



Collective Digital Rights For Patients

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digitalpublic

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Help people articulate the problems



Organize community around goals



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How to Use the Guide

We at The Light Collective and Digital Public have created this guide to help patient advocacy organizations negotiate digital civil rights issues with health technology companies.

Digital civil rights are the legal rights and protections that people hold based on their interactions with software and hardware, as well as with the healthcare providers that use and access the information (data) that the software and hardware hold. It's the software, hardware, and data that make digital rights distinct from general rights, but digital rights are an extension of rights, not an entirely new set of rights.

This guide is designed to help you clarify your position, needs, and stance on protecting the digital rights of those you serve. It is focused narrowly on negotiation with health technology companies on issues of digital civil rights. This guide is intentionally designed as a complement to our guide to Building Digital Civil Rights¹ with patients, but each document also has a unique, standalone focus.

We hope to see this resource grow and change over time as it gets used, so please adjust it for your purposes. Shorter versions of this guide are available as stand-alone sections².



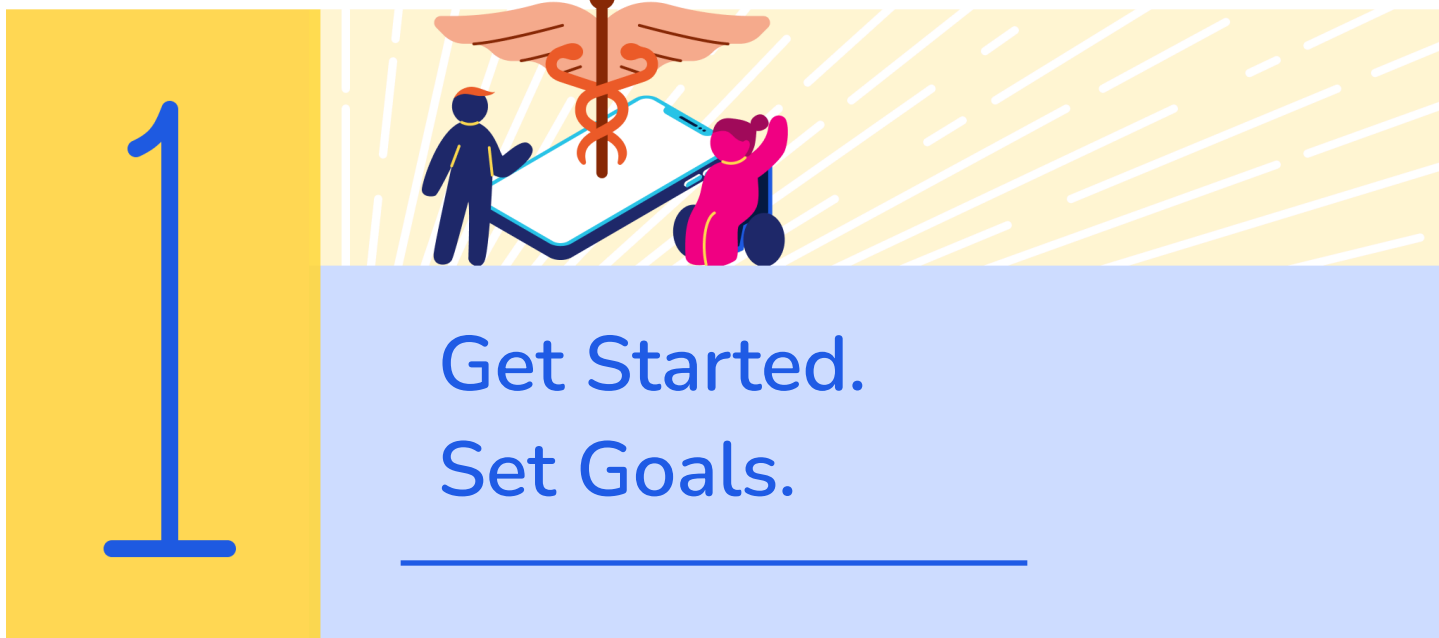
Thank you for taking a part in fighting for digital rights! **Email us at contact@lightcollective.org** for any feedback to help us make this guide better.

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1. The Building Digital Civil Rights guide explores a broad set of issues related to defining digital civil rights, understanding the relationships that make them work, and looking at a range of organizational advocacy approaches to safeguard them.

2. The stand-alone documents: an introduction to the issue of digital platforms in healthcare and setting negotiation goals (section 1), formalizing value and relationships (section 2), and developing a stance and negotiating strategy (section 3).



Why should organizations consider an approach of negotiation with platforms and service providers? Technology companies are playing an increasingly large role in many aspects of medical research and practice. Whether we're talking about finding medical service providers, creating or accessing health records, conducting medical research, or providing critically important patient peer-support, technology companies are one of the actors that determines the tools, terms and conditions, and rights that patients have.

When we hear about digital transformation, it's generally positioned as a positive trend. Digital transformation offers ways for patients to be more involved and/or in control of their medical information. It is also said to have improved our access to medical providers. Unfortunately, there are downsides too. The digital transformation of health care can also minimize and marginalize our patient voices and make systems more inaccessible.

Worse, many of the business models, data sharing practices, and technology infrastructures in health are actively harmful for patients. The more that health providers use technology, the more they invite the risks and exploitation dangers of the digital economy into our lives, often without providing the transparency, accountability, or governance that we as patients need to mitigate those risks.

New Tech Needs New Rules

The digital transformation of healthcare creates a paradox. We as patients undeniably need the things that well-governed digital platforms provide, and platforms need engaged users and feedback to work and grow. Sometimes patient portals can function more like a moat or a wall that medical professionals can choose to hide behind rather as a means for meaningful interaction.

So even though it is in the best interest of both patients and technology companies to have fair and equitable relationships, there are very few, if any, examples of health technologies governed by, or with,

patients. That has to change. While negotiating with digital service providers and platforms isn't the only way to create change, it is an under-used way to grow the power of patients and users in the governance of the systems that support their healthcare.

