

March 31, 2009

# Health Information Security and Privacy Collaboration

## Final Report—Provider Guidelines for Engaging Consumers in EHRs and HIE: What Your Patients Need to Know

Prepared for

**RTI International**

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Chicago, IL 60606

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**Office of the National Coordinator for Health IT**

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Washington, DC 20201

Prepared by

Consumer Education and Engagement Collaborative  
West Virginia

Health Information Security & Privacy  
**COLLABORATION**



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# CONTENTS

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<b>Section</b>	<b>Page</b>
<b>1. Background and Introduction</b>	<b>1-1</b>
1.1 Background .....	1-1
1.2 Introduction .....	1-2
<b>2. Creating the West Virginia Provider Guidelines for Engaging Consumers in EHRs and HIE</b>	<b>2-1</b>
2.1 Literature Review .....	2-1
2.2 Expert Review .....	2-2
2.3 Consumer Feedback .....	2-2
2.4 Summary .....	2-3
<b>3. Provider Guidelines for Engaging Consumers in EHRs and HIE</b>	<b>3-1</b>
<b>4. Provider Guidelines for Engaging Consumers: Consumer Version</b>	<b>4-1</b>
<b>Appendices</b>	
A: Provider Guidelines for Engaging Consumers in EHRs and HIE .....	A-1
B: Consumer Version: Provider Guidelines for Engaging Consumers in EHRs and HIE .....	B-1
C: Literature Review Methods .....	C-1
D: Guideline Web Search .....	D-1
E: Consumer Pretest Evaluation .....	E-1

# 1. BACKGROUND AND INTRODUCTION

## 1.1 Background

In 2006, the West Virginia Medical Institute (WVMI) and its partners received a Health Information Security and Privacy Collaboration (HISPC) subcontract from RTI International (RTI) to perform work on a contract funded by the Office of the National Coordinator for Health IT (ONC) to assess the variation in privacy and security business practices, policies, and laws governing electronic health information exchange (HIE) in West Virginia.

During the stakeholder outreach process required in HISPC Phase I, it became apparent that there was a lack of consumer knowledge and involvement in health information technology (IT) and HIE. In 2007, WVMI and its partners set out to address that gap through a HISPC Phase II project focused on understanding consumers' attitudes about health information exchange in general and about privacy and security, more specifically. The project team also wanted to develop information and materials of value to consumers. The project team targeted rural seniors and chronic care patients, especially those with diabetes. The team chose these populations because 70% of West Virginia is rural, while 15% is older than 65 compared to 12.4% nationally. West Virginia also has the highest diabetes rate in the country at 12.1% in 2006.

The West Virginia HISPC team partnered with the West Virginia Health Information Network (WVHIN) to take advantage of the focus group data that WVHIN had collected (under a separate funding source) and the data collected through a statewide telephone survey of 500 randomly selected residents. The HISPC team also conducted 20 consumer educational presentations about electronic health records (EHRs) and HIE. The presentations, which were funded by WVHIN in HISPC Phase II, explained the basics of the subject and offered consumers a chance to discuss the information.

The telephone survey, focus groups, and feedback from the educational presentations yielded the following observations:

- Consumers, while not resistant in general to EHRs and HIE, are concerned about security, confidentiality, and identity theft.
- Older consumers tend to be suspicious of EHRs at first, but the more they learn about them, the more open they are to their use.
- Consumers often said EHRs were more efficient, especially when physicians used them to exchange information with one another.
- Consumers of all ages believe EHR systems could provide crucial life-saving information in an emergency situation, such as when someone ends up in an emergency room in another state.

An equally important finding was that consumers wanted to learn more about the topics from their health care physicians. The project team learned that

- consumers have a great deal of confidence in their physicians, and
- consumers, especially seniors, want their doctors to educate them about EHRs.

## 1.2 Introduction

All of the literature reviewed suggested that the best way to engage consumers in a conversation about the privacy and security of EHRs was to have their physicians initiate the discussion in their offices. However, the project team realized that this could be burdensome for physicians and determined that patient brochures would be a more efficient approach. The project team developed two brochures as part of an eight-state Consumer Engagement and Education (CEE) Collaboration through HISPC.

This is the genesis of the “West Virginia Provider Guidelines for Engaging Consumers in Electronic Health Records and Health Information Exchange” project, which resulted in the following brochures:

- **“Provider Guidelines for Engaging Consumers in Electronic Health Records and Health Information Exchange: What Your Patients Need to Know.”** This brochure outlines the main points for physicians to keep in mind when discussing EHRs and HIE with their patients. (See Appendix A.)
- **“Electronic Health Records: What You Need to Know.”** This brochure takes the developed physician guidelines and transfers them into language and graphics that can be provided directly to patients. (See Appendix B.)

