Investigating the Process-Platform Gap: How a Patient Community's Efforts Teach us About the Limits of Social Platforms in Supporting Institutional Processes

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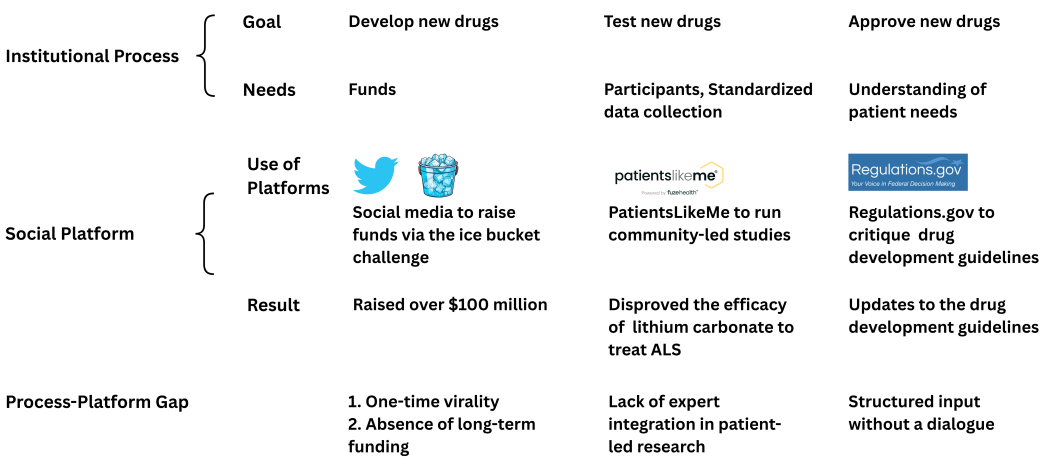

Fig. 1. The ALS community has used multiple social platforms to intervene in drug development–raising millions through viral campaigns, running their own studies, and critiquing regulatory policy. While successful in meeting some goals, platforms like Twitter, PatientsLikeMe, and a federal portal also fell short of institutional requirements like sustained funding, expert integration, and dialogue.

Social platforms are often used by communities to spread awareness and advocate for change; such platforms are rarely *designed for participation* in institutional processes. We call this the *process-platform gap*: institutional processes require structured, sustained forms of participation that social platforms are not designed to support. How might social platforms evolve to support greater participation in institutional processes? We study this question via a case study of the scientific drug development and regulatory process and how it is informed by contributions from the Amyotrophic Lateral Sclerosis (ALS) patient community. The ALS community intervenes at multiple stages of the research process with *flexible*, novel use of current social platforms. Our work focuses on three ways the ALS community uses social platforms to expedite drug development. First, the community *directly* uses general-purpose features–like hashtags and tagging on Twitter–to raise funds through viral campaigns like the Ice Bucket Challenge. Second, patients *repurposed* self-tracking features–like functional assessment scores on PatientsLikeMe–to run studies for novel drugs. Third, the community uses specialized platforms–like regulations.gov–for *focused formal work* by submitting public comments that critique and help shape the Food and Drug Administration's (FDA) drug development guidelines. One

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limitation of the community's use of social platforms is the lack of institutional involvement, which makes these efforts one-way. This limits the potential for sustained dialogue, collaboration, and significant integration of community-led efforts into institutional decision-making. We detail how mismatches between social platform affordances and institutional workflows contribute to a persistent *process-platform gap*. Our work provides design recommendations to improve collaboration at different stages of scientific research.

CCS Concepts: • **Human-centered computing** → **Collaborative and social computing**.

Additional Key Words and Phrases: Social Platforms, Institutional Processes, Online Community, Patient Community, Design

1 Introduction

Online communities increasingly use social platforms–like Twitter, Facebook, and online health forums–to spread awareness or advocate for change in policy and rules. Despite becoming prominent places for people to organize, social platforms are rarely used to *actively participate* in institutional processes. For instance, scientific research and clinical trials have traditionally been conducted within institutional settings–such as universities, hospitals, and pharmaceutical companies–with limited involvement from the public [42]. Most clinical trials for novel drugs often proceed without input from patients during the initial planning and study focus determination phase [3]. Unlike technical domains where expertise is narrowly specialized (e.g., aerospace engineering), health and clinical research directly impact the lives of patients, who hold unique experiential knowledge about symptoms, treatment burdens, and quality-of-life tradeoffs [13]. Including affected people at multiple stages of institutional processes can potentially bring beneficial systematic changes.

Patient communities increasingly use social platforms to attempt to shape scientific research and institutional decision-making. One such example is the Amyotrophic Lateral Sclerosis (ALS) community, which has used social platforms to raise awareness, to generate funds, conduct studies, and participate in institutional decision-making (Figure 1). Unlike many online communities that use social platforms primarily for support or advocacy, ALS patients have used *the same platforms* to share data, critique policies regarding drug development, and raise funds via viral challenges. These practices illustrate a shift in how participation in science and policy-making is evolving *with social platforms*. Specifically, patients are expanding their roles from subjects to active contributors in how knowledge is produced and used.

Our work answers the following research question: how does the ALS community use social platforms to participate in institutional processes? We characterize three mechanisms used by the ALS community to address gaps in drug development. First, to support new drug trials, the community generated research funds and raised awareness through the Ice Bucket Challenge [31, 47]. This campaign spread via viral engagement on platforms like Twitter, using posts, threads, and videos to reach wide audiences. Second, to accelerate the evaluation of potential treatments, the community designed and ran a patient-led study. They repurposed data tracking tools on platforms like PatientsLikeMe to conduct observational studies by collecting symptom data and making social comparisons between treatment groups [20, 66]. Third, to influence FDA drug approval guidelines and address the urgency of a rare, terminal condition like ALS, the community contributed public comments to regulatory bodies. They submitted patient-authored public comments on the draft guidance document provided by the FDA through platforms like regulations.gov, directly advocating for faster timelines, alternative trial designs, and the inclusion of patient priorities in approval criteria [4]. In each case, the ALS community has used social platforms to participate in drug development and regulatory processes.

A key limitation across all efforts of the ALS community is the lack of institutional involvement in these social platforms, which prevents sustained dialogue, joint decision-making, and formal

integration of community contributions into research and policy. We believe this is in big part due to the design of these platforms that are traditionally geared towards sharing opinions and not for collaborative, participatory work. We call this the *process-platform gap*: institutional processes require structured, sustained forms of participation that social platforms are not designed to support. While these platforms help communities raise awareness and share data, they lack appropriate tools for collaboration and participatory decision-making. As a result, community contributions often remain informal and disconnected from formal research and policy decisions. We offer design recommendations to bridge the gap between patient communities and institutions throughout institutional processes—such as scientific research—by addressing key challenges in enhancing community participation on social platforms.