We imagine your organization using this guide to take a first step in "setting the table" for governance negotiations with health technology companies and service providers. This work falls to patient advocacy organizations because it is not proactively happening at most technology companies and service providers. In many cases, patients become digital rights advocates because they've experienced harms or injustice due to the impacts of digital transformation on their own care. We have often had to face the difficult, often defeating, process of trying to seek redress or having to fix the underlying problem.

It's still early days in the advocacy work around digital civil rights, to be sure. Patients and advocates focused on digital civil rights are often scattered or informally organized, which makes it difficult for even well-meaning platforms to understand who to engage with on this topic, or how. Both parties to this kind of negotiation (patient advocacy organizations and tech companies or service providers) experience difficult, practical barriers to creating the types of engagement necessary to negotiate for more effective, equitable digital civil rights. But those barriers aren't fixed. There are a lot of steps that patients and advocates can take to facilitate, organize, agitate, and negotiate for better governance and outcomes.

To quote author and activist Alice Walker: "the most common way that people lose power is by assuming they don't have any." Patient communities, especially in these relatively early days of digital transformation, have a significant amount of power over digital health providers. One step toward patient communities realizing that power may be to organize and negotiate with platform and service providers, building on the common values and interests that unite us. This is work for us to do toward the end goal of developing the technical, legal, and governance systems that fulfill the promises of digital health.

Define Your Goals

Healthcare's large and growing reliance on data and digital tools creates a number of opportunities and threats for patients. There are more, and more types of, health organizations trying to navigate the collection, use, and management of data. There is also an increasing number of groups considering how to govern that data.

A range of health institutions and companies are asking themselves how to involve patients in the governance of their health data. Those questions create the opportunity for patients and patient advocates to inform the design of the solutions they want. That said, proposing data governance models to digital companies isn't what patient and patient advocacy communities are organized - or designed - to do.

There is a significant amount of labor required to translate the harms caused by digital transformation in healthcare into proactive proposed solutions, ready for action by the platforms and service providers responsible.

Step 1: Set Realistic & Measurable Goals

Step 2: Identify & Define Your Priority Issues

Step 3: Know the Power Players

Step 1: Set Realistic & Measurable Goals

Before getting too far into the discussion, it's worth making a clear distinction about goals and outcomes. Patients and advocates should set their negotiation goals with at least two 'types' of outcomes in-mind: substantive goals; and structural goals.



Substantive goals are specific, outcome-focused actions. For example: a company must maintain security certifications or publish independent audits by civil society organizations.

Structural goals are process-focused outcomes. These goals are aimed at building the patient communities' power in the ongoing governance of the service or platform. For example, a company must allocate a patient-dedicated seat on the board of directors of a health technology company or make commitments to data licenses that require companies to get patient consent for new uses.

The point of this distinction is to recognize two truths about the current state of digital health. First, there are numerous urgent problems in need of fixing. Second, in order to resolve them, patients and advocates need more agency to shape their design and evolution.

It is vital - but not enough - to establish rights. Patients and advocates should also consider how they're contributing to their community's ability to help themselves use those rights both today and well into the future.

Step 2: Identify & Define Your Priority Issues

One of the biggest challenges in negotiating for digital rights is translating the problem a patient is experiencing into a specific governance issue. It can be difficult to identify the specific ways that digital platforms exploit users. And after this step, we must still figure out who is responsible for the harm.

The design of digital technology supply chains exacerbates these challenges. There are often different companies responsible for hardware, the design of software, and the various pipelines of data that shape a platform's outputs. This sometimes makes it difficult to track responsibility for digital decisions to the parties involved. But in order to be able to take action to fix a problem, we as patient advocacy organizations must invest in understanding the specifics of every issue, to be precise about the problem we're trying to solve, who we need to involve to do so, and how.

For example, The Light Collective came together after its founders realized the dangers posed to their hereditary patient peer-support community that was connecting over Facebook. We learned that when we shared information in private and/or closed Facebook groups, that information then became accessible to Facebook and others without our knowledge. While that problem is clear and understandable - this is sensitive data that was not intended for access or use by others - it raises a significantly more complicated question: how were we supposed to solve the problem?

There is definitely more than one way to address this type of problem. But each choice shapes the operations, positions, and incentives of our patient groups. We could, for example, try to convince Facebook to make their technology infrastructure or business model safer for patients. Or we could seek to compel a government to convince Facebook to do this. While there's hopeful progress that the US Government is moving in that direction, Facebook has proven resistant to making changes that protect patient groups.

Alternatively, we could work with technology platforms with aligned incentives to create a different kind of supportive technology infrastructure for our patient peer support communities. This approach also offers promise, but there are a number of patient support activities and communities that:

- are not in a position to change their community's behavior by, for example, convincing them to migrate away from Facebook to a new platform;
- may lack the expertise or capacity to make the financial case for their needs, lead the process of creating technical infrastructure, or define less exploitative business models for digital platforms; and/or,
- are places of solidarity whose integrity can be threatened by the introduction of business models that might be required in an alternative infrastructure/platform;

As a patient community hoping to move away from Facebook, we could also try to build technology infrastructure ourselves, directly ensuring that we have the power to set technical standards, revenue incentives, and data governance practices. Patient community ownership of health technologies is an important area for advocacy, investment, and growth, but it requires those who mostly want to end endemic exploitation and abuse to take on a life-altering set of activities and liabilities as an entrepreneur or organizational leader, and it requires significant resources.

There are many more potential approaches to solving problems for insecure peer support communities on Facebook. The point is that even when we as patients and advocates have a very clear view of a problem, it can be difficult to translate that into specific, achievable solutions. While far from comprehensive, the following list of questions may be helpful for others that are beginning the process of translating problems faced by patient communities into pathways to solutions.



