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LEARNER'S
GUIDE

BECOMING A PARTICIPATING PATIENT

Empowering Individuals to Use Health Information Technology

Becoming a Participating Patient

Overview

The goal of the lessons in the [Becoming a Participating Patient](#) Web site is to provide you with an understanding of online tools that can help you become a more active participant in your own health care. Such tools include credible online health care information, tools for creating personal health records, and social networking tools that can provide support and assistance when you are grappling with acute or chronic health conditions. An additional goal is to provide you with general guidelines for approaching health problems and health care decision making so that you can ask questions of your health care providers.

Important note

Discussions of specific health issues may occur during these lessons. However, your health care needs are unique and your health care provider is best suited to provide advice on your specific health care strategy. While general information is provided in this site and *Learner's Guide*, it should not be used as a substitute for professional medical advice.

Web site structure

You have access to four learning modules through this Web site:

- [finding health information](#)
- [creating a personal health record](#)
- [partnering with your doctor](#)
- [weighing treatment options](#)

Each module includes different avenues for learning: *guidance*, *stories*, *discovery*, and *resources*.



You can create your learning experience using each of the learning avenues in the order shown, but you can also choose avenues of particular interest to you in whichever order you choose.



The **guidance** section of a module will take you to a Captivate™ lesson providing guidelines and tips for learning the information in the module as well as lesson interactions. The lesson is self-paced and narrated. You can proceed linearly through the lesson or use the table of contents (TOC) button to learn about topics of particular interest to you.



The **stories** section of a module will take you to a Captivate™ lesson with interactive scenarios that allow you to consider common experiences related to a learning topic. This section is also self-paced. You can proceed linearly through each scenario or use the table of contents (TOC) button to learn about scenarios of particular interest to you.



The **resources** section of a module will include useful links and explanations of how to use them to enrich your learning experience.



The **discovery** section of a module will include suggested activities and sometimes worksheets to help you apply some of the lessons from the guidance module. They may be complemented by using links in the resources section of the module as well. You can perform these activities on your own or share your experiences using your favorite health social network.

Remember to be cautious about sharing any of your medical information and to always evaluate the credibility of health information you receive. (See [finding health information](#) for tips.)

In this guide

For each module, you will find:

- A module overview
- Objectives
- A suggested way of structuring your learning experience

Getting started

View the [home page](#) of the Participating Patient Web site for an overview of the content in each of the learning modules. For additional information about how to navigate this site, see [navigation guide](#) to help you find your way around this site page. You can access individual modules from this page.

Module 1: Finding health information

Module overview

The goal of the module is to help you find trustworthy health information and develop strategies for making sense of it.

Objectives

You will be able to:

- Search for and locate reliable health information Web sites
- Determine the source of information on a health information Web site
- Identify when information on a health information Web site was last updated
- Identify the evidence supporting online health information
- Describe strategies for making sense of health information

Learner prerequisites

The module lessons assume that you're familiar with some basic terms relating to internet searching (e.g., url, links, menu, scrollbar, etc). However, you can learn these terms or refresh your memory by accessing the [resources](#) section of this module and reviewing *internet basics*.

Suggested learning experience



Enter the [guidance](#) section for tips on how to find, evaluate, and make sense of online health information. You'll find some interactive practice here as well. You can pause the module to complete suggested discovery activities or try your hand at them later.



After completing the guidance section, enter the [stories](#) section to help a fictitious character find and evaluate the credibility of search information.



If you haven't yet, check out the [discovery](#) section to take part in activities related to this module.

Enter [resources](#) at any point to find useful links that can help you as you learn.

Discovery activities

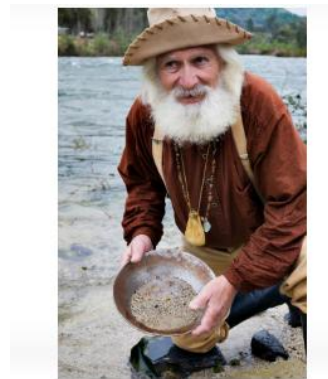
All of the *discovery* activities and their associated worksheets can be found in the [discovery](#) section of this module. It is suggested that you open your Web browser to this page as you follow the activities below.

Activity 1. In your sites

Explore this activity to understand how different search sources provide different types of information. The [resources](#) section of the module provides some examples of different types of search engines and health information Web sites.

