

Patient-Voice RWE: Comparative Burden Collected From an Online Social Platform

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INTRODUCTION

The Mighty: ~3.5M members with predominantly chronic, rare, and mental-health conditions

Will online patients respond to questions about burden of disease?

- Increase patients’ voice in RWE generation
- Quantify burden and other non-clinical measures

METHODS

Survey Mighty communities: May 9-May 20, 2022
5-10 min. survey; 661 Responses

Condition	N
Schizophrenia	41
Ehlers-Danlos Syndrome	194
Inflammatory Bowel Disease	356
Multiple Sclerosis	70

RESULTS

Condition	Productivity Loss: ‘miss work or school’	Productivity loss: Most Common Answer	Economic Burden: Spent >\$1,000 out-of-pocket to manage	Top Challenge/Burden
Schizophrenia	66%	Take a leave or stop completely (63%)	22%	Finding an effective treatment plan (64%)
Ehlers-Danlos Syndrome	71%	Take a leave or stop completely (54%)	31%	Finding a specialist (88%)
Inflammatory Bowel Disease	55%	1-2 days/month (31%)	34%	Finding an effective treatment plan (70%)
Multiple Sclerosis	59%	Take a leave or stop completely (70%)	29%	Impact on mental or emotional health (76%)

CONCLUSIONS

Patients in online platforms are willing to participate in burden analyses, setting a foundation collecting patient-centric RWE.