National Progress Report on eHealth 2010

eHealth Initiative



ACKNOWLEDGEMENTS

The eHealth Initiative would like to acknowledge and extend its thanks to the more than 100 individuals who lent their leadership, expertise, and support to the National Progress Report. A complete list of participants is provided at the end of this report.

eHealth Initiative's Leadership Council, led by eHealth Initiative Board Chairman, Robert Marotta, JD, and eHealth Initiative Foundation Chairman, William Jessee, MD, with executive leadership support by eHealth Initiative and Foundation Chief Executive Officer Jennifer Covich Bordenick and Vice President of Programs and Policy Diane Jones, provided strategic oversight and guidance to the entire effort.

The Co-Chairs, who are listed below, provided leadership and guidance to five workgroups, made up of numerous eHI members who lent their expertise, experiences, review, and hands-on support to the effort. Each of the five committees was supported by an outstanding team of experts and staff.

eHI would also like to thank its members and the many, many organizations that reviewed and provided input to the National Progress Report.

eHealth Initiative National Progress Report Workgroup Co-Chairs and Voluntary Staff:

Aligning Financial and Other Incentives

- Hank Fanberg, MD, CHRISTUS Health System
- Robert Tennant, Medical Group Management Association
- Voluntary staff support by Keith Blystone, GE Healthcare

Engaging Consumers

- Rachel Block, Office of Health Information Technology Transformation, New York State Department of Health, Co- Chair
- Leonard Lichtenfeld, MD, MACP, American Cancer Society, Co-Chair
- Voluntary staff support by Nicole Stephenson, PricewaterhouseCoopers

Improving Population Health

- J. Marc Overhage, MD, PhD, Regenstrief Institute and Indiana Health Information Exchange, Co-Chair
- Brian Keaton, MD, FACEP, American College of Emergency Physicians, Co-Chair
- Voluntary staff support by Paul Ceverha, PricewaterhouseCoopers

Managing Privacy, Security and Confidentiality

- Gerry Hinkley, Pillsbury Winthrop Shaw Pittman
- Mark Frisse, MD, MBA, MSc; Vanderbilt Center for Better Health
- Voluntary staff support by David Kocher, GE Healthcare

Transforming Care Delivery at the Point of Care

- Joseph Heyman, MD, American Medical
- Association,
- William F. Jessee, MD, FACMPE, FACPM, Medical Group Management Association, Co-Chair
- Voluntary staff support by Anwesha Dutta, PricewaterhouseCoopers

The *National Progress Report on eHealth* was supported by the Commonwealth Fund, a national, private foundation based in New York City that supports independent research on health care issues and makes grants to improve health care practice and policy. The views presented here are those of the author and not necessarily of the Commonwealth Fund, its directors, officers, or staff.

NATIONAL PROGRESS REPORT EXECUTIVE SUMMARY

The *National Progress Report* includes a review of progress relative to strategies and actions to utilize health information technology (HIT) and health information exchange (HIE) to improve healthcare quality, safety and efficiency. This review was undertaken by over 100 experts representing the spectrum of health and health IT stakeholders.

BACKGROUND ON REPORT

In 2007, eHI engaged in a six-month process to produce the *eHealth Initiative Blueprint: Building Consensus for Common Action.* The groundbreaking report helped guide the efforts of many policymakers and healthcare leaders. Many of the HITECH Act's provisions directly relate to—and were influenced by—the strategies and actions discussed explicitly in the original report.

Much has transpired in the healthcare and health IT arenas since the release of the 2007 report. The inclusion of over \$30 billion in federal funding through the HITECH Act, a component of the 2009 American Recovery and Reinvestment Act (ARRA) has had significant implications for the development of health IT. Even without the stimulus funding, there has been significant organic advancement in many areas of health IT. In the last two years, the political and economic climate has changed dramatically. Healthcare reform has risen to occupy a prominent place on the national agenda, accompanied by rising public awareness of issues related to healthcare quality, costs, access, and information. In light of this, eHI developed the *National Progress Report* to help facilitate a national dialogue vis-à-vis advancing healthcare through health IT.

The *National Progress Report* is intended to support current leadership efforts, including those involving the Administration, Congress, and private sector organizations that have been working on healthcare IT for many years. The *National Progress Report* does the following:

- Identifies activities and assesses progress against goals set in 2007;
- Highlights key trends, actions and strategies that still need to be addressed;
- Reevaluates plans and priorities in light of developments of the past two years; and
- Creates a framework for a national dialogue among relevant stakeholders.

In the spirit of building social capital and supporting a collaborative agenda for change, the *National Progress Report* included the hands-on involvement of leaders from every sector of healthcare. Multi-stakeholder committees, co-chaired by experts were charged with compiling information and assessing progress in the five focus areas. The project included eHI's members —who deliver care, manage care, and pay for care; protect the public's health; lead collaborative efforts at the state and local levels; and develop tools, services, and therapies to support improvements in healthcare. Finally, and most importantly, the project included representatives who actually receive healthcare — consumers.

SURVEY ASSESSES PERCEPTIONS ABOUT PROGRESS:

As part of this process, the eHealth Initiative conducted an online, informal survey where stakeholders around the country were asked a series of questions to gauge perceptions of progress. Twelve ordinal questions were asked, seeking replies using a scale from strongly disagree to strongly agree. The majority of responses were from the health systems, hospitals and other healthcare organizations, consultant, and clinician categories. While not conclusive, the survey responses offer a snapshot about the HIT and HIE landscape and provide valuable insights for further consideration:

- The majority of respondents believe significant progress has been made: 61 percent of respondents agree or strongly agree with the statement that significant progress has been made in the successful adoption and use of HIT since 2007.
- The value of HIE is not clearly understood by the majority of respondents: 54.9 percent disagree or strongly disagree with the statement that the value of HIE is clearly understood.
- The majority of respondents believe outreach to consumers about the value of EHRs and HIE is not effective: 66.6 percent disagree or strongly disagree with the statement that current outreach to consumers about the value of EHRs and HIE is effective.
- There are mixed reviews about the effect of differences between federal and state privacy laws: 55.5 percent of respondents disagree or strongly disagree with the statement that differences between eHealth Initiative: National Progress Report on eHealth

- federal and state privacy laws are not a barrier to ensuring protection of consumer's rights to healthcare privacy.
- There are mixed reviews about the effect HIT and HIE have had on care delivery: 56 percent agree or strongly agree with the statement that HIT and HIE have had a positive effects on care delivery.
- The majority believe Regional Extension Centers and the National Health Information
 Technology Research Center (HITRC) will be vital to educating providers: 66.1 percent of
 respondents agree or strongly agree with the view that Regional Extension Centers and the National
 Health Information Technology Research Center will be vital to educating providers about adoption and
 meaningful use of health IT.

HIGHLEVEL FINDINGS ON PROGRESS

As part of the development of the report, groups conducted a thorough review of literature, research, policy and market activity since 2007. Progress was assessed against the original strategies and actions proposed in the original 2007 report. Five groups were convened to review progress in five areas: engaging consumers, transforming care delivery, improving population health, aligning financial and other incentives, and managing privacy, security, and confidentiality. Detailed findings are presented in the full report.

Stakeholders reviewing progress in HIT and HIE noted the changes in the overall healthcare market, the economy, and the state of technology available to health professionals and consumers. Changes in each of these areas influenced the progress that occurred within the five areas of focus of the National Progress Report. After reviewing the landscape, several high-level findings emerged:

- The American Recovery and Reinvestment Act (ARRA) was the key driver of progress. ARRA will provide a policy foundation and financial support for programs at the federal and state level to drive provider adoption of certified technology and drive the exchange of health information.¹
- Implementation of multiple ARRA programs will be the dominant story in the years ahead. Much of the implementation activity will occur at the state level² along with provisions in health reform that build upon the HIT and HIE infrastructure³.
- Many providers are concerned about the lack of coordination across the government Health and Health IT initiatives. Provider stakeholders are concerned that the processes and metrics for accelerating adoption and use of HIT and HIE may deter provider participation and delay the transformation to a patient-centered system.⁴ Also, there is concern that concurrent programs driving payment reform and coding updates could discourage HIT adoption.
- More education and outreach to consumers about HIT and HIE is required. The value of HIT and HIE needs to be presented in terms meaningful to consumers. Examples from successful engagement models need to be studied and replicated. Insight into the challenges to consumers with disabilities, low health literacy rates, language barriers and cultural differences, and those who serve particular groups of consumers must be a focus of education and outreach initiatives, so that all consumers benefit from the expanding HIT and HIE capacity.⁵
- The strategies identified on population health in the 2007 report still apply. Work is still needed to reach consensus on the foundational strategies that will support clinical data use for population health purposes.
- Knowledge and transparency of privacy and security policies will be the key to building consumer trust of HIT and HIE. A privacy and security framework with clear rules for accountability, transparency, and access, use and disclosure of personal health information remains vital for building public trust of HIT and HIE. The framework by which organizations collecting, using, storing and sharing personal health information, and government agencies policies, need greater clarity. ARRA created new rights for consumers relative to their access and control of their data. The ability to extend the collection, use and sharing of personal health data outside of clinical settings requires continued efforts to develop common policies and principles for clinical data use.
- The healthcare system still needs business models that are sustainable and support transformation of care delivery. Health IT that is designed, implemented and used effectively to support value-added care processes and longitudinal care (rather than silo processes and functions such as order entry) will enable clinical transformation.

RECOMMENDED NEXT STEPS:

The passage of the American Recovery and Reinvestment Act (ARRA) changed the HIT and HIE landscape from a vision of what is possible to a present reality, with definite actions within a prescribed timeline. To achieve the goal of HIT and HIE that supports a patient-centric, quality and value driven health care system, actions were recommended within several areas. Some recommendations include:

- Implement ARRA policies and programs, on behalf of all sectors of the healthcare community. While a significant step forward, elements of the current proposals delay the inclusion of all providers and may leave behind some populations of consumers. Advancing a broader array of financial and other incentives will be needed to transform care.
- Advocate and advance policies that enable adoption of HIT by all consumers, and ensure that the value of HIE to the consumers, patients and their families is clearly articulated and measurable. Getting information to consumers, and to heath professionals about the need to engage their patients, will be essential to empowering consumers to be participants in their health and healthcare. Tools that further facilitate consumers to access and use their health information can help enable their participation in their own health.
- Build consensus on strategies that support the value case of HIE for population health. The use
 of clinical data is important for population health purposes, but a common set of principles and policies
 about data use are needed.⁹
 - Progress can be achieved on the National Progress Report Population Health strategies if the foundational strategies are prioritized for consensus building:
 - Characterize and explain current laws on clinical data
 - Gather evidence of natural experiments
 - Document the benefits and risks of clinical data for population health purposes
 - Define and prioritize needed common data elements for population health uses
 - Define where common data elements reside
 - Identify common standards for representing common data elements
 - Define the users of common data elements
 - Advancement of the eight remaining strategies is unlikely without progress on these foundational strategies. Dissemination of information about the value of clinical data for these purposes also is necessary to support this ongoing consensus building process.
- Educate on the new privacy and security laws and regulations, and identify gaps for further action. A reconsideration of the existing definition of de-identification and its implications is needed, in light of technological advances that nullify the effectiveness of the HIPAA de-identification criteria. The application of privacy and security laws and regulations to new tools used for data collection and data sharing needs to be examined.

CONCLUSION

The expert panels found that the shared vision, and set of principles articulated by stakeholders in 2007 remain valid, and provide a strong foundation for advancing principles and strategies for expanded HIT and HIE. A complete progress report on each of the five areas follows this executive summary.

Stakeholders still believe that over time HIT adoption can be an effective tool to improve quality in care delivery when the underlying processes also are transformed. ¹⁰ Ultimately, the varied nature of the strategies and their interdependencies underscore the need for ongoing efforts to convene stakeholders, share lessons learned and best practices, as a pathway to achieve consensus policies and principles that will improve the quality, safety, efficiency and efficacy of healthcare through HIT and HIE.

PROGRESS REPORT: ALIGNING FINANCIAL AND OTHER INCENTIVES

INTRODUCTION

Since 2007, significant process has been made in the area of aligning financial and other incentives. The passage of the American Reinvestment and Recovery Act (ARRA) included several provisions supporting progress in aligning financial incentives in a manner consistent with the strategies proposed in the 2007 report ARRA created meaningful use incentive payments to eligible health professionals and hospitals to encourage a rapid adoption and use of Health IT over time. Regional Extension Centers (RECs) and the Health Information Technology Research Center (HITRC) were established to provide assistance with technology selection, implementation and use - tasks that have posed a barrier to adoption.

Provider adoption and effective use will be supported by a final rule on standards, certification and implementation specifications. The proposed rule on certification provides assurance to purchasers that EHR systems support technological capability, functionality, and security needed to enable achievement of meaningful use requirement.

Additional federal level activities have contributed to significant progress on aligning incentives since 2007. The Medicare e-prescribing program created a foundation for incentives that based on technology use and supportive of quality improvements. Physician Quality Reporting Initiative (PQRI) in Medicare includes incentives for quality reporting using evidence-based measures that are based upon clinical guidelines, preparing for future pay-for-performance programs. The new health reform laws promise to further advance the filed with incentives for administrative simplification, and with a recognition that programs that provide incentives for, and ease the burden of, implementation, must consider the challenges of these changes for certain health care providers, particularly those serving rural or underserved areas, and must ensure coordination with standards, implementation specifications, and certification criteria being adopted under the HITECH Act. Additional federal models, such as the Patient Centered Medical Home (PCMH) and Accountable Care Organizations (ACO), are expected to catalyze more powerful quality incentive models: risk- and quality-adjusted capitation, episode of care payments, and enhance fee-for-service payments for quality dimensions, such as prevention.

EXAMPLES OF PROGRESS

Some states and localities are driving realignment of incentives. One example is the Massachusetts eHealth Collaborative (MAeHC), that launched three pilot projects to demonstrate the costs and benefits of wide-scale EHR deployment, understand the barriers to adoption of EHRs and health information exchange (HIE), and test an organizational model for managing and executing communitywide use of EHRs and HIE. The NY Primary Care Information Initiative (PCIP) offers another example, recruiting primary care providers caring for the underserved across a large metropolitan area, aiming to enroll 25–30 percent of high-volume Medicaid primary care providers, to more precisely understand how to assess the investment return of EHR adoption for public programs such Medicaid IT.

Preliminary results of the demonstrations to realign incentives indicate positive results in terms of increased rates of technology adoption and improvements in quality and cost, which will further incentivize adoption. Some early lessons from the demonstrations indicate the importance of assuring certainty, frequency, and sustainability of incentive payoffs, and tailoring the incremental rewards to align with, and therefore support, quality improvement. Together, these changes offer the prospect of significantly enhancing quality beyond the modest impacts of prevailing pay-for-performance (P4P) programs.

A number of other initiatives are referenced in the Overview of Key Initiatives section of this report.

REMAINING GAPS

Significant work is still needed to align incentives for use of health information exchange. Many stakeholders continue to lack understanding about the value of health information exchange. In a review of existing demonstrations, studies indicate that motivation to utilize health information exchange was driven by a

combination of financial incentives, and non-financial incentives, such as technical assistance with the adoption and use of health information exchanges, or improvements in quality and efficiency of care.

Health information exchange initiatives must foster trust, appeal to interests of the medical community as well as the interests of consumers within communities, and meet stakeholder expectations of benefits from quality measurements and population health interventions. A role for eHealth Initiative is sharing best practices from HIEs, whether realigned incentives that drive participation in HIEs that benefit multiple stakeholders, and HIE sustainability models. These non-financial reasons to adoption and use health information exchange will involve strategies found in other portions the National Progress Report, but are important to the success of financial incentive strategies.

More research is needed to help clarify the benefits of Health IT adoption for different stakeholders. Hypothetically, health plans should benefit through better care and cost avoidance due to improved health, but it is unclear how often this occurs and the savings resulting from preventive care. Physician practices should benefit with greater efficiency and effectiveness at the same payment rate, but it is not clear how to translate efficiency into cost-savings. Incentives cannot be meaningful, phased or appropriately aligned until decision-makers have incontrovertible and quantitative information describing the benefits. This means that payors and providers need to work together toward meaningful pilots or demonstration projects that help clarify these benefits.

PRINCIPLES

The principles below cover four key areas identified as important aspects of any incentive program. Among the expert workgroup which reviewed these principles, there was strong consensus on the first three principles, and a strong recognition that the fourth principle will require more research.

- **1. Meaningful Incentives:** Any financing or incentive program involving health IT should be meaningful and result in improvements in quality, safety, efficiency or effectiveness in health care.
- 2. Phased Approach: Financing or incentive programs should utilize a phased approach involving health IT beginning with the implementation of health IT and leading up to the use of electronic information to support performance improvement.
- **3. Assure Interoperability:** Any financing or incentive program involving health IT should lead to the use of existing standards to assure interoperability.
- 4. Cost Reflects the Benefit: Stakeholders that benefit should share some of the cost related to health IT financing or incentives. To achieve this, more study is needed to ascertain specifically who benefits, and by how much. This information is critical to ensuring that incentives programs are meaningful, phased, and appropriately aligned. In addition, incentive structures should be altered to accommodate those groups that do not have the ability to pay (e.g. underserved populations).

STRATEGIES AND ACTIONS

Strategies Proposed in 2007	Progress To Date
Create demonstration projects and private payer pilots to develop and test strategies for aligning incentives.	Significant progress on this strategy has been achieved by government programs and pilots, which are advancing the incentive development process.
	 For example, one Medicare physician group practice demonstration offered performance payments to large practices for improvements in quality and cost efficiency achieved via care coordination and investment in care management process change.
	Our assessment of progress concluded:
	Medicare medical home demonstrations drove creation of work.

	Relative Value Units (RVUs) for medical home services are gaining
	 momentum in the public and private sector programs. The newly funded Beacon Communities will present opportunities to test strategies for aligning incentives. Some activity in the private sector has slowed down or is on hold. Some in the private sector are waiting for HITECH demonstrations to move forward before investing more funds in private demos.
2. Implement provider recognition strategies to encourage effective use of certified systems.	Significant progress has been made in this area. Regional Extension Centers and CMS meaningful use incentives are now driving adoption and use of certified EHRs. There are new opportunities for HIEs and RECs to work together to recognize providers who are effectively using certified EHRs.
3. Work with malpractice carriers to develop risk reduction strategies to lower malpractice insurance premium rates for providers who implement and effectively use certified systems to improve quality and safety.	In 2010, this strategy is still applicable. However, very little empirical evidence has evolved in the last three years. One 2008 AAFP study published in Archives of Internal Medicine showed that physicians with EHRs had fewer paid malpractice claims. But, many carriers are waiting to see if their costs as a result of potential litigation are lower.
4. Educate small practices and small hospitals to empower them to make wise purchasing decisions and provide them with the tools to make necessary workflow changes to improve the health and healthcare of their patients using EHRs and health information exchange.	 Significant progress has been made on this strategy since 2007. Most significantly, Regional Extension Centers have been assigned the primary education role through HITECH. There are other programs, already in existence, which need to be studied further to ensure these new efforts are successful. There are more lessons to be learned from the Quality Improvement Organizations (QIO) experience. The original mission for the QIOs was education and outreach, but their ability varied with their respective resources. The effectiveness of the Stark safe harbor and anti-kickback exemptions also need to be explored, to understand if there were positive results from this policy. Research has shown that it is important to engage small practices on an individual level and find out what they need. One study, using a small sample size of small and medium-sized family practices in CO found technical assistance and support during and after implementation, along with financial incentives, were great facilitators of participation in health information exchange.
5. Implement tax incentives to encourage improvements in health and healthcare through HIT adoption by physicians in small practices and small hospitals.	Some progress has been made in this area. ARRA incentives are a step in the right direction, but the amount is insufficient and tax incentives are still needed, particularly for physicians in smaller practices. Legislative proposals providing tax relief to physicians in small practices were also recently introduced in the House and Senate, this will also provide some small assistance.
6. Examine HIEs that are sustainable and study the data to identify exact sources of sustainability and provide a how to	Significant work is still needed in this area. There is still a need to examine who benefits and who faces burdens with health information exchange. All HIEs are different, and the definition of a health information exchange initiative is still not clear.

guide to sustainability, recognizing	
that one size doesn't fit all.	It will be important for the Beacon Communities and State Designated Entities to share their findings on how they maintain sustainability. The lessons learned from these programs can help guide other HIEs reach sustainability. These learnings should be shared publicly and become part of an emerging toolkit for HIEs.
	The eHI survey of HIEs is one method to help understand sustainability, and identify best practices. Other groups such as the Electronic Healthcare Network Accreditation Commission (EHNAC) are working to identify requirements for HIE certification.
	EHNAC is looking at HIE certification from the perspective of technology, developing certification processes.
7. Provide grants and loans to offset	Significant progress has been made on this strategy.
start up costs of exchanges in geographic areas where no or limited data exchange currently exists.	ONC funding to State Designated Entities for health information exchange (SDEs) for planning, coordination and implementation of HIE activity within a state and coordination with other states supports this strategy.
	ARRA funding for broadband deployment in rural areas will support HIE development in communities with limited capacity for data exchange
8. Harmonize and leverage efforts of current organizations that are creating evidence-based performance measures to maximize impact, streamline and standardize reporting.	Some progress has been made on this strategy. In 2008, the National Quality Forum (NQFs) Health Information Technology Utilization Expert Panel initiated a process that identified 84 high priority quality measures, their associated data elements, and a framework to evaluate the quality of electronic information required by performance measures through electronic health records. In 2009, NQF's Health Information Technology Expert Panel II worked on recommendations for a standardized Quality Data Set (QDS). An organization is still needed at the consumer level, to create a guide that uses patient feedback to inform the perception of performance.
9. Identify and standardize electronic data elements for each consensus performance measure (as part of the development/approval process) so that measures can be readily incorporated by vendors into EHR systems and by health information exchange initiatives, and data can be electronically transmitted and collected from clinical sources and rewarded.	Some progress has been made, but work on this strategy is still needed. The NPRM on meaningful use specifically references measures where consensus performance measures are supported by electronic data elements. It is likely the ongoing work of NQF and the HIT Standards Committee will address this.
10. Coordinate HIE and quality data aggregation activities to assure interoperability and make administrative start up and ongoing costs associated with them as efficient as possible, thereby reducing burden of participation by	Some progress has been made on this strategy. EHNAC certification of HIEs, on interoperability issues, addresses this strategy. CMS is also working with the vendor community on meaningful PQRI, as 7 vendors were just certified who have successfully exchanged quality data. There is still a need to collect the wisdom from this activity at a state level and to identify how the learning can be shared across states.

both payers and providers.	It is not clear who will aggregate the experiences of the state HIEs. The role of the HITRC as an aggregator is still unclear.
11. Transition from performance measures that rely on manual chart abstraction and claims data to measures that rely on not only claims data but also electronic clinical data sources.	Very little progress has been made on this strategy. Ideally, EHRs should have the capability to eliminate manual chart abstraction. Meaningful use requirements are moving things in the right direction. The use of registries by providers will also help drive this change.
	The move from ICD-9 to ICD-10 or SNOMED CT will also be helpful, but it will not solve this issue. Two code sets will still be used for several years.

PROGRESS REPORT: ENGAGING CONSUMERS

INTRODUCTION

In 2007, there was confidence that Health IT would usher in a new standard of care, with information, self-care tools and decision aids to patients as important as the tests and treatments. Central to patient-centered health care is the engagement and empowerment of consumers as full participants in a partnership with providers and the larger health system. Health IT tools have the ability to enable this degree of consumer engagement and empowerment. Some progress has been made in the development of Health IT tools, and in the process of engaging consumers in their health and wellness. Overall, significant work remains in the area of engaging consumers.

The American Reinvestment and Recovery Act (ARRA) created meaningful use incentive payments to eligible health professionals and hospitals to encourage a rapid adoption and use of Health IT over time. The proposed rules for the program include objectives and measures requiring patient receipt of results or health information in electronic form, upon request. The rules also propose to send reminders to a subgroup of patients via electronic means. At the time of publication of this report, it was not clear if the final rules would still include these requirements.

