

LESSON INTRODUCTION

Welcome to Ethics and Patient Rights, part of the Oncology Patient Navigator Training: The Fundamentals course. My name is Reesa Sherin, and I am the Director of Clinical Strategy at the Association of Cancer Care Centers, and I will be your presenter for this lesson of the course.

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After completing this lesson, you will be able to:

- Define ethical standards as it relates to the health care system
- Describe a process for ethical decision-making
- Describe strategies to build ethical relationships with patients
- Describe the Patient's Bill of Rights

- Identify opportunities to support patient rights
- Identify ethical principles related to compliance with laws, policies and regulations

This lesson is organized into three videos that will guide you through key topics, including an introduction to ethics, ethical principles related to patient rights, and important ethical and legal considerations. Let's begin.

LESSON SECTION I

Let's begin this lesson by exploring the foundations of ethics. In this section, you will gain a general overview of ethics, an introduction to philosophical approaches, and a framework for making ethical decisions.

To grasp the meaning of ethics, it's helpful to first clarify what ethics is NOT:

- Ethics is not the same as emotions. While emotions can influence our decisions, they may sometimes lead us away from doing what is right, especially if the right choice is difficult.
- Ethics is not the same as religion. Although many people draw their moral compass from religious beliefs, ethics applies universally, regardless of religious affiliation.
- Ethics is not the same as law. Legal standards may not always align with what is considered ethical in certain situations.
- Ethics is not the same as culture. Cultural norms can shape behavior, but they may not always meet ethical standards.
- Ethics is not the same as science. While science describes how people behave, ethics provides guidance on how people ought to behave.

Ethics is the formal study of morality from various perspectives. In healthcare, ethical decision-making is guided by four key principles: Autonomy, Beneficence, Non-maleficence, and Justice. These principles serve as the foundation for ethical practices and patient care.

Let's take a closer look at the four key principles of ethics:

- Autonomy refers to an individual's right to make their own decisions.
- Beneficence goes beyond avoiding harm; it involves actively doing what is best for another person.
- Non-maleficence is the commitment to not cause harm and to prevent intentional harm.
- Justice relates to ensuring fairness and addressing what a person or community rightfully deserves.

Now that we have reviewed the principles of ethics, let's explore the five key sources that can guide ethical decision-making. These approaches help navigate complex situations, though they are not universally agreed upon. People may interpret human rights, civil rights, or the concepts of "the common good" and "harm" differently. While each approach defines ethics uniquely, they often lead to similar solutions in ethical dilemmas.

- The Utilitarian Approach focuses on the outcomes, aiming to choose actions that produce the most good and the least harm.

- The Rights Approach is grounded in the belief that we must respect the inherent rights of others.
- The Fairness or Justice Approach emphasizes treating everyone equally, unless there is a valid and ethical reason to treat someone differently.
- The Common Good Approach highlights the interconnectedness of all people and encourages actions that promote respect and compassion, especially for the vulnerable.
- The Virtue Approach suggests that ethical decisions should be guided by universal virtues, such as honesty, fairness, courage, compassion, and prudence.

The ethical decision-making framework serves as a valuable guide to help navigate difficult decisions. It is designed as a tool to use when facing complex ethical situations. Before taking any action, it is important to consult with your manager or supervisor and ensure you are familiar with your organization's policies.

Now, let's review a brief simulation of an ethical dilemma where the Patient Navigator is pushed to bend the rules. Afterward, we will go through each of the steps in this framework.

[VIDEO]

In step one of the ethical decision-making framework, begin by asking, "How should I define and describe this issue?"

This is where patient-centered care plays a key role. Communicate with members of the healthcare team to inform them of the situation your patient is facing and collaboratively explore potential solutions.

In Thelma's case, the key facts are:

- The patient's income does not meet the eligibility criteria for the financial assistance in question.
- Thelma is not responsible for making the application decision.

Reflecting on the scenario: If Thelma were to falsify the application, it could jeopardize her ability to secure future funding for patients.

Step two of the ethical decision-making process involves gathering all the necessary facts.

Consider these questions: What are the relevant facts of the situation? What facts are still unknown? Is it possible to gather more information? Do I have enough details to

make an informed decision? Make sure to collect all the pertinent information before taking action.

