Collective AI Rights For Patients

Written By Patients Experts and Community Leaders

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Introduction

This document was created by a cohort convened by The Light Collective, a national community of patient activists, clinicians, and health data experts committed to building tech and digital rights for patients. The cohort is a diverse task force of patients with lived experience and community leaders. Our aim is to define standards for the design, use, and governance of artificial intelligence (Al) in healthcare in order to advance the rights, interests, and concerns of patient communities. This is a living document that will continue to solicit and incorporate perspectives from a wide range of communities. By shifting the narrative to establish patient rights, a new governance space can emerge where diverse patient communities can debate and learn about emerging issues in health AI, resulting in initiatives crafted by the patients they are meant to serve.

We believe that patients are the ultimate end user and stakeholder for which health AI must be designed. Our goal is to advocate for a space where this fair representation of patient communities’ interests and goals can be cultivated to shape the future of health AI. Establishing a space for patient-led governance and rights in the emerging field of health AI is the only path towards fair, ethical, and equitable integration of its usage in patient care.

Executive Summary

The collective impact of AI holds the potential to advance research, accelerate cures, and improve care. Simultaneously—as it pertains to patient health—it is one of the most concerning issues of our time. In shaping this document and reflecting on patient rights regarding Al in healthcare, we wrestled with our duty to both the individual and to the diverse communities of which we are a part. Careful consideration was given to a range of emerging codes of conduct, ethics principles, case law, and policy frameworks for health AI.¹ ² ³

This document outlines seven distinct patient rights critical to the creation and application of AI in healthcare. This patient-led declaration of rights is necessary to establish the patient voice within ongoing and future initiatives forming Al standards, codes of conduct, and ‘Blueprints’ for AI Rights.⁴ Our aim for this document is to establish a baseline for patient rights and remedies through independent and fair representation of patient interests in the field of health AI.

We believe that health AI should be guided by the goals and human values of patients, including the voices of diverse racial and ethnic communities. Nothing should be decided about us, without us.

However, patient advocates like ourselves are often caught in a representation paradox, where we are asked to justify our ability to represent large communities of patients when defining new policies in health technology. This document is not attempting to represent all patients, but rather aims to help shape a future where patients of all backgrounds have the necessary rights, tools, and regulations to advocate for themselves within their personal care. This requires barriers like disabilities, cultural and linguistic appropriateness are equally addressed.

In 2019, the Global Indigenous Data Alliance (GIDA) developed and articulated the CARE Principles for Indigenous Data Governance and a set of rights around ‘data for governance’ and ‘governance of data’.⁵ We cite these principles as inspiration for the definition of patient rights in health AI, and we advocate for data sovereignty and enforceable legal rights for patient communities.
Patient Rights in Health Care Artificial Intelligence: A Call to Action

In the current landscape, health systems and technology developers are fervently embracing AI tools to assist clinicians in their roles, and facilitate various other processes in the healthcare system. However, a significant oversight persists—the exclusion of patient perspectives in the design and governance of AI solutions. Excluding patient representation repeats a troubling history: a power dynamic where influential voices in healthcare at best tokenize and at worst ignore the voices of those they serve. In doing so, they risk creating technologies that not only fail to address fundamental problems they were designed to address–improved care and better outcomes for patients–but that exacerbate existing disparities and directly cause additional harm.

Crucial questions emerge that we must consider:

1. **How might health AI ensure equal benefit for all, while upholding patient rights in the process?**
2. **How might we build AI systems that align with patient rights and interests?**
3. **How do we create independent oversight and validation of health AI solutions which impact patient care?**
4. **How can we build transparency and informed consent into uses of AI in healthcare designed for patients and by patients?**
5. **How might we build governance systems that center the perspectives, interests, and needs of the people and communities who are most impacted by AI?**

As patients with extensive lived experiences navigating healthcare systems, we recognize the potential power of AI to transform our care. However, for AI to be truly transformative, it must prioritize safety, accuracy, fairness, and above all, respect for the human rights of individuals upon whom the algorithms are trained and utilized.