This paper contributes to HCI and GROUP research by studying collaborative practices of an online community that seeks to participate in institutional processes. We share an understanding of the novel ways in which patient communities are using social platforms for goals they were not designed for. Specifically, we describe three case studies in which the ALS community uses social platforms to intervene directly in drug development processes. We analyze the process-platform gap observed in all three cases and provide design claims to overcome this gap.

2 Related Work

In this section, we build on prior work examining community-led efforts on social platforms, such as patient communities organizing clinical research, collecting patient-reported data, and advocating for policy changes. We define community-led efforts as initiatives in which individuals—often those directly affected by a condition or issue—organize participation and carry out activities independently of institutional support. These efforts often use tools like social media, forums, or open-source platforms to pursue goals traditionally led by institutions. We highlight key limitations that prevent such efforts from integrating with institutional processes.

2.1 Existing platforms and frameworks fail to support patient-led efforts because they overlook complete workflows and domain-specific needs.

Many communities use social platforms to organize around causes–such as disaster relief or public health–and advocate for change [9, 27, 38]. Examples include disaster response coordination on social media during crises [44, 57] and mass mobilizations like the Black Lives Matter movement, using platforms to organize protests and shape public discourse [19, 29]. Similarly, patient communities use social platforms to achieve their goals. For instance, long COVID patients used Slack to track and analyze their own data and coordinate studies outside formal institutions [39]. Advocacy organizations like ACT UP and other global HIV/AIDS communities have engaged in cycles of awareness-building, mutual support, and political activism. Their efforts include organizing demonstrations, creating accessible health education materials, and petitioning for drug access and research funding [14, 34]. These examples show how patient communities take on complex work: running studies, interpreting data, and advocating for policy change. But existing platforms are often poorly designed to support such structured and long-term engagement.

We identify two ways in which current platforms fail to support community-led efforts. First, social platforms rarely support entire workflows that community-led efforts require [25, 69]. Consider a patient community that wants to accelerate access to experimental drugs. They might need to raise funds, recruit participants, collect health data, and influence policies [24, 70]. Platforms like Reddit or Facebook might help with recruiting participants, but offer little support for raising millions of dollars, structured data collection, or navigating regulatory policy [12, 55]. The lack of suitable platforms and integrated tools requires communities to stitch together independent solutions. Second, frameworks for supporting community-led efforts are too abstract to address

community-specific challenges [2, 62]. General models–like "problem -> ideation -> action" [52]–don't reflect the regulatory constraints, ethical concerns, or data quality requirements faced by patient communities running studies. For instance, designing a patient-led study on a rare disorder requires careful methodological planning, legal compliance, and clinical insight [13]. Such domain-specific needs are rarely supported by existing frameworks.

These gaps provide insights into why patient communities often struggle to translate community-led efforts into institutional change. Our work contributes an understanding of how one such community navigates these constraints across multiple stages of the institutional process.

2.2 Current platform limitations prevent long-term community-led initiatives and fail to influence institutional processes

2.2.1 Community-led efforts with social platforms often fail to connect with institutional processes. Community-led efforts by patient communities increasingly occur independently and outside institutional frameworks. For example, the Patient-Led Research Collaborative (PLRC) on Slack, formed by patients with long COVID, tracked and analyzed their own data without the support of institutions [39]. While these independent efforts demonstrate the potential of patient-led initiatives, they also reveal limitations: groups like PLRC typically lack access to long-term infrastructure, funding, or institutional recognition. This highlights a broader challenge: without alignment with institutional processes, community-led efforts often struggle to achieve long-term impact. For example, the diabetes online community started the #WeAreNotWaiting movement using Twitter, GitHub, and personal blogs to create and use diabetes management technologies like the DIY artificial pancreas systems (APS). The novel, useful device faced challenges in being integrated into routine clinical care since it was not FDA-approved [53]. This example suggests that effective change requires aligning community participation with institutional workflows and regulatory standards. When aligned with policy frameworks, community data can inform public health decisions. For example, the Centers for Disease Control and Prevention's guidance was updated based on long COVID community findings [18]. Our work identifies challenges faced by a patient community that prevent collaborations with the institutions.

2.2.2 Current platform designs overlook the need for long-term, community-led efforts. Social platforms are typically designed for personal use–such as self-expression, connection, and content sharing–not community-led efforts towards high-stakes goals. For example, platforms like Instagram and Twitter center on individual posting and engagement metrics, offering limited tools for group coordination or collective goal-setting [15]. Community-led efforts by patient communities face two challenges due to such social platform design. The first challenge is the mismatch between the patient community's needs and the goals of many social platforms. When patients attempt to rally support for policy change or research funding, they often struggle to coordinate sustained campaigns using platforms built for short-lived engagement [35, 37]. For instance, while a hashtag might trend for a few days, it provides little support for assigning research tasks or securely managing participant data over months or years, which are crucial for achieving high-stakes goals in patient communities. The second challenge is a limited understanding of how communities repurpose existing tools. Rapid information spread and awareness-building through hashtag activism (e.g., #BlackLivesMatter) have been well documented [36, 54]. However, there is limited research on how health communities adapt platform features—such as data tracking tools, comment threads, or tagging systems—to support ongoing, multi-phase efforts like policy advocacy, peer-led studies, or patient-driven trials.

These two challenges highlight the need for re-imagining platform design—either through evolving existing platforms or creating new ones—to intentionally support the complexities of

long-term, community-led efforts in patient communities. Yet open questions remain about how such communities navigate and adapt these platforms in practice. Do highly motivated patient communities repurpose social platforms in novel ways? Our work addresses this question by examining how the ALS community has leveraged social platforms to raise funds, run studies, and shape policies.

3 Context

Our work describes the process-platform gap for a patient community. We chose the Amyotrophic Lateral Sclerosis (ALS) patient community due to their active (and often successful) online participation in institutional processes. ALS is a rare, progressive neurodegenerative disorder that affects nerve cells in the brain and spinal cord. Patients with ALS experience a gradual loss of motor control, leading to difficulty speaking, swallowing, and eventually breathing. The disorder typically progresses rapidly, with many patients living for two to five years after diagnosis. The urgency of the disorder and limited treatment options have led many patients and families to take an active role in research and policy-making.