The remainder of this report discusses the development of the guidelines. Graphical versions suitable for reproduction and distribution are included as attachments. By providing physicians with guidelines for engaging consumers, as well as an informational brochure they could use to accomplish this goal, the project team hoped to contribute to the public’s knowledge of this important and emerging aspect of their health care.

## **2. CREATING THE WEST VIRGINIA PROVIDER GUIDELINES FOR ENGAGING CONSUMERS IN EHRs AND HEALTH INFORMATION EXCHANGE**

While these guidelines were developed, the project team took multiple steps to ensure that they summarized the best information available on EHRs and HIE and that consumers could easily understand the information. These steps included reviewing available resources, speaking with experts to obtain source materials, and submitting initial and final drafts for expert review (such review included the West Virginia HISPC Steering Committee, the West Virginia eHealth Initiative (WVeHI), WVHIN, a literacy expert, and the HISPC CEE). During the project's final step, drafts were tested with consumer audiences and physician champions. The physician champions were strong supporters of EHRs, and many had worked previously with WVMI on the Doctor's Office Quality-Information Technology (DOQ-IT) project that was part of the Centers for Medicare & Medicaid Services' 8th Scope of Work for Quality Improvement Organizations (QIOs). WVMI is the QIO for West Virginia. Following is a summary of this process.

### **2.1 Literature Review**

The project team's first step in 2008 was to conduct a literature review to learn what was available about privacy and security in journals and on the Internet. A search of journals yielded more than two dozen recent articles that established the importance of the topic but did not address key points in a guideline format. The search terms and titles of the articles are listed in Appendix C.

An Internet search revealed many items, including a report from the Center of Democracy arguing that comprehensive privacy and security protections were critical for health information technology. The search also revealed the Patient Privacy Rights website, which linked to about a dozen national health privacy polls in which Americans expressed grave concerns about the confidentiality of their medical information. The organization's library offered more than 50 online resources for concerned citizens, including studies, interviews, news stories, and websites. The search also revealed a variety of resources at the website of the Health Privacy Project, including several documents for consumers about their privacy rights.

In addition, other HISPC teams were invited to submit any materials that might be useful. Like the West Virginia project team, these teams in other states were working on similar projects, and they provided the online resources they had identified as helpful resources. The online materials from the Internet and those submitted by other states are listed in Appendix D. The print and online resources provided background material and valuable ideas about what kind of information to include in the educational materials that would be developed for physicians to use with their patients.

## 2.2 Expert Review

After completing the literature review, the project team asked the members of the HISPC CEE Collaborative to recommend EHR experts who could review the materials being developed. The members recommended Florida's HISPC project team. Those consulted included Technical Coordinator Christopher Sullivan, Government Analyst Carolyn Turner, and Business Analyst Lyric Cobb, all from the Florida Center for Health Information and Policy Analysis, Agency for Health Care Administration in Tallahassee, Florida. Additionally, the HISPC CEE Collaborative recommended the team consult with Barbara Lund, a Senior Pilot Executive with the Massachusetts eHealth Collaborative in Waltham, Massachusetts.

The experts recommended that the guidelines focus on the benefits of EHRs and how they can help physicians provide safer, more effective care. They also suggested that the guidelines mention the Health Insurance Portability and Accountability Act of 1996 (HIPAA) security requirements that help safeguard personal health information.

Next, the project team drafted the brochure and submitted it for review by experts in the state, as well as the WVHISPC Steering Committee, and the other states that worked together on the HISPC project. In addition, the brochure was submitted to a literacy expert, who provided extensive suggestions about simplifying the brochure to make it easier for consumers to understand. The brochure was revised and sent for a second review by the experts, including an expert in HIPAA and privacy law.

## 2.3 Consumer Feedback

While experts evaluated the draft of the provider guidelines, the project team created a list of consumer organizations that would be willing to provide feedback on the consumer brochure (guidelines recast in consumer-oriented language). Two groups of volunteers, one at a diabetes support group and another at a senior center, reviewed the brochure for content and design. Reviewers were asked to read the brochure and provide comments on its clarity, usefulness, and appearance. The support group members read the brochure and provided written comments, while the seniors read the brochure and provided verbal comments only. There were 15 volunteers altogether split roughly evenly among the two groups.

