# 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 X, PatientsLikeMe, and a federal portal also fell short of requirements like sustained funding, expert involvement, and two-way dialogue. These shortcomings lead to the *process-platform gap*: a misalignment between what platforms provide and what institutional processes require.



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 influenced 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* used general-purpose features–like hashtags and tagging on X–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 shape the Food and Drug Administration's (FDA) drug development guidelines. One limitation of the community's use of social platforms is the mismatches between social platform designs and institutional workflows, leading to a persistent *process-platform gap*. This limits the

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potential for sustained dialogue, collaboration, and significant integration of community-led efforts into institutional decision-making. Our work provides design recommendations to reduce the process-platform gap.

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 X, Facebook, and online health forums–to spread awareness about rare disorders or advocate for change in policy. 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 are conducted within institutional settings–such as universities, hospitals, and pharmaceutical companies–with limited public involvement [57]. Most clinical trials for novel drugs often proceed without input from patients during the initial planning and study focus determination phase [6]. Unlike technical domains where expertise can be narrowly specialized (e.g., prosthetic engineering), many aspects of health research directly impact the lives of patients, who hold unique experiential knowledge about symptoms, treatment burdens, and quality-of-life tradeoffs [20]. 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 policy-making (Figure 1). ALS is a rare, progressive neurodegenerative disorder that affects nerve cells in the brain and spinal cord. Unlike many online communities that use social platforms primarily for support or advocacy, ALS patients have used *the same platforms* to share data, critique drug development policies, and raise funds via viral challenges. Such 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.

While patient communities are creating new ways of using social platforms, institutional experts already use such platforms to conduct scientific research: they identify emerging research questions, recruit participants and increase the visibility of their research [3, 17, 71]. In most cases, science evolves in parallel with only a *partial intersection* with social platforms: such platforms are used for a few stages of the research process rather than throughout the entire research process. For example, researchers have identified research questions or recruited participants with rare disorders like Lynch Syndrome using Twitter and Facebook [3, 11, 17]. In a few rare cases, science has evolved with social platforms by demonstrating (greater overlap) across many stages of research. For example, the highly motivated Long COVID patient community–involving people with advanced degrees–used WhatsApp and Slack to document their symptoms and helped institutions formally recognize Long COVID [52]. Similarly, the ALS community intervenes at multiple stages of the institutional process–like fundraising, running studies, and contributing to drug development policies–by using social platforms to expand their roles from subjects to active contributors.

Our work answers the following research question: how do communities use social platforms to participate in institutional processes? We answer this question by studying the ALS community and the platforms they use. 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 on general-purpose platforms like X and Youtube [42, 61]. This campaign reached wide audiences via viral engagement on platforms like X, using posts, threads, and videos. 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 [28, 83]. Third, to influence FDA drug approval guidelines and address the urgency of a rare, terminal condition like ALS, the community contributed public comments on regulatory documents. They submitted patient-authored public comments on the draft guidance document provided by the FDA through a federal platforms (`regulations.gov` [10]). In each case, the ALS community has used different social platforms to participate in drug development and regulatory processes.

Despite such success, community-led efforts to participate in institutional processes are not common and rarely successful. 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 how social platforms support communities that seek to participate in institutional processes. This paper also introduces the idea of the process-platform gap. We share an understanding of the novel ways in which patient communities are using social platforms for goals such platforms 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

Our research builds 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. Community-led efforts refer to initiatives in which groups of people–often directly affected by a condition or motivated by a shared cause–carry out activities independently of institutional support. When done digitally, such efforts often use tools like social media, forums, or open-source platforms to pursue goals traditionally led by institutions. Our synthesis of prior work identifies key limitations that prevent such efforts from integrating with institutional processes.

### 2.1 Challenges in supporting patient-led efforts using existing platforms

Many communities use social platforms to organize around causes and advocate for change [15, 36, 51]. Examples include disaster response coordination on social media during crises [59, 74], mass mobilizations like the Black Lives Matter movement, and organizing protests and shaping public discourse [27, 39]. Specific to our work, patient communities use social platforms to achieve goals that impact them. For instance, Long COVID patients used Slack to track their symptoms, analyze the data, and coordinate studies outside formal institutions [52]. 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 [21, 44]. These examples show how patient communities can take on complex work like running studies and interpreting data.

Current platforms fail to support community-led efforts for complex work in two ways. First, social platforms rarely support entire workflows that community-led efforts require [34, 87]. Patient communities often need to stitch together features from different platforms since platforms like Reddit or Facebook offer limited support for raising funds, collecting data, and navigating regulatory policy [19, 72]; all of these activities are necessary to accelerate access to experimental drugs [33, 88]. Second, frameworks for supporting community-led efforts (like "problem → ideation → action" [69]) are too abstract to address community-specific challenges [4, 80]. For instance, designing a patient-led study for a rare disorder requires careful methodological planning, legal compliance, and clinical insight [20]. Such domain-specific needs are rarely supported by existing frameworks.

One way in which platforms can support community-led efforts is through participatory infrastructuring. In CSCW and HCI research, participatory infrastructuring is the process by which communities work across organizational, political, and technological boundaries to sustain their initiatives [7]. This is done through the participation of users in the ongoing creation and maintenance of systems, rather than simply adopting predesigned technologies [50]. For example, Wikipedia editors collaborated to build and maintain systems for banning vandals [32]. This demonstrates how a community (of editors) collectively creates and sustains a complex system involving policies, tools, and social norms to maintain their shared initiative. Patient-led efforts operate in a similar way to bridge informal patient networks with formal institutional processes. For example, patients with Long COVID organized on various platforms including WhatsApp and Slack to document their experiences [52]. The Long COVID patients used survey tools to share data-driven insights about their experience to make institutions recognize the Long COVID syndrome. Our work extends this line of inquiry by examining how one patient community navigates institutional and technological constraints on social platforms across multiple stages of the institutional process.

