Rhetoric and linguistic strategies in an online advocacy movement

Nastaran Jadidi
nastaran.jadidi@utah.edu
University of Utah
Salt Lake City, USA

Vineet Pandey
vineet.pandey@utah.edu
University of Utah
Salt Lake City, Utah, USA

Abstract

Collective intelligence research has traditionally focused on formal, structured groups such as teams and organizations. In contrast, many collective efforts on digital platforms operate without predefined structures. Such emergent efforts often take on open-ended work in novel contexts. For example, *advocacy movements* on digital platforms actively engage in policy conversations around issues of significance to them. This paper contributes an empirical understanding of the efforts of the Amyotrophic Lateral Sclerosis (ALS) advocacy movement to engage with Food and Drug Administration (FDA) on a social platform. We draw on two ideas: rhetorical and linguistic choices reveal community orientations; and prior linguistic models miss crucial nuances in community-driven discourse. To reveal rhetoric and linguistic strategies, we perform a digital ethnographic inquiry of the ALS advocacy movement. We follow this inquiry with a content analysis of a subset of posts using an updated linguistics model for stance and engagement. Our work highlights that people use various linguistic strategies to integrate knowledge claims into context-specific rhetoric. Our work suggests multiple directions for further analytical and design work to support advocacy movements' attempts at engaging with institutional agencies.

CCS Concepts

• **Human-centered computing → Social media**; *Empirical studies in collaborative and social computing*; Empirical studies in HCI.

Keywords

Advocacy movement, Online discourse, Rhetoric, Linguistic model, Digital ethnography, Participation, Rare disorder

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1 Introduction

Collective intelligence is defined as "a group's capability to collaborate and coordinate effectively across a range of tasks, which is predictive of a group's future performance" [74]. Traditional markers of collective intelligence include clear goals [67, 73], hierarchical structure [12, 67, 73, 75], collaboration [58, 64, 67, 73], and structured information aggregation [44, 66, 67, 73]. While collective intelligence research has traditionally focused on structured groups like teams and organizations, other groups increasingly demonstrate markers of collective intelligence with various mechanisms on digital platforms. For example, patient communities on the PatientsLikeMe platform use structural crowdsourced methods for aggregating patient-reported data about drug effects [72]. Citizen science projects provide workflows via apps for volunteers to collect and analyze data, ensuring systematic knowledge aggregation [20]. The Galileo platform enables people to design, review, and run their own experiments rather than solely contributing data to expert-led research [52]. Such cases expand the scope of collective intelligence beyond traditional teams and organizational structures.

Many emergent collective efforts on digital platforms perform open-ended work in novel settings. For instance, *advocacy movements* vigorously engage in policy conversations on topics of significance to them [76]. Such efforts find poor match with hierarchical setups like teams/organizations. This paper investigates how a patient advocacy movement attempts to engage with policy questions via a social platform, and explores whether its behavior represents a form of collective intelligence. Concretely, this paper contributes an empirical understanding of the Amyotrophic Lateral Sclerosis (ALS) advocacy movement's efforts to engage with Food and Drug Administration (FDA) on the X social platform.

Developing a rich contextual understanding of a community helps understand how its online efforts are animated by real-world needs and constraints. For instance, patient communities typically position themselves in nuanced ways to questions of knowledge that affect them. To achieve this understanding, two ideas guide this research. First, understanding a community's positioning toward institutions requires paying close attention to rhetorical strategies and linguistic choices. Second, prior linguistic models are not sufficient for this work: they clarify structural choices but overlook the community-specific context that animates such discourse.

Our work builds on these insights with a multi-method approach. We perform a digital ethnography inquiry of the ALS advocacy movement followed by content analysis of a subset of posts using an updated linguistics model for stance and engagement. Our efforts highlight that people use thoughtful approaches to highlight their perspectives. Specifically, they integrate knowledge claims into context-specific rhetoric and use linguistic cues in ways that are not captured by context-agnostic linguistic models. Our findings do not reveal evidence of collective intelligence (as defined in prior work) but suggest new directions to better understand the knowledge work done by online communities striving to meet their needs.

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2 Related Work

Our research builds on prior work in advocacy movements, digital ethnography, and linguistic models for stance.

2.1 Advocacy movements can sometimes succeed but a nuanced understanding of their use of digital platforms is missing

Advocacy movements are a varied collection of initiatives aimed at influencing policy and effecting social change around specific issues [7, 18, 49]. Some advocacy movements have historically demonstrated remarkable success in addressing complex institutional challenges. HIV/AIDS advocacy efforts successfully secured research funding, and nudged institutional agencies in including AIDS patients in policy-making [23, 24]. A more contemporary example is the ALS advocacy movement which attempts to improve support for individuals living with Amyotrophic Lateral Sclerosis (ALS), a fatal and progressive neuro-degenerative disease [8]. The ALS Ice Bucket Challenge was a viral social media campaign that raised public awareness and generated funds that led to new drug trials [55].

Advocacy movements (unlike advocacy organizations) are different from the structured settings typically asserted for collective intelligence, such as teams or organizations. Advocacy movements typically lack elected leaders and deal with issues like justice [65], human rights [53], and environmental protection [33] where advocates' knowledge is often qualitative and experiential. Advocacy movements display emergent, adaptive strategies driven by urgency and lived experience rather than concrete top-down planning [59]. Moreover, advocacy movements might have multiple goals [48], *e.g.* raising public awareness [15] or influencing institutional policies [19], and their efforts might be better assessed on timelines of years rather than days or weeks [59]. Prior work has primarily studied social movements (*e.g., Black Lives Matter* [14]) which are typically broad in scope and challenge both policy-making and societal norms [1]. Every social movement involves some advocacy efforts; however, not all advocacy movements are social movements, as some may focus on specific policy objectives and lack the broader socially transformative goals that define social movements [49]. Our study focuses on advocacy movements because their targeted goals make them suitable for examining whether new forms of collective intelligence can emerge in less structured settings. Specifically, this study focuses on how advocacy movements use digital platforms to conduct their practices around critiquing knowledge.

While many digital platforms are designed to enable groups of people to collaborate and share knowledge, they rarely meet the needs of advocacy movements. Advocacy movements need ways to develop and deliberate on strategies; avenues for self-education; spaces to communicate with decision-makers; and tools to manage campaigns. Social platforms aren't designed to support these needs that require long-term planning, and sustained knowledge-building that advocacy efforts demand. Lacking dedicated platforms, many advocacy movements rely on social media sites for organizing and sharing knowledge [49]. Prior research on activism suggests that efforts such as *hashtag activism* can benefit from the use of social media sites like X [14]. The Long COVID community is another advocacy movement whose members have used X to share their symptoms, experiences, and research findings [10, 62, 63]. Their advocacy efforts eventually gained mainstream attention and influenced research priorities [68]. As communities increasingly self-organize to advocate for issues such as health and environmental crises, a deeper understanding of how they use digital platforms can inform the design of tools that better support their specific advocacy goals and likely benefit a wide range of societal stakeholders.

2.2 Collective intelligence is evaluated through the quality of outputs, yet advocacy movements often lack tangible artifacts

Studies of collective intelligence in structured settings often rely on measurable outcomes or tangible artifacts. For example, the quality of articles on Wikipedia can be assessed using measures including accuracy (based on verifiability sources), neutrality (adherence to neutral point of view), and style (professional writing standards) [38]. However, studying collective intelligence in advocacy movements presents several challenges when relying on measurable outcomes. Advocacy movements' efforts rarely produce tangible artifacts [59]. Additionally, these movements often pursue multiple goals: persuading audiences and shifting public or institutional opinion [15, 48]. Evaluating advocacy movements is difficult without a clear understanding of who the actors are, the constraints they face, the strategies they use, and the goals they pursue.

Since most online advocacy efforts include text-based posts on social media, paying close attention to linguistic cues can provide valuable insights. Rhetoric—the use of language to influence audiences [17]—and other linguistic strategies can provide useful clues towards characterizing advocates' behavior. Social media posts on sites like X contain advocacy efforts at two levels: strategic positioning and engaging arguments [49]. Characterizing a movement's position on a topic may require understanding its concrete challenges and needs, cultural norms, and the intended audience [5, 69]. Digital ethnography helps by requiring researchers to immerse themselves in online communities to understand social interactions and behaviors [34]. For instance, digital ethnography has revealed technical expertise and mechanisms of self-regulation for a drug-use community [11]. In this example, digital ethnography helped uncover both "what" was happening in the community and "how" meanings and relationships were emerging and evolving—insights that traditional content analysis would have missed. Ethnographic content analysis (ECA) blends aspects of both approaches (ethnography and content analysis) and yields ways to systematically categorize online content while also interpreting its broader social and cultural significance [4].