Next, identify who has a significant stake in the outcome. Are certain concerns more pressing than others, and why? As a patient navigator, your primary concern is always the patient. Understand what specifically concerns the patient and how they are impacted by the situation.

Additionally, explore the possible options for action. Have all relevant individuals and groups been consulted? Have creative solutions been explored? Here is where patient-centered care becomes essential. Engage with the healthcare team to discuss the patient's situation and gather their input for potential solutions.

In Thelma's case, the facts are:

- The patient does not meet the eligibility criteria for the financial assistance program.
- Other resources may be available to support the patient.
- The patient is seeking financial help.

Thelma could either misstate the patient's income on the application, risking future integrity, or she could explore alternative resources that the patient may be eligible for.

Step three involves evaluating the potential actions using ethical standards. To guide your decision-making, consider the following questions:

- Utilitarian Approach: Which option will generate the most good and cause the least harm? This considers the overall impact of your decision.
- Rights Approach: Which option most effectively respects the rights of everyone involved? Reflect on the rights of all stakeholders in the decision.
- Justice Approach: Which option ensures fairness and treats people equally or proportionally? Focus on equity in your actions.
- Common Good Approach: Which option benefits the community as a whole, rather than just a few individuals? Consider the broader societal impact.
- Virtue Approach: Which option aligns with the type of person you aspire to be? Think about the values and character you wish to uphold.

Using these ethical standards, the most appropriate action for Thelma would be not to falsify the application, as doing so would undermine fairness, integrity, and long-term trust in the system.

Step four is about making a decision and testing it. After evaluating the options through various ethical lenses, ask yourself: Which option best addresses the situation?

In Thelma's case, she could reflect on whether she would feel comfortable sharing her decision publicly. Additionally, she should ensure that her choice aligns with her organization's policies and values.

If you're uncertain about an ethical choice, it's always a good idea to consult with your supervisor to determine the most appropriate course of action.

Finally, step five involves taking action and reflecting on the outcome.

Consider these questions:

- How can the decision be implemented with the utmost care and attention to the needs of all stakeholders?
- How did the decision ultimately play out, and what lessons can be drawn from this experience?

If you were in Thelma's position, think about how the situation was resolved and what insights you gained from the interaction.

In this section of the lesson, we went over a general overview of ethics, provided you with the four principles of ethics, and introduced a framework for making ethical decisions. Join me in the next section where we will dive into ethical principles as they pertain to patient rights.

LESSON SECTION II

An ethical healthcare system upholds certain standards, and the entire healthcare team, including patient navigators, should strive to integrate these principles into care delivery.

These standards include:

- Respecting the rights, dignity, and safety of patients: This involves showing respectful attitudes and treating patients as individuals of worth. For example, helping patients understand their care and respecting their preferences for involving family and friends.
- Respecting clinician judgments: A clinician's judgment reflects their beliefs on the best course of action for a patient, informed by professional experience, scientific evidence, and the patient's values. However, in cases of clinical uncertainty or limited evidence, the weight of this judgment may be lessened.
- Providing optimal clinical care: Ethical care requires assessing whether the expected clinical benefits of an action outweigh the benefits the patient would have experienced without the intervention.
- Avoiding unnecessary risks and burdens on patients: Ethical decision-making involves weighing the risks and burdens of an action against its potential benefits.
- Understanding and addressing health inequalities: Patient navigators must ensure their actions do not perpetuate or exacerbate unjust inequalities. Ethical care seeks to reduce disparities in outcomes and access to services.
- Engaging in continuous learning: Ongoing education and improvement are essential to enhancing the quality of clinical care and health systems.
- Contributing to the overall improvement of healthcare: Navigators should work towards the common goal of enhancing both the quality and value of healthcare systems for all patients.

Working closely with patients can be both emotionally rewarding and challenging. Building trust is an important part of the patient navigator role, but it is equally important to maintain professional boundaries and care for your own well-being. As you help patients address barriers and connect them with services, you may learn personal details about their lives, leading to the development of trusting relationships. This can sometimes blur the line between a professional and personal relationship.

Patients may request assistance beyond the scope of your role as a patient navigator. Although it can be difficult to decline a patient's request, it is important to remember your professional boundaries and communicate them clearly, as discussed in the

previous lesson. If you are ever uncertain about what is appropriate, consult your supervisor for guidance specific to your setting.

