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Consumer Collaborative Workgroup — Inventory of Consumer Health IT/HIE Materials

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Resource Creator	Brief description of who the resource creator is	Website Link	Brief Description of Resource	Resources available on website	Key Word(s)
Aetna	Aetna is one of the nation's leaders in health care, dental, pharmacy, group life, and disability insurance, and employee benefits	http://www.aetna.com/about/aoti/aetna_perspective/health_information_technology.html	Education on why healthcare needs Health IT	Education	Education
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.	http://www.aetna.com/about/aoti/aetna_perspective/health_information_technology.html	Provides an overview of Health IT	Consumer health care tools, survey results, brief paragraphs on: FAQs, background and why Health IT is necessary	Health IT, health plan
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.	http://www.ahrq.gov/consumer/phrvid.htm	Video on why consumers need a PHR; panel of experts include Carolyn Clancy, Ron Stock, and David Lansky	Video; HIE education	Video

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Agency for Healthcare Research and Quality		http://psnet.ahrq.gov/resource.aspx?resourceID=7362&sourceID=1&emailID=9827	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/book download	Report
Agency for Healthcare Research and Quality		http://healthit.ahrq.gov/portal/server.pt?open=514&objID=5554&mode=2&holderDisplayURL=http://prodportallb.ahrq.gov:7087/publishedcontent/publish/communities/k_o/knowledge_library/features_archive/features/accessible_health_information_technology__it__for_populations_with_limited_literacy__a_guide_for_developers_and_purchasers_of_health_it.html	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	Report; literacy

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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 healthcare 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.	http://www.myphr.com/	Defines PHRs and issues associated with using PHR.	Glossary of terms; links to other resources; Free PHR forms; PHR tools and services; Health info news; FAQs; PHR definitions; Consumer privacy rights	PHR; Education; FAQs; privacy and security; glossary
AHIMA		http://www.youtube.com/watch?v=TZzIw6RpQVg	Video with consumers and AHIMA experts about use of importance of HIE and PHRs	Video; HIE education	Education; PHR
AHIMA		http://www.myphr.com/rights/your_privacy_rights.asp	Links to handouts and articles concerning privacy and the public's rights under HIPAA	Handouts, HIE educational materials	Education; privacy and security
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.	http://www.medicaid.alabama.gov/news/EHR_Medicaid_AL.aspx?tab=2	News about Alabama being selected to be in the EHR Medicare demonstration project	News, EHR fact sheet	EHR, Medicare, Medicaid

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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.	http://www.aafp.org/online/etc/medialib/aafp_org/documents/press/fixhealthwomen/fixhealthwomendoc.Par.0001.File.tmp/Executive_Summary_Fixing_Health_Care_200408.pdf	Survey results of 1,270 women regarding what they would like to see in healthcare reform.	Report	Survey
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.	http://www.amia.org/inside/initiatives/healthdata/2007/draftconsumerchecklist.pdf	Consumer checklist for privacy and security	Checklist	Privacy and security
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 (Health IT) through education and research	http://www.azhec.org/index.jsp	The website in general is a glossary of HIE/Health IT terms	Glossary of terms; resource links	Glossary

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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 right information to the right place at the right time, BHIX promotes improvements in the quality, safety and efficiency of medical care.	http://www.bhix.org/index.html	Information accessed through BHIX comes from a variety of Health Information Sources. These Health Information Sources may include Participants, 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.	Educational materials, contact info	BHIX, consent, interoperable
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.	https://www.bcbskc.com/eprise/main/Public/Content/Health_and_Wellness.html	Consumers can create a personal health record	Online personal health record, health risk appraisal, privacy and security policies	PHR, health, wellness, privacy, security

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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.	http://www.chcf.org/topics/index.cfm?topic=CL108	Website on Health IT	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 Health IT 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	Health IT, HIE, consumer control, PHR, Health Information, Community Health Clinics, E-prescribing
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.	http://www.ohi.ca.gov/calohi/	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 glossary	HIPAA