Translating Digital Harms into Pathways for Potential Solutions Exercise

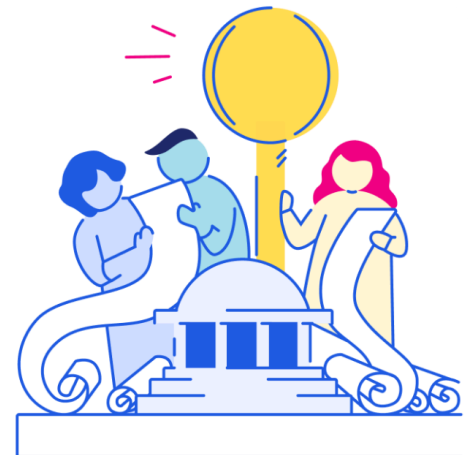
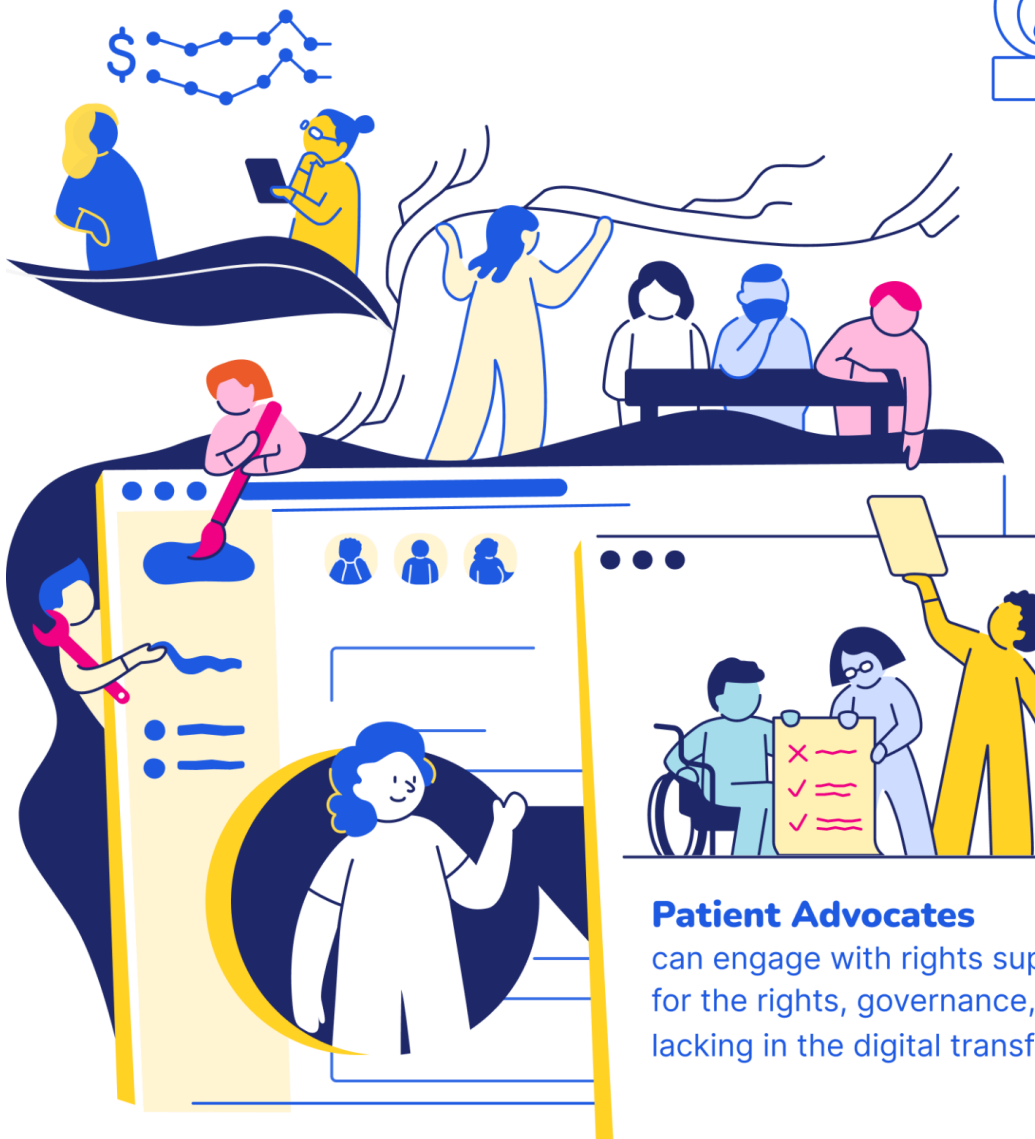
1. Are you trying to solve for a specific requirement (for example, stopping a company from selling patient data) or a more general problem (for example, ensuring that patients can seek peer support in ways that are safe and fair)?
2. How would you articulate what aspect or behavior needs to change? Who needs to do what differently in order for your problem to be solved?
3. Are you trying to change or end an existing practice? Is that practice a technology design, a business model, a data sharing practice, or... something else?
4. Is there a model solution that already exists? For example, is there a platform or company performing the same role (even in another industry) in a way that demonstrates success?
5. Alternatively, are you trying to build something new? How much of what you want to be different already exists in one form or another? What separates or prevents existing models from meeting your needs?

Step 3: Know the Power Players

There is no such thing as a self-executing right. Our rights only exist if we use them, and all rights rely on being activated. Every norm, standard, and protection that patients have comes from an organization or institution with the power to set and enforce rules in the provision of healthcare. We refer to those organizations and institutions as “rights suppliers.”

Rights Suppliers

are the organizations that control the design of health services and/or the digital technologies that shape them. Almost every strategy for advancing patients’ agency and protections in digital spaces involves some form of engagement with rights suppliers, either as partners, adversaries, or both.



Rights Enforcers

are usually governments or government agencies. They may also be other structures with influence over a digital health service, such as: insurers, high-value markets and customers, and certifying bodies.

Patient Advocates

can engage with rights suppliers toward negotiating for the rights, governance, and enforcement currently lacking in the digital transformation of health.

There are a number of patient advocacy organizations involved in the digital transformation of health. But one of the primary challenges that we face, at present, is a lack of adequate formal authority to ensure, protect, or enforce our basic rights. As a result, patient advocacy movements - especially those focusing on digital transformation - often have to rely on our ability to influence those with more direct authority to implement the changes we'd like to see happen. Many patient advocacy organizations are already very good at this, but health tech as a specific areas of concern often isn't a priority, or even on an organization's radar yet. In many cases, the first step is for us to engage directly with "rights suppliers," like the health service providers and technology platform companies described in this guide.

