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Assessing Social Media Sentiment to Analyze Patient, Caregiver and Healthcare Professionals Experience With Immunoglobulin (IVIG and SCIG) for Chronic Inflammatory Demyelinating Polyradiculopathy (CIDP)

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BACKGROUND

- Intravenous immunoglobulin (IVIG) is first-line and maintenance therapy option for CIDP.[1]
- IVIG is associated with improved function and QoL in patients with CIDP; however, it is also associated with burden related to infusions, adherence and accessibility challenges.[2,3]
- SCIG offers an alternative long-term treatment option and has demonstrated effectiveness in studies; however, its utilization may be influenced by patient preferences, logistics and insurance considerations.[4]
- Social media offers a valuable complement to traditional data sources by capturing unfiltered and unprompted perspectives from patients, caregivers, and HCPs on treatment experiences, access barriers, QoL, and support challenges.[5,6]

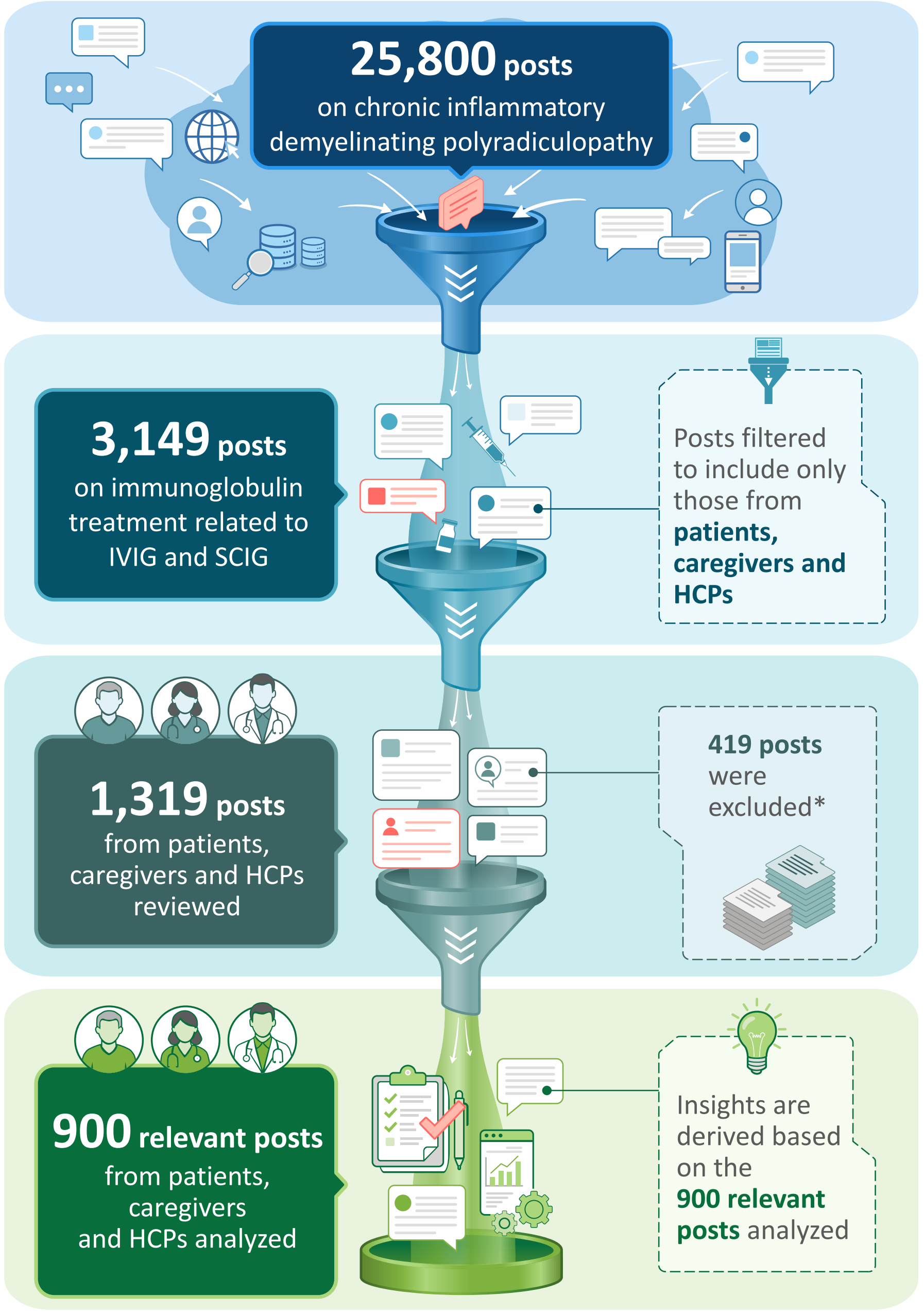
OBJECTIVE

- To categorize and quantify social media posts related to the use of IG in CIDP, from patients, caregivers, and HCPs.
- To analyze their expressed sentiments and generate insights that inform research and patient engagement tactics.

