5/14/2010

INSTRUCTOR'S GUIDE

BECOMING A PARTICIPATING PATIENT

Empowering Individuals to Use Health Information Technology

Becoming a Participating Patient

Course overview

The goal of this course is to provide individuals with an understanding of online tools that can help them become more active participants in their 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 individuals are grappling with acute or chronic health conditions. An additional goal is to provide individuals with general guidelines for approaching health problems and health care decision making so that they can ask informed questions of their health care providers.

Course structure

There are four modules in this course:

- Finding health information
- Creating a personal health record
- Partnering with your doctor
- Weighing treatment options

This course is supported by the *Becoming a Participating Patient* Web site
As the instructor, you will be enabling learners (who will have diverse backgrounds) to create their own productive learning experiences using the Web site, while providing basic background, practice activities, and assessment challenges to engage learners in the material and increase their confidence. If you are a member of a health social network, consider using the discussion forum of your social network for discussions and to complete discovery activities associated with these learning modules. However, you also can use any suitable learning management system, such as Moodle, for example.

Learning theories and instructional methods

Learning theories applied in the course include: adult learning theory (establishing personal relevance whenever possible) and cognitivism (allowing to learners to consider their prior knowledge structures and sequencing learning modules to build on prior knowledge). There are constructivist elements to the modules in that learners can build individualized learning experiences using the Web site, but there are objectives and assessment activities so a pure constructivist approach isn't adhered to. Component display theory was used to develop presentation, practice, and assessment activities, and to match these to the content required to master objectives.

The instructional approach in the *guidance* sections of these modules generally relies on

Gagné's Nine Events. Bloom's Taxonomy was considered to create practice and assessment activities. Students will generally have a range of practice and assessment activities (comprehension, apply, synthesis and evaluation activities). Case-based learning activities are provided in the *stories* section of the modules, allowing learners to explore realistic scenarios to facilitate transfer of knowledge to their daily lives.

Important note

Discussions of specific health issues may occur during these lessons. Avoid offering medical advice, providing opinions on treatments, or doctors, etc. Remind students that they should consult their doctors about any health information they may hear about during the course or find on the internet.

In this guide

For each module, you will find:

- A module overview
- List of instructional materials required
- List of student materials required
- Objectives
- Learner prerequisites
- Instructional strategies including:
  - o Presentation and/or experience suggestions
  - o Suggested chunks of instructional materials
  - o Discussion topics
  - o Practice activities
- Assessment challenges
- Tools for enhancing transfer

There will also be tips and suggestions for alternate instructional strategies.

Instructor tools and prework for course

Instructors should have access to a tool for presenting information online that allows for learner discussion, polling, screen sharing, and the ability to allow students to form breakout groups for discussion. Adobe Connect Pro® is one example of such a tool.

Instructors should familiarize themselves with *Becoming a Participating Patient* Web site and to view the navigation guide.

Course Introduction (5 minutes)

1. Introduce the course. Give an overview of what will be learned and establish relevance to learners' needs. You can use the introductory text and video on the home page of the *Becoming a Participating Patient* Web site as an example.

2. Poll the audience to assess common experiences (e.g., frustration in finding credible health information, rushed doctor visits, perceived involvement, or lack thereof, in decisions affecting their health care).

3. Introduce the use of the *Becoming a Participating Patient* Web site as a learning tool. Provide an overview of the Web site's structure, the four modules of the course, and the four learning avenues provided for the course (e.g., *guidance*, *stories*, *discovery*, and *resources*). (The *getting around this site* module can be used as a reference.)

4. Make sure each student understands how to access their Learner's Guide and worksheets for the lessons (described further below).

5. Remind students that the internet is not a substitute for medical advice.

Instructor notes:

Module 1: Finding health information (30 minutes)

Module overview

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

Instructor tools and prework

- Access to Adobe Connect Pro®
- Review the finding health information module on the Participating Patient Web site
- Practice a search for health information
- Identify some trustworthy health information Web sites and some problematic Web sites

Student materials

- Learner's guide
- *In your sites* (internet search) worksheet (Activity 1 in discovery)
- *That's incredible!* (aid to evaluate credibility) worksheet (Activity 3 in discovery)

Objectives

A learner 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

Conditions: The learner can use the worksheets and *Learner's Guide* to help him or her accomplish these objectives.

