

# Social Media Sentiment Toward Anti-Amyloid Therapies in Early Alzheimer's Disease: Implications for Real-World Evidence and Decision-Making

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## Background

- Alzheimer's disease accounts for ~60–80% of dementia, affecting ~55 million globally. Prevalence of Alzheimer's disease is expected to nearly double by 2050<sup>[1,2]</sup>
- Burden of Alzheimer's disease extends to caregivers and healthcare systems, with significant societal impact<sup>[3]</sup>
- Recent anti-amyloid therapies (e.g., lecanemab, donanemab) have demonstrated amyloid reduction and cognitive benefit, and biomarker-driven diagnostics have enabled earlier detection<sup>[3]</sup>
- Despite this, the real-world adoption of these novel therapies remains limited due to concerns about safety, monitoring burden, cost, access, and uncertainty around long-term benefit
- Social media offers unsolicited, real-world insights into patient and caregiver experiences, complementing existing real-world evidence

## Objective

To evaluate global social media sentiment towards anti-amyloid therapies in early Alzheimer's disease and identify key perception-driven factors influencing real-world treatment decision-making and access beyond clinical trial evidence

## Methodology

### Framework and Sub-Theme Definition

- 15 sub-themes were defined to capture awareness, diagnostic journey, access, treatment journey, impact on daily life, prevention, 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 anti-amyloid therapies for Alzheimer's disease 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)

