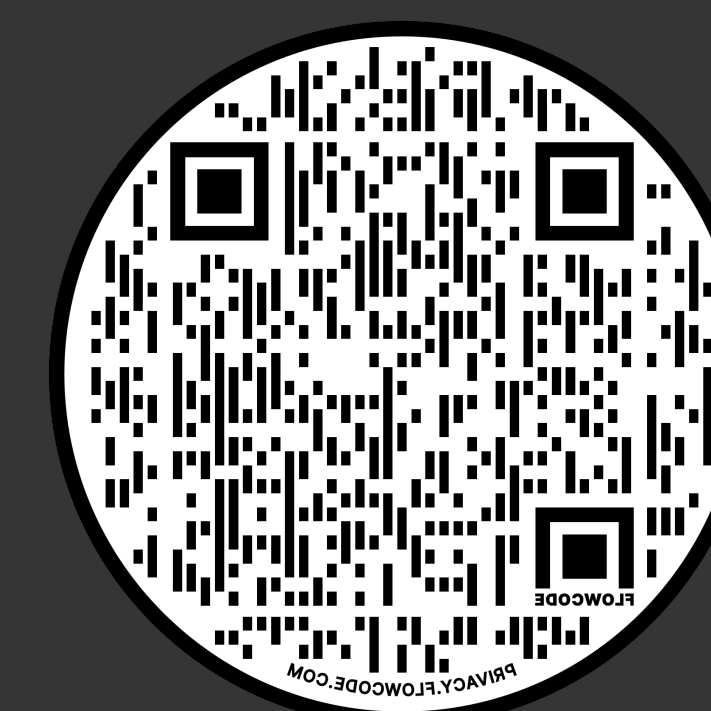


Using Real-World Evidence to Understand the Diagnostic Journey of People Living With Myasthenia Gravis and Its Impact on Mental Health

Enming Zhang,¹ Maurice Flurie,¹ Monica Converse,¹ Anthony J. Amatucci,² Kristina Davidson,² Wei Li,¹ E. Robert Wassman,¹ Christopher DeFelice,¹ Maria Picone¹

¹TREND Community, Philadelphia, Pennsylvania; ²Horizon Therapeutics plc, Deerfield, Illinois

