

ATTACHMENT 2

Evaluating MedlinePlus Connect: A Qualitative Analysis

As an initial partner in the development of MedlinePlus Connect, The Institute for Family Health was uniquely positioned to pilot test a qualitative study of the use and usability of this patient resource directly from an existing patient portal application. MedlinePlus Connect was implemented within the Institute's patient portal, *MyChartMyHealth*, an application of Epic, in August 2009. Links to Spanish-language content were added in January 2010, when the Institute implemented the Spanish version of the patient portal, *MiRecordMiSalud*.

The Institute conducted usability testing for the portal application prior to the introduction of MedlinePlus Connect, with the goal of addressing potential barriers to its use among its patients with low levels of health and computer literacy. A number of modifications had previously been made to page layouts, text, and navigation options in the portal site. Under the current contract with The University of Pittsburgh, the Institute worked with a research team to develop and assess a protocol for studying the use and usability of MedlinePlus Connect from within a patient portal. Building on previous usability testing for the patient portal, the team developed a protocol that would assess patients':

- 1) ability to identify links to MedlinePlus Connect pages on the MyChartMyHealth webpages;
- 2) ability to find health information through the links;
- 3) ability to read and understand the health information presented through the links; and
- 4) opinions about the usefulness of the links in their own health management.

This pilot study was approved by the Institute's Institutional Review Board.

Patient Demographics: Thirteen patients of the Institute were recruited to participate in usability testing from three of its health centers, the Sidney Hillman Family Health Center, the Phillips Family Health Center, and the Family Health Center at North General. All patients were age 18 or over, had not attended college, spoke English, and had an existing appointment at a health center. Patient recruitment was specifically focused on patients with limited formal education as a proxy measure for low health and/or computer literacy in order to best identify barriers for this population. A description of participating patients, based on responses to a background questionnaire, is provided in Table 1 below.

Table 1. Patient Demographics

	Totals
1. How often do you use a computer?*	
At least a few times a week	9
Once every week or so	1
Once or twice a month	1
Every few months	1
Never	2

*One respondent checked two responses.

2. Do you use the Internet? Yes No Not sure	11 2 0
2a. If you answered no: Why don't you use the internet? (check all that apply) I don't know what the Internet is I don't know how to use the Internet I don't have access to the Internet I'm not interested in using the Internet Other	1 2 1 0 0
2b. If you answered yes: Where do you use the Internet? (check all that apply) At home At a friend or relative's home At work At a public library Other	8 2 1 3 1
3. If you use a computer, what are the reasons you use it? (check all that apply) Email Look up information Write or keep records Play games Listen to music/watch videos Other	10 11 5 5 6 2
4. If you use the Internet, do you use it to search for health information? Yes No Does not apply to me	9 4 0
4a. If you answered yes: Do you feel that the health information you find on the Internet is helpful to you? Yes No	10 0
4b. If you answered yes: Do you ever have problems understanding the health information you find on the Internet? All of the time Most of the time Some of the time Once in a while Rarely	2 0 4 4 1
5. What is your age range? 18-34 35-49 50-64 65 or older	1 3 8 1
6. What is the language you prefer to use with your doctor? English Spanish Other	13 1 0
7. Are you Hispanic or Latino? Yes No	7 6

8. What is your race? (check all that apply) Black/African American White Asian/Pacific Islander Native American/Alaskan Native Multi-racial Other	5 3 0 0 0 4
9. How would you rate your health? Excellent Good Fair Poor	1 5 7 0
10. How far did you go in school? (choose one) Did not complete high school Completed high school or GED Completed vocational/technical/trade school Some college or two year degree Complete college (4 years) Graduate school or higher	5 6 2 0 0 0
11. Are you currently employed? (choose one) Full time Part time Retired Unemployed	1 0 2 9

Usability testing: Patients were scheduled for usability testing sessions which lasted from 30 to 50 minutes per patient. Two Institute staff members were present at each session; one facilitated the session and one served as a notetaker. The usability testing protocol was described in detail to patients, and each was asked to sign a consent form. Patients completed the background questionnaire described above. They were then asked to complete a series of specific tasks using the patient portal account of a test patient, “Mercedes.” Patients were encouraged to think aloud as they navigated the portal, and to share their questions and opinions throughout the session. The usability testing guide is provided at Appendix A.

