

Rhetoric and linguistic strategies in an online advocacy movement

Collective intelligence research has traditionally focused on formal, structured groups like teams and organizations. Many emergent collective efforts on digital platforms perform open-ended work in novel settings. For instance, advocacy movements on digital platforms vigorously engage in policy conversations on personally-relevant topics. This paper contributes an empirical understanding of the Amyotrophic Lateral Sclerosis (ALS) advocacy movement's efforts to engage with FDA. 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 various linguistic strategies that integrate knowledge claims with context-specific rhetorical techniques. Overall, our work suggests multiple directions for further analytical and design work to support advocacy movements' attempts to engage with institutional agencies.

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

Additional Key Words and Phrases: Advocacy movement, Online discourse, Linguistic model, Digital ethnography, Rhetoric, Rare disorder

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1 Introduction

Collective intelligence research has traditionally focused on formal, structured groups like teams and organizations. 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" [55]. Traditional markers of collective intelligence include clear goals [48, 54], hierarchical structure [10, 48, 54, 56], collaboration [42, 45, 48, 54], and structured information aggregation [35, 47, 48, 54]. Different groups meet these criteria with an array of mechanisms. For example, to meet their goals of improving patient outcomes, patient communities on the PatientsLikeMe platform use structured crowd-sourced methods for aggregating patient-reported data about drug use and effects [53]. Citizen science projects provide workflows via apps for volunteers to collect and analyze data, ensuring systematic knowledge aggregation [12].

Many emergent collective efforts on digital platforms perform open-ended work in novel settings. Such efforts finds poor match with team/organizations and existing success measures like quality of collaborative artifacts. For instance, advocacy movements on digital platforms vigorously engage in policy conversations on personally-relevant topics. This paper provides an understanding of the work performed by a patient advocacy movement that attempts to engage with regulatory questions on a social platform. Concretely, this paper contributes an empirical understanding of the Amyotrophic Lateral Sclerosis (ALS) advocacy movement's efforts to engage with FDA.

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Our research builds on multiple insights. Developing a rich contextual understanding of a community is necessary to understand how their 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 and that they have lived experiences about. To understand their rhetorical strategies and accompanying linguistic choices, prior linguistic models provide a good (but not great) fit. Prior models illuminate structural choices in communities’ efforts but miss on the context-specific elements. Our work operationalizes 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 various linguistic strategies that integrate knowledge claims with context-specific rhetorical techniques. Overall, our work suggests multiple directions for further analytical and design work to support advocacy movements’ attempts to engage with institutional agencies.

2 Related Work

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

2.1 How do advocacy movements use digital platforms?

Advocacy movements are a varied collection of initiatives aimed at supporting and representing vulnerable individuals to secure their rights and to have their voices heard [20]. Advocacy movements have historically demonstrated remarkable success in addressing complex social and institutional challenges. HIV/AIDS advocacy efforts successfully raised public awareness, secured research funding, and nudged institutional agencies in including AIDS patients in policy-making [15, 16]. 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 [6]. The ALS Ice Bucket Challenge was a viral social media campaign that raised public awareness and generated funds that led to developing new drugs [22]. Understanding advocacy movements’ efforts can yield a deeper understanding of strategies that support greater public participation in institutional processes.

Traditional settings for studying collective intelligence include teams and organizations with structured roles. Advocacy movements (unlike advocacy organizations) are different: they rarely have leaders and roles. Additionally, they might have multiple goals, *e.g.* raising public awareness, shifting public attitudes, or influencing institutional policies that are difficult to assess on timelines of days or weeks. Advocacy movements typically deal with issues like justice [46], human rights [39], or environmental protection [25] where advocates’ knowledge is often qualitative and experiential. Additionally, advocacy movements display emergent, adaptive strategies driven by urgency and lived experience rather than concrete top-down planning.

While many digital platforms are designed to enable groups of people to collaborate and share knowledge, they rarely meet the needs of advocacy movements. Lacking dedicated platforms, many advocacy movements rely on social media sites for organizing and sharing knowledge. People with Long COVID community shared their symptoms, experiences, and research findings on X [8, 43, 44, 49]. Their advocacy efforts eventually gained mainstream attention and influenced research priorities [49]. As communities increasingly self-organize to advocate for topics including health/ environmental crises, better understanding advocacy movements’ use of digital platforms can benefit many societal stakeholders.

