# Successful Moderation in Online Patient Communities: An Inductive Case Study

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## **Abstract**

**Background:** Online patient communities are becoming more prevalent as a resource to help patients take control of their health. However, online patient communities experience challenges that require active moderation.

**Objective:** To identify the challenges of sustaining a thriving online patient community and the moderation practices employed to address challenges and manage the online patient community successfully.

**Design:** An inductive case study of Mayo Clinic Connect that is analyzed using grounded theory methodology. Insights for the analysis are obtained from semi-structured interviews with community managers and community members. Secondary data sources community management documents, observational meeting notes, and community postings were used to validate and triangulate the findings.

**Results:** We identify four challenges unique to online patient communities. These challenges include passion, non-medical advice, personal information, and community participation. We identify five categories of practices used to address these challenges and moderate the community successfully. These practices include instructive, semantic, connective, administrative, and policing practices.

**Conclusions:** Successful moderation in online patient communities requires a multitude of practices to manage the challenges that arise in these communities – some practices acting as more preventative measures and some as more interventive measures, some from authority figures and some from exemplary members.

**Keywords:** Online patient communities; moderation; guidelines; management

#### Introduction

Patients increasingly rely on the internet to look for medical information, ask questions, find peers with similar health concerns, read commentaries and experiences about health issues and consult reviews and rankings of treatments, doctors, and hospitals [1–4]. According to a 2013 study, seventy-two percent of internet users looked at health information online [5]. Online patient communities are becoming forums for patients to share their stories, gain peer support, and search for medical information [6,7]. Studies have shown that membership in patient communities is associated with better health, behavior, and medical knowledge [7–10].

We define successful online patient communities as communities that are vibrant, supportive, and active. They welcome members, encourage active participation and interactions, foster relationships, and provide accurate medical information. Among many potential concerns and challenges for online patient communities, the quality and accuracy of medical knowledge provided in these communities are questioned [11–14]. This is especially important given that members vary considerably in their medical expertise and may have difficulty discerning information quality. To address these issues and assure their success, some online patient communities use moderators [15]. Little academic research exists on effective moderation practices in online patient communities. Our objective is to systematically study the challenges of online patient communities, and identify moderation practices that are employed to address these challenges and maintain a successful community.

To gain a deep understanding of this phenomenon, we conduct an inductive case study of Mayo Clinic Connect, a leading online patient community. Using grounded theory methodology, we collect observational and interview data from key members over three years. Our findings highlight five moderation practices in the community: instructive, connective, semantic, administrative, and policing. Furthermore, these moderation practices are not only enacted by the community's management but also from enlisted volunteer community members who assist in achieving community success. Together, the practices used by both community management and community members successfully address several challenges to create a thriving community.

#### **Prior Work**

Online communities bring together members who share common interests and contribute valuable knowledge and expertise and are recognized as generators of significant knowledge [16]. In healthcare, online patient communities have become a medium for patients to share their stories, gain peer support, and search for medical information [6]. A healthy community retains its existing members, attracts new ones, and elicits their contribution [17]. Research has consistently shown the importance of feedback in driving members' contributions to online communities [18–20]. One challenge facing online

communities is managing the sheer number of contributors and contributions in the absence of monetary incentives and formal managerial structures [21].

Compared to other online communities, online patient communities face additional unique challenges. First and foremost, the quality, accuracy, and trustworthiness of medical knowledge provided over these platforms are questioned [11–14]. Second, there are ethical and privacy issues related to sharing and disseminating patients' information online [22]. Third, there is a mismatch of motives and expectations among members who use these platforms as communication and marketing tools and members who use them for social support and exchanging advice [23].

Community leadership plays an essential role in dealing with online community challenges [20,24,25]. Effective leaders and moderators are characterized by inclusivity, helpfulness, and sociability [20,26,27].-Community Management can be assisted by elevating the status of exemplary members to become trusted volunteer peer leaders [19]. In online patient communities, the involvement of volunteer peer leaders and echoing the voice of patients are essential for community success [28]. However, this inclusivity should not sacrifice the quality of information and trustworthiness of conversation. Such tension is not very prevalent in other grassroots communities because the conversation reflects the shared interests of members without much further consideration. However, understanding how online communities can be other accurate sources of information as well as remain inclusive to members' opinions remains an important research area [16,21].

# Methods

## **Research Context**

We study Mayo Clinic Connect (referred to as Connect hereafter), a leading online patient community sponsored by Mayo Clinic. Connect is designed to "connect patients and family caregivers with each other" [29]. This community enables patients and their families with different medical backgrounds to share experiences, find support and exchange information with others who have faced similar experiences. The community has open boundaries, which means it is open to the public and not restricted to Mayo Clinic patients only. Currently, the community has 85,000 registered members and 10,000+ active members who post at least once a month.