Feedback from the brochure review revealed the following:

- 10 out of 15 volunteers correctly identified that the main point of the brochure was the benefit of EHRs.
- 11 out of 15 volunteers could recall at least one benefit of an EHR.
- 10 out of 15 volunteers said they found the content believable, useful, and attractive.

- 12 of 15 volunteers said they liked the brochure's simplicity, organization and brevity, thorough approach, explanation of HIPAA, and its explanation of up-and-coming technology.

Four suggestions were offered to improve the brochure:

- Provide more information.
- Emphasize the security aspect.
- Make it more colorful.
- Change the cover.

After the provider guidelines and consumer brochure were completed, the final drafts were submitted again to experts for their review. Their responses were positive with no significant changes to either brochure. See Appendix E for the Consumer Pretest Evaluation.

## **2.4 Summary**

The West Virginia project team believes the Provider Guidelines for Engaging Consumers in EHR and HIE and the accompanying consumer brochure are useful resources for health care consumers and physicians. Physicians can use the tips in the guidelines to start a conversation with patients about the privacy and security of their personal health information. Physicians who want to make the move to health information exchange can distribute the easy-to-read brochure to their patients to help provide an overview of the topic. Both brochures can also be adapted by other states and tailored to meet the needs of their targeted population subgroups. The guidelines and the brochure have the benefit of being based on extensive consumer research. In addition, both have been reviewed by a variety of experts, including IT experts, health care experts, attorneys, and a literacy expert.

### **3. PROVIDER GUIDELINES FOR ENGAGING CONSUMERS IN EHR AND HEALTH INFORMATION EXCHANGE**

Provider guidelines in a format suitable for printing are included as Appendix A to this report. These guidelines can be

- copied and pasted into physician educational materials;
- used as a discussion guide; and
- presented in their entirety, in graphic form.

## **4. PROVIDER GUIDELINES FOR ENGAGING CONSUMERS: CONSUMER VERSION**

In Appendix B, the same information is presented in a form that physicians can use directly to engage consumers.

**APPENDIX A:  
PROVIDER GUIDELINES FOR ENGAGING CONSUMERS IN EHRs  
AND HEALTH INFORMATION EXCHANGE**

# Electronic Health Records: What Your Patients Need to Know



**e+Health**WV  
Your care. Your future. Learn more.

## **Electronic Health Records: Provider Guidelines for Engaging Consumers**

With more and more physicians replacing medical charts with electronic health records (EHRs), some of your patients may have questions. They may want to know what kind of safeguards you have in place to help protect the privacy and security of their personal health information, and they may want to know how an EHR can help benefit their health.

You can help your patients make this transition by discussing any privacy concerns they may have and help them understand how their health information will be used or disclosed. For example, you can explain if you participate in a health information organization or some other type of organization to electronically exchange health information and under what conditions you may share their information.

Here are some additional discussion points that address the privacy and security of EHRs.

### **There are laws to help protect medical records.**

State and federal laws help to protect medical records. Many of these laws include standards that are applicable to electronic health records.

### **The Health Insurance Portability and Accountability Act of 1996 helps to protect medical records.**

The Health Insurance Portability and Accountability Act of 1996 created standards to help protect personal health information.



## The HIPAA Security Rule helps keep medical records secure.

The HIPAA Security Rule requires health care providers to implement certain physical, administrative, and technical safeguards to protect the privacy of your medical records so that they can not be accidentally or illegally read, altered, shared or destroyed.



## The HIPAA Privacy Rule created national standards to help protect the privacy of personal health information.

The HIPAA Privacy Rule went into effect in 2003. It created national standards to help protect the privacy of personal health information by doing the following:

- It gives patients more control over their health information.
- It sets boundaries on the use and release of health records.
- It establishes safeguards that health care providers must meet to help protect the privacy of health information.
- It balances the need for patient privacy with the need to help protect public health.
- It generally gives patients the right to look at and get a copy of their health record and to ask that errors be corrected.

## State and federal laws offer increased protections for mental health and addiction treatment records.

State and federal laws offer increased protections for the confidentiality of records dealing with mental health and addiction treatment. The use of EHRs does nothing to alter this higher degree of confidentiality protection.

## An EHR system can benefit physicians and patients in the following ways:



### Reduces errors:

- Eliminates errors caused by illegible handwriting
- Checks to make sure the drugs patients are taking are not harmful when taken with other drugs

### Improves security:

- Allows physicians to back up all medical records. If the office catches fire or floods, the medical records are safe.
- Allows physicians to keep track of, and to limit, who looks at a patient's medical record.

