Introduction

People with health challenges increasingly seek information and support from their peers on social media, as well as from a range of health apps, websites, and online technologies.

The growth and widespread utilization of online technologies by patients both illuminates and fills critical gaps in the formal healthcare system, but there are important ways in which engagement online puts people at risk of privacy violations, exploitation, misinformation, and other serious harms. Patients lack basic digital rights.

OUR MISSION STATEMENT

Our mission is to advance the collective rights, interests, and voices of patient communities in health technology.

OUR VISION:

Our vision is a world in which patients and patient communities using health technologies, especially those who have been historically excluded and exploited, have access to the information and support they need, are safe from exploitation and harm, and have the right to decide how their health information is used.

We seek a future in which patients can engage safely online while navigating their health journeys, and where the role of patients in governing their data, developing research questions, and identifying important outcomes is recognized and supported on equal footing with technology companies and research and clinical partners.

AREAS OF FOCUS

Community Engagement

The Light Collective is dedicated to community-driven approaches to building digital rights. We organize coalitions of patient advocacy organizations which convene bi-weekly to share ideas, develop strategies, and take action for tackling shared problems around digital rights.

Education & Awareness

We provide trainings, webinars, convenings, and resources to grassroots organizations and individuals on:
- Online safety and digital rights;
- Fair partnerships with tech, research, and clinical partners; and,
- Best practices around peer support.

Advocacy & Policy

Policy plays a key role in securing patient digital rights. The Light Collective works with diverse actors to build policies that positively impact patient communities globally.
Programs & Impact

An innovative approach to patient digital rights is necessary for transformational change in health tech.

Security Research: Peer-Reviewed Publications
After Cambridge Analytica, our research and advocacy led to a Congressional Inquiry on the privacy of health-focused Facebook groups. In 2022, our peer-reviewed study and follow-up investigations from STAT led to breach notifications affecting 6.1 million patients. By December of 2022, this research also led to an unprecedented ban of online tracking technologies by HHS for HIPAA-covered entities. TLC continues to engage in research to shed light on the ways in which patient privacy is put at risk by health technologies and identify ways to mitigate these risks.

Collective Digital Rights: Strategy Playbook
TLC has created a guide to help patient advocacy organizations negotiate fair partnerships with health technology companies and continues to build resources for patient communities to interact meaningfully and ethically with technology, research, and clinical partners.

“Don’t Get Hacked” Training: Education & Advocacy
We partnered with Social Proof Security to develop training that is accessible, and bespoke for low resourced organizations in healthcare. The training is available to members of The Light Collective.

Peer Support Research: Publication
The Light Collective has studied how and why people with cancer/at high risk of cancer use online peer support. In 2023, TLC published an article in the Journal of Patient-Centered Research and is currently working on new research in this area.

Patient AI Rights Initiative: April 2024
AI is changing the world and patients have a right to know how.

In response to national initiatives forming artificial intelligence (AI) standards, codes of conduct, and bills of rights in healthcare settings, largely in the absence of input from patient communities, AI Rights for Patients will be launched by The Light Collective in April 2024.

The initiative is designed to help stakeholders in the US healthcare ecosystem, including health systems, payers, and technology developers define standards and rules in health AI that respect and advance the rights, interests, and voices the ultimate stakeholder: patients.
Health Sites Let Ads Track Visitors Without Telling Them
by Lily Hay Newman

Privacy policies didn't tell the whole story about third-party tools gathering personal information from the sites of medical and genetic-testing companies. This story broke our research in February 2022.

To become an Amazon Clinic patient, first you sign away some privacy
by Geoffrey Fowler

You agreed to what? The 'HIPAA authorization' for Amazon's new low-cost clinic offers the tech giant more control over your health data. The Light Collective served as a source and advised during the journalist's investigation.

A cyberattack on one hospital can disrupt an entire network of medical providers
by Jenna McLaughlin

You agreed to what? The 'HIPAA authorization' for Amazon's new low-cost clinic offers the tech giant more control over your health data. The Light Collective served as a source and advised during the journalist's investigation.

Patients Advance Meta Lawsuit Over Collecting Health Information

Privacy policies didn't tell the whole story about third-party tools gathering personal information from the sites of medical and genetic-testing companies. This story broke our research in February 2022.