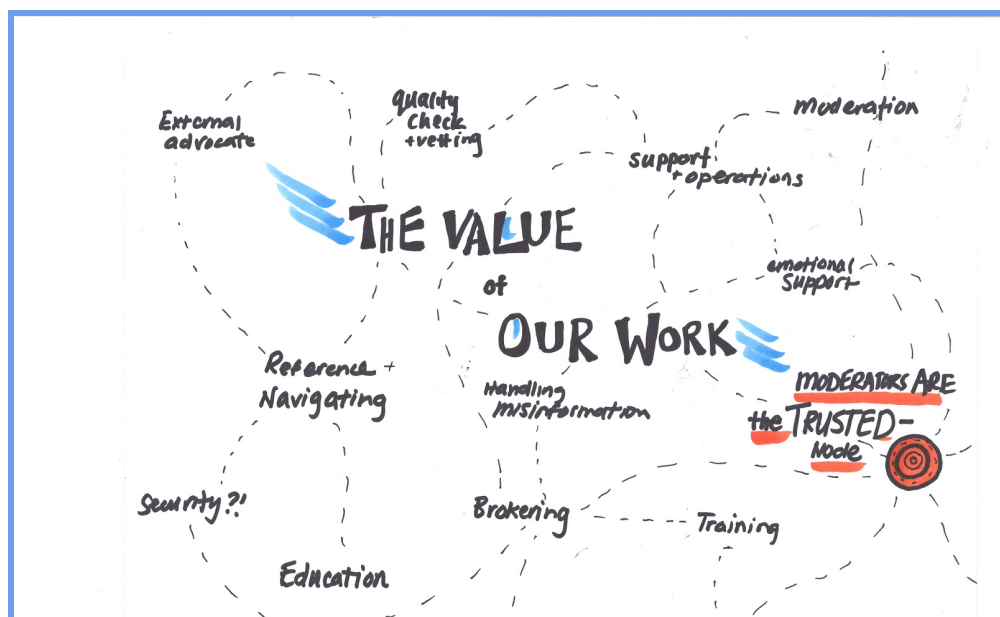


# THE LIGHT COLLECTIVE: MODERATION BEST PRACTICES



## Introduction

Peer-to-peer support is an important and effective part of the continuum of care for many people experiencing health challenges. Increasingly, peer support is found not in the local advocacy organization or cancer center but online in peer support groups on social media (Fox and Duggan, 2013; Rideout and Fox, 2018).

An essential component of any support group, in person or online, is the moderator or moderators. Moderators set the group rules, screen prospective members, establish the tone and focus of the group, facilitate discussions, curate and steward the content of the group, maximize group member privacy protections, and connect users to additional resources. As one group member we interviewed stated, "The moderator is what makes or breaks a group."

[The Light Collective](#), with the generous support of the [Robert Wood Johnson Foundation](#), held workshops and discussions with its [Community Advisory Board](#), surveyed 279 members of multiple cancer-focused online groups, and conducted focused interviews with moderators of these and other online cancer support groups in order to answer key questions about the use and value of online cancer-focused support groups, including the role of moderators and moderation.<sup>1</sup>

Based on the results of these surveys, interviews and discussions, as well as a review of the literature, The Light Collective has developed a set of Best Practice Guidelines for Online

<sup>1</sup> The survey and interview questions can be found [here](#).

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Support Group Moderation. Our intention is that these guidelines be useful not only for the hereditary and non-hereditary online cancer communities but also for many other online peer to peer communities.

## Two Levels of Engagement: Group + Technology

Moderators of online support groups operate within two spheres of engagement. The first is internal and is the group itself, over which the moderator has considerable authority and within which the moderator can ensure the enforcement of certain rights and fulfillment of certain responsibilities to the group's users. The second is external and is comprised of both the technology platform where the group convenes and the traditional healthcare system. Moderators traditionally have had little ability to shape or even influence the basic terms of engagement with these latter entities, and users generally have little awareness of the rules and policies of their groups' host platforms that determine certain aspects of their online experience, including their privacy and security.