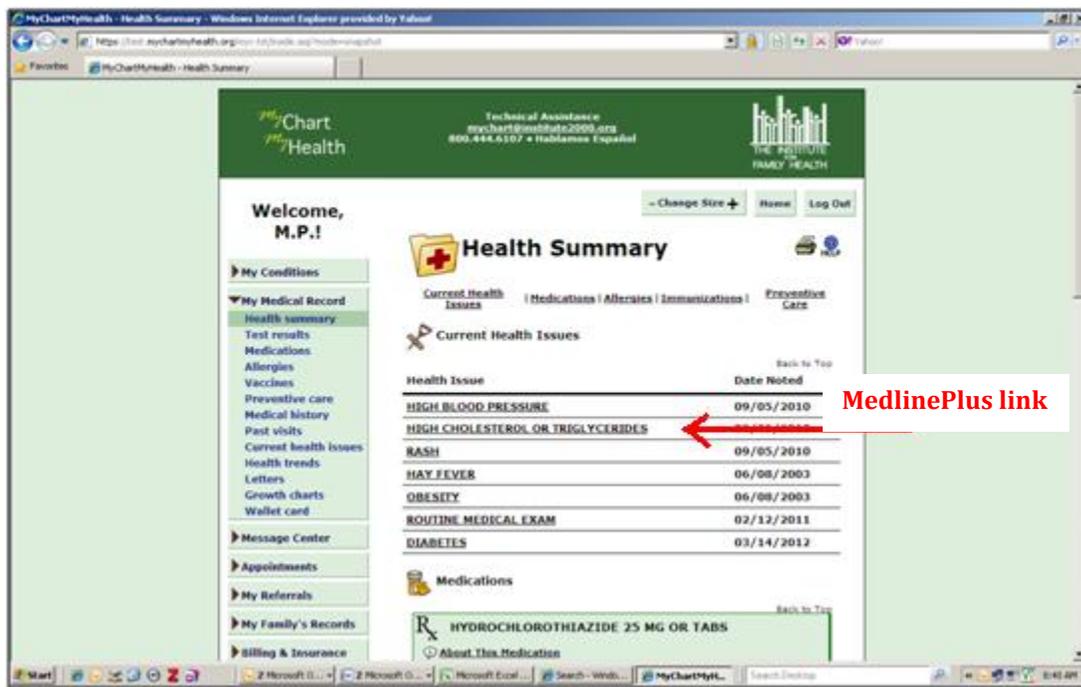
Initial login pages: The vast majority of participants were able to correctly identify the functions of the patient portal from the descriptions on the pre- and post-login home pages, they could navigate adequately, and felt that the amount of information presented was “just right”. One patient found the pages confusing, and one patient preferred to conduct the session in Spanish after attempting to read the English pages.

Health conditions: Most patients were able to locate information in the portal about the test patient’s health condition within one to three “clicks” as they searched through the page. Two patients needed significant help from staff to find the health conditions list. All patients appeared to readily understand the list of health conditions, which included high blood pressure, high cholesterol or triglycerides, rash, hay fever, obesity, routine medical exam, and diabetes, although triglycerides was an unfamiliar term to more than half the patients. At least one patient read the words phonetically and did not appear to comprehend the terms. One patient was unfamiliar with the word “obesity.”

Patients were then asked where they would go on the website to find additional information about diabetes. About half the patients were familiar with hyperlinks and immediately clicked on the word “diabetes”. The other half searched through the page and tried several locations,