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California Office of HIPAA	A link to Federal FAQs	http://aspe.hhs.gov/admnsimp/final/pvcguide1.htm	Standards for Privacy of Individually Identifiable Health Information	FAQs, privacy and security laws	Privacy and security
CareEntrust - Kansas City	An employer-based regional health information network (RHIO)	http://www.careentrust.org/	CareEntrust is currently offered as a health benefit by sponsoring organizations	Markle foundation statistics, Benefits of PHR	PHR
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.	http://carespark.com/index.php?option=com_content&task=view&id=62&Itemid=63	Survey results of consumer attitudes about HIE in Appalachian, TN region	Survey results	Survey
Center for Democracy and Technology	CDT is a non-profit 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.	http://www.cdt.org/healthprivacy/	Brochures for consumers on HIE in general and myths and facts about HIPAA.	2 page overview of HIE, "Putting Patients First," and longer FAQ on HIPAA and privacy rights	Education; FAQs; privacy and security
Center for Democracy and Technology		http://www.cdt.org/healthprivacy/	Recommended policy framework for addressing health privacy in a policy framework	See CDT policy post 14.9 and "Beyond Consumer Consent"	Education; privacy and security

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Center for Democracy and Technology	Works to promote democratic values and constitutional liberties in the digital age. With expertise in law, technology, and policy, CDT seeks practical solutions to enhance free expression and privacy in global communications technologies.	http://www.cdt.org/healthprivacy/20080514HPframe.pdf	Report calls for the adoption of a comprehensive privacy and security framework for protection of Health IT is used to support E-HIE	Report	Report; privacy and security
Center for Democracy and Technology		http://www.cdt.org/privacy/	How to protect your online privacy	Top 10 ways to protect your online identity (checklist); glossary; explanation of Privacy and security policies	Education; privacy and security
Center for Democracy and Technology		http://www.cdt.org/healthprivacy/	Various links to issues related to consent, HIPAA, etc.	Links from the health privacy project (see resource #16)	Privacy and security
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.	http://thielst.typepad.com/	Weblog with opinions about various healthcare topics, including PHRs; RHIOs; Health IT	Blog	Blog

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Committee on Veteran's Affairs	US Veteran's Affairs	http://veterans.house.gov/Media/File/110/5-8-07o-i/110-20transcriptO-I5-8-07.htm	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.	Not applicable	EMR
Creighton Health Services Research Program	A multi-professional team of scholars engaged in interdisciplinary health services research.	http://chrp.creighton.edu/Documents/HISPC_Report_3.pdf	Consumer views about privacy and security in E-HIE	Report	Privacy and security
Creighton University Health Research Services Program	NE University-based health research center	http://chrp.creighton.edu/Documents/HISPC_Report_3.pdf	Survey of 16 diverse people in Nebraska	Consumer survey results	Survey; eHealth
Department of Defense – Privacy Office	TRICARE Management Activity – Component of Military Health System	http://www.tricare.mil/tmaprivacy/default.cfm	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.	Privacy impact assessment, HIPAA and Privacy Act Information, Data Use Agreement, Breach response and modification, Policies	Health Information, Privacy, Policies, Security, Data Use, Agreements

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Department of Veterans Affairs (VA)	VHA Software Document Library – This web site 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.	http://www.va.gov/vdl/section.asp?secid=4	My HealtheVet (MHV) is an online environment where veterans, family members, and clinicians may come together to optimize veterans' healthcare. Web technology combines essential health record information with online health resources to enable and encourage veteran/clinician collaboration.	Manuals, Release Notes, Technical Security Guide, Glossary	PHR
Department of Veterans Affairs (VA)	VHA Software Document Library – This web site 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.	http://www.va.gov/vdl/section.asp?secid=4	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.	Information about VISTA	Health IT, VISTA, EMR