#### **Data Collection**

Our primary source of data came from semi-structured interviews that were collected over five phases. Levin et al. claim that fidelity to data "may be procured by inviting participants to interview or describe their experiences" [30]. First, data collection was initiated when one author became acquainted with the director of Connect and participated in an early interview with her. This interview was instrumental in establishing our initial understanding of the community and in guiding our sampling of subsequent interviewees

through a snowballing approach[31] ②. Second, we conducted four interviews with managers of the community over the phone. Third, we attended a community meeting of managers and members who discussed the concerns, successes, and goals of the community. At this meeting, we participated as silent observers to understand the community in general and collected four onsite interviews from community members that were participating.

After the initial analysis of these interviews, we focused on theoretical sampling for subsequent interviews. Therefore, our fourth phase included the collection of additional 13 phone interviews from members of the community. Through probing questions, we asked about their participation in Connect, and what they felt the community did to achieve success. We asked them to expound on their experiences with the community – including challenging ones. Overall, we let all interviewees talk about being a member of Connect and their interactions with others. Each interview lasted approximately 30 minutes and was recorded and transcribed verbatim. We continued to interview individuals until we reached theoretical saturation, and gained no additional insights from additional interviews [32]. Fifth, we conducted a final interview with the director of Connect to discuss and validate our findings.

After the completion of the interviews, we supplemented this primary data source with additional observational data sources to triangulate the findings from the interviews. First, all authors joined the community as passive members and observed community members' contributions and interactions over the last three years. Second, we obtained archival community documents which included standardized response templates, a reference guide for exemplary posts, orientation packages, and community management guidelines. The observations gathered from these data sources agreed with the findings that emerged in the interviews, strengthening the fidelity of the findings.

## **Data Analysis**

We adopted a grounded theory coding perspective on the semi-structured interviews in order to let theory emerge from the data. Our initial unfamiliarity with the community was instrumental in allowing the data to inform our insights, rather than pre-conceived theory. However, we were aware of how our prior experiences as researchers might shape the interpretation of our [33]. Therefore, as an added measure to ensure the coding was grounded in the data, the author who coded the majority of the data was the least experienced in online community literature. This perspective management in data analysis enhanced the fidelity of our data [30]. We followed a constant comparative process in that throughout our analysis, we repeatedly compared codes and findings in frequent discussions among the authors [34] .

Two of the authors conducted line-by-line open coding techniques [35] in the first five interviews. After both authors completed the coding of these first interviews, they discussed their findings to agree on emergent themes. One author coded the remaining

interviews and all authors met frequently during the coding process to discuss the inductive insights from the codes. After creating an extensive list of open codes, we conducted a second round of coding to ensure that minor differences in codes from open coding were combined to form unique ideas that did not overlap in the data. During open coding, memos were kept on each interview to provide extended notes and insights.

After completing open coding and discussing emergent themes, we followed an axial coding process to combine and relate codes together to form more abstract themes and relationships [36]. Axial coding helps to identify the who, what, when, where, why, and how of the emerging theory. In our case, it illustrated a clear picture of the moderation practices in the community.

We felt that the results from interview data were sufficient to generate insights, yet we used the observational data of archival documents and community postings to validate those results. While this observational data was not formally coded in the same manner as the interviews, it was used as a source to validate the findings and provide examples of our presented results.

## Results

# **Community Challenges**

Our interviews highlighted certain challenges for online patient communities specifically that require active moderation to address. These challenges include passion, ambiguous identities, giving non-medical advice, providing personal information, and community over-reliance.

First, many members are passionate about Connect and their contributions to it. These members experienced or overcame medical conditions and are passionate to share their experiences and help others. Thus, passion can yield positive consequences, such as increased engagement and participation. Passion, however, leads many individuals to argue about different beliefs and opinions. Ugly and argumentative posts are at times a challenge for Connect. "We might have a member that comes in really opinionated." – Moderator 3

Second, sharing personal experiences is perhaps the overarching activity of members in Connect. Members with similar problems share experiences to encourage, inform, and support one another. Overall, this activity creates positive outcomes, and many members are very grateful for the feeling that they are "not alone." However, challenges arise when experiences are viewed as or claimed to be "medical advice". Members in the community are not medical practitioners, but solely patients who have experienced a similar disease state. Therefore, non-medical advice creates the potential for disappointment if the advice doesn't yield positive outcomes, or worse, legal repercussions if that advice causes further physical or emotional harm. "When it comes to alternative medicine, complementary

medicine, that's where we run into problems. Because members are free to express their views, but when they advise their discussion group and they instruct them to stop taking traditional medications and go for homeopathy or herbal things, that's when we have to step in." – Moderator 4