But when good-faith engagement isn't enough to motivate appropriate change, digital rights advocates often need to turn to another group of institutions, which we're calling "rights enforcers."

A number of digital rights advocates focus their efforts on regulatory interventions, strategic litigation, or otherwise appealing to governmental action. They seek to use law enforcement to act on claims protected by existing rights. As patient communities explore ways to change their rights in digital healthcare systems, it's often most useful to start by understanding whose behavior needs to change, what incentives might motivate that change, and what institutions, markets, or authorities may be able to compel the desired changes, should those responsible not make the changes once informed.



Power Mapping Once patients and patient advocates have a clear articulation of the problem they're trying to solve, it's helpful to undertake an exercise known as "power mapping." Power mapping is the process of identifying the people, companies, governments, and other participants in a system that have the leverage to block, resist, create, or help create, the changes to digital systems that patient communities want.

Regardless of the type of changes that a patient community wants to make, it's useful for groups to consider at least two types of power: soft power and hard power. At a high-level, mapping soft power typically focuses on studying incentives and finding areas of mutual benefit, and developing approaches to influence health service providers and digital platforms through good-faith engagement.

By contrast, mapping hard power typically focuses on developing approaches to compel public health service providers and digital platforms to make the desired changes, even if they are resistant. Hard power approaches often involve working with governing institutions like regulators, developing control over key dependencies like access to business-critical data, and ensuring that patients have a clear, accessible means of enforcing their rights in court.

Soft and hard power approaches aren't mutually exclusive - quite the opposite. It's often most effective for advocates to have plans that enable them to offer both positive and negative incentives and outcomes to prospective negotiating partners.

One of the reasons for patients and advocates to consider both forms of power is that developing hard power is also a way to ensure that platforms implement and sustain the changes made. For example, a health services marketplace might agree to limit the way they share data with insurers as part of a negotiation with patient groups. But unless those patient groups also have some way to enforce that promise, the platform can change its mind without significant consequences whenever it wants.

Digitizing healthcare adds problematic complexity to patient relationships through ambiguity. Health service providers and technology companies typically use legal agreements that absolve each other of liability, without agreeing on their roles and responsibilities. They explicitly avoid naming who is accountable when they cause harm. That ambiguity is often weaponized against patients and advocates, who have no idea where to turn once they're harmed, nevermind know how they can motivate, participate, or compel good practice before anyone is harmed.

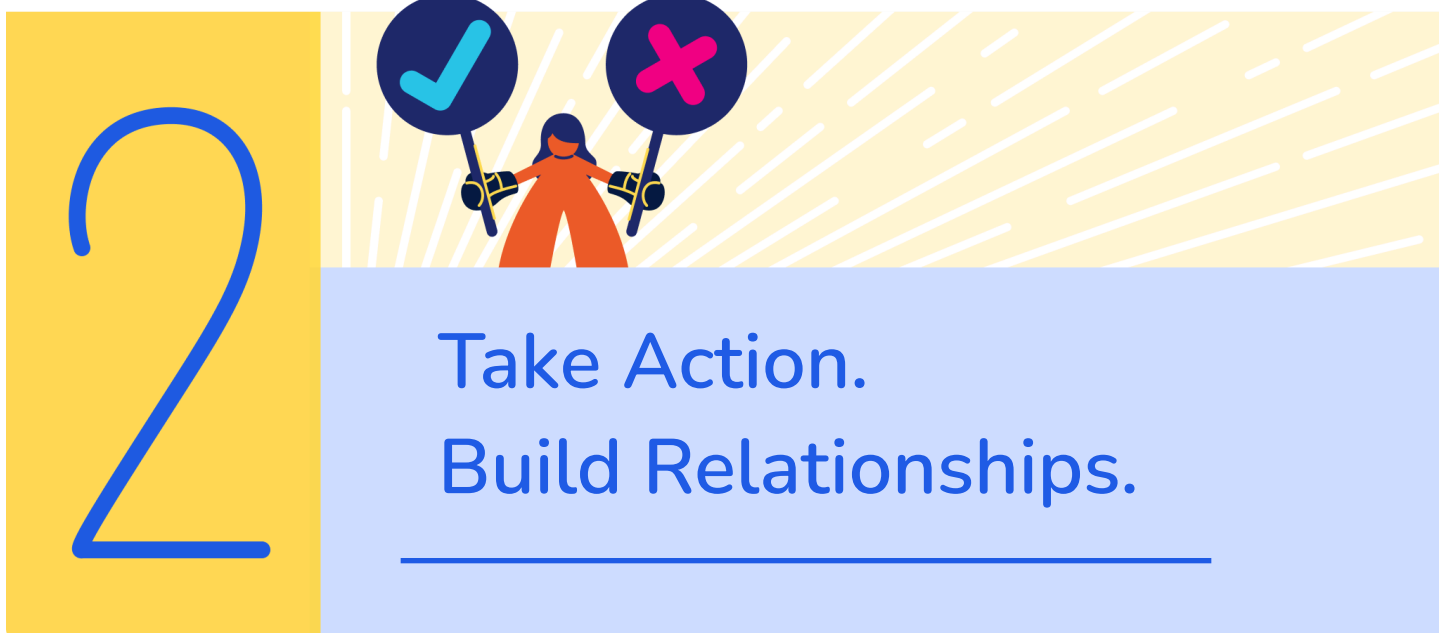
As patient advocates, we should always consider both hard and soft power approaches concurrently. This means being open to and welcoming the good-faith action of aligned interests, while also negotiating for the structural power required to ensure that agreements made are kept.

There are a range of ways to identify rights suppliers and map their dependencies. The easiest way is to start with a few key considerations. The following exercise is intended to inspire your own questions (as opposed to being comprehensive), while introducing a few common approaches to power mapping.