### 2.2 Challenges in integrating efforts on social platforms 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 [52]. The PLRC's independent efforts demonstrate the potential of patient-led initiatives, but also reveal limitations: groups like PLRC typically lack access to long-term infrastructure, funding, or institutional recognition. The lack of access 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 X, GitHub, and personal blogs to create and use diabetes management technologies like the DIY artificial pancreas systems (APS). However, since the DIY artificial pancreas systems were not FDA-approved, they faced issues being used in routine clinical care [70]. The lack of use in clinical care 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 (CDC)'s guidance was updated based on Long COVID community's findings [26].

One way that communities can align their participation with institutional workflows is through methods standardization. Prior CSCW research has shown that methods standardization–the development of shared procedures for labeling and collecting data–is necessary for cooperation across different communities [48]. Yet current social platforms fail to provide this form of coordination. Patient-led studies on Slack or X, for instance, often develop their own data collection routines; however, without shared standards for data quality, institutions cannot use these datasets [52]. Our work identifies this absence as an instance of the process–platform gap: the mismatch between what platforms can provide

and what institutions require. Prior HCI research on models like Form-From describe platforms in terms of content structure and delivery mechanisms, but do not capture the social and institutional aspects of work by communities on social platforms [86]. In contrast, our work examines the processes people seek to contribute to and how platform features enable or constrain these contributions. Our work looks at the social aspects and reveals deeper design gaps between what social platforms afford and what institutional processes demand.

### 2.3 Current platform designs overlook the need for long-term, community-led efforts

Communities often turn to general-purpose social platforms rather than specialized platforms because they are well-established and contain pre-existing communities. New platforms face the *cold start problem*, lacking enough interactions to generate the network effects needed for growth [13, 46]. General platforms such as X, Facebook, and Reddit offer immediate *access to pre-existing networks*, lowering coordination costs and enabling rapid mobilization among distributed members [43, 68]. Furthermore, general platforms' *familiarity* and *low barriers* to entry make them more accessible than specialized systems that might require onboarding and technical literacy [43, 63]. Popular platforms' *publicness*–extent to which content is visible to others [78]—and *algorithmic amplification*–increase in visibility because of social platform's algorithms [53]–can help movements attract attention from media, policymakers, and potential allies. This creates virality for causes that might otherwise remain invisible. Additionally, pre-existing communities on general platforms can *attract new members* more easily than new communities on specialized platforms [43, 55]. Existing members of a community typically have a *sense of belonging* which motivates them to participate [47].

Despite several advantages general-purpose platforms provide, these platforms are typically designed for personal use–such as self-expression, connection, and content sharing–not community-led efforts [22]. The design of social platforms creates two challenges for efforts by patient communities to participate in institutional processes. The first challenge is the mismatch between 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 [45, 49]. The second challenge is a limited understanding–among tool designers and community members–of how communities can repurpose existing tools. There is limited research on how health communities adapt platform features–such as data tracking tools on PatientsLikeMe, comment threads on Facebook, or tagging systems on Slack–to support ongoing, multi-phase efforts like policy advocacy, peer-led studies, or patient-driven trials. Our work studies how patient-communities adopt platform features by examining how the ALS community raised funds, ran studies, and shaped policies using social platforms.



## 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.

### 3.1 About Amyotrophic Lateral Sclerosis (ALS)

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.

### 3.2 Efforts of the ALS community

The ALS community organizes on multiple social platforms. 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 [28, 42, 61, 62]. The community has used platforms like X, PatientsLikeMe, and `regulations.gov` to raise funds, run studies, and engage with institutional decision-makers. These efforts often seem 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. 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 [14, 83]. 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 Methods

We analyzed three case studies using a qualitative approach to understand how the ALS community intervenes in the institutional process. Multiple data sources were used to analyze each case study.

### 4.1 Selection of Case Studies

We selected three cases that show how the ALS community intervenes in the institutional process: 1) generating research funds through the Ice Bucket Challenge, 2) running studies on the PatientsLikeMe platform, and 3) commenting on `regulations.gov`–a platform that enables formal participation in regulatory processes–to influence the FDA's drug development policies. These cases were selected since they align with major institutional processes: securing funding, running studies, and influencing policies. Additionally, they showcase the important role of social platforms in supporting patient-led efforts to intervenes at various stages of the institutional process.

In summary we selected three case studies to understand and demonstrate how one patient community (the ALS community) strives to participate in institutional processes using social platforms.

### 4.2 Platforms, Stakeholders and Data Sources

*4.2.1 Choice of platforms.* Both X and PatientsLikeMe are well established and have pre-existing communities which are required for fundraising and running studies (Table 1). The ALS community used `regulations.gov`–a federal platform–to comment on policy documents for drug development (Table 1).

