



Shifting the Narrative: Trends in Stigmatizing Language and Sentiment Towards Migraine Treatments on Social Media

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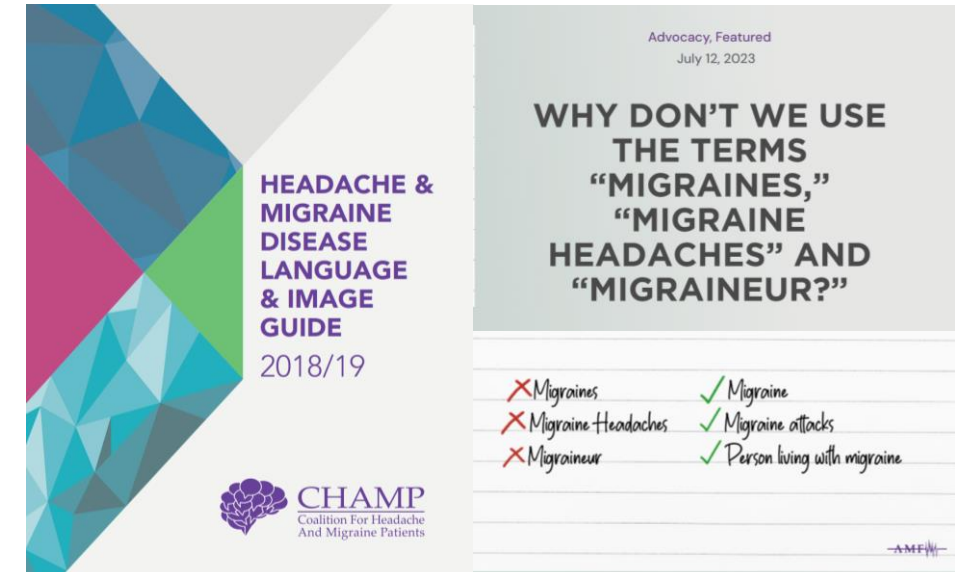


Disclosures

- **TSM has been an advisor to Pfizer, a sponsor for this study, over the past 3 years.**
- TSM has other disclosures over the past 3 years: clinical trial site principal investigator for studies sponsored by Eli Lilly and AbbVie (all paid to the institution), participation in an advisory board/consultancy for AbbVie, Axsome, Teva, Linpharma, e-Neura, Novartis, Merz, and Lundbeck. She has received educational grants from Amgen and AbbVie, personal fees from Medscape, Massachusetts Medical Society, American Headache Society, American Academy of Neurology, AbbVie, Novartis, unpaid co-author for research funded by AbbVie, Pfizer/Biohaven, and Theranica. She is an associate editor for *Cephalalgia* and Continuum Audio, deputy editor for Neurology Minute, and is on the editorial board for *Neurology*, American Migraine Foundation, and *Brain and Life Magazine*. TSM has provided unpaid service on the board of directors for the International Headache Society (2021–2023) and is currently on the executive board for the Florida Society of Neurology and the American Migraine Foundation.

Introduction

- Recent efforts have been initiated to help address the issue of **psychological burden and stigma** associated with migraine^{1,2}
 - June 2019: CHAMP** released a language and image guide to help reduce the use of stigmatizing language³
 - July 2023: AMF** published recommendations for appropriate language to use in migraine advocacy⁴
- Coinciding with this increased focus on migraine stigma and advocacy, **CGRP-targeting therapies** have emerged^{5,6}
 - These new treatments may have reshaped perceptions and experiences of people with migraine^{5,6}