The ALS community organizes on multiple social platforms [20, 31, 47, 48]. Unlike communities that mainly use social platforms to raise awareness, ALS patients and advocates use social platforms to drive research, generate new knowledge, and critique policy. The community has used platforms like Twitter, PatientsLikeMe, and regulations.gov to raise funds, run studies, and engage with institutional decision-makers. These efforts are often driven by necessity: the speed of the disorder and the slowness of institutional timelines push patients to act. As a result, the ALS community offers a powerful case study for how patient-led efforts can impact scientific workflows and nudge institutions toward models of working and decision-making that include communities' inputs.

Drug development includes multiple steps, including the discovery of a novel drug, trials to test the efficacy and safety of the drug, regulatory work to approve the drug for public use, and marketing of the drug. This involves years of research, trials, and regulatory review–timelines often misaligned with the urgent needs of ALS patients. Barriers such as limited funding, recruitment challenges, and rigid approval criteria further constrain progress [7, 66]. Institutions like the FDA shape this process through guidelines on trial design and standards for evidence for drug development. We present three case studies showing how the ALS community intervenes at multiple stages: raising funds via viral campaigns, developing evidence through patient-led research on health tracking platforms, and critiquing regulatory policy through formal comments. These efforts illustrate both the features and limitations of current platforms for enabling community participation in institutional processes.

4 Case Study 1: The ALS community uses social media platforms to raise funds and spread awareness.

The ALS community used social platforms to raise over $100 million through the viral Ice Bucket Challenge. This campaign's success stemmed from its entertaining format and social media features like tagging and trending hashtags. However, its one-time virality reveals a deeper process-platform gap: a lack of sustained, structured support for long-term institutional impact.

4.1 Process: Raising funds for developing drugs for a rare disorder like ALS

Developing and testing new drugs requires significant upfront and continued financial investment; the average cost to develop and gain marketing approval for a new drug exceeds $2.5 billion [11]. Such financial investment supports drug discovery, recruiting participants, running multiple scientific experiments, following up with participants, and regulatory or dissemination activities.

Funding for such trials typically comes from institutions like federal agencies (e.g., National Institutes of Health (NIH)) or pharmaceutical companies. Creating alternate sources of funding can help develop and test more drugs, which are essential for a community living with a fatal disorder. At the same time, raising funds to develop drugs for rare disorders is difficult since people typically donate to communities that are personally relevant or popular [21, 56]. ALS is a rare disorder that most people are unaffected by, making it difficult to raise funds for drug development [64].

The ALS community raised funds and spread awareness through the Ice Bucket Challenge during the summer of 2014. The Ice Bucket Challenge involves people pouring a bucket of ice water over their heads to encourage donations and promote awareness. People nominated others to pour a bucket of ice water over their heads and to nominate others. The nominated person can forfeit the challenge by donating to the ALS fundraiser.

4.2 Platform: Social media platforms helped make the Ice Bucket Challenge viral

The Ice Bucket Challenge became successful due to its intrinsically engaging nature; features of social media platforms helped further popularize the challenge and the cause.

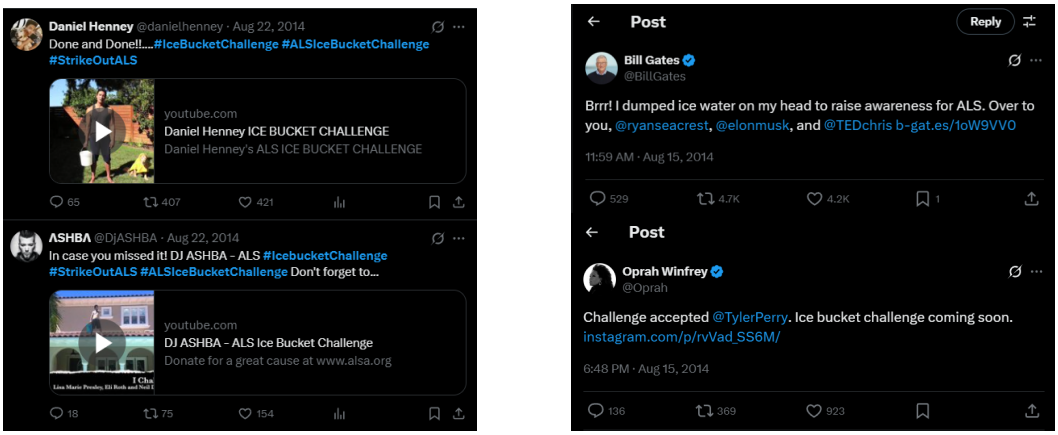
4.2.1 Intrinsically engaging nature of the Ice Bucket Challenge. Unlike other fundraisers' attempts–which mostly involved posting information about the disorder and patients' real-life experiences [51]–the Ice Bucket Challenge took advantage of viral challenges on social media platforms. The Ice Bucket Challenge had three qualities that helped it go viral. First, the challenge entertained a large number of people. Entertaining content–such as videos of pouring ice water over the head–is more engaging than content about the severity of ALS and the struggles faced by people with ALS [22, 58]. Second, unlike other efforts like "Walk to Defeat ALS", which required people to walk, a wide range of people could take part in the Ice Bucket Challenge since the barrier to access is low; people needed a bucket of ice water and a willingness to splash it on themselves. This low barrier to participation might have also appealed more to people with mobility concerns. The third factor that led to the success of the Ice Bucket Challenge was its right timing over the summer. Warm summer conditions matched the activity.

4.2.2 How social media's features contributed. Social media platforms supported fundraising through the Ice Bucket Challenge in three ways (Figure 2). The tagging and nominating feature of the challenge introduced multiple people to the Ice Bucket Challenge and increased its popularity. The credibility of the ALS fundraiser increased when multiple celebrities took part in the Ice Bucket Challenge and donated to the fundraiser (Figure 2b). Multiple people were exposed to the challenge on social media platforms' "trending" pages since people posted content using hashtags such as #IceBucketChallenge, #ALSIceBucketChallenge, and #StrikeOutALS.

The ALS community raised over $100 million by the end of August 2014, driven by the viral spread of their campaign across social media platforms (Figure 3a). Unlike traditional fundraising events, the Ice Bucket Challenge achieved scale and visibility. This allowed ordinary users to become advocates and recruiters in a decentralized campaign. The funds raised through the Ice Bucket Challenge led to the development of Relyvrio, a FDA-approved drug that is intended to slow the progression of ALS (Figure 3b) [28].

