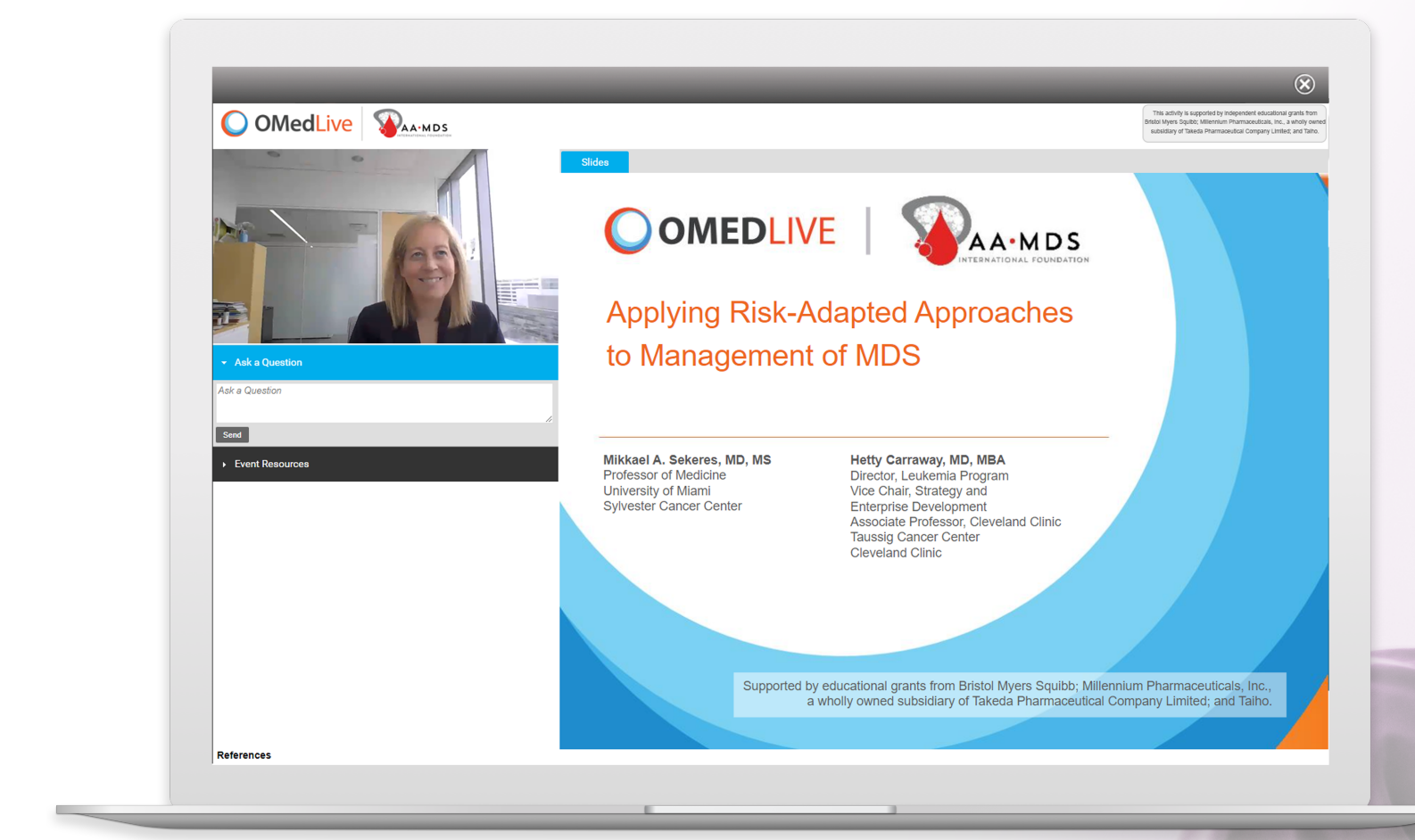


# A Patient Centered and Risk-Adapted Approach to Management of Myelodysplastic Syndrome

This tethered initiative was supported by independent educational grants from Bristol Myers Squibb; Millennium Pharmaceuticals, Inc., a wholly owned subsidiary of Takeda Pharmaceutical Company Limited; Novartis Pharmaceuticals Corporation; and Taiho.