Learner prerequisites

Students should be familiar with basic terms relating to internet searching (e.g., url, links, menu, scrollbar, etc). Students can learn these terms or refresh their memories by accessing the resources section of this module and reviewing *internet basics*.

Instructional strategies

Gain learners' attention using a poll: Ask how many have searched for health information online. Gauge learners' confidence in their searching ability.

State objectives and tie to learners' experiences; explain how objectives will help meet their needs.

Tip: Students may express confidence in their search abilities but may be less confident in their ability to identify credible information.

Presentation: Give learners an overview of different types of search engines (general vs. specialized) and discuss how search results can vary depending on which type of search engine you use.

Stimulate recall of prior learning by asking learners which search engines/health information sites they like and why.

Discuss basic strategies for finding relevant health information.

Tip: Learners will have diverse experiences in searching. If students appear confident in basic search strategies, discuss advanced search techniques (e.g., use of Boolean operators, excluding terms).

Alternative strategy: Consider making the section on searching brief and spending more time on weighing credibility.

Simulation: Share your screen as you perform a search. Allow learners to provide input and ask questions about your search strategy. Explain how search results can be triaged by examining urls.

Alternate strategy: If screen sharing doesn't work, screenshots may be used to demonstrate.

Practice: Ask learners to evaluate the same search terms using different types of search engines, recording their results on the *In your sites* worksheet (Activity 1, discovery). Divide learners into three breakout groups: one using a general search engine, another using a specialized search engine, and another using a health information Web site. Ask learners to report on their findings and comment on differences in search results.

Poll the audience to gauge their confidence in finding reliable health information online. Do they feel that most information is credible?

Present the 3W's for evaluating the credibility of an internet article: Who said it? When was it said? What's the evidence? (See guidance.)

Tip: Learners may feel least comfortable in identifying evidence or lack of evidence. Consider providing more examples to demonstrate this type of evaluation.

Simulation: Share your screen as you perform review a credible Web site (e.g., such as The National Diabetes Information Clearinghouse site). Demonstrate how each W of the 3W's is satisfied by the site. (An example of such a simulation is provided in guidance.)

Practice: Divide the learners into breakout groups again and review some of the sites they found in their last practice and have them identify whether the site is credible. Ask learners to share their findings.

Alternative strategy: Assign learners specific Web sites to review. Consider using some of the comprehension-testing questions in the guidance module.

Present strategies to help students make sense of health information.

Ask learners what strategies they've used.

Practice scenario: Ask learners' how to help a fictional patient make sense of search information. See scenario 1 of the stories section of this module.

Tip: Remind learners that they should not substitute internet information for medical advice.

Summarize the module take-homes. (See the guidance section for suggested take-homes.)

Assessment

Assign learners the task of searching on a health topic that interests them using a general search engine, a specialized search engine, and a health information Web site and report on their search results using the *In your sites* worksheet (Activity 1, discovery). Have learners identify one new health information Web site they have not used before and evaluate it for credibility using the *That's incredible!* worksheet (Activity 3, discovery). Have learners describe strategies they would use to make sense of the information. Learners should post their

answers on the community forum of the health social network the instructor is a member of. (The instructor also might decide to use an LMS for this course such as Moodle.) Allow learners one week to post their answers and provide feedback.

Enhancing transfer: Learners can use the Participating Patient Web site for continued study and resources.

Instructor notes:

Module 2: Creating a personal health record (30 minutes)

Module overview

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

Instructor tools and prework

- Access to Adobe Connect Pro®
- Review the creating a personal health record module on the Participating Patient Web site
- Identify 3 free PHR providers and review their services using the PHR checklist so that you can comment on learners' group practice. Examples can be found in resources ("selecting a PHR provider").

Student materials

- Learner's guide
- *Making a list* (collecting PHR information) worksheet (Activity 1, discovery)
- *PHR checklist* (aid to evaluating PHR providers) worksheet (Activity 3, discovery)

Objectives

A learner 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 his/her needs
- Describe what it means to say that some PHRs are not protected by HIPAA laws

Conditions: The learner can use the worksheets and *Learner's Guide* to help him or her accomplish these objectives.