4.3 The Process-Platform Gap: Structural limits of virality in cause-driven social media campaigns

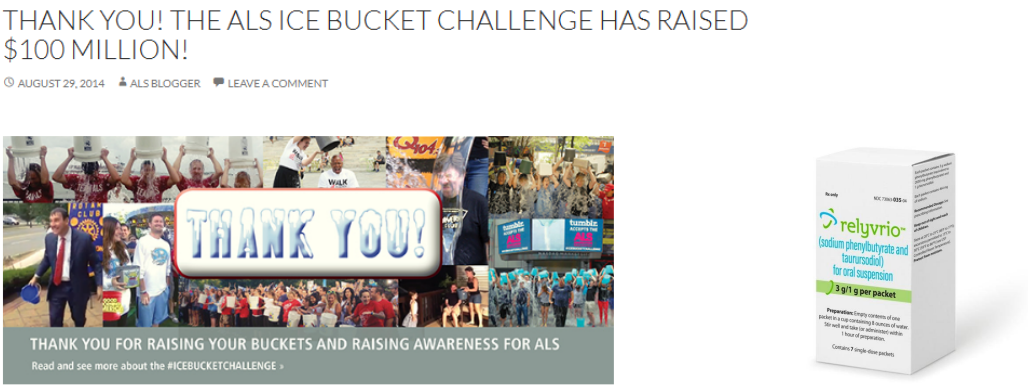
The Ice Bucket Challenge revealed the fundraising potential of social platforms, but also exposed a process-platform gap: the misalignment between what institutional processes require–structured and repeatable forms of participation–and what social platforms provide–short-term, viral bursts of engagement. While the campaign generated over $100 million in 2014, attempts to reproduce its



(a) (b)

Fig. 2. a) Participants who participated in the Ice Bucket Challenge used trending hashtags like #IceBucketChallenge, #ALSIceBucketChallenge, and #StrikeOutALS when sharing their posts. b) The challenge became more popular after celebrities like Bill Gates and Oprah Winfrey took part in it. Participants made use of the tagging feature to nominate others for the challenge, as seen in Bill Gates' post.

success in subsequent years failed, demonstrating the instability of novelty-driven fundraising [61]. Institutional funding mechanisms, such as grants from the NIH or long-term partnerships with organizations, operate through a stable source of support (e.g., taxpayer money), iterative planning, review, and accountability–features that social platforms do not support. Instead, platforms like Facebook and Twitter prioritize viral visibility, where users are more likely to engage with entertaining or low-effort content than complex causes [60]. As a result, participation might draw



(a) (b)

Fig. 3. The Ice Bucket Challenge was massively successful in raising funds in the summer of 2014. a) The ALS association received a total of $100.9 million in donations from existing donors and 2.2 million new donors. The Greater New York Chapter itself received $4.3 million during this time. b) The money raised through the Ice Bucket Challenge was used to develop drugs like Relyvrio, a FDA-approved drug that is intended to slow the progression of ALS.

more on the desire to be a part of the challenge rather than interest in the cause itself, with little infrastructure to retain donor engagement toward long-term goals [61]. This disconnect reflects the core of the process-platform gap: while platforms excel at gaining attention, they lack the affordances necessary to translate that attention into stable, long-term impact, like reliable funding pipelines for causes like ALS research.

5 Case Study 2: The ALS community repurposes social platforms to study drug efficacy

The ALS community used the health platform PatientsLikeMe to conduct a patient-led study evaluating the effectiveness of lithium carbonate for ALS. This effort relied on repurposing platform features–originally designed for tracking symptoms–for data collection, analysis, and patient matching. However, the platform lacked mechanisms for formal collaboration with researchers or integration into institutional science, revealing a process-platform gap in patient-led research.

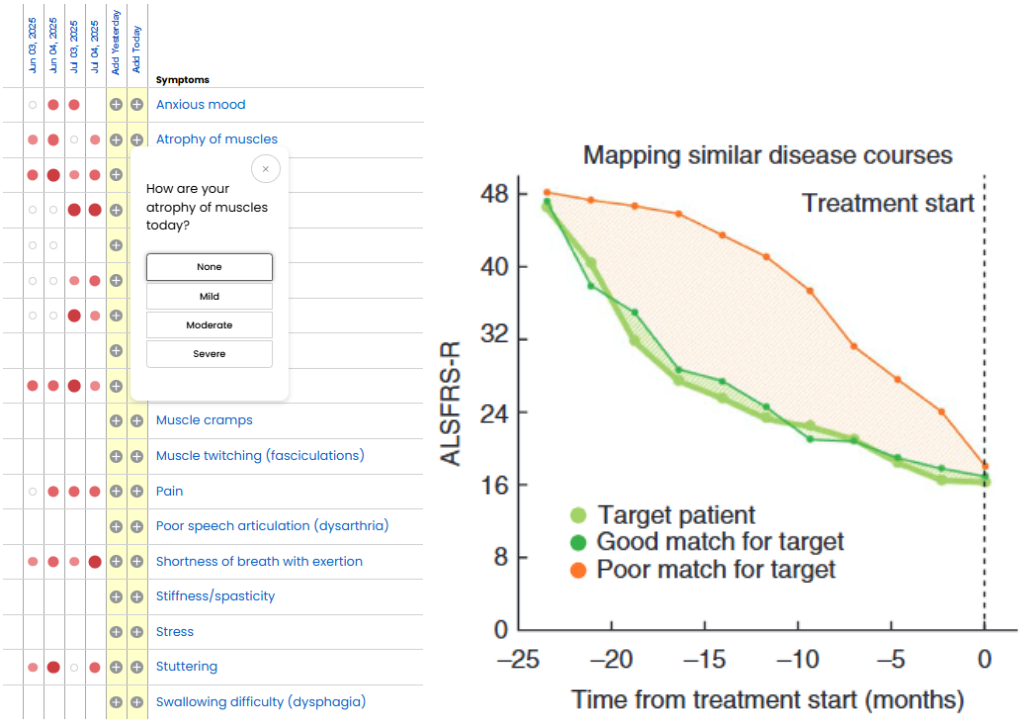
5.1 Process: Improving the rate of drug development for ALS through social platforms

Drug development and clinical trials to test new drugs are time-consuming [7, 66]. Responding to long timelines in securing access to potential treatment, highly motivated patient communities self-experiment with vitamins, unproven supplements, and drugs [50]. One important factor that slows down clinical trials is the availability of participants [17]. This is especially true for rare disorders, like ALS, where 33,000 people live with the condition in the US [40]. Moreover, geographic disparities in access to trial sites limit participation, as many patients–especially those in rural or underserved areas–may be unable to travel to clinical research centers [26]. Given the challenges in recruiting participants for clinical trials, especially for rare disorders like ALS, alternative approaches to accelerate clinical discovery are needed. One promising method is to leverage patient-driven self-experimentation, where individuals track their own symptoms and treatment effects. Some patients maintain personal journals to monitor changes, while others rely on caregiver observations. However, the lack of standardized data collection and reporting methods makes it difficult to use this self-generated data effectively in evaluating new drugs.