*4.2.2 Stakeholders.* Each case study had different stakeholders interacting on the social platforms. The Ice Bucket Challenge included ALS patients and caregivers; participants beyond the ALS community and donors; public figures and media organizations. The PatientsLikeMe case study included ALS patients using PLM as self-trackers; and researchers using the aggregated dataset. The FDA Guidance Document on `regulations.gov` saw contributions from ALS patients,

| Feature | Ice Bucket Challenge | PatientsLikeMe Research Study | FDA Guidance Document Critique |
|---|---|---|---|
| Avoid cold start problem [13, 46] | ✓ | ✓ | |
| Familiarity and low barriers to entry [43, 63] | ✓ | ✓ | ✓ |
| Publicness and algorithmic amplification [53, 78] | ✓ | | |
| Access to pre-existing networks [43, 68] | ✓ | ✓ | |
| Attract new members [43, 55] | ✓ | ✓ | |
| Sense of belonging [47] | ✓ | ✓ | |

Table 1. ALS community chose different platforms for each endeavor since they provided unique advantages. The ALS community used general-purpose platforms for fundraising and running studies since they are well established and provide a pre-existing community. To comment on policy documents, the ALS community used a specialized federal platform (`regulations.gov`).

caregivers, and advocates; and nonprofit organizations. The FDA was the institutional recipient of these comments. The timeline for each case study is shown in Figure 2.

*4.2.3 Data sources.* Our analysis draws entirely on publicly available materials from digital platforms; related documents and websites; and research publications (Table 2). All materials were analyzed retrospectively. The data sources used for each case study are described below.

(1) Ice Bucket Challenge (May–September 2014): Public social media posts, campaign videos, ALS Association webpage (`als.org`) and secondary analyses published in news and academic sources [42, 61, 62, 81].
(2) PatientsLikeMe (2009–2011): PatientsLikeMe platform pages (`patientslikeme.com`), and peer-reviewed publications describing the lithium carbonate study [82, 83].

| | Related documents/websites | Research publications | Posts and comments |
|---|---|---|---|
| Case study 1: Ice Bucket Challenge | ALS Association webpage: `als.org` | [42, 61, 62, 81] | Posts on X, Campaign videos on YouTube |
| Case study 2: PatientsLikeMe | PatientsLikeMe website: `patientslikeme.com` | [82, 83] | — |
| Case study 3: FDA Guidance Document | Publicly available documents hosted on `regulations.gov` | — | Publicly available comments on `regulations.gov` |

Table 2. Three case studies were analyzed using data from documents/websites, research publications, and posts and comments. Case study 1 draws on many knowledge sources due to its popularity. Case study 2 relies primarily on research publications, supplemented by the PatientsLikeMe website. Case study 3 uses the specialized platform `regulations.gov`.

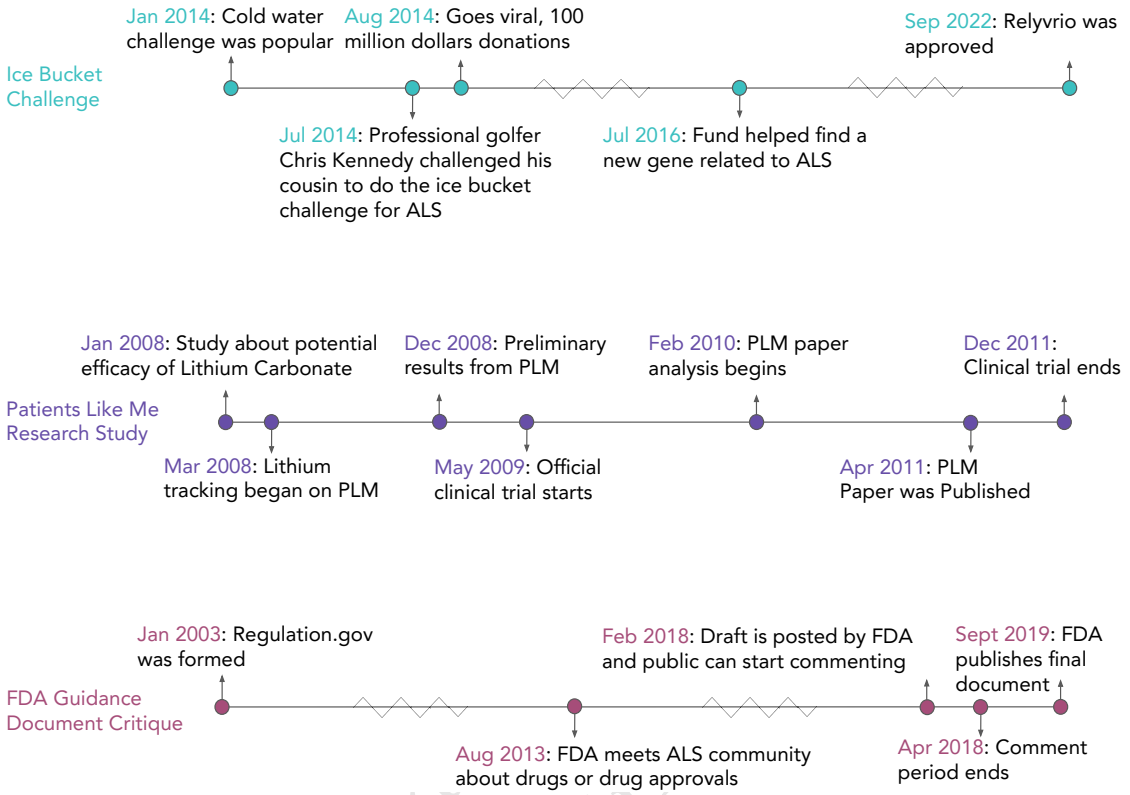



Fig. 2. The nature of the three case studies can be seen on their timelines. The Ice Bucket Challenge, similar to other viral events, was popular only for a short period of time (summer of 2014) during which it raised over $100 million. Furthermore, the PatiensLikeMe case study's timeline shows us how slow clinical trials are (May 2009 to Dec 2011) compared to patient-led studies (Mar 2008 to Dec 2008). Finally, the FDA guidance document case study show us the rigid timelines followed by institutions where all public comment period is 3 months long (Feb 2018 to Apr 2018). The timelines also show us that the ALS community has been participating in institutional processes since 2008. The zig-zag (/\/\/\) lines refers to many months/years being condensed in the timeline.