Learner prerequisites

- None

Instructional strategies

Gain the learners' attention by asking how many have more than one doctor/more than one set of medical records and whether they've ever had difficulty answering their doctor's questions about their medical history.

Tip: Steer the conversation to a general discussion and remind students they should be cautious about sharing the specifics of their health information.

State objectives and tie to learners' experiences; explain how objectives will help meet their needs.

Presentation: Introduce concept of a PHR and show video of doctors describing benefits of a PHR.

Tip: It's anticipated that learners will have a very general idea of what a PHR is at best and may confuse the idea of a PHR with medical records that their doctor(s) keep so it's important to spend some time distinguishing between the two.

Alternative strategy: Poll the audience to identify learners who have a PHR and ask them to describe features they like or wish could be improved.

Discuss learners' opinions of benefits of PHRs.

Tip: The goal of this module is not to "sell" the benefits of PHR so encourage alternate opinions and stress that creating a PHR is a personal choice.

Presentation: Describe components of a PHR and the steps for creating a PHR.

Tip: Present an overview of PHR creation and point learners to the resources section of the module for further details. Consider checking learners' comprehension of data ownership issues with a quiz question. See guidance for an example.

Practice: Have learners reflect on the components that would be most useful for them in a PHR.

Tip: Keep the discussion general to avoid discussing learners' personal medical situations.

Presentation: Describe considerations for selecting a PHR provider and familiarize students with the *PHR checklist* (Activity 3) in the discovery section. Introduce learners to the myPHR site, which provides an interactive tool for identifying PHR providers (scroll to the bottom of the Web page that opens).

Presentation: Discuss the HIPAA privacy law and which PHR types are covered by HIPAA. Test learners' comprehension of HIPAA by selecting a question from the list identified in Activity 6 of discovery.

Practice: Have students enter breakout groups and evaluate 3 different free PHR providers for the services they offer using the *PHR checklist* provided in Activity 3, discovery. Have students present their findings to the group.

Tip: Be ready to display screen shots showing how the different features of the providers' PHRs can be identified using the providers' Web sites.

Alternative practice: Have students help a fictitious person select a PHR provider. See scenario 2 in the stories section of *creating a personal health record*.

Summarize the module's take home lesson. (See the guidance section for suggested take-homes.)

Assessment

Ask learners to reflect on the uses and benefits of a PHR. Have them identify components of a PHR that would be in their ideal PHR. Have learners research the offerings of 3 different PHR providers and describe their features using the *PHR checklist* provided in Activity 3, discovery. Have learners identify whether the offerings are protected under HIPAA and describe what this means. Learners should post their answers on the community forum of the health social network the instructor is a member of. (The instructor also might decide to use an LMS for this course such as Moodle.) Allow learners one week to post their answers and provide feedback.

Enhancing transfer: Learners can use the Participating Patient Web site for continued study and resources.

Instructor notes:

Module 3: Partnering with your doctor (30 minutes)

Module overview

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

Instructor tools and prework

- Access to Adobe Connect Pro®
- Review the partnering with your doctor module on the Participating Patient Web site

Student materials

- Learner's guide
- *Having a Plan* worksheet (Activity 1, discovery)

Objectives

A learner will be able to:

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

Conditions: The learner can use the worksheets and *Learner's Guide* to help him or her accomplish these objectives.

Learner prerequisites

- None

Instructional strategies

Gain the learners' attention by asking them about their experiences with doctors:

- Do office visits go by too quickly?
- Do they feel intimidated?
- Do they sometimes (or often) don't get the information they need?

Tip: Keep discussion general. Avoid discussing specific medical problems.

State objectives and tie to learners' experiences; explain how objectives will help meet their needs.

Ask what learners brought with them to their previous doctor visit. Allow some time for discussion. Provide tips for additional tools/information they might bring. See guidance module for ideas.

Presentation: Describe the importance of having an agenda prior to a doctor visit and discuss important issues to bring up at a doctor visit. See guidance module for ideas.

Discuss creating and prioritizing a list of questions prior to a doctor visit and provide examples.

Tip: Keep discussion general and focused on the idea of understanding a doctor's decision-making process and being part of it. Avoid discussing specific medical problems.