The inclusion of patient voices in health policy and decision-making around AI models is not just desirable, but crucial for the survival of vulnerable patient populations. By actively involving those who have spent considerable time navigating the complexities of healthcare firsthand, we aim to ensure that AI development aligns with the realities of patients, properly addressing the diverse needs and rights it aims to serve. This inclusivity is not just a moral imperative; it is foundational to the responsible and effective deployment of AI in health and in care. These insights are integral to shaping a healthcare AI landscape that is impactful, ethical, and transparent.⁶ ⁷ ⁸

Below we outline specific rights and protections we seek in the context of digital technologies and personal data in the era of health AI. Further, we outline for each right what it means in plain language, why it matters, and how it might be actualized in practice.
COLLECTIVE AI RIGHTS FOR PATIENTS:

1. Patient-Led Governance & Representation

Patients are true partners in the design, scoping, and priority-setting of health AI. Patients collectively have the right to co-create the rules that govern how artificial intelligence (AI) is designed and used in healthcare.

<table>
<thead>
<tr>
<th>What it Means</th>
<th>Why it’s Important</th>
<th>What it looks like in action</th>
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<tbody>
<tr>
<td>Patients whose lives are at stake must be key contributors in designing and developing the rules and standards for how AI is applied in healthcare and in health technologies.</td>
<td>1. Health AI development and usage need to be aligned with real world needs of patients. 2. The assertion of this right also provides an opportunity to rebalance power in healthcare towards communities who are affected by healthcare decisions outsourced to AI.</td>
<td>1. <strong>Patients Co-Create The Rules</strong>: Patients must be active participants in policy making and development of rules that govern AI. 2. <strong>Co-Design In The AI Lifecycle</strong>: The health AI 'design lifecycle' must include patients to co-develop priorities, evaluation metrics, &amp; feasibility measures at every step. 3. <strong>Voting Rights</strong>: Patient community representatives must be active voting members of AI governance bodies as AI policies and standards are developed over time.</td>
</tr>
</tbody>
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2. Independent Duty to Patients

In order to adopt fair, safe, and equitable health AI, patient communities require representation that holds legally enforceable and *independent* duty of loyalty to improve outcomes for patients.\(^6\)

This duty to patients must be part of any negotiations, and must be held independently from fiduciary duties to financial shareholders.

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<th>What it Means:</th>
<th>Why it’s Important:</th>
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</table>
A founding ideal of medicine is the fiduciary relationship between doctors and their patients. Doctors are legally bound by a code of medical ethics, holding the well-being of the patient above all other interests.9

There is an established duty of loyalty to the patient as a primary stakeholder and beneficiary of clinical care. Duty of loyalty is a legally binding duty to act in the best interest of patients, if and when those interests conflict with other stakeholders in health AI.

1. AI is starting to make big decisions in healthcare, like who gets what kind of treatment based on health risks or behaviors. While doctors have to follow strict rules because of their medical licenses and promises like the Hippocratic Oath, companies that make AI are not guided by these same rules. If AI replaces the duties of doctors, we need to make sure that AI also has a strong duty to independently serve patients' interests.

2. Tech companies usually aim to make as much money as possible for their shareholders, which might not always be good for patient outcomes. Therefore, when AI plays a role in healthcare, patients require independent representation with a duty to ensure patients are treated fairly and well, without any other conflicts getting in the way.

3. Duty of Loyalty: In practice, this also means establishing fiduciary duty of loyalty to require AI stewardship of patient interests.10

**3. Transparency**

Transparency in the development and use of health AI is critical to ensure grounding in scientific evidence, clear clinical benefit, and mitigation of harms.

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<tr>
<td>Patients should be informed about why and how their data are being used in generative or predictive AI models.</td>
<td>1. Transparency builds trust between patients and health AI providers.</td>
<td>1. Access to AI Outputs: AI outputs must be recognized as a part of a patient’s designated record set (DRS) and individuals have the right to access outputs if the information is used to make decisions about their care or coordination of care.11</td>
</tr>
<tr>
<td>Patients should be informed when guidance or communication relies on AI rather than direct human input.</td>
<td>2. Transparency ensures patients’ agency in decisions affecting their health.</td>
<td>2. Disclosure of Risk Scores: Patients should have the right to know if ‘risk scores’ are being used to make</td>
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<tr>
<td>Patients require access to accurate and reproducible</td>
<td>3. Transparency allows users to know how AI tools have been developed.</td>
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4. Self-Determination

AI should be developed and used in a way that enables patients to exercise the fundamental right to make informed choices about their own health and healthcare.