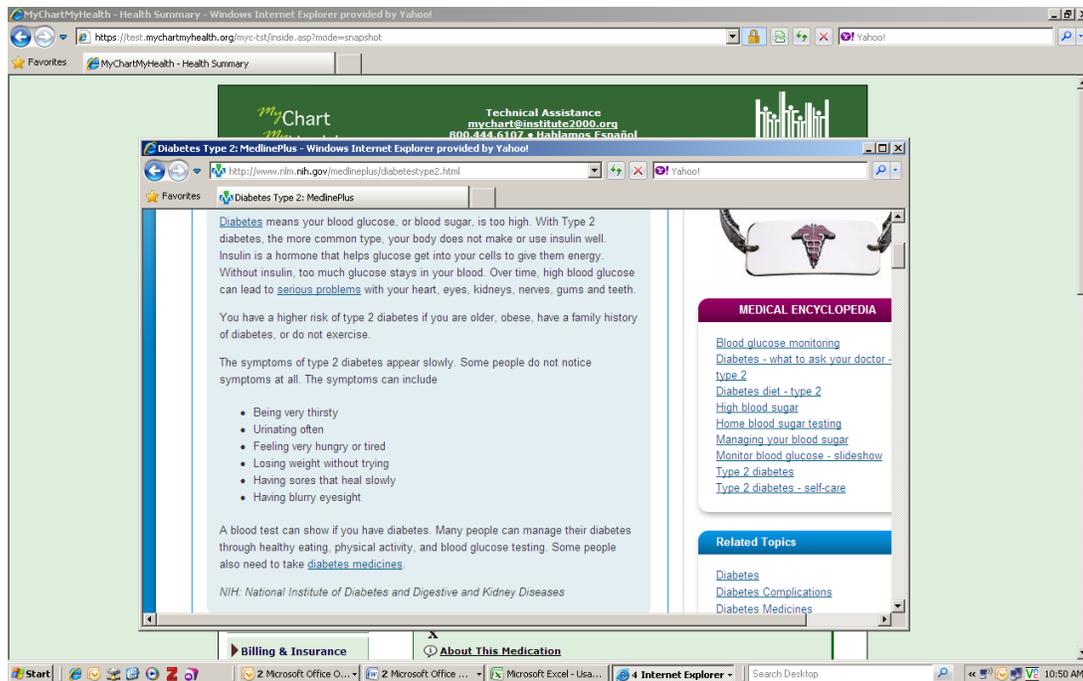
including the open MedlinePlus search box, before clicking on “diabetes”. Several patients could not find the link, and were assisted by staff.

Figure 1. List of Health Conditions Displayed in Usability Testing



Once on the MedlinePlus diabetes page, patients were asked to read the introductory text and define diabetes in their own words. About half the patients were able to explain diabetes based on the text they read. Several said the site did a good job of explaining the condition. Several felt the language was not clear. One patient stated that it was “not simple language that her family could help her with or understand.” Several patients did not appear to read the words on the page, but rather drew on their own knowledge of diabetes to explain it. For example, one patient said that diabetes involves the pancreas, although the word “pancreas” did not appear in the text that was read. One patient pointed out words that were unfamiliar (e.g., what is “insulin”? what is a “hormone”? what is “endocrine”?). Patients were less able to explain how someone with diabetes could manage their illness. More than half of the patients did not continue to read the “diabetes box” on MedlinePlus page to answer that question.

Figure 2. MedlinePlus Diabetes Page



When asked if there was any additional information they would want, several patients gave suggestions. One stated that she would like to know if the condition “has improved, gone down, or stayed the same.” (Test results over time can be graphed in MyChartMyHealth, but changes in conditions are not currently available.) One patient wanted to know about “the machines where you test your blood.” One patient stated that the information on diabetes was “20% of what a patient would need to know.”

Several patients were not familiar with the scrolling function, and did not navigate through the MedlinePlus Connect page. Of those who were more experienced computer users, several scrolled through the site and were impressed by the information options. At least two patients mentioned that they liked the fact that videos were available because “they are personal and they explain it to you.” Several patients also had trouble returning to the patient portal, as they were unfamiliar with the function to close the linked MedlinePlus Connect page (“x-ing out”).

Patients were asked if they trusted the information they had read about diabetes. It had been explained that the information in the portal was linked to MedlinePlus, which is operated by the National Library of Medicine, a branch of the Federal government. Of those who responded to the question, they uniformly felt they could trust government health information, although several said they would also ask their doctors.