For example, during the Black Lives Matter (BLM) movement, advocates used hashtags to frame conversations about racial injustice. Hashtags such as #Ferguson, and #HandsUpDontShoot played a crucial role in organizing and amplifying discourse. However, focusing solely on hashtags in online settings offers limited insight into why people use them *e.g.*, whether they support protesters or not, or what personal experiences caused them to participate in the movement. Understanding the offline context provided a complementary perspective on why these hashtags mattered and why they emerged [14]. Moreover, other efforts on social media, such as the anti-mask groups, demonstrate different forms of engagement with institutions. During the COVID-19 pandemic, anti-mask groups created counter-visualizations to challenge institutional public health guidelines [36]. An ethnographic study found that rather than entirely rejecting institutional analyses, anti-mask groups emphasized raw data over expert interpretations and claimed uncertainties in experts' analysis [36]. As these examples suggest, when researchers embed themselves in communities' online discursive practices over months, they develop deeper understanding of the underlying issues and practices. To examine an advocacy movement on X, our work adopts a combination of digital ethnography and subsequent content analysis of a subset of posts.

2.3 Understanding rhetoric in advocacy movements benefits from characterizing stance and engagement but prior linguistic models have limitations

Since advocacy movements often aim to impact opinions, their linguistic practices are sensitive to their specific context defined by needs, constraints, and intended audiences [15, 16, 60]. Advocates claim institutional discourse is one-sided and argue for actions that deviate from more standard institutional practices [30]. For example, advocates seeking better support for AIDS research shared scientific references to enhance their claims' legitimacy while also criticizing existing decisions [23]. Such movements strategically position themselves with respect to policies while attempting to engage with institutions. Hence, characterizing advocacy movements' discourse requires ways to identify *stance* as well as the arguments advocates use to *engage* their audience.

Many existing linguistic models have limitations that make them inadequate for analyzing advocates' stance. Some linguistic models identify stance through word counts or sentiment analysis [2, 54]. Keyword-based approaches have helped detect specific evidential markers in online discourse; for example, when discussing Unidentified Flying Objects (UFOs), users employed the hedge 'allegedly' to present evidence while avoiding commitment to its truth value [28]. Other approaches characterize stance in conversations that are *internal* to a community [35] or frame stance as a dialogue-based interaction—assuming a two-way communication between speakers and audiences [22]. Additionally, some models provide grammatical markers like affect adjectives ("Our community is so *happy*!") [13] or evaluative claims ("This decision is *irrational*") [31]. While useful in other contexts, these approaches are inadequate for studying advocacy movements. Keyword-based methods overlook the higher-level positioning and engagement strategies that are central to advocacy work. Advocacy movements often seek to engage with *external* institutions without receiving responses. A linguistic model more appropriate for studying advocacy movements' work will identify rhetorical strategies (that subsume keywords) and one-way stance-making practices, yielding a concrete codebook with categories and markers for systematic coding.

One model that meets these criteria is *Hyland's model* for stance and engagement. Developed via an analysis of academic texts, Hyland's model accounts for both writer-oriented (stance) and reader-oriented (engagement) features [32]. Hyland notes that meanings are produced "in the interaction between writers and readers in specific social circumstances". Hyland's model for *stance* and *engagement* has yielded insights from disparate data sources on social, political, and medical topics [3, 9, 26, 41, 45, 50, 51, 70, 77]. Some studies have used Hyland's model without modifying it [3, 9, 26, 50, 51, 70, 77]. For example, Hyland's model when applied to studying stance-taking in academic blogs uncovered that bloggers rely on personal opinions rather than citations while using hedging to compensate [56]. Other research efforts have fit the model to their specific context [41, 45]; for example, a study of YouTube comments on a UN Climate Action speech added a "stance focus" section to Hyland's model and revealed bullying behavior [45]. The utility of the original Hyland model plus its extensibility make it an attractive candidate for studying different online strategies. However, integrating ethnographic insights into Hyland's model and adapting it for specific contexts remains a challenge [45]. Our work combines Hyland's model with contextual insights via digital ethnography to understand rhetorical strategies in an advocacy movement.

3 Our case study: The ALS advocacy movement

Our goal is to characterize how advocacy movements frame their strategies and arguments via social media posts. The Amyotrophic Lateral Sclerosis (ALS) advocacy movement provides a compelling case study due to its clear goals, prior successes, and active social media presence.

ALS is a fatal disorder with no cure and limited treatments. Finding treatments for the disorder is a high-priority goal for people living with ALS. Any potential treatment needs to undergo rigorous testing and evaluation before it can be approved. As the institutional body responsible for regulating medical products [9], the Food and Drug Administration (FDA) makes drug approval decisions based on clinical trials that examine safety and effectiveness. FDA decisions directly impact access to ALS treatments. Advocates critique institutional decisions and highlight their plight. For instance, the ALS advocacy movement often critiques trial designs and outcome measures by arguing that current choices do not match the urgency of ALS [37].

ALS affects 30,000 individuals in the US [46]; yet, the ALS advocacy movement has successfully mobilized collective action for over a decade. For example, the viral Ice Bucket Challenge significantly increased public awareness and funding [29]. The relatively small scale of the ALS advocacy movement compared to other advocacy movements (*e.g.*, Long COVID movement) on social media allows examining advocacy practices without requiring large-scale computational techniques. As a result, research efforts can focus on deciphering complex arguments made by advocates that draw on lived experiences of community members and regulatory updates by the FDA.

Additionally, the ALS community is highly skilled at using social media. Prominent ALS influencers are active across various social media platforms to increase awareness about the disease [47]. People with ALS primarily organize in digital spaces since physical limitations make in-person advocacy prohibitive. Contemporary social platforms (like X) provide a consistent interface for participation: advocates share knowledge, discuss opinions, and provide rapid commentary on regulatory updates.

4 Methods

We conducted a digital ethnographic inquiry of the ALS advocacy movement on X for nine months. Our tasks included observing advocates' posts; educating ourselves about technical terms (*e.g.* 'regulatory flexibility'), regulatory updates (*e.g.* specific drug mentions), advocates' response; and collecting relevant posts for analysis. We initially applied a linguistic model to a subset of posts. After noticing many gaps, we updated the model based on contextual insights from digital ethnography.

4.1 Data collection

Overall, our research team discussed 200 posts. To focus our attention, we prioritized posts with higher engagement (20+ likes) to identify prominent topics. To examine discussions around a particular drug, we used this query:

```
"ALS" and "NurOwn" (FDA) (#NurOwnWorks) min_faves:20
until:2024-01-01 since:2022-01-01
```

This query finds posts with more than twenty likes that discuss ALS, FDA, and a drug (NurOwn) for a duration when the drug was a popular topic within the ALS community's discourse.

4.2 Data coding

Starting with Hyland's model (Section 4.4), the primary author deductively coded the posts. During weekly meetings, a co-author independently coded a subset of posts to offer additional perspectives and discussed reasons with the primary author. Both coders independently spent months observing ALS advocates' posts and interactions. The deductive coding process yielded patterns not captured in the initial codebook. The two coders then used inductive coding to update existing categories in the codebook. The coding stopped when no new codes emerged and the codebook captured multiple relevant themes from the posts. Inter-rater reliability (IRR) wasn't computed because both coders developed a shared interpretation of ALS advocates' posts via digital ethnography, more than thirty meetings, and extended discussions that reached consensus.

4.3 Digital ethnography for ALS advocacy: goals and exploratory steps

Our digital ethnographic approach focuses on the broad set of conditions that shape the strategies advocates use in their online communication. This includes the role of the authors in the community, the real-world context, and how they frame their arguments. Our digital ethnography inquiry of ALS advocacy on X followed three steps: identifying popular accounts and reviewing the authors' profiles; educating ourselves about ALS-related topics and concepts; and characterizing how advocates frame their strategies and arguments.

4.3.1 Identifying popular accounts and reviewing the profiles of the authors. We started by following some of the better known and active ALS patient accounts on X. Reviewing their profiles helped us understand the challenges of living with ALS, the biggest concerns in the community, and the motivations for advocacy. Additionally, we discovered other less popular users who participated in ALS-related discussions. To become familiar with various authors and their backgrounds, we studied all such profiles to assess their affiliations with the ALS community and the topics they engaged in. We did not find evidence of people affiliated with the FDA or pharmaceutical companies participating in these discussions except one account, which was a pharmaceutical company developing one of the experimental ALS drugs.