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<tr>
<td>Respect for patient autonomy. Patients have the right to make decisions about their own bodies and health based on their personal values, beliefs, and preferences. This includes the right to decide whether or not to use</td>
<td>1. With AI becoming increasingly integrated into healthcare systems, it is crucial to ensure that patients retain their autonomy and the right to make informed decisions about their care.</td>
<td>1. <strong>Informed Decision-Making:</strong> Patients should be given the opportunity to make informed decisions about their own health and bodies. This includes opting out of or appealing AI-generated</td>
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</table>
AI-based interventions in their care.

2. AI predictions about health risks are no replacement for informed decision-making by patients. AI models may be subject to biases, errors, or limitations, potentially leading to incorrect assessments of a patient's health risks.

3. If AI predictions are used to determine access to care, patients may be unjustly denied essential resources and opportunities. Patients deserve the right to defy odds, even if the odds are not in their favor.

4. Patients must have control over how their private life data is used in healthcare decision-making.

5. AI must support, not undermine, patients' ability to make informed choices about their care. This can be achieved by respecting the fundamental principles of patient autonomy and self-determination.

decisions that affect patient healthcare.

2. **Choice To Say Yes or No.** Patients should also have the right to refuse AI intervention or inclusion of a predictive risk score in their care. In doing so, patients should not be penalized or lose care if opting out. Patients should also be able to opt in or opt out of having their data used to train predictive AI models.

3. **Right to Appeal & 2nd Opinion:** Patients should have the right to appeal AI-based decisions that determine a person's access to a certain treatment. The appeal process should be transparent and accessible, and with human oversight.

### 5. Identity Security and Privacy

Patients have the right to expect that their security and privacy will be prioritized in the design and use of health AI. Preservation of identity means patients have a right to choose how to share, disclose, all or parts of their identity.

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<td>Health AI must be designed, developed, and used to protect or improve the safety, privacy, and confidential choices of any patient or community in a way that protects patients' individual and shared identities.</td>
<td>1. Privacy and security is not just about protecting data or businesses’ assets. It's about protecting patient lives, safety, and choices when AI can make life-altering determinations, predictions, or diagnoses about a patient’s health that may</td>
<td>1. <strong>Safety First:</strong> Patients have a right to health AI technologies that have been independently evaluated for safety, privacy, &amp; security. A priority in any design process should be a clear articulation of risk,</td>
</tr>
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</table>
impact clinical safety as well as individual well being.\textsuperscript{7} 

2. “Anonymizing” a patient does not prevent harm to a specific part of their individual, ethnic, gender, or health identity if AI tools are used to target, manipulate, or generally misrepresent identity.

utilizing security & privacy-by-design.

2. **Ethical Usage:** Health AI and the health data marketplace should not be stolen or built upon the unpaid labor of patient communities. Health AI solutions should not be weaponized or used as a tool to discriminate against patients.\textsuperscript{13}

3. **Protection of Non-Medical Data:** The personal data of patients, unrelated to their medical care, must be kept private and separate from influencing any care decisions.

4. **Adtech Free Healthcare:** In order to stop the spread of medical mis- and dis-information, health AI services focused on adtech or marketing should be banned from use on social media.\textsuperscript{14}

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## 6. Right of Action

Risk sharing requires tangible ways for health AI developers to have accountability with affected communities. If there is evidence that certain uses of AI cause harm, patients must have the right to stop and remedy further harm through legally enforceable action.

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<tr>
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**What it Means**

**Why it’s Important**

**What it looks like in Action**
Businesses and institutions must hold the burden of risk for people affected by the health AI solutions that those organizations deploy.

If there is evidence that certain uses of AI cause harm, patients should have legal recourse to stop further harm.

1. **Legal Accountability:**
   Patients have a right to take legal action when AI causes harm. Legal action against entities that violate privacy or misuse data is necessary for enforceable accountability and justice.

2. **Fair Consent:**
   Arbitration clauses and waivers of rights should be banned from consent or privacy policies. In other words, patients should not be forced to sign away rights at the point of care.

