

## Health Information Technology Consumer Education and Engagement Inventory\*

If you have comments or questions about this Inventory, please contact Peggy Evans, the Washington State HISPC Project Director, at [peggye@qualishealth.org](mailto:peggye@qualishealth.org)

Welcome to the Health Information Technology Consumer Education and Engagement Inventory Matrix. This Inventory was created by the Consumer Education and Engagement Collaborative, as part of the national Health Information Security and Privacy Collaboration (HIPSC) (see "Authors" tab for a complete list of authors).

The intended audience(s) of this document are organizations, individuals, or HIE stakeholders who wish to see what others have done by way of consumer education and engagement and are looking for a starting point in finding and creating consumer materials for their own efforts. In this document, you will find resources that states involved in HISPC and various health information organizations have created to inform consumers about technology in health care. For a complete list of the inclusion criteria for this Inventory, please see the 'Inclusion Criteria' tab.

This document was created in October, 2008. Because there are new consumer resources being created all of the time, it is possible that some of the links on this inventory may be outdated at the time of user access. To be of the most functional use to interested parties, this resource should be a live document with the most updated materials. It would be helpful if users of this document could add and update it with new and revised links when appropriate.

There are 10 columns in this document. The definitions of each column are as follows:

**Column A (Brief Description of Resource)** – Overview of the types of HIE and health IT information that can be accessed through the resource.

**Column B (Key Words)** – Describes the main purpose of the resource, such as if the link is a video, report, contains a toolkit, etc. Inventory users may want to use the “find” function in Microsoft Excel to search the links.

**Column C (Targeted Audience)** – Describes the intended audience of the resource, such as providers, HIE stakeholders, the direct consumer (patient), etc.

**Column D (Resource Creator)** – The owner of the website and/or document(s).

**Column E (Description of Resource Creator)** – A brief description of the organization that created the resource.

**Column F (Subject Area)** – The resource can relate to several specific areas within health information technology, for instance electronic health records, personal health records, or general health information exchange.

**Column G (Media Type)** – Describes the medium of the resource, such as website, handout, video, or something else.

**Column H (Website Link)** – The link to the resource.

**Column I (Last Updated)** – The year in which the document or website was last updated.

**Column J (Tools Found in Resource)** – Lists the specific tools that can be found on the link.

\* Please note that users can adjust the font size of this inventory to meet their reading needs.

**Limitations of Inventory:** Please be advised that this inventory is meant to be a starting point in searching for consumer materials. While inclusion of consumer education and engagement resources from HISPC states and national HIE organizations is broad, this document nevertheless does not list consumer materials from all health IT and HIE organizations. Additionally, the website links take the user to some of the major resources within an organization, but more information can be found by viewing the rest of the site.

## Authors and Acknowledgements

The following lists the members of the Inventory Project group. This group was created as a sub-group of the Consumer Education and Engagement Collaborative (CEE), which is part of the national HISPC effort.

Peggy Evans, PhD (Inventory Project Lead) - Washington

Margaret Tran, RHIA - Washington

Phyllis Albritton - Colorado

Victoria Wangia, MS, PhD - Kansas

Christina Stephan, MD - Kansas

Ellen Flink, MBA - New York

Lygeia Ricciardi, EdM - New York

The Inventory Project group wishes to thank and acknowledge the contributions of the other members of the CEE : Jerilyn Heinold (Massachusetts), Patty Ruddick (West Virginia), Dawn Bonder (Oregon), Doris Konneh (Georgia), and Alicia McCord-Estes (Georgia). We would also like to thank Eva Powell (National Partnership for Women & Families), Amoke Alakoye (RTI), and all the states and organizations that contributed to this

**DISCLAIMER - PLEASE READ BEFORE PROCEEDING:** These materials were organized by the Consumer Engagement and Education Collaborative of the Health Information Security and Privacy Collaborative (HISPC/CEE). HISPC/CEE is not the author, creator or owner of the materials listed in this index. Please contact the author, creator or owner of the individual materials for information on copyrights and for permission to use each of the materials. HISPC/CEE is not responsible for any misuse or copyright infringement with respect to the materials indexed.

Brief Description of Resource	Key Word(s)	Targeted Audience	Resource Creator	Description of Resource Creator	Subject Area	Media Type	Website Link	Last Updated	Tools Found in the Resource
Provides an overview of HIT	HIT, health plan	Consumers, health plan members, providers, health plans	Aetna	Aetna is a health care benefits company serving members with information and resources to help them make better informed decisions about their health care.	HIT	Website	<a href="http://www.aetna.com/about/aoti/aetna_perspective/health_information_technology.html">http://www.aetna.com/about/aoti/aetna_perspective/health_information_technology.html</a>	2008	Consumer health care tools, survey results, brief paragraphs on : FAQs, background and why HIT is necessary
Video on why consumers need a PHR; panel of experts include Carolyn Clancy, Ron Stock, and David Lansky	Video	Consumers	Agency for Healthcare Research and Quality	As 1 of 12 agencies within the Department of Health and Human Services (HHS), the Agency for Healthcare Research and Quality (AHRQ) supports health services research initiatives that seek to improve the quality of health care in America. AHRQ's mission is to improve the quality, safety, efficiency, effectiveness, and cost-effectiveness of health care for all Americans.	PHR	Video	<a href="http://www.ahrq.gov/consumers/phrvid.htm">http://www.ahrq.gov/consumers/phrvid.htm</a>	2008	Video; HIE education
Summarizes results from a conference of consumers, health care professionals, and administrative leaders about improving the health care system and advancing patient-centered care. The report includes a chapter on partnering with patient safety organizations.	Report	HIE stakeholders; patients; providers	Agency for Healthcare Research and Quality		General HIE	Report	<a href="http://psnet.ahrq.gov/resource.aspx?resourceID=7362&amp;sourceID=1&amp;emailID=9827">http://psnet.ahrq.gov/resource.aspx?resourceID=7362&amp;sourceID=1&amp;emailID=9827</a>	2008	Report/book download
This guide helps developers and purchasers of health IT reach adults with limited literacy. The guide, which includes a checklist, presents design principles and strategies to increase consumer accessibility to health IT.	Report; literacy	HIE stakeholders	Agency for Healthcare Research and Quality		General HIE	Report	<a href="http://healthit.ahrq.gov/portal/server.pt/gateway/PTARGS_0_3882_803031_0_0_18/LiteracyGuide.pdf">http://healthit.ahrq.gov/portal/server.pt/gateway/PTARGS_0_3882_803031_0_0_18/LiteracyGuide.pdf</a>	2007	Report