Third, soliciting personal information is helpful for community members to know how to respond to other members. More information regarding a member's condition and situation helps others relate to the member's issues and provide appropriate support. Members often ask questions such as "how was this diagnosed", "how long have you had the problem", and "what kinds of treatment have you had." However, sometimes this is taken too far. Violations to privacy may occur when a member shares excessive personal health information. "In a HIPAA sense, this individual is asking this person very specific questions on the day, the time and the results of a medical test, and I'm not sure that that's an appropriate place for a public discussion board." – Mentor 6

Fourth, community participation is necessary by definition for the community to thrive. Therefore, a lack of participation is a challenge to the community. Yet, perhaps the more nuanced challenge is that the motivation or form of the participation can vary. For example, many members will come to the community only for answers to their questions or to find a way to schedule an appointment with Mayo Clinic, in contrast to joining to establish relationships and gain social support. When members do not participate in the community to establish relationships, the turnover of community members is high, which will hurt the community.

In addition to the four challenges above – passion, non-medical advice, personal information, and community participation – we also noticed secondary challenges that either were not mentioned sufficiently in the interviews or were related to the main challenges addressed. These challenges included ambiguous identities, lack of physician interest, generational gaps, and technology challenges. However, these were secondary to the main story we saw in the data, and therefore we will focus on the main four challenges for the duration of the paper.

## Moderation Structure in the Community

To successfully responds to these challenges, the community must maximize the potential positive benefits and minimize the potential negative outcomes of addressing them. In the case of Connect, these challenges are addressed by community management. The management team of Connect consists of a director and five staffers. These managers are referred to as moderators in the nomenclature of Connect. Moderators have set formal guidelines such as being careful when giving out medical advice, being respectful, and no commercial advertising. At the outset of the community, the moderators ran the community, moderated others' posting, and provided the support to members that started to join the community.

As the community grew, moderators recognized the need to scale community moderation to maintain members' contributions. At the same time, moderators noted that some members were taking increasingly active leadership roles. They identified these emerging peer leaders and invited some of them to help monitor the community. In the nomenclature of Connect, the emerging peer leaders selected by the moderators are called mentors. Once selected, mentors, who volunteer their time, are trained and guided by moderators to act in accordance with the guidelines of the community. Multiple training practices are implemented in order to onboard and train mentors (Table 1).

Table 1. Training mechanisms for mentors.

Training Mechanism	Example from Interviews
Standard	"I'll send you three or four documents that you can look through
documentation	and understand a little more what we're looking for in a mentor."
Setting expectations	"We're hopeful that you'll agree to spend at least X number of
	hours a month visiting the board and watching things."
Coaching/Individual	"When you are first invited, you spend time with the director, a
Training	one-to-one, doing screen shares and discussing different
	scenarios."
Coaching/Group	Moderators set up a private "mentors & moderators" group on
Training	Connect
Mentor Meetups	"The mentors and moderators, we get together once a year. It is a
	little bit more training and sort of continuing education of being
	a mentor."
Remote Training	"Every quarter we will have a phone call where we can share
	what concerns us and build up a discussion."
Behavior Emulation	"We [Moderators] ask them to emulate us as far as the way we
	would respond"

These training practices communicate and transfer the goals of moderators to mentors. This process brings three advantages. First, it reduces the workload of moderators, which is becoming infeasible with the continuous growth of the community, receiving around 10,000 posts per month. Second, mentors are uniquely qualified to assist members because of their shared experience – an experience that the moderators often do not have. Third, it enables moderators and mentors to specialize in different tasks focusing on desired outcomes. Moderators focus on administrative responsibilities, policing the community, and resolving tensions. Mentors can focus on patient success through the daily postings in community threads.

## **Moderation Practices in the Community**

Through the analysis of the interviews, we found that moderators and mentors enacted different practices to address the challenges of the community. Groups of similar practices

were abstracted into five high-level categories to add parsimony to our understanding of the moderation. While some practices are employed by *both* moderators and mentors, in general, practices were not shared equally between moderators and mentors. The three practice groups associated more often with mentors were instructive, semantic, and connective practices. The two practice groups associated more often with moderators were administrative, and policing practices.

Instructive practices are actions that provide medical information relevant to member experiences. While the community acts as emotional support for individuals, the community also strives to empower members by educating them on how to make better decisions about their health. Specific examples of instructive practices include pointing a member to a doctor, stating that the community is not a replacement for professional help. Mentors not only point people to doctors, but assist them by sharing appropriate questions that could be asked, or tips of ways to talk to a doctor. Additionally, mentors in the community have become proficient in using tools like google scholar to search and provide relevant links to patients who have medical-related questions, inspiring them to learn for themselves through peer-reviewed literature. At times, moderators invite doctors to participate in Connect through live webinars that answer common questions that patients have asked recently.