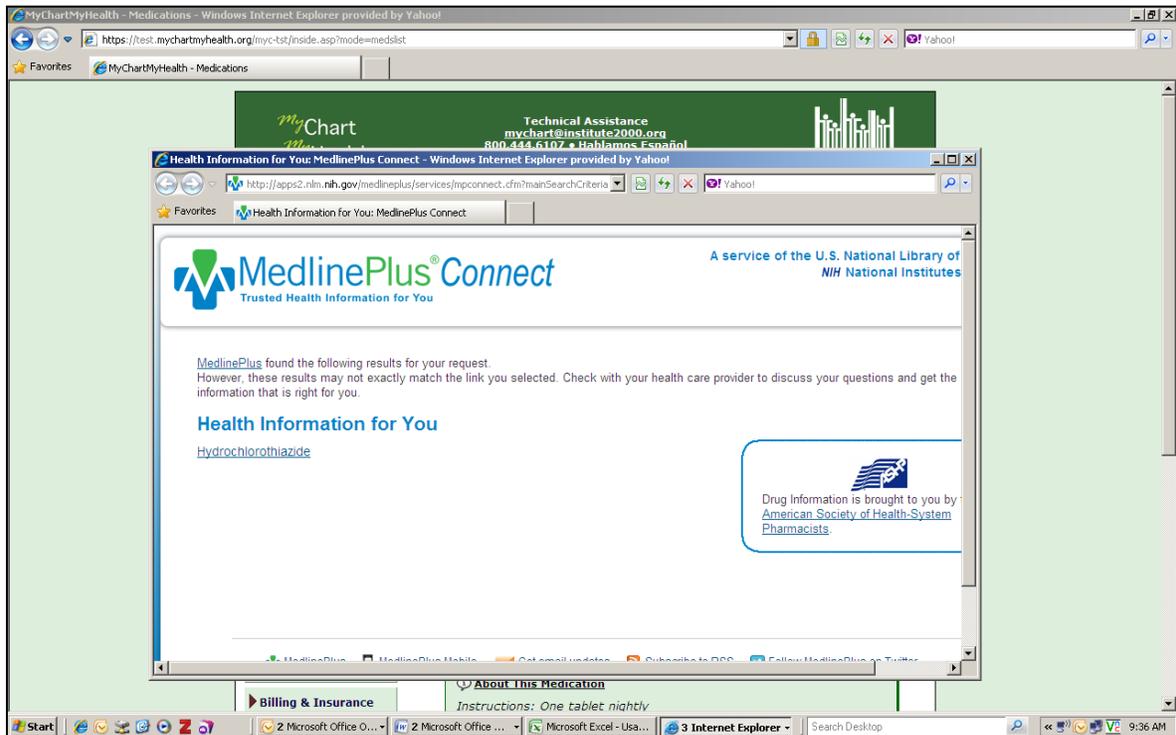
Patients were asked to find information about a second illness in Mercedes’s record: high cholesterol. Several patients had trouble navigating back to the list of health conditions. One patient went to the medications section and inferred Mercedes’s health conditions based on the prescribed medications. Once at the list of health issues, most patients now understood that they could click on the word “high cholesterol” to find more information, although at least one patient was not able to find more information about the condition. Patient seemed to more easily read back information on high cholesterol and to explain how Mercedes could manage her high cholesterol than they could with diabetes.

Medications: Patients were next asked to find information about Mercedes's prescribed medications. The MedlinePlus Connect links are presented differently on the medication pages, as illustrated in Figure 3. Despite having an information button and the words "About This Medication" appearing at the site of the link, patients had more trouble finding the link to MedlinePlus Connect for the sample medication, hydrochlorothiazide. Most patients had significant problems finding the medication information once they had been linked to the MedlinePlus Connect page. They most commonly clicked on the MedlinePlus link and the American Society of Health-System Pharmacists link before clicking on the word "hydrochlorothiazide." A few patients thought they had made a mistake or thought there was not a good page match for the medication when they read the lines, "However, these results may not exactly match the results you selected. Some patients appeared not to notice the word "hydrochlorothiazide" on the page. Once they found the additional link to the medication information, or were guided there, most patients found the information easy to understand.

Figure 3. List of Medications Displayed in Usability Testing



Figure 4. Medication Link Page to MedlinePlus Connect



Test results: Although the Institute’s portal does not yet have direct links to the test result pages in MedlinePlus Connect, patients were asked to look at test results as an additional measure of health literacy. Epic, the Institute’s electronic health record, does not support the LOINC codes required for the current MedlinePlus Connect link to medications; therefore, a MedlinePlus search link was programmed by Institute staff until LOINC codes are available. This link leads patients to a page of search results.

Patients found the test results section but the information links did not stand out clearly on the page for most patients; several thought the link should be more prominent. Overall, patients could read through the types of test results in the record. Most patients correctly interpreted the cholesterol test result as being a problematic result (i.e., some values higher than the standard range and some values lower than the standard range – see Figure 5.). However, several patients incorrectly interpreted the results as “fine”. One patient did not carefully review the numbers, as she noted that a concerning result would “flash or be in a different color,” indicating the expectations that computer users have about the display of information that requires their attention. One patient stated, “this is confusing to me, the numbers are confusing, this is just really confusing.” When clicking on the link for more information, most patients found the list of search results overwhelming and did not want to look through the pages.

