

THE LIGHT COLLECTIVE GOVERNANCE

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The word governance in this document can refer to two types of governance:

1. The governance of The Light Collective as an organization or “organizational governance” or
2. The governance of health related peer support groups on social media that adopt The Light Collective principles (and may also be hosted on The Light Collective platform), also known as “group governance.”

There are also governance issues related to partnerships with outside organizations, but those will be addressed in the “partnerships” section rather than in this section.

What is Governance?

Governance of any organization, including an individual support group, determines who has power, who makes decisions, how players make their voices heard and how to ensure accountability. (Institute on Governance)

To engage in self-governance, a group needs to have processes, structures, traditions and rules in place so it can:

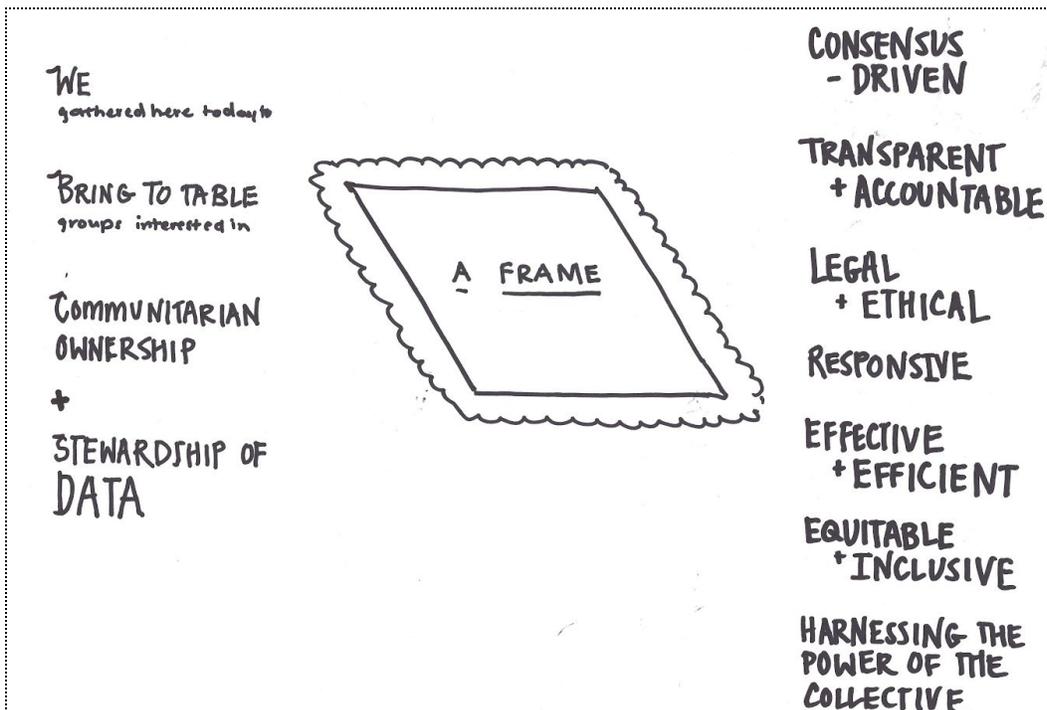
- determine who is a member of the group
- decide who has power, and over what
- ensure that power is exercised properly
- make and enforce decisions
- hold decision-makers accountable
- negotiate with others regarding their rights and interests
- establish the most effective and legitimate arrangements for getting those things done

The UN has articulated a set of eight principles of good governance, which The Light Collective has adopted:¹

¹ The principles, endorsed by the Economic and Social Council on 2 July 2018, highlight the need for pragmatic and ongoing improvements in national and local governance capabilities to reach the SDGs.

- Consensus-oriented
- Transparent
- Equitable and inclusive
- Responsive
- Effective and efficient
- Follows the rule of law
- Participatory
- Accountable

The Light Collective has adapted these principles to include the following guiding principles, unique to the needs of online peer support communities:



Caption: The following is a summary of the draft 'framing' for governance discussed by The Light Collective in March 2019. We have expanding on this initial frame with support and input from our Council of the Wise and Community Advisory Board.

What Is Peer Support?

A Shared Definition

"Peer Support is the act of sharing information with people who have a similar identity or lived experience."