Engaging with patients beyond your professional responsibilities can expose you to personal liability and create unrealistic expectations. For example, offering rides in your car or lending money can quickly lead to complications. To maintain professionalism, consider the following tips:

- Clearly define your role from the start. Provide a list of duties or explain your role and limitations to patients. This helps manage expectations and reduces stress for both you and the patient.
- Set expectations for the future. Let patients know that your goal is to empower them to find services on their own and that your assistance may eventually come to an end.

Additionally, the Health Insurance Portability and Accountability Act (HIPAA) imposes strict privacy requirements, which we will cover later in this lesson.

Ensure patient information remains confidential. You will often hear patients discuss their conditions, treatments, and side effects, but it is important not to share this information with others, as doing so would violate privacy laws and have serious legal consequences. Always ensure patient files are closed when not in use and make sure conversations cannot be overheard.

Finally, practice patience. Some patients may not follow the advice or use the resources you provide, while others may delay or refuse care. Although this can be frustrating, it is important to remember that patients are ultimately responsible for their own health. Always treat them with respect, understanding, and patience.

It is important to maintain clear boundaries with patients. These boundaries differentiate a professional relationship from a social or personal one. Setting clear limits helps to:

- Keep the focus on both your goals and the patient's goals within the professional relationship.
- Ensure patient confidentiality is upheld.
- Prevent inappropriate or dual relationships from developing.

These boundaries are essential for maintaining professionalism and ensuring the best outcomes for your patients.

[VIDEO]

Pam is well-intentioned but crosses a professional boundary. She feels conflicted, yet ultimately offers the patient her personal cell phone number, which not only oversteps ethical standards but may also violate her organization's policy. Additionally, Pam's comment at the end—"Don't worry, you'll beat this"—shifts her role from patient navigator to trying to be a friend. It's important to remember that Pam cannot predict the outcome, and making promises she cannot control could undermine the trust the patient places in her.

[VIDEO]

Pam offers support and validation to the patient while appropriately directing her to another qualified member of the care team who can assist with managing her anxiety.

In patient navigation, certain behaviors can blur the lines of professional boundaries with patients. Let's explore common challenges for navigators and offer some tips to help maintain appropriate boundaries.

The first behavior that can blur the line is sharing personal information. It may seem natural to talk about your own life, but doing so can cause the patient to view you more as a friend than a healthcare professional. This might lead the patient to take on your concerns in addition to their own. To stay within professional boundaries, avoid discussing personal life details unless necessary, and never share information to help yourself feel better. Remember that your relationship with the patient should remain therapeutic, not social.

Accepting or giving gifts, or doing special favors, can also blur professional boundaries. Receiving a gift from a patient might even be perceived as unethical or inappropriate by others. To stay in bounds, always follow your facility's policies on gifts, and practice graciously declining gifts that exceed these boundaries. It's helpful to explain to patients that you're not allowed to accept gifts or tips. If you're offered a significant or unusual gift, be sure to report it to your supervisor.

Over-involvement can also blur professional boundaries. Signs include spending too much time with a particular patient, visiting off-duty, or believing that only you can meet the patient's needs. On the other hand, under-involvement can manifest as neglect or disinterest. To avoid either, focus on your patient's needs, not personalities. Avoid confusing your needs with the patient's, and maintain a consistent level of care for every patient, regardless of your emotional connection. If you feel you are becoming too personally involved, discuss your concerns with a supervisor.

Physical contact can further complicate professional boundaries. While touch can be comforting, it can also be misinterpreted or unwelcome. Sexual or romantic contact

with a patient or family member is never allowed. To stay in bounds, use touch only when necessary and with the patient's consent. Let the patient initiate any contact, and ensure it serves their needs, not your own. If a patient exhibits flirtatious behavior, discourage it, and if you feel attracted to a patient, seek guidance from a supervisor immediately.

Lastly, always follow any specific guidelines from your organization regarding physical contact. These practices will help you maintain professionalism while supporting your patients effectively.