EXAMPLES OF PROGRESS

Some progress has been achieved at the state level. Several states have initiated programs that leverage HIT to support the consumer engagement in programs targeting childhood obesity, the management of chronic health conditions, or wellness strategies. Medicaid programs around the country have made significant progress in the use of HIT and HIE to engage providers and engage consumers. Twelve state Medicaid agencies have implemented a variety of HIT initiatives for Medicaid beneficiaries and participating providers. These include claims-based electronic health records initiatives, electronic prescribing initiatives, remote disease-monitoring initiatives, and personal health records initiatives. In addition, many state Medicaid agencies are in the process of developing similar HIT initiatives. Twenty-five state Medicaid agencies are currently involved in planning and developing statewide HIE networks that will allow for the secure exchange of health care information. The main goal of these networks is to develop a statewide infrastructure to support the widespread use of HIT. Thirteen state Medicaid agencies are also incorporating MITA into their HIT and HIE planning.

In the private sector, a number of pilot programs are now experimenting with self-directed care or remote, supported monitored care using technology in areas such as the management of chronic conditions. Empowering consumers with self-directed technology that allows individuals to personalize and take greater control of their healthcare experience can help meet that expectation while improving the quality and lowering the costs of care delivery. If positive findings from these pilots can be replicated, self-directed care or remote care can make an important contribution to improving health care quality and effectiveness.

New media technologies that will enable new collaborations between doctors, patients, and communities are being developed or are currently in use among some groups or in some areas of the country.

GAPS REMAINING

Significant work remains in order to make real the vision of patients that are fully engaged, supported by information, and equipped with tools that enable informed consumer action and decision-making. While there has been an increase since 2007 in the availability of HIT tools to segments of consumers, a sustained, collaborative effort is needed to support outreach and education that reaches all consumers. Federal and state governments, utilizing public programs like Medicare and Medicaid, should partner with multiple consumer and provider organizations and work collaboratively to ensure that geographic regions or segments of consumers are not left behind. Absent this concerted effort, the new health system may build an assumption about consumer ability to engage as participants in their health care that is incorrect and that could inadvertently lead to adverse health outcomes. There is an ongoing need for collaboration from multiple constituencies to prevent this from happening.

PRINCIPLES

The following principles, strategies and actions are designed to catalyze the development of health IT applications and the flow of information to support them in a way that emphasizes the fullest possible engagement of consumers in their own healthcare.

- 1. Consumer Engagement in Healthcare: Engaging consumers is critical in improving healthcare safety, equity, timeliness, quality, efficiency, and patient-centeredness. Health IT and health information exchange should support informed consumer action and decision-making about health and healthcare, in partnership with providers. The absence of health IT and health information exchange serves as a barrier to achieving these goals. In addition, consumers need clear information, shaped by their input, about health IT, health information exchange, and how to participate more fully in their own health and healthcare.
- 2. Consumer Access and Control of Personal Health Information: Consumers have the right to access all of their personal health information in an understandable form, as well as to annotate and request corrections to this information. Providers, payers and others who hold personal electronic health information have an obligation to make that information readily accessible or to facilitate its availability to the consumer. Individuals should be able to limit when and with whom their identifiably personal health information is shared.
- 3. Consumer Access to Electronic Health Information Tools and Services: Tools that engage consumers through the mobilization of electronic health information should be universally available to consumers regardless of whether or not they have health insurance, serve consumers' varied needs, be integrated in the delivery of care and conveniently available outside of care delivery settings. These tools should also be designed explicitly to meet the needs of diverse groups including the economically and geographically underserved, disabled, older, and culturally diverse populations.
- 4. **Consumer Privacy:** Consumers have a right to privacy of their personal health information, consistent with all applicable federal, state and local law. (See also additional principles in Privacy, Security and Confidentiality.)
- 5. **Consumer Trust:** Consumers must be able to trust that their personal electronic health information is kept and used, with appropriate consent, in a secure, reliable and auditable manner. All stakeholders in healthcare who handle personal health information must make their policies regarding privacy and information use public, understandable and easily accessible.
- 6. **Consumer Participation and Transparency:** All entities that govern, oversee, operate and/or create policy for the electronic exchange of health information should be transparent and open to meaningful consumer participation.

STRATEGIES AND ACTIONS

Strategies Proposed in 2007	Progress to Date
CONSUMER ENGAGMENT IN HEA	
Compile and analyze research, literature, and best practices relevant to successful consumer engagement in HIT/HIE.	Some progress has been made in this area, but much work remains. Since 2007, there have been some efforts to aggregate and analyze best practices:
	 In July 2009, AHRQ has examined consumer engagement in developing HIT ONC developed a Consumer Preferences Draft Requirements Document in October 2009 Robert Wood Johnson compiled a series of briefing papers on strategies to engage consumers in October 2007
	In some areas work has begun, but more study is needed:
	The results of CMS pilot projects like the S.C. PHR demonstration need to be studied. Organizations like Kaiser, Geisinger, and Mayo Clinic are examples of the private sector using portals to engage consumers. These practices should be closely examined.
	Our assessment of progress concluded that there is still a great need for additional aggregation, analysis and dissemination of best practices in the area of engaging consumers.
2. Lay out the value case for HIT and HIE (including benefits & risks) from consumers' perspective.	While work is underway in this area, little progress has been achieved in this area. Research thus far has revealed little formal analysis of the value case for HIE and HIT, from consumers' perspective. Our assessment of progress concluded:
	 The value case for HIE and HIT has been designed without the consumer in mind. The definition of the value, objectives and goals of HIE and HIT should expanded to incorporate consumer needs. Consumers must drive this activity if we are to make progress. Clinicians need to be involved in the drive for more consumer engagement. Consumers trust their physician, not their health plan or their health insurer. Messages resonate if the most trusted source, the clinician, offers patients a tool to help them coordinate their care. The value proposition expands when we speak to consumers about access to health information and PHRs. Much of the online health activity is consumer driven. Consumer guides are needed that state that discuss the value of PHRs and other technology. There have been few studies assessing value of initiatives from the consumer perspective.
3. Develop an outreach and education plan for consumers and providers, and execute the plan [This strategy combines previously separate strategies: Strategy 3: Develop an outreach	A plan for outreach and education to consumers has not occurred. Significant planning is underway for outreach and educate to providers about HIT and HIE, via RECs. Education materials should be provided to the RECs to make available to providers. Our assessment of progress concluded:
and education plan for consumers and providers. Strategy 4: Execute the outreach and education plans]	Identification and dissemination of best practices for engaging consumers are needed, and this information must be shared with consumers and providers. The Health 2.0 movement includes the development of outreach and education plans to consumers and

- should inform the thinking about this topic.
- Successful execution of the plan will include outreach and education to Federally Qualified Health Centers (FQHCs), Community Health Centers, and other safety net providers.
- The VA and MHS have launched education and outreach plans to their enrollees.
- Many private insurers have launched interactive outreach and education plans to engage consumers about the use and value of HIT within their plans

CONSUMER ACCESS AND CONTROL OF PERSONAL HEALTH INFORMATION

5. Create consensus principles and standards that support consumer-control of electronic personal health information.

Little progress has been made on this strategy. The outstanding question is who performs this role – government or NGO or public-private initiative. Our assessment of progress concluded:

- Education should be considered a necessary component of consumer access and control.
- Summary of care materials must be usable to people with different education levels, and languages, must be practical and useful in the real world.
- More of an emphasis should be placed on the understandability of the health information shared with consumers, so that they have a context for the information so that it is useful and enables them to become empowered.
- ONC has engaged in some research to codify consumer preferences.
- FTC and OCR final rules in 2009 on data breach contributed to creation of consumer control standards regarding the treatment of consumer data and notification requirements to consumers.
- CMS NPRM for meaningful use is contributing to principles on timeliness of access to medical results.

CONSUMER ACCESS TO ELECTRONIC HEALTH INFORMATION TOOLS AND SERVICES

6. Where electronically available, consumers should be able to acquire historical data from providers, payers and other entities to generate a more complete longitudinal record.

There have been some advances in the implementation of and demand for electronic personal health records (PHRs). Our assessment of progress concluded:

- CMS has experimented with PHR pilot programs (e.g., MyPHRSC in South Carolina)
- Significant examples of insurers and integrated delivery networks utilizing PHRs to make health information available.
- DOD project allowing MHS enrollees to request data in PHRs.
- State Medicaid programs are developing initiatives that include PHRs for enrollees.

7. Make a variety of types of useful tools and services available to consumers.

Some progress has been made in this area.

In the private sector, an increasing number of vendors, organizations and providers are working to make applications, tools and services available for consumers in digital form. There has also been some progress in the public sector, for example, there is a high degree of interest by the National Library of Medicine (NLM) at the National Institutes of Health (NIH) and AHRQ in making existing terabytes of data available to consumers in a useful way free of charge. More work is needed in both the public and private sector.

8. Design content, tools, and interfaces to support different consumer needs, including but not limited to different languages, levels of health literacy, cultural perspectives, geographic access needs, and physical disabilities.

Much more work is needed in this area. Our assessment of progress concluded that:

- Engagement with diverse consumer organizations is needed to inform preferences among diverse segments of consumers.
 However, there is insufficient documentation of the implementation of tools intended to serve populations with limited health literacy, physical disability, different language needs, cultural perspectives or geographic access needs.
- Furthermore, it is unclear whether a government agency, NGO or public-private collaborative should undertake the role of developing a based of knowledge on tools to meet needs of specific communities.

9. Develop tools that explicitly help people to make evidence based decisions about their health. Little progress has been made in this area.

Health 2.0 and the Internet have played a significant role as enablers, and will play a large role in the future. But, more tools are needed that lead consumers through the decision-making process. While a number of organizations in the private sector have developed ways to get evidence-based information to consumers, more work is needed.

CONSUMER PRIVACY

See Principles in Privacy, Security and Confidentiality

See Principles in Privacy, Security and Confidentiality

CONSUMER TRUST

10. Develop, post, and adhere to Notices of Information Policies that explain how health information is handled.

Some progress has occurred in this area.

ONC published in 2008 a nationwide privacy and security framework for electronic exchange of individually identifiable health information of draft model PHR privacy notice.

Breach notification regulations in 2009 from HHS OCR covering HIPAA covered entities, and the FTC on regulations covering non-HIPAA covered entities, inform the public about policies that govern the treatment of health data.

11. Establish accreditation processes for HIE networks and services and certification of HIT tools.

Some progress has been made in this area. Our assessment of progress concluded:

- ONC and NIST are creating an accreditation and certification process for HIT tools.
- There are also examples from the states where recommendations on HIE accreditation are underway and may serve as a model for other states.
- The Electronic Healthcare Network Accreditation Commission (EHNAC) announced the finalization and adoption of the Healthcare Network Accreditation Program for Electronic Health Networks in January 2010.
- There remains a need for a business model accreditation of HIEs, which addresses financial sustainability and governance.

CONSUMER PARTICIPATION AND TRANSPARENCY	
12. Define organizational requirements for consumer participation and transparency and require compliance with those requirements.	Insufficient progress has occurred in this area and additional research is recommended.
13. Strengthen and expand the cadre of consumer organizations well-versed in HIT/HIE policy issues at the national, state, and local level.	Some progress could be made in this area as a result of the HITECH act: Regional Extension Centers could educate providers on how to engage consumer engagement. RECs will have flexibility in how they execute this and may not rely upon, and in turn build up, consumer organizations to achieve this objective.
	Ideas concerning consumer engagement were incorporated into ONC's Consumer Preferences Draft Requirements Document of October 2009.
	Some existing consumer, health and disease-focused organizations offer examples of best practices.

PROGRESS REPORT: IMPROVING POPULATION HEALTH BY LEVERAGING ELECTRONIC DATA

INTRODUCTION

The strategies proposed in 2007 reflected the idea that electronic clinical data can help support health and healthcare improvements including public health interventions, disease management, quality improvement, provider performance measurement, epidemiologic surveillance, research, and more.

Progress in this area was significant in some areas. It is clear that, while all the strategies proposed in 2007 are important, sequencing is required in order for all strategies to advance. Some strategies that have shown progress will enable others to advance in the years ahead. In other cases, more work is required to build consensus.

Policies for how these data should be used and shared are still in an early developmental stage, though they are emerging rapidly. The passage of ARRA accelerated the demand for common data elements that can be reported by EHRs. Important work remains to be done to build consensus around privacy issues, consent, data control, and who can profit from the use of such data. Understanding and agreement must be developed to define the appropriate uses of both identified and de-identified data. The public does not fully understand the value of using personally identifiable data for the purposes of population health improvement. Thus it is difficult to have an informed debate around the trade-offs between individual privacy and the benefit of using health information to improve the health of all individuals (i.e., the public).

The principles for Improving Population Health lay the groundwork for the policy development that must be undertaken. The strategies and actions directly support engagement of multiple stakeholders to develop and implement those policies, as well as to create the resources, tools and data to support the use of electronic clinical data to improve the health of a population. With these policies, resources and tools in place, electronic clinical data can be used to enrich population health improvement functions, including disease management and wellness programs, quality improvement of healthcare delivery, disease surveillance, and research.

PRINCIPLES

1. The Use of Electronic Clinical Data is Beneficial and Necessary to Improve Population Health

The use of electronic clinical data that is derived from the care delivery process is both beneficial and necessary for improving population health, including but not limited to the following critical areas:

- Improving the quality, safety, efficiency and effectiveness of healthcare
- Monitoring, detecting and responding to hazards and threats, to protect the public's health
- Expanding knowledge about disease, diagnosis and appropriate treatments and services

2. Everyone Who Uses Clinical Data for Population Health Purposes Should Abide by a Common Set of Principles and Policies

Everyone who utilizes clinical data derived from the care delivery process for population health purposes should, in addition to abiding by current federal and state laws, rules and regulations, agree to and comply with a common set of principles and policies developed through a transparent, open process involving multiple stakeholders, including but not limited to consumers, providers, payers, purchasers, and researchers to build trust and confidence in the use of such data.

3. Those Who Use Clinical Data for Population Health Purposes Should be Transparent About Their Principles, Policies and Practices

Those who utilize clinical data derived from the care delivery process for population health purposes should clearly disclose, in a transparent, easily accessible and understandable way, how the data is being used, as well as the principles and policies by which they abide.

4. Healthcare Organizations Should Support the Use of a Common Set of Data Derived Directly From Care Delivery Processes for Multiple Purposes

Healthcare organizations should seek to use the clinical data derived from electronic clinical data systems as well as other sources to support population health improvement in a "one data source, multiple uses" approach. Agreement on and widespread implementation of a set of common data elements, standards for interoperability, policies for data sharing that build trust, and agreed upon business models will accelerate the use of data to support population health and other purposes.

5. Financial or Other Incentives Will be Required to Accelerate the Use of Clinical Data for Population Health Purposes

While the results of improving population health include increases in healthcare quality, efficiency, and safety, such benefits do not always translate to financial benefits to the healthcare organizations that capture the data. Therefore, widespread use of clinical data will not occur without the creation and implementation of financial or other incentives.

STRATEGIES AND ACTIONS

Ctratagica Drawagadin 0007	Duamaga ta Data
Strategies Proposed in 2007	Progress to Date
1. Clearly characterize, explain and raise awareness of the current laws, rules and regulations governing the use of clinical data for uses other than care delivery (population health purposes).	 Some significant progress has been made in this area. Our assessment of progress concluded: HITECH revisions to HIPAA prohibit the sale of PHI data without consumer consent, extension of HIPAA coverage to HIEs ARRA Meaningful Use proposed rule includes initial reporting guidelines for clinical data to be reported to public health registries. These requirements have not yet been finalized. The large amount of HITECH funding for Health Information Exchanges indicates the large role that state and local governments will have in shaping local and provider-specific approaches to electronic health records and the use of clinical data. The new SHARP grants provide \$60 million, and population health is specified in two of the four focus areas.
2. Gain multi-stakeholder consensus on and widely disseminate a common set of principles and policies for use of clinical data for population health purposes.	Significant progress has been made in this area. The Markle Foundation Connecting for Health has examined the strategic and implementation issues related to population health. The group created a vision statement articulating the role of population health information in the future high-performing healthcare system. Connecting for Health also created a set of principles for network design to support Population-Level Data Analysis and Decision-Making. A 2009 PwC and Healthcare IT News survey indicates that stakeholders agree that: New incentives must be created in order to induce all stakeholders to collect, report and use the data. The incentives must be patient-centric and aligned with quality and value. In the initial stage, to be meaningful and not overwhelming, especially for providers, a minimal set of high-use, high-value subsets of data around things such as specific disease states should be collected, piloted and deployed.
3. Develop and widely disseminate tools, resources and guides to support healthcare organizations' use of the common set of principles and policies.	Some work has begun in this area. Our assessment found a number of examples: • i2b2 (Informatics for Integrating Biology and the Bedside) is an NIH-funded National Center for Biomedical Computing based at Partners HealthCare System. The i2b2 Center is developing a scalable informatics framework that will enable clinical researchers to use existing clinical data for discovery research • A 2008 AMIA conference of experts outlined stewardship principles for the management of health information. • PwC and Healthcare IT News survey of 2008 indicates that stakeholders believe that government should develop new, realigned incentives for the private sector to: - Collect, share and use data. - Establish standards. - Redefine technical architecture. - Identify minimal initial data sets.

PRIORITY-SETTING AND COALITIC	Sponsor an industry consortium to develop industry standards, and Communicate and promote the opportunities and benefits of secondary data. ON-BUILDING FOR THE USE OF CLINICAL DATA FROM CARE
DELIVERY FOR POPULATION HEA	LTH
4. Define and prioritize a set of common data elements that are needed for multiple priority population health uses.	 Some significant work has been undertaken in this area. Our assessment found a number of examples: eMerge Network is studying the relationship between genetic variation and a common human trait, using the technique of genome-wide association analysis. A fundamental question is whether EMR systems can serve as resources for such complex genomic analysis of disease susceptibility and therapeutic outcomes, across diverse patient populations. The National Quality Forum released a new quality data set in 2009, a common technological framework for defining clinical data necessary to measure performance and accelerate improvement in patients' quality of care. The QDS framework provides a standardized set of data that should be captured in electronic health records, and is applicable to all care settings. HL7 SDK for v3 messaging methodology provides the needed common definition to the data that is exchanged and computed upon between systems. It provides the syntactic (structural) as well as semantic (meaning-based) interoperability. HITSP and CDISC are working on harmonizing standards for clinical research at the NHIN level: industry standards to support the electronic acquisition, exchange, submission and archiving of data to streamline biomedical research (open via www.cdisc.org)
5. Document and widely disseminate the benefits and risks of using clinical data for population health purposes, using language that "data sources" such as consumers, clinicians, hospitals and other providers, and laboratories as well as "data users" such as employers, health plans, researchers, and public health agencies, understand.	 The Observational Medical Outcomes Partnership (OMOP), a public-private partnership designed to help improve the monitoring of drugs for safety, is conducting a two-year initiative to research methods to analyze existing healthcare databases to identify and evaluate safety and benefit issues of drugs on the market. This activity will include assessing different types of data from across the United States, developing tools and methods to analyze the databases, and evaluating how analyses can contribute to decision-making. Together, these studies should provide the objective evidence needed to inform best practices for using such data. The eHealth Initiative's Connecting for Drug Safety Collaboration project findings indicated the feasibility of using electronic health information at the community level including clinical data alone, claims data alone, and clinical and claims data togetherto detect adverse events in the context of drug exposure and to detect designated medical events.

6. Define the "users" of data elements for population health uses with sufficient granularity to lay the foundation for changes that will dramatically increase the demand Some progress has been made in this area. Our assessment of progress found:

The 2007 National Committee on Vital and Health Statistics (NCVHS) report, Enhanced Protections for Uses of Health Data,

for such data for population health recommended a data stewardship conceptual framework permitting purposes. organizations to evaluate intended users and uses, and recognize where enhanced data stewardship processes are needed AMIA 2008 white paper, Toward a National Framework for the Secondary Use of Health Data, includes recommendations on a taxonomy of defining users and different uses. CDC formed a workgroup of public health agencies to discuss the appropriate use and release of public health data per AMA article 7. Define where the common data Minimal progress has been made in this area. HL7 and other standards elements currently reside with organizations are working in this area, but today's common data elements are not ideal. More work is needed to determine how we can sufficient granularity to lay the foundation for driving changes that get as much as possible from imperfect data sources while moving to will dramatically increase the more generally accepted standards. availability of such data for population health purposes.

BUILDING SUPPORTS FOR WIDESPREAD IMPLEMENTATION

8. Define the systems, filtering rules, workflow changes and functionalities needed to support electronic capture of, transmission of and access to the common data elements.

Little progress has been made in this area. A successful deployment of a model that incorporates the output of population health data directly into decision-support tools at point-of-care has not yet occurred. The historically slow adoption of evidence into practice at the point-of-care would indicate that the value of population health analytics demands a closed-loop between evidence-generation and tools to drive adoption at the clinic and bed-side.

9. Develop a set of alternative business models that will support the costs of making the data available and access to such data from population health data users.

Some significant progress was made in this area:

- The Accountable Care Organization (ACO) business model was developed to enable measurement of performance and results at the level of a population of patients, rather than at the level of an episode of care or measuring delivery of a particular service.
- The Medicaid Transformation Grants and the Medicaid Information Technology Architecture (MITA) program are enabling an integrated state health system that emphasizes interoperability between Medicaid and other state agencies involved in health.
- Agency for Healthcare Research and Quality (AHRQ) and the Joseph H. Kanter Family Foundation/Health Legacy Partnership has explored models to enable developing a large database of anonymized EHRs for the purposes of outcomes research
- Etheridge's Rapid Learning initiative proposes combining existing databases (i.e. VHA, Kaiser, American Cancer Society Clinical Trials) and applying data modeling to perform lookup functions across EHR's. Using the Archimedes Data Model will help identify retrospective trends and may also help with forecasting future healthcare evidence.
- 10. Define common standards for representing such common data elements.

Significant progress was made in this area.

The Interim Final rule for Standards, Certification and Implementation Specifications advanced this strategy with new rules and standards for most of these elements. The HIT Standards Committee, HITSP and CDISC are also working on harmonizing HIT standards in general. There is an assumption that the Stage 2 and 3 Meaningful Use objectives and measures will continue to drive progress in this strategy

11. Bringing it all together, develop and widely disseminate tools, resources and guides to support healthcare organizations who serve as "data sources", addressing the common data elements, required systems, workflow and process changes, policies for data sharing, legal and regulatory considerations, and business models to support data capture, data availability, and data access.

Some progress has been made in this area. Federal healthcare reform legislation that increases the use of bundled payments for services could further incentive use of organizations serving as data sources

12. Develop and implement drivers that will rapidly accelerate the capture, availability and use of the prioritized common data elements.

Some work was achieved in this area:

- The proposed meaningful use requirement to use certified EHRs to report information on clinical quality measures electronically to a state, registry, HIE or CMS will accelerate demand for sharing data and the common data elements that support the reporting requirement.
- Disease progression "scores" or other discrete metrics could be captured in PHRs or similar, incentivized by insurer.
- AHRQ's Patient Safety Organization (PSO) final rule and implementation framework enable PSOs to leverage the power of health IT to help providers improve patient safety.
- Healthcare Financial Management 2010 article states that EMR data may become the most important strategic asset for a provider organization. Providers and other generators of healthcare data are using actionable information to enable partnerships, share investment in informatics initiatives, and in some cases create revenue streams

BUILDING THE EVIDENCE FOR WIDESPREAD IMPLEMENTATION

13. Conduct "learning laboratories" to test and evaluate the "supports" identified above, in several markets.

Meaningful Use incentive payments, and the creation of Regional Extension Centers will accelerate the adoption and use of EHRs into provider practices

AHIMA has developed a Virtual Lab in conjunction with multiple Universities, that now teaches students practical use of EHR data and understanding of EHR software

14. Conduct research to gather evidence of natural experiments in using clinical data for a variety of use cases. Note: A **natural experiment** is a naturally occurring instance of an observable phenomenon which approximates or duplicates the properties of a controlled experiment. In contrast to laboratory experiments, these events are not created or directly controlled by scientists. However, they can yield data that can be used to make causal inferences.

