

Amplifying Educational Impact Through Collaboration: Rare Disease Education Designed to Improve Diagnosis, Quality of Care and Outcomes

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INTRODUCTION

Persistent clinician and public education on rare diseases is critical to raising the index of suspicion, decreasing the time to diagnosis, and providing optimal management of patients with rare diseases (1 in 10 Americans have a rare disease). In 2019, The National Organization for Rare Disorders (NORD) launched a partnership with a healthcare education organization, PlatformQ Health, to develop CME curricula focused on a wide variety of rare-disease topics, and aimed at enabling HCPs to better recognize, diagnose, and treat rare conditions, and to develop crucial patient education resources. Through this multi-stakeholder collaboration, we have developed a library of rare disease education to address identified needs and subsequently evaluate for educational impact on clinicians' practice and patients' outcomes.



METHODS

Since 2019, **67 educational sessions** have been developed for clinicians, patients and caregivers.

Education: Sessions were designed and distributed in partnership with NORD member organizations. Education on rare conditions was provided online via live and on-demand HCP and patient/caregiver dedicated learning channels and promoted through social media and partner websites. Learners were invited to submit questions in advance of the live events. Programs featured interactive panels, patient-story vignettes, polling, and live Q&A.

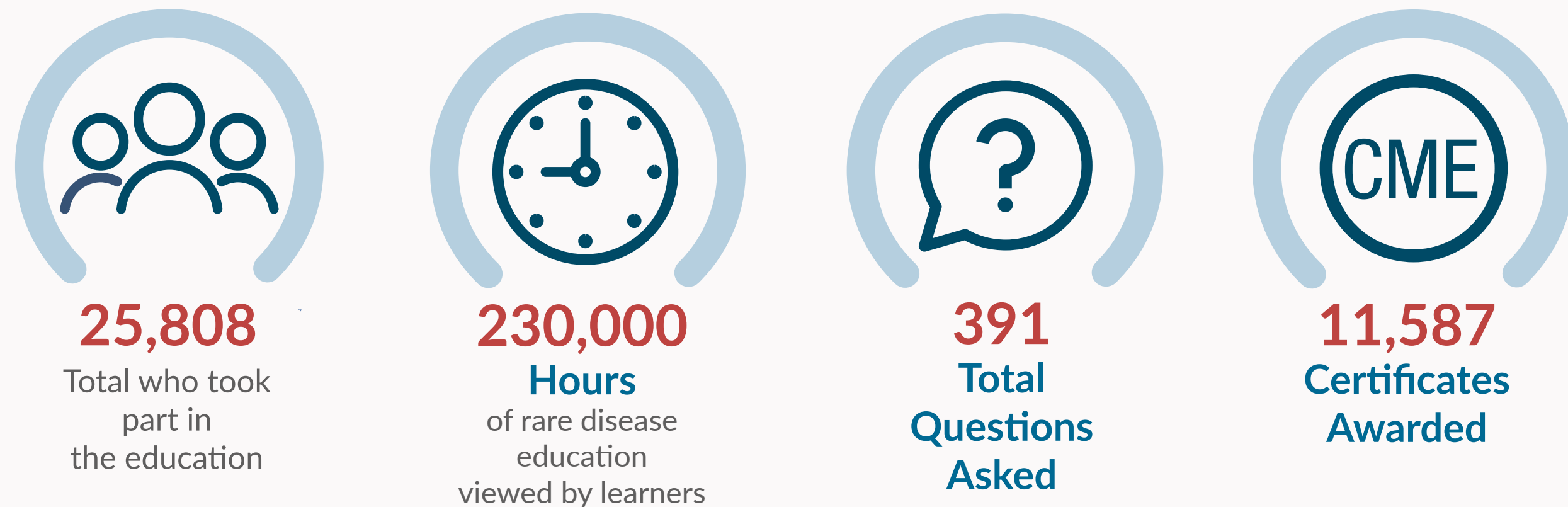
Panelists included key stakeholders from NORD, advocates from NORD member organizations, healthcare professionals, and patients/caregivers. Unique program formats included "joint" CME and patient/caregiver education, "tethered" CME and patient/caregiver education, and CME programming featuring the patient voice. Programs incorporated the patient voice to share compelling experiences with providers and to increase HCP engagement. NORD member organizations provided key insights into the needs of their patient, caregiver, and provider communities.