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E-health initiative	The eHealth Initiative and the Foundation for eHealth Initiative are independent, non-profit affiliated organizations whose missions are the same: to drive improvement in the quality, safety, and efficiency of healthcare through information and information technology.	http://toolkit.ehealthinitiative.org/communication_and_outreach/default.mspx?	Toolkit for stakeholders trying to build an HIE effort; specifically, there is a link for communication and outreach to consumers	Glossary of terms; Research findings about consumer behavior; public education tools;	Toolkit; education; survey; glossary; handouts
E-health initiative		http://www.ehealthinitiative.org/2007HIESurvey/	Survey of 130 community based HIE efforts around the nation	Survey results	Survey
E-health initiative		http://www.ehealthinitiative.org/blueprint/	Report describing stakeholder consensus on improving healthcare using Health IT. Opinions from 200 Organizations representing different types of stakeholders are included. Materials in Appendix A about how to engage consumers	Report	Report
E-health initiative		http://www.ehealthinitiative.org/toolkit/getOrg/InfoSTAT.mspx	Downloadable public announcements for radio, print-ready artwork for advertisements and billboards, case examples that bring life to the key messages. For emergency situations, travel, natural disasters, visit to your doctor	Handouts; advertisements; case studies	Toolkit; handouts; education

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e-health initiative Connecting Communities for Better Health	The eHealth Initiative Foundation's Partnership for Connecting Communities for Better Health Program with support by the Joseph H. Kanter Family Foundation, is a national multi-stakeholder initiative designed to raise national awareness of the value of and accelerate the use of electronic health information to address current U.S. health care challenges, including those related to quality, safety and efficiency.	http://www.ehealthinitiative.org/partnership/	Website with materials on policy, HIE, Health IT, connecting communities, blueprint	Glossary, Annual HIE surveys, Toolkit, Webinars, Consumer Engagement Tools, eHI blueprint report: building consensus for common action	HIE, Health IT
e-health initiative Connecting Communities for Better Health	The eHealth Initiative Foundation's Partnership for Connecting Communities for Better Health Program with support by the Joseph H. Kanter Family Foundation, is a national multi-stakeholder initiative designed to raise national awareness of the value of and accelerate the use of electronic health information to address current U.S. health care challenges, including those related to quality, safety and efficiency.	http://www.ehealthinitiative.org/toolkit/getOrg/InfoSTAT.mspx	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 (HIE). 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 healthcare of Americans.	Consumer engagement materials	Consumer engagement

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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.	http://www.fhin.net/PHR/ePHRbasics.shtml	PHR resources: content, privacy and security, checklists for consumers, free PHR forms	Checklist; privacy and security; education; free forms	PHR
Florida Health Information Network (FL-HISPC)		http://www.imageresearch.com/FHIN/	PowerPoint Presentations related to HIE in Florida	PowerPoint Presentations	PowerPoints
Florida Health Information Network (FL-HISPC)		http://www.fhin.net/eprescribe/	E-prescribing information	Clearinghouse of information related to e-prescribing	e-prescribing
GA Dept of Community Health	Office of Health Information Technology and Transparency	http://dch.georgia.gov/00/channel_title/0,2094,31446711_69326946,00.html	Fact sheet	General information	Health information exchange; fact sheet
GA Dept of Community Health	Office of Health Information Technology and Transparency	http://dch.georgia.gov/00/channel_title/0,2094,31446711_69326946,00.html	Community forum	Prioritization of health information	Community forum; transparency; health information