People who share similar challenges or experiences share knowledge, emotional support, experiences, and guidance to one another in order to help each other manage their shared

experience. Increasingly, peer support is sought and found online in groups organized by shared experience or characteristic. One of the things that occurs when peer support groups convene online rather than in person is that all of the knowledge and experience that is shared between peers is necessarily shared in written form, leading to the creation of huge stores of personal data. These vast stores of data associated with given conditions or experiences lead to huge opportunities: both for the violation of privacy and exploitation of people's information by the technology companies that so often collect and store the data, and for the discovery of new understandings, which may lead to advances in the screening, prevention, and/or treatment of disease.

Why Is Governance Important for Peer Support Groups Online?

Decisions about support groups and about participation, use of data and metadata, partnerships with other organizations and other decisions must be driven and stewarded by patient-driven collective action and shared decision-making. We do this in partnership with experts who help us to make informed decisions about data-sharing practices and technologies that impact us as support groups. Just as this nation's founders called for "no taxation without representation" in a democracy, we believe in "no data aggregation without representation" and "no decisions about us without us." We also seek to clearly define both the rights and responsibilities of patients, and patient peer support groups, as they engage with each other on social media. Support group leaders and members need to know what rights and responsibilities they have as part of a support group, and what rights and responsibilities the platform and other platform participants have.

Living by the good governance principles articulated above, The Light Collective will be able to develop and implement its vision of the future in a manner that is authentic and that respects and advances the interests of its patient members.

Vision of the Future

The Light Collective supports a trusted patient-driven and patient-governed online collective for peer support groups sharing health journeys, curated content, and research, and connecting individuals, including patients, caregivers, and clinicians. The Light Collective is transparently identified and committed to respecting patient privacy, and being held to account for doing so.

The value of the collective governance is derived from the ability of an online community to make and carry out decisions. Stewardship of that value is for the benefit of the members who are part of that online community. Therefore, the potential for both individual and group benefit, and the potential for both individual and group harm, must be considered in decision-making.

Mission of The Light Collective

The charter that founded the Light Collective, its Certificate of Incorporation, states:

The Corporation has been organized to operate for purposes including:

1. development of peer support community standards, guidelines, governance best practices, content moderation, data stewardship and data privacy for communities engaging in discussion of health-related issues on various platforms on the internet,
2. education of the public regarding privacy risks associated with sharing personal health information on the internet and elsewhere,
3. development of safe and secure place(s) on the internet for communities to connect for peer support for health related matters,
4. education and training for peer support moderators of health related matters,
5. education and advocacy regarding data privacy, data sharing, and the impact of new technologies,
6. research and development of new technologies to secure personal health information shared by users in peer support groups,
7. fostering discussion and public discourse regarding the privacy issues raised by the internet and new technologies, and
8. engaging in activities such as public education and advocacy in furtherance of any of the foregoing.

Practical Details of Governance

The first order of business is to articulate the organizational governance design that will enable The Light Collective to achieve its vision. Once we have a framework and structure for organizational governance, we will be able to self-govern as a community of members and moderators of online peer-support groups. This structure ensures the inclusion of diverse patient and expert voices, centered on group moderators and members, in organizational governance.

Members. Organizational governance is driven by the patient members of the community. Patients are represented initially by the community members present at the March 2019 retreat in Washington, DC. Ultimately, the membership will grow and change, and we will need to decide whether we want to continue long-term, a direct representational democracy model (each member of each member group is a Member with a vote) or an indirect model (each group names a specific number of Members and the Council of the Wise (The Light Collective's expert advisors) names a specific number of Members, those Members being the members of the "Town Meeting.")

Board of Trustees. The Members elect the Board of Trustees. The Board will have staggered terms to ensure continuity. Term limits will be three years after an initial three year startup period, with terms for individual Trustees renewable once. There will be an odd number of Trustees. Moderators and patients will constitute a majority of the Trustees. Over time, TLC should explore the idea of having a specified number of the patient Trustee positions held by patients who complete a TLC-developed or TLC-recognized curriculum, such that the Board will be composed of three groups equal in number: “patient experts and moderators,” other patients, and non-patient “experts.”

