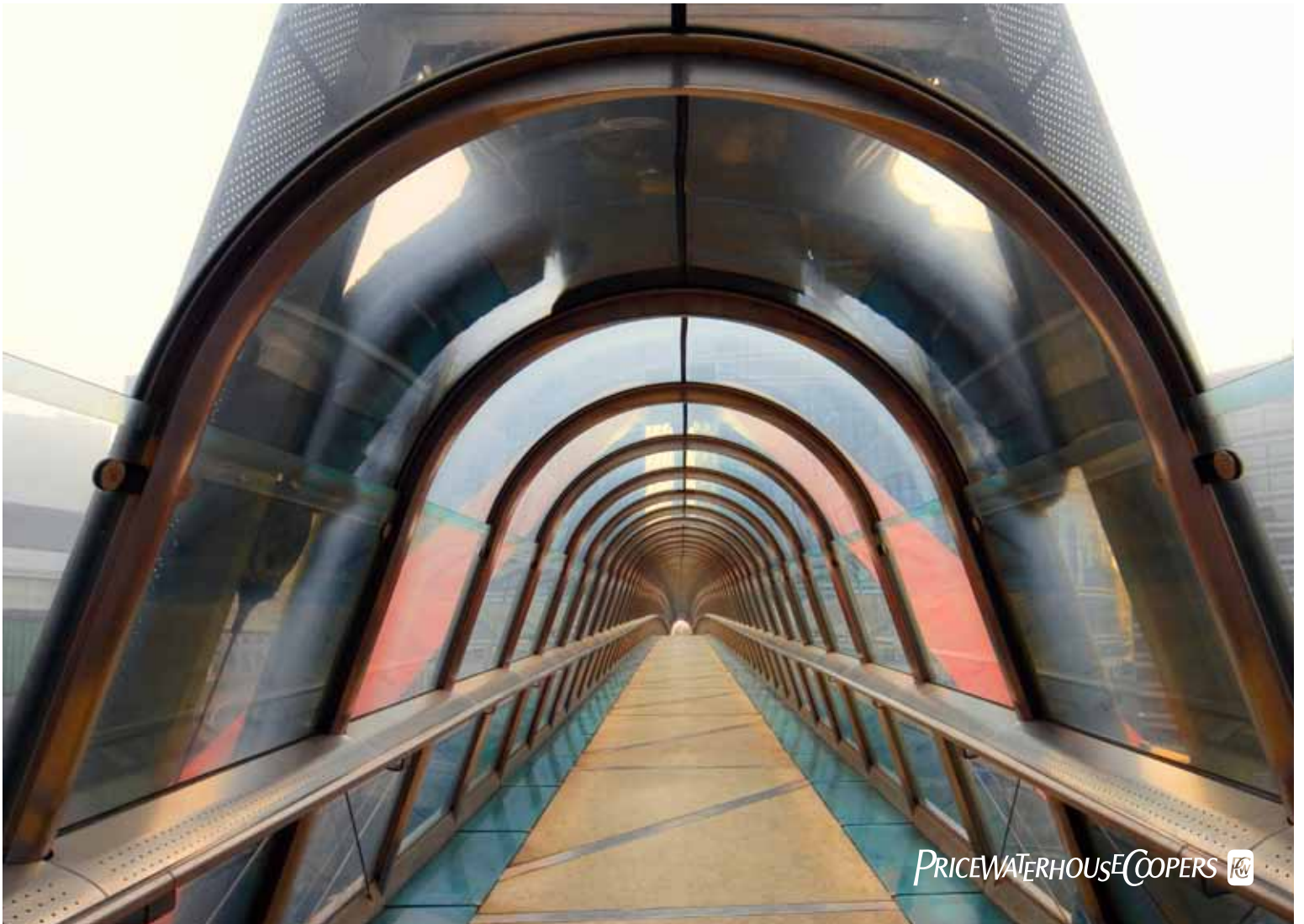


Health Industries

# Transforming healthcare through secondary use of health data





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The heart of the matter

The health industry is challenged to make use of the data that will result from current investments in IT.

## Transforming healthcare through secondary use of health data

A handful of forward-thinking healthcare organizations have understood that the data they have been amassing in their various IT systems holds enormous potential outside of their enterprises. They have launched into uncharted territory by using their data for secondary purposes such as clinical-studies validation and post-market surveillance of drugs. Absent any model to follow, they developed their own guidelines and infrastructure. As more organizations implement health IT, more data will be produced and the potential for secondary use of that data will grow, as well. In the near future, organizations may be asked to submit data to participate in initiatives or collaborations, or use their data to create business opportunities. Before any of these scenarios can occur, however, the industry needs to come together, address barriers head on and develop a framework that can be deployed by all.