Power Mapping Exercise

1. Who owns the service or system responsible for the issue or change in question? If that's not obvious, what organizations have the information necessary to understand the underlying problem?
2. How is the service or technology company funded? Who are their most important shareholders, customers, and/or sources of data? What does the service rely on in order to work and/or succeed?
3. Where is the organization located? What government, public, and/or publicly accessible authorities have the ability to influence the way the company behaves? Are there regulators, customer protection authorities, and/or courts that patients could work with to enforce existing protections?
4. Are there private organizations who might be able to shape the incentives of digital healthcare providers and platforms (i.e. insurers, journalists, professional standards associations, unions, campaigners)?
5. What standards of practice exist for the service or platform in question? How are those standards enforced? By whom? What kind of power or leverage do they use to enforce those standards?
6. Where is the digital rights "supplier" in their life-cycle? Are they, for example, early stage and therefore, in-need of a competitive advantage against exploitative incumbents? Or are they more well-established and looking for ways to manage liability? How are they funded? What are their pressures and incentives?



In ideal scenarios, digital healthcare service providers and technology companies are proactive in seeking out, understanding, and being adaptive to the interests and concerns of our patient communities. For aligned health organizations, building trust with patient communities is a foundational motivation and part of their culture, even if it's only because they're necessary to enable financial growth.

But for many more organizations that have an impact on the provision of healthcare, the problem isn't just that they don't have the information they need to uphold patient rights and support our needs. It's that their incentives don't require them to change their practice. In this situation, patients and advocates may struggle to get responses, solutions, or meaningful redress for harms experienced. These unfortunately common circumstances are one of the main reasons for patients and advocates to establish forms of engagement and collective action, toward developing "hard power" leverage over health service providers and technology companies.

The following section is aimed at helping patient advocacy organizations explore three key dimensions of establishing hard power (for example, increasing their ability to secure and enforce their rights) in digital health ecosystems:

A. Collective Action for Digital Rights

B. Understanding Rights-Suppliers Operations & Incentives; and

C. Formalizing Patient Interests & Organizing

A. Collective Action for Digital Rights

While most digital healthcare providers rely on patient participation, their priorities and dependencies are very different based on what they're trying to accomplish. For example, online marketplaces for health services often rely on patients to help evaluate, compare, and flag the service providers they use or advertise, but with different intentions than health research platforms, who rely on patient participation to drive discoveries and outputs.

Both of these digital health service providers rely on patient participation, and therefore have a vested interest in engaging us as patient communities and advocates, but they want different things. The marketplace, for example, needs patients to participate as users and to directly contribute ratings data based on their experiences, but not in defining ratings categories or sharing referral revenues.

By contrast, research support platforms want patients to participate in studies, and proactively consent to sharing whatever data is expected to inform the study, but don't necessarily confer any recognition or special access to treatments subsequently developed. And while both types of organization may be responsive to 'soft' power, patients and advocates can create 'hard' power by developing collective actions built on those needs.

Here are a few examples of collective action activities that may influence digital rights suppliers, or give a patient advocacy group the foundation for representing their community in negotiations. This list is not comprehensive and is intended as a starting point for patient groups exploring the types of collective action they might prioritize to advance their digital rights.

Collective Action Options



1. **Guide community use of specific technologies** Many platforms rely on patients as users and customers, so when patient communities can organize to adopt or leave platforms as a group, it creates a strong incentive for service and technology providers to negotiate.



2. **Mobilize users into service boycotts and/or orchestrated strikes** Essentially this is the opposite of the option listed above. The digital health marketplace is precarious enough that patients and advocates can have outsized impacts by publicizing the problematic aspects of digital services. Even more so when they organize specific collective action responses like service boycotts and user strikes. See Meta Case study on p16.



3. **Investigate platforms for compliance and fairness** One of the challenges of the digital healthcare space is that it's under-investigated, especially in ways that prioritize the perspectives of patients. Patients and advocate groups that investigate and evaluate health platforms can have big impacts, using soft power to shape markets and sharing investigation results that demonstrate rights violations with rights enforcers, toward exerting hard power when possible.



4. Become a patient-focused digital service provider or data broker

The digital transformation of healthcare isn't all bad. But patient communities understandably need groups they can trust to be engaged stewards and protectors in digital spaces. For some patient communities, the best way to bridge the trust gap is to become a trustworthy service provider or data broker themselves, centering the representation of their community's interests in the design and governance of their work.



5. Develop patient engagement as a service A number of digital healthcare organizations want to engage with patients and prospective users, but have no practical capacity to identify or engage with them beyond requesting volunteerism. This is an opportunity for patients and advocates to organize and facilitate ways for their communities to influence the design and development of digital health services.



6. Provide patient expertise to digital health services There are a number of digital health services that need patient feedback across their enterprises. This can include feedback on the design of their products and plans for new features, and is especially needed if they're building more systems for patient participation. These services are an indirect way to represent patient communities, but, when focused on popular platforms, can have a large impact.



7. Get legal While there's a lot of excitement about technology, health services are often defined by a combination of contracts, regulators, and public protections. These are all important places for patients and advocates to intervene. That might be directly with rights suppliers, helping platforms improve their data licenses and terms of service. Or it might be indirectly with rights enforcers, informing regulator actions or organizing patient communities around class action lawsuits.



8. Get creative We are still in the early days of designing the systems to realize fair, equitable, digital health services. There are a number of legal structures, professional standards organizations, collective actions, technology processes, and ways to argue for more participation in health systems. Whether a health service is funded by tax revenue or venture capital, building patient rights is not just the right thing to do - it's the only way to grow. Let's think about novel ways to do it.

Meta Case Study: Exercising Your Data Rights



The Challenge

After seeing repeated harms and privacy breaches with patient groups on Facebook, patients begin to build evidence by downloading their own data. Rather than simply deleting their accounts, a group of advocates studied how the platform was violating their own policies on health data.



The Approach

Facebook's Platform did give patients one right: the right to download their own individual data. Patients exercised this right to gather evidence of which companies and health organizations were tracking them. Patients organized by collectively downloaded their raw JSON data from the platform to study how different Health Companies were tracking communities and advocates.