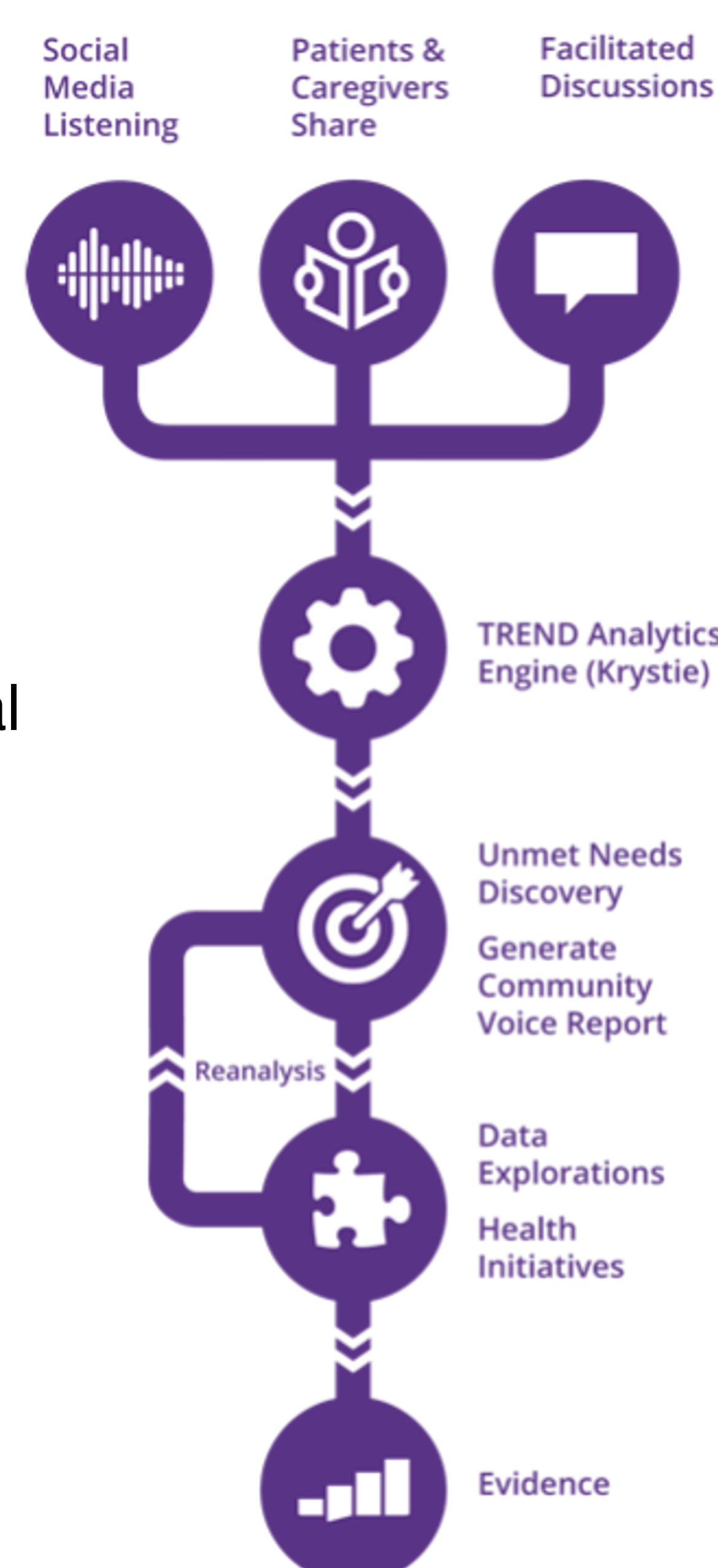


BACKGROUND

Listening to and understanding the patient experience are essential to determine the needs of a particular community. A proprietary artificial intelligence (AI) analytics engine was applied to social media conversations to gain insights into emotional and mental health experiences in various online communities dedicated to those living with myasthenia gravis (MG). MG is a neuromuscular autoimmune disease characterized by fluctuating muscle weakness and fatigue resulting from autoantibodies binding to receptors at the neuromuscular junction of skeletal muscles.¹ This complex disease has been known to negatively affect mental health in patients, which can reduce health-related quality of life (HRQoL) and exacerbate symptoms.^{2,3} The exact cause of these mental health issues and when they appear is not fully understood. The goal of this study was to characterize how mental and emotional health might be affected by the *prediagnosis (pre-dx)* vs *postdiagnosis (post-dx)* stages in the diagnostic journey.

METHODS

The analytics engine employed a range of natural language processing (NLP) techniques to identify prevalent terms and concepts in conversations. We evaluated users from 3 public subreddits: r/Myasthenia Gravis, r/Myasthenia_Gravis, and r/Myasthenia_Support. These sources included more than 15,000 posts/replies from more than 1,500 active members from 2013 to 2023. We also extracted submissions/replies from these members across 12 mental health-related subreddits (e.g., r/mentalhealth), which provided an additional 10,000 submissions/replies.