Tariqa Ackbarali, MS, PhD<sup>1</sup>; Mikkael A. Sekeres, MD, MS<sup>2</sup>; Hetty Carraway, MD, MBA<sup>3</sup>

1 - PlatformQ Health, Needham, MA; 2 - University of Miami, Sylvester Cancer Center, Miami, FL; 3 - Taussig Cancer Center, Cleveland Clinic, Cleveland, OH



## INTRODUCTION

The latest research advances in myelodysplastic syndrome (MDS) pave the way for new treatment options and improved outcomes for patients with this rare and challenging-to-treat disease. Several investigational agents are in late-phase trials and recent approvals require physicians to stay up to date with emerging data on clinical efficacy and safety to make appropriate and individualized treatment choices. Patients and caregivers also require education to help understand disease subtypes, prognosis and expectations of treatment, management of side effects, and the benefits of enrollment in clinical trials.

## METHODOLOGY

### Educational Initiative and Evaluation

**Partners**  
 Advocacy group: Aplastic Anemia & MDS International Foundation (AAMDS)  
 Education: PlatformQ Health, Postgraduate Institute for Medicine

**Assessments**  
 HCPs: practice patterns, knowledge, competence, engagement, and perceptions  
 Patients/Caregivers: knowledge, communication and self-efficacy behaviors

**Interventions**  
 Tethered education comprised of one 60-min CME activity for HCPs and one 60-min patient/caregiver activity

**Measurements**  
 Questions asked before and immediately after the activity. Two-month follow-up survey was sent to learners to evaluate changes in practice and behavior. Chi-Square tests used for statistical analysis.

### Faculty



**Hetty Carraway, MD, MBA**  
 Director, Leukemia Program  
 Vice Chair, Strategy and Enterprise Development  
 Associate Professor,  
 Cleveland Clinic  
 Taussig Cancer Center  
 Cleveland Clinic



**Mikkael A. Sekeres, MD, MS**  
 Professor of Medicine  
 University of Miami  
 Sylvester Cancer Center

### Patient Vignette Speaker



**Ruth Cuadra**  
 MDS Patient and Advocate  
 Ruth discussed the symptoms she experienced and how they were managed. She also explained how she was diagnosed, the limitation of treatment choices, her goals for treatment, and how she worked with her doctors to decide what treatment would work best for her.