Figure 5. Test Result Displayed in Usability Testing

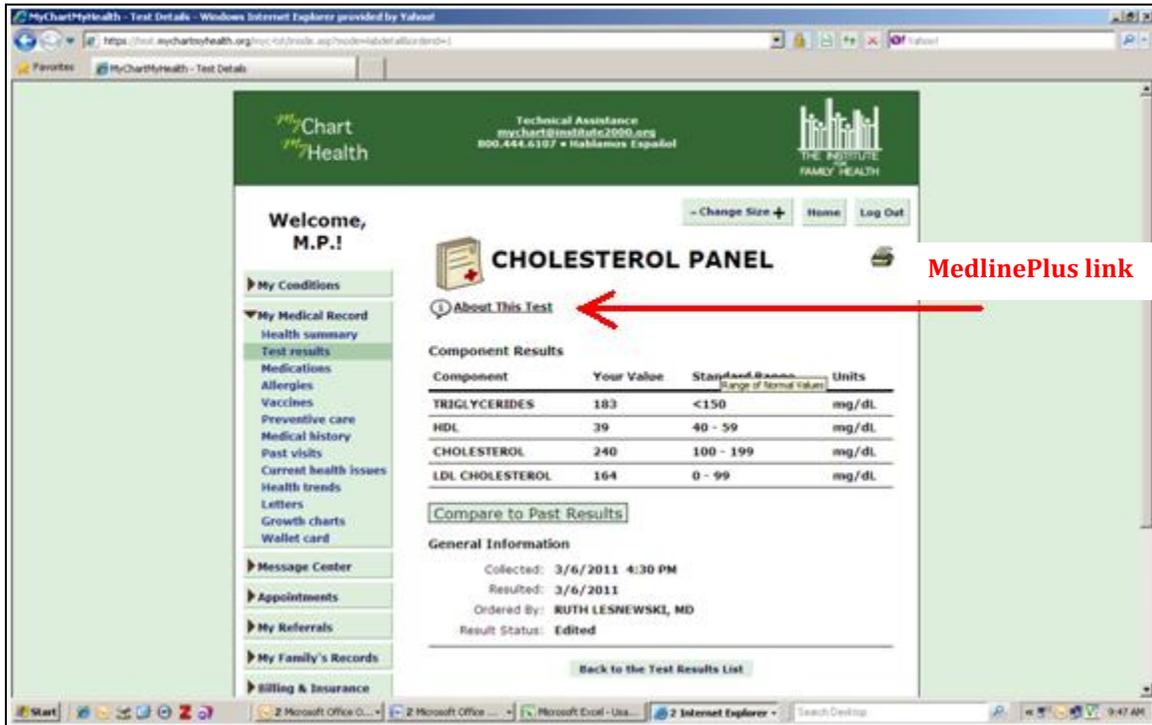
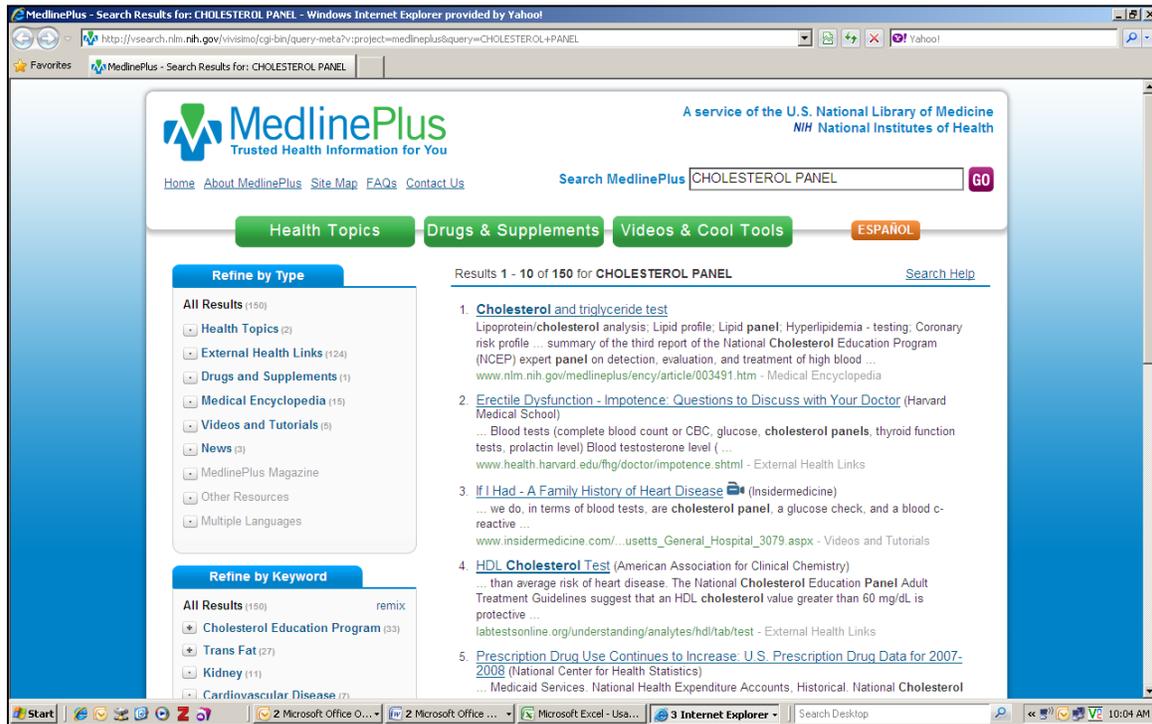