(3) FDA Guidance Document (February 2018–September 2019): Publicly available comments and response documents hosted on `regulations.gov` under "Amyotrophic Lateral Sclerosis: Developing Drugs for Treatment."

We selected three different platforms (X, PatientsLikeMe, and `regulations.gov`) that supported similar set of stakeholders including ALS patients and caregivers while using a number of data sources including websites and documents.

### 4.3 Researcher Roles and Analytic Framework

The study sought a deeper understanding of the ALS community and the ALS community's activities on social platforms. The research team acted solely as observers and interpreters, and did not interact with community members. Our analytic lens draws on interpretive qualitative analysis, focusing on how community actions led to success and also revealed mismatches between platform designs and institutional processes–what we define as the process–platform gap.

Early exploration to understand the ALS community's work showed similar categories of work and challenges across platforms. Each case was further analyzed using three dimensions shared across the community's efforts.

(1) Needs from institutional processes: The ALS community needs can be left unmet by the institutional processes leading to community actions like fundraising, running studies, and changing policies. The needs of the ALS community were identified using prior knowledge sources such as research papers, news articles, etc.
(2) Platform support: Social platforms supported the ALS community's actions to try and meet their needs. The support provided by the social platforms was identified by studying the platform's features and through prior knowledge sources including research papers and articles.
(3) Gaps: Despite the platform's support, some aspects of the community's efforts did not match with institutional standards or did not meet some needs of the community. These gaps were identified by comparing what institutions and the community required with what the platform is able to support.

In summary, the research team explored the ALS community's work across platforms by identifying the community's needs from institutional processes, support provided by platforms, and the gaps between the community's efforts and institutional standards.

## 5 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 use.

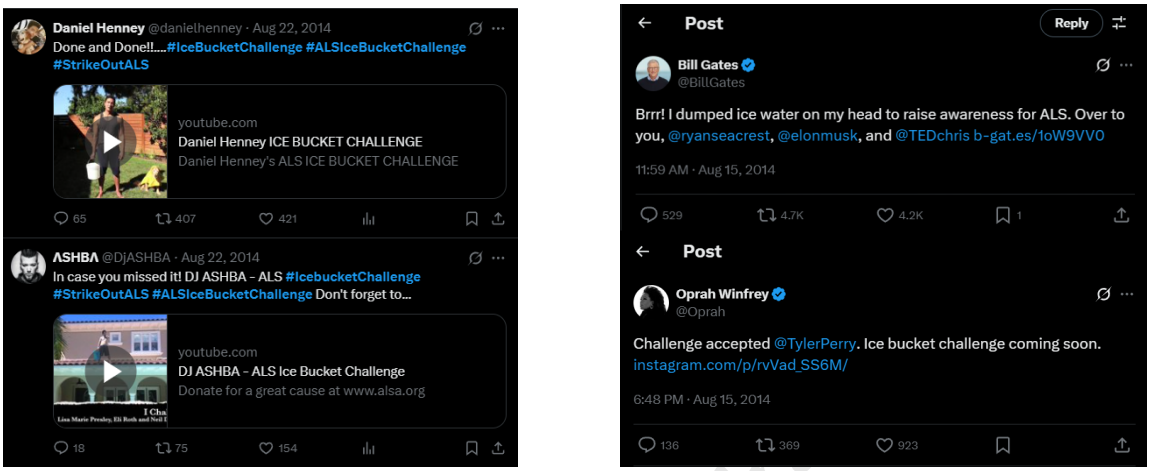
### 5.1 Process: Raising funds for developing drugs for a rare disorder like ALS

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 [18]. 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 alternative sources of funding can help develop and test more drugs–essential for communities living with fatal disorders. 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 [29, 73]. ALS is a rare disorder that most people are unaffected by, making it difficult to raise funds for drug development from solely those affected by it [81].

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.

### 5.2 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.




(a) (b)

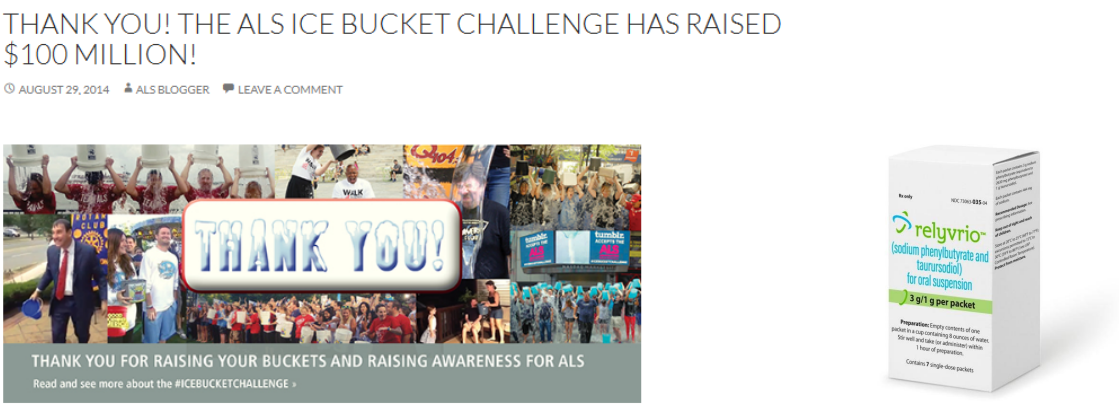
Fig. 3. a) Participants who participated in the Ice Bucket Challenge used trending hashtags like #IceBucketChallenge, #ALSIceBucketChallenge, and #StrikeOutALS when sharing their posts. b) The challenge became more popular after celebrities like Bill Gates and Oprah Winfrey took part in it. Participants made use of the tagging feature to nominate others for the challenge, as seen in Bill Gates' post.