- **Board of Trustees Charter** The Members issue a charter to the Board of Trustees to govern The Light Collective and direct the Officers to implement the directives of the Town Meeting, consistent with the Vision of the Future and the collective interests of the patients who (are/will be) using the resources provided by The Light Collective.
- **Authority of Board of Trustees** The scope of authority of the Board of Trustees is to include:
 - Adopting policies of TLC, including
 - Moderation guidelines and other policies applicable to all groups
 - Policies applicable to different “flavors” of groups (see Group Governance, below, and section on Moderators)
 - Approved menu of options of “add-on” policies that may be adopted by a group (see Group Governance, below, and section on Moderation)
 - Oversight of training programs, curriculum, and selection criteria for moderators
 - Admission of groups to TLC (The Board of Trustees may delegate its authority to officers of TLC or to the appropriate Advisory Committee (see below), e.g., the Moderator Advisory Committee, subject to specific guidelines set forth by the Board) (See section on Moderation.)
 - The Board of Trustees will also have all of the usual responsibilities of the board of any nonprofit, and may delegate responsibilities to committees (e.g., nominating, finance, executive committees)
 - The Board of Trustees will also have a committee that is the “Court of Last Resort for Bad Actors” (CLRBA). Each group should police its own membership (under group governance rules that are approved by The Light Collective), but if a participant feels they have been unfairly treated by the group, they can appeal to the CLRBA; the CLRBA adjudicates these disputes.

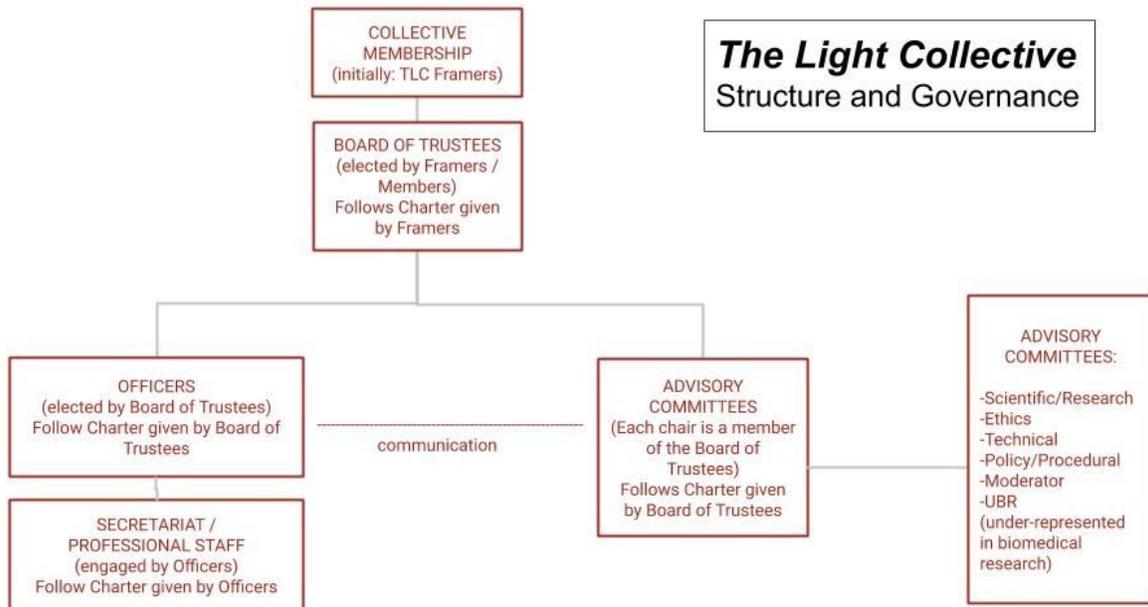
Advisory Committees The Board of Trustees will issue a charter to each of the Advisory Committees. The chair of each Advisory Committee will be a Trustee. Other members of Advisory Committees need not be Trustees. The Board will solicit nominations of outside experts as members of Advisory Committees. The initial Advisory Committees are:

- **Scientific/Research**

- Advise the Board on the integration of research activities within the platform.
- **Ethics**
 - Advise the Board on a range of issues including research, privacy, domains of other advisory committees, etc.
- **Technical**
 - Advise on platform architecture, regarding feature set, data security, etc.
- **Policy/Procedural**
 - Advise the Board on best practices to sustain the support groups, including the fundamental policies and procedures for TLC, for all groups, for different “flavors” of groups, for “add-on” options of groups.
- **Partnerships**
 - Advise the Board on the evaluation of fair partnerships that are transparent to the members of The Light Collective.
- **Responsible moderation of groups**
 - Made up of current active moderators to advise the Board on overarching issues relating to moderation.
- **UBR (underrepresented in biomedical research)**
 - Advise the Board on the needs of populations traditionally underrepresented in biomedical research to ensure that The Light Collective explicitly addresses their needs

Secretariat / Professional Staff

The officers and staff of the organization are empowered to act within the charter given to them by the board. Officers will engage professional staff as needed, and give staff a mandate or charter. Staff will be responsible for communicating with the organization’s officers, with the advisory committees and, as appropriate, with the Board of Trustees.