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### 7. Shared Benefit

Diverse patient communities must equitably share in the benefits created as a result of health AI.¹⁵

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| Patient communities who make the highest risk contributions to AI must also have a fair stake or share in the benefits of health AI. | 1. Historically, digital medicine has relied on unpaid labor of patients to “engage” with researchers and technologists. When patient advocacy only allows those with privilege to donate their time and data, we build biased knowledge systems that serve to deepen health, knowledge, and economic disparities. 2. Training AI on community data only serves to further health disparities without building capacity for diverse patients and people with disabilities to share benefits. 3. Sharing equally in the benefits of AI can help | 1. **Patient Alignment:**
   Health AI must first align with patient interests, and actively work to reduce risk of harms it seeks to prevent. Patient perspectives are needed in the regulatory space to ensure that regulations accurately target the harm patients experience.¹⁷ 2. **Community Benefit:** As our collective data is increasingly commodified, institutions, governments, and industry must actively give back knowledge, opportunities, resources, |

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¹⁵ This is a placeholder for a larger table that is not included in the image.

¹⁶ This is a placeholder for a larger table that is not included in the image.

¹⁷ This is a placeholder for a larger table that is not included in the image.
promote human rights, social justice, and inclusion.

and funding to support patient communities.

3. **Patient Community Investment**: Resources and funding must be shared back with patient communities to create shared infrastructure, education, and projects driven by patient priorities, and led by diverse patient communities.
Conclusion

Now, more than ever, technology enables seemingly irrelevant sources of behavioral and personal data to be used for the benefits of health or healthcare. However, the use of such data is often hidden or unclear to the generators of the data, and its original owners (i.e., patients). This contributes to privacy violations and potential harm, all while blocking patient access to their personal data.⁷

Digital technologies—such as hospital portals, search engines, apps, and online support groups—can be vital, often life-saving tools for people navigating health challenges. However, as patient communities adopt these technologies, we generate new risks to patient safety while enriching the companies that collect and control them.¹⁸ These technologies risk exposing patients to privacy breaches, illegal data sharing, exploitation of health vulnerabilities, mis- and dis-information¹⁹, fraud, and other harms, which we refer to as “cyber harms.”²⁰

To date, there is little transparency or accountability for the variety of cyber harms that impact patient populations. The obstacles patients face in trying to access or transport their data further enables these cyber harms to persist, undermining the positive roles health technologies can play in care. Patients not only have the right to access their own data with ease, but also to be informed and included in deciding how this data is aggregated to build emerging health AI applications. This aggregation of our data cannot happen without representation.

Historically, the patient voice has been excluded from decisions on how health information is used and shared. This must change to ensure that our data is utilized, above all other interests, to improve our care and our health. We therefore advocate for the creation of an independent, patient-led governance body for health technology. This body will define digital rights for health AI, free of influence from the profit-driven interests of companies, or the haste in academia to publish new AI research. This body will collaborate with regulatory authorities and stakeholders to enforce these digital rights.

Including patient voices in governance is essential to ensuring that lived experiences within the healthcare system guide the integration and regulation of health AI. Without patient perspectives, health AI will be detached from our realities, ensuring that our struggles are never properly addressed. It is imperative that health AI be governed by those facing the direct impact of its use: the patient.
References