Significant work has begun in this area. As a result of ARRA & HITECH, there is new funding for Beacon Communities and state-designated HIEs. The Meaningful Use incentives will create opportunities for natural experiments to occur.

CREATE FORUMS FOR DATA SHARING AND LEARNING

15. Create a forum or set of forums for sharing of learning and best practices to support success in the field.

Some work has begun in this area.

- The ARRA-generated activity will accelerate the need for forums where best practices are shared.
- The Health Information Technology Research Center (HITRC) addresses the needs for sharing best practices among the Regional Extension Centers.
- Several stakeholder organizations are creating conferences to address the need for learning forums.

PROGRESS REPORT: MANAGING PRIVACY, SECURITY AND CONFIDENTIALITY

INTRODUCTION

In 2007, consensus was reached on principles for privacy, security and confidentiality. It was agreed that discussions should continue in a multi-stakeholder task force that would address and give guidance to emerging questions and issues on the topics. In the last few years, stakeholders continued to educate one another and worked to build consensus. Consensus has been reached on several issues. Yet in other areas, such as opt-in vs. opt-out, consensus has not been achieved. Stakeholders reviewed the events of the past three years and considered whether we are closer to consensus in several key areas.

EXAMPLES OF PROGRESS

The significant change in the landscape since 2007 was the passage of American Recovery and Reinvestment Act (ARRA), and the Health Information Technology for Economic and Clinical Health (HITECH) Act provisions within ARRA. HITECH included many revisions to HIPAA that reposition the baseline for privacy and security policies. HIPAA coverage was extended to Health Information Exchanges. Business Associates are directly obligated under HIPAA, whereas they were previously subject to privacy and security rules indirectly. Direct data breach notification to individuals has become a requirement. The HIPAA enforcement authority was extended to the state attorneys general. The FTC issued rules clarification of responsibilities of non-HIPAA Covered Entities to consumers concerning security breaches of their electronic health information. The HITECH Act also created new rights for consumers regarding the use of their information.

In addition to changes in federal law, technology advances in the past three years have shifted the landscape. To increase our knowledge, the HITECH Act requires reports on de-identification and re-identification of health data. It also creates the Strategic Health IT Advanced Research Projects (SHARP) program to foster research focused on achieving breakthroughs in four areas, including the area of developing security and risk mitigation policies and technologies necessary to build and preserve the public trust as health IT systems become ubiquitous.

Stakeholders have reached agreement that the federal government HITECH Act and subsequent regulations have settled, and will settle, many previously open questions. In these instances, the task ahead is to educate consumers, providers and other stakeholders about the changes in laws and regulations and their application to them.

REMAINING GAPS

Consensus has not been reached on permissible uses of personal health information (PHI), or a definition of consumer control of PHI. Inconsistencies in the application of federal and state privacy and security laws will continue until there is ownership of this challenge. Resolution of the ownership question is vital to supporting stakeholder trust in an expanded health information exchange.

The increasing use of new PHRs and social media raises new questions and challenges. What level of consent and how much control are consumers given over the flow of their PHI, to review and amend their PHI, and to determine the use of their PHI. The need exists for these tools to have consistent and consumer-oriented privacy and security protections. Additional research is needed in this area. Additional study, including learning from the experience of other nations, would help inform our development of the necessary strategies.

Knowledge and transparency are crucial to building the trust that is essential for health IT and health information exchange to grow and support the larger vision of a health care system that is patient-centered, evidence-based, and continuously learning. Ultimately, the path forward will require a significant amount of education and outreach on privacy and security, laws and regulations, policies and technology, to all stakeholders. Consumer empowerment will not be fully realized absent knowledge and transparency. HIPAA and the state laws are a starting point for enabling these factors, but is not the entire solution. There should be a larger policy of openness about developments, practices, and policies with respect to personal data. Individuals should be able to know what information exists about them, the purpose of its use, who can access and use it, and where it resides.

PRINCIPLES

1. Transparency

- Policies for the permissible use of personal health information by those other than the patient should be clearly defined, accessible, and communicated in an easily understood format.
- Individuals have the right to know how their personal health information has been used and who has
 access to it.

2. Collection and Use of Personal Health Information

- Personal health information of the individual consumer should be obtainable consistent with applicable federal, state and local law. It should be accurate, up-to-date, and limited to what is appropriate and relevant for the intended use.
- Consumers have a right to privacy of their personal health information, taking into account existing
 exceptions under law. Consumers should be apprised when they have a choice in how their personal
 health information will be used and shared and when they can limit uses of their personal health
 information.

3. Individual Control

- Individuals should be able to limit when and with whom their identifiable personal health information is shared. Individuals should be able to delegate these responsibilities to another person.
- Individuals should be able to readily obtain an audit trail that discloses by whom their personal health information has been accessed and how it has been used.

4. Security

- Measures should be implemented to protect the integrity, security, and confidentiality of each •
 individual's personal health information, ensuring that it cannot be lost, stolen, or accessed or modified
 in an inappropriate way.
- Organizations that store, transmit, or use personal health information should have in place mechanisms for authentication and authorization of system users.

5. Audit

- Each such organization must have a comprehensive audit process to examine compliance with its internal privacy, security, and confidentiality policies and procedures.
- Organizations have a responsibility to ensure that an individual is notified when the organization learns of unauthorized or inappropriate access to that individual's personal health information.

6. Accountability and Oversight

• Individuals should be apprised as to who monitors policy compliance with privacy, security and confidentiality policies, how complaints will be handled, how individuals will be informed of a violation and existing remedies available to them.

7. Technology and Privacy

- Technological developments must be adopted in harmony with policies and business rules that foster trust and transparency.
- Privacy protections must be at the forefront of all technological standards. Privacy issues can not be addressed post-system design and implementation.

ISSUES AND PROGRESS TO DATE

Issue Raised in 2007	Progress to Date
1. Is there agreement on policies and practices on permissible uses of PHI by those other than the consumer?	Stakeholders have not reached consensus on this point. After careful review, the group came to the following conclusions: • HITECH will require a study by ONC on de-identification and reidentification of PHI. Stakeholders need clarification on the definitions and implications de-identification, in light of technological advances that nullify the effectiveness of the HIPAA de-identification criteria. eHI will help support these efforts by helping to clarify the meaning and implications of policies and practices on permissible uses of PHI.
How should be privacy and security policies be communicated to the consumer?	 After careful review, the group came to the following conclusions: It is still unclear which governmental agency has responsibility to inform consumers about health privacy and security policies. The field needs research on which government entity has responsibility to communicate privacy and security policies to consumers. Examples from HITECH which need to be addressed: consumer ability to request that data is not shared by HIPAA covered entity if a service is paid out of pocket. consumers ability to provide consent to sell their data. HITECH included changes to privacy (new rights), but many stakeholders are not aware of them and do not understand how they are applicable to them. The current notices of privacy practices generally are unhelpful to the consumer, as they do not convey information that is meaningful to them. eHI recommends developing a standardized short form of privacy practices to educate consumers, in language understandable and meaningful to consumers.
3. What policies should govern the collection, maintenance, storage, sharing and transmittal of personal health information?	It is not clear that we have made progress on defining what consumer control means. In the area of Social Media, more research is needed on privacy policies and social media. Consumers need education about the implications of sharing their PHI via social media. In the HIE area, there is good thinking about patient consent. eHI will support the SHARP program and Beacon Communities, and support an expanded research agenda by ONC that includes privacy and security. eHI will also support US and international efforts to study this question and build awareness for consumers based on the research.
4. How should we address differences in the treatment of health information at the federal and state level, and between states?	Progress was made in this area. The Health Information Security and Privacy Collaboration (HISPC) phase 3, representing 42 states and territories, produced a compendium of 5 reports detailing variations in state laws, business practices and policies related to privacy and security and the electronic exchange of

health information. Phase 3 also focused on developing tools to help harmonize state privacy, tools and strategies to educate and engage consumers, and recommending basic security policy requirements
Progress has occurred in this area as a result of HITECH.
HITECH extended HIPAA to HIEs.
HITECH extended business associate status to entities that transmit PHI and have routine access to PHI, whether HIPAA covered entities or non-HIPAA covered entities.
HITECH also extended business associate status to entities that routinely transmit PHI and have routine access to PHI, even if they are not HIPAA covered entities. Subcontractors of business associates, including subcontractors of HIEs are now treated as business associates.
Agreement has not been reached on levels of consent and control over the flow of health information available to consumers, whether an information flow among providers or an information flow that include HIEs.
Progress has occurred in this area as a result of HITECH:
In 2009 HHS OCR and FTC published rules on data breach, covering HIPPA and non-HIPAA covered entities.
Enforcement authority for data privacy was extended to state attorneys general.
Much more work is needed in this area. After careful review, the group determined that the field needs an analysis on how this will be managed, and by whom, given the pace of technology innovation.

TRANSFORMING CARE DELIVERY AT THE POINT OF CARE

INTRODUCTION

The passage of the American Reinvestment and Recovery Act (ARRA) included several provisions supporting the transformation of care delivery in a manner consistent with the strategies proposed in 2007. Strategies to move providers to adoption of HIT systems could potentially be addressed by the new Regional Extension Centers (RECs) and the Health Information Technology Research Center (HITRC). Provider adoption and effective use will be supported by incentive payments for the meaningful use of HIT, and the interim final rule on standards, certification and implementation specifications. The proposed rule on certification will provide assurance to purchasers that EHR systems support technological capability, functionality, and security needed to enable achievement of meaningful use requirement. The ARRA funding for state HIEs through cooperative agreements activity will enable the development of information sharing across the health care system, including establishing health information exchange (HIE) capacity among health care providers and hospitals in their jurisdiction, ultimately enabling exchange across states.

REMAINING GAPS

While ARRA placed in motion activities that will significantly advance the transformation of care delivery, some barriers remain. The availability of capital to cover upfront adoption costs is a challenge, particularly for small and medium sized practices. Continued awareness and advocacy for financial support for these providers, who provide the majority of healthcare services, so that they and their patients are not left behind, will be required. Concurrently, examples of physician practices creating networking arrangements to jointly purchase technology and apply for grants to assist in that purchase should be examined and results shared, so that a one-size—fits-all model of collaboration and coordination is not mandated on providers.

In time, evidence-based decision support tools will become an integral part of EHRs, and the ability to meet increased meaningful use requirements and increased regulatory reporting mandates should be relieved by the increasing power of software in certified EHRs. However, this time has not yet arrived. As CMS meaningful use incentive requirements scale in complexity over time, this timing will need to be calibrated to reflect other developments in the field, such as the move from ICD-9 to ICD-10. Appropriate timing of these activities will result in EHRs utilization of evidence-based tools that support collaborative and inter-disciplinary care, evidence based practice and creation of new knowledge.

The interoperability of health information technology is a fundamental requirement for the health care system to derive benefits promised by the adoption of (EHRs), but significant progress will be required to achieve this result.¹

Greater consumer engagement will include greater reliance on information from the personal health record (PHR), integrated into health information exchange infrastructure, as consumers become much more empowered with opportunities to engage their providers and to become participants in decision-making.⁴ This development will support the use of Health IT that is designed, implemented and used effectively to support more patient-centered care delivery, where value-added care processes and longitudinal care will support clinical transformation, and will result in corresponding improvements in outcomes and satisfaction for patients and providers.⁵

¹ Electronic Health Record Use and the Quality of Ambulatory Care in the United States, http://archinte.ama-assn.org/cgi/reprint/167/13/1400?ijkey=6c4f9f6bd0c91d346182d75ce50d1cbd9bbc9ce5

² Interoperability: The Key To The Future Health Care System; J Med Syst. 2009 Jun;33(3):223-31.

³ HIMSS Clinical Informatics Insight, November 2009

⁴ Personal Touch. Personal Health Records for Consumers of Healthcare, JHIM November 2009. Interoperability of Electronic Health Records and Personal Health Records, Key Interoperability Issues Associated with Information Exchange, JHIM, November 2009 5 Personal Health Management Systems: Applying The Full Power Of Software To Improve The Quality And Efficiency Of Care; Health Affairs, March/April 2009

PRINCIPLES

- 1. Patient-Centered Care: Standards-based HIT and health information exchange (HIE) will support new models of care delivery that are patient-centered, for a lifetime, and physician-guided, reflecting a coordinated, collaborative approach. HIT and HIE will help providers and consumers improve the quality, safety, effectiveness, timeliness, efficiency and equity of care delivered across the U.S. healthcare system. In order for HIT and HIE to be truly patient-centered, the system should also provide meaningful, understandable and useful information for patients and providers at the point of care.
- 2. Patient and Clinician-Centered Workflow: The transformation to patient-centered care will be facilitated by making more complete, timely and relevant patient-focused data and clinical decision support tools available in a secure manner to both clinicians and patients as part of the workflow at the point of care. Information at the point of care through HIT and HIE will help integrate care across multiple care settings and facilitate team-based care.
- 3. Everyone Plays: All healthcare providers regardless of size, specialty, or location, and especially small physician practices (that deliver a majority of care in the U.S.) need to be engaged and supported in both local and national efforts to make patient-focused electronic health information available at the point of care. Furthermore, the acquisition strategy, support for workflow change, resources required to overcome implementation barriers, and ongoing maintenance of HIT and electronic healthcare information will differ.
- **4. Across Care Settings:** There is value in adopting HIT in care settings, but greater value when the exchange of electronic health information is implemented across care settings. Care transformation will be supported by the deployment and use of HIT and secure data exchanges with all relevant stakeholders, including:
 - Patients/Consumers
 - Hospitals
 - Emergency departments
 - Laboratories and diagnostic centers
 - Public health agencies
 - Quality reporting and benchmarking organizations
 - Health plans
 - Pharmacy benefit managers
 - Physician practices
 - Long term care facilities
 - Home health agencies
 - Pharmacies
 - And other
- 5. HIT and HIE Are Enabling Tools: HIT and HIE are essential infrastructure elements that add value and efficiency for clinicians, other care providers and the patients they serve through information management and information sharing with each other and with other stakeholders in healthcare.
- **6. Overcoming Challenges:** Selecting and implementing HIT and HIE tools, as well as the required process changes, are challenging endeavors. Overcoming these challenges to maximize effective use of HIT and HIE is critical to supporting, informing and improving care delivery at the point of care.
- 7. Reality The Journey Begins Here: The transformation of US healthcare requires immediate attention but will happen over a period of years with multiple iterations at different paces across various care settings.

STRATEGIES AND ACTIONS

Strategies Proposed in 2007	Progress to Date
MOVE PROVIDERS TO ADOPT HEA	
	ision and Understand Effective Use)
Understand provider purchase motivations regarding HIT adoption	 Progress has occurred in this area: Provider activity to avail themselves of HITECH incentive payments and grant opportunities will indicate whether incentives are aligned with motivation to adopt HIT PPACA requirements and Medicare regulations are anticipated to motivate providers to link HIT adoption with compliance with new care coordination and payment models, and with regulatory reporting compliance
2. Educate and motivate providers to adopt HIT and use it effectively.	Activity toward progress has occurred pursuant to HITECH, specifically the creation of Regional HIT Extension Centers (RECs) and the Health Information Technology Resource Center (HITRC) Hospital system or Integrated Delivery Network-led HIE initiatives are educating and motivating providers to adopt HIT Health care reform initiatives, including Accountable Care Organizations and Medical Homes will drive awareness of the benefits of sharing and using electronic health information across care settings and at the point of care.
3. Educate providers regarding the availability of incentives and financing options to support adoption and effective use of HIT.	Some progress and activity is occurring in this area: CMS will maintain a website specifically for education about meaningful use incentive payments. RECs are tasked with outreach to priority primary care providers that includes education on financing options that support adoption and meaningful use of HIT. Not all providers qualify for meaningful use incentive payments and an education on other incentives and financing options available to these providers is needed.
4. Monitor adoption rates based on agreed upon methodology. Report on rates to all healthcare stakeholders, including the government, in order to continue to incentivize and support adoption and effective use.	The HIMSS adoption model indicates that in 2009 7.4% of 5000+ hospitals have CPOE, while about, 17% has CDR, 50% have nursing documentation and only 1.6% have physician documentation.

SUPPORTING ADOPTION AND EFFECTIVE USE (Providers Have Made the Decision to Adopt HIT, What Do They Do Now?)	
5. Increase the availability of incentives and financing options to	Significant progress has occurred in this area as:
support adoption and effective use.	HITECH includes meaningful use incentives payments

Vendors are offering varied pricing options and service models for EHRs, as an incentive to support adoption

Examples of state level, non-governmental initiatives include:

Mass General Physicians Organization, working with Massachusetts General Hospital, designed an incentive and communications campaign to encourage doctors to use health information technologies (including a new electronic medical record system and electronic radiology ordering system), and to adopt other, department-specific quality and safety measures. The innovative program, which offers rewards of up to \$5,000 annually for physicians who meet pre-established goals, led to increased use of these technologies and to other quality and safety improvements.

Other incentive programs have reported lukewarm physician response. The Hawaii Independent Physicians Association in 2009 ended its program after nine months to provide \$3,000 to any member who implemented EMRs, after only two of the 728 members participated. The Hawaii IPA had hoped to get 30 physicians to sign up and found that cost was a prohibitive factor

See also Aligning Incentives Actions

6. Provide education, tools and technical and other assistance to prepare and assist providers for selection, implementation and effective use of HIT. Education, tools and assistance should be tailored to provider size and specialty.

Some progress has occurred in this area:

Regional Extension Centers (RECs) and the Health Information Technology Resource Center (HITRC) are tasked with providing education, tools and assistance to navigate the HIT selection and implementation process.

Workforce development programs funded by ONC are tasked with increasing the number of highly skilled HIT specialists via community college training and university programs and competency examinations

TRANSFORMING CARE DELIVERY THROUGH HIT AND HIE (Providers Have Implemented the System, How Do They Transform Care?)

7. Ensure interoperability between and across all relevant stakeholders, using an open and interoperable architecture based on common principles and standards to reflect changing requirements.

Some activity has occurred in this area.

HITECH meaningful use standards require interoperability not only between ambulatory and inpatient settings but also the ability to exchange data across organizations and submit information to registries

A universal lack of fully accepted standards lengthens the likely implementation timeline for national programs. Standards continue to converge towards a smaller set of common standards (e.g. HL7), albeit with some customization.

8. Design HIT and HIE processes and supporting applications to collect data at all points of care as part of the normal workflow in a way that enables utilization for multiple purposes, such as healthcare quality improvement, care management, billing, decision support,

Activity in this area has occurred per HITECH.

ONC is creating a certification program to test and certify HIT for technological capability, functionality and security in order to provide assurance to purchasers relative to meaningful use criteria as it scales over time. NIST is developing the functional and conformance testing requirements, test cases and test tools to support the certification

performance data reporting, and research and population health initiatives, including disparities reduction efforts.	program.
9. Utilize HIT connected to HIE to transform care at the point of care, in a team environment and across settings.	Some progress has occurred in this area:
	Passage of health reform legislation, supporting Accountable Care Organizations and Medical Homes is expected to increase activity in this strategy.
	It will remain important to educate and incentivize smaller physician practices to participate in HIEs. HIE state grants are competitive and hence its critical for providers to form consortiums and utilize funding effectively connect their EHRs to regional and ultimately state level HIEs.
	HIEs building a compelling business case, but there remains a need to integrate PHR data within the HIE infrastructure initiatives.
10. Establish and use quality measures and decision support tools.	Progress continues in this strategic area. Many software vendors who specialize in developing clinical decision support tools have robust built-in rules engine that follow EBM guidelines. These tools include order sets, alerts, multi-disciplinary clinical documentation (nursing care plans, flowsheets etc.), reference materials, reports related to patient data, and regulatory agency clinical guidelines.

APPENDIX A - RESOURCES

Aligning Financial and Other Incentives Resources

Adler-Milstein, J., McAfee, A. P., Bates, D. W., and Jha, A. K. The State Of Regional Health Information Organizations: Current Activities And Financing. Health Affairs, January/February 2008; 27(1): w60-w69.

http://content.healthaffairs.org/cgi/content/abstract/27/1/w60?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=Adler-

Milstein%2C+J.&andorexactfulltext=and&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

AHIMA Foundation. Advancing Effective State-Level Approaches to Interoperability in the New Federal Context: A Report of the State Level HIE Consensus Project. May 2009. http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1 045665.pdf

Chen, C., Garrido, T., Chock, D., Okawa, G., and Liang, L. The Kaiser Permanente Electronic Health Record: Transforming And Streamlining Modalities Of Care. Health Affairs, March/April 2009; 28(2): 323-333.

http://content.healthaffairs.org/cgi/content/abstract/28/2/323?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=Chen%2C+C.%2C+Garrido%2C+T.&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

Clancy, C. M., Anderson, K. M., and White, P. J. Investing In Health Information Infrastructure: Can It Help Achieve Health Reform? Health Affairs, March/April 2009; 28(2): 478-482.

http://content.healthaffairs.org/cgi/content/abstract/28/2/478?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=clancy+anderson+investing&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

Dentzer, S. Health Information Technology: On The Fast Track At Last? Health Affairs, March/April 2009; 28(2): 320-321.

 $\frac{\text{http://content.healthaffairs.org/cgi/content/extract/28/2/320?maxtoshow=\&hits=10\&RESULTFORMAT=\&fulltext=dentzer+fast+track\&searchid=1\&FIRSTINDEX=0\&resourcetype=HWCIT}{\text{NDEX}=0\&resourcetype=HWCIT}$

Diamond, C. C. and Shirky, C. Health Information Technology: A Few Years Of Magical Thinking? Health Affairs, September/October 2008; 27(5): w383-w390.

http://content.healthaffairs.org/cgi/content/abstract/27/5/w383?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=diamond+magical+thinking&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

Feldman, S. The 'Millionaires Tax' And Mental Health Policy In California. Health Affairs, May/June 2009; 28(3): 809-815.

 $\frac{\text{http://content.healthaffairs.org/cgi/content/abstract/28/3/809?maxtoshow=\&hits=10\&RESULTFORMAT=\&fulltext=feldman+millionares+tax\&searchid=1\&FIRSTINDEX=0\&resourcetype=HWCIT}$

Goldzweig, C.L., Towfigh, A., Maglione, M., and Shekelle P. G., Costs And Benefits Of Health Information Technology: New Trends From The Literature. Health Affairs, March/April 2009; 28(2): w282-w293.

http://content.healthaffairs.org/cgi/content/abstract/28/2/w282?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=Goldzweig&searchid=1&FIRSTINDEX =0&resourcetype=HWCIT

Himmelstein D. U., Wright A., Woolhandler, S. Hospital Computing and the Costs and Quality of Care: A National Study. Am J Med. www.amjmed.com/webfiles/images/journals/ajm/AJM10662S200.pdf

Lohr, S. Little Benefit Seen, So Far, In Electronic Patient Records. (November 15, 2009) New York Times. http://www.nytimes.com/2009/11/16/business/16records.html?_r=1

Mostashari, F., Tripathi, M., and Kendall, M. A Tale Of Two Large Community Electronic Health Record Extension Projects. Health Affairs, March/April 2009; 28(2): 345-356.

http://content.healthaffairs.org/cgi/content/abstract/28/2/345?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=Mostashari+Tripathi&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

Organizing, Delivering, And Paying For Health IT Systems. Health Affairs, March/April 2009; 28(2): 453. <a href="http://content.healthaffairs.org/cgi/content/extract/28/2/453?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=Organizing%2C+Delivering%2C+And+Paying+For+Health+IT+Systems&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

S. Ross, L. Schilling, D. Fernald, A. Davidson, D. West, Health information exchange in small-to-medium sized family medicine practices: Motivators, barriers, and potential facilitators of adoption

International Journal of Medical Informatics, Volume 79, Issue 2, Pages 123-129 http://www.ijmijournal.com/article/S1386-5056(09)00179-8/abstract

Roxana Maffei, Daniel Burciago, Kim Dunn, Determining Business Models for Financial Sustainability in Regional Health Information Organizations (RHIOs): A Review". Population Health Management. October 2009, 12(5): 273-278. doi:10.1089/pop.2008.0045.

