



Patient Rights in a Complex Healthcare Environment

Executive Summary

Patient rights form the foundation of ethical, legal, and patient-centered healthcare delivery. As healthcare systems become increasingly complex, patients face challenges navigating treatment decisions, understanding consent, accessing medical records, protecting personal health information, and advocating for quality care.

Healthcare is undergoing unprecedented transformation driven by electronic health records (EHRs), telehealth, artificial intelligence (AI), interoperability initiatives, cybersecurity threats, healthcare consumerism, and increasingly complex insurance requirements. While these innovations have improved access to care and patient engagement, they have also created new risks involving privacy, information access, cybersecurity, and healthcare affordability.

This white paper examines the importance of healthcare patient rights in our healthcare environment and explores the responsibilities of healthcare providers, payers, and policymakers in protecting those rights. It highlights key areas including informed consent, privacy protections, access to healthcare information, treatment autonomy, grievance processes, and health equity.

There is also discussion on emerging challenges associated with digital health technologies, artificial intelligence, and evolving care delivery models.

As healthcare organizations navigate these complex regulatory requirements and patient expectations, ensuring that patient rights remain at the center of care delivery has never been more critical. Whitley Penn Healthcare Advisory assists healthcare organizations in strengthening governance, enhancing compliance programs, improving patient experience initiatives, and developing strategies that promote transparency, accountability, and equitable access to care. Through its extensive industry expertise, Whitley Penn helps providers evaluate operational processes, mitigate regulatory and compliance risks, optimize patient engagement efforts, and navigate the changing healthcare landscape while maintaining a steadfast commitment to patient-centered care.

By aligning organizational practices with regulatory expectations and patient advocacy principles, healthcare leaders can build greater trust, improve patient outcomes, and create a more transparent, efficient, and equitable healthcare system for the communities they serve.

Introduction

Healthcare is built upon a foundation of trust between patients and healthcare professionals. Patients entrust physicians, nurses, and care teams with their most personal information, physical well-being, and often life-altering decisions. In return, healthcare organizations are expected to provide care that instills the principles of dignity, safety, respect, transparency, and accountability. These principles form the basis of patient-centered care and are essential to fostering positive health outcomes and public confidence in our healthcare system.

While significant advancements in our medical technology, diagnostics, treatments, and healthcare accessibility have improved the quality of care available to many individuals, patients continue to face numerous challenges when navigating the healthcare system. High healthcare costs, fragmented care coordination, disparities in access to services, complex insurance requirements, and increasing administrative burdens can create substantial obstacles to obtaining timely and appropriate care. These challenges often leave patients feeling overwhelmed, confused, and disconnected from decisions that directly affect their health and well-being.

Patient rights serve as critical safeguards designed to ensure that individuals remain active participants in their healthcare journey. These rights are intended to establish clear expectations regarding informed decision-making, privacy and confidentiality, access to medical information, respectful treatment, and equitable access to care regardless of race, ethnicity, gender, age, disability, religion, income, or geographic location. They reinforce the principle that patients are not passive recipients of care, but informed partners in the healthcare decision-making process.

Patient rights also protect individual autonomy while establishing mechanisms for transparency, accountability, and dispute resolution when concerns arise. In the United States, these protections are supported by a combination of federal and state laws, regulatory standards, accrediting organizations, and

healthcare provider policies. Key legal and regulatory frameworks include the Health Insurance Portability and Accountability Act (HIPAA), the Emergency Medical Treatment and Labor Act (EMTALA), Medicare Conditions of Participation, and provisions of the Affordable Care Act (ACA), all of which provide important protections related to privacy, access, nondiscrimination, and patient safety.

Importantly, there is no single, universally adopted list of patient rights in the United States. Rather, patient rights have evolved through multiple sources, including the American Hospital Association's (AHA) original Patients' Bill of Rights, federal legislation, state regulations, and consumer protection initiatives. As a result, healthcare organizations may reference different frameworks while adhering to a common set of core principles.

Historically, the most influential framework was the American Hospital Association's 1973 Patients' Bill of Rights, which established 12 foundational rights addressing informed consent, privacy, participation in treatment decisions, emergency care, discharge planning, and other essential patient protections. These principles continue to serve as the foundation for many hospital policies and state-level patient rights laws.

In 1998, the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry expanded upon these concepts by identifying eight fundamental consumer rights,

including access to information, choice of providers, emergency services, participation in treatment decisions, respect and nondiscrimination, privacy and confidentiality, complaint and appeal mechanisms, and consumer responsibilities.

More recently, healthcare organizations and advocacy groups often simplify these protections into seven core patient rights, including:

- The right to informed consent
- The right to participate in care decisions
- The right to refuse treatment
- The right to privacy and confidentiality
- The right to access medical records
- The right to respectful, non-discriminatory treatment
- The right to file grievances, complaints, and appeals

Although the number and terminology may vary among frameworks, the underlying protections remain remarkably consistent. Across healthcare settings, patients generally have the right to:

- Receive respectful, non-discriminatory care
- Make informed decisions regarding treatment
- Accept or refuse medical interventions
- Maintain privacy and confidentiality of health information
- Access their medical records and healthcare information
- Receive safe, quality healthcare services
- Voice concerns, complaints, and appeals without fear of retaliation
- Access medically necessary care in a timely manner

As healthcare continues to evolve, protecting patient rights is no longer simply a regulatory obligation, it is a strategic imperative. Organizations that prioritize patient rights strengthen patient engagement, improve satisfaction and trust, support better clinical outcomes, enhance organizational reputation, and reduce the risk of disputes, litigation, and compliance violations. In an increasingly complex healthcare

environment, a strong commitment to patient rights remains a cornerstone of ethical, equitable, and high-quality care.