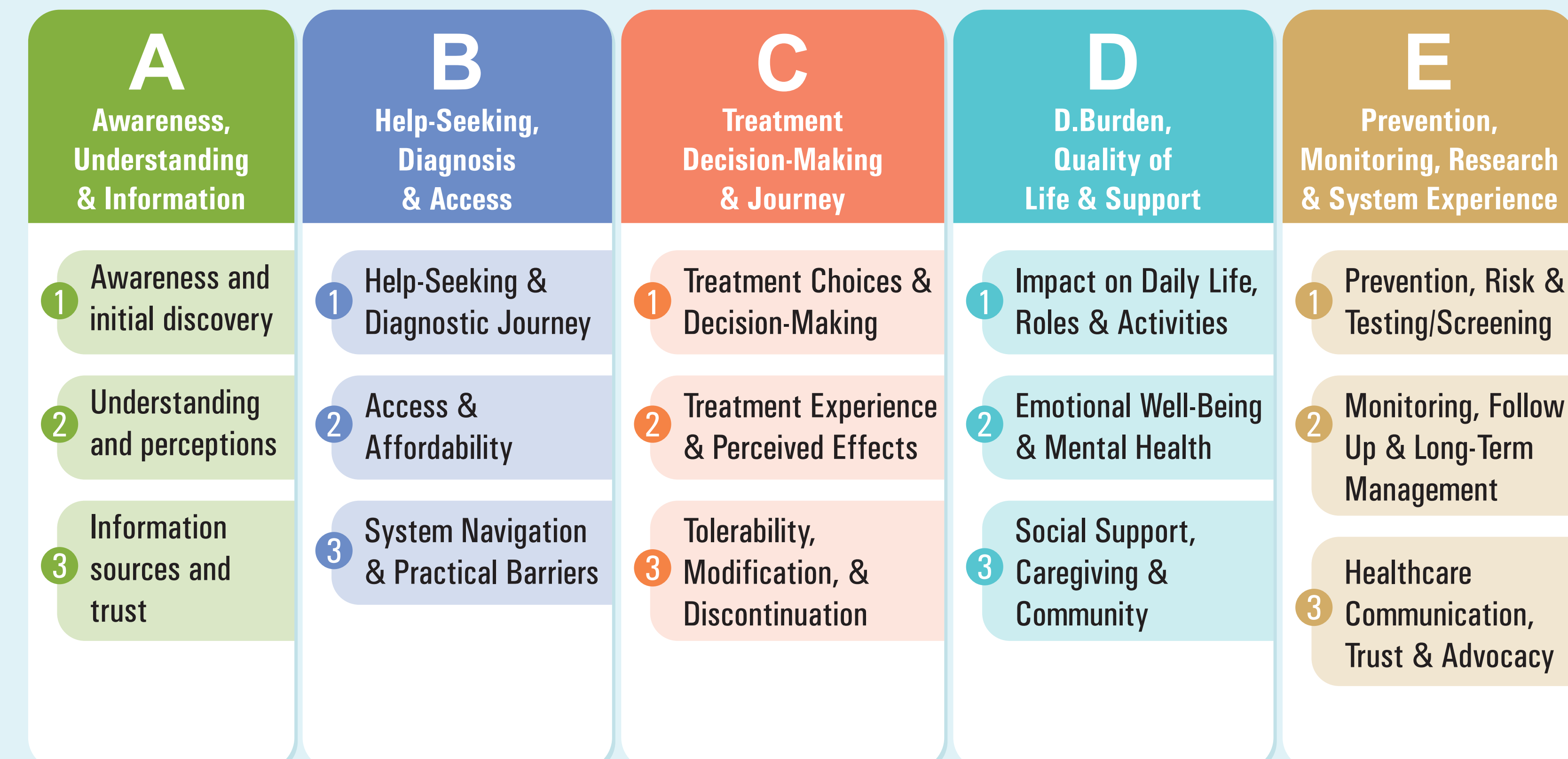
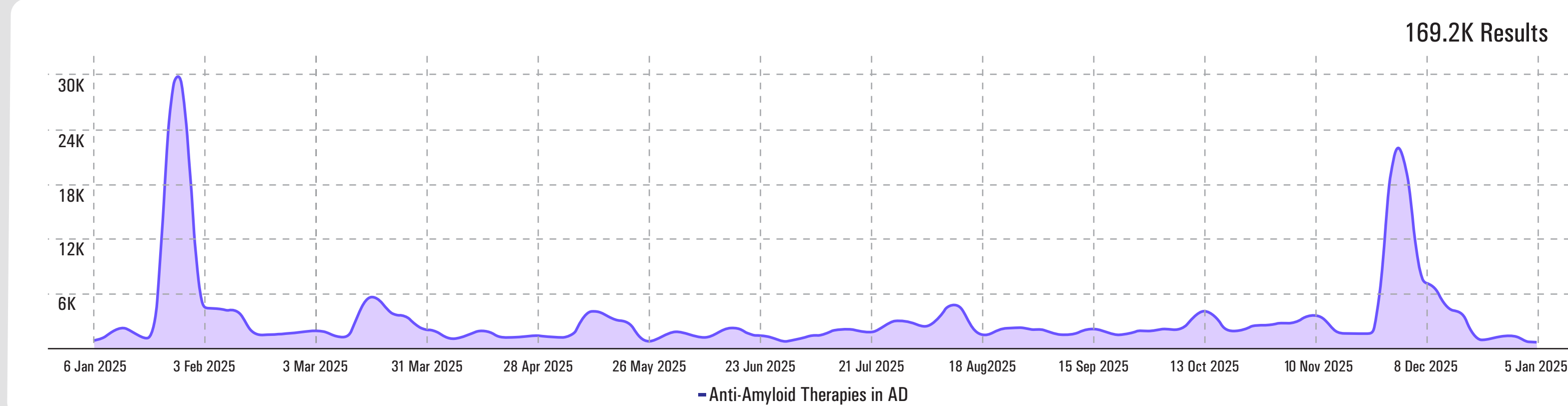