Although some accounts popular within the ALS community engaged in advocacy, we did not find leaders directing advocacy strategies. Many of the most engaged advocates were ALS patients who seemed motivated by the urgency of surviving.

4.3.2 Educating ourselves about ALS-related topics and concepts. Understanding the posts required understanding items like disease progression using clinical scores, *e.g.,* Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS)—a score measuring functional impairment. Posts also included many institutional and clinically related concepts. In response, the research team familiarized itself with terms like "regulatory flexibility," which refers to expedited treatment approvals, and "endpoints," which are the predefined outcomes used to assess clinical trial success. Additionally, as we analyzed posts, we encountered references to past events and discussions that preceded our study, which led us to investigate those contexts to fully understand the posts. For instance, many users criticized a letter that neurologists had sent to the FDA:

> " I ask that AANmember retract the SHAMEFUL letter that was sent to the #FDA recommending against approval of intrathecal treatments for #ALS because they are "cumbersome.""

Without background knowledge of that letter, we would not have been able to understand posts like the one shown above.

4.3.3 Characterizing how ALS advocates frame their strategies and arguments. ALS advocates critique institutional processes: they discuss regulatory decisions and scientific results around experimental treatments. Specifically, they mention multiple drugs in posts and hashtags. Our exploratory coding showed that advocates highlight their lived experience using numbers, statistical terms, and related qualifiers that demonstrate both concerns and data literacy. Qualifiers like "some" and "many" highlight variable disease progression among people with ALS. Conditional "if" clauses allow advocates to construct hypothetical scenarios that highlight better possibilities with novel treatment options. Advocates challenge conventional risk-benefit calculations and assessment criteria for ALS. For example, advocates state that even partially successful treatments' benefits outweigh corresponding risks when the alternative is certain death. Specifically, they use terms from clinical trials ("safe", "effective") and present their lived experience using phrases and metaphors that are often dark and hint at death ('death', 'black hole'). Advocates amplify their claims with formatting choices by frequently using ALL CAPS, exclamation marks (!!), and **bold text** for critical words such as 'URGENT!,' 'DYING,' or 'CURE NOW!'.

Overall, digital ethnography helped the research team identify patterns of behavior and language use that likely would have been oblivious otherwise.

4.4 Choosing a model

Hyland's model of stance and engagement helps characterize specific rhetorical strategies. We describe this model below. However, there were aspects of language use that were not fully captured in the original model. We have updated this model by adding new codes specific to ALS advocacy discourse based on our digital ethnography inquiry. Such updates are highlighted in *italics.*

4.4.1 *Stance.*

Stance reveals how advocates express opinions and attitudes about a topic. It indicates how certain or committed the advocate is to their statements, and how the advocate aligns with or against other viewpoints [32]. Identifying stance helps understand and analyze arguments, uncover potential biases, and interpret purported meanings behind statements. Stance comprises four elements (*text in italics* shows updates to an element via our digital ethnography approach):

(1) **Hedges** indicate a tentative commitment to a proposition. Common hedges include 'possible,' 'might' and 'perhaps'. They allow advocates to blur the lines between opinions, speculation, and facts. Example: "I think the research study was well done, but it's possible I missed details." The hedge 'possible' helps the speaker add uncertainty to their claim about the quality of the research study. They point out that the claim about the quality of the research study is provisional and could be potentially influenced by a lack of complete information.
*ALS advocates also use adjectives that serve as quantifiers including adjectives like **'some'** and **'many'**. Such quantifiers help with acknowledging variable disease progression. Hedges can also include **if clauses** because they introduce an element of conditionality or uncertainty to a statement. For instance, statements like "If I had access to this drug, I would do better" demonstrate the impact of regulatory decisions while also maintaining caution by framing the argument as a possibility rather than as an absolute claim.*

(2) **Boosters** emphasize confidence in claims and express certainty in arguments. Common boosters include words like 'clearly,' 'obviously' and 'demonstrate'. Example: "Obviously, investing in new treatments is the most effective strategy to combat chronic illnesses."
*ALS advocates also use adjectives like **'safe,' 'clear,' 'obvious,'** and **'effective'**; formatting boosters such as ALL CAPS and (often multiple) exclamation marks; indefinite pronoun boosters like **'everything'**,**'everyone'**, and **'all'** to express how this disease impacts all aspects of life and add to the emotional impact. **Numerical boosters** highlight the magnitude of suffering and loss within the ALS community by using phrases like 'Hundreds of people'.*

(3) **Attitude markers** serve as emotional cues and allow advocates to express a range of emotions and opinions on the topic at hand. Attitude markers include attitude verbs (agree, prefer), sentence adverbs (unfortunately, hopefully), and adjectives (appropriate, logical). Example: "This new policy is unfortunately a step backward." In this sentence, 'unfortunately' expresses the advocate's negative feelings.
*ALS advocates also use strong expressions and metaphors including words like **'death'**, **'die'** and **'hate'**.*

(4) **Self-mentions** serve as markers of personal perspectives or first-hand experiences. Words like 'I' and 'my' explicitly reference the advocate's presence and perspective in the text. Example: " I think I know better because I experienced it myself." The self-mentions in this post make the message personal and demonstrate a first-hand experience.

4.4.2 *Engagement.*

Engagement reveals efforts to involve readers in the discourse by indicating different strategies which guide readers through the arguments presented. Being involved makes readers more likely to align with the advocate's viewpoints, even when the advocate presents questionable opinions [32]. Engagement comprises five elements (*text in italics* shows updates to an element via our digital ethnography approach):

(1) **Reader pronouns** explicitly bring the reader into the discourse as a participant. Often, this signals membership in the community. Common reader pronouns are the second person 'you/your' pronouns and inclusive 'we' and 'our'. Example: "As you read this article, you'll discover how you can do scientific research." By using several pronouns aimed at the readers, the advocate strives to directly speak to them.
The ambiguous use of 'we' in ALS community's posts can mean ALS community; ALS community + society, or the ALS community + regulators. Such use includes various readers in the discourse

(2) **Personal aside** allows the writer to insert a comment and briefly interrupt the main narrative. Example: "The human brain contains approximately 86 billion neurons (here I am, struggling to remember this number!) and these neurons allow us to feel and perceive the world." In this example, the author gives an opinion in the middle of explaining a concept.
We did not find any example of personal asides. Hence, we decided to not include it in our final codebook.

(3) **Appeals to shared knowledge** aims to present information as commonly accepted and familiar to readers. Example: "We know this treatment works on many people." This sentence frames a claim as an accepted idea in a community.
ALS advocates make claims based on their interpretation of scientific results. Advocates appear to demonstrate familiarity with scientific concepts and expertise by using domain-specific terms and specialized language. This includes technical jargon, acronyms, and field-specific references typically used by experts. Three main categories of such "mentions of knowledge" include: knowledge about institutional processes, scientific knowledge, knowledge about specific drug/trial. For example, "The phase III trial for Remdesivir showed a faster recovery time for COVID-19." The advocate talks about a specific drug and gives information about it

(4) **Directives** function as instructions to the reader through imperatives (*e.g.*,"Take your medicine"), obligation modals (*e.g.*,"You must act now"), and necessity statements to perform actions. Directives commonly instruct or command the reader, using imperative verbs and clear instructions. For example, " You must stop worrying and actually start

doing something." The advocate uses several imperatives to command the reader to take an action.

Advocates use implicit directives to imply a desired course of action through suggestions, expectations, or consequences without directly telling the reader. For example, " It would be better if we all made an effort to search before asking" implicitly directs people to search first before posting.

(5) **Questions** seek to obtain information and facilitate an interactive dialogue. "Based on the observed improvements, should the FDA approve the new drug?" is a regular question that seeks a response that considers the evidence and weighs the risks and benefits of a new drug.

Many questions can be rhetorical: they do not expect a direct answer; instead, they emphasize a statement. "Who wouldn't want to have access to health care?" is a rhetorical question that does not seek an actual answer but claims that everyone would like to have access to health care.

5 Results

We share our results via representative examples of posts that showcase different elements of stance and engagement. Given the depth of insights and the extensive time needed to analyze these posts, we treat each example as a case study. We report on 13 case studies that highlight how the ALS advocacy movement demonstrates stance and engagement. Additional 27 case studies are summarized in the supplementary material.