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GA Dept of Community Health	Georgia Health Information Technology and Transparency Advisory Board	http://dch.georgia.gov/00/channel_title/0,2094,31446711_69326946,00.html	Advises on matters of HIE and privacy and security of electronic health information	General Information	Health IT and transparency
GA Dept of Community Health	Electronic Health Record Community Partnership – Office of Health Information Technology and Transparency	http://dch.georgia.gov/00/channel_title/0,2094,31446711_69326946,00.html	Project that studies the impact of Electronic Health Record adoption among targeted physicians on quality of care.	General information	EHR, EMR, Security and Privacy
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.	http://grrhio.org/	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.	Educational materials, FAQs, brochure, consent form, privacy	Privacy, Education, Consent, HIE
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.	https://www.google.com/health/html/about/partners.html	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.	FAQs, tour, Google Health Privacy Policy, Information for Partners, Advisory Council Video, Help Center	PHR
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	http://www.centerforhealthstudies.org/sciresc/readability/readability_home.html	PRISM readability toolkit helps researchers and healthcare professionals make materials for consumers more literacy-friendly	Report	Toolkit

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Harris Interactive	Harris Interactive believes that market research helps their clients understand the drivers of decision making and can strengthen enterprise equity.	http://www.harrisinteractive.com/NEWS/allnewsbydate.asp?NewsID=1174	Survey results on attitudes toward Health IT, awareness, impact of technology access, benefits and risks of EMR, Consumer access and interest in having access	Consumer market trends white paper, Surveys, News	Research, polls, survey, EMR
Harris Interactive	Harris Interactive believes that market research helps their clients understand the drivers of decision making and can strengthen enterprise equity.	http://www.harrisi.org/news/allnewsbydate.asp?NewsID=1096	"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	Consumer market trends white paper, Surveys, News	Research, polls, survey, EMR
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.	http://www.healthprivacy.org/	Site is devoted to health information privacy and security, but the focus is not HIE. Many of the links are older than 2004.	FAQs, privacy and security laws; HIPAA; fact sheets;	Privacy and security
Health Privacy Project		http://www.healthprivacy.org/	Myths and facts about HIPAA, written for the consumers	HIPAA	HIPAA; privacy and security
Health Privacy Project		http://www.healthprivacy.org/	Knowing your rights about health privacy	Privacy and security	Education; privacy and security
Healthcare IT News	Provides the industry's healthcare IT news – delivered by email or RSS	http://www.healthcareitnews.com/story.cms?id=6671	Healthcare IT News: Does Santa Barbara RHIO shutdown affect California HIE efforts?	News, NHIN Watch	HIE, RHIO

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HIMSS	The Healthcare Information and Management Systems Society (HIMSS) is the healthcare industry's membership organization exclusively focused on providing global leadership for the optimal use of healthcare information technology (IT) and management systems for the betterment of healthcare.	http://www.himss.org/ASP/topics_phr.asp	Tabs related to educating consumers about PHRs, including links to tools and resources	Links to PHR tools and services	PHR
HIMSS		http://www.himss.org/ASP/privacySecurityTree.asp?faid=78&tid=4	Privacy and security toolkit	Resources for privacy and security	Privacy and security
HIMSS		http://www.himss.org/ASP/topics_FocusDynamic.asp?faid=204	Privacy and security issues for PHRs	PowerPoint discussing privacy and security issues for PHR	Privacy and security; PHR
HIMSS		http://www.himss.org/ASP/topicsHome.asp	Links to topics related to EMRs, PHRS, clinical informatics, privacy and security; standards, interoperability, etc. Lots of resources for all audience types	Links to different HIE resources on a variety of Health IT topics	EMR; PHR; privacy and security
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.	http://www.ivhin.org/patientPortal.php	Survey questions about HIE attitudes	Survey questions	Survey

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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	http://www.internetifmc.com/	5 reasons your doctor is using an EMR	Education	EMR; education
Iowa Foundation for Medical Care		RTI Portal	Materials to run a consumer focus group on HIE, including topics, questions, and results of the Iowa consumer focus group.	Consumer focus group questions and results of Iowa focus group	Focus group
Kaiser Network	Kaiser Family Foundation is a non-profit, 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 non-profit research organizations or major media companies.	http://www.kaisernetwork.org/health_cast/hcast_index.cfm?display=detail&hc=1462	Video with panel of David Brailer, Dean Rosen, and Winston Price, on adoption of Health IT and HIE	Panel of experts, education; video	Education
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 healthcare informatics through knowledge, integration, research and empowerment of faculty and students in the expanding field of biomedical science and information technology.	http://www2.kumc.edu/healthinformatics/HISPC/hispc.htm/	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)	Glossary, Related Projects, Educational Materials Toolkit (coming in the future), Reports, Useful Resources, HISPC and related activities	Health IT, HIE, privacy, security