Secondary data use offers business and collaboration opportunities, potential benefits and value to all stakeholders. Consensus exists across all stakeholders that the following principles should guide the build-out of an industry framework on secondary use of data:

- The patient should always be the focus of any data use; therefore, the patients' rights and privacy must always be protected.
- Data must be transparent and overseen by honest brokers or stewards to gain everyone's trust. Data transparency should be driven by the private sector, but everyone should take on the role of stewards and deploy the highest standards for privacy and security.
- 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.
- The industry needs to shift the focus of data from transactions to quality and outcomes, which will require a new data architecture. The private sector should foster collaboration and innovation to build a new data architecture that enables interoperability among IT systems.
- The increase in data aggregation and analysis, and the need for that data to be transformed into actionable information will require new training and skills in health IT, including clinical informatics.



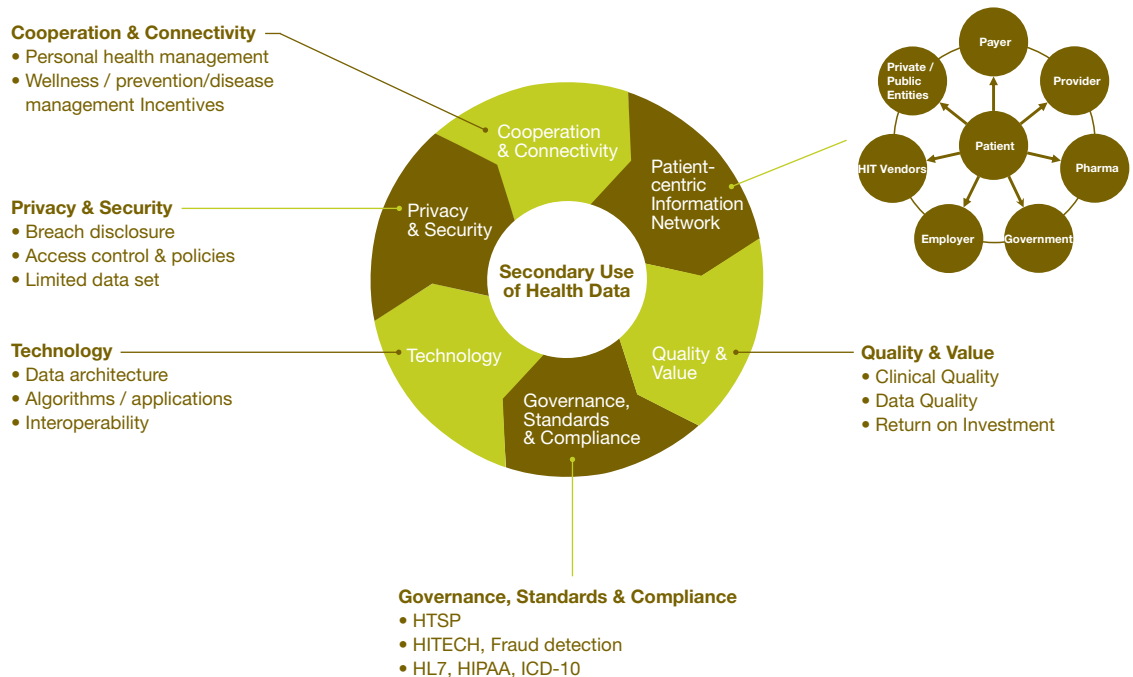
David Chin, MD, PricewaterhouseCoopers

There is a strong consensus on the need for standards and guidance in secondary data use. However, rather than create mandates around health IT or secondary data use, 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.
- Sponsor an industry consortium to develop industry standards, and
- Communicate and promote the opportunities and benefits of secondary data.

**Figure 1. Secondary Use of Health Data Framework**

Key issues and related policies health organizations need to consider in assessing their readiness for secondary data use.



An in-depth discussion

Using data for secondary purposes is one of the most promising ways to improve health outcomes and costs.

# Turning health data into actionable information

These are exciting times for the transformation of the healthcare industry. The Obama Administration cited healthcare reform as the top domestic issue in the country. The HITECH Act of the American Recovery and Reinvestment Act of 2009 earmarks billions of dollars for health IT, and multiple federal and state pilots and demonstrations are deploying health IT to improve the quality while decreasing the cost of healthcare. Amidst these efforts, using data for secondary purposes is one of the more innovative and promising initiatives in the industry primed to improve healthcare on a much broader, more impactful basis.