2.2 Digital ethnography provides a rich way to understand emergent behavior in online settings

Studies of collective intelligence in structured settings often rely on measurable outcomes or tangible artifacts like Wikipedia articles [29]. However, advocacy movements' efforts don't always yield a concrete artifact. Hence, rather than seeking to study a collaborative artifact, researchers could focus on contributions by advocates. Additionally, since advocacy efforts often aim to alter public or institutional opinions, rhetoric and linguistic practices 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. Any useful characterization of a movement's position on a topic requires understanding its concrete challenges and needs, cultural norms, and the intended audience [4, 50]. *E.g.*, advocates for greater investment in AIDS research aligned *with* some institutional processes [15]: they spoke with experts at scientific conferences. They also engaged in street-level protests *against* institutional decisions. Such approaches now show up on digital platforms. For example, during the COVID-19 pandemic, anti-mask groups created counter-visualizations to challenge institutional public health guidelines [28]. Rather than outright rejecting institutional analyses, anti-mask groups emphasized raw data over expert interpretations and claimed uncertainties in experts' analysis. To understand such approaches, researchers at MIT embedded themselves in the community's online discursive practices over months [28].

More generally, digital ethnography requires researchers to immerse themselves in online communities to understand social interactions and behaviors [26]. By staying rooted in smaller samples, digital ethnography yields deeper understanding [17] about a range of communities' behaviors. For drug-use communities, digital ethnography revealed the communities' technical expertise and mechanisms of self-regulation [9]. Unlike traditional content analysis that shows thematic patterns about "what" happens in a community, digital ethnography also helps answer "how" questions by observing how meanings and relationships emerge and evolve. Ethnographic content analysis (ECA) blends aspects of both approaches and yields ways to systematically categorize online content while also interpreting its broader social and cultural significance [3]. To examine an advocacy movement on X, our work adopts a combination of digital ethnography and subsequent content analysis of posts.

2.3 Understanding rhetoric in advocacy movements requires ways to characterize stance and engagement

Since advocacy movements often strive to impact opinions, they demonstrate linguistic practices sensitive to their context (such as needs and constraints) and to the audience. Advocates challenge one-sided nature of institutional discourse and argue for actions that deviate from the usual. *E.g.*, advocates seeking better support for AIDS research shared scientific references to enhance their claims' legitimacy while also criticizing existing decisions [15]. Characterizing such discourse requires ways to identify *stance* aka positioning and arguments that seek to engage.

Linguistic models often identify stance through word counts or sentiment analysis [1, 40]. While useful, these keyword-based approaches overlook the higher-level positioning and engagement work central to advocacy. Other approaches characterize stance in conversations that are *internal* to a community [27] or frame stance as a dialogic social action shaped through interaction [14]. In contrast, advocacy movements often seek to engage with *external* institutions without always receiving a response. Other models provide grammatical markers like affect adjectives ("Our community is so *happy!*") [11] or evaluative claims ("This decision is *irrational!*") [23]. A suitable linguistic model to study 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 [24]. 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 [2, 7, 19, 32, 36–38, 51, 57]. Some studies use Hyland’s model without modifying it [2, 7, 19, 37, 38, 51, 57]. Others fit the model to their specific context [32, 36]. *E.g.*, YouTube comments on an UN Climate Action Summit speech demonstrated bullying behavior when a novel ‘stance focus’ section was introduced to the original Hyland’s model [36]. The utility of the original Hyland model plus its extensibility make it a attractive candidate for studying different online groups. Furthermore, using ethnographic methods to update Hyland’s model remains an open challenge [36]. Our work combines Hyland’s model with contextual insights via digital ethnography to understand rhetorical strategies in an advocacy movement.

3 Choosing a 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.

Clear motivation: ALS is a fatal disorder with no cure and limited treatments. Developing treatments and cures for the disorder is a high-priority goal for people living with ALS. 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 these don’t match ALS’ urgency.