RESULTS

FIGURE 1A. CONVERSATION TYPES

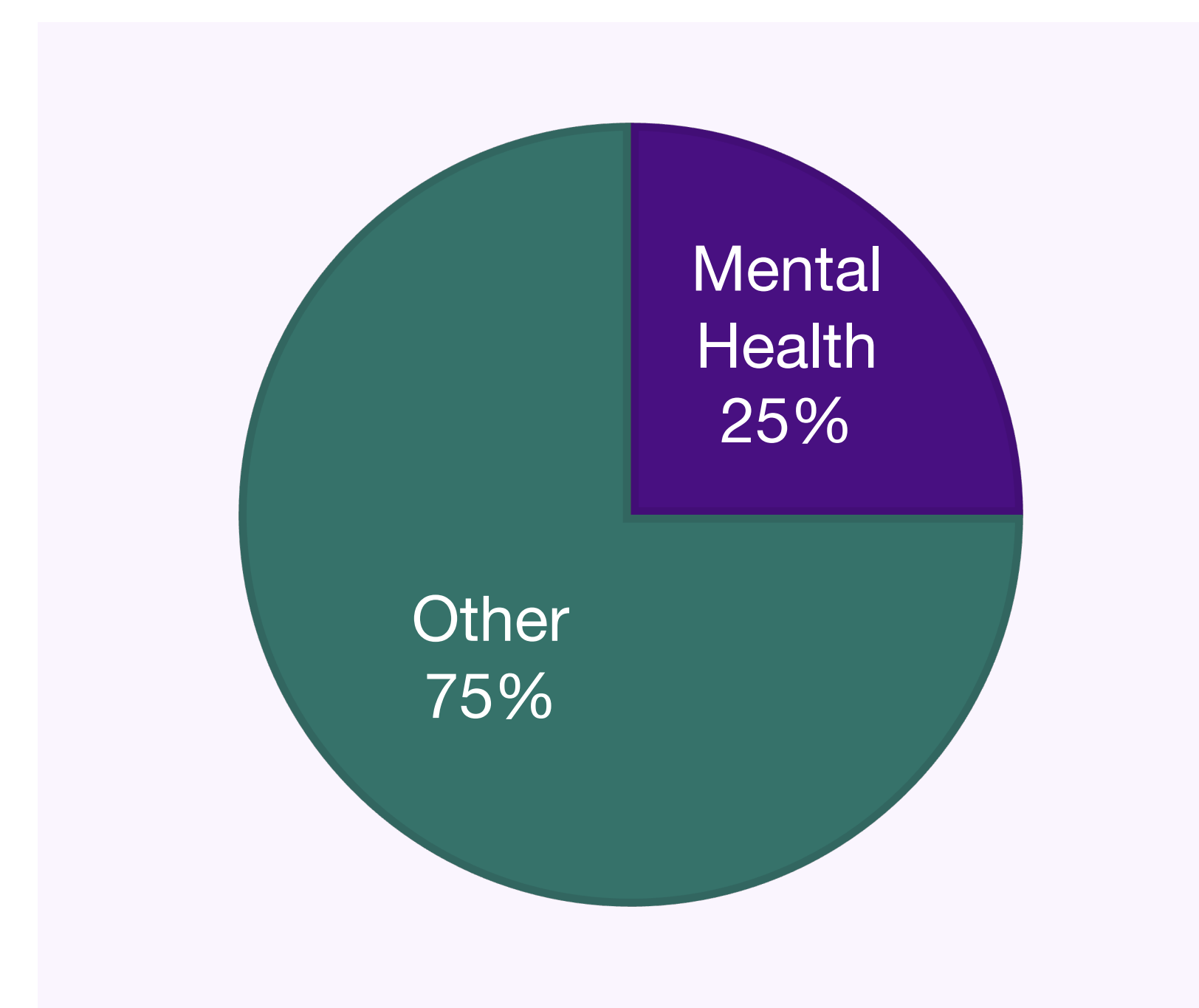
