

## Providing Autonomy and Respect: A Primer on Patient Rights

Elisa Reiter and Daniel Pollack | September 25, 2024



Patient rights are a fundamental aspect of modern health care, encapsulating key ethical principles and legal protections for individuals receiving medical care. These rights have evolved over the past several decades, in part due to changing societal values, landmark legal cases, and policy developments. At their core, patient rights aim to ensure that patients are treated with dignity and respect, have autonomy in medical decision-making, and are protected from discrimination and abuse or within the health care system.

## Key Patient Rights

Some of the most important patient rights include:

1. **Right to informed consent:** Patients have the right to receive clear information about their diagnoses, treatment options, risks and prognosis in order to make informed decisions about their care. Providers must obtain informed consent prior to undertaking procedures or administering treatments.
2. **Right to confidentiality and privacy:** Patient medical information and records must be kept confidential, with strict limits on disclosure. The HIPAA Privacy Rule mandates federal protections for personal health information.
3. **Right to access medical records:** Patients have a right to view and obtain copies of their medical records in a timely manner.
4. **Right to refuse treatment:** Competent adult patients can refuse or discontinue treatment, even if their decision results in death.
5. **Right to emergency treatment:** Hospitals must accommodate a patient's need for emergency treatment regardless of the patient's ability to pay, thanks to the Emergency Medical Treatment and Labor Act (EMTALA).
6. **Right to be free from discrimination:** Patients have a right to receive care without discrimination based on race, ethnicity, national origin, religion, sex, age, mental or physical disability, sexual orientation, or source of payment.
7. **Right to respectful care:** Patients should be treated with dignity and respect.
8. **Right to pain management:** Patients have the right to an appropriate assessment and management of pain.

9. **Right to designate visitors:** Patients can decide who may visit them during a hospital stay, including opening the door to partners or closing the door to those they do not wish to see in troubled times.
10. **Right to advance directive:** Patients have a right to create advance directives specifying their wishes for end-of-life care.

## **Legal and Regulatory Framework**

Patient rights are protected through a variety of federal and state laws, as well as via institutional policies. Key federal laws and regulations include:

- **Patient Self-Determination Act (1990)**: Requires health care providers to inform their patients of the patients' rights to make decisions about their medical care, including the right to accept or reject treatment.
- **Health Insurance Portability and Accountability Act (HIPAA) (1996)**: Mandates maintenance of data privacy and security provisions for maintaining privacy as to patient records.
- **Emergency Medical Treatment and Active Labor Act (EMTALA) (1986)**: Requires hospitals to provide emergency medical care to anyone, regardless of their ability to pay.
- **The Affordable Care Act (2010)**: Provides expanded patient protection in areas like coverage for preexisting conditions and appeal rights for denial of insurance claims.

Many states have enacted their own patient bills of rights, which may provide additional protections beyond federal laws. In addition, most health care institutions have their own patient rights policies as well.

## **Historical Development**

The modern concept of patient rights emerged in the last century, in part driven by the civil rights movement, consumerism, and changing attitudes toward medical care. Milestones include:

- 1973: The Patients' Bill of Rights is issued by the American Hospital Association.
- 1980s-1990s: States began enacting their own patient rights legislation.
- 1990: Patient Self-Determination Act passed.
- 1996: HIPAA enacted.
- 2010: Affordable Care Act expanded patient protections.

## **Challenges and Controversies**

Patient rights are accepted in principle, but their implementation can be contentious. Ongoing challenges include:

- Balancing clinical judgment and patient autonomy.
- Protecting patient privacy in an era fraught with cybersecurity breaches.
- Addressing continued disparities in care and outcomes for vulnerable populations.
- Navigating end-of-life decisions and right-to-die laws.
- Reconciling religious and moral objections of patients and providers regarding treatment decisions.
- Fighting for rights before hospital ethics' committees, particularly when a patient does not have an advanced medical directive and the patient is unable to speak for themselves.

- Ensuring meaningful informed consent given the complex nature of modern medicine.

## **International Perspective**

Patient rights are recognized internationally, although specific protections vary by country. The World Health Organization and other international entities have issued declarations on patient rights. Many countries have national patient rights laws or charters. The European Union has begun the process of harmonizing certain patient rights across member nations.

## **Enforcement and Remedies**

Patients whose rights have been violated have several potential avenues for recourse:

- Filing a complaint with the health care provider or institution.
- Reporting to state licensing boards or health departments.
- Filing a complaint with the U.S. Department of Health and Human Services Office for Civil Rights for HIPAA violations.
- Contacting patient advocacy groups for support and direction.

## **Conclusion**

Patient rights empower people to be active participants in their care, providing important protections against abuse and discrimination. The legal and ethical framework for patient rights is well-established. However, ongoing vigilance and advocacy are a must. Having a caretaker/loved one present during a hospital stay may be both a sword and shield. As health care continues to evolve—particularly with the

advent of online care—patient rights will likely expand and adapt to address new ethical challenges and societal needs and expectations.

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