Semantic practices are actions that focus on the content of messages and responses; that is, what is being communicated inside a post. Mentors are instructed to share beneficial content in addition to sharing it in a caring and empathetic manner. Some of the beneficial content that mentors can post are their own experiences with past illnesses which relate to patients and show them that they are not alone in their journey. Mentors provide words of welcome to establish a sense of security, love, and care for new members. Additionally, mentors ask questions to spur further discussion and better understand the individuals they are communicating with. The content of a message, however, is only half of the meaning of semantic practices – how the message is delivered is also important. Mentors must, when appropriate, validate the concerns of the posts through their words to make patients feel heard and important. This is enhanced when mentors use encouraging language and positive reinforcement, rather than critical and negative comments that are so often seen online.

Connective practices are actions that create relationships inside the community and bring individual members into a community setting. This connection is achieved through the platform design of "tagging" members as seen in many social media sites. Mentors go beyond tagging, however, and take a proactive approach to create relationships. Two examples include proactively following up with individuals who have not posted recently and attempting to connect them with similar members. Additionally, mentors who receive private messages (a feature on Connect) will often ask to bring them public so that the entire community can see the questions and participate in supporting that individual. So,

while the feature of tagging is often how connections are made, the proactive mindset to foster relationships is a significant element for connective practices.

Administrative practices are performed by moderators outside of discussion threads to keep the community growing with a "positive community feel." What is done behind the scenes plays an important role in creating an environment for the community discussion to stay vibrant and productive. Administrative practices include increasing the number of volunteer mentors to help scale the moderation of the community. And once mentors are selected, moderators coach them on the proper conduct in the community. Additionally, moderators will at times coach regular members that act inappropriately. Finally, moderators of the community attempt to build community unity by spotlighting select members frequently.

Policing practices are interventions against anti-social behaviors and departures from community guidelines. Ideally, the community would like to not have to implement these practices, but due to the sensitivity of medical information, they are implemented when needed. Moderators act as the authoritative hand more than mentors. Mentors may indirectly police the actions of members by asking for evidence of claims or diffusing negative and criticizing remarks, but typically they are used as eyes on the community to report posts. Moderators alone implement policing interventions through muting members, taking down posts, and acting as an intervention when posts get out of hand.

# Addressing Challenges through Moderation Practices

After we independently identified specific challenges and moderation practices of Connect, we utilized axial coding to relate the challenges and practices together. By doing so, we uncovered processes by which mentors and moderators worked together to maximize the benefits that come from challenges and minimize their negative impacts. Below we identify each challenge that was introduced above and discuss the practices implemented by moderators and mentors to address the challenge. We highlight the insights with relevant excerpts that came from interviews of community members.

#### **Passion**

Passion was fostered by mentors showing interest in members' posts. Particularly, semantic practices such as asking questions and validating concerns were used to leverage the positive benefit of passion and expound on the member's interest. When a member's passion turned negative and argumentative, however, mentors addressed this challenge through indirect policing practices such as diffusing negative comments and observing the community and reporting to moderators.

"We've had our share of those people who come in and are negative, and as a mentor, I honor that because we're not all going to be positive every day. I will recognize that and say, 'Hey, it sounds like you're having a really bad day. Is there anything that caused that?'" - Mentor 8

"We had a member who was really opinionated, and couldn't be convinced he was giving bad advice, so in the end, what I had to do was call on the director to take a hand in the matter." - Mentor 4

However, when the discussion became too ugly, moderators would intervene and address the situation. Moderators typically did not remove posts or mute members that shared passionate opinions because they recognize that passion is what strengthens the community. Rather, moderators implemented administrative practices such as coaching to work with and correct members' contribution to the community.

"And there was one particular gentleman who was very combative, talked down to members a lot, wrote in all caps, which in an online community, is considered yelling. And with a lot of coaching, that particular person, over the course of many months, ended up becoming a really valuable member." - Moderator 2

If members did not respond to coaching, or if the negative behavior continued, then direct policing practices such as muting members or removing posts were implemented as a final option.

"In one case, the moderators actually did ban the person from the board and say, 'We don't allow people in here who are going to call people names and take things to that extreme." - Mentor 6

#### Non-Medical Advice

Giving "advice" *in a proper way* is a way that the community achieves its goals of educating and supporting patients. In lieu of advice, mentors share their experiences, a semantic practice, that follows the guidelines of Connect. Their post with their experience not only benefits the patient in need but hopefully, the post acts as a model for others to follow. They attempt to include the phrase, "this is not medical advice" before each of their experiences.

"You definitely want people to realize that I'm not a doctor. But you want to be able to offer help to people. So, we have to work in certain ways. And I usually just say, 'based on my experience, this is what happened.'" - Mentor 14

Additionally, mentors have been instructed on how to question non-medical advice by asking, "Where did you find that information?" They use instructive practices that educate members on how to do their research to find valid medical information, and sometimes share those sources with patients.