In this document we propose guidelines to:

- 1. Identify certain practices that make the internal sphere—the internal workings of the group—more effective, transparent, and safe for its users.**
- 2. Redefine moderators' and groups' relationship to the external sphere—the technology platforms on which groups live, and the healthcare institutions to which they are connected through the patients they have in common.** While it may not be always or immediately possible to exercise the rights listed in this section, they serve as aspirational guidelines.

## Moderator Best Practices: Group

The following are a set of moderator/moderation best practices recommended by The Light Collective. Table 2 lists these best practices at a glance.

### Practice 1: Screen & verify identity of members on social network

In order for online peer support to be deemed trustworthy by group members, moderators must screen prospective members and make every effort to verify that they are legitimate users. Moreover, while in some groups, members may choose to be anonymous, the identities of members in terms of their role in the group—administrator, patient, caregiver, professional— must be clear to other users of the group.

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Some online communities grow mainly by word-of-mouth and referrals of new members by existing members, which is a built-in way of maximizing the chance that members are legitimate. Other groups pose a series of screening questions to prospective members and do online 'background checks' using social media in an effort to ensure the person is legitimate.

The Light Collective is working to develop a screening protocol and tool that can be modified and used by any online community on Facebook. The tool will allow moderators to:

1. Collect screening information off of Facebook (or other commercial technology platform), thereby protecting the membership data collected from data-scraping by the technology platform; and,
2. Build a member registry as they build the group. Registries allow moderators to easily contact and engage group members with news, information, opportunities (to participate in research or to vote on use of data, for example) and otherwise.

## Practice 2: Explanations of privacy risks/benefits to new members

Moderators have the responsibility to ensure that they are familiar with the privacy and security practices of the technology they use to convene their groups. In turn, they must explain the risks and benefits of participation in terms of privacy and security clearly to all members.

- As members are added to the group they should receive a clear and simple explanation of the privacy and security risks and benefits of participation and such an explanation should also be pinned to the top of the group page.
- They should become better-informed resources, learning more about what users and moderators should know about participating in health-focused groups on social media platforms by visiting The Light Collective's web resources on [cybersecurity](#).

## Practice 3: Training/certification in moderation and group leadership

Effective moderation of peer support groups is a *practice*. Many good moderators of well-established peer support groups have evolved their practices over time through experience.

We have identified the need to invest in patient communities on an ongoing basis to ensure that administrators and moderators have the training and knowledge to provide safe, informative, supportive spaces for their online support groups. Moderators should have the opportunity to

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receive training in areas that will assist them to better serve their users' and their own needs.<sup>2</sup> Specifically, The Light Collective, through surveys, interviews, and discussions, has identified the following core areas where training would be beneficial:

- Evidence-based information on the condition on which the group is based. E.g., for BRCA-focused groups, moderators should receive training in the basics of BRCA genetics, cancers, prevention and treatment options.
- Facilitation/Leadership.
- Essential cybersecurity practices for keeping group and members safe.
- Setting boundaries and self-care to avoid burn-out.
- Addressing mental health emergencies.

Different groups with different foci will have different needs and different individuals will also have different training interests and needs. We envision a program in which moderators/administrators have the opportunity to attend training in core competencies and also in elective areas of interest or need. Table 1 lists suggested core competencies and potential electives of interest. TLC welcomes input from the broader community of peer support leaders and members on what specific trainings would be useful.