### Appendix

**Definitions/Terminology**

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Algorithm</td>
<td>A computer-generated set of instructions created by looking at a patient or community's health data and finding patterns. Algorithms in health can use data to predict a person's risk of a certain health outcome.</td>
</tr>
<tr>
<td>Algorithmic Transparency</td>
<td>The principle that the mechanisms of decision-making algorithms, especially in AI, should be open and understandable to users and other stakeholders. If the algorithm is a “black box” or protected for intellectual property reasons, the mechanisms by which they generally work and/or the outputs should be transparent, understandable, and auditable to/by the user.</td>
</tr>
<tr>
<td>Anonymization</td>
<td>The process of removing personally identifiable information from data sets, so that the people whom the data describe remain anonymous and unidentifiable.</td>
</tr>
</tbody>
</table>
| Artificial Intelligence (AI)| Technology that can do any of the following:  
1. Learn from data  
2. Make decisions  
3. Solve problems  
4. Understand natural language  
5. Recognize patterns  
6. Adapt to new information.  
AI refers to the development and application of algorithms and software to process complex medical data, assist in diagnosis, personalize treatment plans, and enhance healthcare delivery overall. AI can also be used in a variety of other ways, such as simplifying and translating language to different levels and languages for distinct audiences, purposes, and use cases. |
<p>| AI Output                   | AI Outputs include any AI solution, <strong>outlined further in 'Examples of Types of Health AI.'</strong>                                                                                                                                 |
| Bad Actors                  | Those who knowingly work against the interest of a patient or patient community.                                                                                                                             |</p>
<table>
<thead>
<tr>
<th><strong>Conflict of Interest</strong></th>
<th>A conflict of interest happens when a person or organization's own interests might interfere with their ability to do their job or make fair decisions on behalf of a patient.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cybersecurity</strong></td>
<td>The practice of protecting systems, networks, and programs from cyber criminals, digital attacks, theft, or harm to a person or property.</td>
</tr>
<tr>
<td><strong>Data Portability</strong></td>
<td>The principle that individuals have the right to receive, transfer, and use their personal data across different services.</td>
</tr>
<tr>
<td><strong>Designated Record Set (DRS)</strong></td>
<td>Under HIPAA (Health Insurance Portability and Accountability Act), a Designated Record Set (DRS) refers to all of the health and billing records a healthcare provider or plan uses to make decisions about an individual patient's care. HIPAA ensures that patients have the right to access and review these records to verify their accuracy.</td>
</tr>
<tr>
<td><strong>Discrimination</strong></td>
<td>Limiting choices, access to care, or outcomes of different people based on their medical conditions, disabilities, race, ethnicity, gender choice, age, language, socio-economic and legal status.</td>
</tr>
<tr>
<td><strong>Fiduciary</strong></td>
<td>A fiduciary is someone legally required to act in the best interests of another person, putting those interests above their own. For example, in an attorney-client relationship, the attorney has a fiduciary duty to represent the client's interests faithfully and confidentially, ensuring their legal rights are protected.</td>
</tr>
<tr>
<td><strong>Governance</strong></td>
<td>Governance is a process for making decisions and rules. “Technology Governance” is about making rules and policies that a group of people, like a hospital or a health tech company must use to make sure health technology is used in a good and safe way.</td>
</tr>
<tr>
<td><strong>Health AI</strong></td>
<td>A branch of artificial intelligence technology that focuses on the creation of systems capable of processing health-related data, making decisions, and performing actions with minimal human intervention. It's used in various healthcare applications, from diagnostics to treatment recommendations.</td>
</tr>
<tr>
<td><strong>Health Data Breach</strong></td>
<td>An incident in which sensitive, protected, or confidential health data is accessed or disclosed without authorization.</td>
</tr>
<tr>
<td><strong>Informed Consent</strong></td>
<td>The process by which patients are fully informed about the procedures and risks involved in a healthcare intervention or...</td>
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<tr>
<td><strong>Informed Consent</strong></td>
<td>Requires patients to learn about and understand the benefits or risks to them <em>before</em> they choose to use that technology.</td>
</tr>
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</tr>
<tr>
<td><strong>Legal Resource</strong></td>
<td>The right of an individual to seek or attain legal remedy in court due to a loss or harm, breach of contract, violation of privacy, or misuse of data.</td>
</tr>
<tr>
<td><strong>Patient</strong></td>
<td>A person with lived experience of a health condition.</td>
</tr>
<tr>
<td><strong>Patient Autonomy</strong></td>
<td>The right of patients to make informed decisions about their own healthcare, free from coercion or interference from others.</td>
</tr>
<tr>
<td><strong>Predictive Profile</strong></td>
<td>The use of data analysis tools to predict individuals' future behavior or health outcomes based on their personal data, whether it is health-specific data or other types of data.</td>
</tr>
<tr>
<td><strong>The Public</strong></td>
<td>Refers to the general population who are not patients living with disabilities or chronic health conditions. Although they may not live with chronic illnesses, they are still stakeholders in the emergence of health AI and impacted by these rights or lack thereof.</td>
</tr>
<tr>
<td><strong>Traceability</strong></td>
<td>The ability to know the source and handling of data that is used in health AI.</td>
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**Example Types of Health AI**

In this section we outline two different types of Artificial Intelligence that may be used in a healthcare setting. Depending on the uses of these, we outline potential risks or harms. Specifically, predictive AI models are largely used by health systems ‘ON’ patients but some may be in use directly ‘BY’ patients in patient-facing apps and services but this is much less common. Generative AI models can be used by health systems ‘ON' or ‘WITH' patients but can also be used ‘BY” patients.