As you learned in the [guidance](#) section of the module, you can use these guidelines when searching:

- Use search tips
- Use advanced search functions
- Review search result descriptions
- Consider sponsorship
 - By the government ([.gov](#))
 - By an educational institution ([.edu](#))
 - By a non-profit organization ([.org](#))
- Ask a friend or health social network for recommendations and/or check social bookmarking sites.



Some words about keywords

Think about what you *want* to find...

- broad terms (e.g., flu) – more general results
- narrower (e.g., flu symptoms) – more specific results
- related words (flu OR influenza) AND (symptoms OR



signs) – still specific results

Use the fewest descriptive words possible

- flu symptoms vs what are some flu symptoms?

Also think about what you *don't* want to find...

- flu symptoms in cats

You can use advanced search functions in many search engines to try alternative words and to exclude words.

Use the worksheet provided for this activity to guide your search and compare the information you find using these different search resources.

Activity 2. Call a friend

Explore this activity to learn to tap into your friends as resources for health information. See if you share some of your favorite health information Web sites or if you discover new ones.

Activity 3. That's incredible!

The goal of this activity is to help you evaluate the credibility of health information Web sites. Use the worksheet for this activity provided in the [discovery](#) section to rate sites and information you've found. Remember the 3W's test you learned in the [guidance](#) section of this module.

The logo consists of the letters '3W's' in a large, blue, serif font. The '3' is on the left, followed by 'W's'. The letters are slightly shadowed to give a 3D effect.

1. **Who** said it?
2. **When** was it written or last reviewed?
3. **What's** the evidence?

Activity 4. Evaluating alternative medicines

Explore the credibility of alternative medicine Web sites using the worksheet you obtained for Activity 3. You can also look for some of the red flags identified by the American Cancer Society using this [link](#) provided with Activity 4.

Activity 5. Evaluating blog sites

Blogs can be a useful source of health information, particularly if written by health care professionals. Read the [article](#) associated with activity 5 and the guidelines included in it to weigh the credibility of blog sites providing health information.

Activity 6. Making sense of it

You may come across some discussions of health information in the news, but these articles may require further exploration. Find a health-related article in a general newspaper or science newspaper and apply some of the [tips](#) provided in this article along with activity 6 (although written for teenagers, there's some useful information here). You might also want to take a look at some of the links provided in [resources](#) section of this module as you look into research articles for medical information.

Module 2: Creating a personal health record

Module overview

The goal of the module is to help you understand the benefits of a personal health record (PHR), steps for generating a PHR, and how to evaluate the offerings of different PHR providers.

Objectives

You will be able to:

- State what a PHR is
- Describe at least three potential benefits of a PHR
- Identify the components of a typical PHR
- Be able to distinguish the offerings of PHR providers to select one that suits your needs
- Describe what it means to say that some PHRs are not protected by HIPAA laws

Learner prerequisites

- None

Suggested learning experience



Enter the [guidance](#) section for tips on the benefits and components of a PHR, how to create a PHR, and how to select a PHR provider should you decide that a PHR is right for you. You'll find some quizzes here to check your understanding as well as some suggested discovery activities. You can pause the module to complete the activities or try your hand at them later.



Enter the [stories](#) section to help a fictitious character decide on the type of PHR she wants and to weigh the offerings of different PHR providers.



If you haven't yet, enter the [discovery](#) section to take part in activities related to this module.



Enter [resources](#) at any point to find useful links that can help you as you learn.

Discovery activities

All of these discovery activities and their associated worksheets can be found in the [discovery](#) section of this module. It is suggested that you open your Web browser to this page as you follow the activities below.

A reminder of some of the topics covered in the [guidance](#) section of this module:

An overview of PHRs

A PHR is:

A system for managing health information that can include:

- Paper
- Your personal computer
- A flash drive or zip drive
- The internet
- A combination of these tools



It's personal. That means you:

- Control the information that goes in it
- Maintain it
- Own it
- Can access it when you need to
- Can determine who else has access to it



An overview of what can be in a PHR

- Information from all your health providers
- Information from you

Activity 1. Making a list

Starting a PHR involves taking stock of your health care providers and contacting them for copies of your medical records. Use the worksheet provided for this activity to help you with this task. Remember that you don't have to complete this activity all at once. The steps you'll follow in creating a PHR are summarized below.

How do I create a PHR?