*5.2.1 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 [67]–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 [30, 75]. 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.

*5.2.2 How social media's features contributed.* Social media platforms supported fundraising through the Ice Bucket Challenge in three ways (Figure 3). 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 3b). 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 4a). 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 4b) [38].




(a) (b)

Fig. 4. 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.



### 5.3 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 success in subsequent years failed, demonstrating the instability of novelty-driven fundraising [79]. 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 X prioritize viral visibility, where users are more likely to engage with entertaining or low-effort content than complex causes [77]. As a result, participation might draw 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 [79]. 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.

## 6 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 acknowledgment from institutional science, revealing a process-platform gap in patient-led research.

### 6.1 Process: Improving the pace of drug evaluation for a rare disorder

Drug development and clinical trials to test new drugs are time-consuming [14, 83]. Responding to long timelines in securing access to potential treatment, highly motivated patient communities self-experiment with unproven supplements, and drugs [66]. One important factor that slows down clinical trials is the availability of participants [25]. This is especially true for rare disorders, like ALS, where 33,000 people live with the condition in the US [54]. 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 [35]. 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.

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

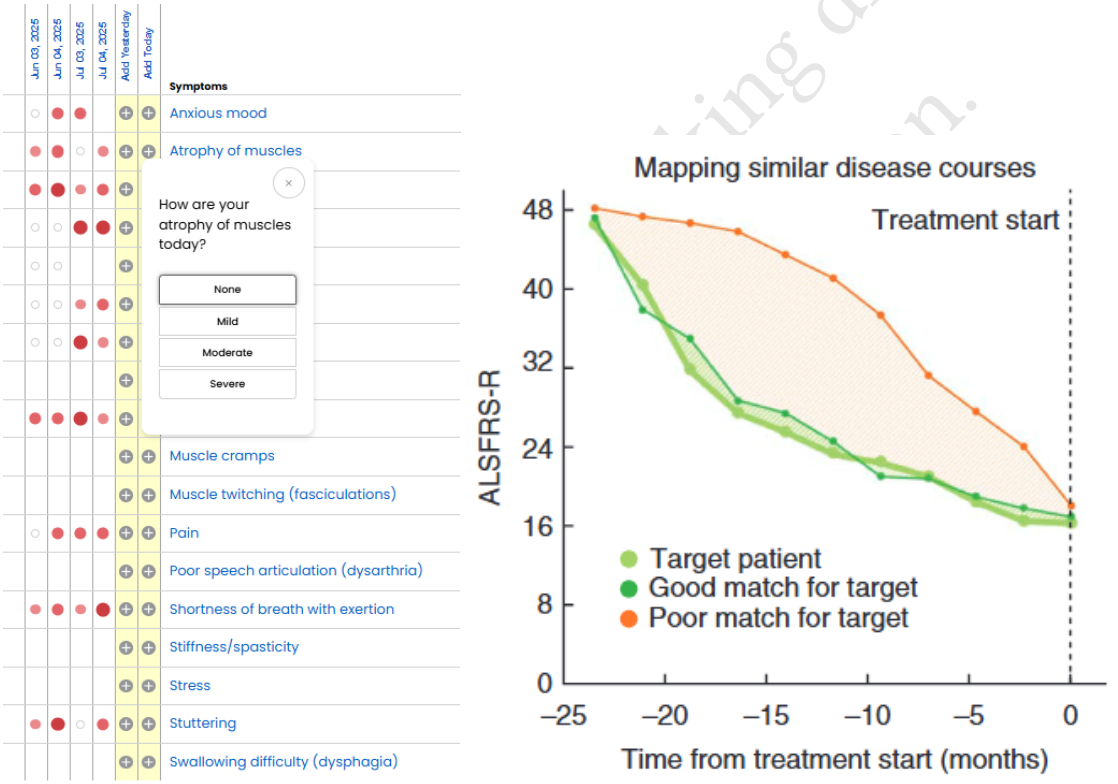
PatientsLikeMe (PLM) is a social platform where patients can track their symptoms and treatment plans (Figure 5a) [82]. Since the website is accessible online, PLM could be used by a patient with an internet connection regardless of their geographic location. Furthermore, PLM provides a standard way 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 [83]. The ALS community managed to repurpose the features of an online health platform to run a study that evaluated the effectiveness of treatments.

*6.2.1 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 rigorous 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 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.

*6.2.2 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 5b). 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.

*6.2.3 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 can create a social feedback loop that reinforces participation and legitimacy [12, 16, 58]. 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.




(a) (b)

Fig. 5. 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 reproduced from [83].

### 6.3 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 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 support patient self-tracking and study coordination and also offer ways for experts to engage meaningfully without displacing the momentum of patient-led efforts. Such platforms can 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.