The Outcome

This patient-led research became a peer-reviewed study in Cell Patterns¹. Their findings showed that 3 out of 5 companies they studied were not following their own privacy promises to patients.

One news outlet, The Markup, expanded the research to find that 30 out of the top 100 hospital systems were illegally sharing data with a marketing tracker called Meta Pixel.

To date, hospitals are continuing to shut down their 3rd party trackers as a result of this work².

1. Downing A, Perakslis E. Health advertising on Facebook: Privacy and policy considerations. Patterns (N Y). 2022 Aug 15; 3(9):100561. doi: 10.1016/j.patter.2022.100561. PMID: 36124307; PMCID: PMC9481952.

https://www.researchgate.net/publication/362720010_Health_advertising_on_Facebook_Privacy_and_policy_considerations.

2. For more case study readings, go to <https://lightcollective.org/trust/>.

B. Understanding Rights-Suppliers Operations & Incentives

In the same way that digital health services and technology companies may have different interests based on what they're trying to accomplish, the teams within those companies also have different priorities and may understand the value and process of patient advocacy work differently.

Once your patient advocacy community has determined your core activities and theory of change, you may benefit from targeting your engagement and negotiation efforts at the most-aligned parts (or interests) of a digital health organization.

Interests Across The Company

Sales

Patients are often drivers of digital health services, if not the customers themselves. Initiatives that impact the behavior of customers are likely to be the most urgent for sales teams.

Marketing

This is similar to sales, but less direct. Actions aimed at impacting the public perception or 'brand' of a digital healthcare service or company are often responded to by marketing departments or, when particularly bad, crisis communications teams.

Research & Development

Patient advocacy communities that use data as leverage often focus on the parts of organizations focused most on research & development. These teams are charged with understanding and making use of new inputs to drive value for the company or service. Their interest in data is often optimistic, and so value-based arguments are often the most effective.

Product

Once a technology or service exists, product teams are responsible for ensuring the ongoing improvement of a product. These teams are often the most responsive to patient community participation and data-driven approaches aimed at adapting and improving existing services at a technological level.

Content Moderation/ Trust and Safety

Depending on the type of service or platform, there is likely a team whose job it is to ensure the safety of the people using the service and the integrity of the information presented through it. These services are often the first point of contact for patients and advocates organizing around sources of harm. They can often offer quick-fix solutions, but are rarely responsive in ways that result in structural improvements.

Legal

The legal team is the one charged with managing risk, especially risk created by business operations. As such, patient advocacy organizations that are interested in using potential liability, whether to improve the legal agreements a digital health services currently uses, like data licenses, or to raise the threat of working with rights enforcing institutions, are likely to first encounter legal teams.

Leadership

At a fundamental level, the ways that digital healthcare services enable and give power to patient communities are issues of values, mission, and corporate governance. The effect of these decisions are expressed in technology design, data and business models, and contractual agreements. But holistic solutions typically involve senior leadership approval, if not internal advocacy.

C. Formalizing Patient Interests & Organizing

Patients and advocates play a critical role in the way that health systems function, despite the fact that this role is largely under-regarded and informal. That informality is a key part of the sense of community and trust that a lot of patient groups share. A doctor recommendation from a patient, for example, is often more trustworthy than advertisements or paid referral services.

That same informality, however, can also make it difficult to organize collective action, even when that action is necessary to protect patients' rights. When patient groups do manage to identify a problem and arrange a negotiation with a responsible platform, the question remains: What authority do patients and advocates have to represent the interests of others? Why should a platform negotiate with one group of patients or advocates, as opposed to another?

Patient advocacy groups that want to negotiate with service providers benefit from designing their activities to establish at least soft power, ideally toward eventually building as much hard power as possible. Said differently: Patient advocates negotiating for digital rights between platform providers and patients will have to answer the same question for both groups: "Why are we the right group to broker this relationship." And the answer, to both, hinges on what the patient advocacy organization does on a day-to-day basis, and how they've earned the trust of the communities they seek to represent.

The below questions are a starting point to frame and formalize the relationships between advocates, patient communities, and digital health services.



Formalizing Relationships Exercise

1. What type of power or leverage do you or your community need in order to participate in setting and/or enforcing the change you want to see happen? Education and engagement? Money? Data? Collective action? Lobbying? Public perception and marketing? Board representation?
2. How might you organize your community to create and/or exert that power?
3. Are you relying on a rights supplier, like a service provider or a technology company, for change? Or are you relying on a rights enforcer, like a court or a regulator? What type of relationships do you need to have in place to be an effective advocate for your community in each forum? What kind of capacity? Does it require funding? If so, how is that capacity funded?
4. What does accountability and/or governance of your initiative look like? How does it ensure that you remain focused on the needs of your community?



Once your organization or community has developed a problem statement, and an awareness of how various types of power are working in the context that interests you, an important next step is to translate your needs into a negotiating strategy. This strategy must include specific, concrete requests of the digital service provider or platform.

For patient advocacy organizations, negotiating strategies vary widely by context. For example, the incentives and requests or demands of a patient advocacy organization that publishes comparative analyses of the digital ethics of health platforms are very likely to be different from the requests or demands of a patient advocacy organization that's acting as a patient-centric data broker to aligned digital platforms. This section highlights three critical framing steps you can take:

A. Collective Action for Digital Rights

B. Understanding Rights-Suppliers Operations & Incentives; and

C. Formalizing Patient Interests & Organizing

Step 1: Frame the Digital Patient Relationship

One of the challenges posed by the digitization of healthcare services is it tends to combine and flatten multiple types of relationships. Consider the digital supply chain in this example: If a patient uses a technology product, such as a mobile phone, to access a doctor's office via their website in order to schedule an appointment, via an installed third-party application, which also installs a cookie that tracks

their behavior and sends it to third-party data brokers, who sell it to the highest bidder (which is happening right now) - who, exactly, is to blame?