METHODS

- Social media posts were identified using predefined keywords related to CIDP and IG treatment (IVIG and SCIG) via Brandwatch (platforms include X, Reddit, YouTube, Bluesky, Forums, etc.).
- Posts collected between September 2023 to August 2025 were categorized by stakeholder type (patient, caregiver, HCP) and analyzed using GenAI algorithms with manual validation.
- Relevant posts were categorized into 5 key topics: 'treatment outcomes', 'treatment experience', 'treatment awareness', 'treatment access' and 'treatment support'.
- Out of 1,319 posts from patients, caregivers, and HCPs, 900 posts were analyzed **(Figure 1)**.
- Majority of the posts were related to IVIG (n=858) and a fewer number of posts mentioned SCIG (n=47).

FIGURE 1 Data extraction and filtration methodology



25,800 posts on chronic inflammatory demyelinating polyradiculopathy

3,149 posts on immunoglobulin treatment related to IVIG and SCIG

Posts filtered to include only those from **patients, caregivers and HCPs**

1,319 posts from patients, caregivers and HCPs reviewed

419 posts were excluded*

900 relevant posts from patients, caregivers and HCPs analyzed

Insights are derived based on the **900 relevant posts** analyzed

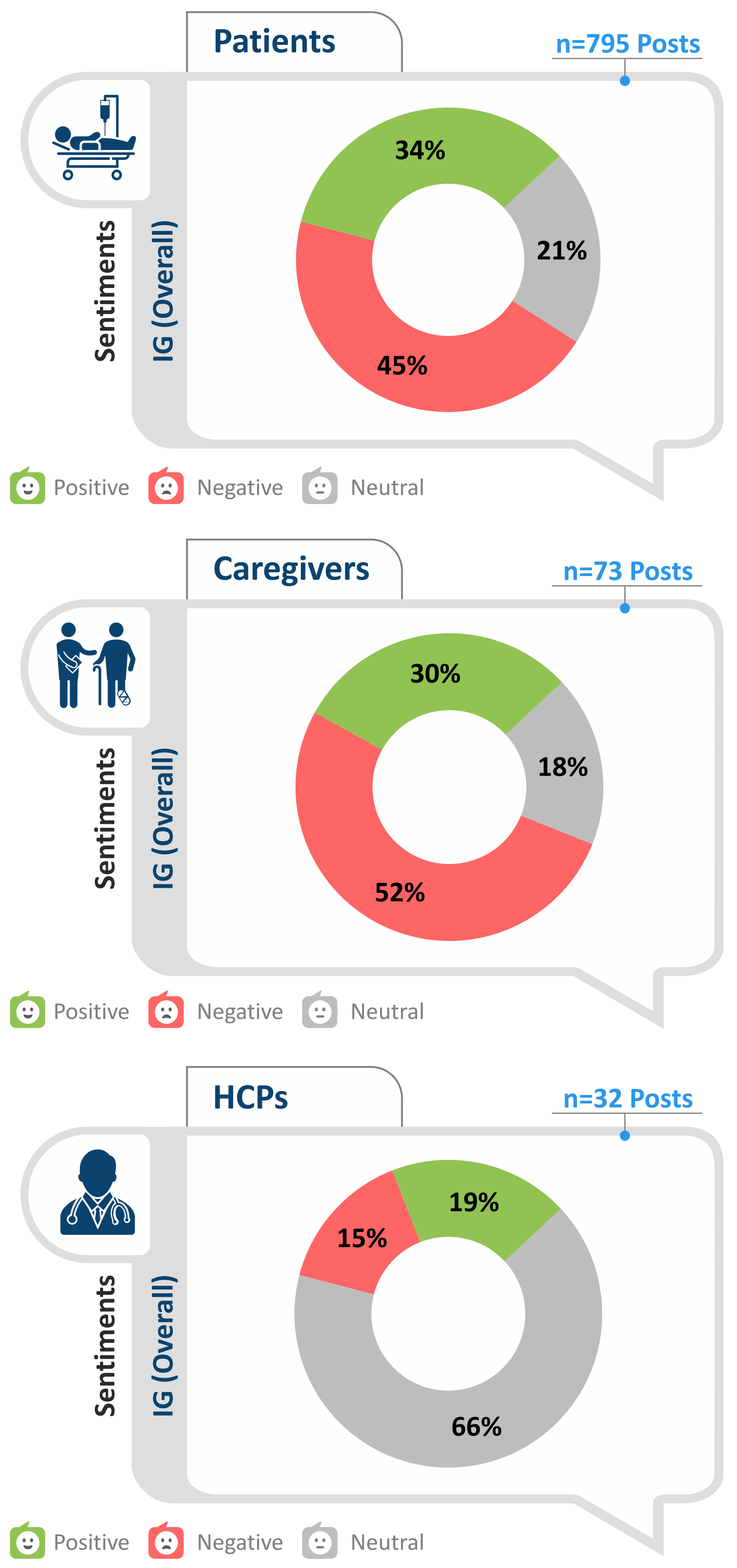
***Exclusion criteria:** Posts that were not relevant to the research objective (i.e., general mentions, pharmacy advertisements, content not specifically related to IVIG, SCIG, or CIDP, and content from stakeholders other than patients, caregivers, and healthcare professionals) were excluded from the analysis. In addition, posts authored by patients who contributed more than 20 posts during the study period were excluded to prevent over-representation and potential data skew.