**Table 1. Moderator training: recommended core competencies and elective topics**

Core Competencies				
Cybersecurity: keeping your group as safe and secure as possible online.	Facilitation: challenging people + situations; encouraging participation; setting tone	Medical focus of group. E.g., BRCA group => training in genetics, cancers, screening	Addressing mental health issues, including emergencies	Setting Boundaries/ Self Care
Elective Training				
Specific subject matter(s) (e.g., breast cancer, genomics) <sup>3</sup>	Understanding data: what it is, how it's used, how it benefits research	Finding clinical trials and the clinical trial process	Why participate in research?	Resources available
Clinical trials	AI and Machine Learning	Ways to sustain work	Grief Counseling/ Management	How to build effective partnerships

<sup>2</sup> TLC plans to establish a moderator training program. Moderators who wish to be TLC-certified and participate in TLC will need to complete core competency training. Visit [TLC's website](#) for updates on activities and opportunities.

<sup>3</sup> TLC will establish formal partnerships/linkages to advocacy organizations and healthcare institutions that will provide moderator training on specific topics.

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The Light Collective is working with subject matter experts from several institutions and advocacy organizations to develop a training program that we hope will be available in the future online to moderators interested in becoming TLC-certified and enhancing the quality of their groups.

## Practice 4: Monitor & communicate data access to members

As described in the preceding section, moderators should make every effort to choose technology platforms that agree to follow the best practices outlined in the Light Collective tech guidelines. One such practice is for platforms to inform moderators what systems and strategies the platform uses to prevent and detect unauthorized access of data. Another such practice is to share with moderators information on all data access, authorized and not, of a group's data, within an agreed-upon time period (e.g., one week), and preferably in real time.

- Moderators have the responsibility to communicate information provided by the technology company on data access and breaches to end users/group members within one week of access event.
- [See partnerships guidelines](#) for details on preferred methods for engaging with researchers and other entities interested in accessing data; see [governance guidelines](#) for recommendations on how to ensure that all members have a voice in decision-making around data use; see [ethical tech guidelines](#) for more details on preferred technical methods and parameters for authorized data access.

## Practice 5: Clear guidelines for group members

In order to minimize confusion and conflict, moderators must establish and clearly post guidelines for appropriate content of the group, for standards of behavior, and for rules on what is and what is not allowed (e.g., photos, fundraising, etc.) Moderators should also strongly consider sharing the guidelines in an interactive format with new members as they join the group.

## Practice 6: Consistent engagement & adherence to group guidelines

An important role of the group moderator is to consistently engage with members, in mediating problems, in removing problematic people, in connecting people to others with similar issues or with external resources.

## Practice 7: Informed consent re: data use/ethical data-sharing

Moderator works with TLC to ensure clear and interactive informed consent of members. I.e., members understand if their group has agreed to participate in a type of data-sharing, if they

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have agreed individually to participate in data-sharing, etc. Informed consent must be interactive in nature rather than a simple check mark at the end of a long narrative.

**Table 2. Group Moderator/Administrator Best Practices<sup>4</sup>**

<b>Screening.</b> Moderator/Administrator uses a rigorous screening protocol to maximize the probability that users are legitimate.
<b>Inform About Risks.</b> Moderator has clear, <u>interactive</u> process of informing group members of risks and benefits of participation, including privacy limitations.
<b>Training.</b> Moderator receives initial training in core competencies identified in Table 1, and commits to yearly refresher courses in core competencies (webinars and/or in person). Moderator receives certification upon completion of initial core competencies trainings and certification renewal each year.
<b>Monitor &amp; Communicate Data Use.</b> Moderators have the responsibility to communicate information provided by the technology company on data access and breaches to end-users/group members within one week of access event.
<b>Guidelines.</b> Moderator establishes and posts clear guidelines for appropriate content of group, for standards of behavior, and for rules on what is and is not allowed (e.g., photos, fundraising, etc.).
<b>Consistency.</b> Moderator(s) is consistent in engagement with members, in mediating problems, in removing problematic people, in connecting people to others with similar issues or external resources.
<b>Informed Consent regarding Data Use.</b> Moderator works with TLC to ensure clear and interactive informed consent of members. I.e., members understand if their group has agreed to participate in a type of data-sharing, if they have agreed individually to participate in data-sharing, etc.
<b>Evidence-based Information.</b> Moderator commits to addressing misinformation promptly and respectfully.
<b>Ethical Data Sharing.</b> To improve prevention and treatment options, communities recognize benefits of sharing some data, with the consent of members. Need advisory oversight for such initiatives.
<b>Facilitation.</b> Moderator has a clear protocol for handling disagreement among members.
<b>Support.</b> Moderator ideally participates in some kind of forum where she/he/they can receive support from other moderators and give and receive input on difficult situations.