Prior success: ALS affects 30,000 individuals in the US. The ALS advocacy movement has successfully mobilized collective action for over a decade. *E.g.*, the viral Ice Bucket Challenge significantly increased public awareness and funding [22]. The small scale of the ALS advocacy movement on social media allows for 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 life experiences and regulatory updates.

Use of social media: People with ALS primarily organize in digital spaces since physical limitations make in-person advocacy prohibitive. X provides 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 of terms (*e.g.* ‘regulatory flexibility’), regulatory updates (*e.g.* specific drug mentions), advocates’ response; and collecting relevant posts for analysis. We initially applied Hyland’s model to a subset of collected 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 20+ likes that discuss ALS, FDA, and a drug (NurOwn, "#NurOwnWorks") for a duration when the drug was a popular topic.

4.2 Data coding

Starting with Hyland's model (S4.5), the primary author deductively coded the posts. During weekly meetings, a co-author independently coded a subset to offer an additional perspective 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 used inductive coding to update existing categories in the codebook. The coding stopped when no new codes emerged and the codebook captured 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, 30+ meetings, and extended discussions that reached consensus.

4.3 Digital ethnography for ALS advocacy

The research team's focus was characterizing *how ALS advocates frame their strategies and arguments*. We highlight some themes below.

ALS advocates' critique institutional processes; they discuss regulatory decisions and scientific results around experimental treatments. Specifically, they mention multiple drugs in posts and hashtags. 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 possibilities with better treatment options.

Advocates challenge conventional risk-benefit calculations and assessment criteria for ALS. *E.g.*, 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 might have been oblivious to us otherwise. Such aspects are not fully captured in the original, context-agnostic Hyland's model. We updated this model by adding new codes specific to ALS advocacy discourse. These updates are highlighted in *italics* in S4.4.

4.4 Choosing a model

Hyland's model of stance and engagement helps characterize specific rhetorical strategies used by advocates.

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 [24]. Identifying stance helps understand and analyze arguments, uncover potential biases, and interpret purported meanings behind statements. Stance comprises four elements (*text in italic 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 introduce uncertainty in 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 influenced by their potential 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, remarkable). 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. It indicates different strategies which guide readers through the arguments presented. This involvement makes readers more likely to align with the advocate’s viewpoints, even when the advocate presents questionable opinions [24]. The goal is to persuade readers that their point of view is correct. Engagement comprises five main elements (*text in italic 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 the community can mean ALS community, ALS community + society or the ALS community + regulators

- (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 (and 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.

Note: We did not find any example of this linguistic element in the ALS community's posts. 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, hashtags, and specialized language. This includes technical jargon, acronyms, and field-specific references typically understood by experts. Three main categories of such "mentions of knowledge": Knowledge about institutional processes, scientific knowledge, Knowledge about specific drug/trial. 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, obligation modals, and necessity statements to perform actions. Directives commonly instruct or command the reader, using imperative verbs and clear instructions. 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. 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. Rhetorical questions do not expect a direct answer. Instead, they emphasize a statement. Example: "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. Example: "Who wouldn't want to be a millionaire?" is a rhetorical question that doesn't seek an actual answer but claims that everyone would like to be a millionaire.

5 Results

We report on 13 case studies that highlight how the ALS advocacy movement demonstrates stance and engagement. Additional 27 case studies are summarized in Supplementary Material.

5.1 Stance

The ALS advocacy 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 also assert their firsthand experiences with the disease or clinical trials. By taking such varied sets of 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 to maintain caution while conveying their perspectives and concerns. Advocates'

perspectives on experimental treatments become difficult to outright dismiss since they avoid strong claims and hedge on 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 then 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 convey frustration and sadness over lost abilities and institutional inaction through metaphors and strong language.

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 by precise data points. By using self-mentions, ALS advocates assert their identity and convey the reality of ALS in ways that statistics don't 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.**" - @emmcormick2005, 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

The 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 for 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. Additionally, advocates use the first and second pronouns to assert that the community and regulators are separate entities.

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 the 'we' and see themselves as part of the solution. The context around this post did not resolve this ambiguity.

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.