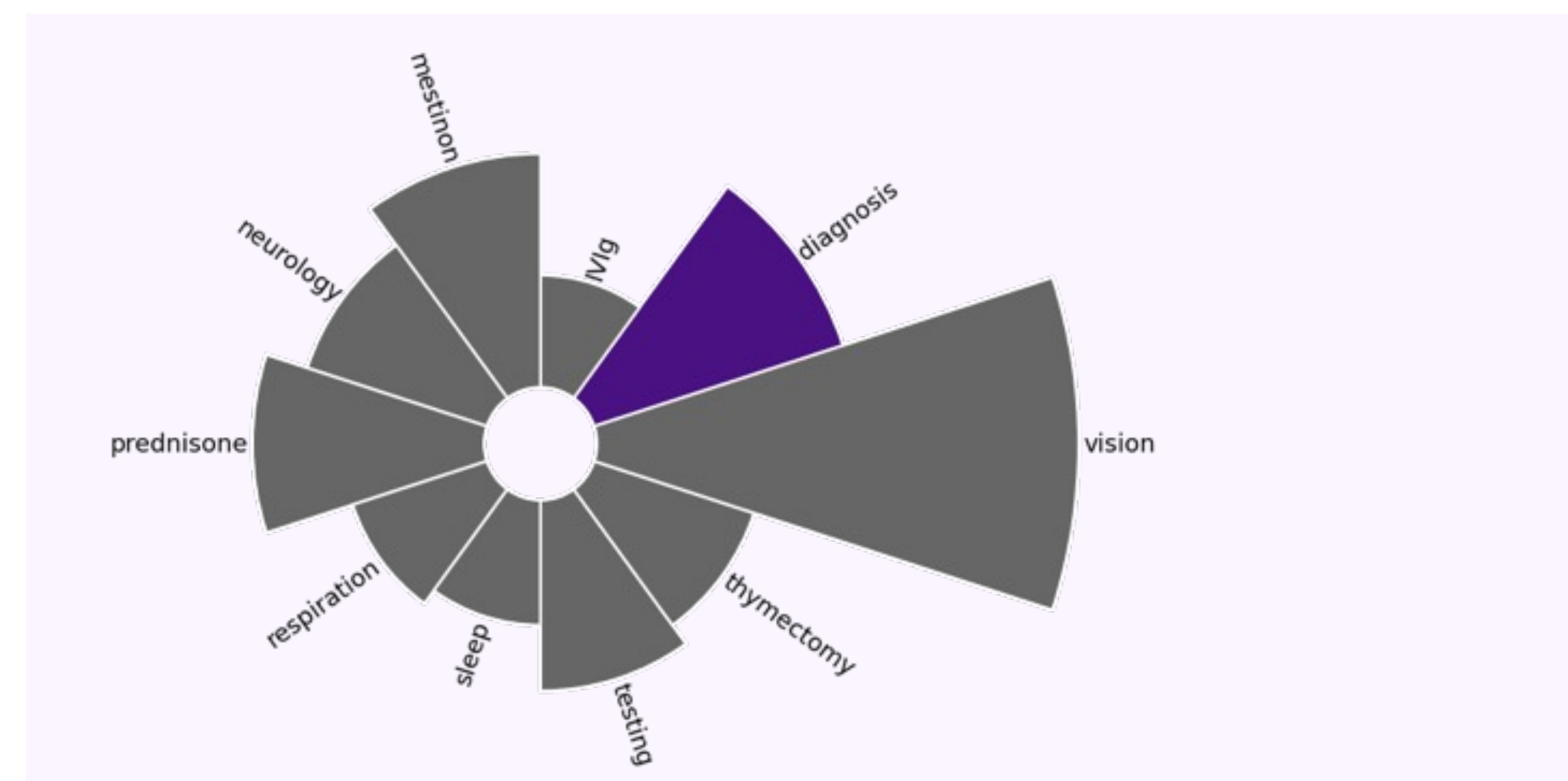
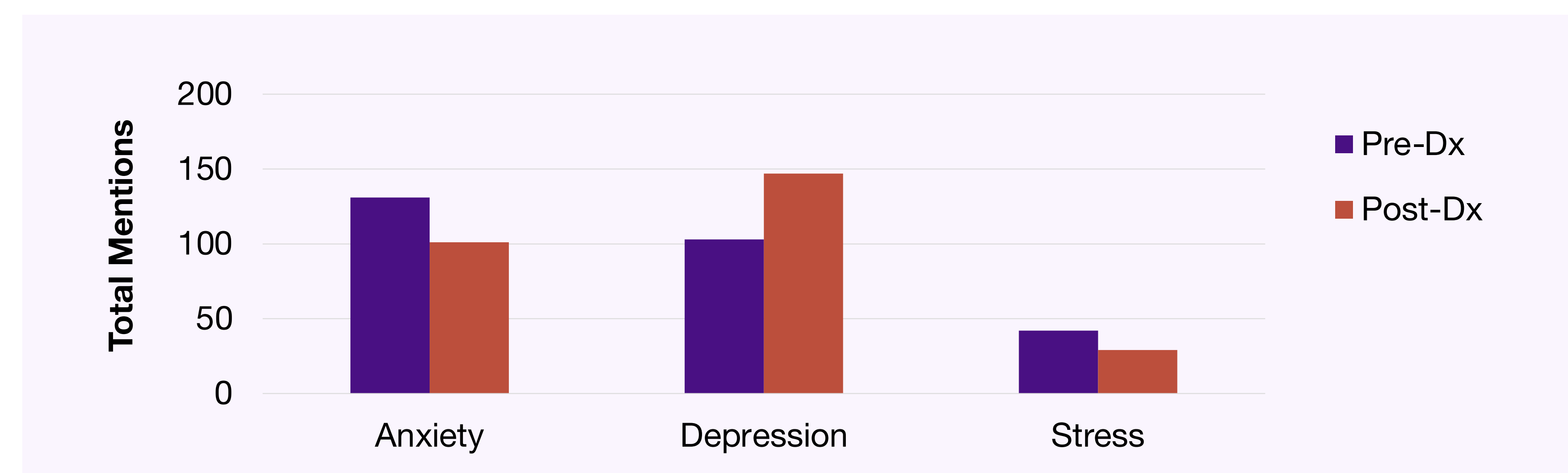