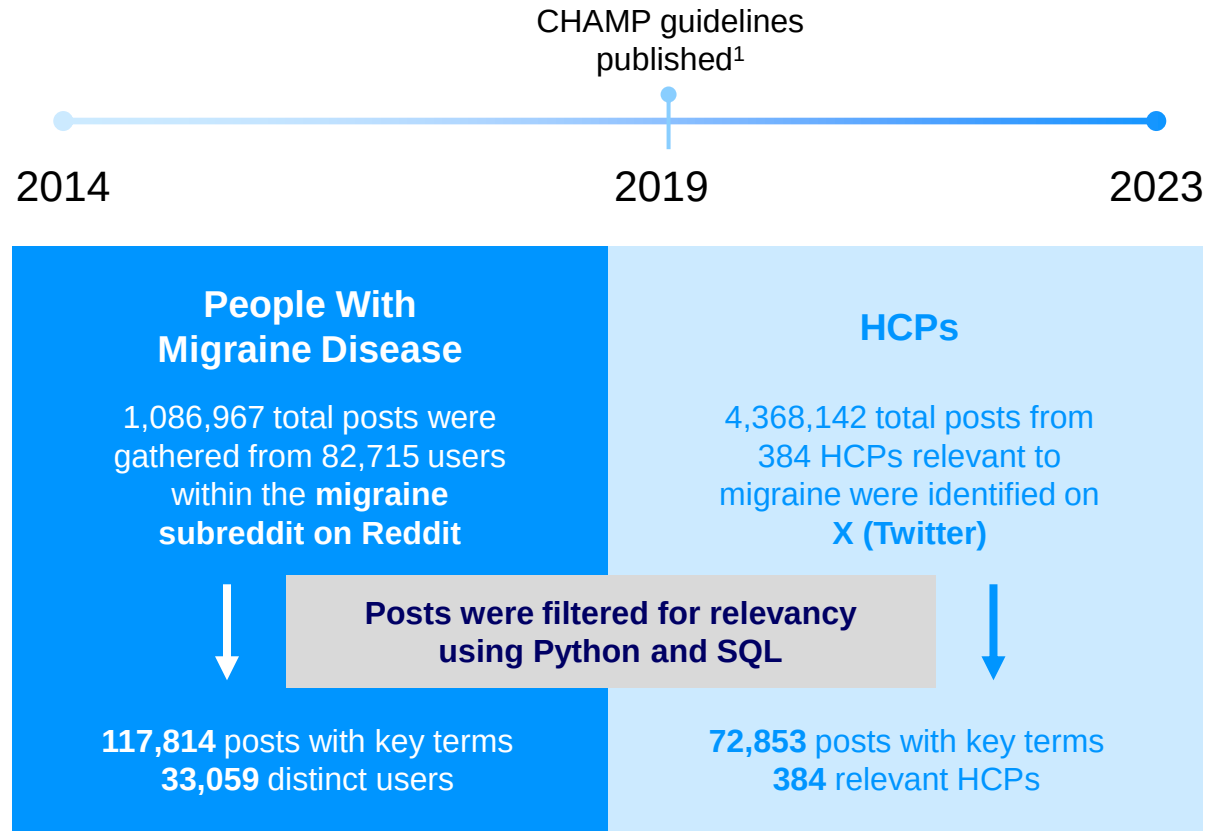
Objective: To understand the potential impact of both the language guidelines and the introduction of CGRP-targeting therapies by examining language use and sentiment on social media

AMF, American Migraine Foundation; CGRP, calcitonin gene-related peptide; CHAMP, Coalition for Headache and Migraine Patients.

1. Casas-Limón J, et al. *J Clin Med*. 2024;13(17):5222. 2. Parikh SK, et al. *Curr Pain Headache Rep*. 2021;25(11):75. 3. CHAMP Coalition for Headache and Migraine Patients. Published online June 2019. https://headachemigraine.org/wp-content/uploads/2021/01/CHAMP_Language_Guide_2019_website.pdf 4. American Migraine Foundation. July 12, 2023. <https://americanmigraine.foundation.org/resource-library/migraine-terms/> 5. Frimpong-Manson K, et al. *Front Mol Neurosci*. 2024;17:1355281. 6. Aditya S, et al. *Saudi J Med Med Sci*. 2023;11(1):11-18.