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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 http://ehealth.ky.gov. 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.	http://ehealth.ky.gov/	Standards for Privacy of Individually Identifiable Health Information	FAQs, privacy and security laws	Privacy and security
Louisiana Health Care Review	LHCR's mission is to improve the quality of health and health care by using information and collaborative relationships to enable change. We believe that better care begins with better care management	http://www.ehrtoday.org/	FAQs for consumers about EMRs	EMR FAQs; resource links	FAQs
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.	http://www.ehrtoday.org/	Website designed by Louisiana for HISPC	FAQs, Acronyms, White paper, Brochures, Newsletter, News, Expert Profiles, Links, Media, HISPC team,	EHR, privacy, security

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Louisville Health Information Exchange, inc.	LouHIE is a not-for-profit organization, governed by a healthcare community board. Its vision is to improve quality and contain rising costs of healthcare in the Louisville area… by providing consumers and their providers anytime, anywhere access to complete healthcare information and decision-support.	http://www.louhie.org/Downloads/LouHIE%20research%20report%20v9%20Final%20Exec%20Summ.pdf	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.	Survey and focus group results about what consumers and other stakeholders think about e-health	Report
Louisville Health Information Exchange, inc.		http://www.louhie.org/	Educational video that describes why e-health is needed (the current state of healthcare), and explains how a health record banking model could be useful to the patient.	Video about e-health and HRB in particular	Video; education
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.	http://www.maehc.org/resources.html	Website related specifically to bring together network of stakeholders in order to build an EMR provider network	Resource links	Links

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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.	http://www.connectingforhealth.org/phti/	"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.	Discussion about networked PHRs	PHRs; report
Markle Foundation		http://www.markle.org/downloadable_assets/katrinahealth.final.pdf	Report about Hurricane Katrina and its aftermath, including disaster planning and e-health	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	Emergencies; disasters; Katrina; report
Markle Foundation		http://www.markle.org/downloadable_assets/research_doc_120706.pdf	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	Survey results about consumer attitudes toward e-health.	Report; survey results

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Minnesota – 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.	http://www.health.state.mn.us/e-health/index.html	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 mandate statewide plan, communications plan, fact sheet, glossary consumer website, privacy and security laws/forms/ principles, overview on e-Health standards, workgroups	EHR, privacy, confidentiality, security, PHR, public health, infrastructure, e-health, consent, standards
Mississippi – Mississippi Health Information Security and Privacy Center	No description provided about Center - Website still under construction	http://mshispc.com/	Web site is the result of Mississippi's work in the HISPC- it is still under construction	Brochures, FAQs, A few links to consumer and provider education materials, self-study modules for professionals, Health IT initiatives, Glossary, Acronyms, News and Events, Educational toolkits	Privacy, security, HIPAA, tool kit
Mississippi Health Information Security and Privacy Center.	Website is the result of Mississippi's work in HISPC	http://mshispc.com/	HIE privacy and security, including consumer education of HIPAA	HIE privacy and security; HIPAA FAQs	HIPAA; privacy and security
MN 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.	http://www.health.state.mn.us/e-health/consumers/index.html	Website link to consumer HIE education materials with links to PHRs	Resource links; HIE definitions; privacy and security	PHR; EMR; privacy and security; education

