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# Collective self-experimentation in patient-led research: How online health communities foster innovation

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## ABSTRACT

Researchers across academia, government, and private industry increasingly value patient-led research for its ability to produce quick results from large samples of the population. This study examines the role played by self-experimentation in the production of health data collected in these projects. We ask: How does the collaborative context of online health communities, with their ability to facilitate far-reaching collaborations over time and space, transform the practice and epistemological foundations of engaging in  $n = 1$  experimentation? We draw from a digital ethnography of an online patient-led research movement, in which participants engage in self-experiments to develop a protocol for using psilocybe-containing mushrooms as a treatment for cluster headache, an excruciating neurological disease for which there is little medical research and huge unmet treatment need. We find that the collectivizing features of the internet have collectivized self-experimentation. Group dynamics shape everything in “collective self-experimentation,” from individual choices of intervention, reporting of outcomes, data analysis, determinations of efficacy, to embodiment. This study raises important questions about the role that individuals play in the creation of medical knowledge and the data that informs crowdsourced research.

## 1. Introduction

Researchers across academia, government, and private industry increasingly value patient-led research for its ability to produce quick results from large samples of the population. These endeavors take multiple forms, ranging from top-down crowdsourcing studies organized by researchers to grassroots, citizen science projects, but nearly all rely on data produced beyond the clinic and, in many cases, by individuals engaged in self-experimentation practices (Brownstein et al., 2009; Swan, 2012; Wicks et al., 2011). Some researchers consider this a benefit of crowdsourced data, arguing that people who self-experiment may discover innovative treatments (Wicks et al., 2011).

Despite this broad interest in patient-led research, little is known about how people in online groups use self-experimentation to produce this data. To fill this gap, we ask: How does the interactive context of online health communities, with their ability to facilitate far-reaching collaborations over time and space, transform the practice and epistemological foundations of engaging in  $n = 1$  experimentation? Our analysis pays particular attention to the singularity of the embodied researcher-subject because like Swan (2012), we are curious whether, in the context of an interactive online health community, “ $n$ ” continues

to equal “me,” or whether it begins to equal “we” and, if so, what the implications may be.

We investigate this question using data drawn from a digital ethnography of the Clusterbusters, a networked patient-led research movement that has both online and offline components, in which participants engage in self-experiments as part of an effort to discover better treatments for cluster headache, an excruciating neurological disease for which there is little medical research and a huge unmet treatment need (Hoffmann and May 2018). To date, the Clusterbusters have produced multiple medical technologies, DIY treatments, and informal techniques in wide use across the cluster population (Schindler et al., 2015). In this article, we focus on the Clusterbusters’ best-known innovation: the development of a treatment protocol now in clinical trial that uses small doses of psilocybin, the active drug in magic mushrooms (Sewell et al., 2006; Psilocybin for the treatment of cluster headache, 2019).

As Swan (2012) hypothesized, our analysis finds that within the context of an online health group, the “ $n$ ” of 1 does, indeed, become an “ $n$ ” of we. Our analysis demonstrates how the collectivizing features of the internet have expanded possibilities for self-experimentation, not only by creating spaces where sick people can self-experiment together,

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but by transforming self-experimentation—a typically isolated method—into a collective way of producing knowledge. We call this knowledge production “collective self-experimentation,” a way of knowing in which individuals cooperatively self-experiment within the context of a group, collectively analyze data, and use these analyses to iterate through new self-experiments with the goal to produce novel treatments.

In addition to raising questions about how the data underlying crowdsourced research is produced, elaborating the concept of collective self-experimentation has a certain urgency given the frequency with which people now turn to the internet to discover novel treatments for their health (Fox and Duggan, 2013). This imperative to take initiative is further valorized in media stories about citizen scientists compelled to take control of their health. In an example made famous by the 1992 movie “Lorenzo’s Oil,” Augusto and Michaela Odone developed a treatment for their son’s fatal, incurable disease adrenoleukodystrophy (ALD). More recently, Sean Ahrens (2016) who has Crohn’s Disease, published a paper detailing a self-experiment in which he intentionally ingested parasites as therapy. Self-experimentation increasingly seems like a way of life in the United States. Yet like much of American folklore, these stories frame citizen science successes as individual ingenuity. We seek to counter this framing by instead considering the collaborative, intersubjective processes that make the production of novel health knowledge online possible.

## 2. Background

Scholars have brought to light remarkable stories of people who, marginalized from the medical system, organized their collective embodied experiential expertise to contribute to, challenge, and transform dominant epistemologies of science. Prominent examples of embodied health movements include the Boston Women Health Collective’s production and dissemination of feminist health practices in the form of *Our Bodies, Our Selves* (Davis, 2007); the Black Panther movement’s resistance towards eugenic theories of criminality (Nelson, 2011); breast cancer activists in Long Island’s use of “popular epidemiology” to study environmental carcinogens (Brown, 1997) and HIV activists, whose interventions convinced policymakers to change the design of clinical trials (Epstein, 1996).

The ubiquity of online platforms that allow for social networking and data sharing has increased the ability of people to form new bio-social communities based on their illnesses and other shared biological traits (e.g. Barker, 2008; Whelan, 2007). Like their analog predecessors, online health communities have become a powerful force in biomedical research, particularly for patients who have contested, rare, or otherwise under-resourced diagnoses. However, unlike their offline counterparts, online health communities can leverage diffuse patient networks in their efforts to guide research on their diagnoses, using their online platform to create public awareness and fundraising campaigns, recruit previously difficult-to-find patient populations for research on rare diseases, organize data collection efforts, and disseminate their own research (e.g. Bedlack and Hardiman, 2009).

At the same time, government agencies and corporations have embraced public participation in research. For example, the US National Science Foundation and the US-based Patient-Centered Outcomes Research Institute actively foster scientific collaborations with patients, while the UK National Health Service requires patient participation in research. In addition, several for-profit entities, such as 23andme, Quantified Self, and PatientsLikeMe, now generate income using anonymized, user-generated data. Biomedical researchers appreciate crowdsourcing’s ability to access hard-to-find populations and inexpensively and quickly collect large samples, often magnitudes larger than traditional clinical trials (e.g. Kallinikos and Tempini, 2014). In addition, observational studies that rely on patient reports can be conducted with much less institutional oversight than clinical trials.