## 7 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.

### 7.1 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 [31]. However, the process is often slow, and promising drugs remain inaccessible to most patients until they receive full approval [14]. 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 the FDA's drug development policies and guidelines. 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 [76, 84]. Digital critiques via posts on social media platforms–such as X or Instagram–do not guarantee communication with FDA officials [40].

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

| | |
|---|---|
| **Explains the need for wider inclusion criteria in clinical trials**<br>"My Godfather was affected by ALS and as something near to my family's hearts I feel necessary to speak out against this. | **Personal experience** |
| It is cruel to withhold access to treatments that have been proven safe and show promise, but are stuck in a 15-year, billion-dollar approval process. We need to widen the criteria and expand access into clinical trials. Current guidelines to rigid and only 13% of ALS patients qualify. This outdated one size fits all approach to medicine is failing the ALS community and something should be done. " | **Need for wider inclusion and statistical proof** |
| **Provides personal experiences and argues for special regulatory treatment**<br>I have been living with ALS for 7 years. Being diagnosed with ALS can really mess with your head. But after digesting the news, I did some research and found that innovative solutions in technology were helping people live with ALS, while medical research and trial designs were not. Because I was given 2-5 years to live, I chose to focus not only utilizing existing technologies, but finding alliances to help advance them further. After 7 years, I made the right choice. But, I also recognize that I am more fortunate than most others diagnosed with ALS.<br><br>Most people living with ALS do not have the financial and physical support I have. Many cannot afford the technology, care, and equipment I use daily. Simply put, many people with ALS cannot afford to live. So, those people invest all their hope, time and effort in finding a treatment or cure.<br><br>In the first 2 years of my diagnosis, I didnt ignore the possibility of any new drug or treatment and tried several. The most promising trial drug I was on, I later learned was a placebo. While I dont know if the actual drug would have slowed or stopped my progression, taking time out of my life for a useless compound cannot be pleasantly described.<br><br>In the last 7 years, our organization has participated in communication with the FDA and played a role in the Community Draft Guidance Committee that submitted suggestions to the FDA. Given this Draft Guidance provided by the FDA, you, quite frankly did not listen. Practically speaking, I understand there has to be scientific methods for evaluating efficacy. But, with a disease like ALS, we asked you to take a tactical approach that was not cautious, nor conservative. We continuously implore you to become part of the solution in encouraging researchers and industry alike to think differently. | **Personal experience** |
| In your Draft Guidance: "FDA strongly recommends that sponsors conduct randomized, placebo-controlled, double-blind studies. Generally, these studies are the most efficient way to demonstrate efficacy of drugs for the treatment of ALS."<br><br>Outdated statistical "golden rules" like the above must be challenged and, when necessary, modified -- particularly when applied to attacking a disease like ALS. We are asking the FDA to encourage those who design clinical trials and those who evaluate their outcomes to be more creative and flexible and to leverage recently assembled datasets and modern analytics.<br><br>On your website, you state: FDA partners with stakeholders to address critical public health needs and bridge scientific gaps. With no effective treatment for ALS since the discovery of the disease, as a person living with ALS, I believe this qualifies as a critical health need and its time to bridge existing scientific gaps. | **Argument for special regulatory treatment** |

Fig. 6. 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.

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.

### 7.2 Platform: Leveraging `regulations.gov` for formal policy intervention

While general-purpose platforms like X 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

| Comment from the ALS community | Text added to the FDA guidance document |
|---|---|
| "... ALS is a cruel and ruthless disease and the population living with it don't have time to wait! This guidance document needs to match this disease and move forward with a rapid progression in getting promising drugs into patients ASAP! A few ideas to improve it are: allow for the use of technology, NO placebos, **expansion of patients at all different stages into the trials and mobile sites.**" | "There is a need to understand the safety and effectiveness of investigational drugs for ALS across disease stages. Although sponsors may have good reasons to use prognostic enrichment to increase the likelihood of demonstrating a drug effect (e.g., to enroll patients who are more likely to experience rapid progression) or to use predictive enrichment to direct therapy to patients with a particular disease characteristic (e.g., a specific genotype or phenotype), **sponsors should not unnecessarily exclude patients from trial enrollment based on characteristics such as** age or **disease stage unless scientifically justified.**" |

Table 3. A key recommendation from many public comments was the inclusion of patients at all stages of ALS in clinical trials (left). The FDA's guidance document was updated and reposted on September 2019 with the addition of the text on the right, which encourages drug developers to include patients at all stages of ALS in clinical trials.



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 6). Furthermore, the platform effectively allowed the presentation of personal stories and lived experiences within a formal context, which served to underscore urgency, demand FDA accountability, and humanize the impact of policy decisions.

*7.2.1 Changes made to the guidance document based on the community's comments.* After receiving comments from the community, the guidance document was updated and reposted on September 23, 2019. For example, several comments asked for patients at all stages of the disorder to be included in clinical trials. The FDA updated their guidance document to encourage the inclusion of people in trials across different stages of the disorder (Table 3).

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.

### 7.3 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 submission portal, is that agencies cannot respond 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 interaction with other submitted comments. This prevents community members from jointly refining policy suggestions and forming consensus around shared regulatory concerns. Third, the absence of built-in features for categorizing or tagging submitted comments might place a 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.

## 8 Discussion

In this section, we discuss the possible ways to reduce the process-platform gap and potential challenges communities might face when using social platforms to influence the institutional process. Furthermore, we identify similarities and differences between the process-platform gap and the social-technical gap. Finally, we discuss how communities beyond the United States and beyond the health topic can learn from the ALS community.