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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.	http://www.nclnet.org/	Includes principles and best practices on protecting personal information	News, Publications, Policy Framework, Letters, Online Essentials, Testimonies, Comments, Consumer Guide to Internet Safety, Privacy and Security	Privacy, Health Information
National Partnership for Women & Families	The National Partnership is Washington DC based non profit that works to further policies that benefit women and families, including the improvement of health care quality through IT.	http://www.nationalpartnership.org/site/PageServer?pagename=ourwork_hcq_hit	The national Partnership coordinated a group of influential consumer organizations in developing guiding policy principles that apply to Health IT and consumers in numerous contexts.	Consumer principles, also link to Markle Foundation Common Framework	Privacy and security, health information
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 healthcare.	http://www.hhs.gov/healthit/healthnetwork/background/	The NHIN will enable health information to follow the consumer, be available for clinical decision making, and support appropriate use of healthcare information beyond direct patient care so as to improve health	Privacy & security policy, HIPAA, Health IT, public forums	Privacy & security. Health IT, HIPAA, FAQ
Nebraska Information Technology Commission	State commission on Health IT	http://www.nitc.ne.gov/eHc/clearing/index.html	Helps policymakers reach a common understanding of eHealth	General information	
NJ Consumer Affairs	New Jersey Division of Consumer Affairs, Office of the Attorney General	http://www.state.nj.us/lps/ca/briefs.htm	NJ state briefs	Consumer briefs	Privacy

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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.	http://www.health.state.ny.us/technology/	Health IT resource of information related to activities in NYS with related links to national initiatives	HISPC reports, HEAL NY grant information, resource links	DOH, OHITT, Health IT, HISPC, HEAL
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.	http://nyehealth.org/	NYeC is a public private partnership with the NYSDOH and facilitates the statewide collaboration process for Health IT	Reports, educational materials, related links, privacy and security	NYeC, privacy, security, EHR, ehealth, Health IT, Education, Consent, Public Health,

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Office of Civil Rights (OCR)	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. Through prevention and elimination of unlawful discrimination and by protecting the privacy of individually identifiable health information, OCR helps HHS carry out its overall mission of improving the health and well-being of all people affected by its many programs.	http://www.hhs.gov/ocr/index.html	Health Information Privacy Resources	Fact Sheets, Educational Materials, FAQs, Information on Filing Complaints, Legal Information	Education, Privacy, Health Information, HIPAA, Legal Information
Ohio Health Policy Institute	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.	http://hispc.pbwiki.com/	Wiki for people interested in Health IT and HIE	Resource links; privacy and security	Links; privacy and security

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Patient Privacy Rights	A non-profit organization located in Austin, TX. Founded in 2004, Patient Privacy Rights is dedicated to ensuring Americans control all access to their health records.	http://www.patientprivacyrights.org/site/PageServer?pagename=Homepage	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	Checklists, toolkit, links, questions to ask, HIPAA	Privacy and security; toolkit; PHR; EMR; education; HIPAA
PCHIT	This initiative will improve adoption of health information technology (Health IT) 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.	http://ixcenterblog.org/	Topics related to patient centered health info technology	Blog	Blog
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.	http://www.privacyrights.org/medical.htm	Site is about privacy rights in general, with one section specifically about privacy and medical records	HIPAA; fact sheets; resource links	HIPAA; privacy and security

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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	http://www.projecthealthdesign.org/elsi/ELSIgroupresources	Ethical, legal, and social issues related to PHRs	Links to the PHR ethics, other info about PHRs and vendors who are offering PHRs (e.g., Google Health)	PHR; privacy and security;
QIO	Health Care Quality Improvement Organizations within West Virginia, Pennsylvania and Delaware	http://www.qiwv.org/wv/medical_professionals/default.aspx	Medicare QIO description on the development of a comprehensive healthcare system	General information, reports, fact sheets	Health care system
Reactions and Opinions, inc.	Market Research firm, with one of their specialties being healthcare	RTI Portal	How to write consumer materials with literacy levels in mind. Talks about what to do/what not to do	Literacy	Literacy
RI DOH	Rhode Island Department of Health	http://www.health.state.ny.us/			
RIQI	Rhode Island Quality Institute	http://www.riqi.org/matriarch/default.asp	Website devoted to developing database system for the state of Rhode Island and informing the public on status	General information, reports, fact sheets, reviews, surveys	Health Care Transformation, IT database
Rural Health Resource Center	A national non-profit 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.	http://www.ruralcenter.org/hit_profiles/tn/#other	Tennessee Health Information Technology State Profile	State Demographics, Legislation, Telemedicine, HIEs and RHIOs. Grant Funded Health IT Projects, Health IT Survey Information, Other Health IT Activities	Health IT, HIE, RHIOs, Survey, Legislation, Telemedicine