5.1 Stance

The ALS advocacy movement expresses varied opinions and claims in its discourse. Some advocates try to make cautious arguments for a drug's effectiveness by carefully framing their claims. Others intensely criticize FDA's decisions by emphasizing the urgency of ALS and the dire consequences of delayed treatment approvals. Additionally, advocates try to foster empathy by highlighting the emotional toll of regulatory delays and construct a moral argument for access to treatments. Finally, some advocates assert their first-hand experiences with the disease or clinical trials. By taking such varied stance, the ALS advocacy shows its positions on different treatments with a combination of reason and personal conviction.

5.1.1 Hedges. Hedges serve to avoid claims with absolute certainty in knowledge. ALS advocates use hedges to advocate for potential treatments and maintain caution while conveying their perspectives and concerns. Advocates' perspectives on experimental treatments become difficult to dismiss outright since they avoid strong claims and highlight positive aspects of the experimental treatments.

> **Case Study 1**: "The @US_FDA rejected a safe treatment that **wasn't full proof** but **could** have still **possibly** saved hundreds of people. Inhumane is an understatement. #ALS #NurOwn #Dyingwaiting @NYDailyNews @nytimes @CBSNewYork @NY1 @fox5ny" - @Mayuri_Saxena, a person with ALS

Case Study 1 makes the claim about the efficacy of a drug more reasonable by hedging its possibility of saving people. While admitting that the drug is not 'full proof', the advocate also does not discount the drug's potential power for "saving hundreds of people" by using 'could' and 'possibly'.

5.1.2 Boosters. Boosters emphasize a strong commitment to knowledge claims. ALS advocates use boosters to strengthen claims about the safety, efficacy, and overall utility of treatments in two ways. They present their claims as accepted facts and convey the urgency of living with ALS.

> **Case Study 2**: "#NurOwn has the power to change **so many** ALS patient's lives- including my mother's life. NurOwn has **repeatedly** been **proven safe!** It's time to give ALS patients and their families hope for a better future**!!** @DrWoodcockFDA @FDACBER @US_FDA @als_now @alsadvocacy" - @JessiTrev, family member of a person with ALS

Case Study 2 strengthens its claim about a drug's efficacy by noting the drug has 'repeatedly' been 'proven safe'. The advocate frames the claim as a fact rather than an individual perspective. The word 'so many' emphasizes the drug's potential value of saving a large number of people.

5.1.3 Attitude Markers. Attitude markers reflect the advocate's personal feelings towards what is presented. ALS advocates use metaphors and strong language to convey frustration and sadness over lost abilities and institutional inaction.

> **Case Study 3**: "The inaction of @biogen and the US_FDA has left me paralyzed and on life support. There is only so much you can **beg for your life** until you become a **statistic buried in a report somewhere collecting dust** #ALS #ALSawarenessmonth **#dyingwaiting"** - @Mayuri_Saxena, a person with ALS

Case Study 3 notes that patients 'beg' for their lives and criticizes FDA for its perceived ignorance toward ALS patients. The advocate uses the phrase 'a statistic buried in a report' to make the claim that ALS patients are being ignored by FDA. The hashtag #dyingwaiting adds to this criticism by claiming that FDA's ignorance is causing patients to die while waiting for drugs.

5.1.4 Self-Mention. Self-mentions serve to assert identity. Traditional scientific and policy discussions rely on statistical approaches where people are represented as data points. By using self-mentions, ALS advocates assert their identity and convey the reality of ALS in ways that statistics do not capture.

> **Case Study 4**: "Friends - **I'm asking** for your help calling on the FDA to schedule a hearing to consider compelling evidence of an effective treatment for ALS [called] NurOwn. This request is **personal to me** because **I participated** in a clinical trial for Nurown and **I know it works**." - @emmccormick2005, a person with ALS

Case Study 4 expresses first-hand experience to persuade FDA to approve a new treatment. The speaker personalizes the request, using firsthand trial experience—'I participated' and 'I know it works'—to strengthen their argument for the drug's efficacy.

5.2 Engagement

ALS advocacy often demonstrates two behaviors when attempting to interact with regulators. Advocates seek to persuasively influence regulators based on their sense of being disregarded. They also demand recognition of their voices and lived experiences.

5.2.1 Reader Pronouns. Reader pronouns ('we', 'us', 'you') strive to engage readers in the argument. First-person pronouns ('we', 'us', 'our') can be ambiguous: advocates might try to show they are talking on behalf of the ALS community and foster a sense of unity and shared experience. They might also use 'we' to blur the line between the ALS community and society, referring to them as one entity. The broader use of 'we' creates a sense of collective responsibility.

> **Case Study 5**: " **We** need to change how @US_FDA evaluates therapies for terminal diseases like #ALS. **We** need to be more creative in collecting the necessary science while giving dying people an opportunity to try these investigational therapies. **We** have to do better!" - @pjgreen, a person with ALS

Case Study 5 uses 'we' repeatedly in an ambiguous way. Here, 'We' could refer to the ALS community, but it can also refer to the community and society as one entity. The latter creates a sense of collective responsibility and encourages the reader to identify with 'we'. The context around this post did not resolve this ambiguity. Additionally, advocates use the first and second pronouns to assert that the community and regulators are separate entities.

> **Case Study 6**: "I hope the @US_FDA realizes/understands that some persons speaking this week regarding approval of treatments, are using what's left of their last words/breath to do so....That's how determined **we** are! Just thought **you** should know what **you're** up against. #ShitOrGetOff" - @AlsDads, a person with ALS

Case Study 6 highlights the tension between the ALS community ('we') and the FDA ('you'). The phrase "Just thought you should know what you're up against" positions the FDA as an entity to be confronted or persuaded to act.

5.2.2 Appeals to shared knowledge. Appeals to shared knowledge ('we know') attempts to make claims less questionable by framing them as accepted knowledge.

> **Case Study 7**: "Day 800 asking @US_FDA to approve @BrainstormCell's #NurOwn and @FDACDERDirector @POTUS @DrCaliff FDA to help. **We KNOW** from patients that had NurOwn that it can help some stop, slow, or reverse ALS progression. Without it, they and others WILL die faster. Please approve NurOwn!" - @lauramanhardt, family member of a person with ALS

Case Study 7 uses the phrase 'We KNOW...' to frame the claim as shared knowledge within the ALS community regarding the effects of a particular drug.

ALS advocates reference different kinds of ALS-related knowledge that seem to serve multiple purposes. Mentions of knowledge enable the community to critique institutional decisions from an informed standpoint. Sharing relevant knowledge conveys the advocates' grasp of the issues from multiple perspectives which could make their viewpoint less likely to be dismissed. Such mentions appear in three distinct forms: knowledge about institutional processes, scientific knowledge, and knowledge about specific drug/trial.

> **Case Study 8**: "The Energy and Commerce Committee oversees FDA. FDA did NOT use **regulatory flexibility during Nurown AdCom** that they used for other ALS therapies. FDA also ignored Real World Data and 2000 public comments. Can we ask Congress to investigate FDA conduct?" - @Vita_Victoria2, family member of a person with ALS

Case Study 8 critiques the FDA's drug approval process by demonstrating knowledge of multiple institutional agencies and their connections. The advocate also names institutional terms like 'regulatory flexibility' and talks about institutional processes like 'AdCom' (AdCom refers to Advisory Committee which is a FDA panel comprising experts and patients who are consulted during decision-making).

> **Case Study 9**: "Qalsody's approval was based largely on **NfL data**. The companies' **Phase III VALOR study** failed its **primary endpoint** and showed that Qalsody could not induce a significant functional improvement in ALS patients after 28 weeks. Qalsody was approved April 2023 with FDA flexibility." - @ScottsFight, a person with ALS

Case Study 9 demonstrates scientific knowledge by mentioning multiple terms that are relevant to clinical trials such as neurofilament data (a biomarker), VALOR study (a specific clinical trial) and primary endpoints (measurable outcomes of a trial). The advocate uses these terms in their criticism of the FDA for inconsistency in decision-making such as approving some drugs based on biomarkers but not others.

> **Case Study 10**: "**#AMX0035 is safe and effective.** In a large, **placebo-controlled study**, it was found to be safe and effective with minimal side effects for #ALS. It met its primary endpoint – an endpoint specifically highlighted for use in the @FDA_US 's own drug development guidance document." - @mdemaria2017, Lost a family member due to ALS

Case Study 10 names a specific drug (AMX0035) and mentions trial-related terms like 'placebo-controlled study' to bolster its claim about the drug's efficacy.