Practice scenario: Ask learners' to help a fictitious patient prepare for a doctor's visit. See scenario 1, in the stories section of the module.

Alternative practice: Have learners discuss, in general terms, strategies that made particular office visits more efficient/effective.

Ask learners if they've ever discussed internet information with their doctor. Were their experiences positive?

Tip: Caution learners not to identify their doctors by name.

Practice scenario: Ask learners' how a fictional patient can improve her experience discussing internet research. See scenario 2, in the stories section of the module.

Alternative practice: Have learners discuss, in general terms, strategies that made their own discussions more positive.

Presentation: Provide tips for remembering information provided by a doctor. See guidance for tips.

Ask learners to share their experiences (again, in general terms).

Presentation: Describe how learners can follow-up on questions they have after a doctor visit. Remind learners that they should "ask and ask again."

Presentation: Provide considerations for changing doctors when a relationship isn't working.

Guides: Alert students that they can find links of consumer rating sites for doctors in the resources section of the Becoming a Participating Patient Web site.

Tip: Alert learners that many consumer rating sites allow for anonymous ratings which means that ratings should be taken with a grain of salt.

Summarize the module's take-home lesson. (See, the guidance section for suggested take-homes.)

Assessment

While learners are provided with real-world practice tasks, the instructor should be cautious about creating assessments that might cause learners to reveal personal medical information. One type of assessment can include providing a fictional scenario of a patient preparing for a doctor visit and unable to ask all of the questions he/she has. Have learners assist the patient in preparing a list of questions and describe how they would coach the patient to follow-up. Also have learners identify how they would help this patient remember information obtained at a doctor visit. Provide an additional scenario where the patient has a less than positive experience in discussing internet research and have learners reflect on how the patient might have improved his/her experience. Ask learners to help the fictitious patient identify considerations for choosing a new doctor.

Learners should post their answers on the community forum of the health social network the instructor is a member of. (The instructor also might decide to use an LMS for this course such as Moodle.) Allow learners one week to post their answers and provide feedback.

Enhancing transfer: Learners can use the Participating Patient Web site for continued study and resources.

Instructor notes:

Module 4: Weighing treatment options (30 minutes)

Module overview

The goal of the module is to help learners develop questions for their doctors about treatments and to appreciate the importance of having a voice and participating in their treatment.

Instructor tools and prework

- Access to Adobe Connect Pro®
- Review the weighing treatment options module on the Participating Patient Web site

Student materials

- Learner's guide
- *Learn about your condition* worksheet (Activity 4, discovery)
- *Rating hospitals* worksheet (Activity 5, discovery)

Objectives

A learner will be able to:

- Identify and prioritize a list of questions for his/her 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

Conditions: The learner can use the worksheets and *Learner's Guide* to help him or her accomplish these objectives.

Learner prerequisites

- None

Instructional strategies

Gain the learners' attention by asking them to relate to situations where they've felt vulnerable in making treatment decisions.

State objectives and tie to learners' experiences; explain how objectives will help meet their needs.

Stimulate recall of prior experiences: Ask learners if they've felt that they played a central role in treatment decisions.

Tip: Keep the discussion general and caution learners not to disclose the specifics of their medical situation.

Presentation: Present guidelines for asking questions of doctors about treatments and sample questions.

Discuss creating and prioritizing a list of questions prior to a doctor visit and provide examples.

Tip: Keep discussion general and focused on the idea of understanding a doctor's decision-making process and being part of it. Avoid discussing specific medical problems.

Practice: Ask learners how much they know about a condition they're being treated for. Introduce learners to the *Learning about your condition* worksheet (Activity 4, discovery) and have them fill out the worksheet outside of class.

Alternative practice: Assign learners a particular condition to investigate and divide them into breakout groups to fill out different sections of the worksheet (identify relevant urls only) and report on sites they found.

Presentation: Present guidelines for reading a prescription label.

Test comprehension by pointing to part of the label and asking learners to help identify it (e.g., ask them to point out the expiration date on a label).

Presentation: Present guidelines for finding trustworthy information about medications online. **Simulate** a search for medication information using Daily Med and/or the NIH Drug Information Portal. Present guidelines for reading the Patient Information Sheet that comes with a medication and for reading a medication's prescribing information (PI).

