

Hypoxic Ischemic Encephalopathy

Community Voice Report



Prepared for Hope for HIE Support (Hypoxic Ischemic Encephalopathy) Parent Forum



Nervous System



Capturing Patient Experience Data

The Problem

Capturing patient experience data and applying it to the drug development and regulatory process is often lengthy, laborious, and expensive. This is further complicated for rare diseases where affected patient populations are typically small, heterogeneous, and widely dispersed.

The Solution

TREND analyzes years of real-world experience data shared within social networks to gain valuable insights into the community's perspective on living with rare disease. These data are de-identified and summarized into a Community Voice Report, which can then lead to Data Explorations and Health Initiatives.

Community Voice Report

The Community Voice Report follows the FDA's patient input Guidelines for Patient-Focused Drug Development meetings and aims to quantify disease burden, disease management strategies, and possible unmet needs.

Data Explorations

TREND Data Explorations further analyze existing social data to uncover deeper insights. Unlike the breadth of a Community Voice Report, Data Explorations examine a single topic and reanalyze the surrounding posts, comments, and feedback to better understand the community's interest.

Health Initiatives

TREND Community Health Initiatives bring community members together on the TREND Community™ platform to collectively track specific data and explore potential solutions to address an identified unmet need.

"The TREND report was invaluable in helping us define the questions and multiple-choice answers that should be included in our Externally Led Patient Focused Drug Development Meeting last June."

*—Kyle Bryant, FARA, rideATAXIA Founder/
Program Director*

TREND Community categorizes diseases using the Genetic and Rare Diseases (GARD) Information Center database.



Cancer



Congenital/Genetic



Viral Infections



Musculoskeletal



Skin Diseases



Nervous System



Metabolic



Blood Diseases



Endocrine



How It Works

All of our projects start with community engagement. Due to the unique difficulties of rare and chronic disease, many groups have created social networks online to support and validate each other. In these groups, community members are able to tell stories, promote advocacy, and share advice for managing symptoms, navigating the health care system, and living with a rare or chronic disease. We connect with individuals and leaders in these communities to learn about their illnesses, understand the current state of medical knowledge, and determine how our partnership can best address their unmet needs.

Once we have established a relationship with the community and gained consent, we download the deidentified data from these social media streams. These data are run through our analytics engine, named Krystie after the dear daughter of one of our community members. Krystie quickly analyzes vast amounts of data from years' worth of community discussion. Analysts manually code a sample of the data to validate the algorithms and train the engine to identify deeper insights (for example, to detect whether the speaker is a patient or a caregiver). This analysis culminates in a custom Community Voice Report.

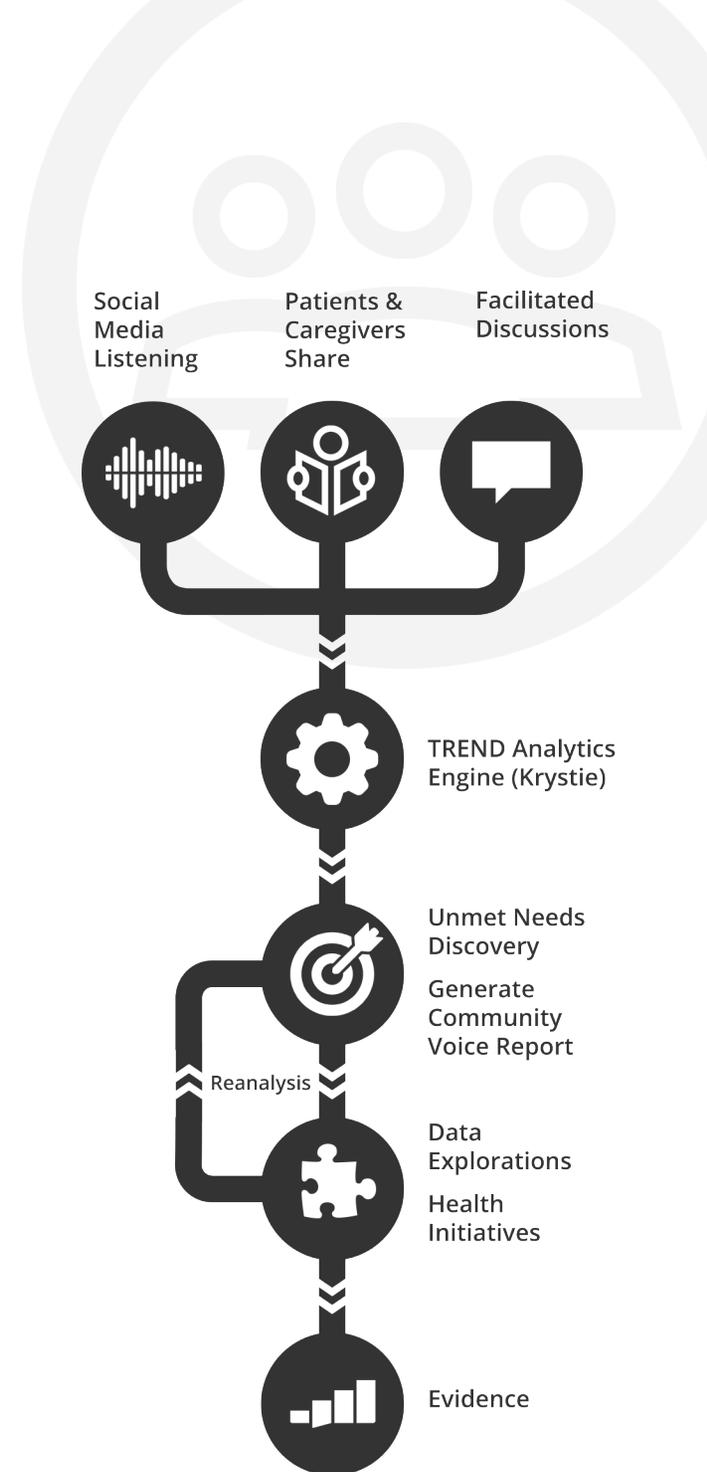
These Community Voice Reports are shared with the community free of charge, and our industry stakeholders have the opportunity to license the data for projects that address unmet needs and improve quality of life. These insights may be used to design Data Explorations or Health Initiatives.