"When I see something that I am not familiar with I will definitely say, 'I am not familiar with that. Have you checked that research?' And we do have guidelines to help refer people to approved sites." - Mentor 5

Moderators, invite doctors to participate in live webinars to provide a professional answer regarding questions that have spurred non-medical advice. Hopefully, these webinars

provide the needed answers that the community can refer to when they encounter an instance of non-medical advice. However, moderators will use policing practices as well and intervene with the if there is any shared information that could be harmful to patients.

"We will do a live Q&A session between a physician and the surgeon. Members are able to ask questions prior. They can watch the video live, and then we link that to Mayo connect so that the information is housed on Connect too." - Moderator 3

"There are times where it is bad advice. That's where we step in, in those situations. And we'll, I wouldn't say squash the conversation, but relay how important it is to seek an appointment with a medical provider." - Moderator 2

#### Personal Information

In order to gather information to help patients, mentors will use semantic practices to validate concerns and ask questions to members. These questions prompt further discussion and deeper insights that allow the community to help a member's concerns. Many members, however, do not understand the proper information to divulge and to retain when they join the community. Mentors will help new members with welcome messages that establish expectations, often teaching them what is appropriate, what are the goals of Connect, and who are some of the other people in the community.

"I try to relate empathically to what they're going through. That makes it easier to discuss how we feel, or have felt in a similar situation" Mentor 12

"Asking questions to the person is a good thing. I know that people don't always like to post on a public forum, so I always start a sentence with, 'if you are comfortable sharing more information about yourself, would you please tell us... etc.'" - Mentor 7

"If they're brand new, I welcome them to the site and explain a little bit how it works." -Mentor 9

Moderators will promote the sharing of personal information by spotlighting members. These spotlights are a good example of personal information that is appropriate to share in order to help others know how to communicate with a patient. Moderators also use the administrative practice of coaching to help instruct members when they are sharing too much. Additionally, moderators use policing practices of deleting posts in order to remove information that is potentially HIPPA sensitive.

"We do a spotlight to get to know people personally. Their favorite things, where they live, what they like to do, and beyond having a condition, that we are people too." - Mentor 8

"You might not want to give all that information and I've had to refer them to the director and say, 'There is a little too much information shared here. Let's talk to this person, edit their post, and take out the exact department building where they are living." - Mentor 8

## Community Participation

Mentors enact multiple practices to maintain member participation. Participation includes the amount of content that a user posts, but it can also signify if a member remains involved in the community. Mentors help to increase the amount of participation by semantic practices, namely asking questions, and welcoming members. Mentors additionally focus on retaining members through connective practices, particularly tagging members to foster relationships and proactively following up with patients that have not been heard from recently.

"I think you just ask a lot of open-ended questions. Usually, I say, 'I'm fascinated by what you've told us, please tell us something else." – Mentor 10

"If a member has been posting and then suddenly stops, we tag members to connect them to our members." – Moderator 4

Moderators also implemented connective practices in the same manner as mentors, without a major distinction between roles. Our interpretation is that moderators of the community were the initial "mentors" of the community when the community was in its early stages, and those moderators have continued to maintain the relationships that were created then. Additionally, moderators implement connective practices to model how to properly tag members.

"When I first started, it was really more about fostering relationships and, no pun intended with the word connect, but in the beginning really our job was to connect members with other members who had talked about the same thing." – Moderator 2

We provide two figures to help readers understand the context and the findings. First, in Figure 1 we include a redacted screenshot of a post from Connect to illustrate the practices implemented by both moderators and mentors. We highlight some specific semantic, connective, and instructive practices to the right. However, our main purpose for including the screenshot is for readers to form their own opinions of the community and familiarize themselves with the context. Second, in Figure 2 we provide a graphical summary of the roles that implement the practices, the five main practices identified and the four challenges that those practices address. We provide this graphic to help quickly and visually outline the dynamics of the community.

Figure 1. Moderation practices employed in one example post

## Posted by @new member

I was diagnosed with \*\*\*\*\* about a year ago. I WAS a very active \*\*\*\*\* year old \*\*\*\*\* all of a sudden, not being able to get out of bed on her own and having severe \*\*\*\*\* pain. As is customary, after waiting 3 months to see a \*\*\*\*\* doctor, she administered the \*\*\*\*\* test and I was VERY high. So, she diagnosed me with \*\*\*\*\* and prescribed \*\*\*\*\* mg of \*\*\*\*\*. I don't like taking meds (as most of us don't), but I was in pain and had no quality of life. I'm a swimmer and could hardly dog paddle! One year later, I have been weaning off the \*\*\*\*\* mg down to \*\*\*\*\* mg. My \*\*\*\*\* said that now it's a matter of determining if I have \*\*\*\*\* or \*\*\*\*\* ... so, she prescribed \*\*\*\*\* mg of \*\*\*\*\* for a month. I will say my \*\*\*\*\* pain seems better, but my \*\*\*\*\* are awful!!! I don't want to go back on \*\*\*\*\* – the devil drug. I would like to get to the "crux" of what is CAUSING my \*\*\*\*\*??? No doctors seem to address that? What would be my next step? A nutritionist? I am \*\*\*\*\* of taking supplements, as well. Thank you for any help or sharing your experience. Weird disease ... I just want my old life back – being able to move without pain, etc. Too much to ask?