The patient in this example is contributing value to each of the named products and services in ways that are often invisible to the patient themselves. The single, relatively benign, act of digital patient participation takes the doctor-patient relationship and stretches it across at least four other companies who may, or may not, even be aware that the doctor is using their tools, let alone whether their revenue model is appropriate for medical practice.

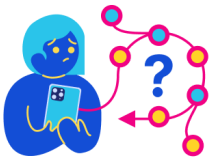
And it goes both ways. Doctors are rarely directly responsible for making the digital design decisions necessary to protect the integrity of their professional relationships. Even if they were, technology companies are often intentionally vague about the ways they use data to generate revenue. The point here isn't to focus too much on one use case, the digital transformation of healthcare means that the same issue is happening in a lot of different places. When approaching service providers or platforms, framing the negotiation in ways that are an appropriate reflection of the underlying relationships is critical.

8 Ways to Frame Communities

Below is a subset of different relationship frames that have an impact on the rights, responsibilities, and expectations of patients and digital service providers.



1. **Customer** Whether of the doctor or the technology service itself, there are a number of healthcare technologies that frame patients as vendor-customers, which may or may not include provisions for the specific ways that health services are regulated.



2. **User** There are a number of healthcare technologies, like appointment systems, that are primarily used by patients and advocates, but are paid for by others, like a medical practice. In these cases, the rights afforded to patients may be even lower, only protecting against the most basic forms of malicious harm. This is significantly less than normal for most medical service relationships. In addition, the complexity of digital service supply chains can also make it hard to understand the platform's use of data and its impacts on patients.



3. **Laborer** There is a large number of digital technologies that use data collected through patient participation to design critical and highly profitable systems. One example is the training of algorithms and 'artificial intelligence' using patient data, collected when patients moderate content on medical information services and marketplaces. Another example is leveraging community volunteerism to perform revenue-generating services. In each of these cases, patients are performing value-creating labor for digital platforms without any remuneration or consideration.



4. **Investor** Patient data represents not only a reflection of past participation, but its ongoing use means that patients have an ongoing interest in the things that are built based on their data. Technology companies use patient data to create products and services in the same way they use investor capital. There are arguments to make that patients deserve similar rights and ownership interests.



5. **Subject Matter Expert** The lived experience of being a person with health challenges and, often, user of a health technology is a source of expertise. That expertise is valuable to a range of aspects of digital health service provision. Patients and advocates can be paid experts and consultants for digital healthcare service providers, which creates a trade-off. On the one hand, consulting may give an expert advocate disproportionate influence over design choices. But doing so may reduce their ability to demand that a rights supplier make the recommended changes to their system. In other words, once a patient advocate takes on the consulting work, they can improve the system in question, but lose the ability to act as 'independent' oversight in their advocacy work.



6. **Product** Digital healthcare is one of the biggest sources and customers of surveillance capitalism. Patient attention and potential engagement are the products that technology companies sell to advertisers. While not a strong stance for creating rights, the product frame is often used to explain why patients feel as though they should be monetarily compensated for participating in the platform economy.



7. **Participant or Subject** The field of medicine invented most of the ethical, legal and procedural protections that governments require in order to perform research on human subjects. Those protections are a way that patients can influence the terms of their participation. The digital transformation of healthcare has created a large gray area, where patients and their data continue to be the subjects of life-altering research, but without the protections typically required of medical experimentation.



8. **Patient** The doctor-patient relationship is unique and heavily regulated, for a range of good reasons. One of the most important reasons is that doctors have a direct and legally recognized series of responsibilities to their patients, called fiduciary duties. These duties require them to act in their patients' interests at all times. Unfortunately, there is little guidance or interpretation of the fiduciary duties of digital medical services providers. That said, those duties exist, and offer patients and advocates a number of legally actionable claims.

Step 2: Define The Level of Agency You Want

One of the reasons for patient advocacy organizations to frame the relationship based on their contributions to said platform or service is that these contributions often come with different levels of protection. For example, shareholders in technology companies often have more transparency and voting rights than customers, who are only owed fair treatment in a commercial transaction.

The role of patients and advocates, understandably, varies significantly by context. And so should the types of commitments, rights, and agency expected in negotiations with digital healthcare service providers. Below is a high-level breakdown of three common models of agency that patient advocates can use as inspirations to establish their own models.



Levels of Agency

- 1. Protection from harm** This is the most basic level. Patients shouldn't be subjected to high-risk behaviors and/or predictable harms by virtue of seeking medical care. While that's true, the digital transformation of health has introduced a number of harms that service providers and technology companies contribute to, by omission and commission. Patients and advocates focusing on protection from harm can highlight specific, substantive harms (for example, advertising business models embedded in hospital websites), as well as the need for participatory mechanisms for flagging harms as they emerge (for example, patient advisory boards, clarity on trust and safety procedures).
- 2. Participation in governance decisions** There are a number of decision-making structures that have direct and indirect impacts on the ways that patients are treated by digital health services, many of which can be opened to patient participation. Patient and advocate participation in these processes can have an impact on a range of levels, from representing important considerations in board of directors' meetings to affecting product design by denying legally required data consents to changing the presentation and rating of marketplaces by coordinating their use of the tool. Each of these requires different types of participation, with different amounts of buy-in from the leadership of the rights supplier. At this level, patients and advocates are meaningfully capable of shaping important characteristics of digital services, but do not directly control or benefit from those decisions, beyond improvements in the underlying service. A common mechanism used to define how this participation might work is called a Terms of Reference document, which applies contractual tools to aligning expectations about decision-making processes. Terms of Reference documents may include language about the non-binding nature of decision-making or advice from the advocacy group(s), and the right to have different opinions within the group, rather than unanimous opinions or guidance, on matters of community governance.
- 3. Ownership and benefit** Even in situations where patients and advocates have a meaningful say in the governance of a multi-stakeholder system, their participation may not be recognized as an investment. Yet the time and energy patients spend learning to use a new platform, sharing sensitive data during a period of vulnerability, and participating in shaping digital health services - even if indirectly through their behavior - are real investments. Patients and advocates may push for digital health services to recognize their role in generating value, especially when their

data and participation is re-used by the companies involved. That benefit may extend beyond participation in decision-making to measures like revenue sharing, equity ownership, or other non-monetary responses. These might include priority access to research products or treatments. The defining characteristic for this level of agency is that patients not only have a role in making decisions that affect their community, they also share in the benefits of the work their participation supports.