RESULTS

Overall posts volume and sentiments

- Of the total posts, majority were from patients (n=795, 88%) with relatively fewer posts from caregivers (n=73, 8%) and HCPs (n=32, 4%).
- Patient and caregiver posts predominantly reflected negative sentiment towards IG treatment, whereas the HCP posts were largely neutral and informational in tone **(Figure 2)**.
- Positive sentiment among patients and caregivers was largely driven by regained functioning and disease stability, while negative sentiment was driven by inconsistent or partial treatment effectiveness, side effects and barriers to treatment access **(Figure 2 and 4)**.

FIGURE 2 Overall post volume and sentiments



Positive: Posts that express satisfaction related to IG in CIDP such as effective symptom management, improved QoL, ease of access, and convenient administration. These posts often highlight favorable individual experiences with the treatment.

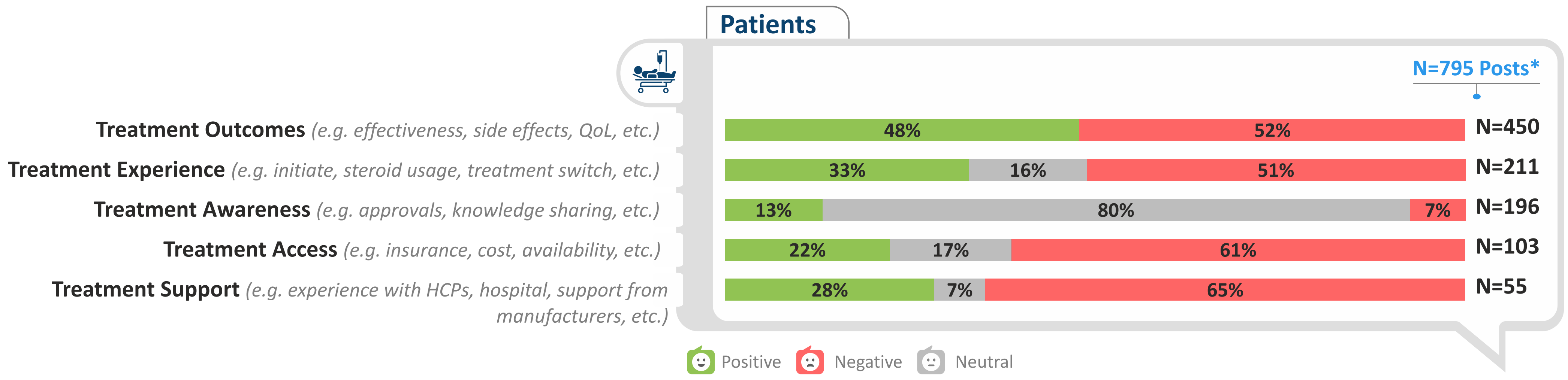
Negative: Posts that convey dissatisfaction related to IG in CIDP such as insurance hurdles, high out-of-pocket costs, side effects, and lack of effective symptom relief. These posts reflect negative sentiments or concern regarding the treatment.