5.2 Platform: Online health tracker provided scientific, data, and social infrastructures.

PatientsLikeMe (PLM) is a social platform where patients can track their symptoms and treatment plans (Figure 4a) [65]. Since the website is accessible online, PLM could be used by a patient with an internet connection regardless of their geographic location. Furthermore, PLM provides a standard way to track symptom and treatment data. This data can be used for observational studies to evaluate new drugs and treatment plans. The ALS community used the PLM platform to show that lithium carbonate treatment–thought to be effective in slowing down the progression of ALS–had no effect on disease progression [66]. The ALS community managed to repurpose the features of an online health platform to run a study that evaluated the effectiveness of treatments.

5.2.1 Data infrastructure: From sharing opinions to tracking functional scores. The PLM platform provides data infrastructure that supports standardized and structured data collection, which is critical for developing systematic insights. Traditional self-tracking approaches–such as paper journals or ad-hoc spreadsheets–often vary across users, making it difficult to aggregate knowledge or develop comparative insights. PLM addresses this issue by offering patients predefined categories to log treatments, track symptoms, and evaluate progression of ALS using the Revised ALS Functional Rating (ALSFRS-R). This standardization transforms individual health tracking into population-level datasets, enabling the scale needed for observational studies. Importantly, this infrastructure is embedded within a platform originally designed not for scientific research but for peer support and health tracking. This highlights how general-purpose social platforms can be



(a) (b)

Fig. 4. a) PatientsLikeMe allows patients to rate the severity of their symptoms on a 4-point scale: none, minor, moderate, and major (figure from www.patientslikeme.com). b) Illustration of disease progression curves for two control patients—one a good match and one a poor match—for a specific ALS patient generated using the data collected on PatientsLikeMe. The PatientsLikeMe algorithm selects matches by minimizing the area between their progression curves, resulting in a more precise, trajectory-based comparison. (figure from [66]).

strategically repurposed to serve as community-owned data repositories. The ability to aggregate standardized data from people across the world enables decentralized research when participants are geographically dispersed and patients are not easy to find.

5.2.2 Scientific infrastructure: Patient matching for quick hypothesis testing. In addition to enabling data collection, PLM provides a scientific infrastructure that allows patient communities to run rapid, observational studies beyond traditional institutions. The urgency faced by patients living with terminal ALS disorder—combined with institutional timelines they find slow—necessitates informal experimentation. PLM lowers the barrier to conducting such studies by enabling large-scale comparisons between 227 patients taking lithium carbonate treatment with other users who were not taking the treatment (Figure 4b). This comparison generated evidence that lithium carbonate treatment had no measurable effects on the progression of ALS. Scientific studies come with an inherent trade-off between speed and methodological rigor. The PLM ALS study is not double-blinded, and unmeasured covariates can affect results. While not equivalent to clinical trials, such analysis supports quick hypothesis testing that would be otherwise inaccessible. Platforms like

PLM enable patients to collectively assess treatments–particularly in high-stakes, time-sensitive contexts–without waiting years for randomized trials to conclude.

5.2.3 Social infrastructure: Social feedback loop to reinforce participation. PLM also provides social infrastructure by encouraging people to participate. The presence of others who are tracking, experimenting, and reporting might create a social feedback loop that reinforces participation and legitimacy [6, 10, 43]. In this way, PLM does more than provide data tracking: it cultivates the social conditions necessary for sustaining long-term, community-led inquiry. Moreover, PLM connects geographically distributed patients into a cohesive research community. Many ALS patients live far from clinical trial sites and would otherwise be excluded from formal studies due to location, eligibility criteria, or progression stage. PLM lowers these barriers by providing a space where most people can contribute data, participate in shared experiments, and learn from others' experiences.

5.3 The Process-Platform Gap: Missing infrastructure for expert–community collaboration in patient-led research

A fundamental process-platform gap for the PLM ALS lithium carbonate study is the absence of features that enable institutional experts—such as clinical researchers—to formally collaborate with patients in designing, monitoring, or validating studies. While PLM effectively enables community-led inquiry, it currently offers limited support for integrating external scientific oversight or collaboration on methods. This separation reinforces a divide between patient-led and expert-led research, where community-generated findings may be viewed as informal or unverified despite their methodology. As a result, even when these studies yield actionable insights, they might struggle to influence formal medical guidelines. Bridging this gap will require platforms that not only support patient self-tracking and study coordination but also offer ways for experts to engage meaningfully without displacing the momentum of patient-led efforts. Such platforms will provide experts the opportunity to access rich, real-world data and collaborate on questions with direct patient relevance. To close this gap, we suggest design claims 1 and 2.

> *Design Claim* 1: Helping communities and experts co-create research questions that are both experience-driven and scientifically relevant can facilitate useful collaborations between communities and institutions.
>
> *Design Claim* 2: Creating pathways for methodological support can strengthen institutional trust in community-led studies

6 Case Study 3: The ALS community participates in focused formal work by critiquing the Food and Drug Administration's drug development guidelines

The ALS community engaged directly with the FDA by submitting public comments on drug development guidelines via regulations.gov. This platform enables formal participation and policy critique, including calls for faster trials and access to experimental drugs. Yet its design limits dialogue, transparency, and collaboration–highlighting a process-platform gap in regulatory engagement.

6.1 Process: Critiquing the FDA's policies on drug development

The Food and Drug Administration (FDA) regulates the development and approval of new drugs, including treatments for ALS [23]. However, the process is often slow, and promising drugs remain inaccessible to most patients until they receive full approval [7]. For people with ALS, this delay is critical: the disorder progresses rapidly, and time is a limited resource. As a result, the ALS community has pushed for policy changes that would provide access to experimental treatments, improve the design of clinical trials, and accelerate the overall development pipeline.

Highly motivated patient communities, like the ALS community, critique FDA policies in an effort to make more drugs available to the community. A central challenge is that policies often fail to reflect the lived experiences of patients, as there are limited formal mechanisms for integrating their perspectives into decision-making. Until 2002, if a member of the public wanted to comment on a proposed rule or regulation, they had to know when the proposed rule or regulation would be published. However, patient communities–especially those with mobility concerns (like the ALS community)–might find it difficult to travel and visit sponsoring agencies [59, 67]. Digital critiques via posts on social media platforms–such as Twitter or Instagram–do not guarantee communication with FDA officials [30].