## Posted by @mentor

Hello @new\_member — welcome to Mayo Connect. We are glad you found us. Connect is a great place to ask questions and learn what others with similar health concerns are doing for treatments. I also have \*\*\*\*\* . As my \*\*\*\*\* explained it to me \*\*\*\*\* is like \*\*\*\*\* all over the body. My first episode of \*\*\*\*\* was in \*\*\*\*\* and I was started on \*\*\*\*\* mg \*\*\*\*\*\* . It took me \*\*\*\*\* years to taper off of \*\*\*\*\* and the \*\*\*\*\* went into remission and stayed gone for \*\*\*\*\* years, It came back in \*\*\*\*\* and again I was started on \*\*\*\*\* mg of \*\*\*\*\* . I'm now controlling it with \*\*\*\*\* mg dosage and hoping to be off of the nasty stuff in a month or so but there are no promises. The one thing I can tell you is we are all different so you just need to take it one day at a time and keep moving but not over doing it.

Welcoming members

Validating concerns

Sharing experiences

You have asked the \*\*\*\*\* question – what is causing the \*\*\*\*\*? Unfortunately I think the answer is the disease itself, but I'm no doctor and have no medical training. Mayo Clinic has a good overview of \*\*\*\*\* here: https://www.mayoclinic.org/diseases-conditions/\*\*\*\*\*

Providing information

I'm tagging other members who have discussed \*\*\*\*\* and \*\*\*\*\* to see if they can offer you any suggestions or more information. <a href="mailto:@member1">@member2</a>, <a href="mailto:@member2">@member3</a>, <a href="mailto:@member4">@member4</a> can you offer any suggestions or information for <a href="mailto:@new\_member">@new\_member</a>?

**Tagging** 

Asking questions

I would also like to mention that I think you are on the right track with nutrition. You might want to check out a book by Dr. \*\*\*\*\* – The \*\*\*\*\* Protocol. She has \*\*\*\*\* and has a great story about using nutrition for \*\*\*\*\* to reduce or eliminate her \*\*\*\* symptoms. You can read more about her here: <a href="https://external-site.com">https://external-site.com</a>

Providing information

## Posted by @moderator

Hello @new\_member,

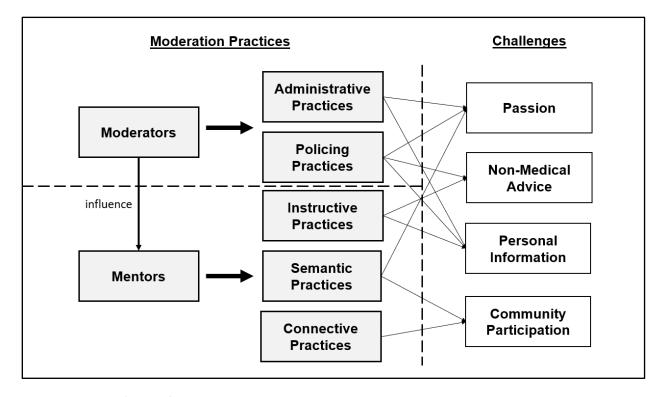
I'd like to add my welcome, and thank you for joining the Connect community, and sharing your concerns. @mentor has offered some great insight, and while we wait for members to add to the conversation, I thought you might wish to view these step-by-step instructions to help you get the most out of Connect. Here's the link to the webpage: https://connect.mayoclinic.org/get-started-on-connect/

Welcoming members

If you need additional help, you can also contact a Connect community moderator by filling out this form: https://connect.mayoclinic.org/contact-a-community-moderator/

Providing information

Figure 2. Graphical summary of our findings



#### **Discussion and Conclusion**

Like most online communities, Connect experiences multiple challenges. We have identified and explicated many practices jointly used by Connect moderators and mentors to address these challenges and maintain a thriving community. We have provided a graphical summary of our findings in Figure 1. These practices are not solely emergent nor wholly prescribed. The nature of the practice matches the needs of the community and its members. Some of these practices are *interventive*. They are mostly used to provide a quick and direct resolution to time-sensitive challenges. Other practices are *preventive*. They promote members' behavior that leads to desired outcomes by avoiding tensions. These practices can be a guide and reference for an online patient community to promote the success and well-being of its members.