Industry Stakeholders use TREND data to:

- Establish disease natural history
- Identify unmet therapeutic needs
- Understand quality of life issues
- Design better clinical trials
- Build a case for patient-centered regulatory approvals

Community Stakeholders use TREND data to:

- Inform medical and support teams
- Educate family members
- Catalyze research
- Spread awareness and advocacy



Overview

Hypoxic Ischemic Encephalopathy (HIE) is a neonatal brain injury caused by oxygen deprivation or reduced blood flow to the brain. HIE can occur before, during, or after the birth process, and can be caused by a variety of complications (including, but not limited to, umbilical cord complications, placental or uterine complications, blood clotting disorders, extremely low maternal blood pressure, trauma during delivery, cardiac arrest, or near SIDS events). There is a wide range of outcomes associated with HIE, including cerebral palsy and other neuromuscular issues, seizure disorders, difficulty breathing and swallowing, vision and hearing issues, gastrointestinal issues, and cognitive or developmental delays.¹ Prevalence estimates vary from 2 to 9 in every 1,000 live births.²

In 2011, the non-profit organization Hope for HIE created a private Facebook group for individuals and caregivers in the community to connect, share advice, and support one another. In May 2019, TREND analyzed and compiled this conversation data. The following report provides perspectives and insights on living with Hypoxic Ischemic Encephalopathy.

¹ What Can HIE Cause? (n.d.). Retrieved June 28, 2019, from https://www.hopeforhie.org/what_can_hie_cause
² Wu, Y., MD, MPH. (2019, April 19). Clinical features, diagnosis, and treatment of neonatal encephalopathy. Retrieved June 28, 2019, from <https://www.uptodate.com/contents/clinical-features-diagnosis-and-treatment-of-neonatal-encephalopathy>

Facebook Group Stats

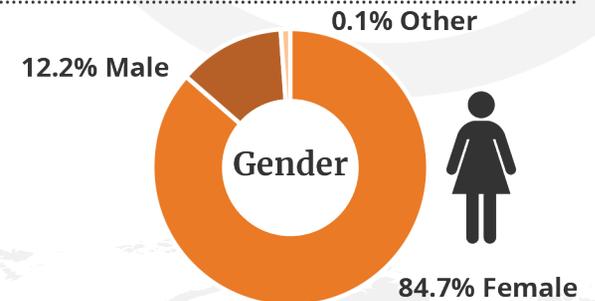
Hope for HIE Support Parent Forum

As a key component of the Hope for HIE foundation outreach networks, this is a private discussion group for parents, and approved immediate family members, of children diagnosed with Hypoxic Ischemic Encephalopathy (HIE).

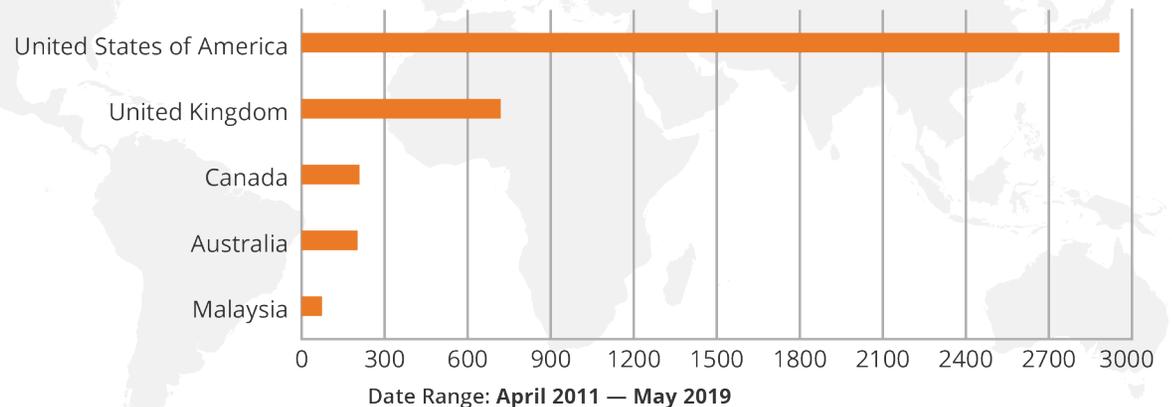
4,637
Members

43,213
Posts

513,659
Comments



45%
Ages 25-34



Disease Burden

In this community, parents and caregivers express the symptoms and burdens of HIE through stories, questions, and discussions. From these conversations, we have identified the predominant disease burdens. The results of this analysis are illustrated on the right.