Neutral: Posts that present information or questions about IG in CIDP without expressing clear positive or negative emotions. These may include trial data, general discussions, news, educational content, or individual experiences shared in a descriptive, factual manner without a strong emotional tone.

Patient posts topics volume and sentiments

- A greater volume of patient posts were associated with treatment outcomes, experiences, and awareness, whereas posts focusing on treatment access and support were fewer **(Figure 3)**.
- Within patient posts, sentiments varied widely, with treatment outcomes showing both strong positive (48%) and negative (52%) sentiments **(Figure 3)**.
- Posts related to treatment access and treatment support more frequently reflected negative sentiment (61% and 65%, respectively; **Figure 3)**.

FIGURE 3 Topic volume and sentiments



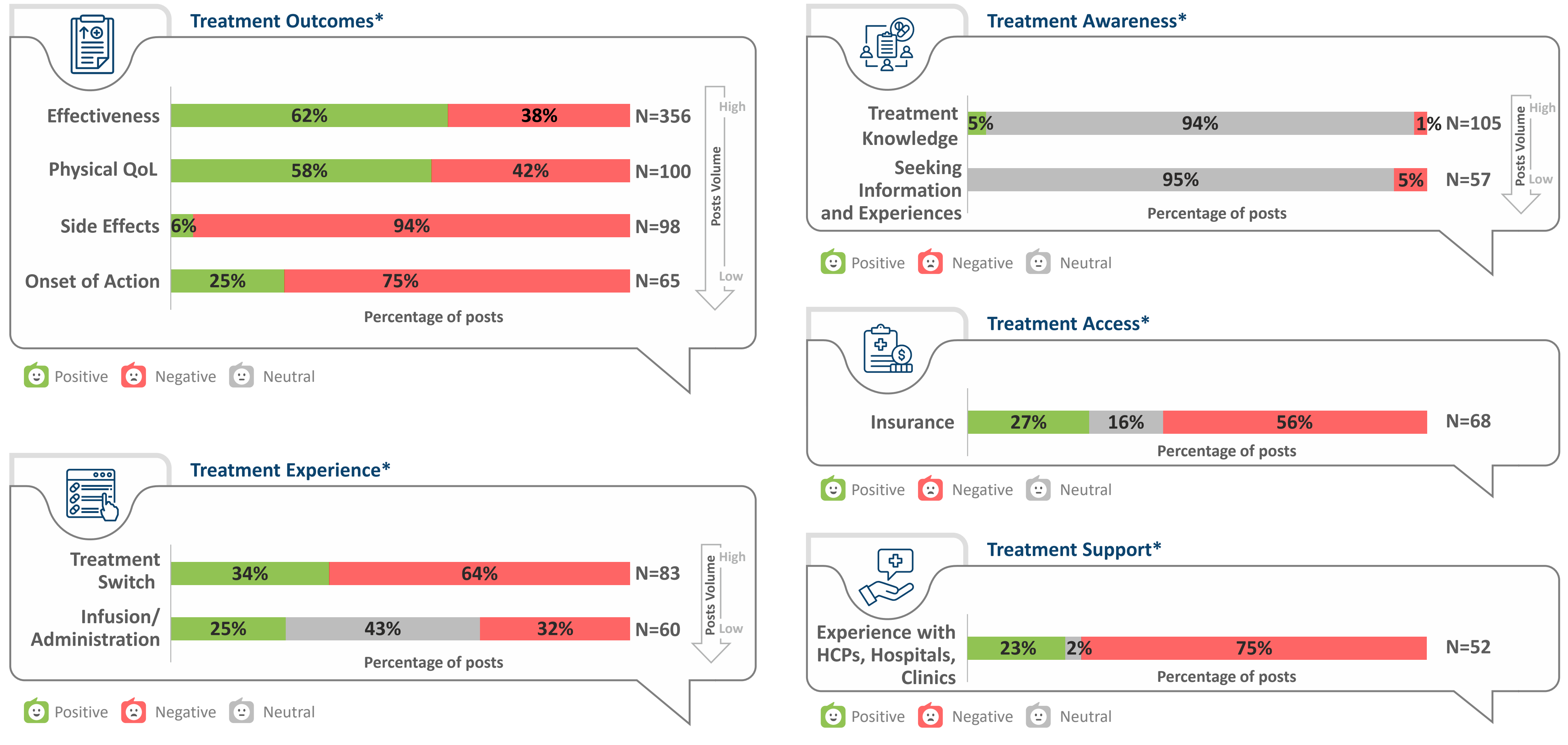
Time Frame: 01 Sep 2023 – 31 Aug 2025; Language: English; Source: Brandwatch
*One post can contain mentions of multiple topics, hence addition of posts may exceed total N size and isn't mutually exclusive.