These investments are already beginning to pay off. For example, in

2011, PatientsLikeMe demonstrated how their crowdsourcing platform could produce innovative research using data they collected from member-patients engaged in self-experimentation. In this particular case, PatientsLikeMe were able to demonstrate that lithium, a drug many of their members began taking after a small clinical trial suggested it might slow the progress of amyotrophic lateral sclerosis (ALS), was not effective (Wicks et al., 2011). PatientLikeMe’s study ended the use of lithium as an off-label treatment for ALS, but Paul Wicks et al. (2011), PatientsLikeMe’s CEO, argued that analyzing patients’ experiential data in the aggregate might lead to new effective treatments.

Crowdsourcing, like that done by PatientsLikeMe, relies on aggregated reports from patients, many of whom typically engage in self-experimentation. Nevertheless, analyses of these data remain guided by the institutional logics of formal scientific research, in this case the presumption that each human subject reporting data did so as an independent actor. The resulting database thus becomes a collection of individual “ $n = 1$ ” experiments or experiences, with no consideration of how the digital platform itself, which enables patients to interact and analyze their data collectively, might alter individual experience, including their reported outcomes (e.g. Kallinikos and Tempini, 2014). However, as Delgado and Callén (2017) note, the internet is not comprised of atomized individuals, but instead serves as a “shared repository for the collective imagination.” Online health communities are no exception. In the next section, we argue that these technological platforms have the potential to create a more collective form of patient self-experimentation.

### 2.1. Self-experimentation as an individual and as a collective practice

Multiple scholars have investigated self-experimentation as a method in medical research (e.g. Altman, 1998; Herzig, 2006). Historically, scientists have been lauded for their willingness to risk their bodies for the greater good, despite the limitations inherent in self-experimentation (Herzig, 2006). Prominent examples include Jonas Salk’s insistence that the polio vaccine first be tested on himself and his family; Barry Marshall’s ingestion of *Helicobacter* culture as a demonstration of how the bacteria could cause gastrointestinal disease; and Werner Forssmann’s insertion of a catheter into his own heart to prove the procedure’s survivability (Weisse, 2012). Members of the general public also engage in self-experimentation, albeit usually as a more explicit effort to improve their health (Karkar et al., 2016).

This research literature typically presumes self-experimentation is an individual practice in which a single researcher designs and enacts a study with their own body as a subject. However, embodied health movements have found self-experimentation to be a powerful method of inquiry in patient-led efforts to challenge the dominant medical system. For example, the 1970s women’s health movement relied on self-experiments conducted within group contexts to develop innovative technologies like “menstrual extraction” (Murphy, 2012). Self-experimentation has also proliferated within social organizations whose sick members see no other recourse but to experiment on their own bodies. Members of the Wo/Men’s Alliance for Medical Marijuana (WAMM), a nonprofit dedicated to medical marijuana research and providing cannabis to patients with chronic illness, used their bodies in ongoing experiments involving medical marijuana (Chapkis and Webb, 2008) and the French organization POSITIFS encouraged AIDS patients to experiment with marginalized and sometimes illegal alternative medicines when little else was available (Barbot, 2006).

Murphy (2012) argues that the collaborative nature of the women’s health movement’s knowledge-making relied heavily on technologies like the mimeograph that enabled the mass distribution of their women-led research. Just as the ability to make carbon copies altered lay knowledge practices in the 1970s, the technologies accompanying Web 2.0’s rise, like social networking and collective content creation, have produced new spaces where the public can create and disseminate knowledge about treatments (Yoo et al., 2014). The Internet age has

thus made communal production of self-experimentation more apparent.

We still have little idea, however, of what happens when self-experimentation occurs within these communal settings, despite the fact that ethnographic research in science studies has consistently demonstrated that knowledge production is a social process, best understood as situated, interactive, and deeply cultural, even when it takes place in the most sterile-seeming laboratories (Felt et al., 2016).

Our study seeks to reconcile the empirical reality of intersubjectivity in online health collectives with existing literature on self-experimentation and knowledge production more generally, by drawing on an in-depth case study of an online health community as its members attempt to develop a novel treatment for their disease. We ask: how does recursive engagement between individuals affect their practices of self-experimentation? Does participating in a group where individuals learn about their own bodies from reading about others' experiences alter their bodily perceptions and behavior? If so, how does collective embodiment alter their experimental practices? Do intense online interactions change how individuals determine which interventions to pursue or how individuals determine which symptoms are important or unimportant to report? How do these interactions change how individuals determine if their interventions are working?

Our analysis underscores how the collective experience of engaging in an online community fundamentally alters each self-experiment, including the independent variables used, the subjective experience of the experimentation, and the interpretation of results. Thus, rather than an aggregation of "n = 1" experiments, we theorize a more collaborative process of self-experimentation structured as  $n \leftrightarrow n \leftrightarrow n$ , with each *n* iteratively and recursively refashioning their self-experiments in collaboration with and in response to feedback from similarly positioned experimenters (See Fig. 1). Ultimately, we describe how the internet has transformed self-experimentation into a collective practice, representing a novel form of health knowledge production.

### 2.2. Our case: The Clusterbusters

Our analysis comprises a case study of a group called the Clusterbusters, a networked patient-led research movement seeking to develop new therapies for cluster headache. Case studies are an appropriate method for in-depth analyses of complex issues in their real-life context, and can be chosen for their intrinsic usefulness, e.g., their ability to understand a unique or particular phenomenon or for their instrumental usefulness, e.g., because they exemplify processes that

enable an analysis of a broader phenomenon (Crowe et al., 2011). The case of the Clusterbusters is both intrinsically useful, as it represents a rare disease being responded to with an even rarer form of intervention, and instrumentally illustrative, as it represents a form of collective knowledge production that signifies a potentially broader phenomenon (Stake, 1995).

Cluster headache is a severe, poorly understood, and challenging-to-treat neurological disease characterized by an excruciating one-sided headache accompanied by red, swollen, droopy, and tearing eyes, a congested or runny nose, facial sweating, and pupil dilation or contraction. Attacks last between 15 and 90 min and can occur up to eight times per day, often at the same hours of the day. Episodic cluster headache typically occurs in predictable annual or biannual cycles that last weeks or months. Cluster headache becomes chronic when they fail to remit for longer than a year. Cluster headache affects about 1 in 1000 adults, which makes it as common as multiple sclerosis (Rozen and Fishman, 2012). Nevertheless, it takes an average of five years for a person with cluster headache to receive a proper medical diagnosis (Rozen and Fishman, 2012) and, once diagnosed, treatment options are limited.