With the expansion of AI in healthcare discussions regarding patients' rights and the implementation of AI in the healthcare setting suggests that we may see a regulatory or legislative approach to the use of AI and how it interacts with a patient and their data. It is possible that we could see an adoption of a regulatory standard of patient rights included in such legislation regarding how a patient's information is recorded and used during and after a patient's services. This could also include additional provisions or specific protections regarding a patient and their consumer rights regarding shopping for healthcare services and how their data may be handled during that process.

Defining Patient Rights in Healthcare

Healthcare patient rights represent legal, ethical, and professional principles that protect a patient's autonomy, dignity, and participation in their healthcare.

The patient rights include:

- **Right to Informed Consent:** this means the patient has the right to receive understandable information regarding treatment options, diagnoses, all potential risks involved in the decision-making process, expected outcomes, and available alternatives before making any healthcare decisions.
- **Right to Privacy and Confidentiality:** Patients have the right to expect that all their personal health information will be protected from unauthorized access, disclosure and/or misuse.
- **Right to Access Medical Information:** Patients should have timely access to their health records, care plans, test results, and relevant information needed to manage their own healthcare efficiently.
- **Right to Healthcare Treatment Decisions:** Competent adults have the right to accept, refuse, or discontinue treatment, even when the physician or clinician may disagree with the patient's decision.
- **Right to Respect and Non-Discrimination:** Patients will receive treatment free from discrimination based on race, ethnicity, religion, sex, disability, age, veteran status, sexual orientation, or economic circumstances.
- **Right to Voice Concerns and Grievances:** Patients should have accessible mechanisms for reporting concerns, filing complaints, and seeking final resolution when care expectations are not met.

Protecting patient rights produces benefits that extend well beyond regulatory compliance. When patients understand their rights and have the knowledge to participate in medical decision making for their care, they are more likely to become active partners in achieving positive healthcare outcomes.

The Challenges

Several emerging challenges are reshaping the discussions around patient rights:

Artificial Intelligence (AI) and Algorithmic Bias in Healthcare

As AI becomes part of the healthcare process in clinical and operational workflows, organizations and physician practices must ensure human oversight is still part of the decision-making process. This tool needs to be used with caution and nothing with patient private information should be uploaded into an AI unless it is a closed AI tool only for that establishment use.

There are many systems boasting about their AI tool innovation for streamlining of processes for any healthcare organization, however, not all are applicable for every workflow. Caution is key when deciding how any patient information gets processed through these systems.

Information Overload and Health Literacy

While patients have greater access to health information than ever before, understanding complex medical and insurance information remains a challenge. Healthcare organizations must prioritize clear communication and patient education.

The key to all of this is educating patients on their rights with both the provider side and the insurance side. If the patient has no idea how or what their insurance covers for their treatment.

Effective patient education should include information about coverage eligibility, prior authorization requirements, network restrictions, appeals processes, and available financial assistance resources. When patients are equipped with the knowledge and tools to navigate both the healthcare delivery system and the insurance landscape, they are better positioned to advocate for themselves, participate in shared decision-making, and achieve improved health outcomes.

Ultimately, patient rights and insurance literacy are inseparable components of patient-centered care. Empowering individuals with the knowledge to understand their rights, benefits, and responsibilities strengthens trust, reduces barriers to care, and promotes a more equitable and transparent healthcare experience.

Strategic Recommendations for Healthcare Organizations

Healthcare organizations should:

1. Strengthen patient education and healthcare literacy initiatives.
2. Enhance transparency surrounding data use, disclosure, and AI-enabled technologies.
3. Invest in robust cybersecurity and privacy programs.
4. Improve patient access to health information through integrated technologies.
5. Establish ethical governance frameworks for AI and digital health solutions in accordance with compliance guidelines.



Conclusion

Patient rights have evolved significantly beyond their historic role as privacy and consent protections. In today's healthcare environment, patient rights serve as the cornerstone of trust, transparency, safety, equity, and accountability across increasingly complex healthcare systems.

While HIPAA remains the legal foundation of healthcare privacy, the modern healthcare environment demands a broader view of patient rights that incorporates access to information, shared decision-making, cybersecurity, and responsible technology governance.

The strategic rights of access, privacy, transparency, participation, and accountability provide the "why" behind patient-centered care, while HIPAA's specific regulatory protections including access, amendment, restrictions, breach notification, confidential communications, accounting of disclosures, privacy notices, and complaint rights provide the "how." Together, these protections create a comprehensive framework that safeguards patient autonomy while enabling innovation across healthcare delivery systems.

As healthcare continues to apply artificial intelligence, interoperability, telehealth, and consumer-driven care, organizations must ensure that patient rights remain central to every clinical, operational, and technological decision. Healthcare leaders who successfully balance innovation with privacy, transparency, and accountability will strengthen patient trust, improve outcomes, and build sustainable healthcare organizations prepared to meet the challenges of the future.

Establishing and adhering to a workflow that protects patient rights requires more than regulatory compliance, it needs a comprehensive strategy that integrates into patient engagement. Whitley Penn Healthcare Advisory assists healthcare organizations in developing and strengthening frameworks that support patient rights across the continuum of care. This includes evaluating governance structures, assessing regulatory compliance and privacy practices, enhancing patient communication and education programs, along with strengthening grievance and appeals processes, and implementing controls.

With new technologies and care delivery models emerging continuously, Whitley Penn helps the physicians and organizations identify risks related to data privacy, informed consent, information access, AI, and digital health solutions while ensuring that patient-centered principles remain at the forefront. Whitley Penn supports healthcare organizations along the way in establishing, operationalizing and adhering to patient rights standards that align with regulatory requirements, industry best practices, and creates value to the patient care.

References

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