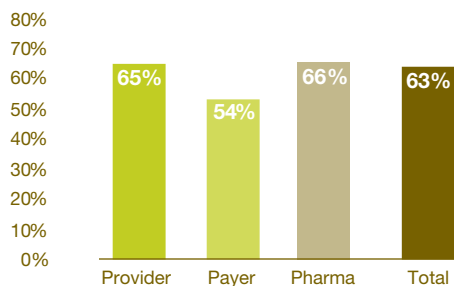
Despite the low adoption rate of IT in the industry, many healthcare organizations are using some form of secondary data, most often for quality management, according

to PricewaterhouseCoopers Health Industries' survey on secondary use of data (see Exhibit 1). The online survey was conducted in May-June 2009 with more than 700 participants, comprising 110+ pharmaceutical and life sciences companies, 130+ payers and 480+ providers. The federal stimulus funds are expected to accelerate health IT implementations, which will drive the exponential growth of data and create even greater opportunity for secondary use. Indeed, many of the survey participants indicated that they anticipate their secondary use to increase (see Exhibit 2).

While the opportunity clearly exists, healthcare organizations across the country face major challenges and barriers to secondary use of data.

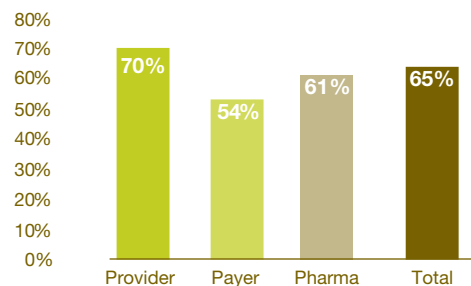
## Exhibit 1: Majority of organizations use some form of secondary data

Does your organization use secondary data?



## Exhibit 2: Most expect their secondary data use to increase

Will you use secondary data within the next two years?



Source: PricewaterhouseCoopers survey.

Secondary use of data is defined as clinical, financial, administrative and self-reported data which is aggregated, analyzed and presented in a concise, actionable format for the purpose of identifying trends, predicting outcomes and influencing patient care, drug development and therapy choices.

PricewaterhouseCoopers Health Industries convened a Health Information Technology Executive Roundtable on June 22, 2009, to identify the barriers and determine how the industry can address those challenges and create value for all stakeholders. Executives from five forward-thinking organizations —Aetna, the American Heart Association, MedMining (a Geisinger Health System business), Partners HealthCare System and WellPoint—presented case studies on how they transformed the data they collect within their enterprises into actionable information. Along with the case-study panelists, 12 high-level executives representing a cross-section of the healthcare industry contributed to the dialogue on secondary use of data, which is defined as clinical, financial, administrative and self-reported data which is aggregated, analyzed and presented in a concise, actionable format for the purpose of identifying trends, predicting outcomes and influencing patient care, drug development and therapy choices.

## Identifying the barriers

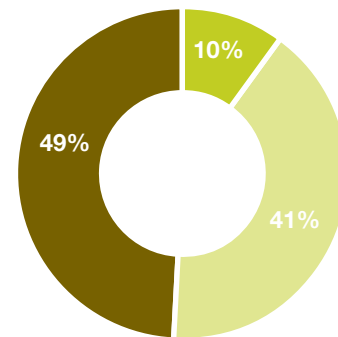
### Data issues: access, transparency, quality and management

The majority of survey participants cited problems surrounding data, including access, transparency, quality and management. Ninety percent of the pharmaceutical company survey respondents have limited or no access to clinical informatics contained in electronic health records (see Exhibit 3). It's been well documented that EHR adoption is low among providers (see Exhibit 4).

While personal health records (PHRs) have been highly touted, with major vendors releasing PHR products and services, payer survey respondents reveal limited offerings. Among those who do offer PHRs, member uptake is low (see Exhibit 5).

### Exhibit 3: Half of pharma companies have some access to clinical informatics

Pharma: Does your organization have access to clinical informatics contained in electronic health records?