FIGURE 1B. TOPICS IN MENTAL HEALTH CONVERSATIONS



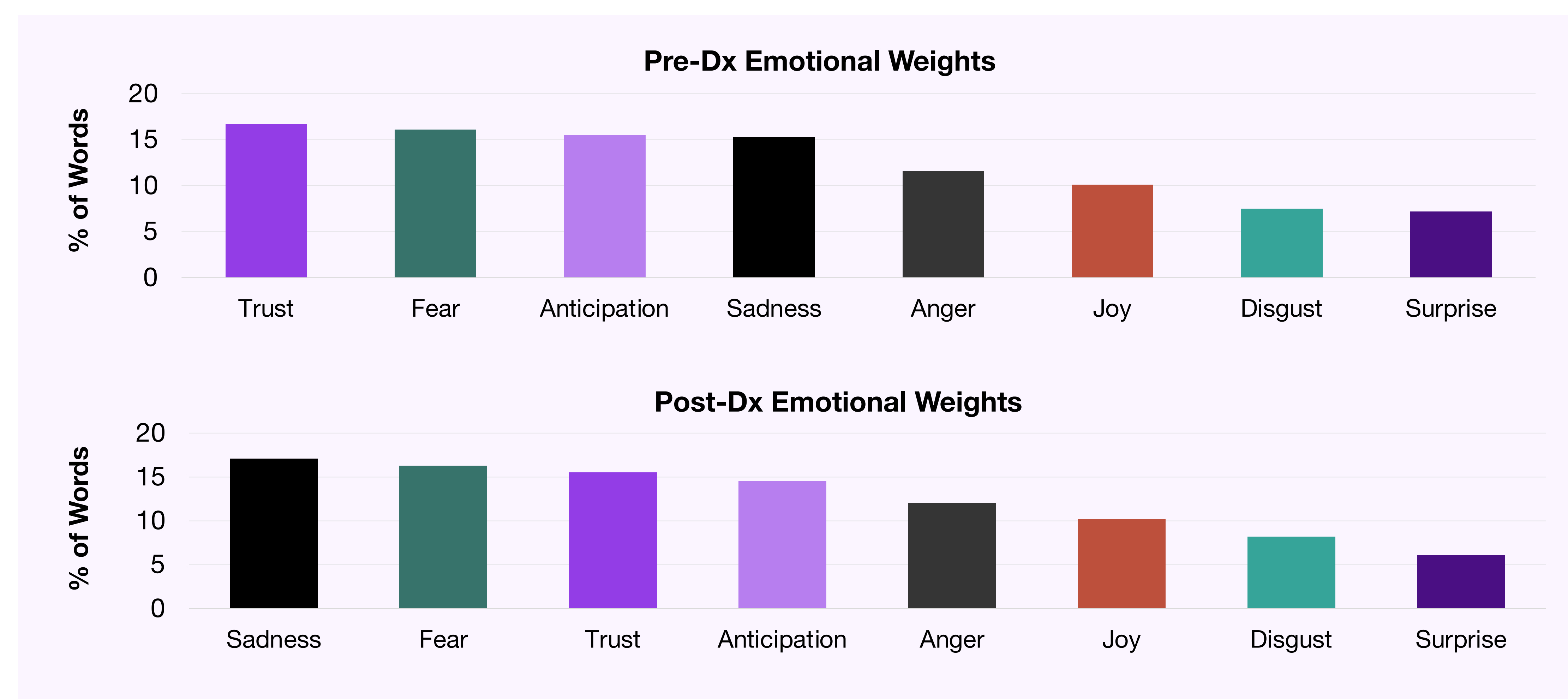
The AI engine identified conversations with a high probability of discussing mental health. Approximately 25% of all conversations among community members included language related to mental health (Fig. 1A). These conversations were then submitted to topic modeling to characterize prevalent themes when mental health terms were mentioned. This approach clusters words that occur in similar contexts and have similar meanings to identify common topics. The wheel in Figure 1B shows the most common topics in mental health conversations, where “diagnosis” emerged as the second largest topic, with 213 submissions/replies.