Methods: Lexicon Analysis on Social Media Pre- vs Post-publication of CHAMP Guidelines

Data Collection



Data Analysis

- The number of posts with CHAMP/AMF recommended language vs discouraged legacy language was examined as a ratio
- Posts were normalized by number of posts per month:

- Monthly average of:

$$\frac{\text{\# posts using CHAMP/AMF language}}{\text{\# posts using discouraged legacy language}}$$

AMF, American Migraine Foundation; CHAMP, Coalition for Headache and Migraine Patients; HCP, healthcare professional; SQL, structured query language.

1. CHAMP Coalition for Headache and Migraine Patients. Published online June 2019. https://headachemigraine.org/wp-content/uploads/2021/01/CHAMP_Language_Guide_2019_website.pdf

Methods: Lexicon Analysis on Social Media Pre- vs Post-publication of CHAMP Guidelines (cont'd)

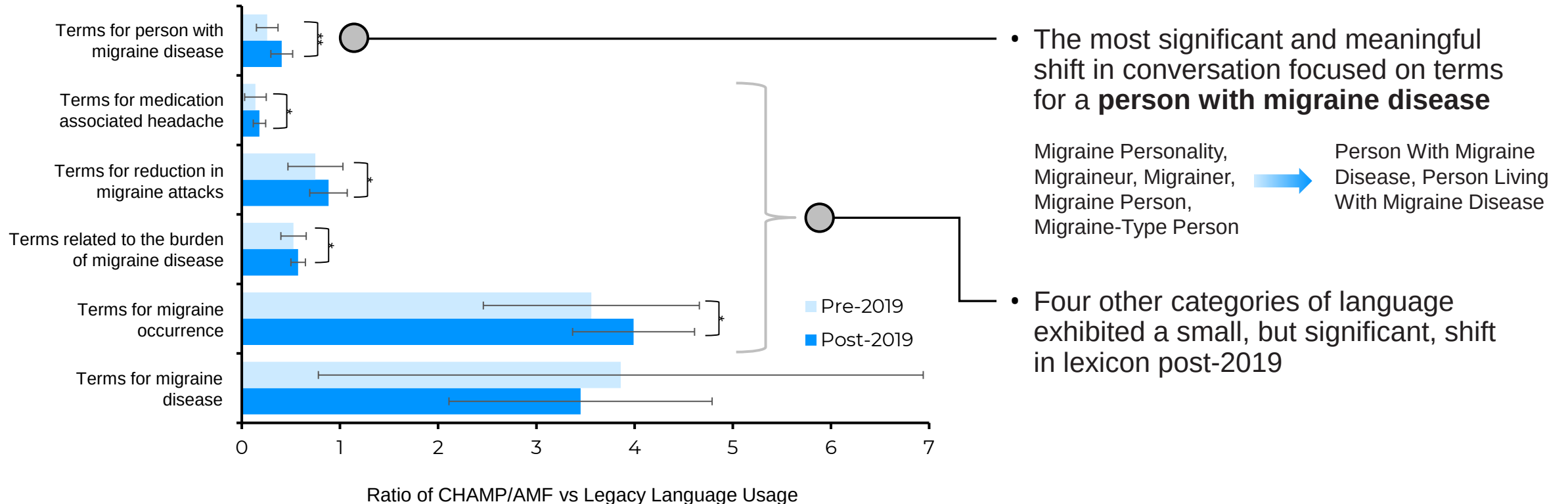
CHAMP/AMF Recommended Language Changes^{1,2}