In 2003, regulations.gov was launched to remove physical barriers, making it easier to participate in regulatory processes. The platform provides people with centralized access to regulations and policy documents. After a draft document is released by agencies like the FDA, the public has a few months to submit comments. People affected by conditions like ALS can use this opportunity to voice their concerns and priorities. The platform also offers resources on how to write better comments in order to participate effectively. At the end of the comment period, regulatory agencies make any required changes based on the comments provided. The FDA uses this platform to receive input from the public on developing drugs for ALS treatment.

6.2 Platform: Leveraging regulations.gov for formal policy intervention

While general-purpose platforms like Twitter facilitate informal advocacy, regulations.gov stands as a distinct and crucial platform for patient communities to formally critique and influence drug development policies. The platform provides a structured, centralized portal for direct engagement with specific governmental processes. This is evident in the substantial participation surrounding the *"Amyotrophic Lateral Sclerosis: Developing Drugs for Treatment; Guidance for Industry"* draft, which has 676 comments, since its initial posting on February 16, 2018. This platform uniquely enabled the ALS community to offer criticisms of the regulatory framework. Commenters systematically addressed issues such as slow approval processes, rigid clinical trial designs, and specific limitations within the guidance document itself. A key strength of regulations.gov is that it gives patients a formal space to explain the urgent and aggressive nature of ALS, argue for special regulatory treatment, and call for access to experimental drugs (Figure 5). Furthermore, the platform effectively allowed integrating personal stories and lived experiences within a formal context, which served to underscore urgency, demand FDA accountability, and humanize the impact of policy decisions. The platform's direct feedback mechanism proved instrumental in fostering accountability: after receiving comments from the community, the guidance document was updated and reposted on September 23, 2019. This outcome underscores the unique utility of regulations.gov as a formal channel for public input, demonstrating its potential effectiveness in translating patient advocacy into tangible policy adjustments within institutional workflows. Its structured, albeit rigid, nature facilitates this direct influence and public accountability in regulatory processes.

6.3 The Process-Platform Gap: The limitations of one-way design in policy engagement

Despite its utility as a structured and official channel for formal public input, the regulations.gov platform has several limitations that create a disconnect between the public and regulatory agencies like the FDA. One major limitation, inherent in its design as a formal submission portal, is that agencies cannot respond directly to individual comments. This prevents the FDA from engaging in crucial follow-up questions for clarification on complex issues or acknowledging specific patient concerns, effectively halting any potential for direct dialogue. This design choice is likely intended to maintain agency neutrality, manage the immense volume of submissions, and ensure a standardized, legally admissible review process. Second, the platform's architecture does not support public

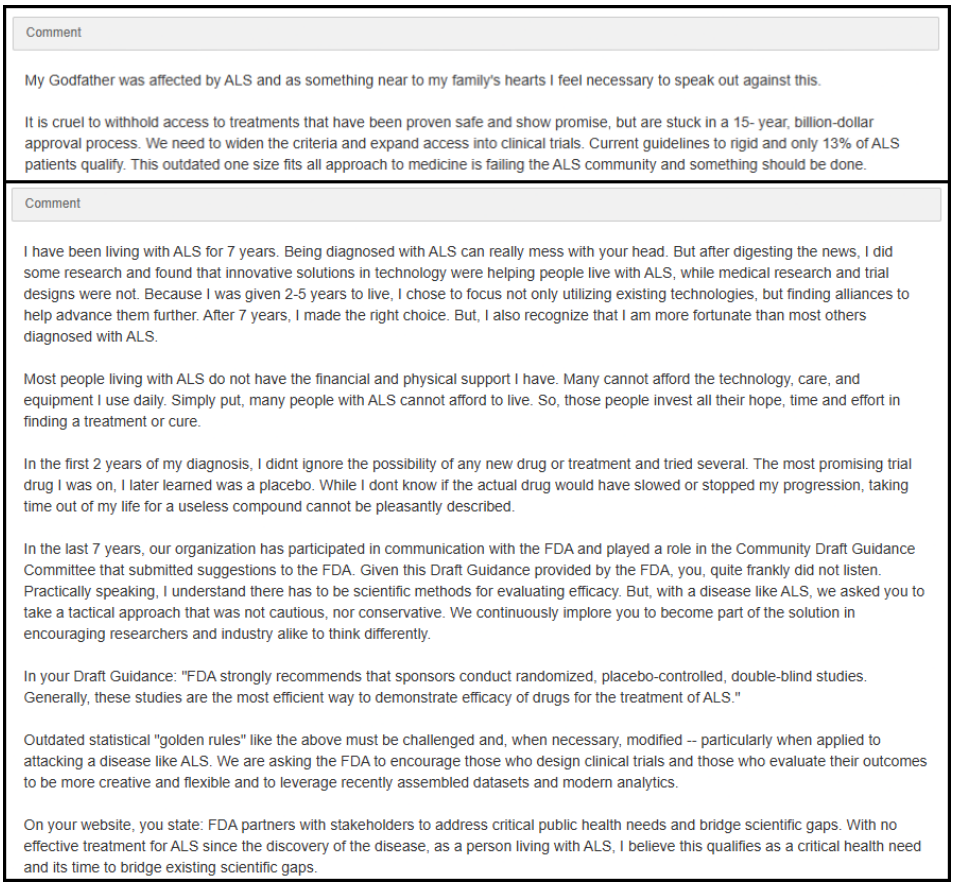


Fig. 5. Members of the ALS community post comments on regulations.gov that critique the current regulations placed by the FDA. They often use personal experiences and examples to strengthen their argument to make new drugs more accessible.

interaction with other submitted comments. This prevents joint refinement of policy suggestions and the emergence of consensus among community members around shared regulatory concerns. Third, the absence of built-in features for categorizing or tagging submitted comments places a significant burden on agencies to manually extract recurring themes and on the public to determine common priorities. This design hinders identifying shared concerns and prevents a more focused, data-driven dialogue on specific regulatory issues. Fourth, input is restricted to the document as a whole; there is no mechanism to link comments to specific sections or paragraphs. This structural limitation hinders the precision required for detailed policy revisions. Fifth, the public is rarely informed about which specific comments, if any, influenced revisions to the final policy. This critical lack of transparency and feedback establishes a one-way communication flow, leaving patient communities uncertain about the tangible impact of their advocacy efforts.

This inability of regulations.gov to support multi-way communication reveals a significant process-platform gap between patient community critique and regulatory decision-making. While the platform provides access to institutional processes, its design does not support structured dialogue, robust community collaboration, or transparent feedback loops with regulators. Bridging

this critical gap requires the development of a more participatory policy infrastructure that actively enables dialogic engagement.

