Left to their own devices: How people with ALS use digital platforms as advocacy space

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Abstract

Institutional decisions deeply affect people's lives. Many communities seek to influence policy and science by advocating for themselves. Self-advocacy is especially important for people with disabilities who may have different needs or ways of interacting with the world. While formal advocacy groups such as nonprofit organizations or government agencies provide structured support, people increasingly advocate independently through digital platforms in ways that might offer more *accessible participation*. One community that uses digital platforms for advocacy is the ALS community. Amyotrophic Lateral Sclerosis (ALS) is a fatal neurodegenerative disorder that causes motor disability, with no cure and limited treatment options. Our research examines the advocacy strategies of the ALS community on two platforms: a public comment system (`regulations.gov`), and a social platform (X). Our work compares how people with ALS advocate across different platforms for policies and institutional processes that better accommodate their lived experience. Our results suggest that digital platforms can complement traditional advocacy by enabling faster, more direct participation for anyone with internet access. By connecting themes from ASSETS and CSCW scholarship, we suggest ways to design more inclusive civic technologies that better support disabled communities in influencing policymaking.

CCS Concepts

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

Keywords

Advocacy, participation, accessibility, ALS, neurodegenerative disorder

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1 Introduction

People with disabilities often face unique challenges. For example, some people need to travel several hours to reach specialized clinics [30]. Hence, people with disabilities can benefit from spaces to advocate for their needs and be able to participate in decisions that affect their lives. Formal channels such as advisory committees and organizations representing disabled communities can help with such advocacy needs [19]. For example, the National Council on Disability (NCD) advises public policy on the concerns of people with disabilities [22]. Such institutional ways of representing the disabled community have had successful outcomes in the past; *e.g.*, the NCD was instrumental in the passage of the Americans with Disabilities Act (ADA). Many individuals also engage in advocacy outside of formal structures through decentralized means such as digital platforms. For people with physical disabilities that make in-person engagement difficult or impossible, digital spaces become essential tools for civic participation and advocacy.

The Amyotrophic Lateral Sclerosis (ALS) community offers an example of a community that mobilizes online to influence public policy. ALS is a fatal neurodegenerative disorder with no cure and limited treatment options. Hence, the ALS community is highly motivated to influence drug policy and regulatory decisions made by the Food and Drug Administration (FDA). The ALS community uses social platforms to discuss their needs and experiences, including the progression of their disability, their need for more accessible support, and access to experimental treatments that could affect their health outcomes [13, 16].

Our research connects topics on accessibility and collective action, examining how the ALS community uses digital platforms to advocate for policy change through two complementary studies. In the first study, we analyze public comments submitted by the ALS community on FDA policy drafts and identify the strategies and claims employed by people. In the second study, we explore how community members advocate for greater inclusion in policymaking through a social platform. We study the rhetorical and linguistic approaches that people use when discussing policies or attempting to engage with the FDA by combining a seminal linguistic model with contextual insights from digital ethnography. Together, these studies demonstrate that digital platforms can complement formal advocacy structures by enabling more immediate, inclusive, and accessible participation.

2 Related Work

Advocacy represents a form of collective action where communities organize around issues of importance to their members [8, 21]. Advocacy efforts encompass several goals, from raising public awareness [6] to directly influencing institutional decision-making [9].

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Advocacy matters because it bridges the gap between people's lived experience and policy development [7]. This gap can have consequences, particularly in health contexts where policies directly determine quality of life, access to care, and even survival [14]. Advocacy in communities of people with disabilities popularized the phrase "Nothing about us without us," promoting the principle that those affected by policies should have a central voice in their development [26, 28]. This principle reflects a fundamental challenge to traditional top-down policymaking approaches and advocates for more participatory governance structures.

Participatory governance can be supported by digital platforms; public consultation systems exist for topics like city budgeting, transportation, and municipal planning [12, 18, 20]. Though less abundant, there are platforms that allow public participation in health-related policymaking. For example, `regulations.gov` allows people to comment on FDA policies. Public comments on this site haven't been studied, even though it is a key platform for the public to participate in federal decision-making. For such new data sources with unique contexts, inductive thematic analysis is a useful way to gather insights into *what* people say and *how* they say it [3, 4].

Public participation in health policy has historically been driven by informal advocacy efforts rather than government-established platforms, as seen with AIDS and Long COVID advocacy [2, 10, 11, 24, 25]. Advocates use social platforms to influence public opinion, and align their language with their specific goals and target audiences [6, 16, 23]. Hence, studying linguistic strategies is beneficial for understanding advocacy efforts aimed at increasing inclusion in policy-making. The linguistic model of stance and engagement offers a suitable framework for this analysis by providing a structured codebook with specific categories that enables systematic analysis of advocacy discourse [15]. Analyzing linguistic strategies becomes more effective when combined with contextual insights about the communities being studied. Digital ethnography provides this deeper understanding by requiring researchers to immerse themselves in online communities to grasp the nuances of social interactions and behaviors [17].