<table>
<thead>
<tr>
<th>Health AI Category of Outputs</th>
<th>Who</th>
<th>Example</th>
<th>Patient risks/harms</th>
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<tbody>
<tr>
<td></td>
<td>Provider</td>
<td>Diagnosis: Developing predictive models for diagnosing diseases early, such as cancer detection from imaging data.</td>
<td>Bias in training data leading to inaccurate or unfair outcomes; overreliance may reduce human oversight.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Treatment: Using a predictive AI model for treatment recommendations such as the optimal medication for treating hypertension or diabetes.</td>
<td>Patients with multiple comorbidities may not have the same outcome if being compared to patients without those same comorbidities. Algorithms may reinforce existing disparities and cause direct harm to patients.</td>
</tr>
<tr>
<td></td>
<td>Payor</td>
<td>Using AI to determine a patient’s likelihood of paying for care and determining whether or not they would approve care.</td>
<td>This causes direct harms to patients when potentially biased algorithms deny care to patients and regulation is moving against payors being able to use AI models in this space.</td>
</tr>
<tr>
<td>Generative AI (A type of AI that generates text, images, other content types)</td>
<td>Patient</td>
<td>Using GPT-4 to simplify complex medical jargon into easier to understand language.</td>
<td>Risk to patients to consider is that the model may not accurately translate medical information and furthermore may share data with unwanted third parties.</td>
</tr>
<tr>
<td></td>
<td>Provider</td>
<td>Using GPT-4 to listen to doctor-patient conversation and generate documentation</td>
<td>Patients may not be aware that the healthcare system is using AI; in the space of documentation there may be errors that the system creates that patients should be able to review. Furthermore the inclusion of these systems can interfere with human interaction between patient and clinician, which has the potential to disrupt trust if implemented improperly.</td>
</tr>
</tbody>
</table>
Case Examples/Vignette Collection:

*False Risk*: Amelia is a newly diagnosed stage 4 cancer patient. She had a recurrence after an early stage diagnosis. Looking for help, she finds an app that uses AI to match patients to clinical trials. Amelia downloads the app, enters her medical history, but the app does not have information on her specific subtype. As she continues to use the app, the AI shares information on clinical trials for brain mets. Amelia does not have brain mets, but she begins to wonder if she does in fact have brain mets. She questions if her oncologist has withheld information about her health.

*Early Detection*: Steven is an avid runner, watches what he eats, and is in overall good health. For a period of two days, he is not feeling well, and assumes he has the flu. He goes to see his primary care physician. The PCP's office has started using AI to track patients' wellness and potential symptoms. The report generates a warning about a possible AKI (Acute Kidney Injury). Steven was able to get the help he needed before his condition became worse. AI can now predict an AKI up to 2 days before it occurs, whereas these types of injuries are often not diagnosed until after they have happened.

*Automated Denials*: Jack needs a specific medication to treat the cancer he has been diagnosed with. The insurance company uses AI to automate medication approvals and denies the coverage. Jack's oncologist, with the help of AI, submits an appeal on the medical necessity of this medication for the diagnosis. The insurance company responds with another denial (using AI as its only source of information). This back and forth continues for weeks, until finally, a judge (human) needs to make the final decision on whether Jack should receive his treatment. The insurance company solely relied on AI powered decision making without human intervention to make its “informed” decision.

*Targeting a Community*: Maria organizes a patient group on social media, with the goal of helping her community find support, resources, and access to research. Unknown to Maria and the participants, a health startup begins to develop a list of members. Another startup scrapes the group's posts to train a model that predicts suicidal behavior in people with her condition, without consent. This predictive model is then used in clinical care. A pharma marketing firm acquires the members' posts and uses the data to create predictive profiles, enabling more targeted advertisements towards them. A malicious actor acquires the list of Maria's community, and uses the information to target them with vaccine misinformation during the Covid19 pandemic.

