Left to their own devices: How people with a neurodegenerative disorder use digital platforms as advocacy space

Institutional decisions deeply affect people's lives. Hence, many communities, especially those with disabilities, 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. This paper focuses on how the ALS community uses platforms such as the FDA comment system and X to advocate for policies and institutional processes that better accommodate their lived experience. We argue that digital platforms can complement traditional advocacy by enabling faster, more direct participation for anyone with internet access. We conclude by suggesting ways to design more inclusive civic technologies that better support disabled communities in influencing policy and scientific development.

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

Additional Key Words and Phrases: Advocacy, participation, accessibility, 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 [25]. 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 [16]. For example, the National Council on Disability (NCD) advises public policy on the concerns of people with disabilities [19]. 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

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Author's Contact Information:

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Drug Administration (FDA). The ALS community actively 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 (like NurOwn mentioned in the post below) that could affect their health outcomes. For example:

> "#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"

This research examines how the ALS community uses digital platforms to advocate for policy change through two complementary studies. For the first study, we analyze public comments submitted by the ALS community on FDA policy drafts and identify the varied strategies people employ and the types of claims they make when engaging online with formal policy processes. For the second study, we explore how community members advocate for more 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 [7, 18]. Advocacy efforts encompass several goals, from raising public awareness [5] to directly influencing institutional decision-making [8]. Advocacy matters because it bridges the gap between people's lived experience and policy development [6]. This gap can have consequences, particularly in health contexts where policies directly determine quality of life, access to care, and even survival [12]. 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 [23, 24]. 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 *e.g.*, public consultation systems for city budgeting, transportation, and municipal planning [11, 15, 17]. 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 [2, 3].

Public participation in health policy has also historically been driven by informal advocacy efforts rather than government-established platforms, as seen with AIDS and Long COVID advocacy [1, 9, 10, 21, 22]. Advocates use social platforms to influence public opinion, and align their language with their specific goals and target audiences [5, 20]. 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 [13]. 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 [14].

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

`Regulations.gov` is a website where over 220 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. This study analyzes comments on the FDA docket "Considerations Regarding Food And Drug Administration Review and Regulation of Drugs for the Treatment of Amyotrophic Lateral Sclerosis", which includes proceedings from a public hearing on the regulation of drugs for ALS in 2013, and several versions of an industry guidance document for the development of drugs for ALS.

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 claims, arguments, and recommendations do they make? The research team downloaded 612 public comments which were posted on regulations.gov in 2018 in response to the FDA's draft guidance document. The comments range in length from 3 words to 701 words. Comments less than 100 words in length and extremely long letters were removed, leaving 275 final comments for coding.

Comments were coded to characterize the claims, arguments, and recommendations that people make when they advocate for patient perspectives in policymaking processes. The data coding process consisted of an exploration phase followed by iterative coding, discussions, and updates to codes.

3.2 Results

3.2.1 Claims: We categorized commenters' claims into *criticisms*, and *knowledge claims*. We identified five types of criticism and six types of knowledge claims. Commenters criticize the regulatory body they're addressing, its processes, or the document they're commenting on. Criticisms range from generic statements of disapproval to specific actionable critiques. Knowledge claims are used by commenters to support criticisms and recommendations. These include information about institutional processes, drugs, ALS, and personal experiences.

3.2.2 Recommendations: We organize commenters' recommendations into *suggestions* and *calls to action*, with thirteen specific recommendations in total. Suggestions refer to possible ways of doing things or pointers to alternatives, but do not directly argue for action. In contrast, calls to action are statements of what should or must be done, commands, and pleas. Calls to action range in specificity from generic requests for the FDA to "do something", to specific recommendations for trial designs. Interestingly, several of the specific recommendations are included in the final guidance doc posted by the FDA in 2019.

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

Moral (Patients' Rights): Commenters frequently state that people living with ALS deserve access to potential treatments. Commenters assert that people 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): Commenters made moral arguments holding 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. Death is discussed in 169 of the 275 coded comments and "urgent" or "urgency" shows up in 98. 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): Commenters also build up logical arguments. 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 mention that ALS is a rare disorder and can make travel very difficult, using these as reasons for suggesting mobile trial sites to make it easier for people to participate in clinical trials.

Logical (Comparisons to Other Cases): Commenters compare and contrast 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 commenters demonstrate a nuanced understanding of the risk-benefit trade-off for the approval of drugs and other clinical research 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. 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 [13]. 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 [13]. 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:

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

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 *e.g.*, the ALS community, use digital platforms not merely as convenient alternatives, but as vital accessible spaces for civic participation and self-advocacy. Even though ALS causes severe disability, the ALS community's attempts to participate in policy making 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. For instance, this comment on the FDA docket calls for leniency in regulation:

> "...I spoke at the FDA to argue that more lenient rules for the approval of experimental drugs. Those suffering from ALS have little hope as their timeline is too short to wait for the normal regulatory process."

The expansive focus of the ALS advocacy shows how disability advocacy can reach beyond narrowly defined 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 [4]. This dual-platform approach allows them to work within established policy frameworks while creating new spaces for collective action.

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