[VIDEO]

How could Fernando have improved? He started the conversation professionally and composed, but soon crossed his boundaries by feeding into the patient's concerns. Instead of staying calm and neutral, Fernando became personally involved, even offering opinions about what he might do in the patient's situation. His non-verbal communication and actions suggested he lost sight of the health professional/patient relationship. He touched the patient and encouraged her to leave and be with her family, rather than referring her to a professional equipped to help her process this difficult information. Some ways to improve might include:

- Acknowledge the difficulty of the situation: He could say, "I'm sorry to hear this news. It must be incredibly tough for you. Would you like me to get assistance from our social worker? She's very experienced and could offer helpful support."
- Focus on the patient's needs during this stressful time.
- Be mindful of his body language and non-verbal cues, avoiding looking surprised or upset.
- Avoid touching the patient, especially without permission.
- Refrain from offering advice or attempting to counsel the patient; instead, refer her to a trained team member, like a social worker or clergy member.

As we've discussed, being a patient navigator is distinct from being a patient's friend. As a representative of this profession, it is important to act in accordance with the role defined by your profession and your facility or agency's guidelines. Your responsibilities include:

- Utilizing institutional and community resources to provide patients with support and information
- Delivering that support in an effective manner
- Establishing a relationship with patients that is temporary and professional

Navigators do not act based on personal rules or preferences. Instead, they are expected to uphold the appropriate boundaries set by both the profession and the organization they represent.

Jean Watson developed a theory that emphasizes the idea of a caring relationship as reciprocal, particularly in terms of empathy. As a patient navigator, your interest in the field likely stems from a desire to help others. In a "caring relationship," the professional, guided by a natural inclination to care, connects with the emotions of the patient—this connection is known as empathy. This relationship creates a mutual bond, fostering trust between the patient and navigator, which is essential for providing effective support.

However, the focus of the relationship is not reciprocal. The purpose of the encounter is to address the personal needs of the patient, not the professional. It is natural for the patient to focus on how the patient navigator can assist them, often with a "What's in it for me?" mindset. The patient should remain centered on their own concerns, while the professional's role is to be other-oriented, fully focused on the patient's needs.

The caring relationship is also not reciprocal in perspective. The way the navigator views the relationship is different from how the patient experiences it. For example:

- The navigator's perspective is external
- The patient's perspective is internal

This dynamic allows the navigator to combine:

- Observations of the patient's emotions and a sense of commitment
- With an objective view of the patient's situation

As discussed in other lessons, it is important for the navigator to actively listen to the patient. Navigators must hear what the patient identifies as their needs, rather than imposing their own views or assumptions. Some helpers may have a strong "need to be needed" and unknowingly operate from this desire, rather than being an objective observer of the patient's genuine needs. This can manifest as a desire to "fix" or "rescue," imposing values or priorities that may not align with the patient's own. It is important for navigators to understand their motivations for doing this work. While it is gratifying to know you are making a difference, that should not be the primary motivation for helping others. Sometimes, you may not be able to change patient outcomes, but by maintaining an external and objective perspective, you can offer practical support and resources that genuinely benefit the patient.

To stay within professional boundaries, it's important to consistently evaluate your behavior. Before taking any action, remember that patients view you as a representative of both your profession and organization. Consider these questions:

- What are my intentions, and how might they be perceived by others?
- Whose needs am I meeting? Is this aligned with the expectations patients have of a healthcare team member?
- What are the likely consequences—both intended and perceived—of my actions? How will this affect patients, their families, other patients, or colleagues?
- Do I have any Bias? - the same thought processes that make people smart can also make them biased. This tendency for stereotype-confirming thoughts to pass spontaneously through our minds is called implicit bias. It sets people up to overgeneralize, sometimes leading to discrimination even when people feel they are being fair. Implicit bias comes from unconscious and unintentional associations, and results in both favorable and unfavorable judgements of others based on characteristics such as race/ethnicity, religion, and gender. Additional trainings on Implicit Bias can be found in our resources section.
- Am I maintaining a professional relationship? Does my decision uphold the standards of conduct expected by my employer and profession?

Navigators must be aware when emotions or personal experiences shift the focus away from the patient. Patients rely on us to keep their best interests at the forefront.

As you work to meet your patient's needs, you may encounter situations that challenge your ability to remain professional. In this part of the lesson, we will discuss conflicts of interest and how to navigate them effectively.

Conflicts of interest occur when a navigator's personal needs or interests interfere with their ability to act professionally and prioritize the patient's needs. These situations can compromise professional objectivity and make it difficult to maintain sound judgment.