Tips: Many learners may be intimidated by the complexity of a PI. Stress that

the strategy behind reviewing a PI is simply to identify sections for further discussion with their doctor.

Alternative strategy: If screen sharing doesn't work, present screen captures showing relevant portions of a reliable Web site for finding information about medications.

Practice scenario: Ask students to help a fictitious patient find patient-friendly information on the Daily Med site (see scenario 2 in the stories section of weighing treatment information) and to identify the section of a PI where they can find information about side effects.

Presentation: Present guidelines for choosing a hospital. Familiarize learners with the worksheet for selecting a hospital (Activity 5, discovery).

Practice: Have learners identify and rate local hospitals in their area using the worksheet after class.

Alternative strategy: Have learners share their general experiences with hospitals and tie the discussion to the worksheet criteria.

Presentation: Tell students that clinical trials can be a treatment option. Present information on clinical trials (benefits and risks) and **simulate** a search for a clinical trial using the NCI clinical trial database.

Alternative strategy: Consider shortening this section to present an overview of when learners might consider clinical trials and point learners to the resources provided in the resources section since learners will be most receptive to remembering the information at time of need.

Discuss why identifying the eligibility criteria for a trial and discussing it with your doctor is important.

Presentation: Present information on social networks for health and the potential benefits of such groups. Alert learners that they should be cautious about sharing the specifics of their health information and that they should evaluate any health information for credibility using the 3Ws test (see, guidance in finding health information).

Ask learners if they belong to any and what they gain from these groups. Ask students to share how they assess information for credibility.

Tip: The instructor may point out the features of a site he/she has experience with but remember the point of this lesson is not to promote one social network over another. Learners should only be encouraged to join such a network if they feel comfortable doing so. Remind learners that even if sites include professionals (e.g., doctors, nurses), the sites are not a substitute for obtaining professional medical advice.

Presentation: Present information on patient advocate (PA) groups. **Poll** the group to see if they've heard of or used patient advocates before. (Many people haven't.) Describe the potential benefits of these groups and point to the resources section of this module for links to some PA organizations.

Tip: Don't overpromise the services of these groups as many organizations differ. Caution that learners should view these organizations as consumers and balance the offerings against their needs.

Summarize the module's take-home lesson. (See the guidance section for suggested take-homes.)

Assessment

As with the previous module, while learners are provided with real-world practice tasks, the instructor should be cautious about creating assessments that might cause learners to reveal personal medical information. One type of assessment can include providing a fictional scenario of a patient dealing with a new diagnosis.

- Ask learners to prepare a question list for this patient and help the patient find more information on a medication prescribed by the fictitious patient's doctor.
- Have the learner identify the url of a Web page providing access to the Patient Information Sheet associated with the medication and the PI.
- Have the learner compare the side effects listed in the Patient Information Sheet and in the PI.
- Also ask learners to reflect on different criteria for selecting a hospital.
- Have learners describe at least one benefit and risk of enrolling in a clinical trial as a treatment option. Consider having learners find information on clinical trials for an assigned disease (e.g., recurrent non-small cell lung cancer) and have them identify one or two trials in their location.
- If the learners are already part of the instructor's health social network, have learners reflect on the ways they've used the network. If the course is being administered by Moodle, have the learners review some social networking sites listed on the resources page and comment on ways in which they could be used to promote a health strategy. Ask learners to point out cautions they should have when using such a network.
- Ask learners to investigate some patient advocacy groups using the resources page and to reflect on some of the different services offered by these groups. Ask learners to identify which services are free and which services are fee-based.

Learners should post their answers on the community forum of the health social network the instructor is a member of. Alternatively use an LMS for this course such as Moodle. Allow learners one week to post their answers and provide feedback.

Enhancing transfer: Learners can use the Participating Patient Web site for continued study and resources.

Instructor notes:

Course wrap-up

Provide learners with a big picture summary of some of the topics they've learned about and stress that the learners' learning experiences will be a continuous process. Reiterate that the Participating Patient Web site can be used for resources and activities. Refer students to the *Learner's Guide* provided at the Web site.