Beyond the context of healthcare, these findings illustrate how knowledge-creating online communities [16] can balance the need to promote the contribution of accurate and trustworthy knowledge with the need to remain inclusive to members' opinions and interests. Such endeavor requires the investment of time and effort to promote a culture of trust as well as the joint stewardship of the community by its management and volunteer

members. Finally, this research presented the findings of one case study. Future work can improve the generalizability of the findings to other online communities in other contexts.

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## **Conflict of Interest Statement**

The authors have no conflicts of interest to declare.

# **Data Sharing Statement**

The data that support the findings of this study are available from the corresponding author, upon reasonable request and approval of IRB.

## References

- Fox S. The Social Life of Health Information, 2011. Pew Internet Am Life Proj [Internet] 2011;1–33. Available from:
  http://www.pewinternet.org/~/media//Files/Reports/2011/PIP\_HealthTopics.pdf%5Cnht tp://pewinternet.org/Reports/2011/Social?Life?of?Health?Info.aspx
- 2. Beck F, Richard J-B, Nguyen-Thanh V, Montagni I, Parizot I, Renahy E. Use of the Internet as a Health Information Resource Among French Young Adults: Results From a Nationally Representative Survey. J Med Internet Res [Internet] 2014 May 13;16(5):e128. [doi: 10.2196/jmir.2934]
- 3. Diaz JA, Griffith RA, Ng JJ, Reinert SE, Friedmann PD, Moulton AW. Patients' use of the Internet for medical information. J Gen Intern Med 2002;17(3):180–185. PMID:11929503
- 4. Hesse BW, Nelson DE, Kreps GL, Croyle RT, Arora NK, Rimer BK, Viswanath K. Trust and Sources of Health Information. Arch Intern Med [Internet] 2005 Dec 12;165(22):2618. [doi: 10.1001/archinte.165.22.2618]
- 5. Fox S, Duggan M. Health online 2013. Pew Research Center. Natl Surv by Pew Res Center's Internet Am Life Proj. 2013.
- 6. Yan L, Tan Y, Peng J. Network Dynamics: How Can We Find Patients Like Us? Inf Syst Res [Internet] 2015;26(3):496–512. [doi: http://dx.doi.org/10.1287/isre.2015.0585]
- 7. Goh JM, Gao G (Gordon), Agarwal R. The Creation of Social Value: Can an Online Health Community Reduce Rural-Urban Health Disparities? MIS Q [Internet] 2016 Jan 1;40(1):247–263. [doi: 10.25300/MISQ/2016/40.1.11]
- 8. Ziebland S, Wyke S. Health and Illness in a Connected World: How Might Sharing Experiences on the Internet Affect People's Health? Milbank Q [Internet] Blackwell Publishing Inc; 2012 Jun 1;90(2):219–249. [doi: 10.1111/j.1468-0009.2012.00662.x]
- 9. Richardson CR, Buis LR, Janney AW, Goodrich DE, Sen A, Hess ML, Mehari KS, Fortlage LA,