### Saves time:

- Ends searching for a lost medical chart
- Ends thumbing through the pages of a patient's medical chart

### Improves care:

- Tells the physician when it's time for a patient to get tests and shots, such as a yearly flu shot
- Tells the physician when he/she needs to follow up on lab tests, especially if the tests show a patient has a problem



## An electronic health record can be good for your patients' health.

An electronic health record can let physicians send and receive health information about patients over the Internet. Physicians can share information about patients with other physicians, as well as with hospitals, labs and the pharmacy. That can benefit patients in many ways:

- Patients don't have to fill out their medical history over and over.
- Once a patient informs the physician about medications and allergies, the patient doesn't have to worry about forgetting to inform a new doctor.
- Other than routine tests, patients won't have to get the same tests twice because the physician can see if another physician has already ordered it.
- Patients' medical history will be easily accessible in an emergency.
- A physician can send a patient's prescription to the pharmacy, so the patient doesn't have to take it or wait for it to be filled.

**For more information, visit the eHealthWV Web site at [www.ehealthwv.org](http://www.ehealthwv.org).**

*This publication is made possible by the Health Information Security and Privacy Collaboration (HISPC) a contract managed by the Office of the National Coordinator for Health IT (ONC).*

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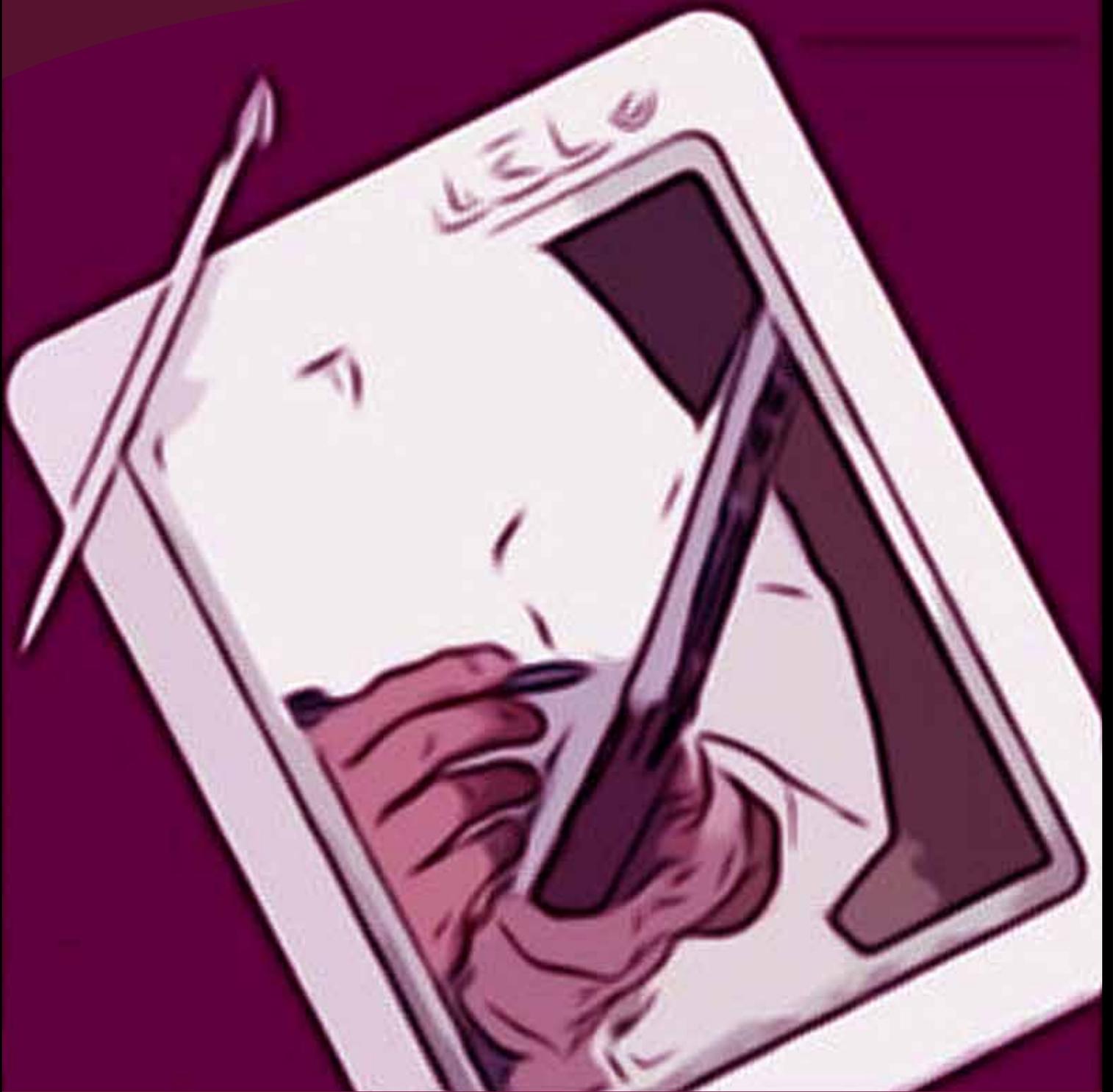
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**APPENDIX B:  
CONSUMER VERSION: PROVIDER GUIDELINES FOR ENGAGING  
CONSUMERS IN EHRs AND HEALTH INFORMATION EXCHANGE**