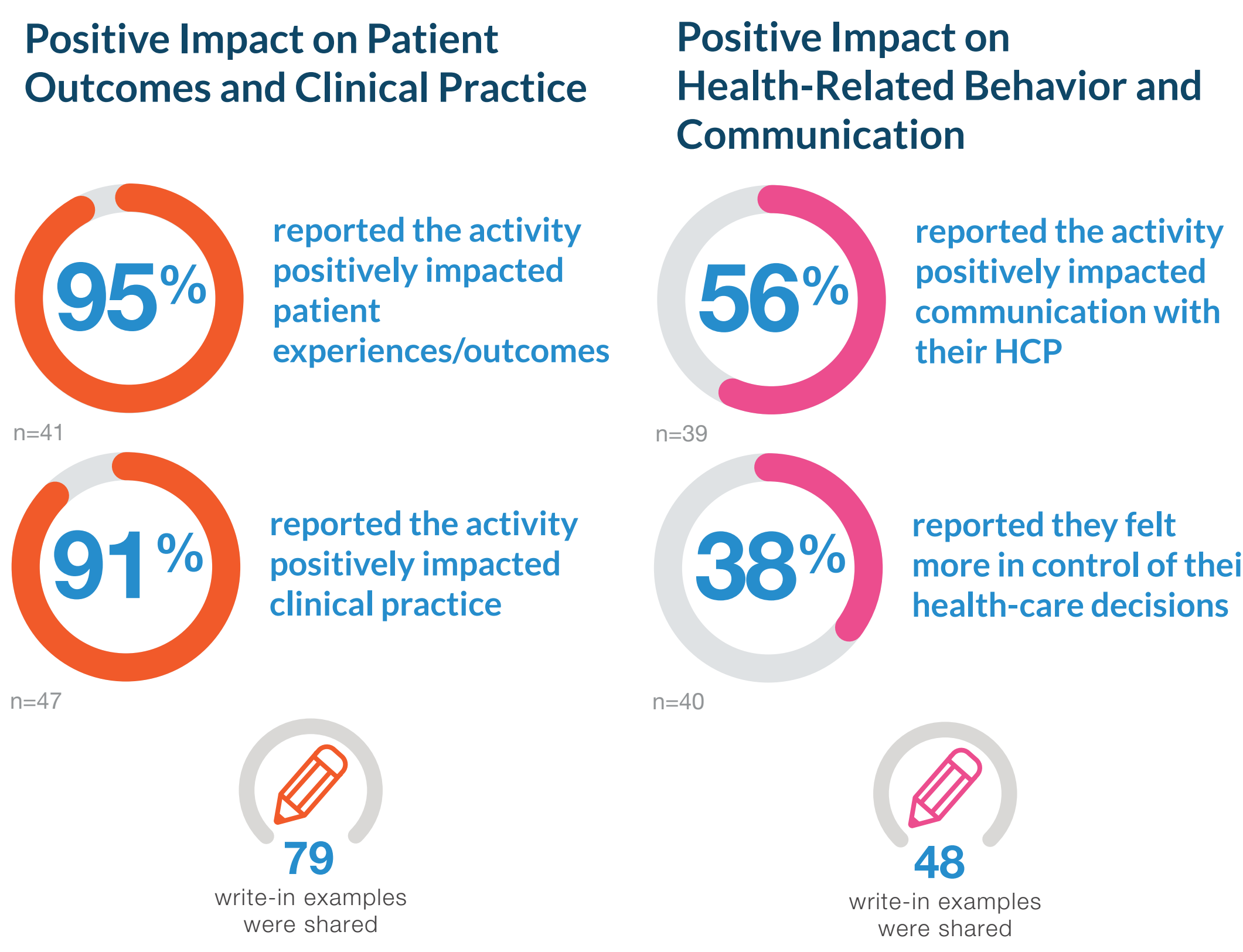