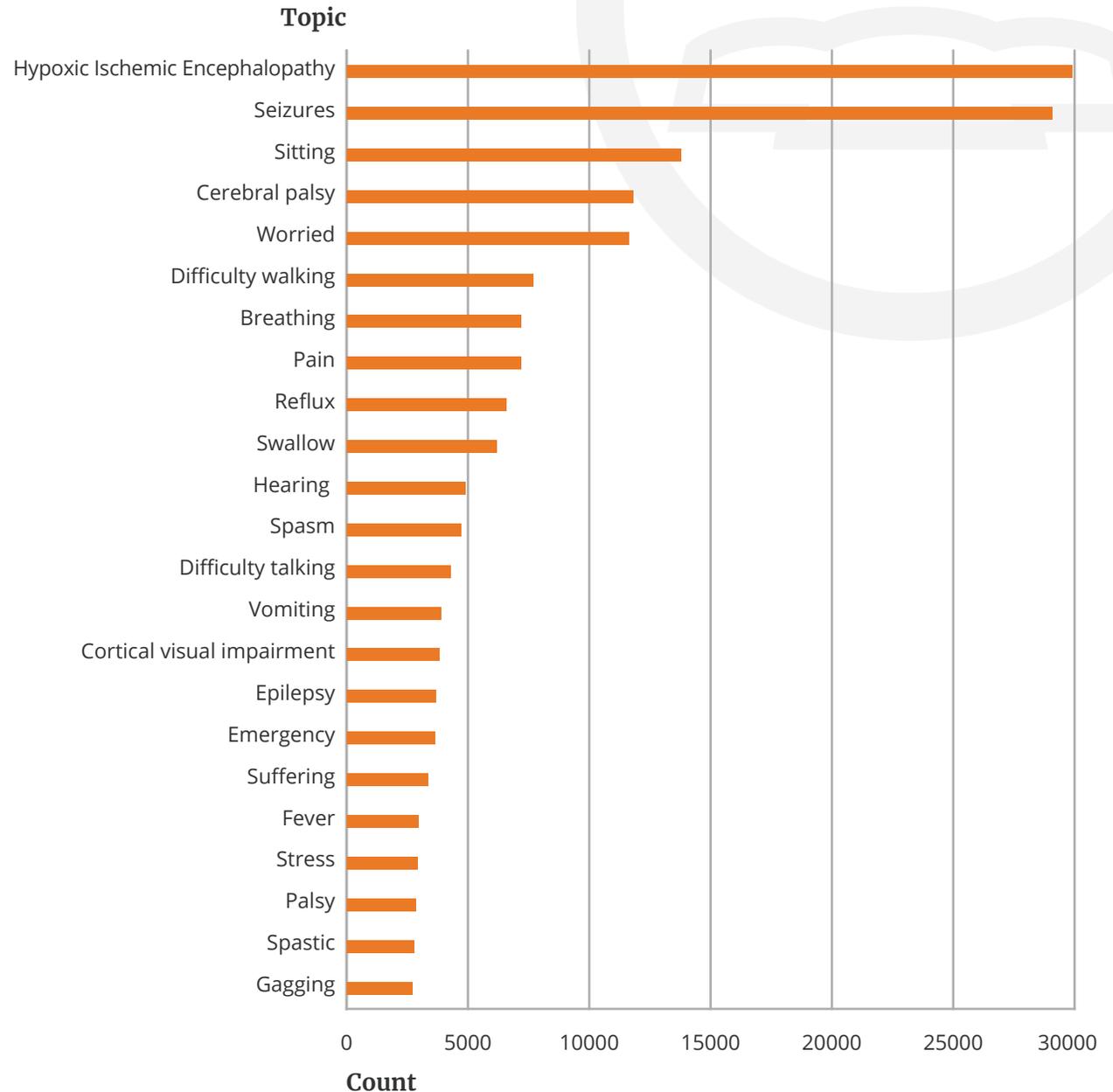
Given the range of outcomes and symptoms associated with HIE, we have identified five major categories of burden.

These include:

- Seizures and Epilepsy: 32,735
- Mobility: 32,229
- Breathing and Swallowing: 18,558
- Worry and Anxiety: 14,205
- Gastrointestinal issues: 10,464

“I worry the most about how my son will make his way in the world. Between physical challenges, significant speech challenges, and then society making assumptions about his intelligence and capabilities, he’s got a lot of obstacles to overcome.”