## Practice 8: Evidence-based information

An important role of moderators is to ensure that misinformation is not spread on their groups. This can be a tricky area to navigate as questions may arise as to who is the arbiter of 'good' or 'valid' information and where should the line be drawn between peer-reviewed evidence-based information and information that may not be scientifically validated but may still be worth exploring for some individuals (e.g., keto diets, certain supplements, etc.). Moderators also must walk a fine line, providing information and connection to resources, while not offering medical advice.

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<sup>4</sup> This set of best practices is also available as a simplified infographic at [lightcollective.org](http://lightcollective.org) [here](#).

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## Practice 9: Ethical data-sharing driven by collective governance

Administrators and members recognize the benefits of sharing some data about the community with research institutions in order to help drive research that results in improved, evidence-based prevention and treatment options,. Community members must have the option to opt in or out of such data-sharing, either individually or by proxy, depending on the specific governance structure of the group. In addition, a governing body of community leaders must help guide decisions for any data transactions and ensure that they are ethical, collaborative, and beneficial to the community. Please see 'fair partnerships' on [TLC's website](#) for details.

## Practice 10: Facilitation

Moderators should develop clear protocols for handling conflict and disagreement among members, and skills to address challenging people and situations. Moderators should also have the ability to engage members, connect people to others with the same conditions or challenges, and have protocols in place for handling mental health emergencies (e.g., threatened suicide).

## Practice 11: Support + self-care

The job of a moderator of a peer health support group can be exhausting and overwhelming (as well as rewarding). It's important that moderators build into their lives opportunities for self-care and for receiving support from other moderators who can understand their challenges and share appropriate resources and counsel. In the future, The Light Collective hopes to offer a forum in which moderators can connect and offer the kind of information and support to one another that they provide to their group members.

Table 3 lists key qualities of good moderators identified in our community needs assessment.

**Table 3. Qualities of Successful Moderators**

Respectful	Objective/Impartial	Engaged
Empathetic	Focus on poster, not moderator	Strong mediation skills
Information broker: Share information; allow people to make own decisions	Able to set boundaries, personally and regarding behavior of others	Knowledgeable about condition and can refer to credible resources
Ability to connect newcomers with others with the same challenges	Use of the 'sandwich' method: affirmation, suggestion, affirmation.	No patient/person left behind. Ability to meet people where they are

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## Moderator Rights: Tech Platforms + Healthcare System

*Historically, online support groups have had few if any rights in relation to the technology platforms where they convene or the healthcare systems they help support by providing critical information, support, and connection to millions of patients.*

We articulate here elements of a new relationship to these entities, in which moderators and the groups they run have:

- Rights to privacy, data mobility, decision-making over how and by whom data are used, and benefits/proceeds from data use in relation to the technology platforms where they convene, and,
- Recognition by and support from the healthcare system and the health research enterprise of which they are an unrecognized but critical element.

Table 4 shows these rights at a glance.

### Right 1: Privacy/Security

*Groups of people sharing vulnerabilities and sensitive health and genetic information in closed groups online have the right to have a reasonable expectation of privacy/security.*

Ideally, the technology system itself is guided by principles that, while unable to *guarantee* user safety, prioritize it. Here we invoke Jack Balkin's principle of information fiduciaries<sup>5</sup>, in which when a tech platform like Facebook is considered an information fiduciary it has an obligation, as doctors and lawyers do, to "act in a trustworthy manner in the interests of another", where "another", in this case, is users of the platform. Peer to peer groups should make every effort to ensure that they are convening on technology that prioritizes user safety and security. See No Tech About Us Without Us Guidelines for more details on making a good choice.