3 Study 1: The ALS community comments on regulatory documents on regulations.gov

`Regulations.gov` is a website where over 220 United States agencies post their regulatory *dockets* (groups of documents) for the public to view and comment on, created as part of an e-Government initiative to increase public participation in rulemaking. The Food and Drug Administration (FDA) is one of these agencies. In 2018 the FDA posted a draft guidance "Amyotrophic Lateral Sclerosis: Developing Drugs for Treatment Guidance for Industry" to one of their dockets. This study analyzes comments submitted to the docket in the two-month public comment period that followed.

3.1 Methods

A qualitative study answered the research questions: How does a patient community digitally participate in policy-making processes that affect their lives? What kind of criticisms, recommendations, and arguments do they make? The research team downloaded the 612 public comments that were posted on regulations.gov during the two-month comment period in 2018 for the FDA's draft guidance document. Comments range from 3 to 701 words. Comments less than 100 words were removed because they contain the same themes as longer comments with much less detail. Long group letters were also removed to keep the focus on individual participation, leaving 269 final comments for coding.

The research team conducted inductive thematic analysis of comments to characterize the criticisms, suggestions, and calls to action that people make, and the supporting information, claims, and arguments used. The data coding process consisted of an exploration phase followed by iterative coding, discussions, and updates to codes.

3.2 Results

Our analysis revealed multiple categories of criticisms, recommendations, claims, information, and arguments in public comments.

3.2.1 Criticisms, Suggestions, and Calls to Action: Criticisms assert that something is wrong, bad, could be better, or bring up specific issues ("The proposed guidance document doesn't adequately address the urgent needs of patients who have a terminal illness"). Suggestions give an idea of a way to think about or do something ("Consider having satellite trial locations where there is cluster cases of ALS diagnosis"). Calls to Action are directives or statements that some action should or needs to be done ("Use historical controls from the PROACT data base. STOP the use of placebos"). Criticisms, suggestions, and calls to action address the same topics and were all coded with this set of seven themes: Access to Drugs / Drug Approval Process, FDA's Guidance Document, Clinical Trials, Patient Input / Participation Processes, FDA Generally, ALS Organizations / Community, Money. More examples and sub-themes can be found in the supplementary material.

3.2.2 ALS Claims and Information: ALS Claims make a subjective statement about ALS ("This is an insidious, life-robbing disease"), about ALS patients or caregivers ("The dying patient is willing to take the risk"), what it's like to live with ALS, or what kind of approach ALS requires ("This disease requires urgency of treatment"). Information statements can be on any topic and come in formats such as standalone facts ("50% of the people diagnosed pass within 15 months"), personal experience ("My mother was diagnosed with ALS in October 2017"), or references to what other documents or people have mentioned.

3.2.3 Arguments: We identified six types of arguments that commenters make.

Moral (Patients' Rights): People frequently state that persons living with ALS (pALS) deserve access to potential treatments. People assert that pALS have a right to have a say in their treatment, to assume risk they are willing to assume for themselves ("Right to Try"), and to have their preferences reflected in regulations.

Moral (FDA's Responsibility): People make moral arguments attempting to hold the FDA and the medical research industry accountable to their responsibilities. Some comments quoted the FDA mission statement.

Emotional (Urgency, Death, Hope): Many comments include affective phrases or tone. People describe their difficult experiences living with ALS, caregiving for someone with ALS, or knowing a loved one with ALS. Information about the fatal nature of ALS, its rapid progression, and the lack of treatment is also used to bolster the emotional narrative.

Logical (Facts of ALS as a Basis): People also build up logical arguments in their comments. Information about ALS and what it's like to live with ALS are used as the premises to argue for specific recommendations or make criticisms. For example, some commenters explain that ALS makes travel very difficult, using this as a reason for implementing mobile trial sites to make participation in clinical trials easier.

Logical (Comparisons to Other Cases): People compare ALS and related regulatory efforts to other conditions. They argue that the institutional approach to ALS should be more like the approach for Cancer or AIDS, and should not be the same status quo that is applied to the common cold or acne.

Logical (Risk-Benefit Trade Off): Many people who comment demonstrate a nuanced understanding of the risk-benefit trade-off for the approval of drugs and other clinical decisions. They make arguments about how the risks and benefits are experienced by people living with ALS, who only have a few years left to live and can access limited treatment options.