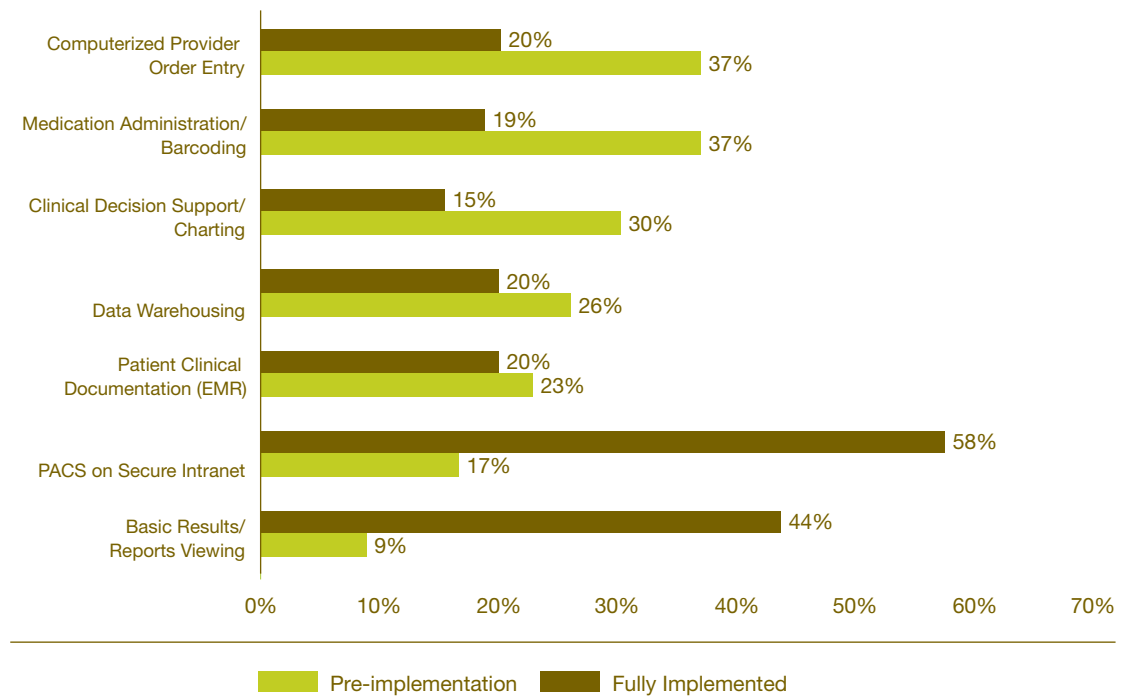


■ No    ■ Yes, full access    ■ Yes, partial access

Source: PricewaterhouseCoopers survey.

## Exhibit 4: Few providers have achieved full implementation of electronic health records

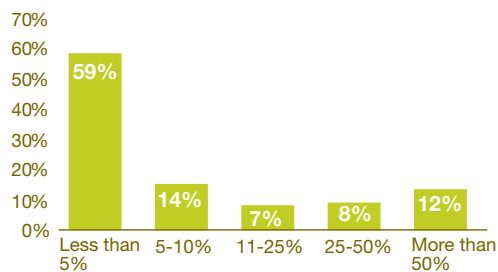
Provider: At what stage are you in adopting EHRs?



Source: PricewaterhouseCoopers survey.

### Exhibit 5: Only 39% of health plans offer personal health records to members, and few members use them

Payer: What percentage of your members has filled out a personal health record?



Source: PricewaterhouseCoopers survey.

While the federal stimulus funds are expected to drive EHR implementations, adoption will remain an issue. “EHRs don’t solve the data acquisition issues,” said David Artz, MD, CMIO of Memorial Sloan-Kettering’s Cancer Center and a Roundtable attendee. Memorial-Sloan Kettering has a full EHR system, but Artz pointed out that a lot of unstructured data is generated from inpatient and outpatient visit notes. “A big barrier is gathering that data and developing fields in the EHR system to capture that data, which negatively impacts physician workflow,” he said. Stephan O’Neill, Vice President of Information Systems and CIO of Hartford Hospital and Hartford Health Care Corp., and a Roundtable attendee, referred to IT systems’ transactions as a “punch list” of things that physicians need to do.

Variability in data entry makes many stakeholders, especially providers, question the quality of the information being generated by the IT system. “Data quality is not ideal, but we can’t let the perfect be the enemy of the much, much better,” said Jim Peters, CEO of MedMining, a Geisinger Ventures portfolio company whose secondary use of data is profiled in a case study. Much of MedMining’s data is derived from Geisinger Health System’s numerous databases, but most notably from its EHR system.