Figure 6. MedlinePlus Search Results for Cholesterol Panel



General comments: Participating patients offered a variety of general comments about the patient portal and MedlinePlus Connect. Regarding the portal, one patient noted that he had heard about it and thought it would be overwhelming, but by participating in the usability testing found that it is not. He further notes that there should be a demo or video that “shows patients that it’s pretty easy to use.” Another patient noted that “it looks simple, it’s confidential – that’s good.”

Regarding MedlinePlus Connect specifically, several patients noted that they liked the fact that additional health information could be accessed from their portal accounts. One patient stated that “Medline information is more convenient because it’s all together on one site and I do not have to do multiple searches.” Another noted that MedlinePlus Connect “takes you where you want to be and concerns you!” One patient stated that having all the extra health information would “calm him down.” He further noted that he would return multiple times, as it would be difficult to read all the information at one sitting. One patient advised that the “words could be broken down better” on the MedlinePlus Connect site.

Post-usability Testing Questionnaire: Following the usability test, patients were asked to complete a questionnaire about the patient portal and MedlinePlus Connect. The aggregated responses are presented in Table 2.

Table 2. Post-Testing Questionnaire

	Totals
1. In general, I found MyChart MyHealth easy to use.	
Strongly Agree	6
Agree	6
Neither Agree nor Disagree	1
Disagree	0
Strongly Disagree	0
2. In general, I found it easy to find the information I needed to do the tasks I was asked to complete today.	
Strongly Agree	10
Agree	1
Neither Agree nor Disagree	0
Disagree	2
Strongly Disagree	0
3. I found the language on the website clear and understandable.	
Strongly Agree	6
Agree	5
Neither Agree nor Disagree	1
Disagree	1
Strongly Disagree	0
4. I found the organization of the website to be clear and easy to navigate.	
Strongly Agree	7
Agree	5
Neither Agree nor Disagree	0
Disagree	0
Strongly Disagree	1
5. I would use MyChart MyHealth to review my health information.	
Strongly Agree	10
Agree	3
Neither Agree nor Disagree	0
Disagree	0
Strongly Disagree	0

<p>6. I found it easy to access (or get to) MedlinePlus when I was using MyChart MyHealth.</p> <p>Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree</p>	<p>9 3 0 1 0</p>
<p>7. I think that MedlinePlus provides useful information for patients.</p> <p>Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree</p>	<p>11 1 1 0 0</p>
<p>8. I would use MedlinePlus to find information about medical illnesses and treatment options.</p> <p>Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree</p>	<p>10 3 0 0 0</p>
<p>9. I would use MedlinePlus to find information about medications.</p> <p>Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree</p>	<p>10 3 0 0 0</p>
<p>10. Based on my experience today, I think that the MedlinePlus website is easy to understand.</p> <p>Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree</p>	<p>8 3 0 1 1</p>
<p>11. Based on my experience today, I think that the MedlinePlus website is well organized and easy to navigate.</p> <p>Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree</p>	<p>8 3 1 1 0</p>
<p>12. I found the language on MedlinePlus too technical.</p> <p>Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree</p>	<p>2 3 1 6 1</p>
<p>13. I think the words on MedlinePlus were large enough to read clearly.</p> <p>Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree</p>	<p>9 3 0 0 0</p>