Step 1: Contact your health providers

Step 2: Fill out an authorization for release form

Step 3: Collect your information

Step 4: Store your information in a secure manner

Step 5: Add to and update your information

- Bring your PHR to your next doctor's visit
- If you use an ePHR, consider providing your doctor with access to your PHR



Activity 2. In your pocket

The goal of this activity is to build a toolkit of information that you can take with you on your next visit to the doctor. Optimally, your toolkit can include:

- Your contact information
- Your current insurance information
- Emergency contact information
- A list of serious medical conditions
- Medicines you're taking (including herbal remedies)
- Known reactions to medicines
- A list of any allergies you have

You can develop a paper record of this information or try putting it on a zip drive or flash drive that you carry with you.

Activity 3. Is it covered?

Do you already have a PHR as part of your insurance coverage? Does your employer or health care provider offer a PHR system? The goal of this activity is to help you understand more about your existing PHR, if you have one. You can use the PHR checklist provided for this activity.

Activity 4. Rating PHR providers

Whether you already have a PHR provider or are interested in finding one, this activity will help you evaluate the different offerings of PHR providers.

Activity 5. Making it personal

Keeping a personal health journal is a good way of being more aware of your health and taking positive steps to maintain a healthy lifestyle. And you may be able to make your health journal part of your PHR. This activity can help you get started.

Activity 6. Are you hip to HIPAA?

Privacy is an important consideration in creating a PHR. HIPAA is a privacy law you should familiarize yourself with. See how many questions you can answer from the question [link](#) provided with Activity 6.

Here's a brief summary.

HIPAA

(Health Insurance Portability and Accountability Act of 1996, 35 C.F.R. §§ 164)

- Limits conditions under which information can be disclosed to third parties
- Gives you certain rights
 - Right to access, inspect, and copy your health information
 - Right to request correction or amend health information
 - Right to request accounting of disclosures of health information



Module 3: Partnering with your doctor

Module overview

The goal of the module is to help you understand how to prepare for a doctor visit and be a part of decision making that relates to your health care strategy.

Objectives

You will be able to:

- Identify health information to bring to your doctor's attention
- Identify and prioritize questions for your doctor
- Describe strategies for discussing internet research with your doctor
- Describe strategies for remembering information your doctor provides and for asking follow-up questions
- Identify considerations for choosing a new doctor

Learner prerequisites

- None

Suggested learning experience



Enter the [guidance](#) section for tips on creating an effective partnership with your doctor. You'll find some suggested discovery activities here. You can pause the module to complete the activities or try your hand at them later.



Enter the [stories](#) section to help fictitious characters deal with common scenarios that can arise during a doctor visit.



If you haven't yet, enter the [discovery](#) section to take part in activities related to this module.



Enter [resources](#) at any point to find useful links that can help you as you learn.

Discovery activities

All discovery activities and their associated worksheets can be found in the [discovery](#) section of this module. It is suggested that you open your Web browser to this page as you follow the activities below.

Activity 1. Having a plan

Having an agenda and a list of questions ready can help you prepare for a doctor's visit and reduce the worry that you'll forget things. Use the tools provided with this activity to help you prepare for your next doctor visit.

Agenda: A list of things to be acted on

- Your health concerns
- Your symptoms and changes in your health condition
- How your medications are making you feel
- Questions you have
- Internet research you've done and would like to talk about



Let your doctor (and his or her receptionist) know ahead of time what you'd like to talk about

Activity 2. Keeping track of medications

Keeping track of medications and how they make you feel is an important part of partnering with your doctor. This activity provides tools for keeping a medication diary. Remember to discuss this diary with your doctor.

Activity 3. What's important to you?

You should assess what's important to you when evaluating your relationship with a health care provider.

- Is the doctor part of your health plan?
- How does he or she rate?
- Does he or she have privileges at the hospital of your choice
- Does he or she have experience that meets your needs?
- Does he or she listen, explain things, and treat you with respect?



This activity provides some resources for rating doctors. How does your current doctor rate?

Activity 4. What's on your record?

If you skipped the [creating a personal health record](#) module, you might want to visit it. Creating a personal health record can be a tool for working with your doctor more effectively by providing the different members of your health care team with shared access to your medical records. Take some time to reflect on how much you know about your own medical history.

Activity 5. Learning more

You also might want to review (or visit anew), the [finding health information](#) module to learn more about your condition. For this activity, perform a search to find information about your personal health condition(s) and take notes so that you can create a list of questions for your doctor. Review the [guidance](#) section of this module for tips on how to discuss internet research with your doctor.