5.2.3 Mentions of Knowledge. ALS advocates reference different kinds of ALS-related knowledge that seems 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' (Advisory Committee, 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. The advocate then uses this knowledge to criticize 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 and mentions trial-related terms like 'placebo-controlled study' to make its claim about the drug's efficacy stronger.

5.2.4 *Directives.* Directives emphasize the need for concrete action. The ALS advocacy strategically combines demands like access to experimental treatments with arguments about their life-saving potential and pushes 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 @kim-french0405'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.

5.2.5 *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 process and results, we reflect on links to collective intelligence, the choice of methods, and design possibilities.

6.1 ALS advocacy movement and collective intelligence

Traditional markers of collective intelligence include clear goals, hierarchical structure, collaboration, and structured information aggregation [10, 35, 42, 45, 47, 48, 54, 56]. Our results suggest that ALS advocacy movement does not demonstrate these dimensions of collective intelligence. *E.g.*, the ALS advocacy movement 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 [18, 29, 52]. Unstructured approach of ALS advocates provides flexibility of use. However, new advocates might also find it difficult to build upon others' knowledge and personal narratives. Having a way to document previous strategies (and their successes) would benefit future advocates who might otherwise start from scratch. A structured documentation system would also help identify gaps, such as overlooked policy opportunities, enabling the community to advocate more effectively.

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 wasn't our research goal. However, it seems important to understand whether such advocacy is successful (and how?). Our results demonstrate multiple mechanisms with which advocates strive to meet 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 the FDA's delays as endangering lives. Further work could create an exhaustive list of mechanisms (including appeals, threats, more) and how they emerge in a movement without explicit collaboration/hierarchy.

6.2 Reflection on the choice of methods

Contemporary advocacy movements in health navigate rapidly changing knowledge landscape in settings including Long COVID [8, 43] and vaccines [28, 30]. 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. The benefits largely came from the two approaches fixing gaps in each other’s results. 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 can be important in studying communities’ orientations. Combining the two formalizes descriptive knowledge into concrete codes and situates a seminal linguistics model in a concrete real-world setting.

Different choices for theoretical frameworks can highlight unique aspects of discourse. While Hyland’s model helped us characterize how an advocacy movement presents its views to FDA, applying another framework could yield complementary insights. 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 [13, 31], especially in patient communities. Another relevant framework is logos/pathos/ethos which identifies the nature of persuasive arguments [21]. Logos presents as strategic references to scientific knowledge. Attempts at pathos include personal narratives that often evoke empathy and convey urgency. Moral arguments include questioning denial of access to potentially life-saving treatments.

6.3 Design opportunities for rare disorders

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 [41] and design of appropriate tools [33]. Unsurprisingly, the ALS advocacy movement has repurposed X to criticize perceived lack of institutional investment and to raise public awareness about ALS. It’s unclear whether the design and affordances of current social platforms [34] are best suited for advocacy movements. Current designs (e.g. hashtags on X or Facebook groups) are often used for *internal* dialogue in communities. Designing platforms for structured collaboration between advocates and institutions is an open challenge [5]. 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. 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.

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1 Supplementary Material

Using the stance and engagement linguistic model updated with insights from our digital ethnography approach proved to be beneficial for studying the ALS advocacy movement.

1.1 Stance

1.1.1 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 outright dismiss since they avoid strong claims and hedge the positive aspects of the experimental treatments.

Case Study 1: "Please @US_FDA, use regulatory flexibility and recognize the urgent unmet need in ALS when you evaluate #NurOwn. **It's not perfect**, and **may** only help **some** patients recover function, but that gives them more time and better QOL. All patients deserve to try. Please approve NurOwn." - @lauramanhardt, family member of a person with ALS

Case Study 1 attempts to align with the FDA's views on a treatment's efficacy by hedging the functionality of the treatment. The advocate uses 'not perfect', 'may' and 'some' to agree with FDA that the drug cannot benefit everyone, but also tentatively claims that the treatment is worth approving.