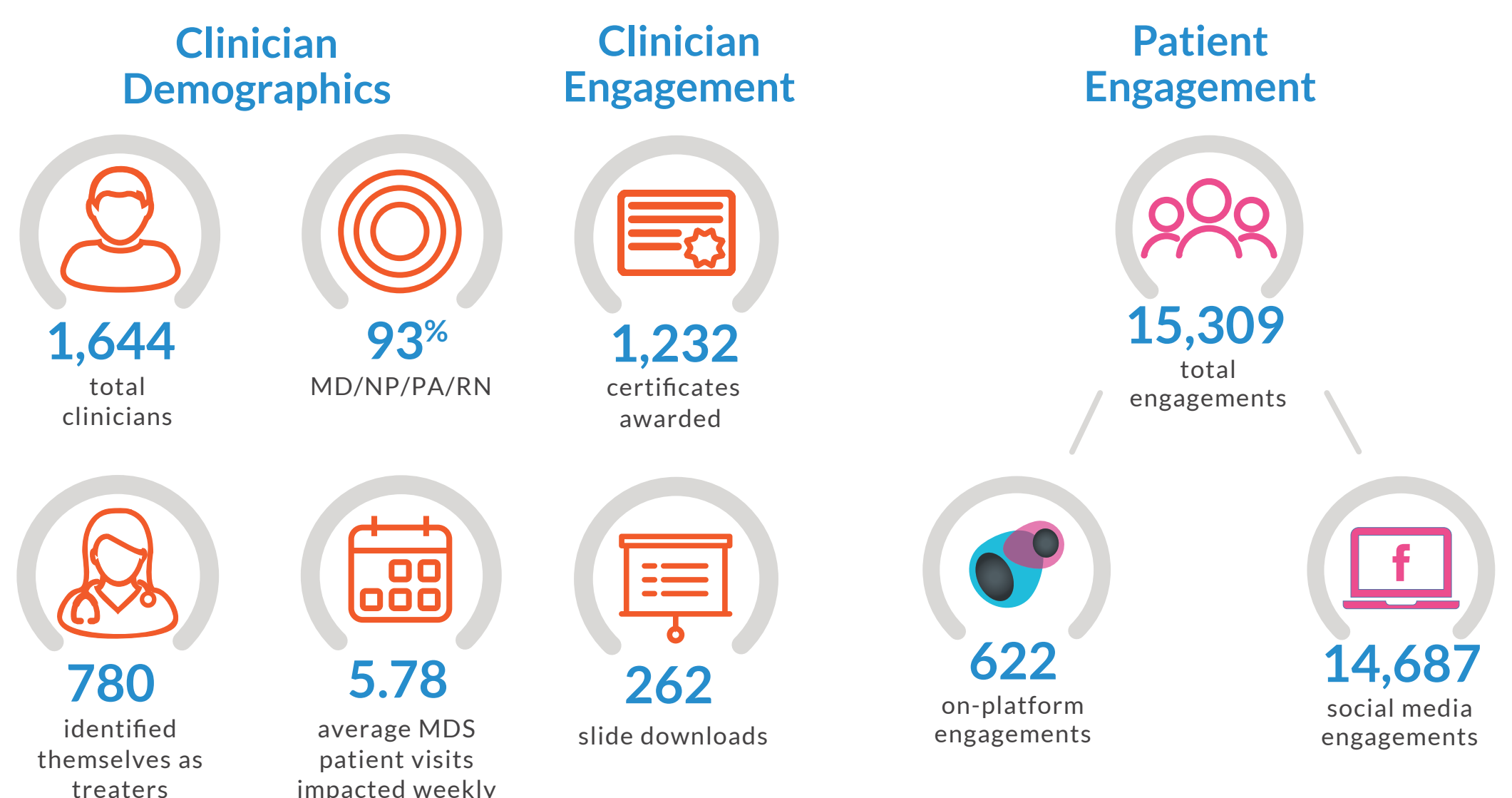
## RESULTS