Step 3: Translate Strategy into Tactics

Regardless of which stance patient communities choose, it's critical to translate the group's intended outcomes into specific requests. Those requests will vary substantially by context. They may be substantive or structural, for example. They may focus on agreeing on mutual interests based on soft power or building leverage to exert hard power. Whatever shape they may take, they need to be actionable enough for the other party to be able to say 'yes'.

Here are a few specific examples of concrete requests or demands that could help advance patients' rights and interests in digital health service governance. These are the kinds of requests or demands that could be used within the course of a negotiation.



7 Requirements for Collective Digital Rights



1. **Patient representation in governance.** Patient communities need representation in leadership and voting rights. This means appointment to the board of directors and/or governance bodies of a digital health service provider, creating ongoing and impactful input in the corporate governance responsible for the design and delivery of that service.



2. **Limited licensing agreements** The status quo for digital contracting is to accept open-ended or ambiguously worded data licenses, meaning that platform companies have a large amount of discretion in how they collect, re-use, and share data on patients. When patients and advocates successfully negotiate for limited data licenses, they increase the amount of participation and power data subjects (like patients) have in making decisions about the way that data gets used. Limited licensing agreements require that patients define both permissible and non-permissible use. Here, the value of pushing for limited licenses is that patients retain the right to make future decisions about the use of their data, and to evolve them as conditions change. Limiting data licenses helps both sides clarify the boundaries of their relationship and, like most contracts, define each party's rights, representations, and responsibilities. For an in-depth guide to improving data-sharing agreements, please see [this resource](#)¹ created by Digital Public for use in the US fisheries system.



3. **Embedding rights mechanisms in technical systems** The concept of 'dark patterns' refers to the way that technology companies design systems to make it hard for people to understand or navigate their rights. By contrast, however, patients and advocates can argue for 'light patterns.' With light patterns, technology providers design their systems to proactively inform, guide, and enable patients to understand how their data is being used, including exercising their ability to opt-out. Patients and advocates can negotiate for the development of governance systems embedded in the technologies patients use, as well as an ongoing role in overseeing and improving the design of those mechanisms.



4. **Revenue or equity sharing agreements** There are a number of ways that digital platforms can share the value they create with patient participants, but some of the most basic are revenue and/or ownership-sharing agreements. These types of agreements typically share some resources with a single, collective action trust or organization, which is then independently governed/used based on the shared interests of the participants. There is a wide range of practices around revenue sharing structures, from equity in the company to percentages of sales.

That results in a similarly broad range of ways the resources are distributed: sometimes it's flat cash payments, in others it's administered or invested toward a public benefit, as sometimes happens with the outcomes of class action lawsuits.



5. **Adversarial interoperability** Patients and advocates should be able to say 'no' to platform requests. In order for that to be possible, rights suppliers need to be engaged in proactively building technical (product) and legal infrastructure so that rights suppliers – such as technology companies – will be bound to respect patient consent and needs. Building interoperability is a critical aspect of building trust with vulnerable communities. As is creating digital relationships that offer opportunities for input beyond the status quo of binary 'yes' or 'no' consent questions.



6. **Fiduciary engagement** One of the founding ideals of medicine is the fiduciary relationship between healthcare providers and their patients. Medical professionals are legally and professionally required to act within the best interests of the patient. At present, however, those interests remain badly defined when it comes to data. This is a problem that patients and data providers, working together, can help solve. Whether it's legislative approaches or contractual approaches, patient advocates can push for fiduciary relationships with health technology providers. They can also participate in negotiating the agreements, trusts, and/or representation agreements that set the standard for the profession.

Similarly, medical service providers could focus their purchasing power on data suppliers, moving toward transparent, fiduciary data supply chains as a market standard. For more on the idea of fiduciary supply chains, see [this piece](#). Not only do fiduciary relationships increase the means of accountability for medical data stewardship, they realize the industry's pre-existing patient relationship standard. For more on the idea of fiduciary responsibilities in general, see [this paper](#).²

Conclusion

Digital patient advocacy is a relatively new field, joining a long tradition of advocacy for patient rights and interests. That means that there's value to creative, local, and unprecedented collective action. But it also means that patients and advocates may or may not get what we want.

The process of digital transformation presents a range of opportunities and challenges, most of which are based in longstanding negotiations over power, resources, and representation. One of the most important opportunities created by digital transformation is the emergence of a new set of actors, incentives, and points of leverage in the design of health systems - each of which will play a role in defining, supplying, and enforcing patient rights.

Too often, ambiguity and complexity are used to obscure and prevent patient participation and advocacy in the design and development of digital healthcare. By contrast, the majority of digital systems benefit from, if not outright rely on, the contributions and participation of patient communities. That reliance offers an enormous amount of potential leverage for us as patient communities, but only if it's channeled through our communities, organizations, and actions in ways that center and grow the power of patients in the systems that supply their rights in practice.

Please consider this guide an invitation for future collaboration and exchange. It's intended to be updated and adapted as all of our experiences help create new learnings, contexts, and guidance. The Light Collective and Digital Public look forward to continuing this conversation and working with you.

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Thank you for taking a part in fighting for digital rights! [Submit a form here](#) OR email us at contact@lightcollective.org for any feedback to help us make this guide better.

1. McDonald, Sean Martin. "The Fiduciary Supply Chain." Centre for International Governance Innovation, 28 Oct. 2019, <https://www.cigionline.org/articles/fiduciary-supply-chain/>.

2. Hartzog, Woodrow, and Neil M. Richards. "Legislating Data Loyalty." SSRN, 21 June 2022, https://papers.ssrn.com/sol3/papers.cfm?abstract_id=4131523.