5.2.3 Directives. Directives emphasize the need for concrete action. ALS advocacy strategically combines demands like access to experimental treatments with arguments about their life-saving potential while pushing for institutional action.

> **Case Study 11**: "My cousin, primarily in a wheelchair, has been on #tofersen since August and now WALKING short distances and LIVING with #als thanks to #tofersen! @us fda, **you MUST approve Tuesday!** So many lives depend on it! #endals #tofersenworks #rockstar" - @conniembecker, family member of a person with ALS

Case Study 11 uses the modal verb 'MUST' to make an explicit directive and adds an exclamation mark for emphasis. The advocate commands the FDA to approve a drug and consider the urgency of the situation.

> **Case Study 12**: "What you take for granted on warm summer days, @DrCaliff FDA, is beyond @kimfrench0405's capability. Can you imagine how helpless and angry she feels over a damn fly that is tormenting her? **She needs #NurOwn because #NurOwnWorks. Let's give it a try!** #ALS " - @sherryquis, a person with ALS

Case Study 12 is an implicit directive because of the phrase 'Let's give it a try!'. The advocate highlights how ALS strips patients of basic abilities and presents a moral argument that the conditions faced by those with ALS are unimaginable. Then, the advocate states definitively that 'She needs #NurOwn because #NurOwnWorks', presenting the treatment as an effective solution to the suffering described.

5.2.4 Questions. The ALS advocacy uses rhetorical questions to implicitly convey statements, persuade, argue, and criticize. Rhetorical questions serve to emphasize both logical and emotional arguments and can function as indirect calls to action.

> **Case Study 13** : "The suicide rate among #MND patients is twice that of the population. #ALS #Veterans are a 4X greater risk than non-ALS Vets. The increased rates are due to the hopelessness of ALS. @US_FDA slow roll of #NurOwn contributes to that hopelessness. **35% response isn't good enough?**" - @KRob8753, a person with ALS

Case Study 13 criticizes the FDA for its slow process of approving new treatments. The rhetorical question '35% isn't good enough?' asserts that a 35% response rate is sufficient for ALS treatment approval. The question criticizes the FDA's standards, suggesting they may be unreasonably high given the disease's severe impact.

6 Discussion

Drawing on our methods and results, we examine how our findings help us understand the ALS advocacy movement with the lens of collective intelligence. We then reflect on our methodological approach, highlighting how ethnographic methods and linguistic analysis complement each other. Finally, we explore the design implications of our findings and discuss how affordances of platforms can support collective intelligence.

6.1 ALS advocacy movement does not demonstrate collective intelligence

Traditional markers of collective intelligence include clear goals, hierarchical structure, collaboration, and structured information aggregation [12, 44, 58, 64, 66, 67, 73, 75]. Our results suggest that the ALS advocacy movement does not demonstrate typical dimensions of collective intelligence except for common goals. The ALS advocacy movement aims to accelerate drug approvals and secure access to experimental treatments. However, the community lacks a coordinated approach to strategically advance these goals. This characteristic is in contrast with other forms of collective intelligence such as Wikipedia where people may have different motivations, but the platform provides mechanisms to achieve shared goals through core policies such as neutral point of view (NPOV), verifiability, and notability [61]. With such mechanisms, people with varying intentions successfully coordinate toward clearly-defined goals.

The ALS advocacy movement on social platforms lacks effective ways to manage information. ALS advocates' insights and experiences are spread across individual posts which doesn't help build collective knowledge. Such distributed attempts at sharing information contrast with other successful attempts like Wikipedia. Wikipedia provides a structured model for managing information: revision histories and talk pages help aggregate, refine, and preserve knowledge over time [25, 38, 71]. The ALS advocacy movement's unstructured approach to managing information likely makes it difficult for new advocates to build upon others' knowledge and personal narratives. Having a way to document previous strategies (and their successes) could benefit future advocates who might otherwise have to start from scratch.

Furthermore, the ALS advocacy movement lacks ways to collaborate; this is in contrast to platforms like Wikipedia. Wikipedia provides established consensus mechanisms, voting procedures, and structured pathways for collective decision-making that result in productive collaboration [71]. In the ALS community, advocacy efforts on X appear independently, with seemingly little collaboration among members. Wikipedia operates through nested governance structures that helps with policy development [25]. However, ALS community's posts primarily reflect individual expressions.

Does the ALS advocacy movement meet its goal of obtaining potentially beneficial treatments? It's unclear. Some drugs (*e.g.*, Tofersen) are approved by the FDA while others (*e.g.*, NurOwn) aren't. Developing a concrete link between advocacy efforts and drug approvals was not a focus of our research. Additionally, such drug approval decisions are influenced by many scientific and policy factors beyond advocacy efforts. Our results demonstrate multiple mechanisms with which advocates strive to push for their goal. One mechanism takes the form of *appeals* to FDA to accelerate drug approvals by claiming that current regulatory standards are outdated and fail to address unique challenges of ALS. Another mechanism involves *threats* where advocates aggressively question decisions and use hashtags (like #DyingWaiting) to frame delays as threatening the lives of people with ALS.

6.2 Using digital ethnography and seminal models can facilitate studying online advocacy movements

Contemporary advocacy movements in health navigate rapidly changing knowledge landscape in settings including Long COVID [10, 62] and vaccines [36, 39]. Many prominently use social media to demonstrate their orientations to institutional policies. Combining a seminal linguistics model with insights from digital ethnography proved to be valuable for our goal of studying how an advocacy movement community attempts to engage with institutional policy makers. The benefits largely came from the two approaches fixing each other's weaknesses. Ethnographic research methods provide a contextually-grounded approach; however, results are often descriptive and tightly integrated to the community of study. Conversely, theoretical models are generalizable but miss on context-specific bits which are important for understanding specific communities' orientations. Combining digital ethnography with a seminal theoretical model formalized descriptive knowledge into concrete codes and situated a seminal linguistics model in a concrete real-world setting.

While Hyland's model helped us characterize how an advocacy movement presents its views to FDA, applying another framework could yield complementary insights. For instance, our results hint that people strategically use their identity to bolster claims. Theories of self-presentation might examine strategic disclosures and flexible presentation of identity [21, 40]. Another relevant framework is *logos-pathos-ethos* which identifies the nature of persuasive arguments [27]. Logos presents as strategic references to scientific knowledge. Attempts at pathos include personal narratives that often evoke empathy and convey urgency. Ethos includes questioning denial of access to potentially life-saving treatments. We believe different choices for theoretical frameworks can highlight unique aspects of advocacy discourse.

6.3 Platform designs can aid advocacy by enabling collective thinking and creating space for particular topics

ALS advocates self-organize and share opinions on institutional decisions. Since ALS is a rare disorder, people with ALS potentially feel ignored at two levels: institutional investment in science [57] and design of appropriate tools [42]. Unsurprisingly, the ALS advocacy movement has *repurposed* a popular social platform to criticize perceived lack of institutional investment and to raise public awareness about ALS. However, it is unclear whether the design and affordances of current social platforms are best suited for community-led efforts like advocacy movements [43]. Current designs (e.g. hashtags on X or Facebook groups) are often used for *internal* conversations within communities. Designing platforms for structured collaboration between advocates and institutions is an open challenge [6]. A relevant platform design *might* provide ways to highlight people's concerns regarding institutional decisions and support more effective ways for deliberation across various stakeholders. Early formative studies in design research can identify needs and platform features for both advocates and institutional experts. Facilitating meaningful engagement between communities and regulators can potentially lead to more responsive regulation and increased public trust in the process. Such avenues provide rich novel possibilities for social computing systems research.

6.3.1 Hashtags have limitations as a way of organizing knowledge. The ALS advocacy movement faces several challenges with hashtag usage that hinder effective knowledge aggregation. Many advocates post about important issues without using any specific hashtags which makes their content difficult to discover. Oftentimes, when hashtags are used, advocates rely on broad, general tags like #ALS or #FDA rather than specific hashtags that match their advocacy focus. Posts calling for policy changes or access to experimental treatments frequently use such general hashtags instead of more targeted ones, which prevents knowledge aggregation around specific issues.