**HCPs**

Applying Risk-Adapted Approaches to Management of MDS

**Patients/Caregivers**

Establishing Goals of Therapy While Managing Myelodysplastic Syndromes



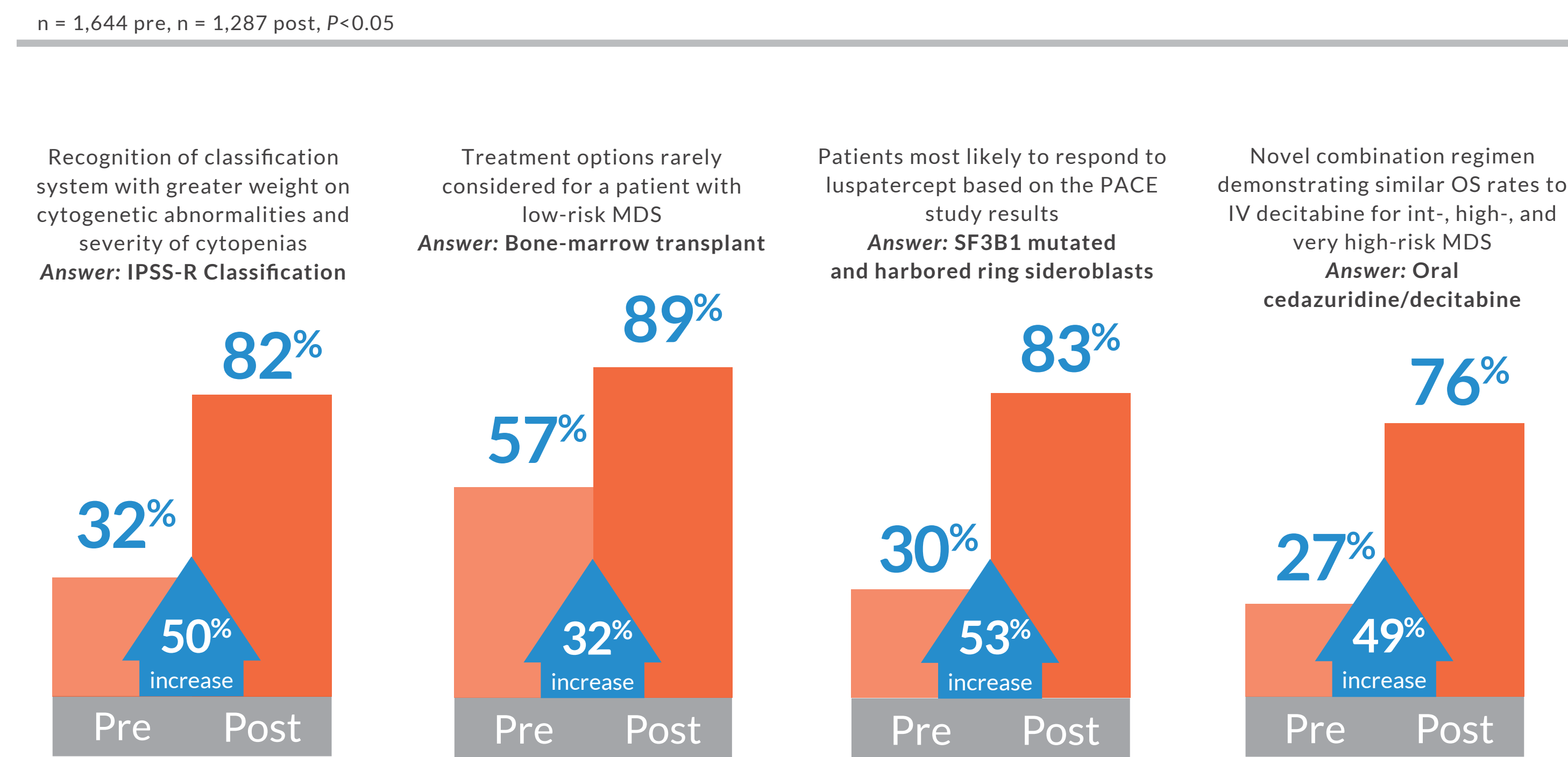
I can identify more patients [who are] eligible for luspatercept.

I feel more aware of making health-related changes that will hopefully influence my journey with MDS in a positive way.