Enrico Coiera, Building a National Health IT System from the Middle Out. Journal of the American Medical Informatics Association, Volume 16, Issue 3, May-June 2009, Pages 271-273. http://jamia.bmj.com/content/16/3/271.extract?sid=ca86324d-1f08-4bc6-9575-7f1b522d9fcd

Robert S. Rudin, SM, Steven R. Simon, MD, MPH, Lynn A. Volk, MHS, Micky Tripathi, PhD and David Bates, MD, MSc, Understanding the Decisions and Values of Stakeholders in Health Information Exchanges: Experiences From Massachusetts.

Deven McGraw, James X. Dempsey, Leslie Harris and Janlori Goldman, Privacy As An Enabler, Not An Impediment: Building Trust Into Health Information Exchange, Health Affairs, 28, no. 2 (2009): 416-427 doi: 10.1377/hlthaff.28.2.416

http://content.healthaffairs.org/cgi/content/abstract/28/2/416?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=Privacy+As+An+Enabler%2C+Not+An+Impediment&andorexactfulltext=and&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

Anil S. Ranawat1, Jonathan H. Koenig1, Adrian J. Thomas1, Catherine D. Krna1 and Louis A. Shapiro,
Aligning Physician and Hospital Incentives: The Approach at Hospital for Special Surgery Hospital for Special Surgery, 535 East 70th Street, New York,
NY 10021, USA. Received: 17 February 2009 Accepted: 29 June 2009 Published online: 14 July 2009

Patrick H. Conway, MD, MSc; Carolyn Clancy, MD, Transformation of Health Care at the Front Line JAMA. 2009;301(7):763-765. http://jama.ama-

 $assn.org/cgi/content/extract/301/7/763? maxtoshow = \&hits = 10\&RESULTFORMAT = \&fulltext = Transformation + of + Health + Care + at + the + Front + Line \&searchi \\ \underline{d = 1\&FIRSTINDEX = 0\&resourcetype = HWCIT}$

Randall E. Marcus1, Thomas F. Zenty III2 and Harlin G. Adelman Esq, Aligning Incentives in Orthopaedics: Opportunities and Challenges—the Case Medical Center Experience. Received: 15 January 2009 Accepted: 15 June 2009 Published online: 8 July 2009

Quality-Based Financial Incentives in Health Care: Can We Improve Quality by Paying for It? Annual Review of Public Health Vol. 30: 357-371 (Volume publication date April 2009) (doi:10.1146/annurev.publhealth.031308.100243)

Reinvigorating the Quality Improvement Incentives of Hospital Prospective Payment Medical Care: March 2009 - Volume 47 - Issue 3 - pp 269-271 doi: 10.1097/MLR.0b013e31819c0bce

Harold S. Luft, Economic Incentives to Promote Innovation in Healthcare Delivery,
Palo Alto Medical Foundation Research Institute, Health Policy Research, 795 El Camino Real, Ames Building, Palo Alto, CA 94301, USA. Received: 1
December 2008 Accepted: 28 May 2009 Published online: 19 June 2009

Overview of Key Initiatives Aligning Financial and Other Incentives

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
American Medical Association (AMA)	Guidelines for Pay- for-Performance Programs www.ama- assn.org/ama1/pub/u pload/mm/368/guideli nes4pay62705.pdf	Principles provide AMA leaders, staff and members with guidelines regarding the formation and implementation of fair and ethical pay-for-performance programs.	To provide safe, effective and affordable health care.	Principles for Pay-for- Performance Programs (specifically, Program Rewards): Programs must be based on rewards and not on penalties. Program incentives must be sufficient in scope to cover any additional work and practice expense incurred by physicians as a result of program participation. Programs must offer financial support to physician practices that implement IT systems or software that interact with aspects of the PFP program. Programs must finance bonus payments based on specified performance measures with supplemental funds. Programs must reward all physicians who actively participate in the program and who achieve pre-specified absolute program goals or demonstrate pre-specified relative improvement toward program goals.	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				 Programs must not reward physicians based on ranking compared with other physicians in the program. Programs must provide to all eligible physicians and practices a complete explanation of all program facets, to include the methods and performance measures used to determine incentive eligibility and incentive amounts, prior to program implementation. Programs must not financially penalize physicians based on factors outside of the physician's control. Programs utilizing bonus payments must be designed to protect patient access and must not financially disadvantage physicians who serve minority or uninsured patients. 	
Bridges to Excellence (BTE)	Physician Office Link www.bridgestoexcelle nce.org/programs/pol .mspx	An employer-based program that promotes physician office use of health IT.	Rewards physicians for adopting health IT or EHRs.	Assess the use of evidence-based standards of care, maintenance of patient registries for the purpose of identifying and following-up with at-risk patients and provision of educational resources to	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				 Patients. Assess whether practices use electronic systems to maintain patient records, provide decision support, enter orders for prescriptions and lab tests and provide patient reminders. Assess whether a practice's electronic systems interconnect and whether they are interoperable with other systems, whether they use nationally accepted medical code sets and whether they can automatically send, receive and integrate data such as lab results and medical histories from other organizations' systems. 	
Blue Cross Blue Shield of Massachusetts	Primary Care Physician (PCP) Incentive Program www.bcbs.com/innov ations/blueworks/prov ider/pay-for- performance- programs.html	An incentive program that gives PCPs the opportunity to earn additional reimbursement above the HMO fee schedule based on their performance on specific quality measures.	To ensure that members receive important preventive services, create performance-based reimbursement opportunities for PCPs and provide PCPs with actionable patient data to enable improvements.	Program Elements: Provides annual reports to physicians on five different measures, a list of patients yet to receive preventative care for those measures, educational tools and materials and payments based on performance. In 2003, BCBSMA expanded its pay-forperformance initiative to engage groups and specialists in quality	The BCBSMA Primary Care Physician (PCP) Incentive Program was designed to offer incentives to physicians who improve the quality of care our members receive. In 2010, the quality measures have been restructured to align PCP incentives with those of the BCBSMA Alternative Quality Contract (AQC), using the same broad set of ambulatory care measures, with incentives based on achieving established performance targets and

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				improvement efforts through the Group Performance Incentive Program. BCBSMA will leverage these programs' resources in 2004 to encourage physicians to invest in and use electronic technologies for disease management, decision support and electronic prescribing. BCBSMA expects this to have far-reaching effects in the delivery of quality care to their members and all the citizens of Massachusetts.	rewarding for both absolute performance and improvement above a minimum target. The measures include three areas of clinical performance: adult preventive care, adult chronic care, and pediatric care. Also, outcome measures are included for chronic conditions and providers are now rewarded for actual results versus reporting only as in prior years. Additionally, quality measure results will be calculated at the group level rather than at the individual PCP level. The generic prescribing and laboratory efficiency measures remain a component of the program. Because Massachusetts now sets the national benchmark for e-prescribing and electronic medical record utilization, physicians are no longer incented for these measures in 2010. However, use of e-prescribing will be a prerequisite for participation in our incentive programs in 2011.
Center for Health Care Strategies	Pay-for-Performance Purchasing Institute www.chcs.org/info- url_nocat3961/info- url_nocat_show.htm? doc_id=375137	Through a competitive process, CHCS selected seven states who are designing, implementing, and testing financial or non-financial incentives;	To assist states in developing Medicaid provider incentive programs.	The seven states and their agendas include: Arizona is partnering with its managed care organizations to develop a statewide provider-level incentive program. The state is	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
		different performance measures; and ways of engaging provider participation		concurrently working on pay- for-performance arrangements targeting hospitals, nursing homes, home health agencies, and health plans.	
				Connecticut seeks to institutionalize incentives for care coordination, preventive care, and other activities for children enrolled in its Medicaid program under a pay-for-performance program.	
				Idaho is incorporating pay- for-performance into its primary care case management Chronic Disease Management Program. The initial pilot focuses on diabetes, using six evidence-based quality indicators. Idaho is in the process of adding depression and hypertension diagnoses to the program. Providers will receive a \$50 incentive payment for every person with diabetes who is enrolled, and \$10 for each of the selected indicators that have been performed or competed.	
				Massachusetts seeks to implement pay-for-performance within its primary care case management program. The state's goals for provider-level	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				 pay-for-performance include: Establishing a framework for MassHealth pay-for-performance activities that focuses on improving the quality of care delivered to members across care delivery settings. Using a phased approach to implementing pay-for-performance in MassHealth. 	
				Missouri proposes to implement financial incentives for providers who actively participate in its disease management program. Ohio Medicaid is planning to	
				coordinate provider pay-for- performance into a statewide managed care program. The state is currently identifying performance indicators for preventive care and for the most costly and prevalent chronic diseases.	
				West Virginia is developing a provider-level "pay-for-play" program to go hand-in-hand with its Medicaid Redesign goals. In the initial year, providers will be reimbursed for time spent with patients explaining the state's member agreement and establishing a self management plan. In the	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				to performance measures.	
Centers for Medicare and Medicaid Services (CMS)	Medicare Pay for Performance (P4P) Demonstrations www.cms.hhs.gov/apps/media/press/release.asp?Counter=1343 Specifically Examples: Hospital Quality Initiative (http://www.cms.hhs.gov/hospitalqualityinits/) Premier Hospital Quality Incentive Demonstration (http://www.cms.hhs.gov/HospitalQualityInits/35_hospitalQualityInits/35_hospitalpremier.asp) Performance Based Payments for Physician Groups Demonstration (http://www.cms.hhs.gov/apps/media/press/release.asp?Counter=1341)	Federal demonstration projects apply incentive payments for different methodologies a wide range of provider types under the Medicare program.	To determine the impact of offering incentive payments to different providers for improving the quality of care rendered to Medicare beneficiaries when such quality of care results in reduced need for additional services and, consequently, reduces cost.	Medicare has various initiatives to encourage improved quality of care in all health care settings where Medicare beneficiaries receive their health care services, including physicians' offices and ambulatory care facilities, hospitals, nursing homes, home health care agencies and dialysis facilities. The foundation of effective pay-for-performance initiatives is collaboration with providers and other stakeholders, to ensure that valid quality measures are used, that providers aren't being pulled in conflicting directions, and that providers have support for achieving actual improvement. Consequently, to develop and implement these initiatives, CMS is collaborating with a wide range of other public agencies and private organizations who have a common goal of improving quality and avoiding unnecessary health care costs, including the National Quality Forum (NQF), the	
	Medicare Chronic Care Improvement			Quality Forum (NQF), the Joint Commission of the Accreditation of Health Care	
	Care Improvement Program			Accreditation of Health Care Organizations (JCAHO), the	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
	(http://www.cms.hhs.gov/HealthPlansGenInfo/Downloads/CCIP%20ReportingTemplate%2009-13-06.pdf) Medicare Care Management Performance Demonstration (http://www.cms.hhs.gov/DemoProjectsEvalRpts/downloads/MMA649_DesignReport.pdf) Standards and Performance Measures Development			National Committee for Quality Assurance (NCQA), the Agency for Health Care Research and Quality (AHRQ), the American Medical Association (AMA), and many other organizations. CMS is also providing technical assistance to a wide range of health care providers through its Quality Improvement Organizations (QIOs). Through these collaborative efforts, CMS is developing and implementing a set of pay-for-performance initiatives to support quality improvement in the care of Medicare beneficiaries.	
Integrated Healthcare Association (IHA)	Pay for Performance www.iha.org	A Pay for Performance Initiative that was launched in 2002. Measures cover clinical areas (50%), patient satisfaction (40%) and IT investment (10%).	This statewide collaboration is designed to create the business case for quality at the physician group level. The goal is to reward physician groups for performance in clinical care and patient experience by providing a clear set of health plan expectations, use of common metrics,	IHA's principles of Pay for Performance are (1) common performance measures for physician groups, developed collaboratively by health plan and physician group medical directors, researchers, and other industry experts; and (2) significant health plan financial payments based on that performance, with each plan independently deciding the source, amount, and payment method for its incentive program.	The Pay for Performance (P4P) program is now in its seventh year. It has grown to include eight health plans, 35,000 physicians, and 11.5 million HMO enrollees, establishing it as the largest private P4P program in the country. Several Findings from a study IHA conducted on 2006-2009 P4P data: • The use of aggregated data from multiple payers to score results significantly increased measurement reliability and the

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
			and public reporting. Six health plans participate		trust of physicians • Average P4P clinical performance has steadily improved every year at a level comparable with national rates of improvement • After an initial encouraging jump between 2003 and 2004, patient experience gains have been marginal • Steady, incremental quality improvements have been realized, but breakthrough improvement has not been achieved, likely because there has not been sufficient physician incentive to do so • Dramatic regional/geographic variations in quality have surfaced • Wide variability in payments by health plans raised concerns about "free riders" motivating plans with higher payments to reduce payment levels
MedEncentive	The MedEncentive Program www.medencentive.com	A program that provides evidence-based medicine guidelines and information therapy to physicians and, in turn, financially rewards physicians (and their patients) based on their usage of this information.	To improve the standard of care and control costs through financial incentives to doctors and their patients for incorporating evidence-based medicine and information therapy methods.	Designed to "bolt-on" to existing health plans to improve the standard of care and control healthcare costs. MedEncentive accomplishes quality improvement and cost containment by dispensing evidence-based medicine (EBM) treatment guidelines and information therapy (lx) to physicians and their patients through MedEncentive's proprietary Internet Website applications	MedEncentive released results of a 5 year study of the program. It is available here: http://www.medencentive.com/ News_Support_Files/MedEncentive%205th%20Anniversary%20Report%20First%20Edition%20-%20Rev%20A.pdf Built on the foundation of the original program, the initiative currently includes e-Prescribing and medication compliance tools, as well as an integrated

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
					incentive tool that encourages patients to take health risk assessments and then follow-through on any risk findings.
Medicare Payment Advisory Commission (MedPAC)	Report to Congress on Pay for Performance in Medicare, March 2005 http://www.medpac.gov/publications/congressional_reports/Mar05_EntireReport.pdf	Recommended that CMS move towards using financial incentives that rewards quality of care.	To financially incentive physicians to provide a higher quality of care.	Pay-for-performance measurement criteria: Measures must be evidence-based, to the extent possible, broadly understood, and accepted Providers and plans must be able to improve quality by using the measures; otherwise care may be improved for only a few beneficiaries Incentives should not discourage providers from taking riskier or more complex patients Information to measure the quality of a plan or provider should be collected in a standardized format without excessive burden on the parties involved. Establish a process for continual evolution of measures. Principles for physician payment: Reward providers based on both improving care and exceeding certain	Building on the Commission's previous recommendations of linking payment to quality, in the June 2008 Report to Congress, MedPAC introduced the concept of accountable care organizations (ACOs). This model would create incentives to control costs and coordinate care across a large set of providers and allow accountability for care over time. MedPAC explored two variations on the ACO model—one in which providers volunteer to form an ACO and one in which participation is mandatory. Voluntary ACO Model In a bonus-only voluntary model, ACOs receive bonuses for meeting cost and quality targets. FFS rates will likely have to be constrained for Medicare to fund those bonuses at a sufficient level to change provider behavior without increasing its overall spending because of random variation.

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
National Business Coalition on Health (NBCH)	eValue8 www.nbch.org/eValue8	A performance tool used by purchasers to compare quality and efficiency of health plans including their use of IT.	eValue8: Seeks to provide standardized information in order to improve their management, administration and/or delivery of health care services. NBCH: Seeks to accelerate the nation's progress towards safe, efficient, high-quality health care and the improved health status of the American population.	 benchmarks. Medicare should fund the program by setting aside a small share of payments in a budget neutral approach. Distribute all payments that are set aside for quality to providers achieving the quality criteria. NBCH Principles: Value-based health care purchasing Measuring the comparative quality and efficiency of hospitals, physicians, and health plans in the community to identify the best value Creating incentives to provide higher-value care through integrated delivery systems and continuous quality improvement Improving the overall health of the community 	Mandatory ACO Model Under a mandatory, bonus-and- withhold model, bonuses could be funded by shared savings and by penalizing providers who fail to meet cost and quality targets.
Prometheus Payment Inc.	Prometheus Payment Model www.prometheuspay ment.org	Seeks to create a payment environment where the patient receives the highest quality of care and the providers and insurers gain a more efficient	To improve health care quality, lower administrative burden, enhance transparency, and support a patient-centered,	Tenets of Prometheus Payment: Providers have the opportunity to negotiate meaningfully their payment amounts in accordance with the Evidence-Based	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
		work environment, in addition to financial savings and additional bonuses.	consumer driven environment.	Case Rate. Mechanisms of payment and systems of reporting are transparent and public. Providers have the option to configure themselves in whatever aggregations they choose. The implementation of PROMETHEUS explicitly seeks to lower administrative burden wherever possible. Providers measured for efficiency will have information about other providers in order to facilitate effective referral choices. Providers have the opportunity to speak to scorecard issues (e.g., data, findings before they are made public.	
The Leapfrog Group	Leapfrog Hospital Recognition Program (Formerly Leapfrog Hospital Rewards Program) www.leapfrog.medsta t.com/rewards www.leapfroggroup.o rg/for_hospitals/fh- incentives_and_rewa rds/hosp_rewards_pr og	A hospital pay-for-performance program based on NQF-endorsed quality measures. A solution to help purchasers and payers obtain more value from their inpatient care in collaboration with their hospital community by creating incentives and rewards for high-value care.	Provides a foundation for hospitals to become national leaders in the movement to improve quality health care and provide exceptional value for the communities they serve.	 The Leapfrog Group principles: Reduce preventable medical mistakes and improve the quality and affordability of health care. Encourage health providers to publicly report their quality and outcomes so that consumers and purchasing organizations can make informed health care choices. 	Name of program has changed to Leapfrog Hospital Recognition Program

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
United HealthCare e-Prescribing Program	UnitedHealthcare's e-Prescribing Program https://www.unitedhealthcareonline.com/b2c/CmaAction.do?channelId=6b8932fc5fc9d110VgnVCM1000007740dc0a	e-Prescribing: (1) Enables prescribers to electronically send prescriptions directly to a pharmacy from the point-of-care (2) Improves the health and financial well-being of patients by helping them avoid preventable medication errors and optimizing their prescription drug benefits (3) Lets physician and other health care professionals verify member eligibility, medication history, drug interaction and the list of drugs on the formulary of their patient's health plan	To improve the health and well being and reduce costs of our members through accurate, informed medication decision making at the point of care. To expand e-prescribing and promote the use of EMR/EHR's and other technology by assisting physicians in the procurement of electronic tools. Currently UnitedHealthcare has rolled out e-prescribing to over 5000 physicians in six states and plans to expand its program include up to 10,000 prescribers in ten states by the end of	Reward doctors and hospitals for improving the quality, safety and affordability of health care. Help consumers reap the benefits of making smart health care decisions. IDirect to physician program — UnitedHealthcare has partnered with preferred e-prescribing and EMR vendors to offer e-prescribing services free of charge to its network physicians in over 10 states. Through community collaboration, UnitedHealthcare has helped to formulate e-prescribing and technology collaboratives to help fund and promote the use of e-prescribing and other technologies. Examples of such endeavors include e-Prescribe Florida, e-Prescribing Collaborative of Illinois with BCBS of	Updates
		·	2010.	IL and Humana and through the	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				convening entity Health Options Inc, in Indiana (3) Promotion of electronic tools through education – UnitedHealthcare continues to provide opportunities for ongoing education of e-prescribing by contributing to nationally based articles and white papers, working directly with local communities and their medical societies to help promote e- prescribing and the use of electronic tools	
United Healthcare UnitedHealth Practice Rewards	UnitedHealth Practice Rewards www.unitedhealthcar eonline.com/b2c/Cma Action.do?channelId=b80ee7a1e193b010V gnVCM100000c5207 20a	UnitedHealth Practice Rewards recognizes and rewards, through fee schedule enhancements, solo practitioners and medical groups who have met the quality and cost-efficiency criteria for the UnitedHealth Premium program and who meet the additional criteria for UnitedHealth Practice Rewards	To improve the quality of clinical care by supporting physicians in their practice of evidence-based and efficient health care delivery.		(1) The program uses national industry, evidence-based and medical society standards with a transparent methodology and robust data sources to evaluate physicians across 20 specialties to advance safe, timely, effective, efficient, equitable and patient-centered care. (2) The administrative metrics include: claims submitted via EDI, electronic prescribing, utilization of the physician portal and electronic payments and

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
					statements. (3) The program recognizes physician performance through fee schedule enhancements.
UnitedHealth Premium Designation Program	UnitedHealth Premium Designation Program https://www.unitedhe althcareonline.com/b 2c/CmaAction.do?ch annelId=dc2bfeff7f0f4 110VgnVCM2000008 040dc0a	The UnitedHealth Premium Designation program serves to align financial incentives, rewarding excellence in quality and cost efficiency. It supports consumers in making more informed and personally appropriate choices for their medical care and supports practice improvement by providing consumers, physicians and hospitals with information about how their clinical practice compares with national standards for quality and local cost efficiency benchmarks. The program has been awarded NCQA's Physician Hospital Quality 2008 certification and adheres to the Consumer Purchaser Disclosure Project Patient Charter standards.	To leverage transparency to improve the quality and affordability of clinical care and to align financial incentives in the healthcare system. Support physicians in their practice of quality and cost efficient medical care, using nationally accepted quality standards and market level cost experience to reduce variability and optimize value. Provide consumers with trusted and credible information about the performance (affordability, quality, usability and access) of physicians and hospitals to help them find them find the right doctor and hospital.	 The program uses national industry, evidence-based and medical society standards with a transparent methodology and robust data sources to evaluate physicians across 20 specialties (including all 3 primary care specialties) to advance safe, timely, effective, efficient, equitable and patient-centered care. The program applies over 300 measures to evaluate over 200,000 physicians in 138 markets. The program supports practice improvement and provides physicians with access to information on how their clinical practice compares with national standards for quality and local cost efficiency benchmarks. Consumers are provided access to a portal that includes physician and hospital quality and cost efficiency ratings. Designations used in care management, customer 	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
			Support employers in their efforts to manage health care costs by promoting quality and cost efficient health care.	service, consumer portal and tiered benefits.	