[Click for full-size organizational chart](#)

Group Governance

In close collaboration with the Moderator Advisory Committee, the Board will determine the initial range of options for group governance. When we say “group governance,” we mean the rules of the road articulated by The Light Collective and adopted by each group. Internal governance of specific groups may be modeled on The Light Collective’s organizational governance, may be less formal, or may be handled differently. The principles underlying each group’s internal governance structure will, however, need to be consistent with The Light Collective’s underlying principles of patient self-determination and self-governance.

We have used the metaphor of ice cream “flavors” to describe a matrix of groups defined by risk profile along one axis and other group characteristics along the other axis. For example, a group that involves sharing and discussion of personal genetic information would be considered a high-risk group (think of “Rocky Road” ice cream, with chocolate and nuts – deliciously appealing to some, triggering allergic reactions and anaphylaxis in others) and would have a real-name policy, while low-risk groups (think vanilla ice cream), where sharing of highly private information would not be permitted, may be joined without the use of a real name. Groups may self-identify as high-risk, low-risk, or somewhere in between. Depending on the risk profile, different policies will govern membership and participation in the group. The Light Collective’s Trustees will need to be flexible in developing the rules about how to manage privacy and risk in

light of real-world experience, but the basic idea is to have transparency, clear rules, and accountability for compliance.

Each group must elect a risk profile that comes with a set of pre-determined policies and procedures corresponding to the risk (baseline Light Collective best practices on patient peer support group moderation etc., plus additional policies and procedures based on risk profile), and may elect selections from a pre-defined “menu” of options (e.g., our policy on prayer chains is either rule A or rule B). Groups then will be given The Light Collective “seal of approval” and/or be invited to be hosted on The Light Collective platform.

The principle of core values and menu options means that the fundamental risk profiles and governance of peer support communities that become part of The Light Collective must fit within a taxonomy established by The Light Collective, both for ease of administration by The Light Collective and in order for the nature of each group or community to be easily communicated and understood by current and potential members and partners.

Selecting a risk profile for a group includes a determination of whether and how that group’s member’s clinical or genomic data may be shared with the group, and possibly with vetted researchers under agreements with TLC that are built on the TLC vision and core values. (See Fair Partnerships.)

Other topics for core rules (e.g., for each risk profile category or flavor: (a) what level of identity verification do members need to have? What level of access is granted based on level of identity verification? What is the weight of the participant consent for joining the group? (b) How curated is content?

[Use some form of the ice cream graphic here?]

The Board may modify the standards of a group risk profile (and the platform as a whole) on the advice of the relevant Advisory Committees and with a vote of the Board or other body, as may be required.

Partners and partnership arrangements may be approved by the Board on the advice of the relevant Advisory Committees (see Fair Partnerships) and each group may elect to participate in each such partnership, as may be applicable to the group.

Definition of Peer Support Community [This is redundant with above “What is Peer Support; one place or the other, but not both. Probably move the “definition” above to this section.]

A Peer Support Community is composed of both the infrastructure and the membership of a supportive community who share the lived experience of a health condition or illness or health risk. It can also address issues beyond health. Members of online support groups self-identify and self-select for mutual support, based on “disease, disease state or stage, status as a patient or as a caregiver, or status as a person with a genetic variant linked to disease or other health risk.”

For the purpose of this document we are focused on a definition of “Online Peer Support Communities” with inclusion criteria, norms, and shared identity that are agreed upon by that specific community or group. This definition is not limited to an online platform.

Online Peer Support Communities are not all alike; they have different identities, defined in part by their reasons for being and their approaches internal governance.

Criteria for Inclusion

Online Peer Support Communities of varied identities or types (and of various risk profiles, discussed above) may affiliate with The Light Collective. In each case, this will be evaluated by The Light Collective and will be determined by the community’s

1. Desire for membership in The Light Collective - as a community
2. Ability to commit to the work required to consistently make and carry out governance decisions.

The inclusion criteria of different community identities must be based on the capability of any community to commit to governance principles outlined in this document. The Light Collective will evaluate communities to bring into the governance based on those communities’ ability to adopt, ratify, and consistently practice the standards that are adopted by the The Light Collective.