Case Study 2: "So, it looks like @US_FDA shot down Nurown. An ALS treatment with real results for patients early in the disease, or with slow progression. Why?!? Why must the treatment help X number of people, when it **can** change the lives of **some** now? I want to [fucking] live!" - @Shankapotomas, a person with ALS

Case Study 2 makes a reasonable claim about why treatment should be accessible by hedging the treatment's potential to change people's lives. The words 'can' and 'some' hedge the treatment potentials and show that while the treatment is not guaranteed to save everyone, it can still help an unspecified number of people.

Case Study 3: "I hear my teen upset but can't get up the f[ucking] stairs to comfort. Thanks [to] #als I can't help but think if I had access to #Toferson and doctors that [that] listened if I could get up those stairs today. #us_fda don't waste [anymore] time. Ugh." - @heavy_sara, a person with ALS

Case Study 3 uses the if clause to create the hypothetical scenario of being able to get up the stairs to demonstrate the potential value of an experimental treatment.

1.1.2 Boosters. Boosters emphasize a strong commitment to knowledge claims. ALS advocates use boosters to strengthen claims about the safety and efficacy of new treatments in two ways: first, by presenting their claims as accepted facts and second, by using boosters to convey the urgency of living with ALS.

Case Study 4: "Real quick: @AmylyxPharma's ALS treatment AMX0035 is **SAFE** and **WORKS** but there is talk that the FDA will not approve it when the alternative is **certain DEATH**. Simple question: **WHY???**" - @thomsontweach, lost a family member due to ALS

Case Study 4 strongly claims to know that a treatment is effective with boosters "SAFE and WORKS...". Moreover, the advocate boosts the urgency of the situation when living with ALS to criticize regulators for their decisions. 'WHY' in ALL CAPS questions the FDA's decision for not approving the treatment. The phrase "certain DEATH" emphasizes that the only outcome of ALS is death, thereby highlighting the need for effective treatments.

Case Study 5: "This will **NEVER** be okay. @Username deserved life. She got sick w/ ALS but what she died from was NOT BEING GIVEN TREATMENT THAT COULD HAVE SAVED HER! She died because the @US_FDA withheld #NurOwn despite ALS being **100% fatal**. This is **UNACCEPTABLE**#ENDALS #diedwaiting" - @ImLolly713, Lost a family member due to ALS

Case Study 5 notes that a drug is effective and accuses FDA for ignoring the drug. 'NEVER' in ALL CAPS amplifies that the regulator's policies are wrong. 'unacceptable' blames the institutions for the death of a patient by withholding a drug. The post uses a numerical booster "100% fatal" to demonstrate the severity of ALS as a lethal condition.

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

Case Study 6: "I hate #ALS it's a **big black hole dragging me into the darkness kicking and screaming**. Please @DrCaliff FDA you can help! #NurOwn works" - @kimfrench0405, a person with ALS

Case Study 6 uses the word 'hate' to describe how much this patient despises the disease. The advocate then uses the metaphor of "a big black hole" to demonstrate how hard it is to live with ALS. The phrase "kicking and screaming" conveys that no matter what the advocate does, this disease is very powerful.

Case Study 7: "@US_FDA **wildly disappointed** in your conviction that ALS patients should **die without a chance** instead of **possibly die or possibly get somewhat better. Mind boggling decision**. Paternalistic and abusive." - @md_wallach, family member of a person with ALS

Case Study 7 conveys frustration and criticism toward the FDA's decision with the phrase "wildly disappointed". The advocate uses the word 'die' to show three different outcomes of the FDA's decisions on withholding potential treatments. One outcome is death without a chance of living, another outcome is possibly getting better and the last outcome is having a chance to live. The phrase "mind boggling decision" describes the FDA's decision as irrational and shows dissatisfaction.

1.1.4 Self-Mention. Self-mentions serve to assert identity. Traditional scientific and policy discussions rely on statistical views of people. By using self-mentions, ALS advocates assert their identity and convey the reality of ALS in ways that statistics don't capture.