ALS advocacy also lacks coordination in hashtag creation and usage. Even when advocating for the same cause, advocates use multiple, overlapping hashtags without coordination. During advocacy efforts for the experimental drug Nurown, the community employed various hashtags including #Nurown, #NurownWorks, #NurownIsSafe, #NurOwnPreservesFunctions, #NurOwnNow, #ApproveNurOwn, #dyingwaiting, and #RealWorldEvidence. Such related but distinct hashtags scatter information. Some advocates develop personal hashtags for broadly relevant issues. For instance, one advocate consistently uses #ShitorGetOff across their posts to demand action from FDA. Without a shared structure for hashtag use, many advocates may be unaware of the most widely used or effective hashtags for a topic.

6.3.2 Some social features can be useful for facilitating collective knowledge-building. Several social platform features enabled ALS advocates to collectively build on each other's knowledge and opinions. Collective intelligent emerges in group settings where people can argue and reach concrete resolutions [74]. The reply function allows community members to fact-check or complete each other's knowledge. For instance, one advocate posted frustration about awareness campaigns.

> "Enough with awareness. Please fight for us, support us to get #Nurown now or explain why you are against it, why you keep quiet"

In response, another advocate provided supporting data.

> "You are right that awareness doesn't work on als. Polls show it's the least known neurodegenerative diseases at 34% even as far back as 2018 only 4 years after ibc it was still at 34%. Awareness for such a rare disease is useless."

Another feature that helps with co-constructing knowledge is quoting. Quoting allows advocates to add information or corrections to existing posts in addition to sharing the original post with their own followers which results in increased visibility of the original post. Additionally, reposting serves as a mechanism for knowledge building. Advocates regularly share each other's content, ensuring that valuable information reaches other advocates.

While our research efforts focused on understanding the text in social posts, the platform's multimodal capabilities support an important form of evidence-building within ALS advocacy. Advocates share personal photos and videos documenting their experiences with the disease and various treatments, creating real-world evidence about different drugs' effectiveness and disease progression. This multimodal content becomes a powerful advocacy tool, providing first-hand experiences to support advocates' arguments.

7 Future Work

Our research team was intrigued by the use of the "mention of knowledge" strategy, which closely resembles 'credibility tactics' observed in AIDS/HIV advocacy efforts [23]. Referencing specific knowledge implies self-education on the topic. However, we lack evidence that this learning process occurs within ALS advocacy. For example, institutional terms like 'regulatory flexibility' or 'trial endpoints' might be used because individuals understand their meaning or because they have encountered these terms frequently within the community and are repeating them to align with institutional language. Future research could explore credibility tactics in ALS advocacy to determine whether there is a structured process by which advocates educate themselves.

Our results hinted at multiple mechanisms with which advocates strive to push for their goal such as appeals to the FDA or aggressively questioning the FDA's decisions. Further work could create an exhaustive list of mechanisms (including appeals, threats) and how they emerge in a movement without explicit collaboration and hierarchy.

Furthermore, throughout our analysis, we found many strategies used by the ALS community that were shaped by its specific circumstances. However, some of the strategies also aligned with those identified in prior research. For instance, a study on YouTube comments has also noted the use of formatting boosters and markers of quantification [45]. Future work could explore how and why different online communities use similar markers to show their stance.

8 Conclusion

Our research examines how an online advocacy movement employs nuanced linguistic strategies, particularly stance and engagement markers, to position itself in relation to institutional processes. Our work focuses on epistemic stance and engagement. Stance refers to the aspects of an utterance that indicate the speaker's degree of certainty or commitment to the truth of their statements [28]. Analyzing engagement features reveals how advocates draw readers into their arguments, making them more likely to adopt the advocate's views. However, understanding a community's utterances toward institutions and engagement strategies requires more than rhetorical analysis—it also requires deep contextual insight into how real-world needs and constraints shape the community's online actions. Combining a seminal linguistic model with contextual insights from digital ethnography proved valuable for examining how online advocacy movements attempt to engage with policymakers.

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References

[1] 2014. *Roundtable on Population Health Improvement; Roundtable on the Promotion of Health Equity and the Elimination of Health Disparities; Board on Population Health and Public Health Practice; Institute of Medicine. Supporting a Movement for Health and Health Equity: Lessons from Social Movements: Workshop Summary.* National Academies Press, Washington (DC; US).

[2] Jai Aggarwal, Brian Diep, Julia Watson, and Suzanne Stevenson. 2023. Investigating Online Community Engagement through Stancetaking. In *Findings of the Association for Computational Linguistics: EMNLP 2023*, Houda Bouamor, Juan Pino, and Kalika Bali (Eds.). Association for Computational Linguistics, Singapore, 5814–5830. doi:10.18653/v1/2023.findings-emnlp.387

[3] Temitope M. Ajayi. 2019. Stances and Engagement in 'The Gang Up to Deal with Buhari'. *The African Review: A Journal of African Politics, Development and International Affairs* 46, 1 (2019), 184–204. http://www.jstor.org/stable/45420263

[4] David Altheide. 1987. Ethnographic Content Analysis. *Qualitative Sociology* 10 (03 1987), 65–77. doi:10.1007/BF00988269

[5] Marcos Ancelovici. 2021. Conceptualizing the context of collective action: an introduction. *Soc. Mov. Stud.* 20, 2 (March 2021), 125–138.

[6] Oghenemaro Anuyah, Karla Badillo-Urquiola, and Ronald Metoyer. 2023. Engaging the Discourse of Empowerment for Marginalized Communities Through Research and Design Participation. In *Extended Abstracts of the 2023 CHI Conference on Human Factors in Computing Systems* (Hamburg, Germany) *(CHI EA '23)*. Association for Computing Machinery, New York, NY, USA, Article 100, 7 pages. doi:10.1145/3544549.3585678

[7] Mariam Asad and Christopher A. Le Dantec. 2017. Tap the "Make This Public" Button: A Design-Based Inquiry into Issue Advocacy and Digital Civics. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (Denver, Colorado, USA) *(CHI '17)*. Association for Computing Machinery, New York, NY, USA, 6304–6316. doi:10.1145/3025453.3026034

[8] ALS Association. 2025. *ALS Association, An advocacy organization with the mission to make ALS livable and cure it, https://www.als.org/advocacy.* https://www.als.org/advocacy

[9] Dina Ayad. 2022. A Corpus Analysis of Engagement Markers in Facebook Status Updates: Exploring Age and Gender Effects. *CDELT Occasional Papers in the Development of English Education* 77 (01 2022), 97–126. doi:10.21608/opde.2022.241790

[10] Kristin Kay Barker, Owen Whooley, Erin F Madden, Emily E Ahrend, and R Neil Greene. 2024. The long tail of COVID and the tale of long COVID: Diagnostic construction and the management of ignorance. *Sociol. Health Illn.* 46, S1 (March 2024), 189–207.

[11] Monica Barratt and Alexia Maddox. 2016. Active engagement with stigmatised communities through digital ethnography. *Qualitative Research* 16 (05 2016). doi:10.1177/1468794116648766

[12] Yochai Benkler, Aaron David Shaw, and Benjamin Mako Hill. 2015. *Peer Production: A Modality of Collective Intelligence.* MIT Press, 175–203.

[13] DOUGLAS BIBER and EDWARD FINEGAN. 1989. Styles of stance in English: Lexical and grammatical marking of evidentiality and affect. *Text - Interdisciplinary Journal for the Study of Discourse* 9, 1 (1989), 93–124. doi:doi:10.1515/text.1.1989.9.1.93

[14] YARIMAR BONILLA and JONATHAN ROSA. 2015. #Ferguson: Digital protest, hashtag ethnography, and the racial politics of social media in the United States. *American Ethnologist* 42, 1 (2015), 4–17. doi:10.1111/amet.12112 arXiv:https://anthrosource.onlinelibrary.wiley.com/doi/pdf/10.1111/amet.12112

[15] Steve Buckley. 2013. Advocacy Strategies and Approaches: Overview Paper. (01 2013).

[16] Julia Coffman and Tanya Beer. 2015. The advocacy strategy framework. *Center for evaluation innovation* (2015).

[17] William Covino and David Jolliffe. 1995. What is rhetoric. *Rhetoric: Concepts, definitions, boundaries* (1995), 325.