Insights derived from social media discussions

From patients' posts

- Patients often described IG therapy as stabilizing, leading to improvements in strength, mobility and daily function. However, long-term effectiveness was perceived as variable due to the absence of sustained or complete improvement in some patients. **(Figure 4)**.
- Many patients reported side effects with IG therapy, such as headaches, infusion reactions, and severe systemic reactions, highlighting the need for better tolerated options.
- Patients also reported that IVIG often had a delayed onset of action, gradually appearing after infusions, with effects wearing off near the next infusion cycle **(Figure 4)**.
- Patients frequently mentioned switching from IVIG to other treatment options such as SCIG and immunosuppressants based on HCP recommendations often due to inadequate symptom control, or side effects **(Figure 4)**.
- Patients discussed IVIG and SCIG pathways online, educating each other on treatment expectations while keeping the tone as neutral.
- Patients discussed challenges with insurance coverage and prior authorization processes, citing restrictive coverage criteria, repeated denials, and delays **(Figure 4)**.
- Many patients reported inadequate and delayed support, with only a few receiving adequate support from HCPs and infusion teams **(Figure 4)**.

FIGURE 4 Subtopic volume and sentiments



*A post can be tagged under multiple topics, subtopics and may carry multiple sentiments, leading to total counts exceeding 100%. Therefore, topics and subtopics are not mutually exclusive.

From caregivers' posts

- Caregiver posts predominantly expressed negative sentiment, driven by side effects, financial hurdles, and insurance challenges.
- Caregivers shared loved ones' treatment outcomes, reporting favorable response to IG while citing noticeable improvement and stabilization.
- Overall, caregivers highlighted difficulties with treatment access and the need for improved support from HCPs.

From HCPs' posts

- HCP posts were limited, and predominantly neutral.
- Discussions were mainly focused on treatment usage, effectiveness and comparison with newer therapies.

KEY TAKEAWAYS

While patient discussions on social media reflect positive sentiment toward the efficacy of IG therapies and their impact on quality of life, a high share of negative sentiment persists around delayed onset of action, side effects, and access challenges

Caregiver and HCP discussions are limited in comparison to patient discussions. Caregiver sentiment are largely centered on treatment burden and access challenges, whereas HCP conversations are predominantly clinical and informational

From a patient perspective, the key opportunities lie in improving management of treatment-related side effects, enhancing access, and strengthening treatment support

LIMITATIONS'

- This study was limited to English-language social media posts only which restricts the findings to interactions conducted in English.
- Demographic details (age, gender, and location) was unavailable for the majority of patients, HCPs, and caregivers; therefore, findings could not be analyzed by demographic subgroups.
- The analysis is limited by the small number of HCP posts, which restricts the depth and diversity of insights from HCPs.

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ABBREVIATIONS

CIDP: Chronic inflammatory demyelinating polyradiculoneuropathy; HCPs: Healthcare professionals; IG: Immunoglobulins; IVIG: Intravenous immunoglobulin; QoL: Quality of life; SCIG: Subcutaneous immunoglobulin.

DISCLOSURES

Tom Hughes, Swapna Karkare, Anthony Carmine Colavecchia, and Lu Shi are employees of argenx. Divya Nagpal, Aditya Batra, Yash Verma, and Aishwarya Nair are employees of ZS Associates and serve as paid consultants for argenx.

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REFERENCES

1. Allen JA, et al. *J Neurol Sci.* 2020;408:116497.
2. Almasri A, et al. *Can J Neurol Sci.* 2025;2:1–7.
3. Hubsch A, et al. *Patient Prefer Adherence.* 2025;19:3999–4019.
4. Ramzi A, et al. *Neurol Sci.* 2024;45(11):5213–5230.
5. Murray C, et al. *Digit Health*. 2024;10:20552076241251715.
6. Kanchan S, et al. *Cureus*. 2023;15(1):e33737.

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