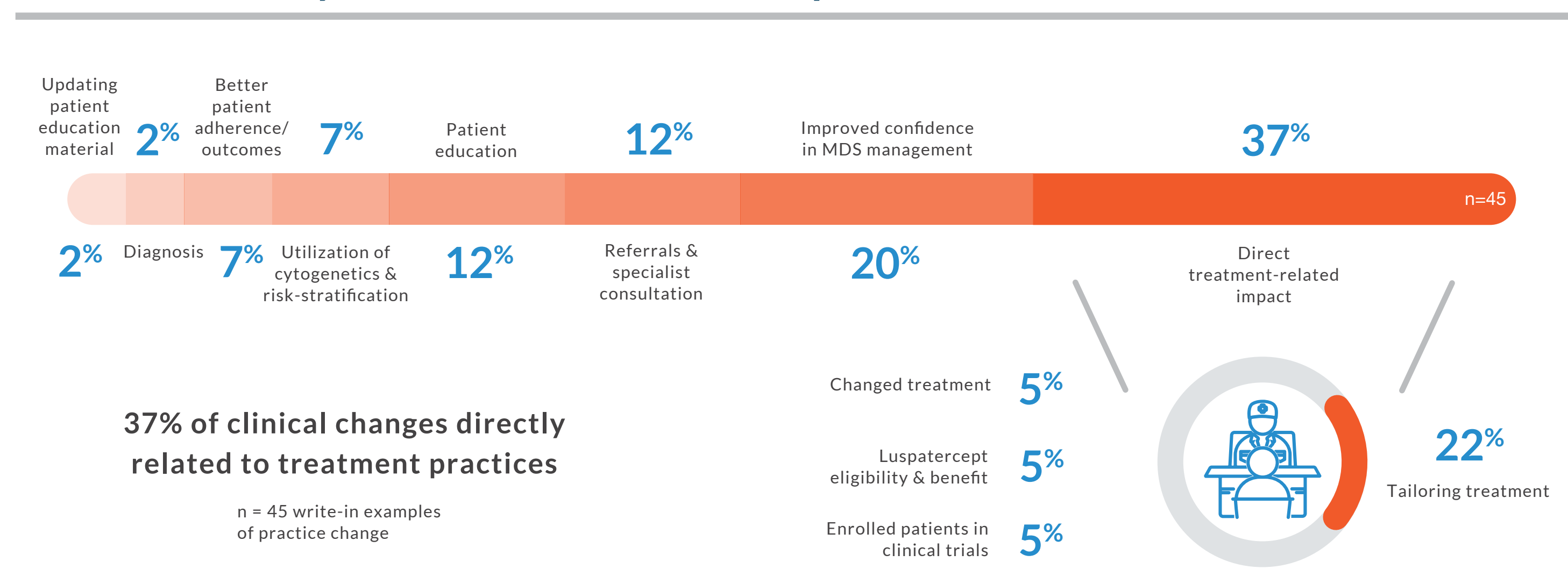
Patient was able to switch forms of their medication which provided improved quality of life.

I feel like I can advocate more for myself as I feel more confident in the knowledge I gained through this program. I learned a lot and appreciated this kind of service being available to patients like me.