Engaging Consumers Resources

"Bodyguard." Government Health IT, HIMSS, November/December 2009. http://www.govhealthit.com/ArticlePrint.aspx?id=72303

iHealth Beat. Health record banks gaining traction in regional projects, 2009. http://www.ihealthbeat.org/features/2009/health-record-banks-gaining-traction-in-regional-projects.aspx

BioMed Central. Integrated Personal Health Records: Transformative Tools for Consumer-Centric Care. http://www.biomedcentral.com/1472-6947/8/45

Robert Wood Johnson Foundation. Feature: The Power and Potential of Personal Health Records, January 2010 http://www.rwjf.org/pioneer/product.jsp?id=49989

MIT Media Lab Projects. New Media Medicine: How radical new collaborations between doctors, patients, and communities will catalyze a revolution in human health. http://www.media.mit.edu/research/groups/new-media-medicine

AHRQ. Impact of Consumer Health Informatics Applications, October 2009 http://www.ahrq.gov/downloads/pub/evidence/pdf/chiapp/impactchia.pdf

Center for Health Transformation. HIE for a New Generation http://www.healthtransformation.net/galleries/wp-HIT/HIE_For_A_New_Generationv2.pdf

Center for Health Transformation. "Putting the Patient in Control: Employing Technology Solutions to Empower Patients, March 2010" http://www.healthtransformation.net/galleries/wp-consumerism/PuttingThePatientInControlFINAL.pdf

AHRQ. Literacy and Health Outcomes Summary http://www.ahrq.gov/clinic/epcsums/litsum.pdf

National Library of Medicine Gateway. Ensuring Low-Literate Adult Access to Online Health Information: Developing a Research Program, 2005 http://gateway.nlm.nih.gov/MeetingAbstracts/ma?f=103622778.html

Apple. Why the iPad Matters for Healthcare, February 2010 http://www.thehealthcareblog.com/the_health_care_blog/2010/02/why-the-ipad-matters-for-healthcare-.html

Markle Foundation - Connecting for Health. Consumers as Network Participants http://www.connectingforhealth.org/phti/reports/overview.html

Markle Foundation - Connecting for Health. Technology Overview http://www.connectingforhealth.org/phti/reports/overview.html

Markle Foundation - Connecting for Health. Limitations on Identifying Information http://www.connectingforhealth.org/phti/reports/overview.html

Markle Foundation - Connecting for Health. Portability of Information http://www.connectingforhealth.org/phti/reports/overview.html

Markle Foundation - Connecting for Health. Security and Systems Requirements http://www.connectingforhealth.org/phti/reports/overview.html

Markle Foundation - Connecting for Health. An Architecture for Consumer Participation http://www.connectingforhealth.org/phti/reports/overview.html

The Commonwealth Fund. International Developments in Self-Directed Care, The Commonwealth Fund, Feb. 2010. http://www.commonwealthfund.org/~/media/Files/Publications/Issue%20Brief/2010/Feb/1370 Alakeson intl devel selfdirected care ib v2.pdf

U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology. Consumer Preferences Draft Requirements Document

http://healthit.hhs.gov/portal/server.pt/gateway/PTARGS 0 10779 891071 0 0 18/20091005 Consumer%20Preferences Draft_Requirements_Document.pdf

Multiple Myeloma Research Foundation (MMRF) http://www.themmrf.org/

Pitney Bowes. Pitney Bowes Employee Wellness Innovations Front and Center at White House Meeting, May 2009 http://news.pb.com/article_display.cfm?article_id=4495

Robert Wood Johnson Foundation. Commonalities and Variations in the Cash and Counseling Programs Across the Three Demonstration States, February 2007 http://www.rwjf.org/pr/product.jsp?id=18621

Robert Wood Johnson Foundation. Improving Asthma Outcomes in Minority Children: A Randomized, Controlled Trial of Parent Mentors, Dec 09 http://www.rwjf.org/pr/product.jsp?id=52468

PatientsLikeMe. PatientsLikeMe: Empowerment and Representation in a Patient-Centered Social Network http://www.jedbrubaker.com/wp-content/uploads/2009/12/patients-like-me-cscw-health-workshop.pdf

PwC. Transforming healthcare through secondary use of health data, October 2009 http://www.cfodirect.pwc.com/CFODirectWeb/Controller.jpf?ContentCode=FSAE-7WZPXJ&SecNavCode=ASPP-4LYRR9&ContentType=Content&ShowEdited=true

AHRQ Final Report: Consumer Engagement in Developing Electronic Health Information Systems, July 2009 http://healthit.ahrq.gov/portal/server.pt/gateway/PTARGS 0 888520 0 0 18/09-0081-EF.pdf

Robert Wood Johnson Foundation. Experts Identify Ways to Spur Consumer Engagement in Health Care: Findings Outlined in a New Series of Briefing Papers, October 2007

http://www.rwif.org/pr/product.isp?id=23077

eHealth Initiative. "Report: Strategies for Engaging the Participation of Patients and Consumers in the Sentinel Initiative FDA." Submitted by eHealth Initiative, October 31, 2008"

http://www.regulations.gov/search/Regs/contentStreamer?objectId=090000648098bad0&disposition=attachment&contentType=msw8

Center for Information Therapy. "IxAction Alliance

Navigating a Changing Health Care System: How Consumers, Clinicians and Policymakers Can Make Sense of Shared Decision Making and Information Therapy

March 2008"

http://www.ixaction.org/publications/documents/whitepaper319.pdf

Health 2.0. Health 2.0 Conference, San Francisco, CA. October, 2009. http://www.health2con.com/past/san-francisco-fall-09/

Healthwise. "Healthwise Releases Breakthrough Tools in Medical Decision Making New Decision Points Feature Cutting-Edge Innovation." September 2009 http://hwinfo.healthwise.org/docs/DOCUMENT/9177.pdf

Kaiser Permanente. "Kaiser Permanente My Health Manager" http://info.kp.org/richmedia/experience/index.htm

Kaiser Permanente. Kaiser's EHR rollout complete across all facilities, March 2010. http://www.cmio.net/index.php?option=com_articles&view=article&id=21025&division=cmio

MyPHRSC. CMS: My Personal Health Record, South Carolina (MyPHRSC) https://myphrsc.com/login.cfm

Cowley County Mental Health and Counseling Center. Notice of Information Practices http://www.ccmhcc.com/files/Notice_of_Information_Practices.pdf

Holy Cross Hospital, Taos, New Mexico. Notice of Information Practices http://www.taoshospital.org/THS.nsf/View/InformationPractices

Electronic Healthcare Network Accreditation Commission (EHNAC). EHNAC HIE Accreditation Market Scan Report, February 2008 http://www.ehnac.org/ehnac/ResourceCenter/imageGallery.ashx?id=2c676279-2960-de11-b6a9-001b78069a3c

HIT Blawg. "Draft Criteria for HIE Accreditation Program. HIT Blawg October 28, 2009"

http://www.hitblawg.com/2009/10/draft-criteria-for-hie-accreditation.html

HealthIT.hhs.gov. "Health Information Technology Extension Program ONC"

http://healthit.hhs.gov/portal/server.pt?open=512&objID=1335&mode=2&cached=true

JAMA Groups Push Physicians and Patients to Embrace Electronic Health Records http://jama.ama-assn.org/cgi/content/extract/299/5/507?hits=10&RESULTFORMAT=&FIRSTINDEX=1410&maxtoshow=&HITS=10&searchid=1&resourcetype=HWFIG

The American Journal of Managed Care (AJMC). Patient-Centered Medical Home Demonstration: A Prospective, Quasi-Experimental, Before and After Evaluation, September 2009 http://www.ajmc.com/media/pdf/AJMC_09sep_ReidWEbX_e71toe87.pdf

Health Affairs The Patient-Centered Medical Home For Chronic Illness: Is It Ready For Prime Time?, 2008
<a href="http://content.healthaffairs.org/cgi/content/abstract/27/5/1231?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&fulltext=%22patient+centered+medical+home%22&andorexactfulltext=and&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

Health Affairs Measuring The Medical Home Infrastructure In Large Medical Groups, 2008

 $\frac{\text{http://content.healthaffairs.org/cgi/content/abstract/27/5/1246?maxtoshow=\&HITS=10\&RESULTFORMAT=\&fulltext=\%22patient+centered+medical+home\%22\&andorexactfulltext=and\&searchid=1\&FIRSTINDEX=0\&resourcetype=HWCIT}{\text{cal+home}}$

Health Affairs A House Is Not A Home: Keeping Patients At The Center Of Practice Redesign, 2008
<a href="http://content.healthaffairs.org/cgi/content/abstract/27/5/1219?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&fulltext=%22patient+centered+medical+home%22&andorexactfulltext=and&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

Health Affairs Using Medicare Payment Policy To Transform The Health System: A Framework For Improving Performance, January 2009 <a href="http://content.healthaffairs.org/cgi/content/abstract/28/2/w238?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&fulltext=%22patient+centered+medical+home%22&andorexactfulltext=and&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

Health Affairs Information Gap: Can Health Insurer Personal Health Records Meet Patients' And Physicians' Needs?, 2009 <a href="http://content.healthaffairs.org/cgi/content/abstract/28/2/377?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&fulltext=phr&andorexactfulltext=and&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

Health Affairs If You Build It, Will They Come? The Kaiser Permanente Model Of Online Health Care, 2009 <a href="http://content.healthaffairs.org/cgi/content/abstract/28/2/334?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&fulltext=phr&andorexactfulltext=and&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

Health Affairs Privacy As An Enabler, Not An Impediment: Building Trust Into Health Information Exchange, 2009 <a href="http://content.healthaffairs.org/cgi/content/abstract/28/2/416?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&fulltext=phr&andorexactfulltext=and&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

Health Affairs Making Space For Disruption: Putting Patients At The Center Of Health Care, 2008 http://content.healthaffairs.org/cgi/content/abstract/27/5/1345?maxtoshow=&HITS=10&hits=10

PwC. What employers want from health insurers in 2010: Better information, more value, January 2010 http://www.pwc.com/us/en/healthcare/publications/what-employers-want-from-health-insurers-in-2010.jhtml

HealthLeaders Media. Hospital Hopes iPhone App Will Improve Patient Satisfaction, Efficiency, February 2010 http://www.healthleadersmedia.com/content/TEC-247194/Hospital-Hopes-iPhone-App-Will-Improve-Patient-Satisfaction-Efficiency

HealthLeaders Media. Social Marketing Helps Translate AHRQ Research Into Practice, February 2010 http://www.healthleadersmedia.com/content/MAR-246665/Social-Marketing-Helps-Translate-AHRQ-Research-Into-Practice

University of Massachusetts Medical School –Center for Health Policy and Research. UMass Work Product: Findings from the State Employee Health Plan Interviews, January 2008 http://www.nga.org/Files/pdf/0801EHEALTHHICDESLIDES.PDF

Citizens Health Initiative. A Strategic Plan for Health Information Technology and Exchange, January 2009 http://www.unh.edu/chi/media/Reports/2009StrategicPlan_Web.pdf

Consumer Advisory Council and Network. "Consumer Engagement in Heath IT in NY" http://www.nyehealth.org/files/File_Repository16/pdf/HealKickoff051208_Consumer.pdf

Overview of Key Initiatives Engaging Consumers

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
America's Health Insurance Plans (AHIP), Blue Cross Blue Shield Association, National Health Council	Personal Health Record Model www.ahip.org www.bcbsa.org http://www.ahip. org/Issues/Tool kit.aspx?docid= 18829	A national effort to develop standards for health plan-based PHRs and policies for PHR data transfer.	Create health plan- based PHR standards	Provide a PHR that will give consumers the ability to take information with them if they change health plans as well as facilitate information provision for both the patient and providers	In November 2007, AHIP and BCBSA completed work to identify recommended standard data domains and data elements for the transfer of laboratory test results and self-reported data for their inclusion in the 2006 initial draft recommendations for Plan-to-Plan PHR portability standards
American Academy of Pediatrics (AAP)	AAP eHealth Programs www.aap.org	The American Academy of Pediatrics (AAP) is a national membership organization of 60,000 pediatricians, pediatric medical and surgical specialists. The AAP is dedicated to the health of all children, adolescents and young adults, and their families.	The AAP Council on Clinical Information Technology continues to focus AAP efforts on education and policy development. Additionally, in late 2009, AAP established a Child Health Informatics Center to serve as a "home" for health information technology initiatives within the AAP.	AAP programs relevant to eHealth include education of pediatricians on the value of health information technology and how to implement it in practice. • We conduct the Pediatric Office of the Future Exhibit at the AAP Annual National Conference & Exhibition (NCE). • We conduct the Pediatric Documentation Challenge, in which we invite several EHR vendors to demonstrate how their software performs using pediatric case scenarios. • On October 1, 2010, in conjunction with the 2010 AAP NCE, the Pediatrics in the 21st Century Symposium will be on HIT and Quality. • The AAP Council on Clinical Information Technology offers an annual educational program that includes scientific abstract	AAP conducted several new activities in response to opportunities created by the passage of the American Recovery and Reinvestment Act and the Children's Health Insurance Program Reauthorization Act of 2009. These include: • Posting resources for AAP Members and Chapters on the AAP Member Center Web site; • Reviewing the Interim Final Rule on Standards, Implementation Requirements, and Certification Criteria for Electronic Health Records and the Proposed Rule on Medicare and Medicaid Incentives for EHR Adoption for public comments; • Submitting testimony to the HIT Policy and Standards Committees; and • Developing proposals to work

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				presentations on real-life use of HIT in pediatrics. • We developed and maintain an EMR Review Web site (http://www.aapcocit.org/emr) which allows AAP members to rate their EHRs and post comments about its performance. • We developed and maintain an EMR Toolkit (http://practice.aap.org - see Practice Toolbox) to help AAP members select and implement EHRs. • We publish a monthly article on HIT designed to educate primary care pediatricians in our member newsletter, AAP News.	with AHRQ's contractors on development of a model electronic health record format for children and evaluation of various elements of the Office of the National Coordinator's HITECH programs.
American Health Information Management Association (AHIMA)	myPHR www.myphr.org	A PHR template for consumers to use in creating and maintaining their personal health records electronically	Ensuring that all medical information collected about you is complete, accurate, and protected, yet, at the same time, readily available for your healthcare providers when it's needed.		The Personal Health Record program my.PHR.com is now in its third generation and has a website as well as programs with various social organizations.
					On the standards side, AHIMA staff has led the effort to have a standard for the exchange of information between a standard EHR and a standard PHR. This will hopefully facilitate some of the Meaningful Use data exchange requirements for providers and consumers.

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
American Health Information Community (AHIC) – Now National eHealth Collaborative (NeHC)	Consumer Empowerment workgroup www.hhs.gov/h ealthit/ahic/cons umer www.nationaleh ealth.org		Develop a plan to realize a specific charge (deployment of prepopulated electronic registrations and medication histories) within one year that is visible to the American public and that works towards a broader charge (widespread adoption of personal health records) over time.	Broad Charge: Make recommendations to the AHIC to gain wide spread adoption of a personal health record that is easy-to-use, portable, longitudinal, affordable, and consumercentered. Specific Charge: Make recommendations to the Community so that within one year, a pre-populated, consumer-directed and secure electronic registration summary is available to targeted populations. Make additional recommendations to the Community so that within one year, a widely available pre-populated medication history linked to the registration summary is deployed.	Please see National eHealth Collaborative (NeHC)
Centers for Medicare & Medicaid Services (CMS)	MyMedicare.go v www.myMedica re.gov	An 18-month pilot project to encourage Medicare beneficiaries to optimize their health using Internet-based tools. Participants include: HIP USA, Humana, Kaiser Permanente, and the University of Pittsburgh Medical Center	 To assess the use of PHRs Identify the features beneficiaries prefer Determine how best to conduct outreach and education Determine how best to encourage adoption and ongoing use of PHRs 	MyMedicare.gov features include: View claim status (excluding Part D claims) Order a duplicate Medicare Summary Notice (MSN) or replacement Medicare card View eligibility, entitlement and preventive services information View enrollment information including prescription drug plans View or modify drug list and pharmacy information View address of record with	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				Medicare and Part B deductible status • Access online forms, publications and messages sent to beneficiary by CMS	
Center for Connected Health	www.connected -health.org	A division of Partners HealthCare leading efforts in the use of technology to deliver quality patient care outside of the medical setting.	To increase access and improve quality medical services and patient care by applying consumer technologies and online resources in innovative ways.	Remote Care: Patient-provider communications which happen on a more continuous basis, instead of only during scheduled visits, improves both the efficacy of care and offers a more patient-centered approach to the exchange. Whether it's an online office visit or a messaging platform delivered via the cell-phone, we are establishing new models of engagement. Self-Care: Access to physiologic data will provide patients with feedback that promote improved decision-making, healthier behavior, and motivation to change. In this area, we are interested in topics such as care plan adherence, behavioral modification, and health engagement.	Remote monitoring for patients with heart failure, hypertension, and diabetes, is being offered throughout the Partners HealthCare system. Almost 1000 patients with heart failure are monitored each year, with recent evaluation showing that these patients have a significant reduction in re-hospitalizations. Primary care practices are also offering the diabetes or hypertension monitoring programs to their patients. Diabetes patients who are active in the program are showing dramatic reductions in their HbA1c levels, after only several months in the program. In addition to the remote monitoring programs, the Center is developing mobile health tools for medication reminders and educational content delivery, aimed at a diverse population of patients.
Center for Health Transformation	Health Information Technology Project	A membership-based collaboration created to drive adoption of health information technology to help create a Nationwide	The Center for Health Transformation's mission is to grow a movement that will accelerate the	Among other principles for HIT adoption, the following are specific to engaging consumers: Pass a federal law giving individuals ownership of	There have been 11 specific priorities identified and established for the HIT Project, in order to achieve the following articulated project goals:

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
	www.healthtran sformation.net	Health Information Network.	adoption of transformational health solutions and policies that create better health and more choices at lower cost. A key goal is to engage consumers on using personal health records in their health and healthcare management. The mission of the Center for Health Transformation's Health Information Technology (HIT) Project is to drive adoption of health information technology to help create a Nationwide Health Information Network, a secure, interoperable system where all stakeholders electronically exchange individual health and healthcare information.	their health records. Pass a law to preserve the confidentiality and security of electronic health records by making the unauthorized access of medical records a felony with sever penalties, including slander if published or posted online. • Engage employers to offer personal health records to their employees by combining consumer portals with incentive programs for wellness and health.	 Drive adoption of electronic health records and other information technologies. Reach consensus and convergence on open data standards for interoperability. Facilitate research of deidentified healthcare data for new treatments, health management, and trends. Engage consumers on using personal health records in their health and healthcare management. (http://www.healthtransformation.net/cs/health_information_technology_hit) Other initiatives include: Communicating a 21st Century Intelligent Health System and Principles of Transformation Through Out the State of Georgia – A project whose purpose is to communicate the vision and principles of transformation through speeches and presentations, meetings and seminars, participation on task forces and hearings, as well as through print and other media in Georgia. (http://www.healthtransformation.net/cs/communicating_in_georgia)

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
					Healthy Georgia Diabetes and Obesity Project – A collaboration of public and private sector leaders dedicated to improving the treatment and outcomes for people with diabetes and to promoting early diagnosis and prevention of diabetes, including decreasing the prevalence of obesity. (http://www.healthtransform ation.net/cs/healthy_georgi a_diabetes_and_obesity_project) The Columbus Project – A project dedicated to building and testing the models of a 21st century intelligent health system at the community level. (http://www.healthtransformation .net/cs/columbus_project)
Connecting for Health – Markle Foundation	Personal Health Technology Initiative www.connecting forhealth.org/pht i	A consumer advocacy effort that promotes patient use of and empowerment through personal health records.	Envisions a future electronic health information environment that: • Allows patients, consumers, and caregivers to take a very active role in healthcare • Supports effective and efficient communication between physicians and other health providers and the individuals and their	 Consumer Principles: Individuals should be able to access their health and medical data conveniently and affordably. Individuals should be able to decide (i.e., authorize) when their health data are shared, and with whom. Individuals should be able to refuse to make their health data available for sharing (i.e., opt-out). Individuals should be able to designate someone else, such as a loved one, to 	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
			families in their care Improves the quality of health care Reduces medical errors and enhances safety Emphasizes continuity and convenience of care Safeguards patient privacy Earns and keeps the public's trust	have access to and exercise control over how their records are shared. Individuals should receive easily understood information about all the ways that their health data may be used or shared. Individuals should be able to review which entities have had access to their personal health data. Electronic health data exchanges must protect the integrity, security, privacy, and confidentiality of an individual's information. Independent bodies, accountable to the public, should oversee the electronic health data exchanges. No single stakeholder group should dominate these oversight bodies. Consumer representatives selected by their peers should participate as full voting members.	
National eHealth Collaborative (NeHC)	NHIN Limited Production Exchange www.nationaleh ealth.org	Through a cooperative agreement with the Office of the National Coordinator for Health IT (ONC), NeHC is providing support to a group of federal and private entities currently exchanging health information using NHIN	Over the next 18-24 months, the participants in the NHIN Limited Production Exchange expect to add exchange partners to the current group of successful data users, including a number of additional federal entities as well as a	 with a shared governance structure, mission, and common implementation of NHIN specifications to securely and interoperably exchange health information; that facilitate information exchange with a broad set of users, systems, geography or community; 	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
		specifications, standards, and policies. These entities are bound by an agreement called the Data Use and Reciprocal Support Agreement (DURSA), developed through a multistakeholder initiative conducted by ONC.	number of entities receiving new grant funds to support health information exchange. In 2010, participants in the NHIN Limited Production Exchange will engage in a process to strengthen and refine the current agreements and policies under which they exchange health data.	 that engage in Internet-based exchange, using common implementation of standards and specifications with secure transport; that comply with testing for conformance and interoperability enabling valid, trusted entities to participate; and who have signed trust a agreement that allocates responsibilities and accountability to protect information exchanged. 	
National Health Council and AHIP	HealthTracks www.ahip.org/H ealthtracks	A pilot program to increase consumer awareness about electronic personal health records and information tools.	Information sharing and promotion of PHRs to those with chronic conditions, health information seekers, and patient advocates interested in improving consumers' quality of care.		
Patient- Centered Primary Care Collaborative (PCPCC)	Patient-Centered Medical Home (PCMH) http://www.pcpc c.net/patient-centered-medical-home	A quality improvement approach to providing comprehensive care where the patient's needs come first. The PCMH is an approach to providing comprehensive primary care to adults, youth and children. The PCMH will broaden access to primary care, while enhancing care coordination.	The PCPCC was created in late 2006, when approached by several large national employers with the objective of reaching out to the American College of Physicians, the Academy of Family Physicians, and other primary care physician groups in order to (1) facilitate improvements in patient-physician relations, and (2) create a more	Principles of a Patient-Centered Medical Home: Personal physician Physician-directed medical practice Whole person orientation Care is coordinated and/or integrated Quality and safety Enhanced access to care Payment is adjusted to reflect value of care coordination (especially as it relates to care outside of a face-to-face setting)	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
			effective and efficient model of healthcare delivery. To achieve these goals, the PCPCC has become one of the major developers and advocates of the patient centered medical home (PCMH) model in America.	PCPCC Centers: Center for Consumer Engagement Center for Employer Engagement Center for eHealth Information Adoption and Exchange Center for Multi-Stakeholder Demonstration Center to Promote Public Payer Implementation	
The Leapfrog Group	Leapfrog Hospital Quality and Safety Survey www.leapfroggr oup.org/for con sumers www.leapfroggr oup.org/for_hos pitals/leapfrog hospital quality and_safety_su rvey_copy	A tool that assesses hospital performance based on quality and safety practices that are proven to reduce preventable medical mistakes and are endorsed by the NQF.	To help consumers make informed decisions about where to receive hospital care based on quality and patient safety results.	 The Leapfrog Group principles: Reduce preventable medical mistakes and improve the quality and affordability of health care. Encourage health providers to publicly report their quality and outcomes so that consumers and purchasing organizations can make informed health care choices. Reward doctors and hospitals for improving the quality, safety and affordability of health care. Help consumers reap the benefits of making smart health care decisions. 	
UnitedHealthcar e UnitedHealth	UnitedHealth Premium	The Premium Designation program	To leverage transparency to improve the quality and	The program uses national industry, evidence-based and	
Premium	Designation	supports consumers in	affordability of clinical	medical society standards with	
Designation Program	Program	making more informed and personally	care.	a transparent methodology and robust data sources to evaluate	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
	https://www.unit	appropriate choices for	Support physicians in	physicians across 20	
	<u>edhealthcareonl</u>	their medical care and	their practice of quality	specialties (including all 3	
	ine.com/b2c/Cm	supports practice	and cost efficient medical	primary care specialties) to	
	aAction.do?cha	improvement by providing	care, using nationally	advance safe, timely, effective,	
	nnelld=dc2bfeff	consumers, physicians	accepted quality	efficient, equitable and patient-	
	7f0f4110VgnVC	and hospitals with	standards and market	centered care.	
	M2000008040d	information about how	level cost experience to		
	<u>c0a</u>	their clinical practice	reduce variability and	2.) The program applies over	
		compares with national	optimize value.	300 measures to evaluate over	
		standards for quality and		200,000 physicians in 138	
		local cost efficiency	Provide consumers with	markets.	
		benchmarks.	trusted and credible		
			information about the	3.) The program supports	
		The Premium	performance	practice improvement and	
		Designation program has	(affordability, quality,	provides physicians with access	
		been awarded NCQA's	usability and access) of	to information on how their	
		Physician Hospital	physicians and hospitals	clinical practice compares with	
		Quality 2008 certification	to help them find them	national standards for quality	
		and adheres to the	find the right doctor and	and local cost efficiency	
		Consumer Purchaser	hospital.	benchmarks.	
		Disclosure Project Patient			
		Charter standards.	Support employers in	4.) Consumers are provided	
			their efforts to manage	access to a portal that includes	
			health care costs by	physician and hospital quality	
			promoting quality and cost efficient health care.	and cost efficiency ratings.	
				5.) Designations used in care	
				management, customer	
				service, consumer portal and	
				tiered benefits.	