# Electronic Health Records: What You Need to Know



# Electronic Health Records: What You Need to Know

More and more doctors are replacing medical charts with electronic health records, but what does that mean? And what does it mean for your health?

In this handout, we will explain the basics of electronic health records and answer some common questions about them. We will cover the following topics:

- What is an electronic health record?
- What information is in an electronic health record?
- How is an electronic health record good for my doctor and me?
- How can sharing my electronic health record be good for my health?
- How could an electronic health record help me in an emergency?
- What does it mean if my doctor participates in electronic health information exchange?
- What does the future hold for electronic health record systems?
- What laws help protect my medical record?
- What is HIPAA, and how does it help protect my medical record?
- How can I help protect my privacy?

## What is an electronic health record?

An electronic health record is when your medical record is in a digital format. That means a computer is used to record, store and review your medical information.

There's an easy way to tell if your doctor uses an electronic health record system. Does the nurse or doctor bring a medical chart into the exam room? Or does the nurse or doctor use a computer or small hand-held device to enter information into your record?



## What information is in an electronic

## health record?

The same kind of information that is in your medical chart is in your electronic health record. Your electronic health record might include:

- Basic information, such as name, address, phone number and who to call in an emergency
- Medical history
- List of medications, allergies and shots you have had
- Laboratory test results, such as blood work
- Radiology images, such as X-rays, CAT scans and MRIs
- Advanced directives, living wills, and health powers of attorney

## How is an electronic health record system good for my doctor and me?

### Reduces errors:

- Eliminates errors caused by illegible handwriting
- Checks to make sure the drugs you are taking are not harmful when taken with other drugs

### Improves security:

- Allows your doctor to make a back up copy of all medical records. If the office catches fire or floods, the medical records are safe.
- Allows your doctor to keep track of, and to limit, who looks at your medical record.

### Saves time:

- Ends searching for a lost medical chart
- Ends thumbing through the pages of your medical chart

### Improves care:

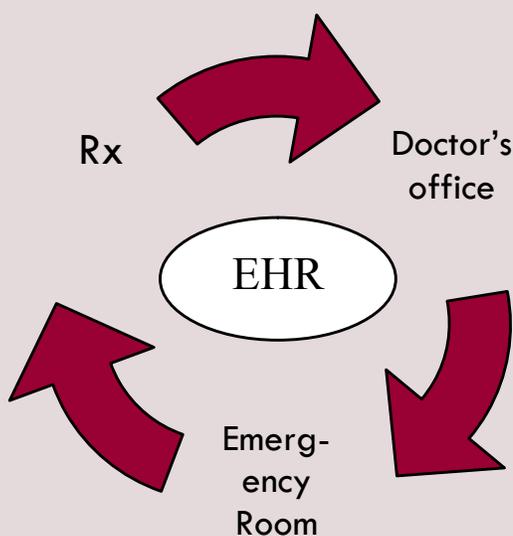
- Tells your doctor when it's time for you to get tests and shots, such as a yearly flu shot
- Tells your doctor when he needs to follow up on lab tests, especially if they show you have a problem



## How can sharing my electronic health record be good for my health?

An electronic health record can let your doctor send and receive health information about you over the Internet. Your doctor can share information about you with other doctors, as well as with hospitals, labs and the drug store. That can benefit you in many ways:

- You don't have to fill out your medical history over and over.
- Once you inform your doctor about your medications and allergies, you don't have to worry about forgetting to inform a new doctor.
- Other than routine tests, you won't have to get the same tests twice because your doctor can see if another doctor has already ordered it.
- Your medical history will be easy to get to in an emergency.
- Your doctor can send your prescription to the drug store, so you don't have to take it or wait for it to be filled.