Case Study 8: "Who do **I** write to discuss the FDA's vote of 17-1-1 to not approve NurOwn. **I** would like for the FDA to tell **my son, Ryan, my granddaughters, my siblings**, that they sentenced **me** to death. Why wont you let **us who fight ALS everyday** decide **if we are willing** to have the right to live." - @mrmaness1, a person with ALS

Case Study 8 makes extensive use of first-person pronouns such as 'I,' 'my,' 'me,' and 'us,' which directly ties the advocate's personal identity to the message. By saying "I would like for the FDA to tell my son, Ryan, my granddaughters, my siblings, that they sentenced me to death," the advocate emphasizes personal aspects of their identity, such as their role as a parent, a grandparent, a sibling. The question "Why won't you let us who fight ALS every day decide if we are willing to have the right to live?" challenges the perceived authority of the FDA over personal treatment decisions. The phrase highlights the advocate's determination to retain control over their life and medical choices.

Case Study 9: "We have lost many #pALS the last few weeks. Some **I have followed** the last 2-3 years. **I hurt** when they die. They are like family. It also **reminds my** of what's to come **for me**. #ALS can be a liveable disease, if only the #FDA cared." - @KickenALSAss, a person with ALS

Case Study 9 persuades the FDA to care more about ALS patients by using two mechanisms. First, it expresses first-hand experience with the disease. The statements "I have followed the last 2-3 years" and "It also reminds my of what's to come for me" indicate a personal journey and experiences with ALS over an extended period. Second, they attempt to humanize the post and make it more relatable. The phrase "I hurt when they die. They are like family" is a personal and emotive self-mention.

Case Study 10: "The Trauma and heartbreak **I have endured** with losing **my only two sons** to ALS is more than one can or should bare. If you experienced this you would know and there would be no nah sayers to anything that could keep their kids alive NurOwn or any drug. Guarantee. @DrCaliff FDA" - @BridgetRebecca4, lost family members due to ALS

Case Study 10 persuades the FDA to approve a new treatment by expressing first-hand experience with the disease. The phrase "The Trauma and heartbreak I have endured with losing my only two sons to ALS" is a direct expression of a deeply personal and traumatic first-hand experience with ALS through the loss of two children to the disease.

1.2 Engagement

1.2.1 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 and expects society and regulators to show care and concern for ALS patients. Advocates use the first and second pronouns to assert that the community and regulators are separate entities.

Case Study 11: "Congratulations @califf001 on **your** new role as @US_FDA Director. **We**, the ALS community, are excited to work with **you**. And **we** have a lot of good work to do quickly. Let's [f'ing] do this." - @bsw5020, a person with ALS

Case study 11 uses 'we' to refer to the ALS community, which is explicitly mentioned. The advocate also uses 'you' and 'your' to refer to the FDA's new director. By stating that the ALS community is ready to collaborate with the FDA, the advocate says these separate entities should work together to be able to solve ALS issues.

Case Study 12: "A chance at life. That is what **we** need from **you**. **You** have the power to allow **us** to live. @senrobportman **you** must cosponsor S1813. the ACT for ALS. Please work with @SenSherrodBrown to urge the FDA to approve NurOwn. Day 128 of begging for **our** lives." - @PatriciaManhar1, a person with ALS

Case Study 12 uses 'we' and 'us,' to represent the ALS community as desperate and dependent on the actions of those in power, while 'you' represents the FDA, who make critical decisions. The post also holds the FDA accountable for its decisions and states their chance of living depends on the FDA's decisions.

Case Study 13: ".US_FDA the #ALS community delivered **you** a petition to grant #NurOwn a transparent and informative AdCom three months ago. While **we** wait, people have died from this 100% fatal disease.

Provide the flexibility & speed **you** promised for ALS. Schedule. The. Adcom." - @Troy_W_Fields, Person with ALS

Case Study 13 uses the reader pronoun 'you' to address the FDA directly. The phrases "...community delivered you..." and "...you promised for ALS." blame the FDA for ignoring the ALS community's petition and not keeping its promise of flexibility and speed. The pronoun 'we' in the phrase "While we wait..." refers to the ALS community.

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

Case Study 14: "Just use the regulatory flexibility you, @US_FDA promised for brutal diseases like #ALS. Just approve #NurOwn already. Why be an obstacle for an **obviously** working treatment, complete with biomarkers? Whose pocket are you in? #DyingWaiting #FDA **#absurdity**" - @farmstronginfo, family member of a person with ALS

Case Study 14 uses the word 'obviously' to claim that the efficacy of a drug is accepted knowledge. The advocate then uses this claim to criticize the FDA for ignoring this recognized understanding.