Activity 6. Weighing treatment options

This activity is just a sneak preview of some of the things you'll be learning in the [weighing treatment options](#) module. It's a reminder that having an effective partnership with your doctor means playing an active role in treatment decisions.

Find out about your doctor's
decision-making process
and be a part of it.

Module 4: Weighing treatment options

Module overview

The goal of the module is to help you develop questions for your doctor about treatments and to appreciate the importance of participating in treatment decisions. The information in this module is meant to complement module 3 ([partnering with your doctor](#)) information, so if you haven't looked at that module yet, you might want to check it out.

Objectives

You will be able to:

- Identify and prioritize a list of questions for your doctor about treatment options
- Identify important information on a medication's label and find out more about a medication on the internet
- List some criteria for choosing a hospital
- Search for information about clinical trials and find information about eligibility requirements
- Find a social network with interests and expertise on a particular condition
- Using the internet, find at least one patient assistance program that can provide advocacy and financial counseling

Learner prerequisites

None

Suggested learning experience



Enter the [guidance](#) section for tips on learning more about your condition and treatment options available so that you can make informed decisions. You'll find some quizzes and suggested discovery activities here. You can pause the module to complete the activities or try your hand at them later.



Enter the [stories](#) section to help fictitious characters deal with common scenarios that can arise when weighing treatment options.



If you haven't yet, enter the [discovery](#) section to take part in activities related to this module.

Enter [resources](#) at any point to find useful links that can help you as you learn.

Discovery activities

All discovery activities and their associated worksheets can be found in the [discovery](#) section of this module. It is suggested that you open your Web browser to this page as you follow the activities below.

Activity 1. Ask and ask again

The stress of a new diagnosis can make you forget your questions. This activity's designed to help you prepare a list ahead of time to take with you to a doctor visit. There's a worksheet you can use and a question list builder.



Activity 2. Your medication

Your doctor may prescribe a medication as part of your treatment strategy. For this activity, use the links provided for this activity to find out more about a medication you're taking or are interested in learning more about. The [guidance](#) section of this module provides tips on finding patient-friendly information on medications.

Activity 3. Taking charge with lifestyle

Sometimes a change in lifestyle can have an important impact on your health. This activity provides worksheets you can use to start replacing old unhealthy habits with new healthy ones.

Activity 4. Learning about your condition

As you explore treatment options, consider learning more about your health condition. You can use the worksheet provided with this activity to help you with your own research. Remember that obtaining this information is not a substitute for seeking professional medical advice.

Activity 5. Rating hospitals in your area

Even if you aren't faced with a hospital stay, you might want to investigate some of the hospitals in your area.

As you learned in the [guidance](#) section of this module, some of the important criteria for evaluating a hospital include:

- Is it accredited by the [Joint Commission on Accreditation of Healthcare Organizations](#)?
- How is it rated by state, consumer, or other groups?
- Is it one where your doctor has privileges?
- Is it covered by your health plan?
- Does it have experience with your condition?
- Procedures to treat your condition?
- Has it had success treating patients with your condition?
- Does it continuously work to improve its own quality of care?

Use the worksheet provided for this activity to review criteria for choosing a hospital and try rating hospitals in your neighborhood using the links provided in the [resources](#) section.

You also may want to investigate clinical trials being offered by hospitals in your area. Review the benefits and risks of clinical trials described in the [guidance](#) section of this module and view the simulation demonstrating how to find a clinical trial using the [National Cancer Institute database](#). Try and see if you can find a clinical trial being conducted in your area (for example, search for a breast cancer or prostate cancer clinical trial). When you identify a trial, see if you can find information relating to the eligibility criteria for that trial.

Activity 6. Finding support

Social networks for health can provide emotional and practical advice for dealing with health challenges, particularly if community members have gone through what you are going through now. The [resources](#) section of this module identifies some health social networks. (This site

doesn't endorse any of these in particular; it's for you to decide if you want to explore and feel comfortable joining one).

You may find that you're interested in the services of a patient advocacy group. Review the [guidance](#) section of this module to consider some of the services offered by such groups. Are any of these, services you want and/or need? Not all advocacy groups are free but the [resources](#) section of this module includes links you can investigate further.

Conclusion

Developing your skills as a participating patient is a continuous process. The goal of the [Becoming a Participating Patient](#) Web site is to provide you with tools for this journey. Remember that any health information on this site is not a substitute for medical advice. Explore the site using this guide but be encouraged to create a personal learning experience that suits your needs.