For example, a conflict of interest could arise if you are navigating care for friends or neighbors—known as dual relationships. Another instance might be when a healthcare professional receives commissions for recommending products to patients. Conflicts of interest can also occur when loyalty to an employer conflicts with doing what is best for the patient or contradicts ethical obligations.

Patients recognize you through both your professional and personal roles, which can sometimes lead to dual relationships. These dual relationships can develop before, during, or after your work with a patient. As a healthcare professional, it is important to maintain clear boundaries in the following scenarios:

- Situations where you are viewed as a professional but want to participate as a peer: For example, if you are facilitating a support group, it's important not to engage as a participant.
- Social relationships: Friendships or intimate relationships with patients, such as connecting on social media, are typically inappropriate.
- Business relationships: Entering into business ventures with patients can create conflicts.
- Financial relationships: Involvement in financial matters with patients should be avoided.

Dual relationships can present ethical challenges for navigators and may:

- Affect the patient's progress by blurring the lines of professionalism
- Hinder your ability to perform your duties competently and objectively
- Risk breaching the patient's confidentiality
- Lead to unrealistic expectations from either the patient or the navigator, complicating the professional relationship

Dual relationships can occur and are often unavoidable. It's essential to recognize the risks they pose and learn how to manage them, even after your patient navigation duties have ended. Staying aware of these risks helps you maintain professional boundaries.

If you're ever unsure whether a dual relationship exists, seek guidance from a supervisor to ensure you're adhering to organizational policies and laws. It's better to err on the side of caution by asking and confirming rather than assuming something is acceptable. This proactive approach helps maintain professionalism and avoid potential conflicts.

Patient navigators can implement various strategies to avoid and manage conflicts of interest. The first step is to consult with your supervisor and review your organization's policies and procedures. Many organizations have specific definitions and protocols for addressing conflicts of interest, so understanding these guidelines is important.

Once you're familiar with the relevant policies, actively work to avoid potentially compromising situations, including interactions in digital spaces like social media. Maintain strong professional boundaries, prioritize your patients' best interests, and adhere to your organization's guidelines when interacting with both patients and external stakeholders.

If you do encounter a conflict of interest, it's important to take immediate action to resolve it. Let's explore some steps you can follow to address these situations effectively.

Always adhere to your organization's policies for reporting a conflict of interest. Inform your supervisor promptly, and in some cases, it may be necessary to disclose the situation to any patients involved.

Take steps to resolve the conflict in a way that prioritizes the patient's best interests.

If applicable, end any dual relationships that could compromise your professional judgment.

Return any gifts or financial contributions from parties that create a conflict.

Consult your supervisor if you believe ending the navigation relationship is in the patient's best interest.

Collaborate with your supervisor to address any conflicts between employer policies and patient needs, ensuring ethical and patient-centered care.

Acting outside of your scope of practice can have significant consequences, depending on the nature of the issue, your institution's policies, and state laws. These consequences may include job loss, personal lawsuits from patients, or even putting your supervisor's professional license or job at risk. In some cases, you might also face fines or jail time.

It is important to understand both your organization's policies and state laws regarding medical liability. Make sure to discuss these with your supervisor to ensure you fully understand your responsibilities and the potential implications.

In this section, we explored ethics within the healthcare system, the importance of maintaining professional boundaries and fostering ethical relationships with patients, and strategies for managing potential conflicts of interest as a patient navigator. In the final section, we will dive into ethical principles related to compliance with laws, policies, and regulations, as well as patient rights and responsibilities.

LESSON SECTION III

Anyone who works with patients or handles medical records must be familiar with key ethical and legal considerations. In this section, we will cover the Patient Bill of Rights, patient responsibilities, HIPAA regulations, and the concept of informed consent.

[CHECKPOINT]

In 1997, President Clinton established the Advisory Commission on Consumer Protection and Quality in the Healthcare Industry to address changes in the healthcare system and recommend improvements. The Commission drafted the Consumer Bill of Rights and Responsibilities to safeguard patients, ensure quality healthcare, and foster trust between patients and healthcare providers. This document also provides protections for healthcare workers and offers patients a way to address issues within the healthcare system. Many healthcare organizations have adopted or adapted the principles of the Consumer Bill of Rights and Responsibilities, so it's important to check if your organization has its own version.