In order to examine role of the self-experimentation practices in online health groups, we began our analysis with an article written by Sewell and colleagues in 2006, who reported a case series of 53 people, recruited via cluster headache support groups and an online survey, who had taken LSD or psilocybin to treat their cluster headache, and who reported overwhelming success. Although the authors of this paper initially learned about this phenomenon from the Clusterbusters, themselves, the article excludes an explicit discussion of patients' crucial role in producing this knowledge. For example, the article does not mention that the support groups where recruitment had occurred were also places that had nurtured self-experimentation of psychedelics. As a result, readers were left to infer that each case report in the study constituted an individual engaged in a highly individualized self-experiment. However, as we argue here, the Clusterbusters' experiments represented the work of a collective rather than a collation of individual experiments.

In many ways, the Clusterbusters' efforts to locate an effective therapy for their disease exemplifies patient-led research. People with cluster headache seek help online because they are desperate. Those who choose to use psychedelics as medicine typically do so only as a last resort (Andersson et al., 2017). That suicide frequently emerged as a topic on the forums eventually gave rise to the Clusterbuster motto "Psychedelics or Suicide." Over half of cluster headache patients have

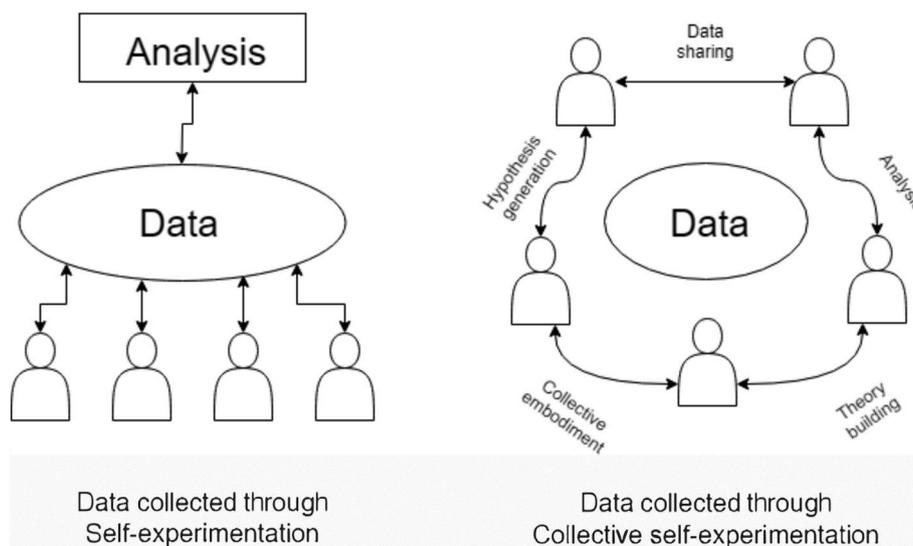


Fig. 1. Self-experimentation vs. Collective self-experiments.

considered suicide and that 2% reportedly have made suicide attempts (Rozen and Fishman, 2012). The Clusterbusters thus represent both the immediacy and the responsabilization that are characteristic of patient-led health care practices in the early 21st century.

On the other hand, the Clusterbusters' experimental use of psychedelic drugs makes this case unusual, as the United States federal government has classified LSD and psilocybin Schedule I substances, a category reserved for drugs with no known medical use, a high potential for abuse, and no accepted safety regulations for their supervised medical use (Nutt et al., 2013). While scientific research on Schedule I drugs is not explicitly forbidden, federal regulations on its conduct are sufficiently burdensome that, until recently, psychedelic science had almost completely ceased (Nutt et al., 2013). Experimenting with psychedelic substances presents novel challenges that other patient-led research groups might not experience, for example, safely obtaining illicit substances, determining a standardizing dose, the stigma of illicit drug use and legal implications. Many of the Clusterbusters' challenges, however, will be familiar to other patient groups—especially the risk of self-experimentation, which is common, even when interventions are legal (See, for example, the list of risk assessments on “Completed Reviews,” ALSUntangled, 2019).

The generalizability of this study is limited, as it is based on a single case. However, we argue that the Clusterbusters' use of psychedelics—a class of drugs that occupies a unique position in the cultural imaginary—not only serves to illustrate a particular phenomenon (albeit an increasingly common phenomenon as psychedelics have reentered mainstream medicine), it has useful analytic potential, as it serves as an “extreme case,” which helps defamiliarize otherwise routine ways of thinking otherwise easily overlooked (Sjoberg et al., 1991).

### 3. Methods

**Data:** Data were collected from forums hosted on two websites, [clusters.com](#) and [cb.com](#) (both pseudonyms). As the [clusters.com](#) boards contained an unwieldy number of posts, our dataset consisted of a subset of discussion threads referencing “shrooms” or “LSD” between 1998, when psychedelic self-experimentation began to be discussed, and in October 2002, when Bob Wold created “cb.com” a forum, which eventually developed in an organization named the “Clusterbusters,” which he dedicated to the development of psychedelic medicine. Our dataset included all 12,618 posts from cb.com between 2002 and 2005. The owners of these forums' archives provided us with permission to download their data.

Additionally, JK conducted fieldwork and interviews at events where members of the Clusterbusters' online membership congregated in person, including six of the Clusterbusters' annual patient conferences, which include talks on topics related to cluster headache treatment, including self-experimentation practices. JK also attended four advocacy events in Washington, DC alongside members of the Clusterbusters as they lobbied Congress for resources. Each event offered opportunities to ask group members about the early days of their organization and to observe the collectives' knowledge production practices in action. Finally, we supplemented online data with audiotaped in-depth interviews, conducted by JK with 11 key informants about their experiences as self-experimenters on the forums between 1998–2005 to gain more insight into individual members' motivations and interactions that happened outside of the forum.