—Community Member

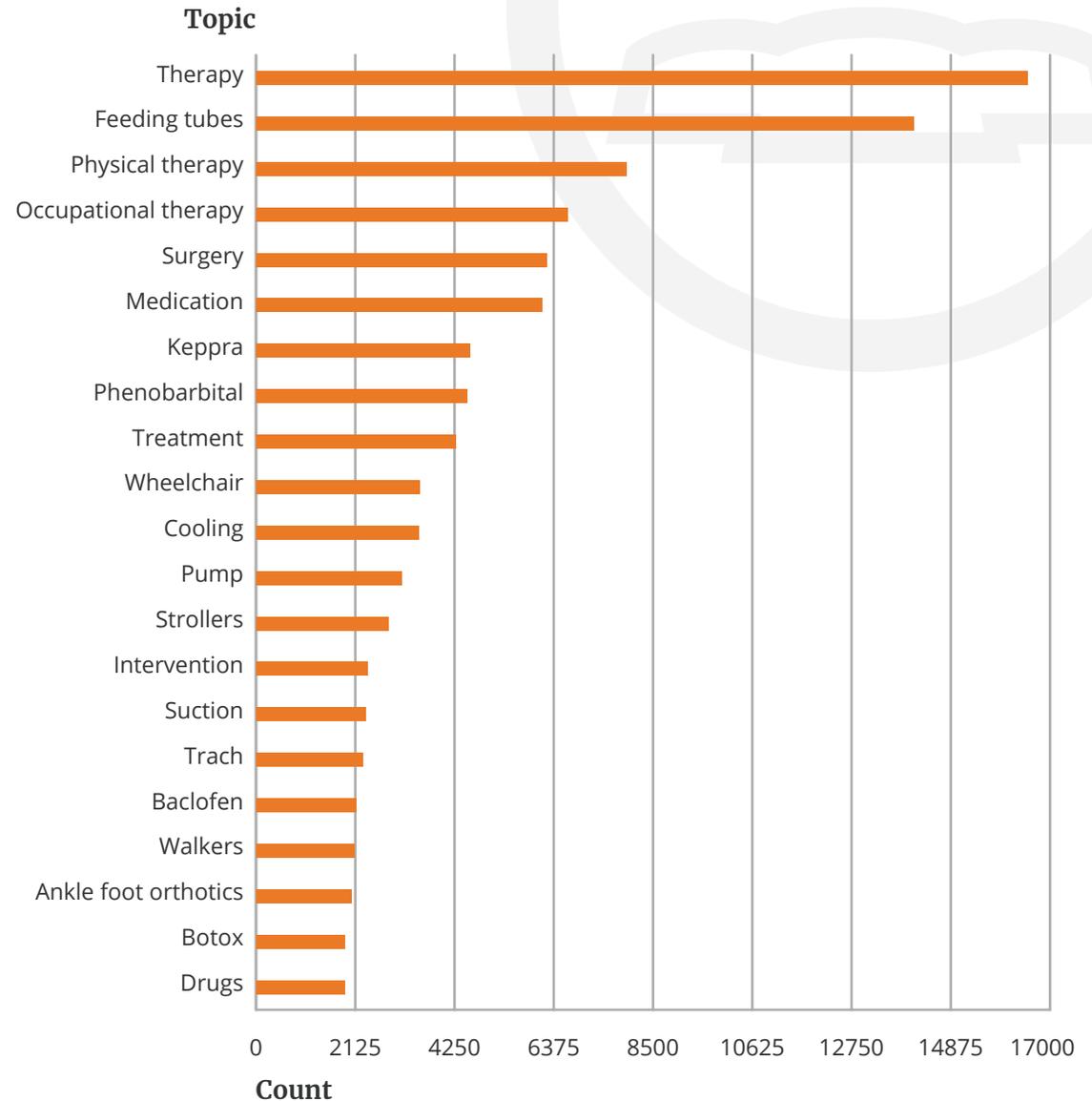


Disease Management

As there is no cure or specific treatment for Hypoxic Ischemic Encephalopathy, caregivers employ a combination of management strategies. Advice and anecdotes about these methods are a major topic of conversation in the community. The results of our disease management analysis are illustrated on the right.

Therapy (16526) is the most frequently mentioned treatment strategy. Common therapies include *physical therapy* (7937) and *occupational therapy* (6666). These conversations often include commentary on the importance of early intervention therapies, difficulty finding and paying for therapies, and other related issues.

Cooling (3489), also known as therapeutic hypothermia, is one of the most important treatments for HIE, and has been proven to reduce outcomes of mortality or major neurodevelopmental disability.³ These conversations often include comments about individual experience with cooling or discussion of recent medical research on the subject.



³ Jacobs, S. E., Berg, M., Hunt, R., Tarnow-Mordi, W. O., Inder, T. E., & Davis, P. G. (2013, January 31). Cooling for newborns with hypoxic ischaemic encephalopathy. Retrieved June 28, 2019, from <https://www.ncbi.nlm.nih.gov/pubmed/23440789>