Improving Population Health Resources

A Tale Of Two Large Community Electronic Health Record Extension Projects; Health Affairs 28, no. 2 (2009): 345–356.

Adding Value to the Electronic Health Record Through Secondary Use of Data for Quality Assurance, Research, and Surveillance; The American Journal of Managed Care, Volume 13, Number 6.

Advancing the Framework: Use of Health Data—A Report of a Working Conference of the American Medical Informatics Association; Journal of the American Medical Informatics Association, Volume 15 Number 6 November / December 2008.

AMIA Invitational Conference: Developing a National Framework Developing a National Framework for the Secondary Use of Health for the Secondary Use of Health Data; July 2007.

Cerner finds a treasure in data mining; Kansas City Business Journal, May 29, 2009.

Collecting And Sharing Data For Population Health: A New Paradigm. Health Affairs 28, no. 2 (2009): 454–466.

Data Challenges on the EHR Agenda; Hospitals and Health Networks, June 2009.

Effectiveness of an intervention to improve the documentation required for diagnosis of metabolic syndrome in clinics serving African-American patients. Qual Prim Care. 2009;17(3):191-6.

Enhanced Protections for Uses of Health Data: A Stewardship Framework for "Secondary Uses" of Electronically Collected and Transmitted Health Data; December 2007.

How the Semantic Web might improve cancer treatment; PricewaterhouseCoopers, June 2009.

Implementing Electronic Health Record-Based Quality Measures for Developmental Screening; Pediatrics. 2009 Oct;124(4):e648-54. Epub 2009 Sep 28.

James M. Gill, Ying Xia Chen, Joseph J. Glutting, James J. Diamond, Michael I. Lieberman. Population Health Management. October 2009, 12(5): 221-226.

Report on the World Health Organization Global Observatory for eHealth Strategic Planning Workshop; WHO, April 2008.

Secondary Uses and Re-Uses of Healthcare Data: Taxonomy for Policy Formulation and Planning; September 2007.

Speed Bumps, Potholes, And Tollbooths On The Road To Panacea: Making Best Use Of Data. Health Affairs Web Exclusive w153. 2007.

Speed Bumps, Potholes, And Tollbooths On The Road To Panacea: Making Best Use Of Data; Health Affairs, January 2007.

Toward a National Framework for the Secondary Use of Health Data: An American Medical Informatics Association White Paper; Journal of the American Medical Informatics Association, Volume 14, Number 1, Jan / Feb 2007.

Toward a National Framework for the Secondary Use of Health Data; September 2006

Transforming healthcare through secondary use of health data. PricewaterhouseCoopers. 2009. http://www.pwc.com/us/en/healthcare/publications/secondary-health-data.jhtml
Twenty-Five Years Of Health Surveys: Does More Data Mean Better Data? Health Affairs; Volume 26, Number 6.

Understanding the Decisions and Values of Stakeholders in Health Information Exchanges: Experiences From Massachusetts; Am J Public Health. 2009;99:950-955

Aaron McKethan and Mark McClellan. Moving from Volume Driven Medicine Toward Accountable Care; Health Affairs Blog, August 20, 2009.

Medicaid Information Technology Architecture (MITA) White Paper. Centers for Medicare and Medicaid Services. http://www.cms.hhs.gov/MedicaidInfoTechArch/Downloads/mitaoverview.pdf

Daniel Garrett. Tapping into the Value of Health Data Through Secondary Use. Healthcare Financial Management Magazine, February 2010. http://www.hfma.org/hfm/2010archives/month02/HFM0210Feature_Garrett.htm

Overview of Key Initiatives Improving Population Health

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
AQA (Formerly known as Ambulatory Quality Alliance)	Data Sharing and Aggregation Workgroup – Subcommittee on HIT www.aqaalliance.or g/datawg.htm Performance Measurement Workgroup	A subcommittee of AQA's datasharing and aggregation.	A subgroup formed to discuss how best to align and apply modern health information technology with the mission and goals of the AQA, namely: the collaborative processes [and] strategy for measuring performance at the physician level; collecting and aggregating data in the least burdensome way; and reporting meaningful information to consumers, physicians and other stakeholders to inform choices and improve outcomes.	 Principles for HIT and Measurement Aggregation: System design, implementation, and use should minimize costs to consumers, physicians' practices, health plans, and data aggregators. Open networks, standards, and protocols should be promoted to ensure that compatibility, connectivity, and interoperability characterize the systems used for physician or group level quality and performance measurement. Security and the protection of the privacy of personal health information are imperative. Software applications for care management (e.g. EHRs, practice management systems, registries) should make standardized quality, performance, and efficiency measurement a routine by-product of their use. Software applications for 	The Performance Measurement Workgroup began a process to evaluate the current measure set, identify gaps in the implementation process, increase adoption of measures, and identify ways that performance should drive accountability and improve patient care. The Data Sharing and Aggregation Workgroup issued a request for information to gather key information and engage a broad number of potential candidates that could serve as the National Health Data Stewardship Entity (NHDSE). One- hundred and thirty-six responses were received; these responses were summarized and presented to the AQA. The AQA also approved the AQA Appropriateness Criteria Principles which provide guidance for measure developers on how to construct

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				care management (e.g., EHRs, practice management systems, registries) should be designed to enable the merger of their data with others for the purpose of facilitating quality improvement efforts or the production of standardized quality, performance and efficiency measurement.	appropriateness criteria and measures that are feasible to implement and meet multi-stakeholder needs. It also approved the Principles for Cost of Care Measures and the prioritized list of Cost of Care Proposed Starter Set of Conditions and Procedures.
AQA	National Health Data Stewardship Entity (NHDSE) www.aqaalliance.or g/files/HealthDataS teward-July06.doc	A proposed public/private entity that has the primary responsibility of setting uniform operating rules and standards for the sharing and aggregation of quality and efficiency data used in both the public and private sectors, for the purposes of performance measurement and reporting.	 Proposed mission: To set uniform operating rules and standards for sharing and aggregating public and private sector data on measures of quality and efficiency. Offer guidance on implementation of such national operating rules and standards. Provide a framework for collecting, aggregating and analyzing data, to afford means of more effective oversight of health care data analyses and reporting in the United States. 	The scope of work shall include setting policies, rules and standards for: Data aggregation Data collection (includes identification of data sources) Attribution Methodologies Data analysis Data validation (audits) Uses of data Data access Data sharing and reporting	In 2009, the AQA decided to discontinue its measure approval activities. The AQA has approved 242 measures in 39 quality domains of primary and specialty care. The AQA was instrumental in increasing the number of measures that were qualified for reporting to CMS' in the Physician Quality Reporting Initiative. With leadership from the Data Sharing and Aggregation Workgroup, a diverse group of potential candidates for the NHDSE were identified.

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
American Health Information Community (AHIC) – Now National eHealth Collaborative (NeHC)	Population Health and Clinical Care Connections Workgroup www.hhs.gov/healt hit/ahic/population www.nationalehealt h.org	AHIC workgroup charged with making recommendations to the Community to facilitate the flow of reliable health information among population health and clinical care systems necessary to protect and improve the public's health.	Specific Charge: Make recommendations to the Community so that within one year, essential ambulatory care and emergency department visit, utilization, and lab result data from electronically enabled health care delivery and public health systems can be transmitted in standardized and anonymized format to authorized public health agencies within 24 hours.	 Guiding Principles: Utilize the conceptual framework of Confidential Morbidity Report form Local and/or state jurisdictions will receive fully identifiable data based on current state regulations for notifiable conditions The focus of the workgroup is limited to hospital/provider reporting to local and/or state health department dependent of the organizational structure of the public health jurisdiction The focus of the workgroup does not include secondary case reporting The minimum set of data elements are intended to be universally applicable to various public health data streams for electronic case reporting needs The template used to categorize data elements traditionally found in confidential morbidity report forms is based on the current structure of case and 	Now the National eHealth Collaborative (NeHC)

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				investigation report forms developed and in circulation by local, state, and federal public health programs. Common data elements and associated standardized vocabulary should apply to all forms of reporting (e.g., paper submission, web form entry, and direct extractions from EHRs).	
American Medical Informatics Association (AMIA)	A National Framework for the Secondary Use of Health Data www.amia.org	An organization dedicated to the development and application of biomedical and health informatics in the support of patient care, teaching, research, and health care administration.		Data Stewardship Principles: Accountability (including governance, oversight, and the extent and level of applicable regulations) Openness and transparency (including structure, processing and delivery of data, and business processes and practices) Notice to patients Privacy and security (including data quality, de-identification, and costs of re-identification) Granularity of patient consent Permitted uses and disclosures (including data aggregation and analyses)	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				Enforcement and remedies	
Centers for Disease Control and Prevention (CDC)	National Electronic Disease Surveillance System (NEDSS) www.cdc.gov/neds http://www.cdc.gov/ phin/activities/appli cations- services/nedss/inde x.html	NEDSS is an initiative that promotes the use of data and information system standards to advance the development of efficient, integrated, and interoperable surveillance systems at federal, state and local levels. NEDSS is the surveillance component of the Public Health Information Network (PHIN). NEDSS supports provision of data to the Nationally Notifiable Diseases Surveillance System (NNDSS). The NNDSS provides the official source of notifiable disease statistics in the U.S. NEDSS has three components: 1. Policy, Standards, Evaluation and Research; 2. Application (e.g., NEDSS-Base System) and Tools; 3. Capacity Building (i.e., Training and Extramural Funding)	A primary goal of NEDSS is the ongoing, automatic capture and analysis of data that are already available electronically in order to design and implement seamless surveillance and information systems.	Based on the following principles: • Utilization of data and information system standards to promote efficient, integrated, and interoperable surveillance systems and to facilitate electronic exchange of data between public health, laboratories, and clinical providers to support disease surveillance. • Utilization of industry standards. • Reliance on off-the-shelf software. • Internet-based secure transmission of data • A common "look and feel" of systems. • Common reporting requirements. • No requirement to use specific software.	Goals have been further considered. NEDSS is intended t strengthen the surveillance capacity of public health in protecting and promoting the health of individuals and communities: A.) Enhance electronic disease surveillance processes and tools to improve the timeliness, completeness and accuracy of reporting, notification and response; B.) Establish interoperability between NEDSS compatible systems and related tools; C.) Ensure sufficient human, financial and technical resources for surveillance; D.) Develop and implement an integrated policy framework for surveillance; E.) Collaborate to create and share knowledge and solutions

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
CDC	National Healthcare Safety Network (NHSN) www.cdc.gov/ncido d/dhqp/nhsn.html	A secure, internet-based surveillance system that integrates patient and healthcare personnel safety surveillance systems managed by the Division of Healthcare Quality Promotion (DHQP) at CDC.	A knowledge system for accumulating, exchanging and integrating relevant information on infectious and noninfectious adverse events associated with healthcare delivery.	Purposes of NHSN: Collect data from a sample of healthcare facilities in the United States to permit valid estimation of the magnitude of adverse events among patients and healthcare personnel. Collect data from a sample of healthcare facilities in the United States to permit valid estimation of the adherence to practices known to be associated with prevention of healthcare-associated with prevention of healthcare-associated infections (HAI). Analyze and report collected data to permit recognition of trends. Provide facilities with risk-adjusted data that can be used for interfacility comparisons and local quality improvement activities. Assist facilities in developing surveillance and analysis methods that permit timely recognition of patient and healthcare personnel safety	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				problems and prompt intervention with appropriate measures. Conduct collaborative research studies with NHSN member facilities	
CDC	Public Health Information Network (PHIN) www.cdc.gov/phin/i ndex.html	A national initiative striving to enhance research and practice through best practices related to efficient, effective, and interoperable public health information systems.	To improve the capacity of public health to use and exchange information electronically by promoting the use of standards, defining functional and technical requirements.	 CDC's role in PHIN is: Supporting the exchange of critical health information between all levels of public health and healthcare, Developing and promulgating requirements, standards, specifications, and an overall architecture in a collaborative, transparent, and dynamic way, Monitoring the capability of state and local health departments to exchange information, Advancing supportive policy, Providing technical assistance to allow state and local health departments to be full and facilitating a network of active, engaged participants active PHIN participants, and 	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				Facilitating communication and information sharing within the PHIN community.	
Connecting for Health	The Common Framework: Architecture for Privacy in a Networked Health Environment www.connectingfor health.org/common framework/docs/P1CFH_Architecture. pdf	A framework consisting of a set of mutually-reinforcing technical documents and specifications, testing interfaces, code, privacy and security policies, and model contract language intended to help health information systems share information.	The Architecture for Privacy promotes a new health network that takes into account the potential for privacy violations, and one which builds privacy and information security into its architecture from the outset, not as an afterthought.	Privacy protection principles: 1. Openness and transparency 2. Purpose specification and minimization 3. Collection limitation 4. Use limitation 5. Individual participation and control 6. Data integrity and quality 7. Security safeguards and controls 8. Accountability and oversight 9. Legal and financial remedies	
Connecting for Health	Connecting for Health RFI regarding a national data stewardship entity www.connectingfor health.org/resource s/cfh ahrg aga rfi	A draft of "First Principles" In this early phase of our exploration into how the Common Framework can be applied to address the requirements related to population health		First Principles for Population-Level Data Analysis and Decision- making: • Designed for Decisions: A 21 st century health information environment will focus on improving	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
Reference		objectives such as quality improvement, research and public health.		the decision-making ability of the many actors in the health sector. • Designed for Many: A 21 st century health information environmen should empower a rich variety of users. • Shaped by Public Policy Goals and Values: A 21 st century health information environmen should achieve society's goals and values • Boldly Led, Broadly Implemented: A 21 st century health information environmen should be guided both by bold leadership and strong user participation • Possible, Responsive and Effective: 21 st century health information environmen should grow through realistic steps. • Distributed but Queriable: A 21 st century health information environmen should be comprised of a large network of	
				distributed data sources Trusted through Safeguards and Transparency: A 21 st	•

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				information environment should earn and keep the trust of the public through policies that provide safeguards and transparency. Layers of Protection: The 21 st century health information environment should protect patient confidentiality by emphasizing the easy movement of queries and responses, rather than of raw data. Accountability and Enforcement of Good Network Citizenship: A 21 st century health information environment should encourage and enforce good network citizenship by all participants.	
eMerge Network	Group Health Cooperative with the University of Washington Marshfield Clinic Mayo Clinic Northwestern University Vanderbilt University The eMERGE Administrative Coordinating Center	Studying the relationship between genetic variation and a common human trait, using the technique of genome-wide association analysis. Such studies involve testing hundreds of thousands of genetic variants called single nucleotide polymorphisms throughout the genome	A fundamental question is whether EMR systems can serve as resources for such complex genomic analysis of disease susceptibility and therapeutic outcomes, across diverse patient populations.		

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
	https://www.mc.van derbilt.edu/victr/dcc /projects/acc/index. php/About	in people with and without a condition of interest.			
National Committee on Vital and Health Statistics (NCVHS)	National Committee on Vital and Health Statistics ad Hoc Work Group for Secondary Uses of Health Data www.ncvhs.hhs.go v	Ad Hoc groups engage all stakeholders in healthcare regarding appropriate use of secondary data including means and ends of data usage.	Commissioned by the U.S. Department of Health and Human Services and the Office of the National Coordinator to develop an overall conceptual and policy framework that addresses secondary uses of health information including a taxonomy and definition of terms as well as develop recommendations to HHS on needs for additional policy, guidance, regulation and/or public education related expanded uses of health data in the context of the developing nationwide health information network with, an emphasis on the uses of the data for quality improvement, quality measurement and reporting.		
National Committee on Vital and Health Statistics (NCVHS)	Meeting Health Information Needs for Health and Health Care www.ncvhs.hhs.go v	This initiative updates an earlier NCVHS report, "Shaping a Health Statistics Vision for the 21 st Century" and includes aspects of health information infrastructure and enhancing health information capacity. The four NCVHS	The report "Meeting Information Needs for Health and Health Care" will serve as a conceptual and policy framework that targets important aspects of health information. Some of the information and direction will be derived from a February 9, 2010 Populations Workshop where participants will consider ways existing and new	The Committee will review key themes from its most recent letters and reports pertaining to Industry Preparations for the Updated HIPAA Standards and Code Sets; Meaningful Measurement of Quality Care; Health	Health Measurement and Contributing Factors NCVHS Population Health Subcommittee Meeting Information Needs for Health and Health Care National Center for Health Statistics February 9, 2010

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
		Subcommittees— Standards and Security, Population Health, Privacy and Confidentiality, and Quality are all contributing to the report, which will be a cornerstone for the NCVHS 60 th Anniversary Celebration/Symposium in, June 2010.	information resources can: 1) inform policy regarding health and health care 2) improve the operations of the health care system. NCVHS is also seeking to ensure that as improvements in electronic health/medical records and breakthroughs in medical technology occur, that simultaneously, tools should be available to monitor the health of the population.	Data Stewardship; and Protection of the Privacy and Security of Individual Health Information in Personal Health Records.	www.ncvhs.hhs.gov/1002 09p3.pdf
National Health Service (NHS) - Connecting for Health	Secondary Uses Service (SUS) www.connectingfor health.nhs.uk/syste msandservices/sus/ index_html	The single repository of person and care event level data relating to the NHS care of patients, which is used for the following secondary use purposes: healthcare planning, commissioning, public health, clinical audit, benchmarking, performance improvement, research and clinical governance	Primary benefits of SUS: Consistency of data collection and analysis across the country Comprehensive coverage of data collection Cohesion of information collection enabling the linkage of patient data across primary, community and acute care settings Timeliness of data which, in time, would be collated directly from local sources A secure environment where patient confidentiality is maintained Increased ability for sharing (of aggregated data) for comparative purposes Common approach to derivation of data	Principles for SUS: There is one national approach to the SUS; User access is managed through the security and confidentiality facilities embedded within NHS CRS; Information provided through the SUS will be anonymized or pseudonymized to remove information that could be used to identify individuals but still allow cases to be tracked and linked for research; Data will, where possible, be collected or derived from clinical systems as a by-product of direct care; SUS will include the tools and services for an	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				effective and secure working environment for analysis and reporting.	
National Institutes of Health (NIH)	Patient-Reported Outcomes Measurement Information System (PROMIS) www.nihpromis.org	Establishes a collaborative relationship between NIH and individual research teams in order to create a publicly available system that allows clinical researchers to access a common repository of items and computerized adaptive tests.	An initiative that aims to revolutionize the way patient-reported outcome tools are selected and employed in clinical research and practice evaluation. It will also establish a national resource for accurate and efficient measurement of patient-reported symptoms and other health outcomes in clinical practice.	Specific Research Objectives: Develop a core set of questions Develop common metrics Create item banks using modern measurement theory Develop computer-adapted tests Create a Web-based, user-friendly repository Plan to maximize acceptance Conduct feasibility studies Plan for a public-private partnership	

Managing Privacy, Security and Confidentiality Resources

American Health Information Community, Recommendations Presented at the September 2008 AHIC Meeting; September 23, 2008. http://archive.healthit.hhs.gov/portal/server.pt/gateway/PTARGS_0_869128_0_0_18/all_materials.pdf

Bloomrosen M, Detmer D. "Advancing the Framework: Use of Health Data -- A Report of a Working Conference of the American Medical Informatics Association" J Am Med Inform Assoc. 2008;15:715-722. http://jamia.bmj.com/content/15/6/715.abstract

Dimitropoulos, L. and Rizk, S. A State-Based Approach To Privacy And Security For Interoperable Health Information Exchange. Health Affairs, March/April 2009; 28(2): 428-434.

http://content.healthaffairs.org/cgi/content/abstract/28/2/428?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=A+State-Based+Approach+To+Privacy+And+Security+For+Interoperable+Health+Information+Exchange&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

Greenberg, M. D., Ridgely, M. S., and Hillestad, R. J., Crossed Wires: How Yesterday's Privacy Rules Might Undercut Tomorrow's Nationwide Health Information Network.

Health Affairs, March/April 2009; 28(2): 450-452.

http://content.healthaffairs.org/cgi/content/abstract/28/2/450?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=Crossed+Wires%3A+How+Yesterday%92s+Privacy+Rules+Might+Undercut+Tomorrow%92s+Nationwide+Health+Information+Network.&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

Kendall, David B. Protecting Patient Privacy Through Health Record Trusts. Health Affairs, March/April 2009; 28(2): 444-446. <a href="http://content.healthaffairs.org/cgi/content/abstract/28/2/444?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=Protecting+Patient+Privacy+Through+Health+Record+Trusts&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

McDonald, Clement. Protecting Patients In Health Information Exchange: A Defense Of The HIPAA Privacy Rule. Health Affairs, March/April 2009; 28(2): 447-449.

http://content.healthaffairs.org/cgi/content/abstract/28/2/447?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=Protecting+Patients+In+Health+Information+Exchange%3A+A+Defense+Of+The+HIPAA+Privacy+Rule&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

McGraw, D., Dempsey, J. X., Harris, L., and Goldman, J. Privacy As An Enabler, Not An Impediment: Building Trust Into Health Information Exchange. Health Affairs, March/April 2009; 28(2): 416-427.

http://content.healthaffairs.org/cgi/content/abstract/28/2/416?maxtoshow=&hits=25&RESULTFORMAT=&fulltext=McGraw%2C+D&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

Rinehart-Thompson LA, Hjort BM, Cassidy BS. "Redefining the Health Information Management Privacy and Security Role" Perspectives in Health Information Management 6, Summer 2009. <a href="http://perspectives.ahima.org/index.php?option=com_content&view=article&id=146:redefining-the-health-information-management-privacy-and-security-role&catid=47:privacy-and-security<emid=91

Tripathi, M., Delano, D., Lund, B., and Rudolph, L. Engaging Patients For Health Information Exchange. Health Affairs, March/April 2009; 28(2): 435-443. 10.1377/hlthaff.28.2.435

http://content.healthaffairs.org/cgi/content/abstract/28/2/435?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=Patients+For+Health+Information+Exchange&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

Blumenthal, D. Stimulating the Adoption of Health Information Technology. The New England Journal of Medicine, April 9, 2009 http://content.nejm.org/cgi/content/full/360/15/1477)

McClanahan, K. Balancing Good Intentions: Protecting the Privacy of Electronic Health Information. Bulletin of Science, Technology & Society, Vol. 28, No. 1, 69-79 (2008). DOI: 10.1177/0270467607311485 http://bst.sagepub.com/cgi/content/short/28/1/69

Burnham, K. The Effects of Experience with a Technology on Privacy Concerns and Disclosure of Health Information. Georgia Institute of Technology Thesis. May 2008. http://hdl.handle.net/1853/21831

Marilyn S. Fetter, PhD, PMHCNS-BC†. Issues in Mental Health Nursing: Electronic Health Records and Privacy. 2009, Vol. 30, No. 6, Pages 408-409, DOI 10.1080/01612840802601374 http://www.informaworld.com/smpp/content~db=all~content=a911995471

Marilyn S. Fetter. Personal Health Records: Protecting Behavioral Health Consumers' Rights. Issues in Mental Health Nursing, Jan 2009, Vol. 30, No. 11, Pages 720-722. http://www.informaworld.com/smpp/content~db=all~content=a916181421

Andres D. Molina, Mastooreh Salajegheh, and Kevin Fu. Conference on Computer and Communications Security Proceedings of the first ACM workshop on Security and privacy in medical and home-care systems. Chicago, Illinois, USA SESSION: Data access and control table of contents Pages: 21-30. 2009 ISBN:978-1-60558-790-5

R. B. Ness. Influence of the HIPAA privacy rule on health research. JAMA, 18(298):2164-- 2170, 2007. http://jama.ama-assn.org/cgi/content/abstract/298/18/2164