Design Claim 3: Ways to aggregate existing comments can better focus public inputs.

Design Claim 4: Enabling public discussion and collaborative editing of comments can help refine collective arguments and highlight shared priorities.

Design Claim 5: Enabling agencies to highlight particularly impactful comments or common themes from previous dockets can serve as a learning resource that guides the public in creating more effective suggestions.

7 Design Recommendation

We share designs for two novel platforms that might overcome the process-platform gap described earlier. Both designs are based on the design claims we listed in the case studies.

7.1 A Platform for Expert-Community Collaboration Across the Research Workflow

To address the lack of structured collaboration between institutional researchers and patient communities, we propose a platform designed to support collaborative work across the entire research process. This platform is particularly tailored to accelerate and refine the drug development pipeline, ensuring that patient insights directly inform the creation and testing of new drugs. This design is based on design claims 1 and 2. Rather than conceptualizing communities as data producers and institutional experts as consumers, this approach treats both groups as collaborators with complementary knowledge. It supports a workflow in which research questions emerge from shared needs, and results can inform both clinical science and individual decision-making. Rather than repurposing existing social platforms, this design embeds community-expert collaboration directly into the structure of the platform. The platform can support a number of collaborative activities.

7.1.1 Co-define Research Questions. Both patients and institutional experts engage in structured discussions to refine the question. A lightweight voting or feedback system helps prioritize questions that are both relevant to the community and feasible to study. For instance, discussions could prioritize questions around unmet medical needs or the efficacy of existing treatments, directly informing early-stage drug development.

7.1.2 Co-design a study. The community and institutional experts collaboratively develop a study plan, including data types, collection methods, and analysis approaches. The platform offers templates and constraints to support methodological rigor, while allowing room for community input. This is similar to Galileo's design and review phase [46]. Galileo is a research prototype that guides citizens through a structured design and review process to transform personal intuitions into scientifically sound experiments without requiring expert oversight. For drug-related studies, templates can support N-of-1 trials, analyses of symptom tracking, or structured off-label use monitoring.

7.1.3 Recruit and Participate. Community members sign up to participate, often serving as the primary data contributors. The platform supports multiple study types, including: 1) observational tracking (e.g., symptoms, behaviors), 2) structured self-experimentation, and 3) feasibility studies. Tools like Hevelius can be used at home by patients to collect digital biomarkers [45]. The platform could also facilitate recruitment for decentralized or patient-led clinical trials.

7.1.4 Analyze and Interpret Together. Preliminary results are shared within the group. Researchers might lead analysis, but community members can contribute insights, flag anomalies, or suggest alternative interpretations. Built-in tools support accessible, collaborative review. This collaborative analysis ensures that the patient's lived experience informs the interpretation of drug efficacy and

side effects, leading to more relevant findings for drug developers.

Such a platform enables community members and institutional experts to align their efforts–creating studies that are not only methodologically sound but also rooted in community priorities. Importantly, it also allows both groups to learn from each other over time, treating research as an ongoing process.

7.2 A Participatory Policy Platform for Two-Way Engagement

Public commenting platforms like regulations.gov offer a formal mechanism for community members to participate in policymaking, but they are limited by a one-way model of communication. Members of the public can submit comments, but they do not receive responses, cannot interact with other comments or users, and have little visibility into whether their feedback made a difference. To better support structured engagement between regulatory agencies and affected communities, we propose a platform—either as an evolution of regulations.gov or as a new system altogether—that enables a more dialogic and transparent process. This design is based on design claims 3, 4, and 5. The platform can support engagement between regulators and community members.

7.2.1 Comment Submission with Section-Level Targeting. Instead of treating policy documents as static blocks of text, the platform would allow users to leave comments on specific sections–similar to commenting in collaborative document editors like Google Docs. This helps agencies understand which parts of a policy are drawing concern and allows commenters to be more precise in their feedback. For instance, instead of a general comment stating "trial designs are too rigid," a patient could highlight a specific clause within the "Clinical Trial Design" section, arguing that "this particular inclusion criterion disproportionately excludes rapidly progressing ALS patients."

7.2.2 Tagging and Categorization of Comments. Submitted comments can be grouped by topic using user-generated or platform-assisted tagging. This makes it easier for agencies to identify recurring themes, prioritize areas of confusion or concern, and respond more efficiently. Tags could include categories like “RealWorldEvidence,” “AccessToTreatments,” “TrialDesignReform,” or “AccelerateApprovals” to organize public input, facilitate the identification of key themes by agencies, and enable the public to determine common priorities within the vast array of comments.

7.2.3 Community Engagement with Comments. Rather than treating comments as isolated messages, the platform would allow users to read, upvote, and reply to others’ contributions. This can help amplify widely shared concerns, reduce redundancy, and allow collectively refining of ideas. Specifically, users could build upon existing arguments, offer nuanced perspectives, or synthesize diverse viewpoints into more comprehensive and robust policy recommendations. Highly engaged threads can surface key arguments or propose alternatives with a broader consensus.

7.2.4 Agency Response and Clarification Tools. Institutional agencies would have the option to respond to comments directly. These responses could clarify misunderstandings, provide rationale behind specific policy decisions, or signal openness to revision. This two-way interaction can build trust and reduce misinterpretation.

Together, these features can create a participatory workflow that supports more than just one-way inputs—they foster iteration, mutual understanding, and collective problem-solving. We recognize that this approach might face pragmatic challenges. One core limitation is the institutional burden of engagement. Agencies like the FDA may not have the capacity to respond to public comments in an ongoing or dialogic way. Replying to comments could raise legal concerns–particularly if engagement is perceived as committing to changes or influencing regulatory outcomes in ways

that bypass formal review. Furthermore, direct interaction could lead to uneven participation, particularly if people with more time and resources dominate the conversation.

These risks must be carefully managed through platform design and institutional policy. For example, agencies could use templated responses for common concerns, or designate moderators (likely senior members of the community) who help synthesize and summarize discussion threads rather than engaging in every exchange. Importantly, the goal is not to require universal engagement, but to make interaction possible where appropriate, and to provide visibility into when and how public input shapes final decisions.

8 Discussion

In this section, we discuss the challenges and possibilities of social platforms that support collaboration between communities and institutions. Furthermore, we reflect on the differences between community goals and the goals of individual members and how platforms can support both. Finally, we discuss how other communities can learn from the ALS community to use social platforms to meet their goals.