[18] Shiva Darian, Aarjav Chauhan, Ricky Marton, Janet Ruppert, Kathleen Anderson, Ryan Clune, Madeline Cupchak, Max Gannett, Joel Holton, Elizabeth Kamas, Jason Kibozi-Yocka, Devin Mauro-Gallegos, Simon Naylor, Meghan O'Malley, Mehul Patel, Jack Sandberg, Troy Siegler, Ryan Tate, Abigil Temtim, Samantha Whaley, and Amy Voida. 2023. Enacting Data Feminism in Advocacy Data Work. *Proc. ACM Hum.-Comput. Interact.* 7, CSCW1, Article 47 (April 2023), 28 pages. doi:10.1145/3579480

[19] Iskander De Bruycker. 2019. Blessing or curse for advocacy? How news media attention helps advocacy groups to achieve their policy goals. *Polit. Commun.* 36, 1 (Jan. 2019), 103–126.

[20] Alex de Sherbinin, Anne Bowser, Tyng-Ruey Chuang, Caren Cooper, Finn Danielsen, Rorie Edmunds, Peter Elias, Elaine Faustman, Carolynne Hultquist, Rosy Mondardini, Ioana Popescu, Adenike Shonowo, and Kishore Sivakumar. 2021. The Critical Importance of Citizen Science Data. *Frontiers in Climate* Volume 3 - 2021 (2021). doi:10.3389/fclim.2021.650760

[21] Michael A. DeVito, Jeremy Birnholtz, and Jeffery T. Hancock. 2017. Platforms, People, and Perception: Using Affordances to Understand Self-Presentation on Social Media. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing* (Portland, Oregon, USA) *(CSCW '17)*. Association for Computing Machinery, New York, NY, USA, 740–754. doi:10.1145/2998181.2998192

[22] John Du Bois. 2007. *The stance triangle.* 139–182. doi:10.1075/pbns.164.07du

[23] Steven Epstein. 1995. The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials. *Science, Technology, & Human Values* 20, 4 (1995), 408–437. http://www.jstor.org/stable/689868

[24] Steven G Epstein. 1996. *Impure Science: AIDS, Activism, and the Politics of Knowledge.* University of California Press.

[25] Andrea Forte, Vanessa Larco, and Amy Bruckman. 2009. Decentralization in Wikipedia Governance. *Journal of Management Information Systems* 26, 1 (2009), 49–72. http://www.jstor.org/stable/40398966

[26] Christoph Hafner. 2023. Multimodal stance and engagement in digital video methods articles. *Ibérica* (12 2023), 155–180. doi:10.17398/2340-2784.46.155

[27] Colin Higgins and Robyn Walker. 2012. Ethos, logos, pathos: Strategies of persuasion in social/environmental reports. *Accounting Forum* 36, 3 (2012), 194–208. doi:10.1016/j.accfor.2012.02.003 arXiv:https://doi.org/10.1016/j.accfor.2012.02.003

[28] Jisoo Hong. 2022. *A Thesis Allegedly.* Master's dissertation. Massachusetts Institute of Technology. https://hdl.handle.net/1721.1/144608

[29] James Hrastelj and Neil Robertson. 2016. Ice bucket challenge bears fruit for amyotrophic lateral sclerosis. *Journal of Neurology* 263 (10 2016). doi:10.1007/s00415-016-8297-7

[30] Robert M. Hughes, Robert L. Vadas, J. Hal Michael, Beverly E. Law, Arthur C. Knutson, Dominick A. DellaSala, Jim Burroughs, and Hal Beecher. 2021. 8 - Why advocate,Äîand how? In *Conservation Science and Advocacy for a Planet in Peril*, Dominick A. DellaSala (Ed.). Elsevier, 177–197. doi:10.1016/B978-0-12-812988-3.00015-6

[31] Susan Hunston and Geoff Thompson. 2000. Evaluation in Text: Authorial Stance and the Construction of Discourse. (02 2000). doi:10.1093/oso/9780198238546.001.0001

[32] Ken Hyland. 2005. Stance and Engagement: A Model of Interaction in Academic Discourse. *Discourse Studies* 7, 2 (2005), 173–192. doi:10.1177/1461445605050365

[33] Bob Jickling. 2003. Environmental education and environmental advocacy: Revisited. *J. Environ. Educ.* 34, 2 (Jan. 2003), 20–27.

[34] Satveer Kaur-Gill and Mohan Dutta. 2017. *Digital Ethnography.* Publisher John Wiley & Sons Inc., 10. doi:10.1002/9781118901731.iecrm0271

[35] Scott F. Kiesling, Umashanthi Pavalanathan, Jim Fitzpatrick, Xiaochuang Han, and Jacob Eisenstein. 2018. Interactional stancetaking in online forums. *Comput. Linguist.* 44, 4 (Dec. 2018), 683–718. doi:10.1162/coli_a_00334

[36] Crystal Lee, Tanya Yang, Gabrielle D Inchoco, Graham M. Jones, and Arvind Satyanarayan. 2021. Viral Visualizations: How Coronavirus Skeptics Use Orthodox Data Practices to Promote Unorthodox Science Online. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems (CHI '21).* Association for Computing Machinery, Article 607, 18 pages. doi:10.1145/3411764.3445211

[37] Gideon Lewis-Kraus. 2023. *When Dying Patients Want Unproven Drugs, https://www.newyorker.com/magazine/2023/06/26/relyvrio-als-fda-approval.* https://www.newyorker.com/magazine/2023/06/26/relyvrio-als-fda-approval

[38] Sharman Lichtenstein and Craig Parker. 2009. Wikipedia model for collective intelligence: a review of information quality. *IJKL* 5 (01 2009), 254–272. doi:10.1504/IJKL.2009.031199

[39] Maxim Lisnic, Cole Polychronis, Alexander Lex, and Marina Kogan. 2023. Misleading Beyond Visual Tricks: How People Actually Lie with Charts. 1–21. doi:10.1145/3544548.3580910

[40] Eden Litt, Erin Spottswood, Jeremy Birnholtz, Jeff T. Hancock, Madeline E. Smith, and Lindsay Reynolds. 2014. Awkward encounters of an "other" kind: collective self-presentation and face threat on facebook. In *Proceedings of the 17th ACM Conference on Computer Supported Cooperative Work & Social Computing* (Baltimore, Maryland, USA) *(CSCW '14).* Association for Computing Machinery, New York, NY, USA, 449–460. doi:10.1145/2531602.2531646

[41] María José Luzón. 2023. Multimodal practices of research groups in Twitter: An analysis of stance and engagement. *English for Specific Purposes* 70 (04 2023), 17–32. doi:10.1016/j.esp.2022.10.006

[42] Haley MacLeod, Kim Oakes, Danika Geisler, Kay Connelly, and Katie Siek. 2015. Rare World: Towards Technology for Rare Diseases. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems* (Seoul, Republic of Korea) *(CHI '15).* Association for Computing Machinery, New York, NY, USA, 1145–1154. doi:10.1145/2702123.2702494

[43] Stephen MacNeil, Zijian Ding, Ashley Boone, Anthony Bryce Grubbs, and Steven P. Dow. 2021. Finding Place in a Design Space: Challenges for Supporting Community Design Efforts at Scale. *Proc. ACM Hum.-Comput. Interact.* 5, CSCW1, Article 172 (apr 2021), 30 pages. doi:10.1145/3449246

[44] Thomas W. Malone, Jeffrey V. Nickerson, Robert J. Laubacher, Laur Hesse Fisher, Patrick de Boer, Yue Han, and W. Ben Towne. 2017. Putting the Pieces Back Together Again: Contest Webs for Large-Scale Problem Solving. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing* (Portland, Oregon, USA) *(CSCW '17).* Association for Computing Machinery, New York, NY, USA, 1661–1674. doi:10.1145/2998181.2998343

[45] Laura McCambridge. 2022. Describing the voice of online bullying: An analysis of stance and voice type in YouTube comments. *Discourse, Context and Media* 45 (03 2022), 100552. doi:10.1016/j.dcm.2021.100552

[46] Paul Mehta, Jaime Raymond, Theresa Nair, Moon Han, Jasmine Berry, Reshma Punjani, Theodore Larson, Suraya Mohidul, and D Kevin Horton. 2025. Amyotrophic lateral sclerosis estimated prevalence cases from 2022 to 2030, data from the national ALS Registry. *Amyotroph. Lateral Scler. Frontotemporal Degener.* 26, 3-4 (May 2025), 290–295.

[47] Caitlin Moscatello. 2025. *When Your Terminal Illness Makes You a TikTok Star, https://www.nytimes.com/2025/01/02/well/brooke-eby-als-tiktok-instagram.html.* https://www.nytimes.com/2025/01/02/well/brooke-eby-als-tiktok-instagram.html

[48] Jennifer E Mosley, David F Suárez, and Hokyu Hwang. 2023. Conceptualizing organizational advocacy across the nonprofit and voluntary sector: Goals, tactics, and motivation. *Nonprofit Volunt. Sect. Q.* 52, 1_suppl (April 2023), 187S–211S.