Brief Description of Resource	Key Word(s)	Targeted Audience	Resource Creator	Description of Resource Creator	Subject Area	Media Type	Website Link	Last Updated	Tools Found in the Resource
Defines PHRs and issues associated with using PHR	PHR; Education; FAQs; privacy and security; glossary	Patients	AHIMA	AHIMA is the premier association of health information management (HIM) professionals. AHIMA is dedicated to the effective management of personal health information needed to deliver quality health care to the public and is committed to advancing the HIM profession in an increasingly electronic and global environment through leadership in advocacy, education, certification, and lifelong learning.	PHR	Website	<a href="http://www.myphr.com">http://www.myphr.com</a>	2008	Glossary of terms; links to other resources; Free PHR forms; PHR tools and services; Health info news; FAQs; PHR definitions; Consumer privacy rights
Video with consumers and AHIMA experts about use of importance of HIE and PHRs	Education; PHR	Patients	AHIMA		General HIE	Video	<a href="http://www.youtube.com/watch?v=TZzlw6RpQVg">http://www.youtube.com/watch?v=TZzlw6RpQVg</a>	2008	Video; HIE education
Links to handouts and articles concerning privacy and the public's rights under HIPAA	Education; privacy and security	Patients	AHIMA		Patient protection	Website	<a href="http://www.myphr.com/rights/your_privacy_rights.asp">http://www.myphr.com/rights/your_privacy_rights.asp</a>	2008	Handouts, HIE educational materials
News about Alabama being selected to be in the EHR Medicare demonstration project	EHR, Medicare, Medicaid	Providers, vendors	Alabama Medicaid Agency	The Alabama Medicaid agency is responsible for Medicaid; a state/federal program that pays for medical and long-term care services for low-income pregnant women, children, certain people on Medicare, disabled individuals and nursing home residents. These individuals must meet certain income and other requirements.	EHR	Website	<a href="http://www.medicaid.alabama.gov/news/EHR_Medicaid_AL.aspx?tab=2">http://www.medicaid.alabama.gov/news/EHR_Medicaid_AL.aspx?tab=2</a>	2008	News, EHR fact sheet
Survey results of 1,270 women regarding what they would like to see in health care reform	Survey	HIE stakeholders; patients; providers	American Academy for Family Physicians	One of the largest national medical organizations, representing more than 94,000 family physicians, family medicine residents, and medical students nationwide. Founded in 1947, its mission has been to preserve and promote the science and art of family medicine and to ensure high-quality, cost-effective health care for patients of all ages.	General HIE	Report	<a href="http://www.aafp.org/online/etc/medialib/aafp_org/documents/press/fixhealthwomen/fixhealthwomendoc.Par.0001.File.tmp/Executive%20Summary%20-%20Fixing%20Health%20Care%20-%20200408.pdf">http://www.aafp.org/online/etc/medialib/aafp_org/documents/press/fixhealthwomen/fixhealthwomendoc.Par.0001.File.tmp/Executive%20Summary%20-%20Fixing%20Health%20Care%20-%20200408.pdf</a>	2008	Report
Consumer checklist for privacy and security	Privacy and security	Patients	AMIA - American Medical Informatics Association	AMIA advances the use of biomedical and health informatics clinical care, personal health management, public health/population, and research with the ultimate objective of improving health.	Patient protection	Handouts	<a href="http://www.amia.org/inside/initiatives/healthdata/2007/draftconsumerchecklist.pdf">http://www.amia.org/inside/initiatives/healthdata/2007/draftconsumerchecklist.pdf</a>	2007	Checklist
The website in general is a glossary of HIE/HIT terms	Glossary	Patients	Arizona Health-e connection	Established in January 2007, AzHeC is a not-for-profit organization whose mission is to lead Arizona's establishment of health information exchange (HIE), and adoption of health information technology (HIT) through education and research	General HIE	Website	<a href="http://www.azhec.org/index.jsp">http://www.azhec.org/index.jsp</a>	2008	Glossary of terms; resource links

Brief Description of Resource	Key Word(s)	Targeted Audience	Resource Creator	Description of Resource Creator	Subject Area	Media Type	Website Link	Last Updated	Tools Found in the Resource
Information accessed through BHIX comes from a variety of health information sources. These health information sources may include <b>Participants</b> , other health care providers (such as doctors, pharmacies and clinical laboratories), health insurers, the New York State Medicaid program and, over time, other health information exchanges, RHIOs and personal health records.	Consent, interoperable	Patients, HIE stakeholders	BHIX	The Brooklyn Health Information Exchange (BHIX) is part of an innovative statewide and nationwide effort to improve our healthcare system through the use of secure and interoperable health information technology. BHIX empowers consumers to allow doctors, nurses and other health care professionals more timely access to their electronic health information. By getting the <i>right</i> information to the <i>right</i> place at the <i>right</i> time, BHIX promotes improvements in the quality, safety and efficiency of medical care.	RHIO, HIE	Website	<a href="http://www.bhix.org/index.html">http://www.bhix.org/index.html</a>	2008	Educational materials, contact info
Consumers can create a personal health record	PHR, health, wellness, privacy, security	Health plan members	Blue Cross Blue Shield of Kansas City	Blue Cross and Blue Shield of Kansas City, a health insurance company, is the area's largest health benefits provider, serving more than 880,000 members in 32 counties in greater Kansas City, northwest Missouri, and Johnson and Wyandotte counties in Kansas.	PHR	Website	<a href="https://www.bcbskc.com/eprise/main/Public/Content/Health_and_Wellness.html">https://www.bcbskc.com/eprise/main/Public/Content/Health_and_Wellness.html</a>	2008	Online personal health record, health risk appraisal, privacy and security policies
Website on health IT	HIT, HIE, consumer control, PHR, Health Information, Community Health Clinics, E-prescribing	Consumers, providers, researchers, educators	California HealthCare Foundation	The California HealthCare Foundation is an independent philanthropy committed to improving the way health care is delivered and financed in California. By promoting innovations in care and broader access to information, our goal is to ensure that all Californians can get the care they need, when they need it, at a price they can afford.	HIT, HIE, Health Information, PHR	Website	<a href="http://www.chcf.org/topics/index.cfm?topic=CL108">http://www.chcf.org/topics/index.cfm?topic=CL108</a>	2008	Lessons Learned, EHR Assessment and Readiness, National Consumer Health Privacy Survey Executive Summaries, Surveys, and Slide Presentation; Patient-Provider Online Communication Tools Overview, Technology Assessment, Measuring HIT costs and benefits studies, Lessons in adoption of online consumer tools, survey results, reports & initiatives, policy brief, market assessment, EHR selection toolkit, Privacy and Security and RHIO, Perspective on PHR future
Identifying stakeholder groups, prioritizing among those groups, and developing a communication plan that will appropriately communicate the policies and standards recommended by the PSAB	HIPAA	HIE stakeholders, consumers	California Office of HIPAA	CalOHI is the California Privacy and Security Advisory Board (CalPSAB) which will provide private and public collaboration to address and coordinate health information exchange (HIE) privacy and security efforts in California. The CalPSAB's four committees; Privacy, IT Security, Legal, and Education will analyze issues, develop and evaluate the effectiveness of alternative solutions, and present recommendations to the CalPSAB.	HIE	Website	<a href="http://www.ohi.ca.gov">http://www.ohi.ca.gov</a>	2007	HIPAA glossary
Standards for Privacy of Individually Identifiable Health Information	Privacy and security	HIE stakeholders, consumers	California Office of HIPAA	A link to federal FAQs	HIE	Website	<a href="http://aspe.hhs.gov/admsimp/final/pvcguide1.htm">http://aspe.hhs.gov/admsimp/final/pvcguide1.htm</a>	2001	FAQs, privacy and security laws
CareEntrust is currently offered as a health benefit by sponsoring organizations	PHR	Consumers/clinicians/employers/insurers	CareEntrust—Kansas City	An employer-based regional health information network (RHIO)	PHR	Website	<a href="http://www.careentrust.org/">http://www.careentrust.org/</a>	2008	Markle foundation statistics, Benefits of PHR