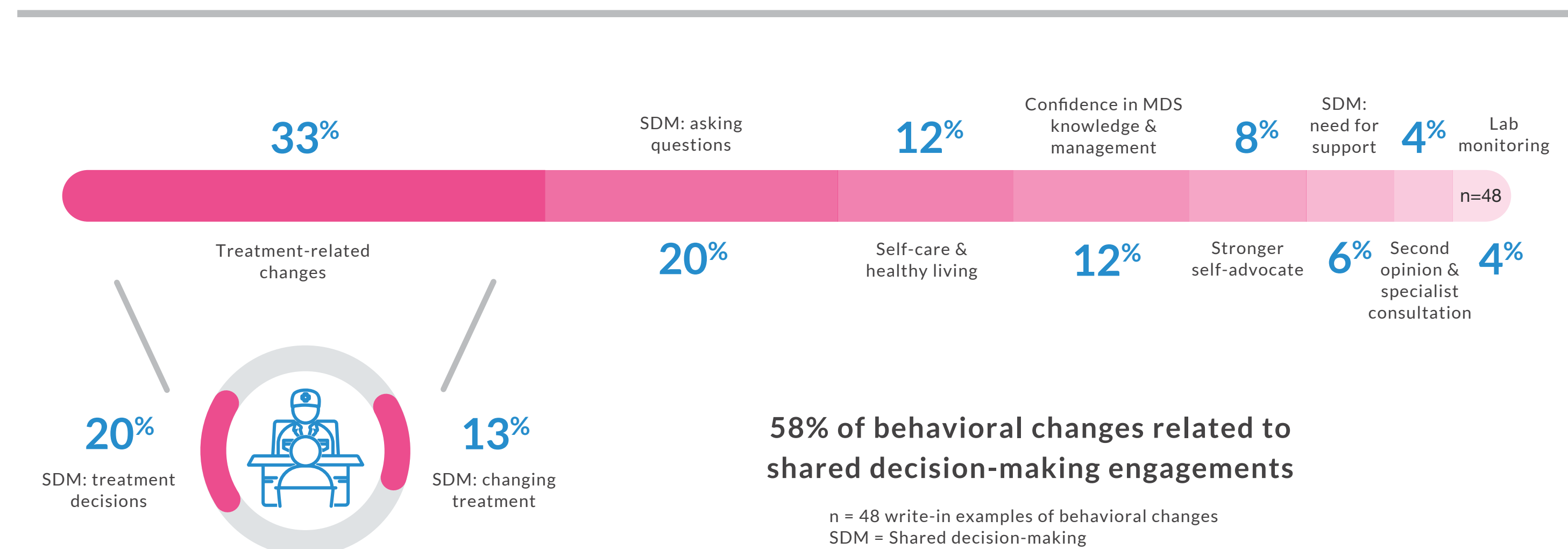
### Changes in Knowledge/Competence



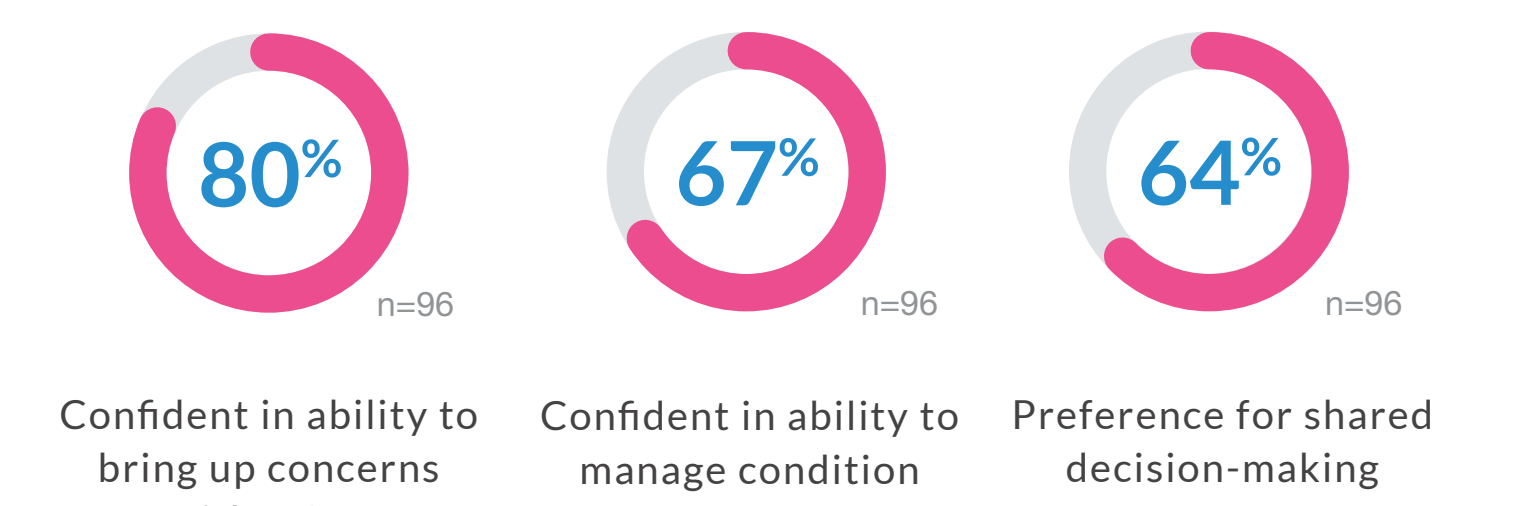
### Thematic Analysis of Clinical Practice Impact