We managed data using ATLAS.ti software, which enabled us to analyze the data using the inductive methodological tools of grounded theory (Charmaz, 2014) but also, when appropriate, as a searchable historical archive. Each author independently free-coded texts. We then collaboratively reviewed and consolidated codes to capture emerging themes and theoretical ideas and recoded our data using our new coding scheme. Finally, we wrote and shared memos to capture our evolving analysis about the logics and practices that the Clusterbusters used to tackle problems, such as determining an effective dosage,

assessing the efficacy of treatment, and best methods of ingestion (Holton, 2010).

Our reliance on forum data allowed analysis of events and discussions collected in an unobtrusive manner, which enabled us to minimize validity problems, like recall bias, which are endemic in contemporary accounts of the past. Our reliance on forum data also meant, however, that we systematically excluded those who chose more private methods of engaging in the forum's experimental practices. This omission does not bias our findings, as we are concerned only with the collective practices of those participating online.

Given the pseudonymous nature of online interaction, we had a limited ability to assess the demographics of forum participants. Fieldwork suggests that the vast majority of participants are white adults, primarily from the United States, Canada, and the UK, and that, with few exceptions, most do not have university training in biomedical science. Except for Bob Wold, whose identification as the president and founder of Clusterbusters is public and Flash, whose alias is practically synonymous with the discovery of psychedelic treatment for cluster headache (Sewell, 2008), we used pseudonyms in this paper to protect subjects' anonymity. We have not corrected the spelling or grammar of quotes pulled from online groups. Rutgers University's Institutional Review Board approved this research.

### 4. Analysis

In contrast to the Sewell et al., 2006 article, which listed each case report as an isolated phenomenon, our analysis suggests that the people interviewed for this article produced their results using a process that we call “collective self-experimentation” (CSE).

CSE is a collaborative, iterative process in which individuals self-experiment within the context of a group, collectively analyze data, and use these analyses to tweak their next set of self-experiments with the goal of producing a common finding. Unlike self-experimentation, which refers to single-subject research in which one individual serves as both the researcher and the subject, who makes observations intimately linked with their own subjective experience, researchers in CSE belong to a collective, so when they experiment on their own body, they draw on the “know-now” of group members (Pols, 2014) and an ever-evolving collective embodied experience. In the following sections, we illustrate these properties through several examples.

#### 4.1. Self-experimentation

Flash discovered the use of psychedelics as a treatment using self-experimentation in the classic sense. In 1995, he hypothesized that his recreational use of LSD in 1993 and 1994 might explain an unusually long remission from cluster headache (interview). He attempted to replicate these results using psilocybe semilanceata—a species of psychedelic mushroom more commonly known “Liberty Caps”—that grew in local cow fields. Over the next three years, he conducted a series of self-experiments, testing cause and effect by ingesting Liberty Caps and assessing the results, intending to identify the lowest dose required to prevent his cycles (interview).

As both the experimenter and research subject, Flash relied on his individual embodied expertise to design, analyze and interpret these self-experiments. He had not yet found a physician who knew how to treat cluster headache, nor had he yet communicated with anybody else who had the disease. He could not provide a control case for his experiments, being the only subject involved, so he drew upon his embodied experience that cluster cycles came predictably in spring and fall as a counterfactual. He thus determined efficacy by observing that taking decreasing amounts psilocybin before expected cycles resulted in a “missed” cycle. This process, he believed, enabled him to determine a minimum effective dosage.

#### 4.2. Self-experimentation goes public

Like all social groups, online health communities involve power dynamics, fluctuating norms, and identities. These dynamics structure how individuals in online health communities assess the potential usefulness and safety of interventions, thus mediating which experimental interventions are taken up more broadly and which are dismissed.

While discussion threads about treatment often generated considerable traffic on clusters.com, members did not embrace every proposed treatment. For example, use of the anti-fungal Diflucan attracted considerable attention based on a user's hypothesis that candida overgrowth caused cluster headache. However, members dismissed another person's testimony that daily methadone worked, because they believed it to be too dangerous and potentially counterproductive, since opioids are contraindicated in cluster headache. Members typically became suspicious if they suspected whoever suggested the treatment did not really have cluster headache. Some were believed to be vendors seeking profit by selling "snake oil." Others, who suggested treatments like hypnosis or lavender oil, just seemed naïve, like maybe they just had a "regular" headache.

Flash decided to go public in July 1998 because he felt certain that he was in possession of an important therapy (interview). But the clusters.com community did not engage seriously with Flash's repeated posts about psychedelic treatments until October 1999, when Tom, a prolific contributor to the board, replied to Flash's fourth post on the topic. "I'm interested in this one. If anyone else give it a try, please keep us posted." Dan offered that he couldn't remember having attacks when he consumed mushrooms in the 70s, "nor do I remember much at all, come to think of it." Tom persisted, recalling Flash's earlier posts suggesting a possible link between psilocybin and LSD: "Looking back on some of Flash's earlier posts he say shrooms are chemically 'close' to LSD in structure and that LSD [is] a relative of ergots & Sansert."

Tom was referring to Flash's earlier posts explaining that, in the 1960s, researchers had demonstrated that LSD effectively treated migraine and cluster headache (see, e.g. Hofmann, 1980; Sicuteri, 1963). However, rather than pursue headache as an indication for LSD, Sandoz, the makers of LSD, chose to develop Sansert (methysergide), a nonhallucinogenic congener of LSD, for use in the prevention of cluster headache and migraine (Hofmann, 1980). Physicians rarely prescribed Sansert, however, because it caused a rare but serious side effect.

In the following weeks, over a dozen members contributed varied responses to the use of psychedelics as therapy. Several members had personal experience with psychedelics—some reported these times coincided with cluster remissions, but others said that psychedelic drugs had not stopped their cycles. Flash expressed curiosity about all of these experiences—especially failures—taking the position that he would "welcome feedback from anyone who has tried similar, cos this has to be the smallest (un)clinical trial in history." However, those who argued that psychedelic drugs were far too risky received a swift rebuttal: Flash told anyone who witnessed any "bad stuff" in their youth that they had probably mistook tainted drugs for "real" psychedelics.

#### 4.3. The role of community support in experimental practices

Flash's early self-experiments fit the traditional model of "lone researcher." The illegality of consuming psychedelic substances frightened him away from consulting physicians or from talking about his treatment publicly (interview). Still, he had some social supports. Friends in his home town taught him how to forage the correct mushrooms, explained the basics of how to brew tea for consumption. A few even kept him company while he consumed the mushrooms.