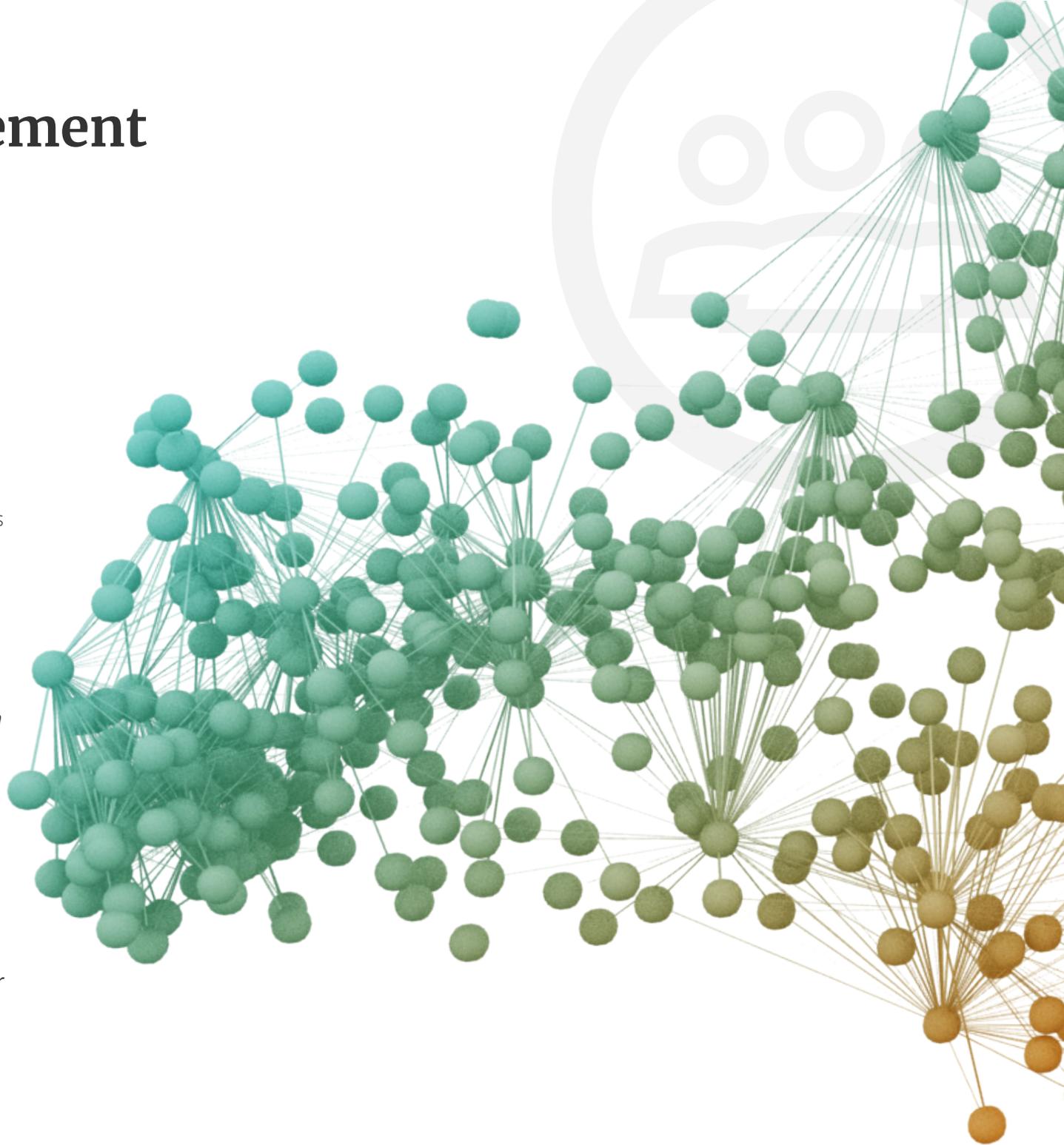
Disease Management

Feeding tubes (14073) also appear regularly in the community conversations. Feeding tubes can be used to address both gastrointestinal issues and difficulty breathing and swallowing.

General terms related to *medication* (6122) and *drugs* (1891) appear 8,013 times. Community members specifically mention *Keppra* (4588) and *Phenobarbital* (4517), which are used to treat seizure disorders, and *Baclofen* (2144), which is used to treat muscle symptoms such as spasms, pain, and stiffness.

“When we found other parents going through the same thing as our child was in the NICU, I felt hope for the first time. Even though we didn't know if our child was going to live or die, not being alone made all the difference in the world. As my son grew, it helped me find a courage I didn't know I had inside me and empowered me to advocate for his needs.”