Let's review these principles, starting with patient rights. Patients have the right to:

- Access their healthcare records and receive accurate, easy-to-understand information about their health and providers. For patients who communicate in another language, have a physical or mental disability, or require ADA accommodations, healthcare teams are required to provide qualified assistance to ensure informed healthcare decisions.
- Choose their doctors and access plans that provide high-quality care.
- Access emergency services whenever and wherever needed, without needing prior authorization or facing financial penalties.
- Be informed about their treatment options and participate in decisions about their care. If they are unable to make decisions, parents, guardians, family members, or designated individuals may act on their behalf.
- Be treated with respect and without discrimination by medical professionals and health plan administrators.
- Have their health information kept private, ensuring confidentiality during consultations and access to medical records only by those involved in their care. Patients also have the right to review, copy, and request corrections to their medical records if they find inaccuracies.
- File complaints about their healthcare experience, including concerns about wait times, the conduct of healthcare personnel, or the quality of healthcare facilities, and have the right to a fair, fast, and objective review of any complaint.

In addition to rights, patients also have responsibilities as outlined in the Consumer Bill of Rights and Responsibilities:

- Responsibility for their own health: This includes maintaining healthy habits like exercising, not smoking, and eating a balanced diet; preventing the spread of disease; collaborating with the healthcare team to make decisions and follow treatment plans; and understanding the limitations and risks inherent in medical care.
- Transparency and communication: Patients must communicate openly with the healthcare team, providing necessary information and clearly expressing their wants and needs. They are also expected to report any wrongdoing or fraud to the proper authorities.
- Financial and administrative responsibility: Patients are expected to make a good-faith effort to meet financial obligations and be informed about their health plan, including covered benefits, limitations, and the process for appealing coverage decisions. They should also follow administrative procedures of health plans, healthcare professionals, and government health programs.
- Respect for others: Patients should show respect for other patients and healthcare workers, while also recognizing that doctors are obligated to provide efficient and equitable care to all patients within the community.

These responsibilities help create a more effective and respectful healthcare environment for both patients and healthcare professionals.

Federal laws require that patients give their informed consent before participating in a clinical trial. However, informed consent is typically required for any medical treatment, not just for clinical trials.

Informed consent ensures that patients are aware of the procedures, risks, and benefits of a treatment or trial, and that they voluntarily agree to participate. Patients provide informed consent by signing a document that confirms they understand:

- The purpose of the treatment or clinical trial,
- What will happen during the treatment or trial,
- The benefits and risks of participating,
- Their rights as a patient, and
- Who to contact with questions or if they feel mistreated.

The rules guiding informed consent are very strict, and it is essential that patients fully understand their treatment. For patients who do not speak English, the informed consent form must be provided in their preferred language. It is important to respect patients' autonomy by presenting the information in accessible formats and ensuring they fully comprehend their healthcare options before proceeding.

Informed consent also requires that healthcare teams cannot withhold health status information from patients. Patients have the right to be fully informed about their health, including any diagnoses, treatment options, and potential outcomes, allowing them to make informed decisions about their care.

You will frequently have opportunities to advocate for patients' rights, including:

- Assisting with understanding their condition and treatment options
- Supporting their decision-making process
- Facilitating access to a second opinion

As a patient navigator, you can provide valuable support by offering resources, helping patients create lists of questions, guiding them in identifying their needs, and empowering them to advocate for themselves.

However, remember that any clinical questions should always be directed to a healthcare professional. A patient navigator should never make decisions on behalf of patients or influence them toward a specific choice.

When a patient receives care, they may interact with various healthcare professionals across multiple locations. This often involves the transfer of medical records and billing information between facilities or systems. Since private patient information can be shared across different platforms, it is essential to ensure the protection and confidentiality of that information.

The Health Insurance Portability and Accountability Act (HIPAA), established in 1996, was designed to protect patient privacy. HIPAA sets strict guidelines on who can access and use a patient's written, spoken, or electronic health information. The regulations also outline how healthcare organizations and insurers must handle and protect this information, including:

- Proper procedures for handling protected health information (PHI)
- Guidelines for sharing information
- The types of information that can be shared
- Identifying who is authorized to receive shared information

Violating HIPAA can lead to civil or criminal penalties, including fines and potential imprisonment. This course provides only a basic overview of HIPAA. Your organization may require you to complete more in-depth HIPAA training. If you have any questions about protecting patient information, consult your supervisor.