Case Study 15: "Over a year ago, we stood before Congress making the "closing argument for our lives" **We knew** #NurOwn worked then. **We know** it works now. @US_FDA people with #ALS & their neurologists deserve an AdCom to present "clinically meaningful" evidence that #NurOwnWorks #NoAdComNoVoice" - @sabrevaya, family member of a person with ALS

Case study 15 uses appeals to shared knowledge to imply that the effectiveness of a drug is a widely accepted fact among the ALS community. The repetition of "we know", once with a past tense and once with a present tense strengthens the claim and shows that the community's stance hasn't changed over time.

Case Study 16: "The ALS Community has been demanding the same regulatory flexibility for AMX0035 and NurOwn. The FDA needs to do the same thing for ALS as they did for Alzheimer's. **Of course**, we need more data, but patients cannot wait. Waiting means death for the majority of ALS patients." - @nicolecimbura, lost a family member due to ALS

Case study 16 claims the community knows and is aligned with the institutions that there should be more data for approving drugs. The advocate frames it as an accepted knowledge among the community.

Case Study 17: "Tomorrow morning @BrainstormCell to provide update on the #NurOwn program for #ALS. Praying the FDA accepted the Phase 3b trial design. Lives depend on it! **We KNOW #NurOwn-Works**. ir.brainstormcell.com/20240408Bra... #EndALS" - @aVoice4ALS, an ALS advocacy account

Case Study 17 uses the "We KNOW #NurOwnWorks" phrase to weigh their argument of why a drug should be approved and align the post and reader as part of a community with a shared understanding of ALS treatments.

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

Case Study 18: "The approval was based on a reduction in plasma neurofilament light" FDA
 Mark this day on your calendars. Today is much more than Tofersen being approved. **Today the FDA acknowledged a biomarker for ALS and effectively opened the door for other possible treatments.**

- @Troy_W_Fields, a person with ALS

Case Study 18 gives information about the newest FDA approval. The advocate includes a quote from the FDA referencing specific biomarker data. The quote indicates that the FDA has recognized this biological marker as crucial for evaluating ALS treatment effectiveness. Quoting shows that the advocate understands the terms related to the regulatory approval process and the types of evidence needed for the FDA to approve a treatment.

Case Study 19: "Why has no one worked to qualify NFL for ALS with the FDA? It's clearly suitable [especially] with the tofersen news. (It appears we can arrive at FDA recognized biomarkerAdComers two ways - through trials like with Tofersen, and through qualification, which is driven by requesters)." - @Jeanc9orf72, family member of a person with ALS

Case Study 19 shows familiarity with the specific qualification process by questioning why no one has worked to qualify for the NFL (neurofilament light) for ALS with the FDA. The advocate also distinguishes between methods for achieving FDA recognition of biomarkers. By claiming to have this knowledge, the advocate criticizes the missed opportunity for the ALS community caused by not qualifying the NFL as a recognized biomarker.

Case Study 20: "I'm convinced the system and priority for ALS in the U.S. is broken. There are things in process and great people at work to help fix but there should be way more for people at this point. Speed up the @US_FDA, pass legislation to make exceptions to provide therapies now. #EndALS"

- @blaesch, a person with ALS

Case Study 20 claims an understanding of systemic issues within the institutional framework and asserts that the system for ALS is 'broken'. The advocate talks about regulatory mechanisms and criticizes the FDA for its slow decision-making processes. The advocate also uses institutional terms like "legislative action" to expedite therapy approvals which implies knowledge of how these institutions operate and how they could potentially improve their efficiency.

Case Study 21: "@DrCaliff_FDA @FDACBER FDA rep at #NurOwn Adcomm steals 30 min lecturing on fetal stem cells when #NurOwn is autologous stem cells another @FDACBER rep talks about #ALS symptoms improving. [c]onfusing #ALS with relapsing-remitting MS statisticians R not aware of floor effect" - @HaterAls, family member of a person with ALS

Case Study 21 criticizes what they perceive as errors made by FDA representatives during the NurOwn Advisory Committee meeting. The advocate names scientific terms like 'fetal stem cells' and 'autologous stem cells.' They demonstrate familiarity with the differences between ALS and MS. Furthermore, the advocate suggests familiarity with research methodology by mentioning the floor effect which is a statistical concept.