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<sup>5</sup> Balkin, Jack. 2016. [Information Fiduciaries and the First Amendment](#) and Balkin and Zittrain, [A Grand Bargain to Make Tech Companies Trustworthy](#)



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**Table 4. Basic Rights of Moderators/Groups: Technology Platforms & the Healthcare System<sup>6</sup>**

<b>Privacy/Security.</b> Groups of people sharing vulnerabilities and sensitive health and genetic information in closed groups online have the right to have a reasonable expectation of privacy and security.
<b>Data Mobility.</b> Moderators are stewards of their groups' cumulative data and have the right to choose to migrate their groups and their historical data to a different platform.
<b>Access &amp; Use of Data.</b> Moderators & members have the right to decide and know how, when and by whom their data is accessed & utilized.
<b>Groups and Members as Beneficiaries.</b> Patient communities and individuals within support groups have the right to be the beneficiaries, at least in part, of any funding, knowledge, tools, or resources that are generated by the use of the group's data.
<b>Recognition/Compensation.</b> Group moderators are entitled to fair compensation and to have their work otherwise valued and legitimized by the healthcare system and the health research enterprise.

## Right 2: Data Mobility

*Moderators are stewards of their groups' cumulative data and have the right to choose to migrate their groups to a different platform.*

Currently, many groups are trapped on the tech platforms where they established themselves and grew. While the moderators and members built the group and generated the data that comprise it, they do not have the right to access or use the group data. Tech platforms that support peer group functionality must permit and enable group administrators to do the following:

- Migrate members of their groups to another platform. Individual members must have the right to opt-out of such a migration.
- Generate and download an archive of their groups' posts in order both to preserve the groups' shared history and, if desired, to re-establish the group in its historical context on another platform.
  - Members must be given options to redact names or otherwise remove their data from the archive.
  - The archive must present information in a usable format, i.e., in a way that enables members to learn and benefit from the historical knowledge contained in the group.

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<sup>6</sup> Further standards for technology platforms hosting patient groups can be found at [lightcollective.org](http://lightcollective.org) and here.

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## Right 3: Access & Use of Data

*Moderators & members have the right to decide and know how, when and by whom their data is accessed & utilized.*

- Moderators must be able to conduct data analyses on the data in their communities, which means they must be able to access it in an analyzable form.
  - Platforms must allow moderators to share this data access with qualified researchers without participation from the platform itself (but with consent of group members).
  - Data sharing must be facilitated using ongoing bulk data downloads or API-based access.
  - Data ideally should be automatically de-identified before researchers receive access.
- There should be a transparent ‘audit trail’ of access to community data that is GDPR-compliant and accessible to all community members.
- Any requests to view or analyze community data must be communicated to group members, at which time they have the opportunity to opt out of a particular request (or all requests). Some group members may choose to automatically opt-in such that if the governing body of the group approves the request, their data will be part of shared datasets.

We are also exploring the idea of asking that platforms provide mechanisms for entities who use de-identified data for machine learning purposes to communicate “emergency information” to users for whom they have discovered a reliable and critical clinical fact if users have not opted out of receiving such communications. We will be soliciting input from the community on this issue.

## Right 4: Groups and Members as Beneficiaries

*Patient communities and individuals within support groups have the right to be the beneficiaries, at least in part, of any funding, knowledge, tools, or resources that are generated using the group’s data.*

Historically, patient communities and the individuals that comprise them often have not been aware when the data they generate are used for research or other purposes, let alone benefited from this use in any direct (or indirect) ways. The work of The Light Collective aims to change this. Along with insisting upon informed and interactive consent for the use of patient data, TLC

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believes that patient communities should directly benefit from the use of their data, whether that be through open access to research results, a voice in the research questions posed, financial remuneration, or all of the above.