L. Ricciardi and A. Rubel. Encouraging the use of, and rethinking protections for deidentified (and "anonymized") health data. http://www.cdt.org/paper/encouraging-use-and-rethinking-protections-de-identified-and-anonymized-health-data

Daniel J. Weitzner . Communications of the ACM: Organic user interfaces Volume 51 , Issue 6 (June 2008). Ppg. 82-87. 2008. ISSN:0001-0782 http://portal.acm.org/citation.cfm?id=1349026.1349043&coll=ACM&dl=ACM&idx=J79&part=magazine&WantType=Magazines&title=Communications%2 0of%20the%20ACM&CFID=84261675&CFTOKEN=83144442

Lisa M. Lee, PhD; Lawrence O. Gostin, JD. Ethical Collection, Storage, and Use of Public Health Data: A Proposal for a National Privacy Protection. JAMA. 2009;302(1):82-84. http://jama.ama-assn.org/cgi/content/short/302/1/82

Nicole Lurie and Allen Fremont. Building Bridges Between Medical Care and Public Health. JAMA. 2009;302(1):84-86. http://jama.ama-assn.org/cgi/content/short/302/1/84

Marc A. Rodwin. The Case for Public Ownership of Patient Data. JAMA. 2009;302(1):86-88. http://jama.ama-assn.org/cgi/content/short/302/1/86

Lawrence O. Gostin, JD; Sharyl Nass, PhD. Reforming the HIPAA Privacy Rule. Safeguarding Privacy and Promoting Research. JAMA. 2009;301(13):1373-1375. http://jama.ama-assn.org/cgi/content/extract/301/13/1373

Robert Steinbrook, M.D. Health Care and the American Recovery and Reinvestment Act. Volume 360:1057-1060 March 12, 2009 Number 11. http://content.nejm.org/cgi/content/full/360/11/1057

Julie Myers 1, Thomas R. Frieden 1*, Kamal M. Bherwani 1, Kelly J. Henning 1. Privacy and Public Health at Risk: Public Health Confidentiality in the Digital Age. New York City Department of Health and Mental Hygiene http://ajph.aphapublications.org/cgi/content/short/98/5/793

Linda Dimitropoulos and Stephanie Rizk. A State-Based Approach To Privacy And Security For Interoperable Health Information Exchange. Health Affairs, March/April 2009; 28(2): 428-434. http://content.healthaffairs.org/cgi/content/abstract/28/2/428

Privacy Protection and Technology Diffusion: The Case of Electronic Medical Records Source Management Science archive. Volume 55, Issue 7 (July 2009) table of contents. Ppg. 1077-1093. 2009. ISSN:0025-1909 http://mansci.journal.informs.org/cgi/content/abstract/55/7/1077

Markle Foundation and Center for Democracy and Technology. HITECH Breach Notification for Unsecured Protected Health Information Rulemaking. Letter to HHS 10/2009. RIN 0991-AB56. www.markle.org/downloadable_assets/20091027 cdtmarklecomments.pdf

McGraw, Deven. Center for Democracy and Technology. Health Information Privacy: Current Trends, Future Opportunities. Testimony at FTC Roundtable. (March 2010). http://www.cdt.org/comments/health-information-privacy-current-trends-future-opportunities

Overview of Key Initiatives Privacy, Security and Confidentiality

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
American Health Information Community (AHIC) – Now National eHealth Collaborative (NeHC)	Confidentiality, Privacy & Security workgroup www.hhs.gov/healthit/ahic/confidentiality www.nationalehealth.org	A workgroup focused on developing recommendations to ensure the confidentiality, privacy, and security of individually identifiable health information in an electronic health information exchange environment.	Broad Charge: Make recommendations to the Community regarding the protection of personal health information in order to secure trust, and support appropriate interoperable electronic health information exchange. Specific Charge: Make actionable confidentiality, privacy, and security recommendations to the Community on specific policies that best balance the needs between appropriate information protection and access to support, and accelerate the implementation of the consumer empowerment, chronic care, and electronic health record related breakthroughs.	Workgroup will address the following issues: Methods of patient identification Methods of authentication Methods for securing data Methods for securing access to health information Policies for breach of health information Guidelines and processes to determine appropriate secondary uses of information A scope of work for a long-term independent advisory body on privacy and security issues.	Now National eHealth Collaborative (NeHC)
American Medical Informatics Association (AMIA)	Invitational Conference on Secondary Use of Health Data http://www.amia.org/inside/initiatives/healthdata/	AMIA initiated three technical working groups that informed the larger gathering in order to develop a comprehensive taxonomy of use and users of secondary health data, to	Develop a national framework for the secondary use of health data that includes: • A taxonomy	Data Stewardship Principles 1. Accountability (including governance,	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
	2007/index.asp	review technologies that are used to de-identify data sets and re-identify data sets of "anonymous" data, and to define data stewardship and related policy issues.	describing types of uses and users of health data • Guiding principles that balance the risk, sensitivity, benefits, obligations, and protections of various uses of health data • Clarifications of terminology associated with various uses of health data	oversight, and level of applicable regulations) 2. Openness and transparency (including structure, processing and delivery of data, and business processes and practices) 3. Notice to patients 4. Privacy and security (including data quality, deidentification, and costs of reidentification) 5. Granularity of patient consent 6. Permitted uses and disclosures (including data aggregation and analyses) 7. Enforcement and remedies	
Connecting for Health – Markle Foundation	The Common Framework www.connectingforhealt h.org/commonframework	A comprehensive resource of policy and technical specifications intended to help health information systems share information.	A new infrastructure for health information sharing will provide the foundation for a transformed, 21 st century healthcare system in which patients and families can better understand their own health and engage more fully in their care through direct access to their	Policy Principles: 1. Openness and transparency 2. Purpose specification and minimization 3. Collection limitation 4. Use limitation 5. Individual participation and control	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
			own health information.	 Data integrity and quality Security safeguards and controls Accountability and oversight Legal and financial remedies Technology Principles: Make it "Thin" Avoid "Rip and Replace" Separate Applications from the Network Decentralization Federation Flexibility Privacy and Security Accuracy 	
Consumer Coalition for Health Privacy	www.healthprivacy.org/homepage2307/index.htm/	A diverse network of patient, disability and consumer advocacy organizations actively engaged in the national and local debate on health privacy.	To inform and empower the consumer community, including the disabled and those with serious illnesses, to more fully engage in the national and local debate on health privacy.	Principles – Committed to the development and enactment of public policies and private standards that: • Guarantee the confidentiality of personal health information • Promote both access to high quality care and the continued viability of medical research.	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
Health Privacy Project	www.healthprivacy.org	An organization dedicated to raising public awareness on the importance of ensuring health privacy.	To raise public awareness of the importance of ensuring health privacy in order to improve health care access and quality, both on an individual and a community level.	Principles (as identified in the Best Principles for Health Privacy report): • For all uses and disclosures of health information, health care organizations should remove personal identifiers to the fullest extent possible, consistent with maintaining the usefulness of the information. • Privacy protections should follow the data. • An individual should have the right to access his or her own health information and the right to supplement such information. • Individuals should be given notice about the use and disclosure of their health information and their rights with regard to that information. • Health care organizations should implement security safeguards for the	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				disclosure of health	
				information.	
				 Personally 	
				identifiable health	
				information should	
				not be disclosed	
				without patient	
				authorization,	
				except in limited	
				circumstances.	
I				 Health care 	
				organizations should	
				provide patients with	
				certain choices	
				about the use and	
				disclosure of their	
				health information.	
				 Health care 	
				organizations should	
				establish policies	
				and review	
				procedures	
				regarding the	
				collection, use, and	
				disclosure of health	
				information.	
				Health care	
				organizations should	
				use an objective and	
				balanced process to	
				review the use and	
				disclosure of	
				personally	
				identifiable health	
				information for	
				research.	
				Health care	
				organizations should	
				not disclose	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				personally identifiable health information to law enforcement officials, absent a compulsory legal process, such as a warrant or court order. Health privacy protections should be implemented in such a way as to enhance existing laws prohibiting discrimination. Strong and effective remedies for violations of privacy protections should be established.	
National Consumers League	www.nclnet.org	A non-profit advocacy group whose mission is to identify, protect, represent, and advance the economic and social interests of consumers.		Health Information Privacy Policies: Right to privacy Informed consent and notice Security safeguards and penalties Individual right to access Right to private access Research access Education Consumer information programs	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
Office of National Coordinator (ONC), AHRQ, Research Triangle Institute (RTI)	Health Information Security and Privacy Collaboration (HISPC) Toolkit www.rti.org/hispc	The toolkit provides guidance for conducting organization-level assessments of business practices, policies, and state laws that govern the privacy and security of health information exchange.	To create long-lasting collaborative networks in states and communities to support future work and inform future health information exchange activities.	Obtaining Interoperable HIE: 1. Identify the variations in organization-level business privacy and security policies and practices and state laws that affect electronic HIE. 2. Engage stakeholders in discussions where they can come to agreement on the common and necessary elements of current practices that will need to be retained and to identify gaps in current protections that are inadequate to cover the requirements for electronic HIE. 3. Identify the policy or legal driver or other underlying rationale for the current practice and work toward identifying consensus-based solutions.	Health Information Security and Privacy Collaboration (HISPC) Provider Education Toolkit Final Report and Implementation Guide (3/31/2009): http://healthit.hhs.gov/p ortal/server.pt/gateway/ PTARGS 0 10779 87 2235 0 0 18/PET 3 F inal Rpt with all app.p df Health Information Security and Privacy Collaboration (HISPC) User Guide: Private Entity Data Sharing Agreement (3/31/2009): http://healthit.hhs.gov/p ortal/server.pt/gateway/ PTARGS 0 10741 87 3998 0 0 18/IOA 2 D SA Private.doc Health Information Security and Privacy Collaboration (HISPC) RTI International HISPC Website: http://www.rti.org/page. cfm?objectid=09E8D49 4-C491-42FC- BA13EAD1217245C0

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				4. Develop a plan to implement the solutions.5. Work through the implementation process, collaborating openly with stakeholders.	
Patient Privacy Rights Foundation (PPR)	Patient Privacy Rights www.patientprivacyrights .org	A national consumer watchdog organization whose mission is to empower Americans to protect and preserve their human rights to medical privacy.	PPR aims to guarantee that all Americans control access to their health records. The mission of PPR is to ensure consumers' rights to control their medical privacy, to protect their jobs and opportunities. PPR's vision is to be the premier guardian and advocate for health privacy rights.	The following Patient Privacy Principles should be included in all Health IT legislation: Recognize that patients own their health data Give patients control over who can access their electronic health records Give patients the right to opt-in and opt-out of electronic systems Give patients the right to segment sensitive information Require audit trails of every disclosure of patient information Require that patients be notified of suspected or actual privacy breaches	PPR created a Report Card on Personal Health Records (PHRs) and graded a number of PHRs available today. PPR did its best to decode PHR privacy policies and spell out what control consumers have over their information. PPR makes no recommendations on specific PHRs. The Report Card is PPR's opinion based on the information available on PHR vendors' websites. PPR utilized the following grading scale: • A (4.0-5.0) – Excellent: No invasive practices; solid protections; ensures consumers' privacy rights; user friendly. • B (3.1-3.9) – Fairly

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				 Provide meaningful penalties and enforcement for privacy violations Require that health information disclosed for one purpose may not be used for another purpose without informed consent Insure that consumers can not be compelled to share electronic health records to obtain employment, insurance, credit, or admission to schools Deny employers access to employees' medical records Preserve stronger privacy protections in state la 	comprehensive efforts and protections; room for improvement. • C (2.6-3.0) – Some safeguards, a number of key flaws, weak protections • D (2.0-2.5) – Few, if any, safeguards and protections, and/or misleading information, and/or very user "un- friendly." • F (1.0-1.9) – Threatens patient privacy and control over personal information either via inaction or actual business practices. (http://patientprivacyrig hts.org/personal-health- records/)

Transforming Care Delivery at the Point of Care Resources

21st-Century Health Care: The Effect of Computer Use by Physicians on Patient Satisfaction at a Family Medicine Clinic; Fam Med 2002;34(5):362-8.

A Big Stimulus Boost for Electronic Health Records; Technology Review, February 20, 2009.

A care revolution. Interview by Lynne Pearce; Nurs Stand. 2009 Feb 18-24;23(24):19-21.

A Systematic Approach Optimization of Healthcare Operations with Knowledge Management. JHIM. November 2009.

A Team Effort; The CIO and CMIO at Orlando Health make sure doctors are involved in I.T.; Health Data Management, 34, Vol.17, No.12.

A Virtual Medical Record for Guideline-Based Decision Support; Proc AMIA Symp. 2001:294-8.

Assessing HIE Stakeholder Readiness for Consumer Access Lessons Learned from the NHIN Trial Implementations. JHIM. November 2009.

Building a National Health IT System from the Middle Out; Journal of the American Medical Informatics Association Volume 16 Number 3 May / June 2009.

Clinical Decision Support: How CDS Tools Impact Patient Care Outcomes. JHIM, Winter 2009.

Clinical Information Systems: Challenges in IT Enhancements and Functionality. JHIM, Spring 2009.

Community-wide Implementation of Health Information Technology: The Massachusetts eHealth Collaborative Experience; Journal of the American Medical Informatics Association Volume 16 Number 1 January / February 2009.

Does Computerized Provider Order Entry Reduce Prescribing Errors for Hospital Inpatients? A Systematic Review; Journal of the American Medical Informatics Association Volume 16 Number 5 September / October 2009.

Double-Edged Sword When It Comes to ARRA, the Devil is in the Details, JHIM, November 2009.

Evolving health information technology and the timely availability of visit diagnoses from ambulatory visits: A natural experiment in an integrated delivery system; BMC Med Inform Decis Mak. 2009 Jul 17;9:35.

Health Information Exchange and Healthcare Utilization; J Med Syst. 2009 Jun;33(3):223-31.

Health Information Technology And Patient Safety: Evidence From Panel Data; Health Affairs, 28, no. 2 (2009): 357-360.

HIMSS Adoption Model, HIMSS 2008 Market Report, HIMSS Ambulatory survey. See attached deck on HITECH and EHR Adoption.

HIMSS Clinical Informatics Insight, November 2009.

HIT Incentives - Rock and a Hard Place. PricewaterhouseCoopers, Health Research Institute, 2009.

Interoperability: The Key To The Future Health Care System; J Med Syst. 2009 Jun;33(3):223-31.

IT & Clinical Workflow, Feb 2008.

Journey to Stage 7 Nursing Adoption: Where Do Hospitals Go from Here?, JHIM, November 2009.

Key Interoperability Issues Associated with Information Exchange. JHIM. November 2009.

Lang, R.D. Personal Health Records: Ready for Prime Time? J Healthc Inf Manag. 2009 Summer;23(3):2-4.

Nursing Admissions Process Redesigned to Leverage EHR, J Healthc Inf Manag. 2006 Spring;20(2):55-64.

Personal Touch Personal Health Records for Consumers of Healthcare. JHIM. November 2009.

Reactive to Adaptive: Transforming Hospitals with Digital Technology. March 2005

The Care and Feeding of Clinical Information Systems: Challenges in IT Enhancements and Functionality; Journal of Health Information Management; Spring 2009 volume 23 / Number 2.

The impact of health information technology on the quality of medical and health care: a systematic review; HIM J. 2009;38(3):26-37.

The Pen is the Tongue of the Mind Developing a Strategy For Computerizing Provider Documentation. JHIM, Summer 2009.

The Value Of Health Care Information Exchange And Interoperability; Health Aff (Millwood). 2005 Jan-Jun; Suppl Web Exclusives: W5-10-W5-18.

Transforming Care in the Physician Workplace Through Electronic Data Exchange; N C Med J March/April 2008, Volume 69, Number 2.

U.S. Health Industry Provider 2009 Top 10 Predictions: The Changing IT Landscape for Healthcare Providers, Health Industry Insights.

Use of an Electronic Medical Record Improves the Quality of Urban Pediatric Primary Care; Pediatrics 2003;111;626-632.

Using Computerized Provider Order Entry and Clinical Decision Support to Improve Referring Physicians' Implementation of Consultants' Medical Recommendations; Journal of the American Medical Informatics Association Volume 16 Number 2 March / April 2009.

Vision Quest: Can the Obama Stimulus Plan Break Health IT's Gridlock?, JHIM, November 2009.

What's Delaying Digital Health Records?; Technology Review, September 2008.

While preparing to adopt or expand electronic records, providers shouldn't overlook the quality of the data these systems will contain. Hospital and Health Networks.

IDC Predictions. U.S. Health Industry Provider 2009 Top 10 Predictions: The Changing IT Landscape for Healthcare Providers, Health Industry Insights.

HIMSS. HIMSS Adoption Model, HIMSS 2008 Market Report, HIMSS Ambulatory survey.

JHIM. Journey to Stage 7 Nursing Adoption: Where Do Hospitals Go from Here?, JHIM November 2009

PwC and JHIM. HIT Incentives - Rock and a Hard Place, PwC Health Research Institute, 2009.

PwC and JHIM. Double-Edged Sword When It Comes to ARRA, the Devil is in the Details, JHIM, November 2009.

PwC and JHIM. Vision Quest Can the Obama Stimulus Plan Break Health IT's Gridlock?, JHIM, November 2009.

Mercom HIT Report. Mercom HIT report

JHIM. Clinical Decision Support: How CDS Tools Impact Patient Care Outcomes. JHIM WINTER 2009 volume 23 / Number 1.

JHIM. Clinical Information Systems Challenges in IT Enhancements and Functionality. JHIM* SPRING 2009 * volume 23 / Number 2

Clinical Informatics Insights. HIMSS Clinical Informatics Insight, November 2009.

JHIM. The Pen is the Tongue of the Mind Developing a Strategy For Computerizing Provider Documentation, JHIM, Summer 2009, volume 23 / Number 3.

BMC Medical Informatics and Decision Making. Evolving health information technology and the timely availability of visit diagnoses from ambulatory visits: A natural experiment in an integrated delivery system; BMC Med Inform Decis Mak. 2009 Jul 17;9:35.

JHIM. Personal Health Records Ready for Prime Time?

Family Medicine. 21st-Century Health Care: The Effect of Computer Use by Physicians on Patient Satisfaction at a Family Medicine Clinic; Fam Med 2002;34(5):362-8

Health Affairs Interoperability: The Key To The Future Health Care System; J Med Syst. 2009 Jun;33(3):223-31.

Health Affairs The Value Of Health Care Information Exchange And Interoperability; Health Aff (Millwood). 2005 Jan-Jun; Suppl Web Exclusives: W5-10-W5-18.

JHIM. Assessing HIE Stakeholder Readiness for Consumer Access: Lessons Learned from the NHIN Trial Implementations, JHIM November 2009.

JHIM. Personal Touch Personal Health Records for Consumers of Healthcare, JHIM November 2009.

JHIM. Interoperability of Electronic Health Records and Personal Health Records Key Interoperability Issues Associated with Information Exchange, JHIM, November 2009 Health Information Management Journal. The impact of health information technology on the quality of medical and health care: a systematic review; HIM J. 2009;38(3):26-37.

JHIM. A Systematic Approach Optimization of Healthcare Operations with Knowledge Management, JHIM, November 2009.

JHIM. Data Challenges on the EHR Agenda By John Glaser

HIMSS Vantage Point. IT & Clinical Workflow. Feb 2008

Journal of Healthcare Information Management. Nursing Admissions Process Redesigned to Leverage EHR, J Healthc Inf Manag. 2006 Spring;20(2):55-64.

Journal of Medical Systems. Health Information Exchange and Healthcare Utilization; J Med Syst. 2009 Jun;33(3):223-31.

Nursing Standard. A care revolution. Interview by Lynne Pearce; Nurs Stand. 2009 Feb 18-24;23(24):19-21.

Pediatrics. Use of an Electronic Medical Record Improves the Quality of Urban Pediatric Primary Care; Pediatrics 2003;111;626-632.

PwC Health Research Institute. Reactive to Adaptive: Transforming Hospitals with Digital Technology. March 2005
Proceedings / AMIA: A Virtual Medical Record for Guideline-Based Decision Support; Proc AMIA Symp. 2001:294-8.

Health Affairs. Health Information Technology And Patient Safety: Evidence From Panel Data; Health Affairs, 28, no. 2 (2009): 357-360

North Carolina Medical Journal. Transforming Care in the Physician Workplace Through Electronic Data Exchange; N C Med J March/April 2008, Volume 69, Number 2

Health Data Management. A Team Effort; The CIO and CMIO at Orlando Health make sure doctors are involved in I.T.; Health Data Management, 34, Vol.17, No.12

JAMIA. Building a National Health IT System from the Middle Out; Journal of the American Medical Informatics Association Volume 16 Number 3 May / June 2009

JAMIA. Does Computerized Provider Order Entry Reduce Prescribing Errors for Hospital Inpatients? A Systematic Review; Journal of the American Medical Informatics Association Volume 16 Number 5 September / October 2009

JAMIA. Community-wide Implementation of Health Information Technology: The Massachusetts eHealth Collaborative Experience; Journal of the American Medical Informatics Association Volume 16 Number 1 January / February 2009

JAMIA. Using Computerized Provider Order Entry and Clinical Decision Support to Improve Referring Physicians' Implementation of Consultants' Medical Recommendations; Journal of the American Medical Informatics Association Volume 16 Number 2 March / April 2009

JHIM. The Care and Feeding of Clinical Information Systems: Challenges in IT Enhancements and Functionality; Journal of Health Information Management; Spring 2009 volume 23 / Number 2

JHIM. Clinical Decision Support: How CDS Tools Impact Patient Care Outcomes; Journal of Health Information Management; volume 23 / number 1 Winter 2009

Technology Review. A Big Stimulus Boost for Electronic Health Records; Technology Review, February 20, 2009.

Technology Review. What's Delaying Digital Health Records?; Technology Review, September 2008.

