



## Call For Advisory Board Members: Application Deadline: March 20th

Connection on social media platforms is an important way that patients exchange critically-needed information and support. But patients on these platforms are vulnerable to data leaks, exploitation, misinformation, privacy breaches, and harassment.<sup>1</sup> In addition, many patients increasingly manage elements of their health or healthcare using a variety of commercial health apps, which have many of the same problems as social media platforms. The purpose of this project is to test whether we can negotiate a new kind of partnership with data holders in which the rights, interests, and voices of patient communities play a central role. As part of the 2021-22 TLC Digital Governance Project we are establishing a **Community Advisory Board (CAB)**. The CAB will help shape and actualize the project plan, will advise and guide the project team as they carry out project activities and produce deliverables, and will be educators and advisors.

### Time/Activity Commitment:

- Participate in a bi-weekly (every two weeks) (on average) 1.5 hour Zoom call to generate and share ideas and contribute to decision-making. 3 hrs/month
- Provide feedback on prototypes, drafts, ideas, resources 2-3 hrs/month
- Do or manage outreach to respective communities, including other advocates, to educate and engage on digital rights, privacy, and data governance 3 hrs/month
- Engage in occasional discussion/decision-making via Signal or email 2 hrs/month
- Participate in an in person or virtual full day workshop, or the equivalent in half day workshops, depending on Covid situation 8 - 10 hours/year

We anticipate an average monthly time commitment of 10 hours and expect the project to continue for 7- 8 months. We aim to hold the kick-off meeting in late March/early April of 2022. **Advisory Board Members will receive a stipend of \$600/month**, paid bi-monthly, plus additional stipends for any half or full-day in person or virtual meetings, if such occur.

### Who You Are

A staff member, leader, or founder of an established grassroots breast cancer organization or community.

### Position Activities

- Represent your community (with support from your organization or community) in an official capacity as part of a collective.
- Help develop standards for governance and partnerships.
- Participate in active negotiations with new health technologies to develop standards for fair partnership with patient communities.
- Serve as liaison between The Light Collective and your nonprofit/community to adopt new standards and best privacy practices online.
- Educate and do outreach with your community about digital rights and data governance with materials you co-design.
- Prepare for & participate in CAB meetings, including reviewing agendas, materials, and minutes.

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<sup>1</sup> Why Facebook is filled with pharmaceutical ads. Washington Post, Nitasha Tiku, March 3 2020