Social Media Conversations on Immune Checkpoint Inhibitors: Treatment Experiences, Safety, Access, and Patient Perspectives

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Background

- Immune checkpoint inhibitors (ICIs) target programmed cell death protein 1 (PD-1), programmed death-ligand 1 (PD-L1), and cytotoxic T-lymphocyte-associated protein 4 (CTLA-4) pathways to enhance anti-tumor immunity, with efficacy across hematologic and solid malignancies[1,2]
- Next-generation ICIs (e.g., T-cell immunoglobulin and mucin-domain containing-3 [TIM-3], lymphocyte-activation gene 3 [LAG-3], T-cell immunoreceptor with Ig and ITIM domains [TIGIT], V-domain Ig suppressor of T-cell activation [VISTA]) are expanding the therapeutic landscape[2,3]
- However, challenges persist in response variability, resistance, and immune-related adverse events (irAEs), reflecting real-world complexity[2]
- Social media listening provides real-time, unsolicited insights into patient experiences, tolerability, and unmet needs beyond traditional data sources

Objective

To characterize real-world social media conversations on immune checkpoint inhibitors, capturing perspectives on awareness, treatment experience, tolerability, access, healthcare navigation, psychosocial impact, and unmet needs

Methodology

Framework and Sub-Theme Definition

- 15 sub-themes were defined to capture awareness, treatment decision-making, access, tolerability, daily life impact, mental health, and long-term management over 5 themes (Figure 1)
- Boolean queries were iteratively refined for topic and sub-themes

Social Media Data Capture

- Retrospective social media data was captured using Talkwalker Social Listening & Analytics Platform across public platforms including X, Facebook, YouTube, Reddit, blogs, forums, and news/press sources
- Global social media posts relating to the topic between January 2025 and January 2026 were identified
- All publicly available posts on immune checkpoint inhibitors were included
- Unrelated content (ads, spam, duplicates, and other unrelated posts) were excluded
- Only public, de-identified social media data was collected; individual-level data was not collected/linked

Data Analysis

- Descriptive analysis was performed across post volume, platform, geography, and gender distribution.
- Sentiments from social media posts were classified into positive/neutral/negative via AI algorithms and validated on a random sample (n = 200–300) by two reviewers (Cohen's kappa = 0.78 indicating substantial agreement)
- Thematic analysis was performed to identify key narratives, concerns, and sentiment drivers within each theme
- Study was conducted in compliance with General Data Protection Regulation (GDPR)
- Since the study involved collection and analysis of publicly available social media posts, ethics approval was not required (as per BPS 2021 Code of Human Research and AoIR 2019 Ethical Guidelines 3.0)

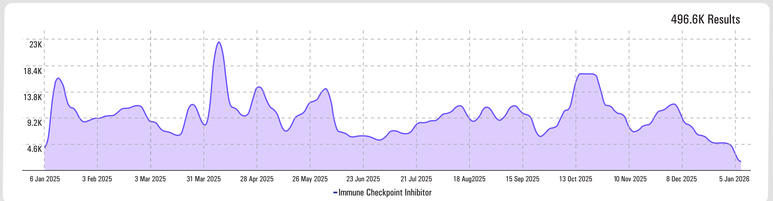
A	B	C	D	E
Awareness, Understanding & Information	**Help-Seeking, Diagnosis & Access**	**Treatment Decision-Making & Journey**	**Burden, Quality of Life & Support**	**Prevention, Monitoring, Research & System Experience**
1 Awareness and initial discovery	1 Help-Seeking & Diagnostic Journey	1 Treatment Choices & Decision-Making	1 Impact on Daily Life, Roles & Activities	1 Prevention, Risk & Testing/Screening
2 Understanding and perceptions	2 Access & Affordability	2 Treatment Experience & Perceived Effects	2 Emotional Well-Being & Mental Health	2 Monitoring, Follow Up & Long-Term Management
3 Information sources and trust	3 System Navigation & Practical Barriers	3 Tolerability, Modification & Discontinuation	3 Social Support, Caregiving & Community	3 Healthcare Communication, Trust & Advocacy

Figure 1: Themes and Sub-Themes Guiding Social Media Data Capture and Analysis

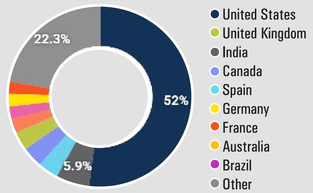
Results

- A total of 496,600 posts were retrieved over the period of 1 year. Posts were predominantly in English (77.2%) and US-based (52%); X contributed the largest share (50%)
- Discussions centered on patients, trials, treatments, and specific agents (e.g., nivolumab, dostarlimab), indicating an informed audience