Without social support, self-experimentation can be extraordinarily isolating and frightening. Perhaps this, plus the stigma of taking an illicit drug, explains why several months passed before anybody admitted to experimenting with psychedelics. Gunner, the first to do so,

posted a message titled "Am I nuts," in which he explained that "in desperation," he had obtained psilocybe mushrooms. Perhaps in a preemptive effort to prevent being labeled as a drug seeker, he emphasized that he did not do drugs ("These things kind of scare me"), but that he had been inspired to conduct further research about psychedelic medicine after reading a post on the topic in this forum. Although the mushrooms seemed to have decreased the frequency and intensity of his attacks, he wondered if he should try again with a new batch, since his tea had been brewed with old and potentially weak mushrooms. Members uniformly encouraged him to experiment and report back. Over the coming weeks, Gunner's updates indicated success: "I've never been able to break a cluster before ... I feel good though. First time in awhile."

Success stories inspired new members to experiment. Days after Gunner posted, Brianna announced she would be treating her husband with mushrooms. Brianna's reported success inspired John. Mary, the first person with chronic cluster headache to try the treatment, reported that her attempt to bust had not worked, but this did not deter Stace, who also had chronic cluster headache. In a post titled "Flash and Others - You saved my life!!!!!!," she exclaimed that she had been pain-free for ten days after a single dose of mushroom tea. By January 2001, dozens of people posted inquiries about mushrooms as medicine, some describing themselves as people who had experienced cluster headache for decades, others as newly diagnosed patients. Parent also wrote in, desperately seeking treatments for their teenaged children.

Success stories not only increased enthusiasm, they also inoculated the board from those skeptical of the treatment. When, for example, Mudpup wrote that people only used psychedelic mushrooms to "justify their own vices," Stace exclaimed, "When I drank that tea, and all feelings of pain STOPPED, what can I say - I found life again. It will be 4 months on Thursday of this week since I became Cluster-free. This is all the proof I need. It makes me very sad that some people are so quick to judge and condemn." Stace's recovery also encouraged others who were initially skeptical to try psychedelic medicine, for example, Drew, who had previously argued the intervention would not work based on his past recreational use of psilocybe mushrooms.

In the meantime, the community worked towards building and synthesizing a shared set of knowledge about the neurochemical and physiological properties of both illegal psychedelic and legally prescribed drugs. Members relied heavily on information they located online. The internet provided access to scientific studies and to novel forms of lay knowledge organized by a network of websites, like Erowid, Mycotopia, and the Shroomery that collected and sometimes curated data uploaded from recreational drug users in order to disseminate information about how to obtain and use psychedelic drugs safely (Langlitz, 2009). This corpus of knowledge exploded as more people reported the outcomes of their self-experiments—reports that the community captured and maintained in an online file titled "Shroom Stories." In addition, several members asked physicians, neurologists, headache doctors, and academics who had publicly expressed an interest in psychedelics for advice and help with research. These efforts often produced positive responses; for the most part, experts seemed optimistic about the use of psychedelic therapy in cluster headache, given what they knew about the history of headache medicine.

#### 4.4. Collective self-experimentation as collaborative and iterative

Collective self-experimentation (CSE) is an interactive process involving dynamic, iterative loops in which embodied researchers design, report, and tweak their interventions based on the group's collective experiential knowledge and insight. CSE typically began when a user posted a narrative report detailing their results. In replies, others requested additional details and compared the user's report to other self-reports, including their own. These exchanges not only helped individuals interpret their results, they also generated new hypotheses

that could be tested in a new set of experiments.

The community cheered successful outcomes, and dissected failed outcomes, since failure often produced more actionable information for those seeking to understand how to produce a better, more universally applicable psychedelic therapy. Of failures, the group sought to discover if there were variations in the experiment that mattered. Was the experimenter taking other medications might have caused interactions and “blocked” psilocybin’s effect? What dose did the experimenter use, how many doses did they take, and over what time period? How were the mushrooms consumed? How psychoactive was their experience?

Bobby’s report exemplifies how forum members engaged with failure to produce actionable information. Bobby reported that he had taken a relatively large dose of mushrooms—three dried grams—that made him feel antsy, anxious, and tired. Worse, an intense cluster attack woke him that night. Members tried to assess the problem in the ensuing discussion. One member suggested the problem might be in measurement; perhaps Bobby required a better scale. However, another member disagreed, having learned from reading recreational user reports on a different site that mode of consumption can make a real difference in “trip experience.” “In an attempt to make the mushrooms more palatable, Bobby mentioned mixing his mushroom powder in ‘a few tablespoons of peanut butter and honey’ ... Peanut butter is the culprit here. That blob of peanut butter was acting as a ‘time release’ mechanism for the psilocybin. The best way to take mushrooms is to have a light meal 2 h before dosing.” Alarmed, another member piped in: “I never thought about the fatty content acting as a time release!!!! YIKES, so chocolate is probably not a good idea unless you have some time on your hands.” The last member to contribute in this particular thread offered to “volunteer to do this [take mushrooms with either chocolate and/or peanut butter] if everyone thinks it is necessary and as long as you don’t need it urgently ...” This brief interaction typifies how the community tackled one of the many small challenges the group faced. A member posted a problem, the collective developed hypotheses, and then members would volunteer to test the hypotheses in subsequent self-experiments. After new results were posted, the process would repeat.

#### 4.5. Participation and leadership in CSE

CSE did not necessitate equal participation by all members. In these forums, some members of the group enjoyed greater authority based on a collective understanding that they had “special expertise.” In addition to Flash, MantaRay emerged as an expert in 2000, based both on his personal experience growing and using psilocybe mushrooms in his young adult years and his ability to navigate the underground networks that linked the broader psychedelic community. Bob Wold became a trusted leader in 2002, after founding cb.com. Together, these three “gurus” played a key role in mediating discussions, particularly those involving puzzles stemming from unexplained success or failure. Their assessments sometimes implicitly and sometimes explicitly guided subsequent decisions about which new hypotheses ought to be tested via collective self-experimentation.

#### 4.6. Collective embodiment and CSE

Members developed more than camaraderie in forums. By sharing their embodied experience of cluster headache, they created a common vocabulary for identifying, quantifying, interpreting, and communicating bodily signs and symptoms. Over time, their collective embodiment became a fundamental resource in CSE, shaping how members interpreted and assessed the efficacy of their experiments.