An electronic health record system can let your doctor send your medical information to the drug store and the emergency room. That can save time and even save your life.

## How could an electronic health record help me in an emergency?

If electronic health records were in use across the nation, they could be a lifesaver. Here's an example of how it could work. Sixty-four year-old Barbara has a pacemaker. She is allergic to penicillin but takes medication for diabetes and high blood pressure. While on vacation, she hops in the car to run an errand. On the way, she is involved in a car accident and knocked unconscious. When she wakes up in the emergency room, she is disoriented and can't remember what medications she takes.

If Barbara's physician in West Virginia had an electronic health record system, he could be contacted and could use the Internet to instantly send her medical record to the emergency room doctor. Her medical information would be complete and organized, and the emergency room doctor would be able to quickly provide safe, appropriate care. Otherwise, Barbara's doctor would have to fax her medical records to the emergency room or try to give the emergency room doctor all the information he needs over the phone.



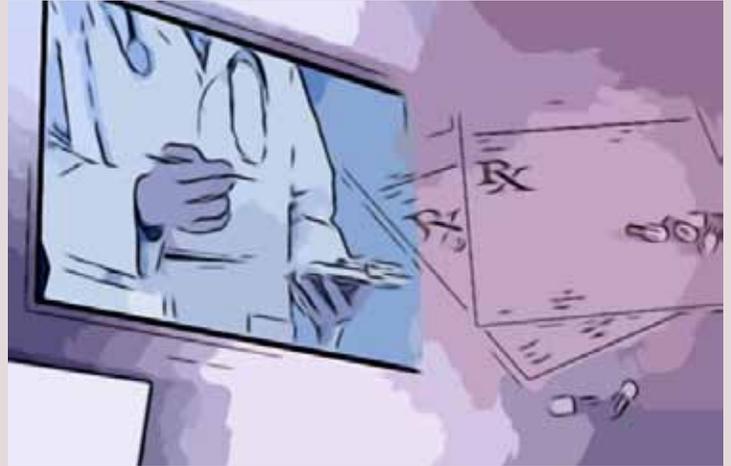
## What does it mean if my doctor participates in electronic health information exchange?

If your doctor participates in a health information organization (HIO) or some other organization that facilitates the electronic exchange of health information, make sure to ask under what conditions your doctor may share your information within this type of organization.

## What does the future hold for electronic health record systems?

In some doctors' offices, patients can already use the computer to do the following:

- View their medical record online
- Get their lab results online
- Schedule or change appointments online
- Receive reminders for regular tests and checkups online
- Print a copy of their medical record and medicines to take to another doctor
- E-mail their doctor to ask a question
- Get their medications renewed online



## What laws help protect my medical record?

You may not realize it, but your medical record is a legal document. It is protected by state and federal laws. Many of these laws include standards that are applicable to electronic health records.

## What is HIPAA, and how does it help protect my medical record?

The federal government passed a law called the Health Insurance Portability and Accountability Act of 1996. HIPAA required the creation of standards to help protect your personal health information.

## How does the HIPAA Security Rule help keep my medical record secure?

HIPAA requires health care providers to make reasonable efforts to protect the privacy of your medical records so that they can not be accidentally or illegally read, altered, shared or destroyed.



## How does the HIPAA Privacy Rule help protect my privacy?

The HIPAA Privacy Rule went into effect in 2003. It created national standards to help protect the privacy of your personal health information by doing the following:

- It gives patients more control over their health information.
- It sets boundaries on the use and release of health records.
- It establishes safeguards that health care providers must meet to help protect the privacy of health information.
- It balances the need for patient privacy with public health needs.
- It generally gives patients the right to look at and get a copy of their health record and to ask that errors be corrected.

## What about mental health and addiction treatment records?

State and federal laws offer increased protection for the confidentiality of records dealing with mental health and addiction treatment. The use of electronic health records does nothing to alter this higher degree of confidentiality protection.

## How can I help protect my privacy?

There are several things you can do to help protect the privacy of your medical records, no matter whether they are kept as traditional medical charts or as part of an electronic health record system. The Health Privacy Project, a group devoted to protecting patients' privacy, offers these tips:

- Read your doctor's notice of privacy practices carefully – Your doctor should give you a written notice about how your medical information will be used.
- Talk about privacy concerns with your doctor – Your doctor should be able to help you understand how your health information will be used.
- Ask how your medical information is shared in a large health care organization – Ask how it may be shared within the organization and with others.
- Read authorization forms before you sign – Find out who you are allowing to receive your medical records and for what purpose.
- Request a copy of your medical record – You have a right to look at and copy your records.
- Review your records – You have the right to review your records and to make sure the information is correct.
- Look for privacy policies on health Web sites -- Be careful about how much information you provide for surveys and health screenings on health Web sites. Look for and read the privacy policies before you use the Web site.