The U.S. Department of Health and Human Services offers helpful videos and infographics to assist in explaining privacy rights to your patients. These resources are designed to ensure patients understand how their health information is protected.

With the advent of new technologies like precision medicine, artificial intelligence, and other innovative treatment methods, it is essential to consider expanded approaches for safeguarding patient privacy. Strategies to address this challenge may include respecting patient-reported privacy preferences, ensuring privacy requirements are consistent across borders, and providing clear explanations of the methods used to protect patient information.

Which entities are subject to HIPAA regulations?

- Health plans
- Health care clearinghouses
- Health care teams that transmit claims electronically
- Medicare prescription drug card sponsors

The following entities are not required to follow HIPAA regulations: Employers, life insurance companies, workers' compensation carriers, schools and school districts, state agencies such as child protective services, and law enforcement agencies or municipal offices. It's important to verify if your organization is subject to HIPAA guidelines. While these entities are exempt from HIPAA, they may still be required to adhere to other privacy policies.

Information protected under HIPAA is referred to as Protected Health Information (PHI). PHI can exist in written, spoken, or electronic formats. For instance, PHI may appear in written or typed entries in medical records, conversations between healthcare professionals about a patient's care, or digital health insurance files that include patient billing details. The specific types of PHI protected by HIPAA include contact information, electronic communication details, dates related to patient care, identifying numbers, device or vehicle identifiers, photographs, fingerprints, voice recordings, or any characteristic that could uniquely identify an individual.

Examples in your work setting may include clinic notes, lab results, or treatment records in a medical file, voice messages left on a patient's phone confirming an appointment, conversations about patients between healthcare professionals, a physician's recorded transcription of a clinic visit, prescription bottles, or photos of patients posted on public websites.

"Identifiers" are pieces of information that can link an individual to their medical records. Examples include a person's name, date of birth, treatment date, and Social Security number. When these identifiers are removed, the information is considered "de-identified," meaning it can no longer be traced back to the individual.

There are significant reasons for using de-identified patient information. De-identified data allows public health organizations to gather and share health information without breaching patient privacy or legal regulations. This data can be used in various ways, such as analyzing health statistics, identifying health disparities, improving treatments, and developing new therapies, among other important purposes.

While de-identified data is important for advancing our understanding of how to improve patient care, its use is not without controversy. Concerns exist regarding the creation, use, and disclosure of de-identified health information in research, particularly when done without the individual's knowledge, consent, or authorization, raising significant privacy and ethical issues.

Additionally, the unauthorized collection and use of de-identified health data can have a profound impact on Indigenous populations and their rights to self-determination. This brings up the issue of Indigenous Data Sovereignty, which emphasizes a nation's right to govern the collection, ownership, and application of its data. This principle stems from Indigenous communities' inherent rights to govern their people, lands, and resources.

Here are some key guidelines to help protect Protected Health Information (PHI):

Guideline 1: Use only the minimum necessary information.

When handling patient information, access only what is needed to perform your job. For example, if you have access to medical records, refrain from viewing clinical notes or unrelated sections unless essential to your duties. When sharing PHI with authorized individuals, ensure you provide only the necessary information.

For example, a transportation service will only need appointment dates, times, and locations, not details about a patient's diagnosis. Information can only be shared with explicit patient consent. This leads to the next guideline.

Guideline 2: When in doubt, get patient authorization.

In general, patient authorization is required to share PHI with entities or individuals not covered by HIPAA. If you are uncertain about sharing information, consult your supervisor and request the patient's signed authorization form. This form permits you to release the necessary information. Additionally, check if authorization forms are

already in the patient's file. If a family member or caregiver requests information, only provide details relevant to their role in the patient's care, and ensure documented authorization from the patient allows this. Always verify your facility's policy on documenting authorization and sharing information.

Guideline 3: Keep PHI secure.