Early on, for example, the forums adopted the “Kip Scale,” a pain measure created by a member to describe the intensity of attacks on a scale from 0 to 10. Unlike traditional 1–10 pain scales, the Kip Scale provided evocative descriptions articulating what each number entailed, from “0,” which indicated “No pain, life is beautiful,” to “10,”

which indicated “Major pain, screaming, head banging, ER trip. Depressed. Suicidal.”

The low end of Kip Scale pain levels included a descriptor called “shadows,” a term that the board had developed to describe some of the sensations that occur when cluster pain is mild. Established members instructed newcomers. Every time they posted about random sensations, like a “battery clap on your nose,” a “tingling scalp,” or “pain running down my jaw,” an experienced member would they were actually experiencing shadows.

Creating a collective vocabulary for the embodied experience of cluster headache not only assisted newcomers in organizing and making sense of their symptoms, it was also essential for members assisting each other with their experiments. For example, members treated their own and each other’s shadows as important indicators, as they believed that the onset of shadows could predict an oncoming cycle. Collective embodiment also enabled members to help each other determine the efficacy of their treatment. For example, Wold often told new members to be on the lookout for a feeling of “head clearing” when they dosed; this, to him, was a good indication the treatment was likely to work. As he explained to one member: “As far as the ‘clearing’ I was referring to your head feeling a sensation of being cleared or pressure release during the trip. I’ll assume you didn’t feel it or you would have known. Honestly, to those that have experienced it, it IS an event you will remember.” Similarly, experienced members tried to calm those who experienced severe cluster attacks after their dose by explaining how, in their collective experience, “slapbacks” were common, typically transitory, and often indicative that the dose had been successful. Collective embodiment thus facilitates the reinterpretation of individual experiences through the collective lens, shifting the individual away from being the sole proprietor of embodied knowledge.

#### 4.7. CSE as flexible and pragmatic

CSE may occur at a group level, but its decentralized organizational structure and focus on maximizing individual experimenters’ beneficial outcomes distinguish it other forms of group experimentation. For example, unlike clinical trials, in which a small set of investigators pre-determine which intervention each experimental group receives, participants in CSE are free to choose their intervention. CSE thus provides patients with pragmatic flexibility in their experimental practices, even as it enables the group to produce more generalizable knowledge. Our example draws upon dosage, one of the most enduring, multi-faceted problems experienced on the boards.

The psychedelic experience frustrated many of those in the group. Early on, the group advised new experimenters to choose a dosage that would cause a mild to medium hallucinogenic effect. Feeling some psychedelic effects, they argued, offered a relatively conservative introduction to the psychedelic experience, while ensuring that the experimenter had, in fact, received a therapeutic dosage. However, many disliked even minor psychedelic experiences. Others, like Bob Wold, believed that the psychedelic component of their treatment might be ultimately prove to be a social and political liability. Nobody knew, though, whether the therapeutic efficacy of psychedelics depended upon their hallucinogenic effects.

Members, therefore, took notice when Brianna reported that her husband Jeff had responded positively to an exceedingly small, sub-hallucinogenic dose of psilocybin mushroom. “I think its great if it is a tiny amount and its working,” wrote Wold. “Maybe many of us are using too much? At that small of a dose, does Jeff experience any effects other than knocking out the cluster?” Brianna replied that not only did the dose have no major side effects, they had been able to use it to prevent cycles and abort individual attacks.

In the iterative process characteristic of CSE, members began to tweak and modify techniques in search of improvement. In one of these subsequent iterations, a member named Robert reported two innovations. First, he was able to abort attacks by placing a small piece of

mushroom under his tongue. Second, he successfully used this method on consecutive days—which confused him, since this seemed to contradict one of the Clusterbusters' rules, which they called “shutting the door,” which posited that psychedelic doses taken too frequently physiologically could not work. Background research, seemingly confirmed by their own experiences, held that psychedelic substances “block” serotonin receptors for several days, rendering daily doses ineffective. But Robert's success in using multiple small doses in short intervals suggested this theory needed to be revisited: “Maybe I am misunderstanding the door deal,” he wrote.

Other group members weighed in with their opinions, such as this post from Eagle:

“As for the ‘door deal,’ my understanding is basically as yours is ... I wouldn't expect [the small piece] to work very well. But weren't there a few people who discovered [a microdose] worked even if it was taken in close proximity to a full dose? Perhaps this is further evidence that a small dose is all that is required for CH.”

Brianna replied that Jeff continued to have success with microdoses, some of which he took on consecutive days. Wold added his experienced voice to the discussion: “I concur that using this piece under the tongue method [...] before bedtime may be a very good idea ... it isn't doing any blocking of further treatments, and it allows you to catch up on your sleep [...] it can only be a good thing.” With Wold's blessing, the group committed to testing microdosing, even coining the catchier term “SPUT” to describe the technique of “small piece under tongue,” and calling those members who attempted the method “SPUTniks.”

The collective nature of the SPUT experiment extended into the support and advice given by members to each other. For example, when Gaby had difficulty using the SPUT technique, Robert advised her to place the piece carefully under the tongue where it would hit the most blood vessels and coached her on the specific feelings one is supposed to experience. He also suggested how to time the dose: one should “try the SPUT PRIOR to getting a CH (like a preventative),” as using it as an abortive “sometimes would be okay and take away the edge,” but that waiting for an attack to start could also be risky once “the beast had a foothold and [it became] harder to ease up the pain.” Here, Robert demonstrated the progression from observation to pragmatic theory-building characteristic of collective self-experimentation. His advice to take medication early was repeated often and iterated into subsequent self-experiments.