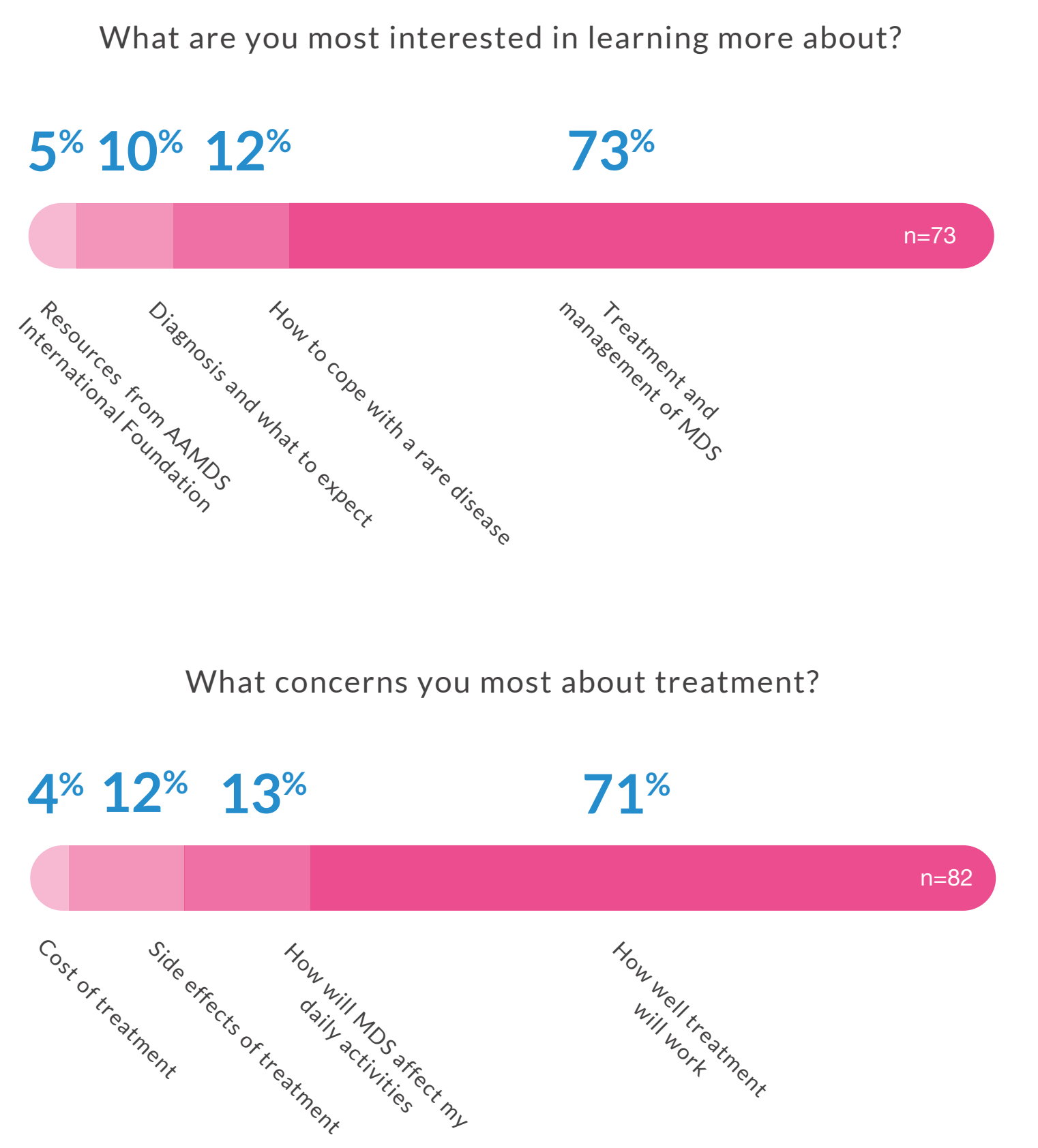
### Thematic Analysis of Patient Behavior Changes



### Patient/Caregiver Empowerment and Decision-Making



### Patient Insights Regarding Treatment and Future Education



## CONCLUSION

This patient-provider (tethered) initiative was successful in improving knowledge and competence of providers from observed baseline levels and increasing confidence of patients to engage in shared decision-making. Insights into patient experiences, concerns, and preferences for education are important to share with providers to better refine patient care practices in the future.