Brief Description of Resource	Key Word(s)	Targeted Audience	Resource Creator	Description of Resource Creator	Subject Area	Media Type	Website Link	Last Updated	Tools Found in the Resource
Survey results of consumer attitudes about HIE in Appalachian, TN region	Survey	Patients; HIE stakeholders	CareSpark	CareSpark is developing a secure network that allows physician offices, hospitals, public health departments, pharmacies, laboratories and imaging centers to communicate electronically in order to improve patient care and safety and reduce costs.	General HIE	Website with PDF survey	<a href="http://carespark.com/index.php?option=com_content&amp;task=view&amp;id=62&amp;Itemid=63">http://carespark.com/index.php?option=com_content&amp;task=view&amp;id=62&amp;Itemid=63</a>	2006	Survey results
Brochures for consumers on HIE in general and myths and facts about HIPAA.	Education; FAQs; privacy and security	Patients; HIE stakeholders	Center for Democracy and Technology	CDT is a nonprofit that works to promote democratic values and constitutional liberties in the digital age. It has expertise in law, technology, and policy, and is among the organizations that most frequently testify for Congress. In 2008 it launched a health program, merging with the Health Privacy Project.	General HIE	Handouts	<a href="http://www.cdt.org/privacy/">http://www.cdt.org/privacy/</a>	2008	2 page overview of HIE, "Putting Patients First," and longer FAQ on HIPAA and privacy rights
Report calls for the adoption of a comprehensive privacy and security framework for protection of HIT is used to support e-HIE.	Report; privacy and security	HIE stakeholders	Center for Democracy and Technology		General HIE	Report	<a href="http://www.cdt.org/healthprivacy/20080514HPframe.pdf">http://www.cdt.org/healthprivacy/20080514HPframe.pdf</a>	2008	Report
Weblog with opinions about various health care topics, including PHRs; RHIOs; HIT	Blog	Patients	Christina's Considerations	Christina Thielst was the principle of a health administration and management consulting and independent contractor business based in Santa Barbara, CA between 1997 and 2006. She is now the COO at Ventura County Medical Center and serves the entire Ventura County Health Care Agency and its Departments of Public Health, Behavioral Health, Ambulatory Care and two hospitals.	General HIE	Blog	<a href="http://thielst.typepad.com/">http://thielst.typepad.com/</a>	2008	Blog
Hearing before the subcommittee on oversight and investigations of the committee on veteran's affairs U.S. house of representatives 110th congress—First session: Sharing of electronic medical records between the U.S. Department of Defense and the U.S. Department of Veterans Affairs.	EMR	Providers	Committee on Veteran's Affairs	US Veteran's Affairs	EMR	Website	<a href="http://veterans.house.gov/Media/File/110/5-8-07o-i/110-20transcriptO-15-8-07.htm">http://veterans.house.gov/Media/File/110/5-8-07o-i/110-20transcriptO-15-8-07.htm</a>	2007	Not applicable
Consumer views about privacy and security in E-HIE	Privacy and security	HIE stakeholders; consumers	Creighton Health Services Research Program	A multi-professional team of scholars engaged in interdisciplinary health services research.	General HIE	Report	<a href="http://chrp.creighton.edu/Documents/HISPC_Report_3.pdf">http://chrp.creighton.edu/Documents/HISPC_Report_3.pdf</a>	2007	Report
Survey of 16 diverse types of people in Nebraska	Survey; eHealth	State policymakers	Creighton University Health Research Services Program	NE University-based health research center	General HIE	Report	<a href="http://chrp.creighton.edu/Documents/HISPC_Report_3.pdf">http://chrp.creighton.edu/Documents/HISPC_Report_3.pdf</a>	2007	Consumer survey results

Brief Description of Resource	Key Word(s)	Targeted Audience	Resource Creator	Description of Resource Creator	Subject Area	Media Type	Website Link	Last Updated	Tools Found in the Resource
To ensure stakeholders' personally identifiable and health information are protected at the highest level as TRICARE delivers the best medical support possible to all those entrusted to our care.	Health Information, Privacy, Policies, Security, Data Use Agreements	Lawyers, consumers, providers	Department of Defense—Privacy Office	TRICARE Management Activity—Component of Military Health System	Health Information Privacy	Website	<a href="http://www.tricare.mil/tmaprivacy/default.cfm">http://www.tricare.mil/tmaprivacy/default.cfm</a>	2007	Privacy impact assessment, HIPAA and Privacy Act Information, Data Use Agreement, Breach response and modification, Policies
The Patient Advocate Tracking System (PATS) is a web-based system used to document, track, and report patient-related issues. PATS replaces the legacy Patient Representative (Patient Rep) system.	HIT, VISTA, EMR	Consumers, patient advocates and providers	Department of Veterans Affairs (VA)	VHA Software Document Library—This website has documentation on the various software created and/or used by the VHA in its mission to provide the best service to our nation's veterans.	PHR; HIT	Website	<a href="http://www.va.gov/vdl/section.asp?secid=4">http://www.va.gov/vdl/section.asp?secid=4</a>	2007	Information about VISTA; manuals; release notes; technical security guide; glossary
Toolkit for stakeholders trying to build an HIE effort; specifically, there is a link for communication and outreach to consumers	Toolkit; education; survey; glossary; handouts	HIE stakeholders	E-health initiative	The eHealth Initiative and the Foundation for eHealth Initiative are independent, nonprofit affiliated organizations whose missions are the same: to drive improvement in the quality, safety, and efficiency of health care through information and information technology.	General HIE	Website	<a href="http://toolkit.ehealthinitiative.org/communication_and_outreach/default.msp?">http://toolkit.ehealthinitiative.org/communication_and_outreach/default.msp?</a>	2008	Glossary of terms; research findings about consumer behavior; public education tools;
Survey of 130 community-based HIE efforts around the nation	Survey	HIE stakeholders	E-health initiative		General HIE	Survey results	<a href="http://www.ehealthinitiative.org/2007HIESurvey/">http://www.ehealthinitiative.org/2007HIESurvey/</a>	2007	Survey results
Report describing stakeholder consensus on improving health care using HIT. Opinions from 200 Organizations representing different types of stakeholders are included. Materials in Appendix A about how to engage consumers.	Report	HIE stakeholders	E-health initiative		General HIE	Report	<a href="http://www.ehealthinitiative.org/blueprint/">http://www.ehealthinitiative.org/blueprint/</a>	2008	Report
Website with materials on policy, HIE, HIT, connecting communities, blueprint	HIE, HIT	Consumers, providers, lawyers, vendors, policymakers	E-health initiative		Health Information	Website	<a href="http://www.ehealthinitiative.org/partnership/">http://www.ehealthinitiative.org/partnership/</a>	2008	Glossary, annual HIE surveys, toolkit, webinars, consumer engagement tools, eHI blueprint report: building consensus for common action
The InformationSTAT™ public education and communications toolkit is a fully customizable set of public relations and communications tools designed to enhance consumer understanding of the benefits of health IT and health information exchange. These public awareness tools can be used by leaders of state, regional and community initiatives to educate consumers about the real difference secure electronic health information exchange can have on the health and health care of Americans.	Consumer engagement	Consumers, educators and consumer advocates	E-health initiative		HIT, HIE	Website	<a href="http://www.ehealthinitiative.org/toolkit/getOrg/InfoSTAT.msp">http://www.ehealthinitiative.org/toolkit/getOrg/InfoSTAT.msp</a>	2008	Consumer engagement materials