In this typical example of CSE, a member's report of a successful self-experiment triggers a cascade of members to conduct a series of follow-up self-experiments. In this particular case, CSE raised questions that conflicted with earlier collectively established knowledge, for example, determining how it might be possible that microdoses could work on consecutive days. As a result, CSE succeeded in producing new hypotheses and generating research questions. However, this example also represents the pragmatic instability inherent in CSE. Although the SPUTniks attempted to test a specific dose, individuals freely altered the independent variables used in their own self-experiments. Indeed, potential tweaks to the SPUT technique appeared as soon as members began volunteering for this collective self-experiment. Jack, for example, suggested that “tea would be faster in aborting an attack,” while Wold thought that breaking off a piece of mushroom might be a more expedient mode of ingestion. Ultimately, members used whatever method they preferred. Moreover, individual experimenters frequently adjusted their dosage and method of administration. These variations made it more difficult to validate the efficacy of SPUT, but they also helped individuals find a treatment that worked for them quickly. Ultimately, we argue, this instability is characteristic of CSE, as the techniques produced can be constantly re-theorized and altered to fit changing conditions. While CSE does not generate knowledge that is epistemologically, or even practically, equivalent to the knowledge produced by clinical trials, it did, in this case, produce pragmatic working protocols.

## 5. Discussion

In this article, we set out to learn how online health communities use self-experimentation to determine their treatment protocols, to understand how online contexts might transform the practice and epistemological foundations of  $n = 1$  experimentation. We found that in the context of an online health community, self-experimentation looks different than the individualistic practice of a researcher intervening on their own body. Instead, online health communities enable multiple sets of embodied researcher-subjects to engage recursively with each other as they expose their bodies to interventions, creating an epistemological approach that we call “collective self-experimentation.” Because collective embodiment plays such an essential role, we wonder whether this epistemological approach might be better termed “collective-self experimentation,” to underscore the collaborative, intersubjective processes at play.

CSE also differs from experimental group designs that assign experimental groups to pre-selected interventions. In theory, a patient-led group could self-organize into a traditional group experiment. However, we suspect these formations are unlikely for two reasons. First, most patient-led research involves individuals with acute needs, who may be unwilling to accommodate the inflexible organizational structure of a group experiment, especially the need to control experiments with placebos. Second, even given the elevated status of certain members' authority to make decisions, CSE is a largely decentralized process.

This study suggests that researchers relying on patient-led data and other forms of crowdsourced data may miss an important intersubjective component of digital knowledge production. Future research might consider whether interactions between individuals have implications for the quality of crowdsourced data. For example, collective production of knowledge may increase individual participants' expectations of either benefit or harm, which could amplify placebo or nocebo effects.

However, we also suggest that these findings may be used to reconsider whether researchers engaged in crowdsourced health studies are correct in presuming that the “individual patient” is the correct unit of analysis within research. Perhaps there are instances in crowdsourced health research when social interaction is fundamental to healing. This perspective aligns with much of the sociological work on embodied health movements, which has historically emphasized shared subjectivity as fertile ground for alternate ways of knowing and alternate modes of treatment.

Our analysis also speaks to a developing literature on the benefits and risks of patient-led research. Patient-led research is valued for its ability to produce fast, innovative and often effective treatments. This speed and efficiency can largely be attributed to CSE's ability to harness the wisdom of the crowd, while catering to individual bodily needs. Dosages can be adjusted easily to fit different bodies, contexts, and experience levels, without approval from an authority. Unlike those seeking experimental treatments within a clinical trial, patients can be sure they are not receiving a placebo. CSE also enables patients to engage in experimental practices on the internet with little institutional oversight. While a lack of regulatory oversight may pose risks to individual experimenters, an ability to experiment free from regulatory constraints enables patients to engage in a wider array of experimental practices than clinical researchers can achieve. This is particularly true in psychedelic science, where many scientists and activists blame regulatory oversight for biomedicine's relative ignorance in this arena (Nutt et al., 2013).

However, CSE also entails multiple disadvantages. Although the Clusterbusters take steps to minimize risks, and engage in multiple harm reduction strategies, CSE operates outside of any external oversight or protections to human subjects. In addition, the nature of CSE, which prioritizes individual participants' benefits over the production of generalized knowledge, does not—at least in this case—include

randomization or controls. Third, online communities engaged in self-experimentation may find it difficult to experiment if, like the Clusterbusters, they cannot obtain a standardized drug. Finally, the process of engaging in CSE may lead to a Hawthorne-like effect, as the Clusterbusters' understanding of their own success is amplified as they become more dedicated to their research.

## 6. Conclusion

Collective self-experimentation is an iterative, collaborative form of knowledge production enabled and facilitated by several strands of social and technological change. In particular, collective self-experimentation is a response to the widespread democratization of science, alongside the increased expectation that patients take their health and even their own cures upon themselves. Within this context, people with underserved diagnoses like cluster headache are frequently left without solutions. Additionally, collective self-experimentation is enhanced through the technological developments behind digital social media and "Health 2.0." These technologies promote a biosociality that enables individuals to locate like-minded individuals with similar embodied experiences, and provide space that may nurture collective efforts to develop therapies that might otherwise be inaccessible or perhaps even "forbidden" through formal channels.

CSE represents a form of knowledge uniquely suited to our technologically mediated era of healthcare. While groups like the Clusterbusters may always struggle to receive complete buy-in from medical researchers and pharmaceutical companies, and while their interventions may always be partial and contingent, their research nevertheless provides an important source of knowledge and a powerful set of tools for their members. As additional tools and platforms for online sociability and knowledge exchange become more widespread, we expect CSE will evolve in order to overcome new challenges. We also anticipate that patient communities embedded in social networks will increasingly become a site of useful knowledge production. Further research with a broader sample of online patient groups will deepen our understanding of how the internet is changing illness experience and knowledge production.

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## References

- ALSUntangled, 2019. Completed Reviews. Retrieved from. <http://www.alsuntangled.com/completed.html>, Accessed date: 4 June 2019.
- Ahrens, S., 2016. Opening (and swallowing) a can of worms to treat my Crohn's disease. *Am. J. Gastroenterol.* 111, 918–920.
- Altman, L.K., 1998. *Who Goes First?: The Story of Self-Experimentation in Medicine*. University of California Press, Berkeley, CA.
- Andersson, M., Persson, M., Kjellgren, A., 2017. Psychoactive substances as a last resort—a qualitative study of self-treatment of migraine and cluster headaches. *Harm Reduct. J.* 14 (60).
- Barbot, J., 2006. How to build an "active" patient? The work of AIDS associations in France. *Soc. Sci. Med.* 62 (3), 538–551 1982.
- Barker, K.K., 2008. Electronic support groups, patient-consumers, and medicalization: the case of contested illness. *J. Health Soc. Behav.* 49 (1), 20–36.
- Bedlack, R., Hardiman, O., 2009. ALSUntangled (ALSU): a scientific approach to off-label