**For more information, visit the eHealthWV Web site at [www.ehealthwv.org](http://www.ehealthwv.org).**

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## **APPENDIX C: LITERATURE REVIEW METHODS**

**Deliverable:** Search of periodical literature for lead HISPC project

**Goal:** To conduct a search of printed materials related to guidelines for engaging consumers in privacy and security issues of health information exchange

To begin, we called the West Virginia Cultural Center and spoke with a librarian at the West Virginia State Library Commission. She guided us to the state's website at <http://search.ebscohost.com/> and gave us the passwords (The user ID is "west" and the password is "Virginia") to log into the commission's statewide databases. Using the EBSCO Research Databases, we searched the MasterFILE Premier and created a folder to store articles.

Designed specifically for public libraries, the multidisciplinary database provides full text for more than 1,750 general reference publications with full text information dating as far back as 1975. Covering virtually every subject area of general interest, MasterFILE Premier also includes nearly 500 full-text reference books; full text from 86,019 biographies; 105,787 full-text primary source documents; and an Image Collection of 293,480 photos, maps, and flags. The database is updated daily via EBSCOhost.

Because electronic medical records can also be called EMRs, electronic health records, or EHRs, we did a variety of basic key word searches. We also did more general searches using terms such as "health information exchange," "health information technology," and "privacy and security." For the complete list of search terms, see Table C-1.

The key words that yielded the most results were "EMR", "electronic medical record," "EHR," "electronic health record," "PHR," "personal health record," "medical record," e-Health," "HIE," "health information exchange," "health information technology," and "privacy and security." Whenever we narrowed the search, such as when we combined "EHR" and "privacy" and "security," we did not get many results.

Each search produced a list of articles. The citation included a description of the article or the full text. We skimmed the article to see if it was relevant, and if it provided some useful insight or background, we added it to a folder. By creating a user name and password for the folder, we could quit searching and resume searching without losing our articles because the folder saves them indefinitely.

**Table C-1. Key Word Search Results**

Basic Key Word Search	MasterFILE Premier
EMR privacy	No results
EMR security	No results
EMR security and privacy	No results
EMR	Checked 100
PHR	Checked all 53
Personal health record	Checked all 104
PHR privacy	No results
PHR security	No results
Personal health record privacy	1 article
Personal health record security	No results
Privacy and security	Checked 50
Medical record	Checked 100
Medical record privacy security	6 articles
Ehealth	Checked 50
Ehealth privacy	No results
Ehealth security	1 article
Ehealth security privacy	No results
Ehealth consumers	No results
Ehealth guidelines	No results
Electronic health record privacy security	No results
Electronic health record privacy	1 article
Electronic health record security	No results
Electronic health record	Checked 150
Electronic medical record	Checked 100
Electronic medical record privacy security	No results
Electronic medical record privacy	3 articles
Electronic medical record security	1 article
Electronic medical record consumers	No results
Electronic medical record guidelines	No results
HIT	No relevant hits
HIE	Checked 50
Health information technology	Checked 50
Health information technology privacy	No results
Health information exchange	Checked all 76
Health information exchange privacy	No results
Health information exchange security	No results
Health information exchange consumers	No results
HISPC	No results
Health information security privacy collaboration	No results
EHR privacy	1
EHR security	1
EHR	Checked 100

After we added an article to the folder, an icon appeared beside the article on subsequent searches. It would have been helpful to have an icon for articles that we read or skimmed and decided were irrelevant. If we did another search like this, we would try to put the useless articles in another folder or at least jot them down, so we would 'not have to skim them more than once.

We kept track of the search words we used and the number of articles we reviewed. Sometimes we reviewed 50 titles and sometimes 100, depending on the articles' relevance. Usually, we reached a point in the literature search where it became clear that we were 'not going to find any more useful information.

After we did an exhaustive search, we realized we could have searched all the databases at the same time, instead of just the one, the MasterFILE Premier. To check ourselves, we searched the MasterFile, along with the following six databases: Business Source Elite; Alt HealthWatch; Regional Business News; Library, Information Science & Technology Abstracts; Health Source—Consumer Edition; and Health Source: Nursing/Academic Edition.