—Community Member



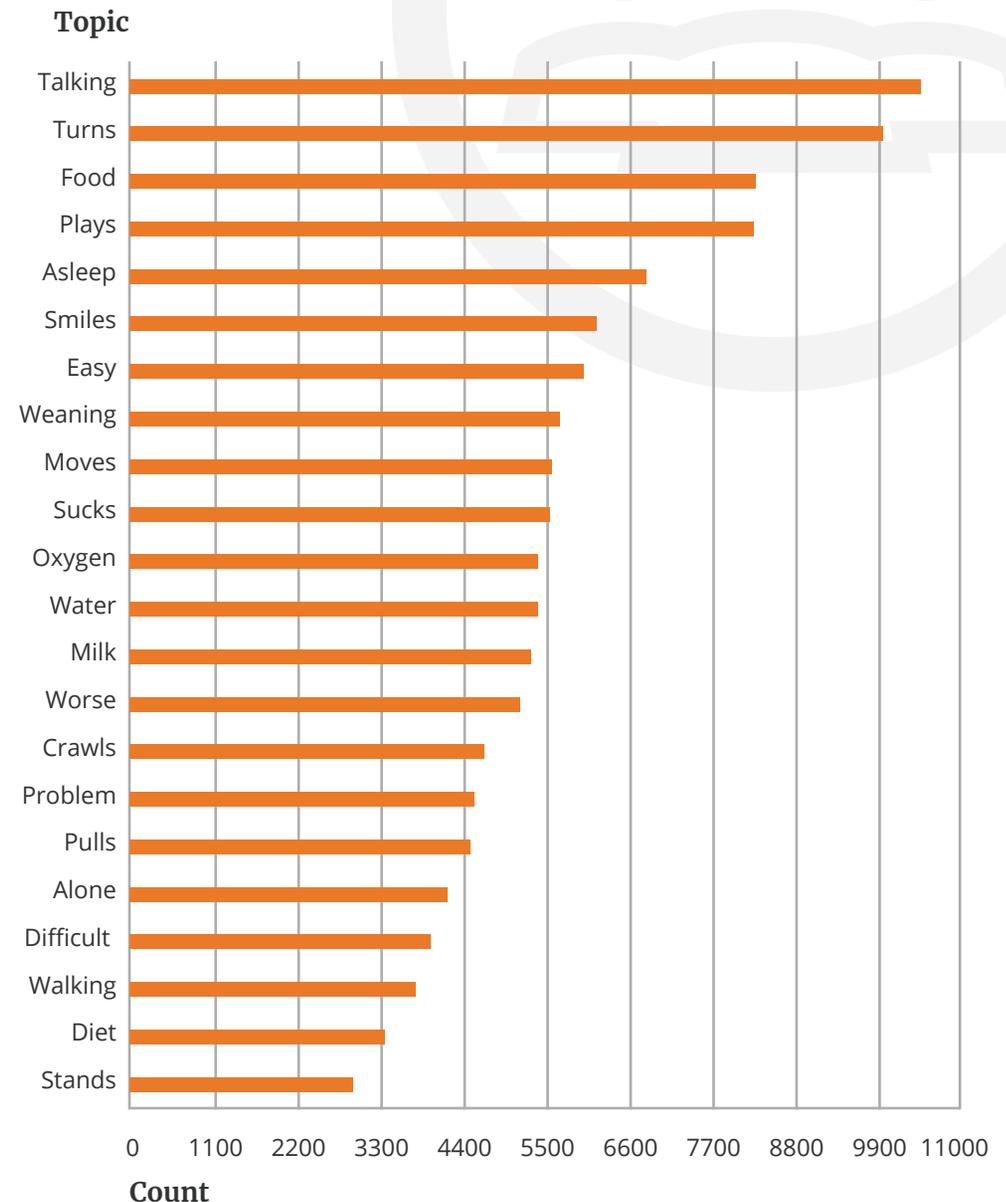
Significant Terms

The graph on the right illustrates significant terms that appear throughout community conversations. The frequent use of these terms indicates their importance; however, they require further investigation to determine how they relate to the symptoms and management of Hypoxic Ischemic Encephalopathy.

Terms related to *talking* and *speech* appear 10,490 times in the community conversations. While some of these comments refer to conversations with care providers and community members, others highlight speech as a major developmental hurdle for children with HIE. Caregivers share stories and updates about verbal abilities and discuss various therapies and alternative communication strategies.

Like speech, many individuals with HIE experience different degrees of mobility. Terms related to movement, such as *plays* (8273), *moves* (5596), *crawls* (4696), *walking* (3788), and *stands* (2955), are mentioned regularly.

Given the prevalence of eating and gastrointestinal issues, conversations related to diet and nutrition figure heavily into the community conversations. *Food* (8298), *milk* (5320), and *diet* (3382) all appear frequently.