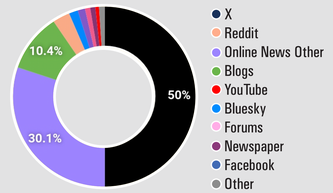
Results over Time



Regional Share of Posts



Share of Media Type



Word Cloud of the Most Frequent Mentions in Social Media Chatter

Overall Sentiment Distribution

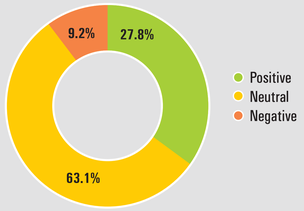


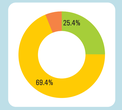
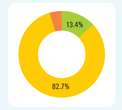
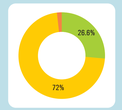
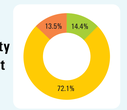
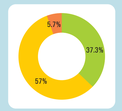
Figure 2: Social media data analysis result

Key Drivers of Positive Sentiment

- Optimism driven by immunotherapy breakthroughs and trial successes
- Confidence in personalized and combination treatment approaches
- Hope driven by durable responses and advances in biomarkers and diagnostics
- Strong reliance on clinician guidance, research evidence, and peer support
- Positive outlook from advances in next-generation ICIs and long-term management strategies

Key Drivers of Negative Sentiment

- Concerns around irAEs, toxicities, and variable treatment efficacy
- High treatment costs, insurance denials, and access inequities
- Anxiety, emotional distress, and quality-of-life burden during treatment journeys
- Delayed diagnosis, monitoring gaps, and healthcare navigation challenges
- Skepticism, misinformation, and uncertainty around long-term outcomes and standard care

Domains and Sentiment Distribution	Key Drivers of Positive Sentiment	Key Drivers of Negative Sentiment
1.Awareness, Understanding & Information 	• Awareness of immunotherapies (e.g., Keytruda, Opdivo) • Understanding of combinations and personalized approaches • Real-world testimonials	• Confusion regarding ICI use in advanced disease • Unmet need for guidance (including genetic factors) • Concerns on side effects and access
2. Help-Seeking, Diagnosis & Access 	• Awareness of immunotherapy supporting earlier diagnosis • Advocacy for screening and affordability	• Delayed diagnosis • High costs, access inequities, pricing concerns • Frustration with healthcare policies
3. Treatment Decision-Making & Journey 	• Promising trial results (e.g., dostarlimab, pembrolizumab combinations) • Confidence in combination regimens Interest in personalized approaches	• Toxicities (e.g., inflammation, neurological effects) • Tolerability issues and comorbidities driving uncertainty and treatment switching
4. Burden, Quality of Life & Support 	• Optimism from immunotherapy advances (e.g., Keytruda, Opdivo) • Support systems and research improving outlook	• Anxiety, depression, and financial stress • Side effects and variable efficacy impacting quality of life (QoL) • Coverage denials driving reliance on online support
5. Prevention, Monitoring, Research & System Experience 	• Vaccine approaches and biomarker testing (mismatch repair [MMR] status and microsatellite instability [MSI] testing) • Strong outcomes (e.g., dostarlimab remission data) supporting durable benefit	• Delayed diagnosis, limited screening, and monitoring gaps • Skepticism toward standard care and declining trust

Positive Neutral Negative

Table 1: Domain-specific Sentiment Distribution and Key Drivers of Sentiments

Discussion

- Social media posts on ICI are event-driven, with spikes linked to trial breakthroughs (e.g., dostarlimab), showing how single studies shape public attention
- Frequent mention of specific agents reflects an informed, treatment-focused audience, unlike lifestyle-driven metabolic discussions
- Ongoing concerns around irAEs, variable efficacy, and affordability highlight real-world complexity, alongside rising alternative therapy narratives
- **Strengths:** Large-scale, real-world insights from unprompted patient discussions
- **Limitations:** Social media bias (English/US skew), event-driven spikes, and presence of non-evidence-based content

Conclusion

Social media discussion on immune checkpoint inhibitors is driven by high-impact research that reflects an informed, treatment-focused audience. Safety, efficacy, and access concerns persist, with alternative-treatment narratives highlighting the need for clearer, evidence-based communication

References

1. Kong X, et al. Cancer Biol Med. 2024 May 24;21(6):451–472.
2. Arafat Hossain M. Int Immunopharmacol. 2024 Dec 25;143(Pt 2):113365.
3. Heumann T, Azad N. Cancer Metastasis Rev. 2021 Sep;40(3):837-862.

[Full list available on request]