4 Study 2: The ALS community uses social platforms to advocate for its needs by integrating knowledge claims and emotional appeals

Social platforms provide a broadly-accessible space for public input, allowing people to discuss their opinions about policies that might otherwise be limited to formal institutional settings. For this study, we focus on the X platform, where advocates often use rhetorical and linguistic strategies to maximize the impact of their advocacy.

4.1 Methods

Our study investigates how the ALS community uses a social platform (X) to advocate for inclusion in health policy decisions in the United States. We combine digital ethnography with a seminal linguistic model to analyze how community members position themselves in relation to FDA policies and engage their audiences through strategic use of language.

4.1.1 Linguistic model + Digital ethnography. A suitable linguistic model for analyzing advocacy discourse is Hyland's model of stance and engagement. Hyland defines stance as the degree of commitment a writer expresses toward their statements, as well as how they align with or oppose other viewpoints [15]. Engagement refers to the strategies that writers use to involve readers in the discourse, increasing the likelihood that readers will align with the writer's perspective [15]. Hyland's model includes stance elements—such as hedges, boosters, and attitude markers for stance—and engagement elements like reader pronouns, appeals to shared knowledge, directives, and questions. Digital ethnography helped us with aligning Hyland's model to the context of the ALS community. Digital ethnography revealed *what* was being said, *why* certain rhetorical approaches were used, and *how* they aligned with the broader goals of the community.

4.1.2 Data collection and coding. We discussed 200 posts from X social platform. To gather our data, we used this query to collect posts that had more than twenty likes, and discussed ALS, FDA, and a drug name (Nurown) for the duration when the drug name was a trend:

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

We began our analysis using Hyland's model to analyze posts from the ALS community and found that Hyland's model needed adjustments for this specific context. Drawing on insights from our digital ethnography, we adapted the model to better capture how ALS advocates express stance and engagement. For instance, we broadened the concept of "hedge" to include quantifying adjectives (*e.g.*,"many") and conditional "if clauses," reflecting how advocates acknowledge uncertainty in disease progression. We made similar expansions to other elements of the stance and engagement model. The updated codebook is included in the supplementary material.

4.2 Results

Our findings suggest that ALS advocacy demonstrates a sophisticated use of language to advance its goals, particularly accelerating drug approvals. ALS advocates employ four key stance-taking strategies to position themselves in relation to FDA policies: hedges, boosters, attitude markers and self-mentions. Through *hedges*, advocates carefully frame claims about drug effectiveness while maintaining caution, such as stating a rejected treatment "could have still possibly saved hundreds of people" rather than making absolute claims. They use *boosters* to emphasize confidence and urgency, declaring treatments have "repeatedly been proven safe" and framing regulatory delays as life-threatening. *Attitude markers* reveal deep frustration through metaphors like becoming "a statistic buried in a report", while *self-mentions* assert the validity of lived experience, with advocates stating "I participated in a clinical trial...and I know it works" to counter statistical approaches that reduce patients to data points.

For engagement strategies, ALS advocates strategically use *reader pronouns* to create solidarity within the community and used ambiguous "we" to sometimes include society broadly and other times to highlight the divide between patients ("we") and the FDA ("you"). Advocates demonstrate *knowledge of institutional processes, scientific terminology, and specific drug trials* to establish credibility, referencing concepts like "regulatory flexibility," and specific clinical endpoints. Through *directives*, they combine urgent commands ("you MUST approve") with implicit suggestions. Finally, advocates used *rhetorical questions* to criticize FDA standards ("35% response isn't good enough?") and emphasize the moral urgency of their situation. These strategies collectively show how advocates integrate technical expertise with personal narratives to challenge institutional decision-making processes.

5 Discussion

People with disabilities use digital platforms not merely as convenient alternatives, but as vital accessible spaces for civic participation and self-advocacy [1, 27]. The ALS community provides one instance of this, but other communities have also used digital platforms for disability advocacy. For example, people with dementia use social media platforms to share personal experiences, advocate for representation, funding, and policy change, and raise awareness [29]. The ALS community provides a unique case study because although ALS causes severe disability, their attempts to participate in policymaking go beyond disability rights. While accessibility remains a concern, the community's advocacy also addresses broader health policy issues, including drug approval timelines, clinical trial design, regulatory flexibility, and research funding priorities.

The expansive focus of ALS advocacy shows how disability advocacy can reach beyond categories of "disability" or “accessibility”. The ALS community's strategies can inform other forms of health advocacy—regardless of disability status—that seek to have their perspectives included in policymaking processes.

The ALS community's strategic use of formal mechanisms (such as commenting on FDA proposals) and informal channels (such as social media activism) exemplifies a concept called “crip legibility”—the practice of disabled people contorting themselves to be understood by existing systems while simultaneously building alternative modes of care, resistance, and collective action [5]. This dual-platform approach allows them to work within established policy frameworks while creating new spaces for collective action.

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