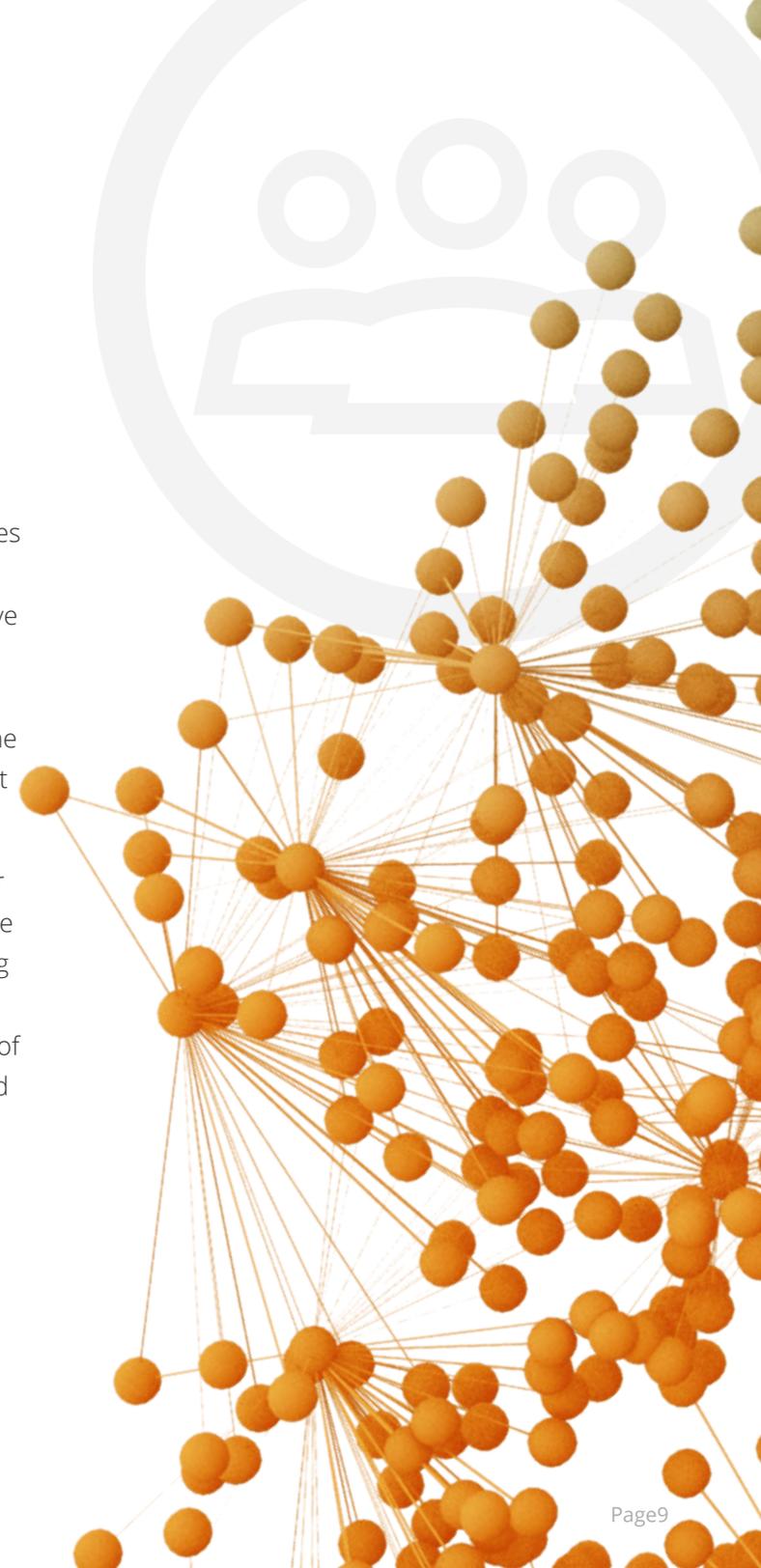
Discovering Unmet Needs

Our conversation analysis indicates several areas of unmet need in the HIE community. Community members regularly express the need for further medical research, education, and awareness to support existing patients and prevent further incidents from occurring. These conversations highlight several key areas of interest, including, but not limited to, hypothermia therapy or cooling, early intervention therapies, accurate assessment, and understanding the initial injury.

As mentioned in the disease management section of this report, cooling or therapeutic hypothermia is an important treatment development for individuals and caregivers impacted by HIE. Cooling is now considered a standard of care for eligible infants; however, not all hospitals are properly equipped, which is problematic because cooling is considered most effective within the first six hours. Community members highlight the need for further research to continue improving care standards and better understand the long-term efficacy of therapeutic hypothermia.

Similarly, community members regularly emphasize the importance of early intervention therapies. Therapy is the most frequently discussed treatment strategy in this community, and many individuals share questions and advice about different therapeutic practices. Recent research indicates that, due to neuroplasticity, various early intervention therapies can dramatically improve developmental outcomes. Many individuals stress the importance of improving research and education on this topic, especially given the emotional upheaval and uncertainty of the first few years with HIE.

Many caregivers mention their desire to better understand the circumstances surrounding the initial brain injury. A few also mentioned having *post-traumatic stress disorder* (696 mentions) or similar emotional responses to the trauma of the birth and moment of injury. Discussing and interpreting what happened within the safety of the group seems to be an important way of processing and gaining acceptance of the events and outcomes.



Data Explorations and Health Initiatives

This Community Voice Report is the first step in understanding the research implications of the conversations happening on social media about living with Hypoxic Ischemic Encephalopathy. Using these findings as a starting point, TREND Community can continue to work with this data and the HIE community to determine priorities for further research.

Building on the breadth of this report, a Data Exploration can examine the existing conversation data to better understand significant topics and areas of interest. Using this evidence, a Health Initiative could then be designed to address the community's specific needs and accelerate research. We have detailed a few possibilities below.

Given the interest and importance of early intervention therapy, we recommend an initial Data Exploration to better understand the conversations about this topic. In addition to expressing their interest in early intervention research, community members regularly share anecdotal reports about the effectiveness of various therapies in the months and years after their child's initial injury. By conducting a thorough examination of the existing conversation data, we could identify the

common intervention strategies and how they correlate to the injury, severity, and outcomes.

The conversations also highlight a desire for better understanding and assessment of the potential outcomes associated with HIE. Despite the vast array of symptoms associated with HIE, the current diagnostic tool, the Sarnat Scale, only offers three classifications of severity and is based on how the baby appears after birth or injury.⁴ Considering that the impact of HIE only becomes apparent as a child develops, many caregivers express interest in a more thorough assessment strategy. A Data Exploration or Health Initiative could be designed to investigate these trends and inform the development of assessment tools that better inform the community needs.