Brief Description of Resource	Key Word(s)	Targeted Audience	Resource Creator	Description of Resource Creator	Subject Area	Media Type	Website Link	Last Updated	Tools Found in the Resource
Findings emerged from the research that will support national, state, and local efforts in communicating the importance of electronic health information exchange to consumers.  Secure Electronic Health Information Exchange Attitude and Opinion Research— Executive Summary Supported by the eHealth Initiative Foundation Released May 2, 2007	Consumer engagement	Consumers	E-health initiative		HIE, HIT	Website	<a href="http://www.ehealthinitiative.org/toolkit/engCon/commonPrinciples.msp">http://www.ehealthinitiative.org/toolkit/engCon/commonPrinciples.msp</a>	2008	Survey findings report
PHR resources: content, privacy and security, checklists for consumers, free PHR forms	PHR	Consumers	Florida Health Information Network (FL-HISPC)	A statewide collaboration of RHIOs and the Agency for HealthCare Administration. Vision is a fully integrated HIE network in Florida.	PHR	Website	<a href="http://www.fhin.net/PHR/ePHBasics.shtml">http://www.fhin.net/PHR/ePHBasics.shtml</a>	2008	Checklist; privacy and security; education; free forms
Information regarding HIT and RHIOs in Florida	Florida RHIO	HIE stakeholders	Florida Health Information Network (FL-HISPC)		RHIO, HIE	Website	<a href="http://www.fhin.net/index.shtml">http://www.fhin.net/index.shtml</a>	2008	Florida RHIO, grants
PowerPoint Presentations related to HIE in Florida	PowerPoints	HIE Stakeholders	Florida Health Information Network (FL-HISPC)		General HIE	Website	<a href="http://www.imageresearch.com/FHIN/">http://www.imageresearch.com/FHIN/</a>	2008	PowerPoint presentations
E-prescribing information	E-prescribing	Patients; HIE stakeholders	Florida Health Information Network (FL-HISPC)		E-prescribe	Website	<a href="http://www.fhin.net/eprescribe/">http://www.fhin.net/eprescribe/</a>	2008	Clearinghouse of information related to e-prescribing
Privacy and security information	Privacy; security	Consumers; HIE stakeholders	Florida Health Information Network (FL-HISPC)		General HIE	Website	<a href="http://www.fhin.net/PSresourceCtr/index.shtml">http://www.fhin.net/PSresourceCtr/index.shtml</a>	2008	Links related to privacy and security
Fact sheet; Community Forum; EHR adoption	Health information exchange; fact sheet	General public, HIE policymakers	Georgia Department of Community Health	Office of Health Information Technology and Transparency	General HIE and HIT	Website	<a href="http://dch.georgia.gov/00/chaannel_title/0.2094.31446711_69326946.00.html">http://dch.georgia.gov/00/chaannel_title/0.2094.31446711_69326946.00.html</a>	2008	General information
Tool to store information of current and past medications, allergies, procedures, immunizations, conditions, and test results. Medical information can be entered or imported from health integrated partners, such as hospitals or neighborhood pharmacies.	PHR	Consumer	Google Health	Google's corporate mission is to organize the world's information and make it universally accessible and useful. Google believes the Internet can help users get access to their health information and help people make more empowered and informed health decisions.	PHR	Website	<a href="https://www.google.com/health/html/about/partners.html">https://www.google.com/health/html/about/partners.html</a>	2008	FAQs, tour, Google Health Privacy Policy, Information for Partners, Advisory Council video, Help Center
Rochester RHIO gives authorized health care professionals instant access to the patient information they need to provide the best care, in a medical emergency or a routine office visit. This includes lab reports, radiology results and medication history.	Privacy, Education, Consent, HIE	Patients, Advocacy groups, stakeholders	Greater Rochester RHIO	Rochester RHIO is a secure online resource developed by and for doctors, hospital systems, health insurers and privacy officers in the nine-county Greater Rochester area. Its purpose is to share essential patient information quickly and accurately with authorized health care providers.	RHIO, HIE	Website	<a href="http://grrhio.org/">http://grrhio.org/</a>	2008	Educational materials, FAQs, brochure, consent form, privacy

Brief Description of Resource	Key Word(s)	Targeted Audience	Resource Creator	Description of Resource Creator	Subject Area	Media Type	Website Link	Last Updated	Tools Found in the Resource
PRISM readability toolkit helps researchers and health care professionals make materials for consumers more literacy-friendly.	Literacy; toolkit	HIE stakeholders	Group Health Center for Health Studies	Group Health Center for Health Studies (CHS) was founded by Group Health Cooperative to promote the prevention and effective treatment of major health problems	Other	Report	<a href="http://www.centerforhealthstudies.org/sciresc/readability/readability_home.html">http://www.centerforhealthstudies.org/sciresc/readability/readability_home.html</a>	2008	Report
"Few Patients Use or Have Access to Online Services for Communicating with their Doctors, but Most Would Like To"—News report on EMR use, EMR may have a challenge on patient's privacy, consumer access and interest to technology, impact of technology access.	Research, polls, survey, EMR	Consumers, researchers	Harris Interactive	Harris Interactive believes that market research helps their clients understand the drivers of decision making and can strengthen enterprise equity.	EMR	Website	<a href="http://www.harrisi.org/news/allnewsbydate.asp?NewsID=1096">http://www.harrisi.org/news/allnewsbydate.asp?NewsID=1096</a>	2006	Consumer market trends white paper, surveys, news
Wiki for people interested in HIT and HIE	Links; privacy and security	HIT stakeholders	Health Policy Institute of Ohio (HPIO)	The Health Policy Institute of Ohio is an independent, nonpartisan, statewide center that informs Ohio health policy by forecasting health trends, analyzing key health issues, and communicating current research to policymakers, state agencies and other decision-makers.	General HIE	Wiki	<a href="http://hispc.pbwiki.com/">http://hispc.pbwiki.com/</a>	2008	Resource links; privacy and security
Site is devoted to health information privacy and security, but the focus is not HIE. Many of the links are older than 2004.	Privacy and security	Patients	Health Privacy Project	The Health Privacy Project is merging with the Center for Democracy and Technology (CDT), creating a major voice to address the privacy challenges posed by the electronic exchange of personal health information.	Patient protection	Website	<a href="http://www.healthprivacy.org/content2310/content.htm">http://www.healthprivacy.org/content2310/content.htm</a>	2008	FAQs, privacy and security laws; HIPAA; fact sheets;
Myths and facts about HIPAA, written for the consumers	HIPAA; privacy and security	Patients	Health Privacy Project		General HIE	Handouts	<a href="http://www.healthprivacy.org/usr_doc/Myths_and_Facts.pdf">http://www.healthprivacy.org/usr_doc/Myths_and_Facts.pdf</a>	2008	HIPAA
Knowing your rights about health privacy	Education; privacy and security	Patients	Health Privacy Project		General HIE	Handouts	<a href="http://www.healthprivacy.org/usr_doc/KnowYourRights.pdf">http://www.healthprivacy.org/usr_doc/KnowYourRights.pdf</a>	2008	Privacy and security
Healthcare IT News: Does Santa Barbara RHIO shutdown affect California HIE efforts?	HIE, RHIO	Providers, vendors	Healthcare IT News	Provides the industry's health care IT news, delivered by e-mail or RSS	RHIO	Website	<a href="http://www.healthcareitnews.com/story.cms?id=6671">http://www.healthcareitnews.com/story.cms?id=6671</a>	2007	News, NHIN Watch
Tabs related to educating consumers about PHRs, including links to tools and resources	PHR	Consumers	HIMSS	The Healthcare Information and Management Systems Society (HIMSS) is the health care industry's membership organization exclusively focused on providing global leadership for the optimal use of health care information technology (IT) and management systems for the betterment of health care.	PHRs	Website	<a href="http://www.himss.org/ASP/topics_phr.asp">http://www.himss.org/ASP/topics_phr.asp</a>	2008	Links to PHR tools and services
Privacy and security toolkit	Privacy and security	HIE stakeholders	HIMSS		General HIE	Website	<a href="http://www.himss.org/ASP/privacySecurityTree.asp?faid=78&amp;tid=4">http://www.himss.org/ASP/privacySecurityTree.asp?faid=78&amp;tid=4</a>	2008	Resources for privacy and security
Privacy and security issues for PHRs	Privacy and security; PHR	HIE stakeholders	HIMSS		PHR	PowerPoint	<a href="http://www.himss.org/content/files/PHRPrivSecCOO_LGV1.0.pdf">http://www.himss.org/content/files/PHRPrivSecCOO_LGV1.0.pdf</a>	2007	PowerPoint discussing privacy and security issues for PHR