FIGURE 2. MENTAL HEALTH TERMS: PRE-DX VS POST-DX



To explore further the topic of diagnosis and mental health, we filtered conversations for users before (suggesting they had not yet received a diagnosis) and after (suggesting they were considering or had received a diagnosis) they contributed to MG subreddits. In other words, *pre-dx* conversations were those from users on mental health subreddits that predate their conversations in an MG subreddit, whereas *post-dx* included conversations across mental health subreddits after they joined an MG subreddit. A Pearson χ^2 test with Yate’s continuity correction showed significant differences in mental health term counts between groups (*pre-dx* vs *post-dx*) ($\chi^2 = 14.175$, $df = 2$, $P < .001$). *Pre-dx* conversations were higher in “anxiety” mentions (13.1% of submissions/replies). *Post-dx* conversations were higher in “depression” mentions (13.7% of submissions/replies). Post hoc analysis with Bonferroni correction indicated significant differences ($P < .001$) between groups in “depression” counts (Fig. 2).

FIGURE 3. EMOTIONAL WEIGHTS BY GROUP: PRE-DX VS POST-DX



We investigated emotional affect between the *pre-dx* and *post-dx* groups. This process involved mapping terms to emotional groups using the NRCLex database (a database of >27,000 words from the National Research Council Canada and NLTK WordNet synonyms).⁴ In this process, words can be weighted on 8 emotional dimensions. Figure 3 shows the proportion of words in each group relative to all words with emotional weights. *Pre-dx* statements were weighted mostly on “trust” words (16.9%) vs “sadness” words in *post-dx* statements (17.2%). We evaluated the most frequent words in *pre-dx* and *post-dx* statements. Symptom words (e.g., “muscle weakness”, “double-vision”) were more prevalent in *pre-dx* statements, whereas diagnosis words (e.g., “diagnosed”, “blood test”) were more common in *post-dx* statements.

CONCLUSION

This study used a proprietary NLP engine to analyze more than 25,000 submissions/replies from various online communities dedicated to MG and mental health. The goal of this analysis was to explore the potential for unique mental health profiles associated with members of the MG community at different stages in their diagnostic journey. *Pre-dx* conversations were defined by more conversations mentioning “anxiety” than for *post-dx*, where conversations included significantly more mentions of “depression”. One possibility is that anxiety mentions in the *pre-dx* group could be prompted by community members attempting to understand their symptoms. For conversations in the *post-dx* group, increased mentions of depression could be driven by the outcome of the diagnostic journey.