### 8.1 Including experts can help and other challenges might emerge

The ALS community's use of three distinct types of platforms–general-purpose social media (e.g., X), repurposed health platforms (e.g., PatientsLikeMe), and formal institutional portals (e.g., `regulations.gov`)–reveals how each platform supports different aspects of participation in scientific and regulatory processes. However, none of the platforms satisfy the institutional requirements because of the process-platform gap: the misalignment between what platforms can produce and what institutions require. We believe one key limitation of current social platforms that causes a process-platform gap is the lack of ways to include institutional experts. For example, after the ALS community independently conducted an observational study and shared real-world data on PatientsLikeMe (PLM)–institutional policies required double-blind randomized controlled trials, which platforms failed to provide. For example, after the PLM study, an NIH-funded study conducted their own double-blinded study to come to the same conclusion: lithium carbonate was ineffective [2]. The presence of institutional experts during the initial PLM study could have validated the process

leading to possible use of study results and save institutional resources. Closing this process–platform gap will require platforms that support collaboration with experts before and during community-led studies.

Communities might face other challenges when using social platforms to influence the institutional process. For instance, patient communities, such as those organizing around ALS, are not monolithic. They contain members with differing capacities, priorities, and goals [40, 85]. Some may focus on accelerating drug development; others may prioritize quality of life, care, or emotional support. 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. As a result, specific community subgroups or individual priorities may be overlooked, even within otherwise "successful" collective efforts [56, 58]. This gap reflects a deeper challenge about how to represent communities with divergent goals and how to prioritize community-led action [43]. Platforms designed to support community-institution collaboration need to recognize the variety of goals and opinions within the community rather than assuming consensus.

### 8.2 Ways to include experts and support a plurality of voices

The process-platform gap occurs due to misalignment between what platforms can support and what institutional processes require. In science and medicine, institutions require data integrity, standardized methodologies, and regulatory compliance but existing platforms are typically designed for personal use–such as self-expression, connection, and content sharing [22]. The ALS community's use of social platforms shows that creative use of social platforms can sometimes produce useful outcomes. However, these workarounds are difficult to scale since they require highly motivated individuals, coordination of community members, and additional labor. Instead, we need components for such platforms that align with institutional requirements and community needs. We share the designs for components that can be integrated with existing platforms or used in new platforms. Both designs are based on the design claims we listed in the case studies.

Our recommendations are grounded in Hollan's seminal work "Beyond Being There" [37]; we frame the challenges around the process-platform gap in terms of needs, mechanisms, and media. We describe "needs" in terms of the requirements of the community and institutional processes. "Mechanisms" are strategies with which the needs can be met to some reasonable degree. Finally, "media" is the features or components of a platform that enables the mechanisms to meet the needs. We identify the needs and mechanisms, and use them to suggest components which act as media.

#### *8.2.1 Components for greater expert-community collaboration: needs, mechanisms, features.*

The community needs to run studies that are acknowledged by institutions to ensure that patient contribution inform decision-making more quickly. Institutional processes can use results from community-run studies when they meet institutional standards. Finally, various goals and opinions of the community members need to be recognized. One possible mechanism for meeting aforementioned needs is supporting greater collaboration between experts and community members while running studies. Such support can improve the odds of institutional standards being met and the results being useful to all parties.

We recommend five components based on design claims 1 and 2 (Section 6.3) which support mechanisms that can meet the needs of the community and institutions. An *expert feedback component* allows institutional experts to provide feedback on the community's hypothesis and study design and help communities run more rigorous studies. In return, experts can assess the feasibility and validity of the study. This is similar to the design process of TummyTrials–a self-experimenting tool to evaluate whether a specific food triggers user's irritable bowel syndrome–which involved input from domain experts in irritable bowel syndrome [41]. A *voting and critiquing component* helps the community

members prioritize questions that are relevant to the community. The results from the voting component can provide insights into the different goals and opinions within the community. *Templated approaches* can support methodological rigor, while allowing room for community input. This is similar to Galileo's scaffolded support for experiment design and review phases [60] . Galileo is a research prototype that guides citizens through a structured design and review process to transform personal intuitions into scientifically sound experiments and then receive feedback from others using scaffolded review interface. For drug-related studies, such templates can support N-of-1 trials, measures that track symptoms, or structured off-label use monitoring. *Subgroups* can be formed within a broader community by members who wish to pursue different lines of inquiry. Members can form or join study groups based on shared interests, priorities, or hypotheses. The *shared results section* can contain preliminary results that is available to both the experts and the community. Experts can lead analysis, and community members can contribute insights, flag anomalies, or suggest alternative interpretations. When subgroups are made, metadata or findings can be shared with the others through the broader platform.

#### *8.2.2 Including different voices in decision-making: needs, mechanisms, features.*

The community can benefit from ways to collaborate and add to each others comments on platforms like `regulations.gov`. Such collaboration can amplify widely shared concerns, reduce redundancy, and allow for collectively refining ideas. Specifically, users could build upon existing arguments, offer nuanced perspectives, or synthesize different viewpoints into more comprehensive and robust policy recommendations. In return, institutional experts might benefit from seeing where public opinions converge and diverge to identify major concerns of the community.

Such public contributions might benefit from critiquing specific parts of the policy document rather than providing summative comments on the entire document's content. Linking each comment to specific topics can help group similar comments, amplify widely shared concerns and build upon existing arguments. Furthermore, viewing similar comments help reduce redundant comments.