Figure 1: Themes and Sub-Themes Guiding Social Media Data Capture and Analysis

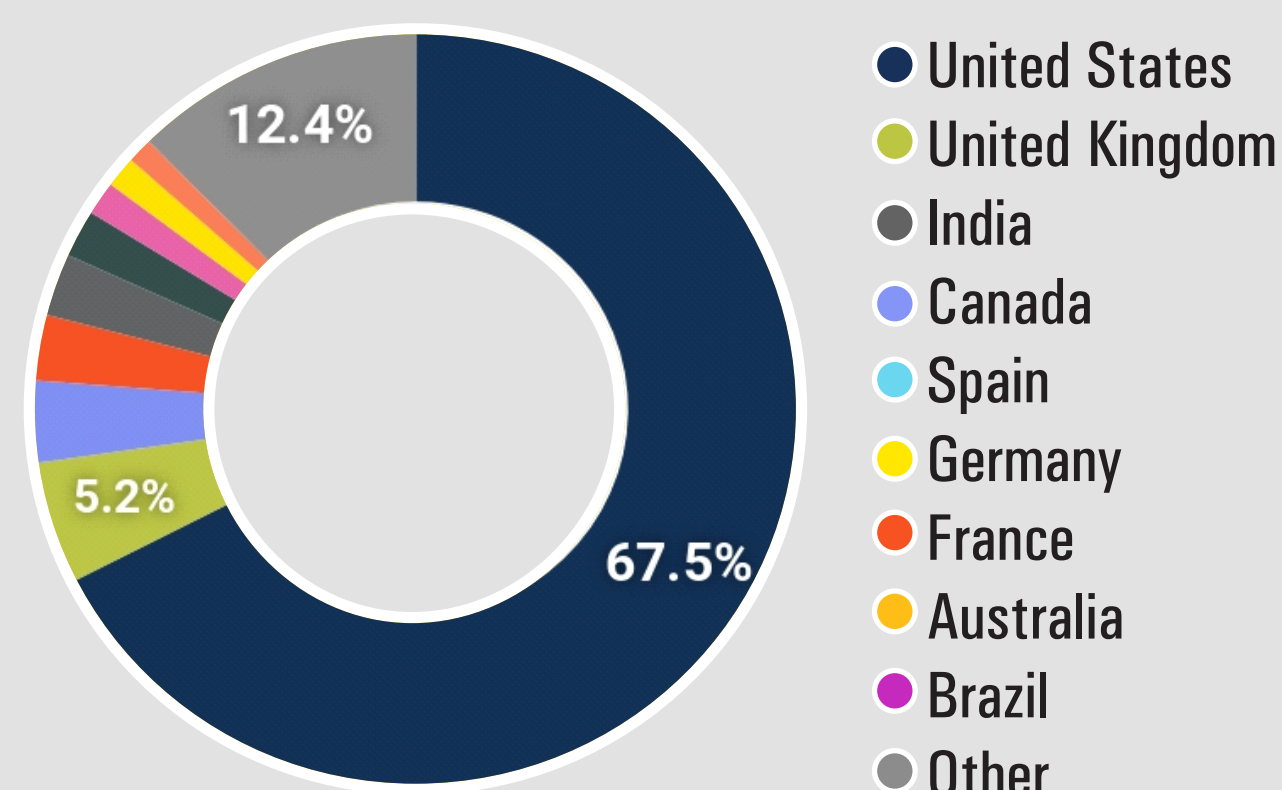
## Results

- A total of 169,173 posts were retrieved over the period of 1 year. Posts were predominantly in English (92%) and US-based (67.5%); X contributed the largest share (62%)
- Discussions centered on general terms ("brain," "amyloid," "drug"), with limited therapy-specific mentions, indicating low treatment awareness

