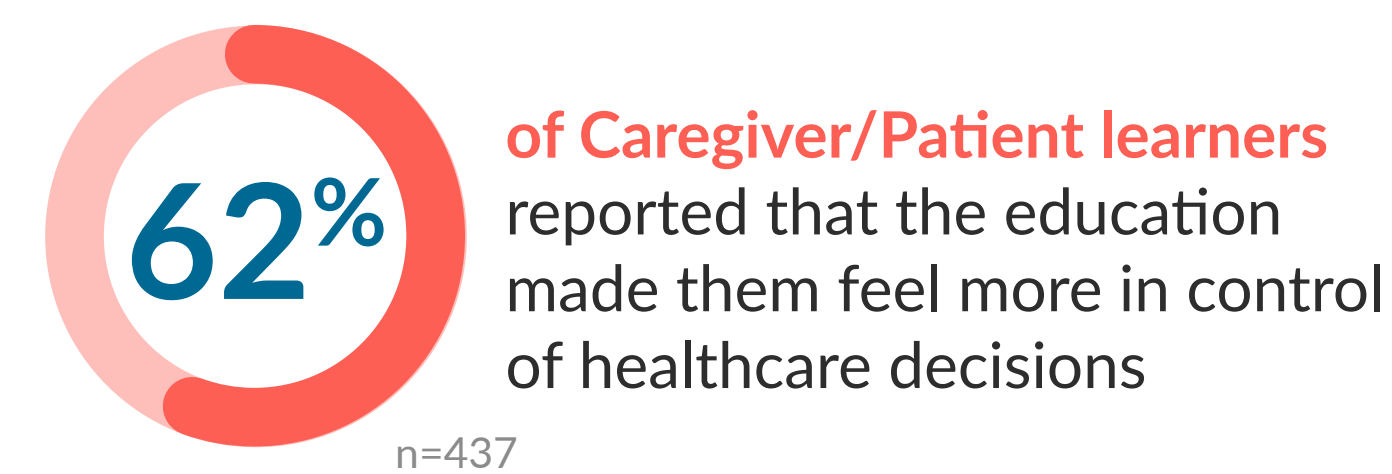
Through HCP education programs



More capable in diagnosing and treating.

Able to provide support and education to patients regarding treatment options.

Through patient education programs



I feel more educated. I feel more empowered. I feel like a more supported advocate. I feel I can drive my healthcare with more confidence.

It gave me more confidence to speak up and be open and honest with my healthcare provider. Before I just went along with what they wanted. Now I add my plans and ideas into my treatment plan.



Programming provided in collaboration with the following patient advocacy organizations:



CONCLUSION

The results provide solid evidence of the effectiveness of online CME, while supporting the positive influence of online rare-disease education on clinicians, patients, and caregivers. Real-world impacts also illustrate the value of multi-stakeholder collaborations to design and deliver educational content that is relevant for the audiences most in need of the education. Continuous education is essential to address the diagnostic and management challenges of rare-disease patients and positively impact their clinical outcomes.