Impact of the education on knowledge, competence, behavior, and engagement were measured using pre, post, 2 mos. post testing and live polling. Analysis of the data also allowed us to identify remaining educational needs. Aggregate data across the 67 educational sessions provides insight into the impact of the overall educational initiative.



RESULTS

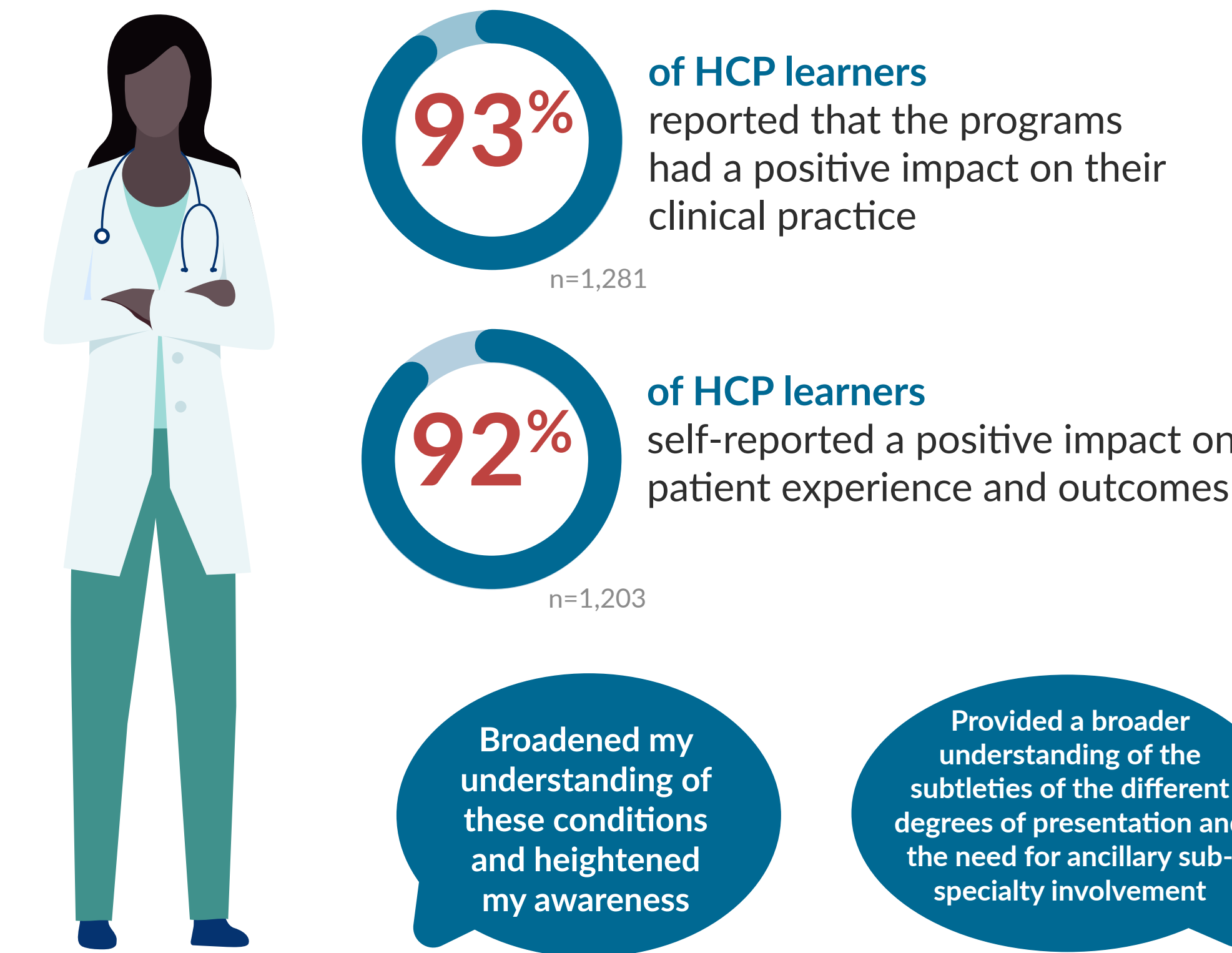
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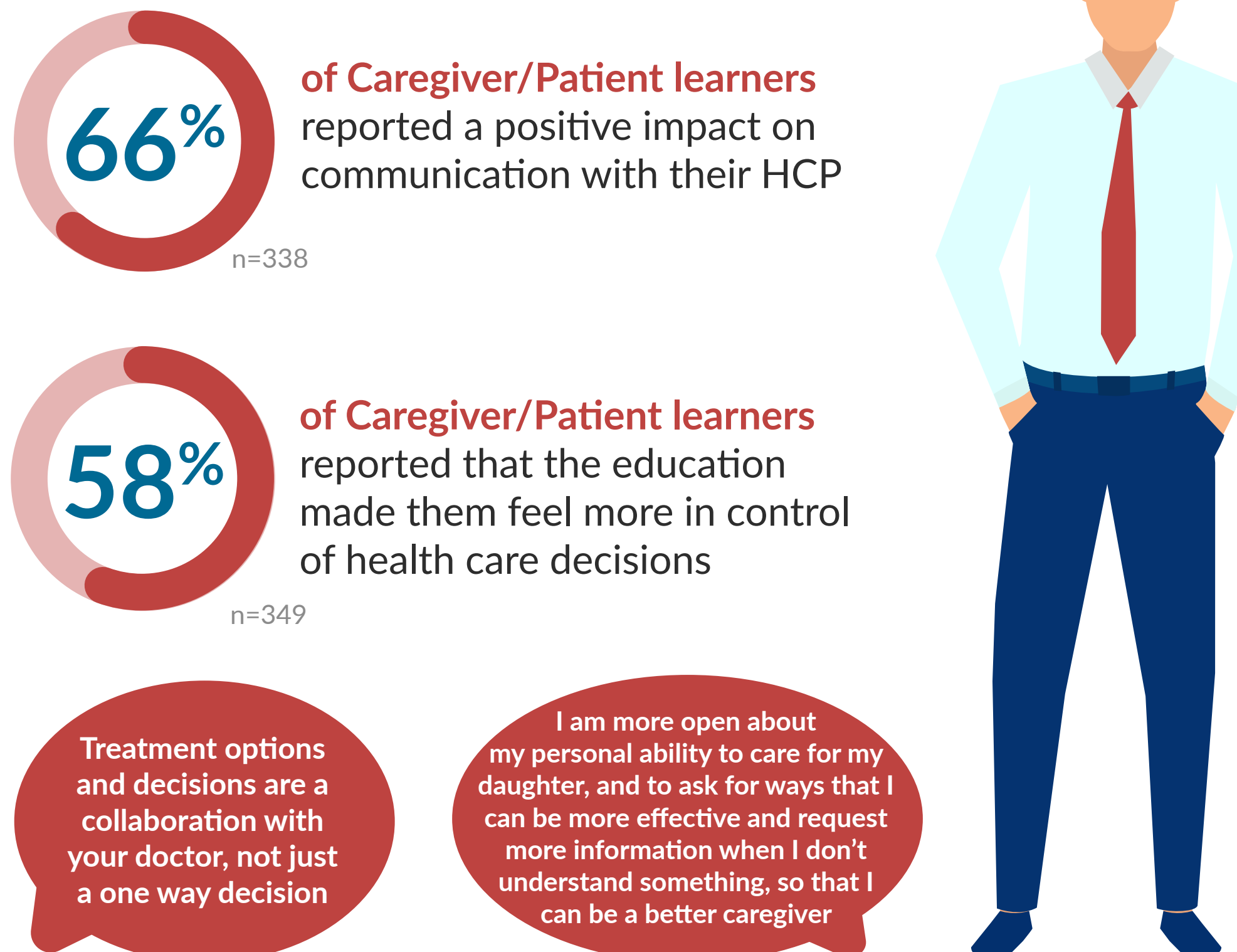
IMPACT

Positive Impact on HCP Practice, Patient Empowerment and Communication

Through HCP education programs



Through patient education programs



Programming provided in collaboration with the following patient advocacy organizations:



CONCLUSION

These results support the effectiveness of online education for clinicians and patient and caregivers, with a special focus on the impact that online education about rare diseases has in positively influencing clinician practices and patient outcomes. The real-world impact of this initiative highlights the value of multi-stakeholder collaboration to design relevant educational content and deliver the education to the audiences who need it the most.