Maintaining the security of PHI means ensuring it is only accessible to those who are authorized. Some practical ways to secure PHI include:

- If PHI is in an area where others could view it, cover or move it.
- Ensure that no one can approach you unnoticed while you work with PHI on your desk or computer.
- When not in use, store PHI in a locked office or file cabinet.
- Promptly remove documents from faxes and copiers.
- Avoid discussing patient information in public areas or where others can overhear.
- Close your office door when speaking with patients.
- Never take files or documents containing PHI out of the office or clinic.
- Shred documents with PHI when no longer needed.
- For electronic PHI, use strong passwords, anti-virus software, regular backups, and encryption.

HIPAA breaches can lead to serious consequences for everyone involved. Here are some real-life examples of breaches:

- A health system unintentionally posted thousands of patient medical records online, exposing sensitive information.
- A pharmacy resold a used computer without properly wiping its data, which still contained customer prescription records, including names, addresses, social security numbers, and medications purchased.
- A county health board member, who also worked as a banker, accessed health records to identify cancer patients and placed notices on their mortgages.

These cases highlight the importance of safeguarding PHI to prevent serious legal and ethical violations.

Now that you're more familiar with HIPAA, let's assess whether these examples are HIPAA breaches:

- Taking home your notebook with all your patient information over the weekend?

YES – Patient information should never be taken home. It must remain in secure, authorized locations.

- Telling your partner about a patient?
MAYBE – If no identifiable information is shared, it may not be a HIPAA breach. However, it's best to avoid discussing patients with anyone not authorized to access that information.
- Checking the lab results of your neighbor, who you are not navigating?
YES – You should not access information about patients you are not directly responsible for navigating.
- Telling the social worker that you believe your patient is suicidal?
NO – Reporting a patient who may pose harm to themselves or others is a professional obligation and not a HIPAA violation.
- Having a patient's information on your computer screen where another patient can see it?
YES – Patient information should not be visible to others who are not authorized to see it.
- Leaving sticky notes containing patient information on your desk?
YES – Patient information should always be kept secure and never left out in the open.

As a member of the healthcare team, it is essential to understand the rules and regulations that health professionals must follow to protect both patient rights and the rights of the public.

In this section, we will cover three key legal obligations: Duty to Warn, abuse reporting requirements, and patient self-harm disclosure.

Duty to Warn, as defined by the National Conference of State Legislatures, is a mandatory obligation for certain professionals to report any suspicion that a patient may pose a threat to themselves or others. The specifics of this law vary by state and may include civil and criminal protections for the professional involved. It is important to consult with your supervisor to understand the Duty to Warn requirements and your organization's reporting procedures.

In any interaction, once rapport is established, a patient may disclose information that raises suspicions of abuse or neglect. Healthcare professionals are mandated to break patient confidentiality and report any suspected abuse or neglect.

If you are uncertain about how to confirm suspicions or feel uncomfortable with this responsibility, speak with your supervisor to understand your organization's reporting process, legal obligations, protections, and available training. Address any concerns you may have.

Most states provide hotlines or helplines to ensure patient safety. As a patient navigator, and even as an informed citizen, it's important to familiarize yourself with local and state laws, as well as reporting agencies on abuse and neglect. Mandatory reporting laws vary by state, so you can look up your state's regulations by searching for mandated reporting guidelines specific to your state.

As a patient navigator and member of the healthcare team, it is not your responsibility to assess a patient's intention to harm themselves—that is the role of the doctor. However, if a patient expresses harmful intentions or suicidal thoughts, it is your duty to immediately notify the doctor or your supervisor. Always ensure that you follow your facility's procedures for reporting any such concerns to safeguard the patient's well-being.

This concludes the lesson on Ethics and Patient Rights, part of the Oncology Patient Navigator Training: The Fundamentals course. In this lesson, we covered several key topics, including:

- Defining ethical standards in relation to the healthcare system
- Describing a process for ethical decision-making
- Exploring strategies to build ethical relationships with patients
- Understanding the Patient's Bill of Rights
- Identifying opportunities to support patient rights
- Recognizing ethical principles related to compliance with laws, policies, and regulations

Thank you for your participation in this lesson. Your dedication to learning these critical concepts plays an essential role in enhancing patient care and ensuring ethical practices in healthcare navigation.

ONCOLOGY PATIENT NAVIGATOR TRAINING: THE FUNDAMENTALS

Ethics and Patient Rights