FUTURE DIRECTIONS

Future work should comprehensively evaluate these differences in emotional and mental health conversations to improve HRQoL for individuals living with MG. Many clinicians focus only on the physical symptoms caused by the disease; however, these findings can be valuable for elucidating the intersection of mental health and disease management, which typically is not explored using traditional approaches. Moving forward, these methods offer a time- and cost-effective approach to understanding patient perspectives.

DISCLOSURES

The study was funded by Horizon Therapeutics plc. A.J.A. and K.D. are employees of and hold stock in Horizon. E.Z., M.F., M.C., W.L., E.R.W., C.D., and M.P. are employees of and hold stock in TREND Community.



USING REAL-WORLD EVIDENCE TO UNDERSTAND THE DIAGNOSTIC JOURNEY OF PEOPLE LIVING WITH MYASTHENIA GRAVIS AND ITS IMPACT ON MENTAL HEALTH

Enming Zhang,¹ Maurice Flurie,¹ Monica Converse,¹ Anthony J. Amatucci,² Kristina Davidson,² Wei Li,¹ E. Robert Wassman,¹ Christopher DeFelice,¹ Maria Picone¹

¹TREND Community, Philadelphia, Pennsylvania

²Horizon Therapeutics plc, Deerfield, Illinois

INTRODUCTION: Understanding individuals' needs within a community necessitates active listening regarding the patient experience. A proprietary artificial intelligence (AI) engine was applied to social media conversations on mental health (MH) for individuals with myasthenia gravis (MG), an autoimmune disease that causes fatigue and skeletal muscle weakness. MG is associated with poorer MH, but it is not well understood how MH might be affected by diagnostic stage.

OBJECTIVE: To reveal differences in MH conversations before and after beginning the MG diagnostic journey.

METHODS: This AI platform used natural language processing to identify prevalent conversational terms/concepts. We evaluated 3 public MG subreddits with 6169 posts/replies from 528 active members from 2013-2022, and an additional 1800 posts/replies from these members across 12 MH-related subreddits.

RESULTS: AI identified conversations with a high probability (>0.80) of discussing 'mental health'; these were used in cluster analyses to evaluate topic prevalence. 'Diagnosis' was a frequent topic. Conversations were filtered for before and after users contributed to MG subreddits. Anxiety terms occurred more in 'pre-dx' statements (13.1%) but depression terms more in 'post-dx' statements (14.2%). Regarding affect, 'pre-dx' statements were weighted mostly on 'trust' words (16.9%) vs 'sadness' words in 'post-dx' statements (17.2%).

SUMMARY/CONCLUSION: We explored MG community member profiles before and after joining MG subreddits. Anxiety in group 'pre-dx' might reflect individuals trying to understand their symptoms, whereas depression in group 'post-dx' could be driven by the

diagnostic journey outcome. These findings can be invaluable for elucidating intersections of MH and disease management, which typically are not explored in traditional approaches.

REFERENCES:

1. Dresser L, Wlodarski R, Rezania K, Soliven B. Myasthenia gravis: epidemiology, pathophysiology and clinical manifestations. *J Clin Med.* 2021;10(11):2235. doi:10.3390/jcm10112235
2. Law C, Flaherty CV, Bandyopadhyay S. A review of psychiatric comorbidity in myasthenia gravis. *Cureus.* 2020;12(7):e9184. doi:10.7759/cureus.9184
3. Wisnu Wardhana IBG, Sri Wahyuni AA, Arimbawa K. Psychopharmacology in myasthenia gravis patients with focus on depression. *Int J Res Med Sci.* 2019;7(8):3230-3234. doi:10.18203/2320-6012.ijrms20193426
4. Mohammad S, Turney P. Crowdsourcing a word–emotion association lexicon. *Comput Intell.* 2012;29(3):436–465. doi:10.1111/j.1467-8640-2012.00460.x