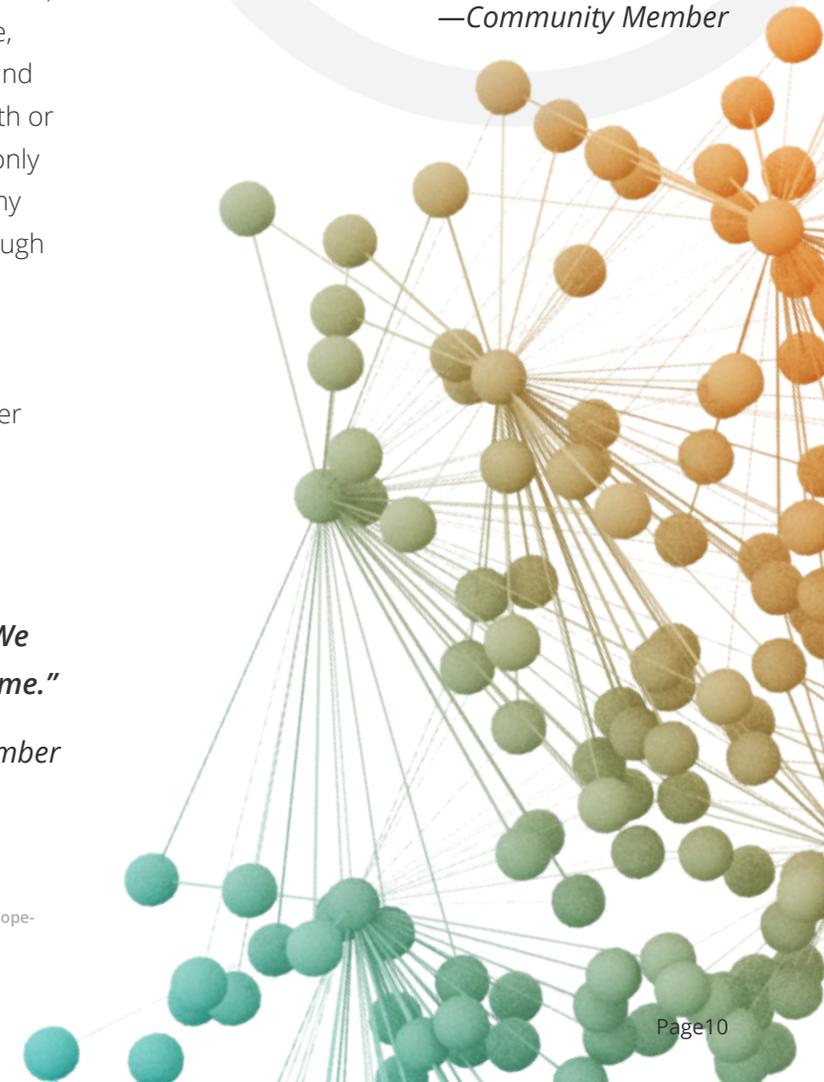
"With every HIE being different, I don't know how it will affect my child's life. We just have to take things one day at a time."

—Community Member

"HIE results in a huge variable of outcomes. No two injuries are alike and therefore no two outcomes will be alike. But each and every life is valuable, regardless of outcome."

—Community Member

⁴ What is HIE? (n.d.). Retrieved June 28, 2019, from <https://www.hope-forhie.org/whatishie>



Data Explorations and Health Initiatives

Developmental challenges related to speech and mobility are a significant topic of interest in this community. A Data Exploration could be designed to analyze the commonalities and differences among these experiences and track the efficacy of various treatment strategies, including therapies, operative procedures, medical devices, and medications.

Given the range of outcomes, many of the symptoms highlighted in our disease burden analysis invite further investigation. Data Explorations or Health Initiatives could be designed to specifically analyze the community conversations surrounding seizure disorders, breathing difficulties, and other major areas of concern.

Finally, we recommend a Data Exploration to investigate the high reports of emotional and psychological distress, including *worried* (11642), *stress* (2907), *anxiety* (2563), *irritable mood* (1745), *emotional* (1386), *post-traumatic stress disorder (PTSD)* (696), and *depression* (510). This research could explore the lasting impact and trauma of the birth or initial injury on both patients and caregivers. Building on this evidence, a Health Initiative could be designed to monitor these symptoms and experiences over time. These projects have the potential to inspire awareness, education, and support for this unmet need.

Like this report, future Data Explorations and Health Initiatives could be used to better educate medical professionals and address these unmet needs. Through this partnership, TREND Community hopes to accelerate these findings and improve the quality of life for individuals and caregivers living with Hypoxic Ischemic Encephalopathy.

“Being able to connect with other parents who understand the daily life we live is just invaluable. It helped me find the strength to not only survive but to thrive. It helped me become an advocate. It helped me become a better me.”

—Community Member



About TREND Community

Founders

TREND Community™ was founded by the parents of a child with Prader-Willi Syndrome who understand the needs of the rare and chronic disease community.

Our mission is to improve the quality of life for everyone living with rare and chronic disease.

Security

TREND secures all social data with state-of-the-art, private cloud servers. Our security practices comply with current HIPAA, FDA, and GDPR guidelines.

Disclaimer

The researchers who prepared this report are not doctors, are not providing medical advice, and are only reporting what was said in the online conversations.

IRB Exemption Status

Western Institutional Review Board determined that this study is exempt under 45 CFR § 46.104(d)(4), because the aim of the research is to collect de-identified information from social media posts to better understand disease

burden, disease management strategies, quality of life, and the unmet needs of patient communities living with rare and chronic diseases. The research is not FDA-regulated nor classified, does not involve prisoners, and is consistent with the ethical principles of the Belmont Report.

Quotes

All quotes were provided by consenting community participants through one-on-one interviews or online focus groups conducted on the TREND Community™ platform. Names are not included to protect participant privacy.

Data Ownership

Ownership of public posts or conversations from other social media platforms shared with TREND for analysis are subject to the social media platform's privacy policy, terms of service and other applicable policies. Participants who share data and experiences on the TREND Community™ platform give their consent for TREND to analyze it. TREND Community owns the results of our analysis and all other data and output that we produce including our Community Voice Reports.

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