[49] Jonathan Obar, Paul Zube, and Cliff Lampe. 2011. Advocacy 2.0: An Analysis of How Advocacy Groups in the United States Perceive and Use Social Media as Tools for Facilitating Civic Engagement and Collective Action. *Journal of Information Policy* 2 (11 2011). doi:10.2139/ssrn.1956352

[50] Opeyemi Olawe and Oluwadamilola Akinyemi. 2023. Stance and Engagement in Participants' Response to the News of Russian War in Ukraine in Facebook Discussion. *Studies in Pragmatics and Discourse Analysis* 4 (12 2023), 49–70. doi:10.48185/she.v4i2.935

[51] Iman Omar, Iman Mahfouz, Sameh Ansary, and Nevine Sarwat. 2023. Expressing stance in brand posts on Facebook: a cross-cultural investigation. *Insights into Language, Culture and Communication* 3 (04 2023), 82. doi:10.21622/ilcc.2023.03.1.082

[52] Vineet Pandey, Tushar Koul, Chen Yang, Daniel McDonald, Mad Price Ball, Bastian Greshake Tzovaras, Rob Knight, and Scott Klemmer. 2021. Galileo: Citizen-led Experimentation Using a Social Computing System. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems* (Yokohama, Japan) *(CHI '21).* Association for Computing Machinery, New York, NY, USA, Article 565, 14 pages. doi:10.1145/3411764.3445668

[53] Baekkwan Park, Amanda Murdie, and David R Davis. 2019. The (co)evolution of human rights advocacy: Understanding human rights issue emergence over time. *Coop. Confl.* 54, 3 (Sept. 2019), 313–334.

[54] Umashanthi Pavalanathan, Jim Fitzpatrick, Scott Kiesling, and Jacob Eisenstein. 2017. A Multidimensional Lexicon for Interpersonal Stancetaking. 884–895. doi:10.18653/v1/P17-1082

[55] Geah Pressgrove, Brooke Weberling McKeever, and S Mo Jang. 2018. What is Contagious? Exploring why content goes viral on Twitter: A case study of the ALS Ice Bucket Challenge. *Int. J. Nonprofit Volunt. Sect. Mark.* 23, 1 (Feb. 2018), e1586.

[56] Sepideh Rahimpour. 2014. Blogs: A Resource of Online Interactions to Develop Stance-taking. *Procedia - Social and Behavioral Sciences* 98 (2014), 1502–1507. doi:10.1016/j.sbspro.2014.03.571 Proceedings of the International Conference on Current Trends in ELT.

[57] Rachel B Ramoni, John J Mulvihill, David R Adams, Patrick Allard, Euan A Ashley, Jonathan A Bernstein, William A Gahl, Rizwan Hamid, Joseph Loscalzo, Alexa T McCray, Vandana Shashi, Cynthia J Tifft, Undiagnosed Diseases Network, and Anastasia L Wise. 2017. The Undiagnosed Diseases Network: Accelerating discovery about Health and disease. *Am. J. Hum. Genet.* 100, 2 (Feb. 2017), 185–192.

[58] Christoph Riedl, Young Ji Kim, Pranav Gupta, Thomas Malone, and Anita Woolley. 2021. Quantifying collective intelligence in human groups. *Proceedings of the National Academy of Sciences* 118 (05 2021), e2005737118. doi:10.1073/pnas.2005737118

[59] Bettina Ringsing and Cees Leeuwis. 2008. Learning about advocacy. *Evaluation (Lond.)* 14, 4 (Oct. 2008), 413–436.

[60] Amy Risley. 2011. The power of persuasion: Issue framing and advocacy in Argentina. *J. Lat. Am. Stud.* 43, 4 (Nov. 2011), 663–691.

[61] Alessandro Rossi, Loris Gaio, Matthijs den Besten, and Jean-Michel Dalle. 2010. Coordination and Division of Labor in Open Content Communities: The Role of Template Messages in Wikipedia. In *2010 43rd Hawaii International Conference on System Sciences.* 1–10. doi:10.1109/HICSS.2010.122

[62] Phillip H. Roth and Mariacarla Gadebusch-Bondio. 2022. The contested meaning of ,Aulong COVID,AU ,Aì Patients, doctors, and the politics of subjective evidence. *Social Science & Medicine* 292 (2022), 114619. doi:10.1016/j.socscimed.2021.114619

[63] David Russell, Naomi Spence, Jo-Ana Chase, Tatum Schwartz, Christa Tumminello, and Erin Bouldin. 2022. Support amid uncertainty: Long COVID illness experiences and the role of online communities. *SSM - Qualitative Research in Health* 2 (10 2022), 100177. doi:10.1016/j.ssmqr.2022.100177

[64] Douglas Schuler, Anna De Liddo, Justin Smith, and Fiorella de Cindio. 2018. Collective intelligence for the common good: cultivating the seeds for an intentional collaborative enterprise. *AI & SOCIETY* 33 (2018), 1–13. https://api.semanticscholar.org/CorpusID:46774248

[65] Victoria C Scott and Susan M Wolfe. 2015. *Community psychology.* SAGE Publications, Thousand Oaks, CA.

[66] Monika Skaržauskaitė, Aelita Skarzauskiene, and Belén Ribeiro-Navarrete. 2015. Emergence of collective intelligence in online communities. *Journal of Business Research* 69 (11 2015). doi:10.1016/j.jbusres.2015.10.044

[67] Shweta Suran, Vishwajeet Pattanaik, and Dirk Draheim. 2020. Frameworks for Collective Intelligence: A Systematic Literature Review. *ACM Comput. Surv.* 53, 1, Article 14 (Feb. 2020), 36 pages. doi:10.1145/3368986

[68] Melody Turner, Helen Beckwith, Tanisha Spratt, Elvira Perez, and Barry Coughlan. 2023. The #longcovid revolution: A reflexive thematic analysis. (08 2023).

[69] Jacquelien van Stekelenburg and Bert Klandermans. 2023. *Context Matters, But How?* Cambridge University Press, 153–171.

[70] Rosana Villares. 2023. Exploring Rhetorical Strategies of Stance and Engagement in Twitter Conference Presentations. *ESP Today* 11 (05 2023), 280–301. doi:10.

18485/esptoday.2023.11.2.5

[71] Esther Weltevrede and Erik Borra. 2016. Platform affordances and data practices: The value of dispute on Wikipedia. *Big Data & Society* 3, 1 (2016), 2053951716653418. doi:10.1177/2053951716653418 arXiv:https://doi.org/10.1177/2053951716653418

[72] Paul Wicks, Timothy Vaughan, Michael Massagli, and James Heywood. 2011. Accelerated clinical discovery using self-reported patient data collected online and a patient-matching algorithm. *Nature biotechnology* 29 (05 2011), 411–4. doi:10.1038/nbt.1837

[73] Anita Woolley, Ishani Aggarwal, and Thomas Malone. 2015. *Collective Intelligence in Teams and Organizations*.

[74] Anita Woolley, Christopher Chabris, Alex Pentland, Nada Hashmi, and Thomas Malone. 2010. Evidence of a Collective Intelligence Factor in the Performance of Human Groups. *Science (New York, N.Y.)* 330 (10 2010), 686–8. doi:10.1126/science.1193147

[75] Anita Williams Woolley, Rosalind M. Chow, Anna T. Mayo, Christoph Riedl, and Jin Wook Chang. 2023. Collective Attention and Collective Intelligence: The Role of Hierarchy and Team Gender Composition. *Organization Science* 34, 3 (May 2023), 1315–1331. doi:10.1287/orsc.2022.1602

[76] Amy X. Zhang and Scott Counts. 2015. Modeling Ideology and Predicting Policy Change with Social Media: Case of Same-Sex Marriage. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems* (Seoul, Republic of Korea) *(CHI '15)*. Association for Computing Machinery, New York, NY, USA, 2603–2612. doi:10.1145/2702123.2702193

[77] Hang Zou and Ken Hyland. 2024. "People should get their booster": Stance towards Covid vaccination in news and academic blogs. *International Journal of Corpus Linguistics* 29, 4 (Dec. 2024), 447–471. doi:10.1075/ijcl.22110.zou