Case Study 22: "It is past time for @FDACBER @US_FDA to admit the standard[s] [F]or approval of therapies like #NurOwn must look past bio markers. Empirical evidence of patients rising from wheelchairs, regaining limb function, and lack of progression are significant proof. Fight for #ALS patients."

- @KRob8753, a person with ALS

Case Study 22 talks about the current standard for approval of ALS therapies by the FDA by referencing the use of biomarkers as the current standard for approval. It contrasts biomarker data with "empirical evidence of patients". The

advocate highlights knowledge that clinical outcomes like improved functional abilities and lack of progression are meaningful real-world measures of a therapy's efficacy.

Case Study 23: "The @US FDA absolutely did the right thing for #Relyvrio. It approved a new drug based on **weak post-hoc evidence** and then required a **confirmatory trial**. Perfect. This is exactly what patients wanted for #nurown, but didn't get. Now there is no "Plan B" for patients alive today." - @als_now, an ALS advocacy account

Case Study 23 names a specific drug that was recently approved by the FDA for ALS. The advocate characterizes the evidence used for the drug and discusses its recent approval by mentioning the nature and quality of the clinical trial evidence. The advocate uses this claim of knowledge to criticize the FDA for its decisions and compares the two ALS drug approval processes.

Case Study 24: "The **Phase II/Phase III Trial for AMX0035** was as large as the **Phase III Trial** for the last FDA approved ALS treatment. Amazingly, unlike that therapy, **AMX0035 slowed progression** of ALS in patients across the board by **two points**, which is huge. #AMX0035facts" - @bsw5020, a person with ALS

Case Study 24 talks about the different clinical trials of a drug to criticize the FDA for approving a previous treatment that was unable to slow progression in patients. The advocate claims that the new treatment can slow the progression in patients based on the results of a trial.

1.2.4 Directives. Directives emphasize the need for concrete action. The ALS advocacy strategically combines demands like access to experimental treatments with arguments about their life-saving potential and pushes for institutional action.

Case Study 25: "I'm so tired of people who are unaffected by #ALS trying to [deciding] our future. If a drug is proven safe we have nothing to lose! **Stop trying to keep us from living.** @US_FDA this **should not** even be a debate, **approve AMX0035 NOW!**" - @SarahNauser, a person with ALS

Case study 25 is an example of an explicit directive since it contains three imperative verbs: 'approve', 'stop', and 'should not'. The advocate commands the FDA to approve a drug because it is proven to be safe and uses a moral argument to strengthen this directive: denying access to a safe drug is equivalent to "trying to keep us from living". This argument appeals to the ethical principle of the right to try potentially life-saving treatments.

1.2.5 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 26: "#ALS is loss of physical strength and attributes, loss of role identity, loss of income, loss of important life figures: life partners, friends. #ALS is THE LOSS. **#why did you @DrCaliff_FDA @FDACBER allow loss of #NurOwn for another 5 generations of people suffering from #ALS?**" - @HaterAls, lost a family due to ALS

Case Study 26 blames the FDA for letting people suffer from ALS by using a rhetorical question. The rhetorical question acts as a statement by asserting that the FDA's action is harmful. The question builds on an emotional argument by presenting ALS as a series of profound losses, then intensifies this emotional argument by implying the FDA is allowing continued suffering.

Case Study 27: "Accomplishing anything is hard. #ALS the thief, is taking things from me daily. **What if I & others had #Nurown? Maybe we'd keep some abilities? Maybe we'd get a few back?**#everypointmatters! Plz help us @FDACBER @DrCaliff FDA @AP FDAwriter #NurOwnWorks for some. #SomelsEnough!" - @crayne128, a person with ALS

Case Study 27 asks "What if...",to speculate that a treatment could help ALS patients maintain or regain some functional abilities that they are losing to the disease.