Previously Used Language	Recommended Language	Category of Language
Headache(s)	Headache Disease(s), Headache Disorder(s)	<i>Not used in analysis due to lack of specificity in legacy language</i>
Headache(s), Migraine(s), Episode(s)	Headache Attack, Migraine Attack, Cluster Attack	<i>Terms for migraine occurrence</i>
Migraine Headache, Migraines	Migraine Disease, Living With Migraine Disease	<i>Terms for migraine disease</i>
Migraine Personality, Migraineur, Migrainer, Migraine Person, Migraine-Type Person	Person With Migraine Disease, Person Living With Migraine Disease	<i>Terms for person with migraine disease</i>
Suffering From Migraine, Migraine Sufferer	Experience(s) the Pain and Disability of Migraine Disease	<i>Terms related to the burden of migraine disease</i>
No Term Previously Used	Migraine Spectrum, Migraine Continuum	<i>Not used in analysis due to lack of associated legacy language</i>
Cured of Migraine, Migraine Cure, Migraine Miracle	Migraine Remission, Break in Migraine Attacks	<i>Terms for reduction in migraine attacks</i>
Medication Overuse Headache, Rebound Headache	Medication Adaptation Headache	<i>Terms for medication-associated headache</i>

AMF, American Migraine Foundation; CHAMP, Coalition for Headache and Migraine Patients.

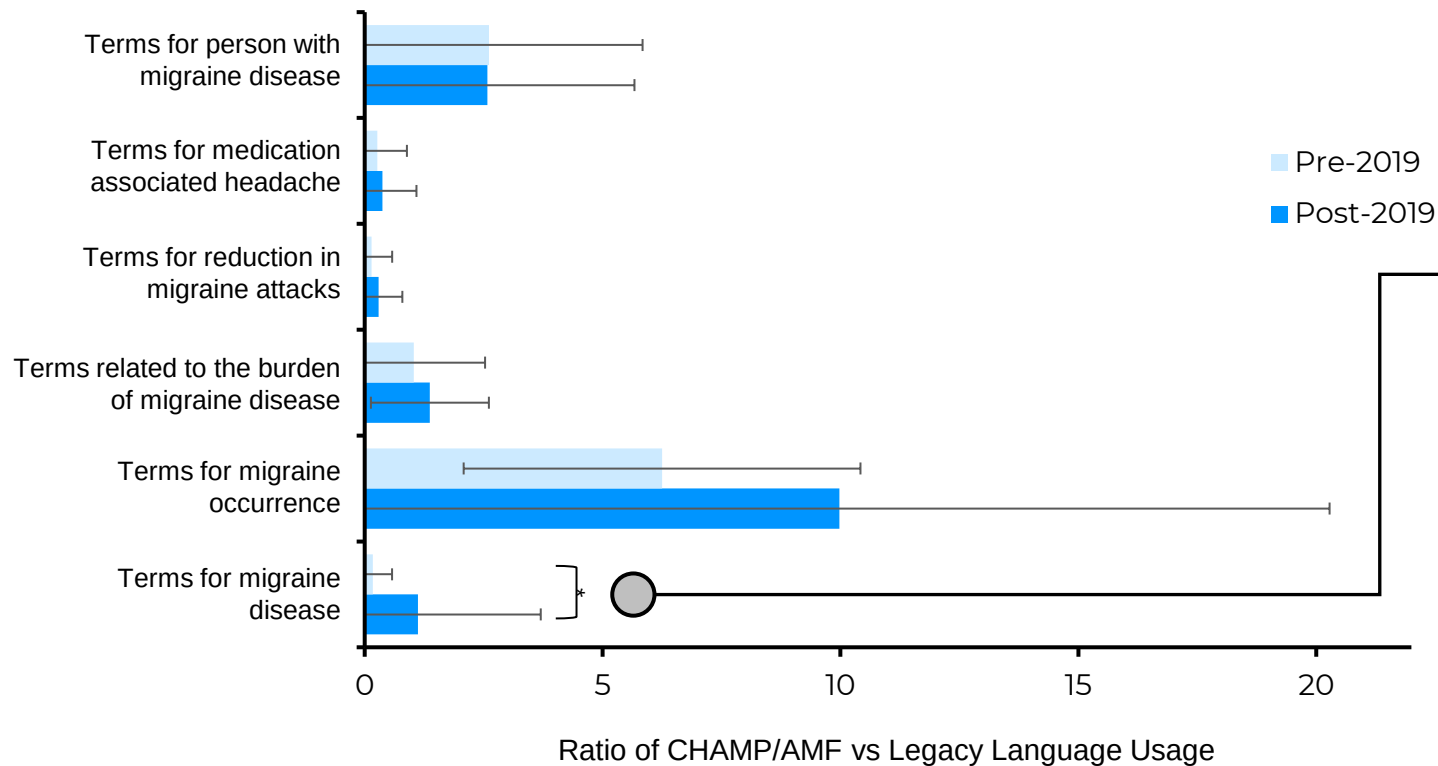
1. CHAMP Coalition for Headache and Migraine Patients. Published online June 2019. https://headachemigraine.org/wp-content/uploads/2021/01/CHAMP_Language_Guide_2019_website.pdf 2. American Migraine Foundation. July 12, 2023. <https://americanmigrainefoundation.org/resource-library/migraine-terms/>