Brief Description of Resource	Key Word(s)	Targeted Audience	Resource Creator	Description of Resource Creator	Subject Area	Media Type	Website Link	Last Updated	Tools Found in the Resource
Links to topics related to EMRs, PHRS, clinical informatics, privacy and security; standards, interoperability, etc. Lots of resources for all audience types	EMR; PHR; privacy and security	HIE stakeholders; providers; consumers	HIMSS		General HIE	Website	<a href="http://www.himss.org/ASP/topicsHome.asp">http://www.himss.org/ASP/topicsHome.asp</a>	2008	Links to different HIE resources on a variety of HIT topics
Report related to HIE privacy and security in the HISPC states	Privacy; security	HIE stakeholders	HISPC	Established in June 2006 by RTI International through a contract with the U.S. Department of Health and Human Services (HHS), the Health Information Security and Privacy Collaboration (HISPC) originally comprised 34 states and territories. As phase 3 of the HISPC begins in April 2008, HISPC now comprises 42 states and territories, and aims to address the privacy and security challenges presented by electronic health information exchange through multistate collaboration.	General HIE	Report	<a href="http://privacysecurity.rti.org/Portals/0/PhaseII_ImpactAnalysis.pdf">http://privacysecurity.rti.org/Portals/0/PhaseII_ImpactAnalysis.pdf</a>		HISPC report
Survey questions about HIE attitudes	Survey	Patients; HIE stakeholders	Innovation Valley Health Information network (TN)	IVHIN is a community coalition teaming with local hospital systems, the Knoxville Academy of Medicine and community physicians, patients/consumers, payers and employer leaders collaborating on creating a consumer-driven interoperable healthcare information network utility that significantly improves healthcare safety and quality while making care more affordable.	General HIE	Survey	<a href="http://www.ivhin.org/patientPortal.php">http://www.ivhin.org/patientPortal.php</a>	2007	Survey questions
5 reasons your doctor is using an EMR	EMR; education	Consumers	Iowa Foundation for Medical Care	IFMC is dedicated to health care quality improvement and medical information management. Today, IFMC is an innovative industry leader at the forefront of providing care management, quality improvement and information management services	EMR	Handouts	<a href="http://www.internetifmc.com/downloads/DOQIT/Five%20Reasons%20Your%20Doctor%20is%20Using%20EHR%20.pdf">http://www.internetifmc.com/downloads/DOQIT/Five%20Reasons%20Your%20Doctor%20is%20Using%20EHR%20.pdf</a>	2006	Education
Materials to run a consumer focus group on HIE, including topics, questions, and results of the Iowa consumer focus group.	Focus group	HIE stakeholders	Iowa Foundation for Medical Care		EMR	Consumer focus group questions and results	RTI Portal	2007	Consumer focus group questions and results of Iowa focus group
Video with panel of David Brailer, Dean Rosen, and Winston Price, on adoption of HIT and HIE	Education	HIE stakeholders; patients; providers	Kaiser Network	Kaiser Family Foundation is a nonprofit, private operating foundation focusing on the major health care issues facing the U.S., with a growing role in global health. Unlike grant-making foundations, Kaiser develops and runs its own research and communications programs, sometimes in partnership with other nonprofit research organizations or major media companies.	HIT	Video	<a href="http://www.kaisernetwork.org/health_cast/hcast_index.cfm?display=detail&amp;hc=1462">http://www.kaisernetwork.org/health_cast/hcast_index.cfm?display=detail&amp;hc=1462</a>	2005	Panel of experts, education; video

Brief Description of Resource	Key Word(s)	Targeted Audience	Resource Creator	Description of Resource Creator	Subject Area	Media Type	Website Link	Last Updated	Tools Found in the Resource
University of Kansas Medical Center—Center for Healthcare Informatics—KS HISPC Consumer Education and Engagement Collaborative Website (site is new and is still being developed, and updated)	HIT, HIE, privacy, security	Consumers/ providers/ lawyers	Kansas—University of Kansas Medical Center—Center for Healthcare Informatics	The University of Kansas Center for Healthcare Informatics (KU-CHI) is an interdisciplinary center of excellence designed to advance health care informatics through knowledge, integration, research and empowerment of faculty and students in the expanding field of biomedical science and information technology.	HIT/HIE	Website	<a href="http://www2.kumc.edu/healthinformatics/HISPC/hispc.htm/">http://www2.kumc.edu/healthinformatics/HISPC/hispc.htm/</a>	2008	Glossary, related projects, educational materials toolkit (coming in the future), reports, useful resources, HISPC and related activities
Standards for Privacy of Individually Identifiable Health Information	Privacy and security	HIE stakeholders, consumers	Kentucky e-Health	Kentucky e-Health Network Board is the body responsible for the development of a statewide e-health network. The HISPC project was one of the first undertaken by the KeHN Board. Their website is <a href="http://ehealth.ky.gov/">http://ehealth.ky.gov/</a> . Kentucky has received a Medicaid Transformation Grant to support development of an e-health network and consumer engagement efforts were included in the grant proposal.	HIE	Website	<a href="http://ehealth.ky.gov/">http://ehealth.ky.gov/</a>	2007	FAQs, privacy and security laws
FAQs for consumers about EMRs	FAQs	HIE stakeholders	Louisiana HISPC	Louisiana HISPC—The Collaboration is funded by the Louisiana Department of Health and Hospitals, the Agency for Healthcare Research and Quality and the Office of the National Coordinator for Health Information Technology. It is administered by RTI International.	EMR	Website	<a href="http://www.ehrtoday.org/home/section/1-5/faq-consumers">http://www.ehrtoday.org/home/section/1-5/faq-consumers</a>	2008	EMR FAQs; resource links
Website designed by Louisiana for HISPC	EHR, privacy, security	Consumers/ providers	Louisiana HISPC		EHR	Website	<a href="http://www.ehrtoday.org">www.ehrtoday.org</a>	2008	FAQs, acronyms, white paper, brochures, newsletter, news, expert profiles, links, media, HISPC team,
Results of what different stakeholders in the community think about e-health (such as consumers, providers, health plan payers, etc). Survey and focus group results.	Report	HIE stakeholders	Louisville Health Information Exchange, inc.	LouHIE is a not-for-profit organization, governed by a health care community board. Its vision is to improve quality and contain rising costs of health care in the Louisville area...by providing consumers and their providers anytime, anywhere access to complete health care information and decision support.	General HIE	Report	<a href="http://www.louhie.org/Downloads/LouHIE%20research%20report%20v9%20Final%20Exec%20Summ.pdf">http://www.louhie.org/Downloads/LouHIE%20research%20report%20v9%20Final%20Exec%20Summ.pdf</a>	2008	Survey and focus group results about what consumers and other stakeholders think about e-health
Educational video that describes why e-health is needed (the current state of health care), and explains how a health record banking model could be useful to the patient.	Video; education	Patients; consumers; providers; HIE stakeholders	Louisville Health Information Exchange, inc.		HRB; general HIE	Video	<a href="http://www.louhie.org/">http://www.louhie.org/</a>	2008	Video about e-health and HRB in particular
Website related specifically to bring together network of stakeholders in order to build an EMR provider network	Links	HIE Stakeholders	MA e-health Collab	The Massachusetts eHealth Collaborative was formed in 2004 as an initiative of the physician community to bring together the state's major health care stakeholders for the purpose of establishing an EHR system that would enhance the quality, efficiency and safety of care in Massachusetts.	EMR	Website	<a href="http://www.maehc.org/resources.html">http://www.maehc.org/resources.html</a>	2008	Resource links