We confined the search to six terms that had yielded the most results (see Table C-2), and we skimmed 100 articles. The search assured us that we had 'not missed anything. After all the searching, we were fairly familiar with the articles that were coming up, and we realized we were getting the same ones as when we searched the MasterFile database. We felt confident we had found all we were going to find.

**Table C-2. Key Word Search Results**

Basic Key Word Search	Seven Databases
Electronic health record	Checked 100
Electronic medical record	Checked 100
Personal health record	Checked 100
PHR	Checked 100
EHR	Checked 100
EMR	Checked 100

In searching the literature, we failed to find anything we would consider to be guidelines for consumer engagement of EHRs in relation to privacy and security, but the articles we did find proved very helpful in providing background for the project. We found many articles about the privacy and security of EHRs, but some of them related to the technical aspects of security, which is not within the scope of this project. The bibliography lists the most relevant articles we found. Not coincidentally, they were also the most recent articles. Almost all of them were published in the past 3 years.

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## APPENDIX D: GUIDELINE WEB SEARCH

**Table D-1. Guideline Web Search**

Web Address	Content
<a href="http://www.cdt.org/healthprivacy/20080514HPframe.pdf">http://www.cdt.org/healthprivacy/20080514HPframe.pdf</a>	Comprehensive Privacy and Security: Critical for Health Information Technology
<a href="http://chrp.creighton.edu/Documents/HISPC_Report_3.pdf">http://chrp.creighton.edu/Documents/HISPC_Report_3.pdf</a>	Report of Nebraska’s HISPC study—Consumer views
<a href="http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1_028577.hcsp?dDocName=bok1_028577">http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1_028577.hcsp?dDocName=bok1_028577</a>	What does the public think about PHRs?
<a href="http://www.himss.org/content/files/vantagepoint/vantagepoint_200805.asp?pg=1">http://www.himss.org/content/files/vantagepoint/vantagepoint_200805.asp?pg=1</a>	Survey results of consumer opinions of PHRs
<a href="http://www.patientprivacyrights.org/site/PageServer?pagename=Polls">http://www.patientprivacyrights.org/site/PageServer?pagename=Polls</a>	Polls of consumer opinions about EHRs and privacy and security
<a href="http://www.patientprivacyrights.org/site/PageServer?pagename=Full_Library">http://www.patientprivacyrights.org/site/PageServer?pagename=Full_Library</a>	Patient privacy rights library listing of resources for concerned patients
<a href="http://www.patientprivacyrights.org/site/PageServer?pagename=PrivacyCoalition">http://www.patientprivacyrights.org/site/PageServer?pagename=PrivacyCoalition</a>	Coalition for Patient Privacy page
<a href="http://www.healthdatamanagement.com/">http://www.healthdatamanagement.com/</a>	Online publication
<a href="http://www.healthcare-informatics.com/ME2/Default.asp">http://www.healthcare-informatics.com/ME2/Default.asp</a>	Online publication
<a href="http://www.healthprivacy.org/">http://www.healthprivacy.org/</a>	Several relevant documents for consumers
3 pdfs—Wellport Brochure and FAQs	Patient communication documents
<a href="http://www.centerforhealthstudies.org/sciesc/readability/readability_home.html">http://www.centerforhealthstudies.org/sciesc/readability/readability_home.html</a>	PRISM Readability Toolkit, a public-domain resource designed to help researchers and other health care professionals develop easy-to-read print materials

## APPENDIX E: CONSUMER PRETEST EVALUATION

1. What is the main point of this brochure?
2. According to this brochure, what are the benefits of electronic health records?

**Rate the following on a scale of 1–5**

	Disagree			Agree	
3. This brochure is annoying	1	2	3	4	5
4. This brochure would be useful for patients	1	2	3	4	5
5. I believe what this brochure tells me	1	2	3	4	5
6. This brochure is annoying					
1 Disagree					
2 Somewhat disagree					
3 Neutral					
4 Somewhat agree					
5 Agree					
7. This brochure would be useful for patients					
1 Disagree					
2 Somewhat disagree					
3 Neutral					
4 Somewhat agree					
5 Agree					
8. I believe what this brochure tells me					
1 Disagree					
2 Somewhat disagree					
3 Neutral					
4 Somewhat agree					
5 Agree					

**Please fill in the blank**

My favorite thing about this brochure is \_\_\_\_\_

What I like least about this brochure is \_\_\_\_\_

I would improve this brochure by \_\_\_\_\_

Additional comments \_\_\_\_\_

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