Caregivers of individuals living with Hypoxic-Ischemic Encephalopathy (HIE) experience high levels of stress at the time of the birth or event and beyond, resulting in a substantial risk for mental health (MH) challenges. These MH difficulties are not fully characterized from the caregiver’s perspective.

Social Listening
Social listening is the process of using and analyzing real-world data (RWD) available on social media networks. Patients tend to share their experience within social networks, and the resulting data can provide information regarding symptoms associated with disease and disease impact on daily life.

METHODS
To evaluate the caregiver journey in HIE using a new method of real-world data collection: social listening.

CONCLUSIONS
TREND Community identified key MH and emotional wellness touchpoints along the HIE caregiver journey through an analysis of the HIE community’s real-world conversations taking place within online support groups.

RESULTS
We used Krystie to identify discussions in the early stages of the caregiver journey that were related to MH and isolated statements with a high-probability (>0.80) of discussing MH (approximately 10% of all statements in Early Stages). The touchpoints identified from the analyses included Birth or Event, Post-Event & Acute Care, Transition Home, Milestone Moments & Transitions of Care, Adulthood & Independence, and Loss (Fig. 1). Figure 2 depicts the frequencies for MH terms (e.g., anxiety, depression) in conversations for each subgroup after isolating high-MH statements.

To understand emotional impact more comprehensively, we characterized the emotional affect of statements by exploring the “emotional weights” of language in MH-related conversations in each group (Fig. 3).

Using Krystie, we isolated statements that were most related to MH (approximately 10% of all data available). Anxiety and stress mentions are relatively high in the More Severe group, whereas anxiety tends to be dominant in the In Between cohort (Fig. 4).