*Targeting an Individual*: Jane is a patient advocate who deals with long term chronic illness. She uses the Internet, not only for herself, but to help others in her community. These online searches have provided mass amounts of data linked to her, which are now being used to market products and services on her social media platforms. The resulting ads focus on death, promoting services that organize funerals and turn bodies into trees. This causes Jane undue mental stress, and she decides to leave the platforms that originally provided her with support.
*Early Discharge:* Carol is a rare disease patient with multiple comorbidities. After being admitted to the hospital with an injury, her care team used an AI model to determine her treatment options based on her risk of developing sepsis. Because these algorithms are based on others without her rare diagnosis, the algorithm did not represent her risk accurately. Carol is recommended for early discharge from her hospital stay, and develops sepsis within 24 hours despite what the risk model predicted. After further investigation and independent validation of the algorithm, it’s discovered that many patients were discharged early due to this newly deployed and highly inaccurate AI model.
Patient AI Rights Initiative: About the Authors

This cohort represents some diverse perspectives, but does not represent all perspectives nor perfectly represent those that are included. Some of the perspectives reflected within this group of authors includes:

Grace Cordovano, PhD, BCPA
- Cancer misdiagnosis patient | primary carepartner to 2 disabled adults
- Board Certified Patient Advocate (BCPA)
- Member, HITAC Interoperability Standards Workgroup
- Member, HIMSS Public Policy Committee
- Co-Chair, The Sequoia Project, Consumer Voices Workgroup
- Advisor, HLTH Foundation Techquity Coalition
- Fellow, CancerX
- Member, NAM AI Code of Conduct Project
- Patient-In-Residence, Digital Medicine Society

Dave deBronkart
- Survivor of near-fatal kidney cancer, 2007
- Avid user of digital health technologies
- Evangelist for patient empowerment, especially through health data access and use
- Co-founder and Chair Emeritus, Society for Participatory Medicine
- BMJ Patient Advisory Panel inaugural member, 2014-2020
- Founding co-chair, HL7 Patient Empowerment Workgroup
- OpenNotes Advisory Board

Andrea Downing
- Co-Founder of The Light Collective
- BRCA Community Advocate, Security Researcher

Ysabel Duron, BA
- 23 year Hodgkins Lymphoma survivor, award winning journalist, Latino agency leader
- Founder/Executive Director, The Latino Cancer Institute

Lesley Kailani Glenn, BS
- Native Hawaiian, living 11 years with metastatic breast cancer
- CEO|Founder - Project Life - a virtual wellness house for those living with metastatic breast cancer

Jill Holdren
- Co-Founder of The Light Collective
- Patient Advocate, Hereditary Ovarian and Appendicial NET Cancer Survivor

Dana Lewis

Marlena Murphy, MA
- African American patient advocate residing in the southeast living with metastatic triple-negative breast cancer (TNBC)
- Program Manager, Guiding Researchers & Advocates to Scientific Partnerships (GRASP)

Valencia Robinson, Ed.S
- Co-founder of The Light Collective
- 17 year Triple Negative Breast Cancer Survivor, Patient Advocate

Liz Salmi, AS
- Person living with a malignant brain tumor for 17 years
- Co-Founder, #BTSM (Brain Tumor Social Media)
- Communications & Patient Initiatives Director, OpenNotes, Department of Medicine, Beth Israel Deaconess Medical Center
- Former Member, Board of Directors, National Brain Tumor Society
Chethan Sarabu MD
- Patient with non-neurogenic neurogenic bladder of unknown etiology since the age of approximately 18 months of age with the lived experience of being a pediatric + adolescent patient with multiple extensive surgeries and still continues to be a daily part of his life
- Significant time spent as family carepartner for those with cancer and dementia
- Clinical Assistant Professor, Stanford Medicine
- Board certified in Pediatrics and Clinical Informatics
- Board member, The Light Collective

Christine Von Raesfeld
- Rare / Autoimmune / Undiagnosed patient
- Board member, Light Collective
- NIH All of Us, committee for Access Privacy and Security, Participant Ambassador, Rare Disease Subcommittee
- Member Patient Senate, Patients Rising
- Partnership for Quality measures, committee member
- Advisor, Research to the People Stanford Medicine

Revisions/Process For This Document

Living breathing document. This is v0.1. TLC will...in order to reflect revisions.

- 1/23: See here for a chart that shows the original set of rights, Dana’s condensed and revised version, and potential revisions to these all in one place
- 1/24: Andrea moved Dana’s Clean version to the top, Re-ordered sections, and deprecated the OLD VERSION
- 1/31: Version 3 & wording of Rights
- 2/5: Consolidated new version into the document
- 2/19: Added / reworded Rights 6 & 7
- 3/12: Added citations (Liz) / Moved Definitions & Types of AI to Appendix
- 6/1: Merged public and private comments from community feedback