8.1 Platform-process gaps exist. Future systems and deployments can assess how well these can be reduced

The ALS community's use of three distinct types of platforms–general-purpose social media (e.g., Twitter), repurposed health platforms (e.g., PatientsLikeMe), and formal institutional portals (e.g., regulations.gov)–reveals how each supports different aspects of participation in scientific and regulatory processes, but none are sufficient alone in their current form. Each platform aligns with a part of the drug development process: Twitter enabled mass fundraising through the viral Ice Bucket Challenge [31], PatientsLikeMe supported patient-led observational studies [66], and regulations.gov allowed for formal critique of FDA policy [4]. However, their respective limitations–episodic nature, lack of collaboration with institutional experts, and one-way communication–show that no single platform supports sustained, structured engagement across the entire institutional process.

We believe that this persistent process-platform gap–where platform affordances fail to meet the demands of institutional processes–is not simply a technical shortcoming, but that it reflects a deeper mismatch between social and institutional expectations. Such a gap extends ideas around technical limitations in CSCW and GROUP work, including the concept of socio-technical gap, the inherent disconnect between what social systems need and what technical systems can feasibly provide [1]. Furthermore, even well-designed workflows inherently constrain the dynamic nature of complex work [49]. Platforms encode specific assumptions about how work should be done, which might limit their ability to support evolving, context-sensitive collaboration–especially in high-stakes, distributed settings like community-led drug development research. This highlights an important question: even when platforms are creatively repurposed or restructured (similar to the work by the ALS community), can they fully accommodate the complexity and flexibility that institutional processes demand?

Ultimately, we need to design with an awareness of these structural limitations–building systems that support collaboration and leave room for negotiation, rather than seeking full integration. Our design suggestions–such as supporting community-expert collaboration on research platforms and enabling two-way, transparent engagement in policy platforms–attempt to align platform affordances more closely with institutional processes. Future work can design and deploy such systems to inform how well they close the process-platform gap.

8.2 Even within a community, not all goals are aligned or supported by platforms

While this paper primarily frames the process-platform gap at the level of communities and institutions, it is equally important to consider the internal differences within communities–and even within individuals–that social platforms and institutional processes often fail to account for [32].

Patient communities, such as those organizing around ALS, are not monolithic. They contain members with differing capacities, priorities, and goals [68]. Some may focus on accelerating drug development; others may prioritize quality of life, care, or emotional support. Some members who are excited by the novelty of an approach might disappear during subsequent iterations. Furthermore, long-term motivation–required to participate in institutional processes–might vary among community members. As a result, specific community subgroups or individual priorities may be overlooked, even within otherwise "successful" collective efforts [41, 43].

This tension is not merely about inclusion, but about prioritizing and aligning goals [33]. When platforms are used to support community–institution collaboration (as in our design recommendations), they still require a mechanism to navigate intra-community goal conflicts. For example, rapid experimental treatments may be supported by some patients but viewed as risky or irrelevant by others. No existing platform–whether Twitter, PLM, or regulations.gov–offers affordances for surfacing or negotiating these internal tensions. For instance, different members of the ALS community commented on regulations.gov about various topics like clinical trial design, patient rights to access drugs, and the urgency of ALS. This gap is not simply technical; it reflects a deeper challenge about who gets to represent "the community" and whose priorities shape community-led action [33].

Moreover, at the level of individuals, platform goals may misalign with personal motivations or capacities. Participating in policy feedback, running self-experiments, or contributing to data platforms all require time, literacy, and emotional labor–not all patients have equal ability or desire to engage in these ways. Marginalized participants in health communities may disengage when platforms fail to reflect their personal needs or lived contexts [43, 55]. In such cases, no amount of institutional responsiveness can compensate for platform-level misalignment with individual goals.

These intra-community and individual-level gaps raise important implications for the design of collaborative systems. For ACM GROUP researchers, this calls for attention not just to collective coordination across groups, but also to internal diversity, conflicting priorities, and differences in representation within communities themselves. Supporting plural participation means designing not only for integration with institutions but also for disagreement and negotiation within communities.

8.3 Other communities can repurpose these platforms, but not without adapting them to their own contexts

While this work focuses on the ALS community, its implications extend to other communities organizing around urgent, high-stakes issues. For instance, movements in climate justice–such as those addressing environmental racism, extreme weather adaptation, or energy transition–similarly navigate institutional processes while turning to social platforms for visibility and coordination.

Like the ALS community, climate advocates have leveraged general-purpose platforms like Twitter to mobilize action (e.g., #FridaysForFuture [16]), used mapping and reporting tools for community-driven data collection (e.g., air quality tracking via PurpleAir), and engaged formal processes through public commenting on environmental regulations [27, 38]. These similarities might suggest that the platforms and workflows explored in this paper could be reused by other communities to intervene in institutional decision-making.

We suggest being mindful of differences across contexts when designing similar platforms. Reapplying a process designed around one domain (e.g., drug development) to another (e.g., climate governance) risks flattening key contextual differences. Climate movements often involve multi-generational participation and distributed impact–all of which introduce unique challenges around coordination, representation, and legitimacy [5]. Institutional processes in environmental governance are frequently more fragmented across local, national, and global levels, demanding different kinds of alignment. Moreover, community knowledge in climate justice is often place-based and experiential, requiring platforms that support storytelling, historical context, and spatial annotation–not just data tracking or formal comment submission [8, 63]. Considering these differences, how might other communities use social platforms to attain their goals?

Flexible infrastructures can help; these can be configured by communities themselves to fit their domain-specific processes. This includes defining what counts as participation, how knowledge is represented, and which parts of the institutional process matter. In this way, the lessons from the ALS case are not blueprints to be replicated–but design recommendations to be considered and possibly reshaped by other communities pursuing different, yet equally urgent, forms of institutional change.

9 Conclusion

The paper highlights the "process-platform gap" by examining how the Amyotrophic Lateral Sclerosis (ALS) community leverages social platforms for scientific participation, despite social platforms not being inherently designed for complex institutional work. Through case studies, including the viral Ice Bucket Challenge, the repurposing of health tracking platforms like PatientsLikeMe for observational studies, and formal engagement with regulatory bodies through regulations.gov, we demonstrate the significant impact patient communities can have in expediting drug development and influencing policy. However, a key limitation is the often one-way nature of these interventions, stemming from a lack of institutional involvement and features on social platforms that would support sustained dialogue, collaborative decision-making, and formal integration into research and policy processes. The paper underscores the need for thoughtful redesign of social platforms to foster more collaborative environments by bridging the process-platform gap and enabling more effective patient participation in scientific research and institutional processes.

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