- Resnick PJ, Zikmund-Fisher BJ, Strecher VJ, Piette JD. An Online Community Improves Adherence in an Internet-Mediated Walking Program. Part 1: Results of a Randomized Controlled Trial. J Med Internet Res [Internet] 2010 Dec 17;12(4):e71. [doi: 10.2196/jmir.1338]
- 10. Cobb NK, Graham AL, Abrams DB. Social network structure of a large online community for smoking cessation. Am J Public Health 2010;100(7):1282–1289.
- 11. Ogah I, Wassersug RJ. How reliable are "reputable sources" for medical information on the internet? The case of hormonal therapy to treat prostate cancer. Urol Oncol Semin Orig Investig [Internet] Elsevier Inc.; 2013;31(8):1546–1552. PMID:23141782
- 12. Benigeri M, Pluye P. Shortcomings of health information on the Internet. Health Promot Int 2003;18(4):381–386. PMID:14695369
- 13. Marrie RA, Salter AR, Tyry T, Fox RJ, Cutter GR. Preferred Sources of Health Information in Persons With Multiple Sclerosis: Degree of Trust and Information Sought. J Med Internet Res [Internet] 2013 Mar 17;15(4):e67. [doi: 10.2196/jmir.2466]
- 14. Rössler B, Lahner D, Schebesta K, Chiari A, Plöchl W. Medical information on the Internet: Quality assessment of lumbar puncture and neuroaxial block techniques on YouTube. Clin Neurol Neurosurg [Internet] Elsevier B.V.; 2012;114(6):655–658. PMID:22310998
- 15. Young C. Community management that works: How to build and sustain a thriving online health community. J Med Internet Res 2013;15(6):1–15. PMID:23759312
- 16. Faraj S, von Krogh G, Monteiro E, Lakhani KR. Online Community as Space for Knowledge Flows. Inf Syst Res [Internet] 2016;7047:1–17. [doi: 10.1287/isre.2016.0682]
- 17. Wasko M, Faraj S. Why Should I Share: Examining Social Capital and Knowledge Contribution in Electronic Networks of Practice. Manag Inf Syst Q 2005;29(1):35–47.
- 18. Moon JY, Sproull LS. The role of feedback in managing the Internet-based volunteer work force. Inf Syst Res 2008;19(4):494–515.
- 19. Zhang C, Hahn J, De P. Continued participation in online innovation communities: Does community response matter equally for everyone? Inf Syst Res [Internet] 2013 Dec [cited 2014 Jun 2];24(4):1112–1130. [doi: 10.1287/isre.2013.0485]
- 20. Johnson SL, Safadi H, Faraj S. The Emergence of Online Community Leadership. Inf Syst Res [Internet] 2015 Mar;26(1):165–187. [doi: 10.1287/isre.2014.0562]
- 21. Faraj S, Jarvenpaa SL, Majchrzak A. Knowledge Collaboration in Online Communities. Organ Sci [Internet] 2011 Oct;22(5):1224–1239. [doi: 10.1287/orsc.1100.0614]
- 22. McKee R. Ethical issues in using social media for health and health care research. Health Policy (New York) [Internet] Elsevier Ireland Ltd; 2013;110(2–3):298–301. PMID:23477806
- 23. Antheunis ML, Tates K, Nieboer TE. Patients' and health professionals' use of social media in health care: Motives, barriers and expectations. Patient Educ Couns [Internet] Elsevier Ireland Ltd; 2013;92(3):426–431. PMID:23899831
- 24. Kane GC, Johnson J, Majchrzak A. Emergent Life Cycle: The Tension Between Knowledge Change and Knowledge Retention in Open Online Coproduction Communities. Manage Sci [Internet] 2014 Dec [cited 2015 Jan 13];60(12):3026–3048. [doi: 10.1287/mnsc.2013.1855]
- 25. Joyce E, Pike JC, Butler BS. Rules and Roles vs. Consensus: Self-Governed Deliberative Mass Collaboration Bureaucracies. Am Behav Sci [Internet] Thousand Oaks: SAGE PUBLICATIONS, INC.; 2013 May 1;57(5):576–594. [doi: 10.1177/0002764212469366]
- 26. Collier B, Kraut R. Leading the Collective: Social Capital and the Development of Leaders in Core-Periphery Organizations. Collect Intell 2012.
- 27. Faraj S, Kudaravalli S, Wasko M. Leading Collaboration in Online Communities. MIS Q [Internet] 2015 Feb 2;39(2):393–412. [doi: 10.25300/MISQ/2015/39.2.06]
- 28. Brubaker JR, Lustig C, Hayes GR. PatientsLikeMe: empowerment and representation in a patient-centered social network. CSCW'10; Work Res Healthc Past, Present Futur 2010.

- 29. About Connect: Who, What & Why [Internet]. 2019 [cited 2007 Sep 20]. Available from: https://connect.mayoclinic.org/page/about-connect/tab/aboutconnect/
- 30. Levitt HM, Motulsky SL, Wertz FJ, Morrow SL, Ponterotto JG. Recommendations for designing and reviewing qualitative research in psychology: Promoting methodological integrity. Qual Psychol 2017; [doi: 10.1037/qup0000082]
- 31. Bryant A, Charmaz K. Sampling in Grounded Theory. SAGE Handb Grounded Theory 2007. p. 656. PMID:6384658
- 32. Glaser BG. Conceptualization: On Theory and Theorizing Using Grounded Theory. Int J Qual Methods [Internet] SAGE Publications Inc; 2002 Jun 1;1(2):23–38. [doi: 10.1177/160940690200100203]
- 33. Finlay L. "Outing" the researcher: The provenance, process, and practice of reflexivity. Qual Health Res 2002; [doi: 10.1177/104973202129120052]
- 34. Charmaz K. Constructing grounded theory: a practical guide through qualitative analysis. Book. 2006. PMID:82ISBN:9780761973522
- 35. Strauss A, Corbin J. Grounded theory procedures and techniques. Basics Qual Res [Internet] 1990; Available from: http://scholar.google.co.uk/scholar?q=Corbin%2C+J.%2C+Strauss%2C+A.+%281990%29% 2C&btnG=&hl=en&as sdt=0%2C5#7
- 36. Corbin JM, Strauss A. Grounded theory research: Procedures, canons, and evaluative criteria. Qual Sociol 1990;13(1):3–21. PMID:10951749