## Right 5: Recognition/Compensation

*Group moderators are entitled to fair compensation and work that is valued and legitimized by the healthcare system and the health research institutions whose work is dependent on patient data.*

The moderators who run online support groups are generally volunteers. Many of them spend 40 hours a week or more screening prospective members, welcoming new members, fielding questions, connecting people to resources and others who share the same specific diagnosis or challenge, posting scientific studies, ensuring that every post receives a response, facilitating resolutions of disagreements, addressing emergency mental health crises, and more.

As groups grow, it becomes impossible for a single moderator, even one willing to work without compensation 40-60 hours a week, to manage the group. Moderators speak of their inability to attract co-moderators or replacements to sustain their groups since they can only offer long hours of work and no compensation.

Support group moderation is essential and taxing work and that work must be recognized and supported by the healthcare system as a critical part of the continuum of care. Moreover, online peer groups are by definition organized patient communities and registries and are valuable partners to institutions engaged in health research. It is time for healthcare and research institutions to recognize the important role organizers and moderators of online health communities are playing to help educate, support, motivate, organize, and empower patients, and partner in meaningful ways with these individuals and groups to support this important work.

Table 5 articulates some key reasons why it is in the interests of the healthcare system and health research institutions to help sustain the work that happens in online peer health groups.

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**Table 5. Why is it Important to Sustain the Work of Online Patient Groups?<sup>7</sup>**

<p><b>Groups are where patients gather.</b> Tens of millions of patients use online groups for information and support, and the numbers are growing.</p>
<p><b>Groups provide critical information and support.</b> Online peer support groups are a primary source of information and support for many patients (TLC Survey Research Results).</p>
<p><b>Group participation can increase health and data literacy.</b> Participation in groups can increase health and data literacy, resulting in patients who are more interested in sharing data and participating in the research process.</p>
<p><b>Engaged patients = lower healthcare costs.</b> Participation in peer support groups leads to more engaged patients and studies suggest that more highly engaged patients have lower healthcare costs (Coulter, 2012; Coulter and Ellins, 2007; Laurance et al, 2013; National Voices, 2019).</p>
<p><b>Engaged patients = better health outcomes.</b> Participation in peer support groups leads to more engaged patients; studies suggest that more engaged patients have better health outcomes (Coulter, 2012; Coulter and Ellins, 2007; Laurance et al, 2013).</p>
<p><b>Partnership = higher quality groups.</b> Training on cybersecurity, group moderation, data governance, and the specific medical focus of the group is essential to ensure that all moderators have the skills and information they need to meet the needs of their members. Partnerships between healthcare institutions/professionals and researchers provides the opportunity for higher quality information-sharing, which ultimately benefits patient communities and those who care for or study them.</p>
<p><b>Partnership = more patients engaged in the research process.</b> Online peer support groups are where patients convene and coalesce around their health challenges. These groups are ready-made registries. With ethical partnerships, both patient communities and the research/healthcare enterprise can benefit in reaching shared goals of better prevention and treatment options.</p>
<p><b>Online groups increase access to information and support and reduce disparities related to access.</b> People in rural or other underserved areas around the globe can, with just a smartphone and data plan, communicate with others receiving care at world-class institutions and learn about their condition, treatment options, how to manage side effects, and more.</p>
<p><b>Participation in online health groups can inspire collective action, which can have important impacts on health policy and can also reduce health inequities</b> (Harris et al, 2015).</p>

<sup>7</sup> This chart can also be found as a simplified infographic at [lightcollective.org](http://lightcollective.org) and [here](#).

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## Conclusion

A key element of fulfilling The Light Collective's mission of empowering peer support groups to become independent, self-sustaining communities is to ensure that the administrators and moderators of peer support groups have the tools, resources, support, and ultimately, funding they require to do their essential work. Through the set of best practices and rights outlined in this document, TLC aims to provide group leaders with some basic guidelines that may help them in their work. In addition, TLC hopes this document will provide professionals outside of the world of peer support with some insight into why it such an important part of the healthcare continuum and the rich opportunity for collaboration it presents.

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