Brief Description of Resource	Key Word(s)	Targeted Audience	Resource Creator	Description of Resource Creator	Subject Area	Media Type	Website Link	Last Updated	Tools Found in the Resource
"A common framework for networked personal health records". This paper explores the possibilities and requirements of networking such applications across the fragmented landscape of health care data and services.	PHRs; report	HIE stakeholders; consumers	Markle Foundation	Emerging information and communication technologies possess enormous potential to improve people's lives. The Markle Foundation works to realize this potential by accelerating the use of these technologies to address critical public needs, particularly in the areas of health and national security.	PHR	Report	<a href="http://www.connectingforhealth.org/commonframework/docs/P9_NetworkedPHRs.pdf">http://www.connectingforhealth.org/commonframework/docs/P9_NetworkedPHRs.pdf</a>	2006	Discussion about networked PHRs
Report about Hurricane Katrina and its aftermath, including disaster planning and e-health.	Emergencies; disasters; Katrina; report	HIE stakeholders; consumers	Markle Foundation		General HIE; disasters	Report	<a href="http://www.markle.org/downloadable_assets/katrinahealthfinal.pdf">http://www.markle.org/downloadable_assets/katrinahealthfinal.pdf</a>	2006	Description of the storm and its impact, the primary hurdles Katrina Health faced, concerns about national disaster response, the context for disaster response, details of the Katrina Health story, and set of recommendations in anticipation of future disasters
National survey results reports public opinion toward electronic personal health records, including consumers' level of interest, the benefits of and concerns about online health information, and the role of the government in encouraging health information exchange networks and establishing privacy protections.	Report; survey results	HIE stakeholders	Markle Foundation		General HIE	Report	<a href="http://www.markle.org/downloadable_assets/research_doc_120706.pdf">http://www.markle.org/downloadable_assets/research_doc_120706.pdf</a>	2006	Survey results about consumer attitudes toward e-health.
The website has resources developed for the Minnesota e-Health Initiative, a public-private collaborative whose vision is to accelerate the adoption and use of health information technology in order to improve health care quality, increase patient safety, reduce health care costs and improve public health.	EHR, privacy, confidentiality, security, PHR, public health, infrastructure, e-health, consent, standards	Consumers/ providers/public health/ IT professionals/ lawyers/ legislatures	Minnesota Department of Health	MDH protects, maintains and improves the health of all Minnesotans. The Minnesota Department of Health performs a wide range of critical public health duties every day. The department also regularly identifies public health issues that need special attention.	EHR/PHR	Website	<a href="http://www.health.state.mn.us/e-health/index.html">http://www.health.state.mn.us/e-health/index.html</a>	2008	EHR mandate statewide plan, communications plan, fact sheet, glossary consumer website, privacy and security laws/forms/principles, overview on e-Health standards, workgroups
Website link to consumer HIE education materials with links to PHRs	PHR; EMR; privacy and security; education	Patients	Minnesota Department of Health		General HIE	Website	<a href="http://www.health.state.mn.us/e-health/consumers/index.html">http://www.health.state.mn.us/e-health/consumers/index.html</a>	2007	Resource links; HIE definitions; privacy and security
HIE privacy and security, including consumer education of HIPAA	HIPAA; privacy and security	Patients; HIE stakeholders	Mississippi Health Information Security and Privacy Center.	Website is the result of Mississippi's work in HISPC	General HIE	Website	<a href="http://mshispc.com/">http://mshispc.com/</a>	2008	HIE privacy and security; HIPAA FAQs
Links to NAHIT accomplishments, including glossary or terms and definition of interoperability	Interoperability; glossary; EMR	HIE stakeholders	National Alliance for Health Information Technology	A diverse partnership of senior health care executives impatient with the pace of change in health care. We believe that electronic health records and related health information technology (HIT) are the platform for propelling the U.S. health system to a higher level of performance.	General HIE	Website	<a href="http://nahit.org/aboutNAHIT/ accomplishments.asp">http://nahit.org/aboutNAHIT/ accomplishments.asp</a>	2008	Interoperability; glossary; report; EMR

Brief Description of Resource	Key Word(s)	Targeted Audience	Resource Creator	Description of Resource Creator	Subject Area	Media Type	Website Link	Last Updated	Tools Found in the Resource
Glossary of consensus on HIT terms	Glossary	HIE stakeholders; consumers	National Alliance for Health Information Technology	The National Alliance for Health Information Technology is a diverse partnership of senior health care executives impatient with the pace of change in health care. Belief is that EHRs and related health information technology (HIT) are the platform for propelling the U.S. health system to a higher level of performance.	General HIE	Report	<a href="http://www.nahit.org/images/pdfs/HITTermsFinalReport_051508.pdf">http://www.nahit.org/images/pdfs/HITTermsFinalReport_051508.pdf</a>	2008	Glossary; report
Among other reports, a standard definition of interoperability	Reports, interoperability	HIE stakeholders	National Alliance for Health Information Technology		General HIE	Report	<a href="http://www.nahit.org/aboutNAHIT/accomplishments.asp">http://www.nahit.org/aboutNAHIT/accomplishments.asp</a>	2008	Interoperability; definitions; glossary
Includes principles and best practices on protecting personal information	Privacy, Health Information	Consumer, consumer advocates	National Consumers League	NCL protects and promotes social and economic justice for consumers and workers in the United States and abroad. The National Consumers League is a private, nonprofit advocacy group representing consumers on marketplace and workplace issues.	PHI	Website	<a href="http://www.nclnet.org/">http://www.nclnet.org/</a>	2008	News, publications, policy framework, letters, online essentials, testimonies, comments, consumer guide to Internet safety, privacy and security
The National Partnership coordinated a group of influential consumer organizations in developing guiding policy principles that apply to HIT and consumers in numerous contexts.	Privacy and security, health information	HIE stakeholders, consumers	National Partnership for Women & Families	The National Partnership is Washington DC based nonprofit that works to further policies that benefit women and families, including the improvement of health care quality through IT.	General HIE	Handout on a website	<a href="http://www.nationalpartnership.org/site/PageServer?pagename=ourwork_hcq_hit">http://www.nationalpartnership.org/site/PageServer?pagename=ourwork_hcq_hit</a>	2007	Consumer principles, also link to Markle Foundation Common Framework
The NHIN will enable health information to follow the consumer, be available for clinical decision making, and support appropriate use of health care information beyond direct patient care so as to improve health	Privacy and security, HIT, HIPAA, FAQ	Patients and providers	Nationwide Health Information Network (NHIN)	The Nationwide Health Information Network (NHIN) is the critical portion of the health IT agenda intended to provide a secure, nationwide, interoperable health information infrastructure that will connect providers, consumers, and others involved in supporting health and health care.	HIT	Website	<a href="http://www.hhs.gov/healthit/healthnetwork/background/">http://www.hhs.gov/healthit/healthnetwork/background/</a>	2008	Privacy and security policy, HIPAA, HIT, public forums
Helps policymakers reach a common understanding of eHealth	E-health	State policymakers	Nebraska Information Technology Commission	State commission on HIT	General HIE	Website	<a href="http://www.nitc.ne.gov/eHc/cearing/index.html">http://www.nitc.ne.gov/eHc/cearing/index.html</a>	2008	General information
NJ state briefs	Privacy	Consumers	NJ Consumer Affairs	New Jersey Division of Consumer Affairs, Office of the Attorney General	General HIE	Consumer brief	<a href="http://www.state.nj.us/ps/ca/briefs.htm">http://www.state.nj.us/ps/ca/briefs.htm</a>	2006	Consumer briefs
Health IT resource of information related to activities in NYS with related links to national initiatives	DOH, OHITT, health IT, HISPC, HEAL	HIE stakeholders, general public	NYSDOH	The Office of Health Information Technology Transformation is a newly created office within DOH charged with coordinating health IT programs and policies across the public and private health care sectors to enable improvements in health care quality, affordability and outcomes for all New Yorkers.	Health IT	Website	<a href="http://www.health.state.ny.us/technology/">http://www.health.state.ny.us/technology/</a>	2008	HISPC reports, HEAL NY grant information, resource links
Video for consumers regarding need for HIE	HRB; video	Consumers	Oregon Health Policy and Research	The Office for Oregon Health Policy and Research (OHPR) is responsible for the development and analysis of health policy in Oregon and serves as the policymaking body for the Oregon Health Plan.	General HIE	Video	<a href="http://video.google.com/video/play?docid=6764524539952681192&amp;hl=en">http://video.google.com/video/play?docid=6764524539952681192&amp;hl=en</a>	2008	Video