Results: Lexicon Analysis Among People With Migraine Disease on Reddit



* $P < 0.05$; ** $P < 0.0001$.

Results: HCP Lexicon Analysis on X

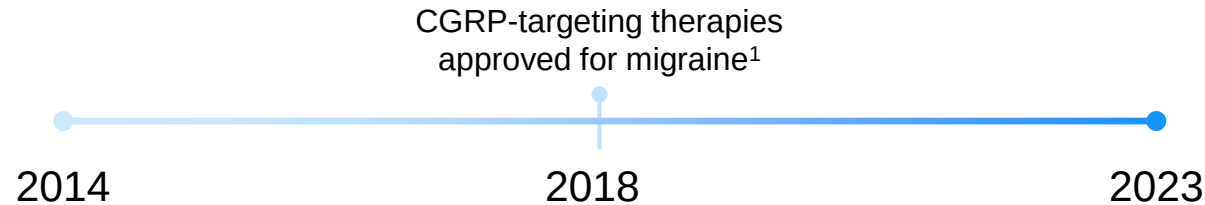


* $P < 0.05$.

- There were few social media posts by HCPs on X that used legacy language and/or CHAMP-recommended language
 - Posts by HCPs revealed a small, but significant, shift in lexicon around terms for migraine disease
- Migraine Headache, Migraines → Migraine Disease, Living With Migraine Disease

Methods: Sentiment Analysis of Migraine Treatments and Symptoms Pre- and Post-approval of CGRP-Targeting Therapies

Data Collection



Sentiment of People With Migraine Disease

85,141 relevant posts out of 1,086,967 total posts were gathered from 21,097 users (out of 82,715 total users) within the migraine subreddit on Reddit

Commercially-available (Google Cloud), pre-trained named entity recognition (NER) models for natural language processing

Sentiment analysis assessing emotional direction and intensity via machine learning models available through Google Cloud

Sentiment score

Data Analysis

- Sentiment scores were assigned to specific named entities within individual Reddit posts
- Distribution of scores assessed as percentile levels
 - Relatively strong negative (10th percentile)
 - Relatively strong positive (90th percentile)
- Score range:



CGRP, calcitonin gene-related peptide.

1. Versijpt J, et al. *Lancet*. 2025;405:1014-1026.

Results: Sentiment Analysis of Migraine Treatments and Symptoms Pre- and Post-approval of CGRP-Targeting Therapies