14. I think that MedlinePlus is an important part of MyChart MyHealth.	
Strongly Agree	11
Agree	1
Neither Agree nor Disagree	0
Disagree	0
Strongly Disagree	0
15. Having access to MedlinePlus makes it more likely that I would use MyChart MyHealth.	
Strongly Agree	11
Agree	1
Neither Agree nor Disagree	0
Disagree	0
Strongly Disagree	0

Conclusions: Overall, the thirteen patients in the usability pilot test were very enthusiastic about MedlinePlus Connect. Because these patients, with one exception, had not been previously exposed to the patient portal, they expressed joined enthusiasm about the portal for accessing their own health record and the availability of the MedlinePlus Connect links to better understand the information in their records. Virtually all the participating patients access the Internet regularly and either are facile with computers or working on skill development (or feel they should). They clearly felt, on the whole, that MedlinePlus Connect brings additional value to the portal, and in fact, all patients agreed or strongly agreed with the statement, “having access to MedlinePlus makes it more likely that I would use MyChart MyHealth.”

Identifying the links to MedlinePlus Connect and navigating through the portal was challenging for some patients, but obstacles were generally easy to overcome with instruction. The Institute plans to make some changes in its page displays to make the links easier for patients to identify.

Once linked to MedlinePlus Connect, patients generally found the health information understandable, although two expressed a preference for videos rather than more text. Several patients felt some of the words were too technical. Patients had significant difficulty navigating past the interim MedlinePlus Connect page for medications. In general, they did not identify the link to the medication information easily or at all and several thought they had made a mistake. Our recommendation is to reformat the page to clearly identify the additional click required to navigate to the medication information, making the hyperlinked word larger and more central on the page, and possibly adding a “click here” instruction. If the link to the American Society of Health-System Pharmacists is not necessary, it may be helpful to eliminate this as it seemed to distract patients.

Usability testing, particularly among patients with low levels of health and computer literacy, is essential to measuring MedlinePlus Connect’s usability, usefulness, and relevance to the target population.

Appendix A MedlinePlus Connect Usability Testing Guide

Introduction

Thank you for coming to talk with me today. My name is _____ and I'll be working with you over the next hour. _____ is here to take notes so that we can better remember and learn from our discussion.

We will begin by reviewing exactly what we are going to do today. The steps are written out on this form, known as a consent form. We'll go through it carefully. Please feel free to ask questions at any time. Once we're finished and your questions have been answered to your satisfaction, you can decide if you want to continue with your participation. If you agree to participate, we'll ask you to sign the form. *Review the consent form with participant.*

Next we're going to ask you to fill out a questionnaire so that we know a little more about you and your experience with computers and the Internet. *Participant completes the background questionnaire.*

Now we are going to take a look at the health center's patient website called MyChart-MyHealth.

Make sure MyChart-MyHealth home page is open

Patients like you can sign up to use this website to look at their own health information. The website also lets you do things like send messages to your doctor, refill your prescriptions or make medical appointments. You can also find information related to health concerns that you might have such as your blood pressure or a medication you might be taking. We've asked for your help today because we want to make sure that this website is understandable, easy to use and helpful to patients. Today, we will demonstrate the website and ask you to perform a few tasks using the website, just as you would if you were looking at your own information. However, because this is a research project and we want to make sure that people's privacy is protected, we will be looking at made-up health information for a fake patient who we will call "Mercedes". So don't worry the information you are going to see doesn't actually refer to you or any other patient. We want your opinions about what you like, find valuable or dislike or find difficult to do or understand.

Do you have any questions? Feel free to ask questions at any time.

When we use the website and you come across something that you particularly like, or something you don't like or don't think is clear, please tell me. We would also like to hear about any suggestions you may have about how the site could be improved. Our job is to take your ideas back to the designers so that they can improve the website. Before we do that, we just to make sure that you are able to use the website, therefore I'm going to review some Computer and Internet basics. Don't be shy or feel that your comments or questions are silly – your input and ideas are very important to us.

The facilitator briefly reviews what the Internet is, basic operations like scrolling and using the mouse.