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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 (Health IT) initiatives that improve health and care in North Carolina. Members include leading organizations in healthcare, research and information technology.	http://www.nchica.org/NCHISPC/Phase2/NC%20CACHI%20Consumer%20Empowerment%20Toolkit.pdf	Consumer toolkit framework – 2007	HIE toolkit, HISPC activities and materials, Council materials, Industry Events	Framework, toolkit, privacy, security, HIE, Health IT
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 (Health IT) initiatives that improve health and care in North Carolina. Members include leading organizations in healthcare, research and information technology.	http://www.nchica.org/NCHISPC/Phase2/NC%20HISPC%20Privacy%20and%20Security%20Consumer%20Toolkit%20Framework.pdf	Consumer empowerment toolkit – 2008	HIE toolkit, HISPC activities and materials, Council materials, Industry Events	Empowerment, toolkit, privacy, security, HIE, Health IT
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.	http://www.riqi.org/matriarch/default.asp	Educational resources for patients; embedded within the text are resource links for HIE stakeholders – consumer survey, info about statewide HIE	Resource links; consumer survey link to Markle Foundation; education	Survey; links; education

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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.	http://www.hhs.gov/ocr/hipaa/	HIPAA facts	Handouts; privacy and security;	HIPAA; education
Visiting Nurse Service of NY	VNSNY is the largest not-for-profit home health care agency in the nation.	http://www.vnsny.org/why-vnsny/getting-started/health-information-exchange/	Consumer friendly information about services provided and how personal health information is stored and exchanged electronically.	Educational materials, fact sheets, consent form	Confidential, consent, privacy, HIE,
Washington State Health Care Authority	State organization tasked with building a health record banking model	http://www.accessmyhealth.org	Consumer education surveys	Education; survey	Survey; education;
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	http://wvmi.org/corp/proj_hispc/education.aspx	EMR Education and training resources for the consumer	EMR backgrounder, benefits of HIE; glossary; FAQs; HIE consumer handouts; privacy and security	EMR; education; privacy and security; glossary; FAQs; handouts

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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 five years.	http://ehealthboard.dhfs.wisconsin.gov/reports/ci-final-report.pdf	Final Report of the Consumer Interests Workgroup - 2006	Reports, Privacy and Security Project, Other resources, Webcasts, Related links	Privacy, security, EMR, ehealth, Health IT, HIE, Education, Data, Consent, Public Health, Legal, Accountability
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 five years.	http://ehealthboard.dhfs.wisconsin.gov/actionplan2006-12.pdf	Action Plan written in 2006. Implementation of the Action Plan Consumer Interests Workgroup recommendations is a work in progress	Reports, Privacy and Security Project, Other resources, Webcasts, Related links	Privacy, security, EMR, ehealth, Health IT, HIE, Education, Data, Consent, Public Health, Legal, Accountability
WV Medical Institute	State commission on Health IT	http://wvmi.org/corp/proj_hispc/default.aspx	Overview: Health Information Security and Privacy Collaboration	Reports and educational material	Privacy and Security
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.	http://wyhir.org/Browse.aspx?S=4	Mostly a resource of links for HIE stakeholders who want to understand privacy and security. Very few original sources.	HIPAA FAQs; resource links; journal articles; HIE scenarios	HIPAA; FAQs