Brief Description of Resource	Key Word(s)	Targeted Audience	Resource Creator	Description of Resource Creator	Subject Area	Media Type	Website Link	Last Updated	Tools Found in the Resource
Website with lots of information for consumers about understanding HIPAA, what questions to ask if you are considering using PHR, how to get access to your own records, consumer privacy toolkit	Privacy and security; toolkit; PHR; EMR; education; HIPAA	Consumers; patients	Patient Privacy Rights	A nonprofit organization located in Austin, TX. Founded in 2004, Patient Privacy Rights is dedicated to ensuring Americans control all access to their health records.	General HIE	Website	<a href="http://www.patientprivacyrights.org/site/PageServer?pagename=Homepage">http://www.patientprivacyrights.org/site/PageServer?pagename=Homepage</a>	2008	Checklists, toolkit, links, questions to ask, HIPAA
Topics related to patient-centered health info technology	Blog	HIE stakeholders	PCHIT	This initiative will improve adoption of health information technology (HIT) tools to better engage patients and families in their own care. We will support learning and implementation by working closely with a variety of organizations to better understand each organization's key levers and barriers to adoption.	HIT	Blog	<a href="http://ixcenterblog.org/">http://ixcenterblog.org/</a>	2008	Blog
Site is about privacy rights in general, with one section specifically about privacy and medical records	HIPAA; privacy and security	Patients	Privacy Rights Clearinghouse	The Privacy Rights Clearinghouse (PRC) is a nonprofit consumer organization with a two-part mission -- consumer information and consumer advocacy. Some goals: Raise consumers' awareness of how technology affects personal privacy. and empower consumers to take action to control their own personal information by providing practical tips on privacy protection.	Patient protection	Website	<a href="http://www.privacyrights.org/medical.htm">http://www.privacyrights.org/medical.htm</a>	2007	HIPAA; fact sheets; resource links
Ethical, legal, and social issues related to PHRs	PHR; privacy and security;	Consumers; HIE stakeholders	Project Health Design	A \$5 million national program (funded through RWJ) designed to support health and information technology pioneers to create a new generation of PHRs. The goal is to design and test a suite of PHR tools and applications that work together to help people achieve their various and specific health goals in an integrated fashion.	PHRs	Website	<a href="http://www.projecthealthdesign.org/elsi/ELSIgroupresources">http://www.projecthealthdesign.org/elsi/ELSIgroupresources</a>	2008	Links to the PHR ethics, other info about PHRs and vendors who are offering PHRs (e.g., Google Health)
Blog on PHRs with consumer-centric themes	PHR; blog	Consumer advocates, consumers	Project Health Design		PHRs	Blog; website	<a href="http://projecthealthdesign.typepad.com/">http://projecthealthdesign.typepad.com/</a>	2008	Blog about PHRs
Website devoted to developing database system for the state of Rhode Island and informing the public on status	Health Care Transformation, IT database	General Public, Consumers, Medical Society	Rhode Island Quality Institute	The pioneers at The Rhode Island Quality Institute are helping reinvent health care. These are senior leaders from hospital administration, public health, business and insurance; physicians, consumers, and university educators.	General HIE	Website	<a href="http://www.rigi.org/matriarch/default.asp">http://www.rigi.org/matriarch/default.asp</a>	2007	General information, reports, fact sheets, reviews, surveys
Tennessee Health Information Technology State Profile	HIT, HIE, RHIOs, Survey, Legislation, Telemedicine	Providers/ Technology Vendors/ Legislators/ Lawyers	Rural Health Resource Center	A national nonprofit organization based in Duluth, Minnesota that serves the knowledge center for rural hospitals, and provides technical assistance, information, education and other resources to rural health care providers and their communities.	HIT/HIE/ RHIOs	Website	<a href="http://www.ruralcenter.org/hit_profiles/tn/#other">http://www.ruralcenter.org/hit_profiles/tn/#other</a>	2008	State demographics, legislation, telemedicine, HIEs and RHIOs grant funded HIT projects, HIT survey information, other HIT activities

Brief Description of Resource	Key Word(s)	Targeted Audience	Resource Creator	Description of Resource Creator	Subject Area	Media Type	Website Link	Last Updated	Tools Found in the Resource
NYeC is a public-private partnership with the NYSDOH and facilitates the statewide collaboration process for health IT.	NYeC, privacy, security, EHR, ehealth, Health IT, Education, Consent, Public Health,	HIE stakeholders, Consumer advocates	The New York eHealth Collaborative	NYeC (pronounced "nice") was founded by health care leaders across the state, with leadership and support from the New York State Department of Health, as a public-private partnership that will serve as a focal point for health care stakeholders to build consensus on state health IT policy priorities, and collaborate on state and regional health IT implementation efforts.	General HIE	Website	<a href="http://nyehealth.org/">http://nyehealth.org/</a>	2008`	Reports, educational materials, related links, privacy and security
Consumer toolkit framework—2007	Framework, toolkit, privacy, security, HIE, HIT	Consumer	The North Carolina Healthcare Information and Communications Alliance, Inc. (NCHICA)	The North Carolina Healthcare Information and Communications Alliance, Inc. (NCHICA) is a nationally recognized nonprofit consortium that serves as an open, effective and neutral forum for health information technology (HIT) initiatives that improve health and care in North Carolina. Members include leading organizations in health care, research and information technology.	HIT, HIE	Website	<a href="http://www.nchica.org/NCHIS/PC/Phase2/NC%20CACHI%20Consumer%20Empowerment%20Toolkit.pdf">http://www.nchica.org/NCHIS/PC/Phase2/NC%20CACHI%20Consumer%20Empowerment%20Toolkit.pdf</a>	2008	HIE toolkit, HISPC activities and materials, Council materials, industry events
Consumer empowerment toolkit—2008	Empowerment, toolkit, privacy, security, HIE, HIT	Consumer	The North Carolina Healthcare Information and Communications Alliance, Inc. (NCHICA)	The North Carolina Healthcare Information and Communications Alliance, Inc. (NCHICA) is a nationally recognized nonprofit consortium that serves as an open, effective and neutral forum for health information technology (HIT) initiatives that improve health and care in North Carolina. Members include leading organizations in health care, research and information technology.	HIT, HIE	Website	<a href="http://www.nchica.org/NCHIS/PC/Phase2/NC%20HISPC%20Privacy%20and%20Security%20Consumer%20Toolkit%20Framework.pdf">http://www.nchica.org/NCHIS/PC/Phase2/NC%20HISPC%20Privacy%20and%20Security%20Consumer%20Toolkit%20Framework.pdf</a>	2008	HIE toolkit, HISPC activities and materials, Council materials, industry events
Educational resources for patients; embedded within the text are resource links for HIE stakeholders—consumer survey, info about statewide HIE	Survey; links; education	Patients; HIE stakeholders; providers	The Rhode Island Quality Institute	Some goals of the organization: demonstrate how the health care system can be improved through collaborative innovation; foster connectivity between and among the health care team and the patient; increase accuracy, responsiveness, and effectiveness in health care by using technology to standardize, streamline, and speed up the retrieval and delivery of patient data statewide.	General HIE	Website	<a href="http://www.riqi.org/matriarch/default.asp">http://www.riqi.org/matriarch/default.asp</a>	2008	Resource links; consumer survey link to Markle Foundation; education
HIPAA facts	HIPAA; education	HIE stakeholders; patients; providers	US Dept of Health and Human Services—Office for Civil Rights	The Department of Health and Human Services (HHS), through the Office for Civil Rights (OCR), promotes and ensures that people have equal access to and opportunity to participate in and receive services from all HHS programs without facing unlawful discrimination, and that the privacy of their health information is protected while ensuring access to care.	HIPAA	Website	<a href="http://www.hhs.gov/ocr/hipaa/">http://www.hhs.gov/ocr/hipaa/</a>	2008	Handouts; privacy and security
Health Information Privacy Resources	Education, Privacy, Health Information, HIPAA, Legal Information	Consumers/providers/ lawyers	US Dept of Health and Human Services—Office for Civil Rights		Legislation	Website	<a href="http://www.hhs.gov/ocr/index.html">http://www.hhs.gov/ocr/index.html</a>	2008	Fact sheets, educational materials, FAQs, information on filing complaints, legal information