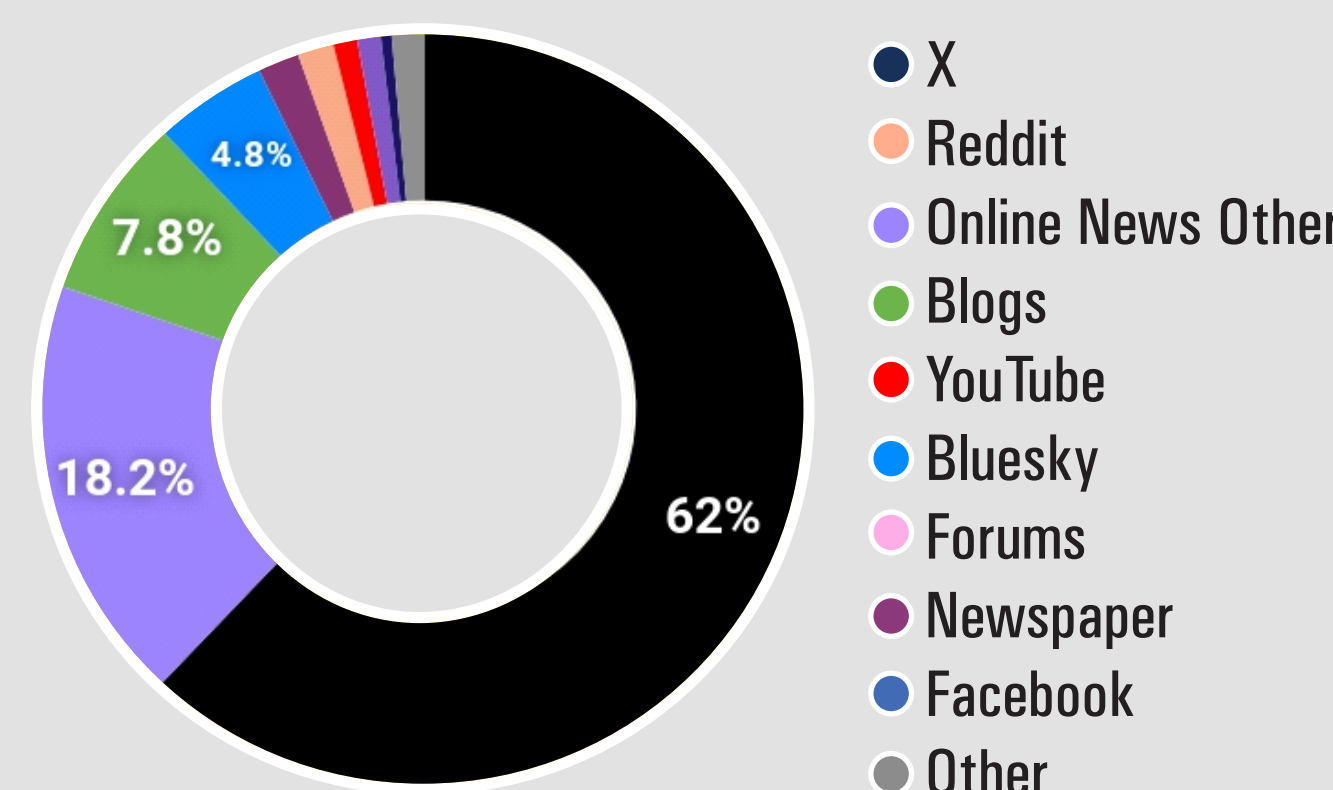
### Results over Time



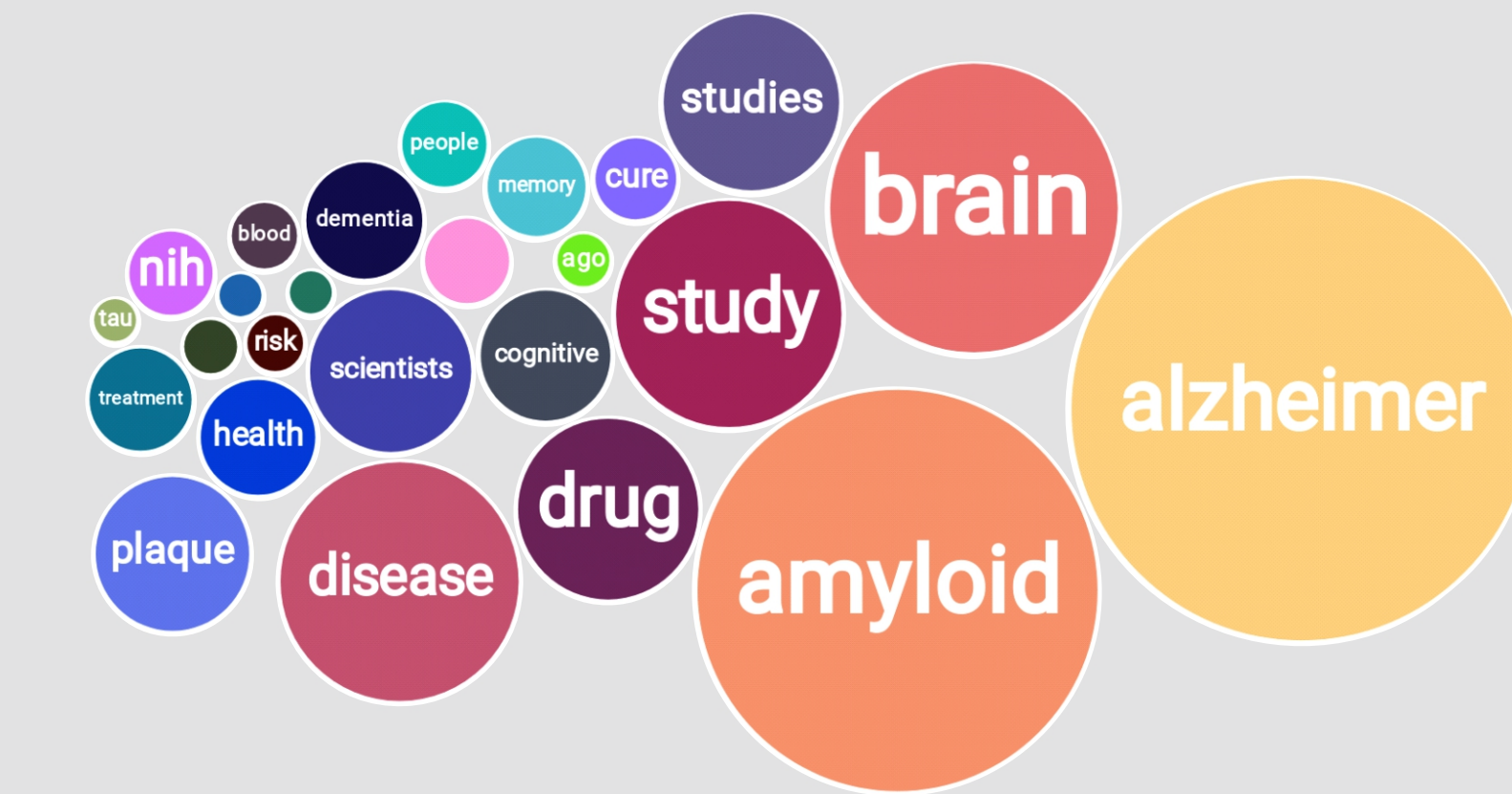
### Regional Share of Posts



### Share of Media Type



### Word Cloud of the Most Frequent Mentions in Social Media Chatter



### Overall Sentiment Distribution

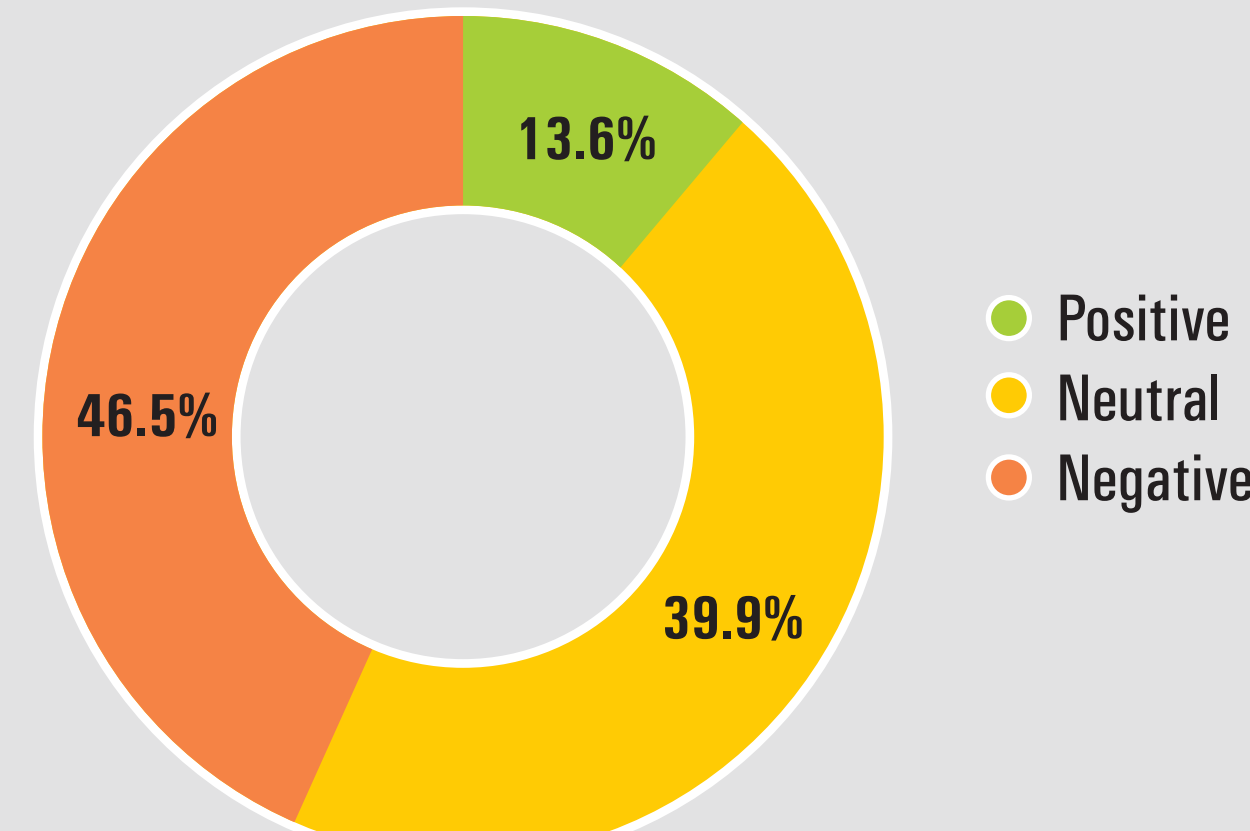


Figure 2: Social media data analysis result

### Key Drivers of Positive Sentiment

- Optimism around emerging anti-amyloid therapies and innovation
- Interest in early detection and blood-based biomarkers
- Hope driven by US FDA approvals (e.g., Leqembi) and ongoing research
- Support for lifestyle, neuroprotective, and complementary approaches
- Growing confidence in advances in diagnostics, monitoring, and disease management

### Key Drivers of Negative Sentiment

- Safety concerns, particularly amyloid-related imaging abnormalities (ARIA) and treatment-monitoring burden
- Skepticism toward the amyloid hypothesis and real-world clinical benefit
- Concerns around limited efficacy, side effects, and diagnostic uncertainty
- Distrust in research credibility, industry influence, and conflicting disease theories
- Emotional burden, low awareness, and confusion driven by misinformation and alternative narratives