We recommend two components based on design claims 3, 4 and 5 (Section 7.3) which enable mechanisms to meet the needs of the community and institutions. Instead of treating policy documents as static blocks of text, *section-level comments* allow users to leave comments on specific sections–similar to commenting in collaborative document editors like Google Docs. This helps institutions 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". A *tagging-system* can help associate comments to specific topics and make visible the different perspectives within the community. For example, tags could include categories like "AccessToTreatments," "TrialDesignReform," or "AccelerateApprovals" to express different priorities and facilitate the identification of key themes by institutions.

### 8.3 The process-platform gap and Ackerman's social-technical gap

The ideas of process-platform gap shares some similarities to the seminal concept of social-technical gap in social computing [1]. The social-technical gap refers to the persistent divide between what must be supported socially and what can be supported technically [1]. The process-platform gap builds on this idea but operates at a different *level*, focusing on the challenges that come up when the design of platforms does not make it straightforward to meet the requirements of institutional processes. The two concepts are similar because both gaps arise due to the rigidity of technology: Ackerman's view of social-technical gap refers to fundamental limitations of technology and our view

focuses on the *designed* limitations of technology platforms. Unsurprisingly, some situations yield both a social-technical gap and a process-platform gap. For example, the ALS community used the PatientsLikeMe platform to conduct studies and share findings. The community-led study struggled with a process–platform gap, where platform-based scientific work (using data from an unblinded study) did not meet institutional standards (such as double-blind randomized controlled trials); At the same time, there was a social-technical gap, where the lack of validated data collection also led to challenges in developing institutional trust in the community's data quality and results. Experts ran their own study for greater rigor and trust in the results produced.

The social-technical gap and process-platform gap are different in a key way. The social-technical gap stems from the intersection between technology's rigidity and social flexibility, whereas the process-platform gap involves rigidity in both the platform designs and institutional processes. While social-technical gap might be impossible to answer for many human behaviors, we believe the situation is different for the process-platform gap. Platforms can evolve to match institutional requirements. With suitable design of platforms, we believe the process-platform gap–unlike the social-technical gap–can be reduced.

### 8.4 Beyond the US: alternative health ecosystems and settings beyond the US

The ALS community's efforts on social platforms presented in this paper are mostly based in the United States. The Ice Bucket Challenge originated in and received the most donations from the United States [62]. Furthermore, the FDA guidance documents and comments provided by the community are for drug development policies in the United States. Cultural background has an influence on multiple social aspects which might lead to different preferences and priorities [65]. However, institutional processes might not be open to feedback in other places. Therefore studying similar questions in non-US countries is impossible. Our research team is unaware of portals, say, in India or Brazil where patients provide critiques on federal guidance documents around drug trials. One possibility might be that a global network of patients use social media to share their opinions on institutional processes. Recent work has studied how the ALS advocacy movement integrates knowledge claims in linguistic choices to share their lived experience and critiques of institutional decisions [40]. Future work can more rigorously assess how communities engage with institutional processes in contexts beyond the US and on platforms beyond the ones studied in this research.

Ideas of repurposing platforms can extend beyond patient communities to broader U.S. health movements such as Make America Healthy Again (MAHA). While the ALS community organizes around a single rare disorder, MAHA seeks a broadly different public health strategy than the status quo; for instance, one goal is reducing chronic illness–especially among children–by emphasizing prevention and addressing the root causes of poor health such as poor diet, chemical exposure, and lack of physical activity [5, 8, 23]. Collaboration platforms for institutional experts and affected parties (e.g. MAHA like communities) that contain an *expert feedback component* and a *voting and critiquing component* could help co-design protocols with expert's technical expertise and the community's lived experiences. Furthermore, systems with *templated approaches* and *shared results section* can help communities develop validated ways of tracking and analyzing data, and engage in nuanced interpretation of the results. Collaboration between communities and experts depends on positive intent and beneficial participation from both: absence of shared values and trust can possibly cause other challenges such as misinformation about science.

Our overall work–with its focus on drug trials, institutional timelines, and notions of quantitative evidence–is situated in the context of Western biomedical research and policy systems. We recognize that some health movements–particularly those engaging with religious values, traditional healing practices, or indigenous beliefs–may operate under different knowledge systems [9, 64]. In such contexts, the platform structures we describe might need to accommodate

alternative forms of evidence, authority, and participation. One of the reasons people need to engage with institutional processes is because access to Western medical treatment is regulated by the FDA. This is different from traditional practices where people might have unregulated access to interventions that might be dietary or physical. Future work could explore how platforms support dialogue across different knowledge traditions, allowing community-led interpretations of health and wellness to coexist alongside institutional scientific frameworks.

Like the ALS community, climate advocates have leveraged general-purpose platforms like X to mobilize action (e.g., #FridaysForFuture [24]), 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 [36, 51]. These similarities might suggest that studying process-platform gap–with respect to its existence, nature, and possible solutions–can be useful beyond the health context.

## 9 Conclusion

The paper describes the process-platform gap by examining how the Amyotrophic Lateral Sclerosis (ALS) community leverages social platforms for scientific participation, despite such platforms not being 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`, our work demonstrates the significant impact patient communities can have in expediting drug development and influencing policy. However, a key limitation is the misalignment between what platforms can support and what institutional processes require. The paper underscores the need for thoughtful redesign of social platforms to reduce the process-platform gap by fostering more collaborative environments and enabling more effective patient participation in scientific research and institutional processes.



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