- treatment options for people with ALS using tweets and Twitters. *Amyotroph Lateral Scler.* 10 (3), 129–130.
- Brown, P., 1997. Popular epidemiology revisited. *Curr. Sociol.* 45 (3), 137–156.
- Brownstein, J.S., Freifeld, C.C., Madoff, L.C., 2009. Digital disease detection—harnessing the web for public health surveillance. *N. Engl. J. Med.* 360 (21), 2153–2155 2157.
- Chapkin, W., Webb, R.J., 2008. *Dying to Get High: Marijuana as Medicine*. NYU Press, New York.
- Charmaz, K., 2014. *Constructing Grounded Theory*. SAGE, London.
- Crowe, S., Cresswell, K., Robertson, A., Huby, G., Avery, A., Sheikh, A., 2011. The case study approach. *BMC Med. Res. Methodol.* 11, 100.
- Davis, K., 2007. *The Making of Our Bodies, Ourselves: How Feminism Travels across Borders*. Duke University Press, Durham, NC.
- Delgado, A., Callén, B., 2017. Do-it-yourself biology and electronic waste hacking: a politics of demonstration in precarious times. *Publ. Understand. Sci.* 26 (2), 179–194.
- Epstein, S., 1996. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. University of California Press, Berkeley, CA.
- Felt, U., Fouché, R., Miller, C.A., Smith-Doerr, L., 2016. *The Handbook of Science and Technology Studies*, fourth ed. MIT Press, Cambridge, MA.
- Fox, S., Duggan, M., 2013. *Health Online 2013*. Retrieved from. <http://www.pewinternet.org/2013/01/15/health-online-2013/>, Accessed date: 15 March 2019.
- Herzig, R., 2006. *Suffering for Science: Reason and Sacrifice in Modern America*. Rutgers University Press, New Brunswick, NJ.
- Hoffmann, J., May, A., 2018. Diagnosis, pathophysiology, and management of cluster headache. *Lancet Neurol.* 17 (1), 75–83.
- Hofmann, A., 1980. *LSD: My Problem Child*. McGraw-Hill, New York.
- Holton, J., 2010. The Coding Process and its Challenges. Retrieved from. <http://groundedtheoryreview.com/2010/04/02/the-coding-process-and-its-challenges/>, Accessed date: 15 March 2019.
- Kallinikos, J., Tempini, N., 2014. Patient data as medical facts: social media practices as a foundation for medical knowledge creation. *Inf. Syst. Res.* 25 (4), 817–833.
- Karkar, R., Zia, J., Vilaradaga, R., Mishra, S.R., Fogarty, J., Munson, S.A., Kientz, J.A., 2016. A framework for self-experimentation in personalized health. *J. Am. Med. Inform. Assoc.* 23 (3), 440–448.
- Langlitz, N., 2009. Pharmacovigilance and post-black market surveillance. *Soc. Stud. Sci.* 39 (3), 395–420.
- Murphy, M., 2012. *Seizing the Means of Reproduction: Entanglements of Feminism, Health and Technoscience*. Duke University Press, Durham.
- Nelson, A., 2011. *Body and Soul: the Black Panther Party and the Fight against Medical Discrimination*. University of Minnesota Press, Minneapolis, MN.
- Nutt, D.J., King, L.A., Nichols, D.E., 2013. Effects of Schedule I drug laws on neuroscience research and treatment innovation. *Nat. Rev. Neurosci.* 14 (8), 577–585.
- Psilocybin for the treatment of cluster headache, 2019. *ClinicalTrials.gov*. Retrieved from. <https://clinicaltrials.gov/ct2/show/NCT02981173>, Accessed date: 5 June 2019.
- Pols, J., 2014. Knowing patients: turning patient knowledge into science. *Sci. Technol. Hum. Val.* 39 (1), 73–97.
- Rozen, T.D., Fishman, R.S., 2012. Cluster headache in the United States of America: demographics, clinical characteristics, triggers, suicidality, and personal burden. *Headache* 52 (1), 99–113.
- Schindler, E.A.D., Gottschalk, C.H., Weil, M.J., Shapiro, R.E., Wright, D.A., Richard Sewell, A.R., 2015. Indoleamine hallucinogens in cluster headache: results of the Clusterbusters medication use survey. *J. Psychoact. Drugs* 47 (5), 372–381.
- Sewell, A.R., 2008. Unauthorized research on cluster headache. *The Entheogen Review XVI* 4 (2008), 117–173.
- Sewell, A.R., Halpern, J.H., Pope, H.G., 2006. Response of cluster headache to psilocybin and LSD. *Neurology* 66 (12), 1920–1922.
- Sicuteri, F., 1963. Mast cells and their active substances: their role in the pathogenesis of migraine. *Headache J. Head Face Pain* 3 (3), 86–92.
- Sjoberg, G., Williams, N., Vaughan, T., Sjoberg, A., 1991. The case study approach in social research. In: Feagen, J.R., Orum, A.M., Sjoberg, G. (Eds.), *A Case for Case Study* (27–79). UNC Press, Chapel Hill.
- Stake, R.E., 1995. *The Art of Case Study Research*. Sage Publications, Thousand Oaks.
- Swan, M., 2012. Crowdsourced health research studies: an important emerging complement to clinical trials in the public health research ecosystem. *J. Med. Internet Res.* 14 (2), e46.
- Weisse, A.B., 2012. Self-experimentation and its role in medical research. *Tex. Heart Inst. J.* 39 (1), 51–54.
- Whelan, E., 2007. "No one agrees except for those of us who have it": endometriosis patients as an epistemological community. *Sociol. Health Illness* 29 (7), 957–982.
- Wicks, P., Vaughan, T.E., Massagli, M.P., Heywood, J., 2011. Accelerated clinical discovery using self-reported patient data collected online and a patient-matching algorithm. *Nat. Biotechnol.* 29 (5), 411–414.
- Yoo, W., Namkoong, K., Choi, M., Shah, D.V., Tsang, S., Hong, Y., Gustafson, D.H., 2014. Giving and receiving emotional support online: communication competence as a moderator of psychosocial benefits for women with breast cancer. *Comput. Hum. Behav.* 30, 13–22.