Domains and Sentiment Distribution	Key Drivers of Positive Sentiment	Key Drivers of Negative Sentiment
<b>1. Awareness, Understanding &amp; Information</b> 	<ul style="list-style-type: none"> <li>Optimism on novel therapies; support for blood-based biomarkers</li> <li>Lifestyle strategies (diet, exercise, cognition)</li> </ul>	<ul style="list-style-type: none"> <li>Concerns on research integrity and bias; skepticism toward amyloid hypothesis; uncertainty on real-world value and diagnostic accuracy</li> </ul>
<b>2. Help-Seeking, Diagnosis &amp; Access</b> 	<ul style="list-style-type: none"> <li>Optimism on therapies and early detection</li> <li>Favorable views on blood-based biomarkers (pTau217) beta- amyloid); lifestyle approaches</li> </ul>	<ul style="list-style-type: none"> <li>Concerns on limited benefit, access, side effects, and diagnostic accuracy; mistrust in research</li> <li>Anxiety around genetic risk (apolipoprotein E 4 allele [APOE4]) and alternative causes</li> </ul>
<b>3. Treatment Decision-Making &amp; Journey</b> 	<ul style="list-style-type: none"> <li>Optimism on emerging therapies (vaccines, antibodies, novel modalities)</li> <li>Interest in neuroinflammation and brain stimulation; complementary approaches</li> </ul>	<ul style="list-style-type: none"> <li>Concerns on limited efficacy, side effects, and monitoring burden</li> <li>Reduced trust from past clinical trial failures (e.g., aducanumab post-approval controversy, earlier BACE inhibitor failures); misinformation driving confusion</li> </ul>
<b>4. Burden, Quality of Life &amp; Support</b> 	<ul style="list-style-type: none"> <li>Interest in neuroprotective compounds; confidence from FDA approval (Leqembi, Kisunla)</li> <li>Focus on neuroinflammation and support systems</li> </ul>	<ul style="list-style-type: none"> <li>Concerns on medication-related risk and microbiome uncertainty</li> <li>Funding gaps, low awareness; conflicting prevention guidance</li> </ul>
<b>5. Prevention, Monitoring, Research &amp; System Experience</b> 	<ul style="list-style-type: none"> <li>Optimism on blood-based diagnostics (e.g., plasma p-tau217 + amyloid beta 42/40 blood test) and therapies</li> <li>Advances in early detection and trials</li> <li>Emerging treatments and patient-reported hope</li> </ul>	<ul style="list-style-type: none"> <li>Conflicting disease theories, limited efficacy; skepticism on risk tests, safety, and industry influence</li> <li>Distrust due to funding and policy challenges</li> </ul>

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

## Discussion

- Predominantly neutral, information-driven discourse reflects growing engagement but limited therapy-specific understanding
- Low mention of specific drugs (e.g., Leqembi, Kisunla) indicates awareness gaps despite recent approvals
- Negative sentiment (46.5%) is driven by safety concerns (ARIA), skepticism toward the amyloid hypothesis, and doubts around research credibility
- High focus on MRI and side effects suggests that treatment burden is a key barrier to real-world adoption. Growing discussion of alternative therapies and non-amyloid approaches reflects uncertainty around current treatment paradigms
- Strengths:** Real-world, unprompted perspectives beyond clinical/survey data
- Limitation:** Social media data may capture broader dementia discourse due to overlapping terminology, with potential selection bias and lack of clinical validation; English/US skew due to platform and query design

## Conclusion

While Alzheimer's disease is discussed widely in social media, anti-amyloid therapies remain poorly understood, with limited awareness of treatments and diagnostics. Safety concerns, monitoring burden, and amyloid skepticism drive hesitation. Lower public engagement highlights the need for clearer, evidence-based communication

## References

- World Health Organization. <https://www.who.int/news-room/fact-sheets/detail/dementia>
- Alzheimer's Disease International. World Alzheimer Report 2023. <https://www.alzint.org/resource/world-alzheimer-report-2023/>
- van Dyck CH et al. N Engl J Med. 2023 Jan 5;388(1):9-21. [Full list available on request]