Now, I'm going to ask you to look at some information on the website and I'd like to get your opinion about it. We will use the website together and I will ask you to find information and read and explain to me what you see. I will then ask your opinion about: the way a page looks, the language that is used (is it too technical or difficult to understand), the way information is organized, how easy it is to get from one part of the website to another part of the website, and your overall likes and dislikes. Don't worry about making mistakes or if you can't figure out how to do something, or find something that is confusing, that's okay. Whether you've used MyChart before or not we want to get your honest reaction to the MyChart-MyHealth website. Our goal is to make sure that the website is designed so it is useful to you and easy for you to use. When we are finished we are going to ask you to complete a short questionnaire that asks questions about the website. Please answer these questions based on your experience today.

Do you have any questions? Are you ready to get started?

I. Home Page

The notetaker records responses to the tasks and observations of things like start and end time, any unusual events that occur, types of problems the participants have with each task or each page, types of questions asked, etc.

This is the very first page you will see when you go onto the MyChartMyHealth website. It is referred to as the "home page". I'd like to ask you some questions about the things you see on this page.

1. What kind of information is on this page?
What can you do / where can you go from this page?

Response: _____

Accurate Inaccurate Needs Assistance

What do you think about the amount of information that is on the page? Is it:

Too much Just right Too Little

Comments: _____

2. For today , we will use this user ID and a password for our "demonstration " patient (Mercedes). Now please use them to sign in to (Mercedes's) MyChart account.

Comments/observations: _____

Now we're in (Mercedes)'s MyChart personal health account. There are many things you can choose to do from here. Now, we would like to find out about health.

3. Where do you think you would find Mercedes's general health information?

Accurate Inaccurate Needs Assistance

Comments: _____

Let's go there and tell me what type of information you can find about Mercedes's health.

Comments: _____

Health Issues

4. Tell me what two of (name)'s current health problems are?

Response: _____

5. This page shows [or you identified] that Mercedes has a diagnosis of diabetes. Now, I would like you to find out more about diabetes. How would you do that from this page? Go ahead and find more information.

[If participant doesn't identify links, facilitator points them out. Do you have any ideas about how we can do a better job of letting patients know that they can click a word on this list to get to a page with more information on it?]

Comments: _____

6. So we're now looking at information about diabetes. Can you take a moment to read this? Can you tell me in just a few words what diabetes is: _____? Can you tell me whether you think this description does a good job of explaining what diabetes is: _____? Is there any other information you would want to have about diabetes if you were (Mercedes): _____? Now tell me about the types of tests and checks ups Mercedes should have to help control her diabetes

Comments _____

Was it hard to find the information you needed?

If so, how could it be made easier?

Was the information easy to understand?

Did you trust the information you found?

If yes, why? If no, why not?

7. Now let's go back and look at one more of Mercedes's health condition. Let's go back to the health record. (if participant can't do this – help them get back to the page and note)

We can also see that (Mercedes) has high cholesterol. Let's find out some more information about this health condition. Can you tell me in just a few words what cholesterol is and what can happen if you have too much cholesterol: _____? How can you lower your cholesterol: _____?

Okay let's go back to (Mercedes's) health record and do a few more tasks

Medications

8. Now let's switch gears and look at (Mercedes's) medications. How could you find out what medicines this patient is taking?

Accurate Inaccurate Needs Assistance

Comments: _____

9. You can see that (Mercedes) is taking a medication called hydrochlorothiazide. Let's find out more about this medication.

If patient can't find link, facilitator will point it out.

10. Let's look at hydrochlorothiazide . Can you tell me in just a few words why someone takes this medication; for what types of health problems: _____? How should this medication be taken: _____?

Was it easy for you to find this information?

Was the information understandable?

Did you trust the information you found?

11. Now let's do one more thing and look for (Mercedes's) test results. Where would you go to find those?

If patient can't find test results, facilitator will point it out.

What recent test(s) did (name) have? Let's look at the first one, cholesterol panel. Was the result(s) normal or something to be concerned about?

Named tests	Yes	No
Correctly interpreted results	Yes	No

Comments: _____

VIII. Close

You've done a lot of work today. How about if we wrap it up?

To do that you need to log out of Mercedes's MyChart account. You will need to do this anytime you finish using MyChart.

Finally, we would like you to complete this basic questionnaire to give us your opinions about My Chart and the tasks you performed today.

Participant completes the usability questionnaire.