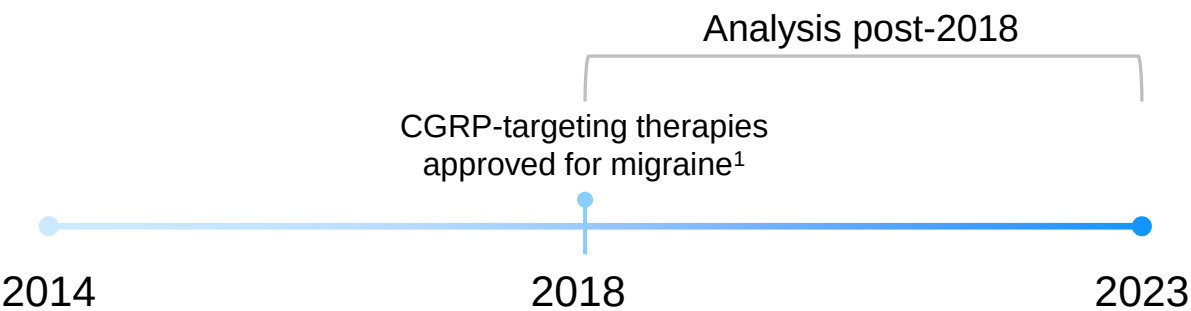
Sentiment Scores Pre- and Post-2018						
Percentile	Relative Sentiment	Mean Pre-2018 ± SD	Mean Post-2018 ± SD	Delta of Mean	Effect Size	Adjusted P-Value
All Sentiment (CGRP– and Non–CGRP-Targeting Treatments)						
10 th	Most Negative	-22.55 ± 4.66	-22.72 ± 2.30	-0.17	-0.05	1
Mean	Average	5.82 ± 2.36	6.67 ± 1.54	0.86	0.45	0.08
90 th	Most Positive	41.25 ± 4.41	46.53 ± 4.28	5.28	1.22	<0.0001
Non–CGRP-Targeting Treatment Sentiment						
10 th	Most Negative	-24.33 ± 4.08	-27.89 ± 2.88	-3.57	-1.05	<0.0001
Mean	Average	5.12 ± 2.61	4.74 ± 1.65	-0.38	-0.18	1
90 th	Most Positive	41.01 ± 4.71	43.15 ± 4.46	2.14	0.47	<0.05
Symptom Sentiment						
10 th	Most Negative	-16.64 ± 12.30	-21.30 ± 9.53	-4.66	-0.44	0.10
Mean	Average	-1.63 ± 14.43	0.67 ± 7.89	2.30	0.21	0.99
90 th	Most Positive	12.62 ± 7.88	22.04 ± 9.75	9.41	1.04	<0.0001

For changes in sentiment towards migraine treatments, the score for the strongest positive sentiment increased by **5.28 points**

The strongest negative sentiment towards non–CGRP-targeting therapies strengthened by **-3.57 points**, and the strongest positive sentiment strengthened by **2.14 points**

The strongest positive sentiment towards the perception of migraine symptoms strengthened by **9.41 points**

Results: Sentiment Analysis of Non-CGRP-Targeting vs CGRP-Targeting Treatments Post-2018



Sentiment Scores for Non–CGRP-Targeting vs CGRP-Targeting Treatments Post-2018						
Value	Relative Sentiment	Mean Non-CGRP ± SD	Mean CGRP ± SD	Delta of Mean	Effect Size	Adjusted P-Value
Mean	Average	4.74 ± 1.65	8.40 ± 1.64	3.66	2.22	<0.0001

The mean sentiment towards CGRP-targeting therapies was **3.66 points** higher than non–CGRP-targeting therapies post-2018

CGRP, calcitonin gene-related peptide.
1. Versijpt J, et al. *Lancet*. 2025;405:1014-1026.

Key Takeaways



Lexicon Analysis

- Self-identifying terms represented the largest shift in lexicon among people with migraine disease, reflecting a potential desire for patient-focused language
- HCP lexicon had minimal changes in response to the CHAMP/AMF language guidelines, with only one shift in terms for migraine disease noted, emphasizing the scientific and clinical focus of HCP language
- Due to the lack of notable changes in language by people with migraine disease and HCPs, this research highlights the need for greater dissemination of destigmatizing migraine language guidelines to engage more of the community



Sentiment Analysis

- There was increased positive sentiment towards migraine treatments since the introduction of CGRP-targeting therapies, suggesting a favorable perception of these treatments
- The growing positive sentiment associated with migraine treatments may suggest that the migraine community feels increasingly acknowledged and hopeful with the continued development of new treatments