CHIME: Survey finds Healthcare CIOs Concerned about Proposed Meaningful Use Standards; August 2009

CHIME Statement for the Record to the National Committee on Vital and Health Statistics on Meaningful Use of Health IT; April 2009

HIMSS. HIMSS Healthcare Information Exchange National / International Technology Guide White Paper; April 2009

Health Affairs. Costs And Benefits Of Health Information Technology: New Trends From The Literature; Health Affairs, January 2009

Health Affairs. From Tasks to Processes: The Case for Changing Health Information Technology to Improve Healthcare; Health Affairs, March/April 2009

Kern, LM, Barron, Y, Abramson, EL, Patel, V, Kaushal, R. Health Affairs. HEAL NY: Promoting Interoperable Health Information Technology in New York State; Health Affairs, March/April 2009

 $\underline{\text{http://content.healthaffairs.org/cgi/content/abstract/28/2/493?maxtoshow=\&hits=10\&RESULTFORMAT=\&fulltext=HEAL+NY\&andorexactfulltext=and\&searchid=1\&FIRSTINDEX=0\&resourcetype=HWCIT}$

Health Affairs. Health Information Technology: Strategic Initiatives, Real Progress; Health Affairs, August 2008

Health Affairs. Personal Health Management Systems: Applying The Full Power Of Software To Improve The Quality And Efficiency Of Care; Health Affairs, March/April 2009

Overview of Key Initiatives Transforming Care Delivery

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
American Academy of Family Physicians (AAFP)	Center for Health Information Technology www.centerforhit.org	An arm of the AAFP that promotes and facilitates the adoption and optimal use of health IT by AAFP members and other office-based clinicians.	To increase the availability and use of low-cost, standards-based information technology among family physicians.	Principles:AffordabilityCompatibilityInteroperabilityData stewardship	
AAFP	TransforMED www.transformed.com	An AAFP-sponsored initiative focused on redesign of care delivery to a patient-centered model of care.	 Develop highperformance family medicine practices through a transformative process of practice redesign focused on patient care and practice team satisfaction Generate transportable new knowledge about the practice transformation process Generate means to allow for the continued financial viability of the organization 	Core Components of the TransforMED Model of Care: Team approach Comprehensive practice offering (e.g., DM, wellness) Open access to care Advanced, data-based information systems (compliant w/ AAFP ChiT guidelines) Redesigned, more functional and efficient offices Patient access to information Emphasis on quality and safety Enhanced practice management	
American College of Physicians (ACP)	Adoption Road Map and Tools Medical Home Builder Tool	A road map and tools to assist College members at each stage in the adoption process.	Integration of EHRs into clinical practice will provide the tools for improving practice	Tools for each stage of adoption: • I investigation	EHR Road Map tool still available. In 2008, released the EHR Partners Program, an

eHealth Initiative: National Progress Report on eHealth
July 2010
Page 98

Source / Reference Init	itiative	Summary	Goals	Strategy / Principles / Tools	Updates
	p://www.acponline.org/p c/l.htm	Tool provides on-line guidance for practices involved in incremental quality improvement changes or significant practice transformations.	efficiency and clinical quality over time. Define and implement policies and procedures Determine if patients are having difficulty following a care plan Provide training to staff and clinicians on cultural competency and health literacy Facilitate coordination of visits to other clinicians or for procedures/tests Track laboratory tests and imaging procedures Use health information technology to identify patients who need clinical interventions	 Selection and Purchase Installation – Getting the I up and running Basic implementation – Achieving base I functionality Enhanced implementation – Exploiting I into the future Tool guides practices through a process for evaluating their practice in seven different areas: Patient-Centered Care & Communication Access & Scheduling Organization of Practice Care Coordination & Transitions in Care Use of Technology Population Management Quality Improvement & Performance Improvement The tool also provides a crosswalk to the National Committee for Quality Assurance (NCQA) standards and elements. 	EHR comparison tool available to ACP members. As of April 2009, the comparison tool included information on 22 CCHIT-certified EHRs, with information that can be sorted and viewed based on desired characteristics. Plans to launch the AmericanEHR Partners Program (developed in partnership with Cientis Technologies), which is an enhanced version of the existing Partners Program. It will enable physicians, practice administrators, and other healthcare professionals to review information on certified HER systems based on functionality, security, interoperability, and meaningful use criteria. www.acponline.org/ehr partners With the help of specialty societies, AmericanEHR Partners will also enable practices to identify systems that provide content and features

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
					best suited to a particular specialty.
Bridges to Excellence (BTE)	Physician Office Link www.bridgestoexcellence.org/programs/pol.mspx	An employer-based incentive program that promotes physician office use of health IT.	Physician practices implement information systems to improve communications and reduce medical errors.	 Assess the use of evidence-based standards of care, maintenance of patient registries for the purpose of identifying and following-up with atrisk patients and provision of educational resources to patients. Assess whether practices use electronic systems to maintain patient records, provide decision support, enter orders for prescriptions and lab tests and provide patient reminders. Assess whether a practice's electronic systems interconnect and whether they are interoperable with other systems, whether they use nationally accepted medical code sets and whether they can automatically send, receive and integrate data such as lab results and medical 	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				histories from other organizations' systems.	
Centers for Medicare & Medicaid Services (CMS)	Doctor's Office Quality – IT (DOQ-IT) www.cms.hhs.gov/Physicia nFocusedQualInits/05_PFQ IDOQ.asp#TopOfPage	A national initiative that promotes the adoption of EHRs and health IT in small adult primary care practices	Support I adoption, improved care management processes and electronic reporting of quality data in 5% of small practices in each state.	 Provide hands-on technical assistance to support I adoption Using a QI framework, support care process and workflow redesign for effective use of EHRs Enable ongoing provider management of patient-population health 	Meaningful Use: Worked with ONC to publish a notice of proposed rulemaking (NPRM), describing how hospitals, physicians, and other health care professionals can qualify for billions of dollars of extra Medicare and Medicaid payments through the meaningful use of EHRs.
Connecting for Health – Markle Foundation	The Common Framework www.connectingforhealth.or g/commonframework	A framework consisting of a set of mutually-reinforcing technical documents and specifications, testing interfaces, code, privacy and security policies, and model contract language intended to help health information systems share information.	A new infrastructure for health information sharing will provide the foundation for a transformed, 21st century healthcare system in which patients and families can better understand their own health and engage more fully in their care through direct access to their own health information.	Policy Principles: 1. Openness and transparency 2. Purpose specification and minimization 3. Collection limitation 4. Use limitation 5. Individual participation and control 6. Data integrity and quality 7. Security safeguards and controls 8. Accountability and oversight 9. Legal and financial remedies	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
The Dossia Founders Group (including large	Dossia Network	An infrastructure designed to gather and	To empower individuals to manage	Technology Principles: 1. Make it "Thin" 2. Avoid "Rip and Replace" 3. Separate Applications from the Network 4. Decentralization 5. Federation 6. Flexibility 7. Privacy and Security 8. Accuracy Dossia's framework will possess the following	With the Dossia Personal Health Record
employers such as Wal- Mart, Intel, BP America)	www.dossia.org	store personal health information for employees of participating employers.	their own health care, improve communications with their doctors, and ensure more complete and accurate information for health care providers.	features: Customizable – allowing consumers to organize and summarize their information in ways they find useful Privacy and security – accessible to the individual only Portability – consumers can access their information despite changing employers, health plans or doctors	Platform, employers are able to provide their employees with access to and control over their personal health information. Dossia further enables employers to costeffectively deliver a variety of employee benefits and wellness initiatives. By offering the Dossia Personal Health Record to employees, employers are enabling individuals to make good health decisions and to take action to improve their health and healthcare.
					Other features of Dossia's personal health record include:

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
The Leapfrog Group	Computer Physician Order	Adopted as a hospital	Leapfrog's CPOE	Building on the goals of	 Patient Info is prepopulated Professionally sourced data for dependents Open API One time identity verification to sign up for multiple data sources Lab data imported The Leapfrog Hospital
тие сеариод отоир	Entry (CPOE) Standard www.leapfroggroup.org/for_hospitals/leapfrog_safety_p_ractices/cpoe Leapfrog Hospital Recognition Program (LHRP) http://www.leapfroggroup.org/for_hospitals/fh-incentives_and_rewards/hosp_rewards_prog	safety standard to leverage major improvements in patient safety.	standard requires hospitals to: • Assures that prescribers enter hospital medication orders via a computer system that includes decision support software to reduce prescribing errors. • Demonstrates, via a test, that its inpatient CPOE system can alert physicians to at least 50% of common serious prescribing errors.	CPOE and LHRP	Recognition Program (LHRP) is intended to recognize and reward hospitals that demonstrate excellence or improvement in the performance areas of patient safety, quality, and resource utilization. The program uses the data captured in the Leapfrog Hospital Survey to evaluate hospital performance within the standardized, national measure set, composed of quality and resource utilization measures. These measures are weighted and rolled up into an overall efficiency score which is used to determine recognition

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
					and rewards levels.
National Committee for Quality Assurance (NCQA)	Physician Practice Connections http://web.ncqa.org/tabid/14 1/Default.aspx	A standards-based evaluation program that recognizes physician practices that use information systematically to enhance the quality of patient care.	Encourage physicians to adopt HIT for the following purposes: Monitor patients' medical histories Work with patients over time, not just during office visits Follow up with patients and with other providers Manage populations, not just individuals, using evidence- based care Assist patients to manage their own health better Avoid medical errors	PPC standards evaluate the following: Enabling patients to communicate with and access the practice easily Using systems to track patients, their treatments and conditions Managing patients' care proactively over time Supporting patients' self-management of their health Using electronic prescribing tools Tracking and following up lab and imaging tests Tracking and following up referrals Measuring performance and working to improve Updating to interoperable electronic systems	NCQA is currently in the process of evolving the standards in the PPC-PCMH, and we expect to adapt the standards for use in Accountable Care Organizations. The PPC-PCMH has been endorsed by the National Quality Forum as a measure to evaluate the use of HIT in a practice. Going beyond PPC-PCMH, we are translating existing HEDIS measures for use in EHRs, as well as creating a new generation of measures that more fully take advantage of the unique capabilities of EHRs.
ONC Department of Health and Human Services — Office of the National Coordinator	Health Information Technology for Economic and Clinical Health (HITECH) Act	The HITECH Act made fundamental change to the ONC and its mission	 Widespread adoption and meaningful use of EHR technology Enhance the 	Create a policy infrastructure: Creation of FACAs: HIT Policy Committee and HIT Standards	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
for Health Information Technology Http://healthit.hhs.gov			performance of the nation's healthcare system • Improve healthcare delivery and outcomes for all Americans	Committee Standards & Certification: Developing rules to ensure the security, interoperability, and functionality of health information technology. Published an interim final regulation (IFR) that describes the standards and certification criteria for EHRs. Intend to release a proposed rule on the certification program and process. Certification: Published rulemaking on the certification process for EHRs Privacy & Security: Strengthened existing privacy protections under the Health Insurance Portability and Accountability Act. Appointed Chief Privacy Officer to advise and coordinate with regard to the privacy, security, and data stewardship of electronic individually identifiable health information. Fund grant programs to	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				 Regional Extension Centers: Provide technical assistance to primary care and safety net providers in adopting and becoming meaningful users of health IT. State Health Information Exchange (HIE): Support state and state designated entities to develop HIE within and across jurisdictions. Workforce Training Programs: Support the education of up to 45,000 new HIT professionals, including curriculum development, competency examinations, and training. Beacon Communities: Create up to 15 demonstration communities to demonstrate how the meaningful use of EHRs can achieve measurable improvement in the quality and efficiency of health services in a given area. 	

Source / Reference	Initiative	Summary	Goals	Strategy / Principles / Tools	Updates
				Strategic Health Information Technology Advanced Research Projects (SHARP): Fund research focused on achieving breakthrough advances that promote the adoption of HIT. Other Initiatives: Nationwide Health Information Network (NHIN): Create a common platform for health information exchange across diverse entities, within communities, and across the country.	

APPENDIX B - COMMITTEE MEMBERS AND LEADERSHIP

Aligning Financial and Other Incentives

Member	Organization	Title
Amiee M. Adasczik	Pharmaceutical Research & Mfgs of America (PhARMA)	PhRMA
Michael Barr	American College of Physicians	VP of Practice Advocacy & Improvement
Julie Beard	3M	Federal Strategic Director
Camilla Hull Brown	Strategies for Tomorrow	
Leigh Burchell	Allscripts	
Jim Clifford	WellCentive, LLC	National Accounts Manager
Jeff Coughlin	WayPoint Advisors	Vice President, Government Relations
Peter Courtway	Danbury Hospital	
Molly Coye	CalRHIO	
Lou Diamond	Thomson Reuters	VP and Medical Director
Kevin Donnelly	College of American Pathologists	
Hank Fanberg (Co-Chair)	Christus Health	Manager of Research and Development
Thomas Fritz	Inland Northwest Health Services	Chief Executive Officer
Ezra Hanz	NextGen Management, LLC	Director of Marketing
Camilla Hull	Strategies for Tomorrow, Inc.	Principal
Michael Kappel	McKesson Provider Technologies	Senior Vice President of Government and Industry Relations
Ann Kitchen	Integrated Care Collaboration	Executive Director
Steven Labkoff	Pfizer, Inc.	Senior Director of Medical Affairs
Len Lichtenfeld	American Cancer Society	
Alex Low	New York eHealth Collaborative (NYeC)	Director of Programs
Trudi Matthews	HealthBridge	Director of Policy & Public Relations
Lorie Mayer	Arizona Healthcare Cost Containment System	Exec Consultant
Will Rice	Vanderbilt Center for Better Health: Regional Informatics	Sr. Consultant
Will Ross	Redwood MedNet	Project Manager
Mark Segal	General Electric Healthcare	Director of Government & Industry Affairs
Robert Tennant (Co-Chair)	Medical Group Management Association	Sr. Policy Advisor
Tom Unger	HEALTHeLINK	Program Director
Allison Viola	AHIMA	Director of Federal Relations
Afton Yurkon	National Association Of Chain Drug Stores	Manager, Pharmacy Technology Standards and Policy

Engaging Consumers

Member	Organization	Title
Rachel Block (Co-Chair)	New York State Department of Health	Deputy Commissioner
Camilla Hull Brown	Strategies for Tomorrow	
Jim Clifford	WellCentive, LLC	National Accounts Manager
Paul Cotton	AARP	Senior Legislative Representative
Peter Courtway	Danbury Hospital	
Lou Diamond	Thomson Reuters	VP and Medical Director
Kevin Donnelly	College of American Pathologists	
Hank Fanberg	Christus Health	Technology Advocacy
David Foster	Healthwise	Director Core Products
Leslie Kelly Hall	Healthwise	Senior VP
Jim Hansen	CareEntrust	CEO
Camilla Hull	Strategies for Tomorrow, Inc.	Principal
Joy Jacobsen	CareEntrust	Chief Privacy/Compliance Officer
Michael Kappel	McKesson Provider Technologies	Senior Vice President of Government and Industry Relations
Steven Labkoff	Pfizer, Inc.	Senior Director of Medical Affairs
John Lau	Maximus	Senior Vice President
Len Lichtenfeld (Co-Chair)	American Cancer Society	
George Margelis	Intel Corporation	Health Industry Manager
Shawn Myers	Healthwise	
Neal Neuberger	RCHN Community Health Foundation	Consultant
Charles Parker	Continua Health Alliance	Executive Director
Traci Parker	ICA Informatics Corp of America	Clinical Consultant
Eva Powell	National Partnership for Women & Families	Director, Health Information Technology Project
Helen Riehle	Vermont Program for Quality in HealthCare	Executive Director
Josh Seidman	Center for Information Therapy	President
Barbara Selter	Maximus	Vice President
Robert Tennant	Medical Group Management Association	Sr. Policy Advisor
Charlene Underwood	Siemens Corporation	
Tom Unger	HEALTHeLINK	Program Director
Andrew Wiesenthal	Kaiser Permanente	

Improving Population Health

Member	Organization	Title
Swati Abbott	MEDai, Inc.	President
Amiee M. Adasczik	Pharmaceutical Research & Mfgs of America (PhARMA)	PhRMA
Deborah Anderson	Chicago Dept of Public Health/NACCHO	Deputy CIO
Julie Beard	3M	Federal Strategic Director
Camilla Hull Brown	Strategies for Tomorrow	
Jim Clifford	WellCentive, LLC	National Accounts Manager
Jeff Coughlin	WayPoint Advisors	Vice President, Government Relations
Peter Courtway	Danbury Hospital	
Lou Diamond	Thomson Reuters	VP and Medical Director
Hank Fanberg	Christus Health	Technology Advocacy
Angela Franklin	American College of Emergency Physicians	AP
Jennifer Frost	CalRHIO	
Camilla Hull	Strategies for Tomorrow, Inc.	Principal
Michael Kappel Brian Keaton, MD, FACEP (Co-	McKesson Provider Technologies	Senior Vice President of Government and Industry Relations
Chair)	American College of Emergency Physicians	President Emeritus
Kraig Kinchen	Eli Lilly and Company	Director, Electronic Exchange of Healthcare Inform
Jim Kirkwood	ASTHO	Senior Director of e-Health
Len Lichtenfeld	American Cancer Society	
Peter Loupos	Sanofi-aventis	Vice President
Janet Marchibroda	IBM Corporation	Chief Healthcare Officer
George Margelis	Intel Corporation	Health Industry Manager
Michael Matthews	MedVirginia, LLC	Chief Executive Officer

J. Marc Overhage, MD, PhD (Co-

Chair) Indiana Health Information Exchange Chief Executive Officer and President

Charles Parker Continua Health Alliance Executive Director

Traci Parker ICA Informatics Corp of America Clinical Consultant

Priya Rajamani Minnesota Department Of Health Consultant

Vanderbilt Center for Better Health: Regional

Will Rice Informatics Sr. Consultant

Will Ross Redwood MedNet Project Manager

Melissa Rutala Arizona Health-e Connection Associate Director

Kim Salamone Health Services Advisory Group Executive Director, Health IT

Raymond Scott Axolotl Corporation Founder and Chief Executive Officer

Padma Taggarse Health Services Advisory Group Medical Informatics Specialist

Brad Tritle Arizona Health-e Connection

Mollie Shields Uehling SAFE-BioPharma Association President CEO

Allison Viola AHIMA Director of Federal Relations

Andrew Wiesenthal Kaiser Permanente

Managing Privacy, Security and Confidentiality

Member	Organization	Title
Paul Cotton	AARP	Senior Legislative Representative
Peter Courtway	Danbury Hospital	
Vicki Estrin	Vanderbilt University Medical Center & Vanderbilt Center for Better Health	Program Manager, Regional Informatics Programs
Mark Frisse (Co- Chair)	Vanderbilt University Medical Center & Vanderbilt Center for Better Health	Director, Regional Health Initiatives
Jennifer Frost	CalRHIO	
Rich Furr	SAFE-BioPharma Association	Head Global Reg Affairs and Chief Compliance Officer/CCO
David Hartzband	RCHN Community Health Foundation	Dir. Of Technology Research
Gerry Hinkley (Co-		
Chair)	Pillsbury Winthrop Shaw Pittman	Partner
Joy Jacobsen	CareEntrust	Chief Privacy/Compliance Officer
Michael Kannal	Mal/accan Drawiday Tachmalagias	Senior Vice President of Government and Industry
Michael Kappel	McKesson Provider Technologies	Relations
Jim Kirkwood	ASTHO	Senior Director of e-Health
Ann Kitchen	Integrated Care Collaboration	Executive Director
Peter Loupos	Sanofi-aventis	Vice President
Robert Marotta	HLTH Corporation / WebMD	Senior Vice President and Chief Regulatory Counsel
Lorie Mayer	Arizona Healthcare Cost Containment System	Exec Consultant
Harry Rhodes	AHIMA	Director of Practice Leadership
Will Ross	Redwood MedNet	Project Manager
Toby Sarver	Misys	Software Architect
Raymond Scott	Axolotl Corporation	Founder and Chief Executive Officer
Evan Smith	Eye Controls, LLC	President
Robert Tennant	Medical Group Management Association	Sr. Policy Advisor
Mollie Shields Uehling	SAFE-BioPharma Association	President CEO
Paul Uhrig	Surescripts	
Laura Walsh	Eli Lilly and Company	Global Public Policy
		Manager, Pharmacy Technology Standards and
Afton Yurkon	National Association Of Chain Drug Stores	Policy

Transforming Care Delivery At the Point of Care

Member	Organization	Title
	Pharmaceutical Research & Mfgs of America	
Amiee M. Adasczik	(PhARMA)	PhRMA
Deborah Anderson	Chicago Dept of Public Health/NACCHO	Deputy CIO
Michael Barr	American College of Physicians	VP of Practice Advocacy & Improvement
Julie Beard	3M	Federal Strategic Director
Camilla Hull Brown	Strategies for Tomorrow	·
Leigh Burchell	Allscripts	
Jim Clifford	WellCentive, LLC	National Accounts Manager
Paul Cotton	AARP	Senior Legislative Representative
Jeff Coughlin	WayPoint Advisors	Vice President, Government Relations
Peter Courtway	Danbury Hospital	·
Lou Diamond	Thomson Reuters	VP and Medical Director
Kevin Donnelly	College of American Pathologists	
Hank Fanberg	Christus Health	Technology Advocacy
Beth Feldpush	American Hospital Association	Senior Associate Director of Policy
Angela Franklin	American College of Emergency Physicians	AP
Jennifer Frost	CalRHIO	
Jim Hansen	CareEntrust	CEO
David Hartzband	RCHN Commuity Health Foundation	Dir. Of Technology Research
Joseph Heyman (Co-Chair)	American Medical Association	Chair, Board of Trustees
Camilla Hull	Strategies for Tomorrow, Inc.	Principal
Feygele Jacobs	RCHN Commuity Health Foundation	CEO
William Jessee, MD (Co-	·	
Chair)	Medical Group Management Association	President and Chief Executive Officer
•	• •	Senior Vice President of Government and Industry
Michael Kappel	McKesson Provider Technologies	Relations
Ann Kitchen	Integrated Care Collaboration	Executive Director
Steven Labkoff	Pfizer, Inc.	Senior Director of Medical Affairs
Len Lichtenfeld	American Cancer Society	
Peter Loupos	Sanofi-aventis	Vice President
George Margelis	Intel Corporation	Health Industry Manager
Trudi Matthews	HealthBridge	Director of Policy & Public Relations
Michele McGlynn	Siemens Corporation	Government and Industry Affairs
Robert McKell	Siemens	Clin Prod Spec
Rosemarie Nelson	Medical Group Management Association	Principal Consultant
Neal Neuberger	RCHN Community Health Foundation	Consultant
Charles Parker	Continua Health Alliance	Executive Director
Traci Parker	ICA Informatics Corp of America	Clinical Consultant
Will Rice	Vanderbilt Center for Better Health: Regional	Sr. Consultant
	eHealth Initiative: National Progress Re	

eHealth Initiative: National Progress Report on eHealth July 2010 Page 113

Informatics

Will Ross Redwood MedNet

Toby Sarver Misys

Raymond Scott Axolotl Corporation

Josh Seidman Center for Information Therapy

Alan Silver Island Peer Review Organization (IPRO)

Padma Taggarse Health Services Advisory Group
Michelle Troseth Elsevier Clinical Decision Support

Charlene Underwood Siemens Corporation
Andrew Wiesenthal Kaiser Permanente

Project Manager Software Architect

Founder and Chief Executive Officer

President Medical Officer

Medical Informatics Specialist

¹ Robert Steinbrook, Health Care and the American Recovery and Reinvestment Act. New England Journal of Medicine, March 12, 2009.

2 AHIMA Foundation. Advancing Effective State-Level Approaches to Interoperability in the New Federal Context: A Report of the State Level HIE Consensus Project. May 2009. http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1_045665.pdf

3HIMSS '10: Blumenthal Outlines Health IT Progress, Next Steps. iHealth Beat, March 4, 2010. http://www.ihealthbeat.org/features/2010/himss-10-blumenthal-outlines-health-it-progress-next-steps.aspx

4 Andis Robeznieks, Doc, Hospital Groups Press CMS on Meaningful Use. Modern Healthcare.com, March 16, 2010. http://www.modernhealthcare.com/apps/pbcs.dll/article?AID=/20100316/NEWS/303169990#

5 Ashish K. Jha, Catherine M. DesRoches, Alexandra E. Shields, Paola D. Miralles, Jie Zheng, Sara Rosenbaum and Eric G. Campbell. Evidence Of An Emerging Digital Divide Among Hospitals That Care For The Poor. Health Affairs, October 2009 doi: 10.1377/hlthaff.28.6.w1160

http://content.healthaffairs.org/cgi/content/full/28/6/w1160?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=ARRA&andorexactfulltext=and&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

6 McGraw, D., Dempsey, J. X., Harris, L., and Goldman, J. Privacy As An Enabler, Not An Impediment: Building Trust Into Health Information Exchange. Health Affairs, March/April 2009; 28(2): 416-427. http://content.healthaffairs.org/cgi/content/abstract/28/2/416?maxtoshow=&hits=25&RESULTFORMAT=&fulltext=McGraw%2C+D&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

7 Improvements and Challenges in Health Privacy Law. Center for Democracy and Technology, March 27, 2009. http://www.cdt.org/policy/improvements-and-challenges-health-privacy-law

8 Robert Wood Johnson Foundation. Experts Identify Ways to Spur Consumer Engagement in Health Care: Findings Outlined in a New Series of Briefing Papers, October 2007 http://www.rwjf.org/pr/product.jsp?id=23077

9 Daniel Garrett. Tapping into the Value of Health Data Through Secondary Use. Healthcare Financial Management Magazine, February 2010 http://www.hfma.org/hfm/2010archives/month02/HFM0210Feature_Garrett.htm

10 Carol C. Diamond and Clay Shirky Health Information Technology: A Few Years Of Magical Thinking?

Technology and standards alone will not lead to health IT adoption, let alone transform health care.

Health Affairs, September/October 2008; 27(5): w383-w390.

http://content.healthaffairs.org/cgi/content/abstract/27/5/w383?maxtoshow=&hits=10&RESULTFORMAT=&author1=Diamond%2C+C&andorexacttitle=and&andorexacttitleabs=and