Brief Description of Resource	Key Word(s)	Targeted Audience	Resource Creator	Description of Resource Creator	Subject Area	Media Type	Website Link	Last Updated	Tools Found in the Resource
Consumer friendly information about services provided and how personal health information is stored and exchanged electronically.	Confidential, consent, privacy, HIE,	Patients, general public	Visiting Nurse Service of NY	VNSNY is the largest not-for-profit home health care agency in the nation.	HIE	Website	<a href="http://www.vnsny.org/main/site/hie/h_index.html">http://www.vnsny.org/main/site/hie/h_index.html</a>	2008	Educational materials, fact sheets, consent form
Consumer education surveys	Survey; education;	Patients; providers	Washington State Health Care Authority	State organization tasked with building a health record banking model	PHR	Website	<a href="http://www.accessmyhealth.org">http://www.accessmyhealth.org</a>	2008	Education; survey
EMR education and training resources for the consumer	EMR; education; privacy and security; glossary; FAQs; handouts	HIE stakeholders; patients; providers	West Virginia Medical Institute	A nonprofit, physician-sponsored organization dedicated to improving the health of the people we serve. WVMI was founded in 1973 as the educational arm of the West Virginia State Medical Association. Since then WVMI has evolved into an independent, multifaceted national resource for quality improvement.	EMR	Website	<a href="http://www.ehealthwv.org/eh/">http://www.ehealthwv.org/eh/</a>	2008	EMR backgrounder, benefits of HIE; glossary; FAQs; HIE consumer handouts; privacy and security
Overview: Health Information Security and Privacy Collaboration	Privacy and Security	General Public	West Virginia Medical Institute		General HIE	Website	<a href="http://wvmi.org/corp/proj_hisp/c/default.aspx">http://wvmi.org/corp/proj_hisp/c/default.aspx</a>	2008	Reports and educational material
Medicare QIO description on the development of a comprehensive healthcare system	Health care system	Medical professionals and people with Medicare in West Virginia	West Virginia Medical Institute		General HIE	Website	<a href="http://www.qiww.org/wv/medical_professionals/default.aspx">http://www.qiww.org/wv/medical_professionals/default.aspx</a>	2008	General information, reports, fact sheets
Final Report of the Consumer Interests Workgroup—2006	Privacy, security, EMR, ehealth, HIT, HIE, Education, Data, Consent, Public Health, Legal, Accountability	Consumer, legislature, providers, researchers, public health	Wisconsin e Health Care Quality and Patient Safety Board	Governor Jim Doyle created the eHealth Care Quality and Patient Safety Board by Executive Order 129 on November 2, 2005. Its purpose is to develop a strategic Action Plan for the statewide adoption and exchange of electronic health records in 5 years.	HIT, HIE	Website	<a href="http://ehealthboard.dhfs.wisconsin.gov/reports/ci-final-report.pdf">http://ehealthboard.dhfs.wisconsin.gov/reports/ci-final-report.pdf</a>	2008	Reports, privacy and security project, other resources, webcasts, related links
Action Plan written in 2006. Implementation of the Action Plan Consumer Interests Workgroup recommendations is a work in progress	Privacy, security, EMR, ehealth, HIT, HIE, Education, Data, Consent, Public Health, Legal, Accountability	Consumer, legislature, providers, researchers, public health	Wisconsin e Health Care Quality and Patient Safety Board		HIT, HIE	Website	<a href="http://ehealthboard.dhfs.wisconsin.gov/actionplan2006-12.pdf">http://ehealthboard.dhfs.wisconsin.gov/actionplan2006-12.pdf</a>	2008	Reports, privacy and security project, other resources, webcasts, related links
Mostly a resource of links for HIE stakeholders who want to understand privacy and security. Very few original sources.	HIPAA; FAQs	HIE stakeholders	Wyoming Health Information Resources	The WYHIR—pronounced “wire”—is Wyoming’s source for information regarding the private and secure exchange of health information. Our mission is to ensure the privacy of protected health information by advancing the knowledge of laws, regulations, policies, and best practices pertaining to health information exchange in Wyoming.	General HIE	Website	<a href="http://wyhir.org/Browse.aspx?S=4">http://wyhir.org/Browse.aspx?S=4</a>	2008	HIPAA FAQs; resource links; journal articles; HIE scenarios

## Criteria Used for Selecting HIT Consumer Education and Engagement Materials

Document adapted and modified from Kansas Selection Criteria (Adapted and modified from - <http://nihlibrary.nih.gov/FAQ/selectioncriteria.htm>, <http://www.library.cornell.edu/olinuris/ref/research/webcrit.html>)

### THE SCOPE

The subject matter should support efforts toward educating and engaging the consumer about HIT and HIE

The resources should be relevant to consumer HIT and HIE, noting privacy and security issues

The purpose of the resource should be explicit and clear

Materials must have a web link to be included

Materials should be vendor neutral

### ACCESS

Resources should be easily accessible at no cost

If a resource is useful and there is a cost, note resource and the cost in the spreadsheet

### AUTHORITY

The resource should have an author/producer and not be produced anonymously

### CURRENCY

Dates associated with the resource should include: When the resource was written/produced, when the resource was last revised/updated (materials not produced/revised after April 2005 will not be included). If the resource is a graph and/or chart, it should clearly show when the data was gathered.

### COVERAGE

Final/completed resources will be included as opposed to materials in draft form

Draft or beta materials can be included if it is evident that they are being updated routinely

### USEFULNESS

Where relevant, the following good design principles should be evident in the materials: Logical and hierarchical organization, uncluttered appearance, feedback mechanism, and cohesiveness

The information should be understandable

Reference for factual information should be documented and verifiable

Resources should be free of grammatical, spelling, and other typographical errors

If statistical charts and/or graphs are included, they should be clearly labeled and easy to read

Where relevant, navigation should be logical

Where relevant, there should be search capability

Overall good writing or documenting style should be observable

## Glossary of Acronyms

AHIMA - American Health Information Management Association

AHRQ - Agency for Healthcare Research and Quality

CEE - Consumer Education and Engagement Collaborative

E-Health - Electronic Health

EHR - Electronic Health Records

EMR - Electronic Medical Records

FAQ - Frequently Asked Questions

HIE - Health Information Exchange

HIPAA - Health Insurance Portability and Accountability Act

HISPC - Health Information Security and Privacy Collaboration

HIT - Health Information Technology

HITT - Health Information Technology and Transparency

HRB - Health Record Banking

PHI - Protected Health Information

PHR - Personal Health Records

RHIO - Regional Health Information Organization