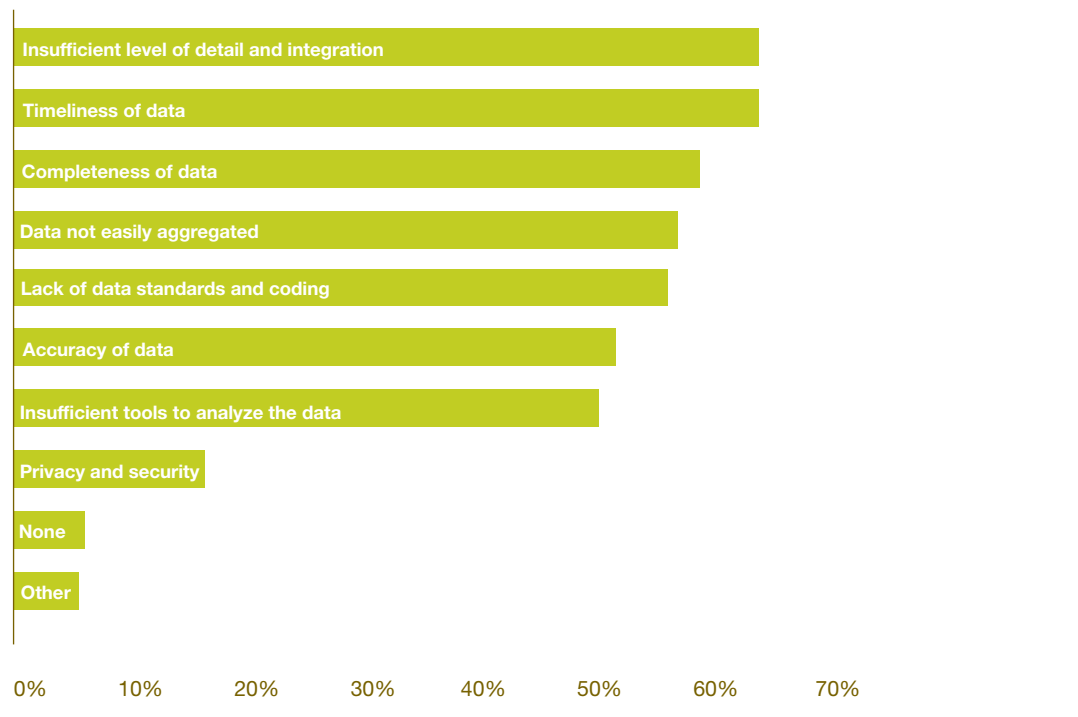
Hartford Hospital’s O’Neill pointed out that transactional systems capture data to support billing efforts and not clinical efforts. He is not alone in this conclusion; survey participants understand that IT systems are not designed for secondary purposes and that limitations exist when users take data that was intended for one use and then extrapolate from that data for another purpose (see Exhibit 6). Further to the quality issue, O’Neill wonders if the federal stimulus funding is creating the unintended consequence of physicians implementing the systems in haste, without regard to how the collected data is going to be analyzed.

Charles Kennedy, MD, Vice President of Health Information Technology for WellPoint, believes that transactional data is very valuable. WellPoint’s Dayton HealthKonnnect, which is one of the case studies, aggregates data from clinical, financial and administrative systems to create a comprehensive, permanent,

## Exhibit 6: Level of detail and integration, as well as timeliness of data, appear to be widely problematic

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What problems have you had with secondary data?



Source: PricewaterhouseCoopers survey.

## Five case studies on the secondary use of data

### **Aetna: Integrated, member-focused healthcare**

Aetna, a national healthcare benefits company, began a major project to take data from its multiple sources and create a comprehensive, personalized view of each member. “What we’re fundamentally trying to do is get as much data as we can so that we can personalize our response to members and get them access to services, tools and health care that are most relevant to their personal health issues,” said Brian Kelly, MD, National Medical Director for Aetna’s National and International Business Solutions. Physicians and patients are sent patient-specific care considerations that identify potential gaps in care based on the use of Evidence-based Medicine. “We’re also trying to get this same information to the provider and patients so that when they come together they’re both seeing the same set of topics that need to be addressed to facilitate that interaction. We also enable the patient to download their PHR data into Microsoft Health Vault so the patient may share it with other physicians”. Kelly said that it’s the best way for Aetna to improve quality and total cost of healthcare. “We believe that the way you’re actually going to make health care better is to basically apply the evidence of medicine to every decision a person makes throughout their healthcare journey,” he said. “Whether that’s a wellness decision to stay well, or whether its care decision once they have a disease or a condition and need to get treatment for it. So we believe the secondary use has to be personalized to the individual level.”

### **American Heart Association/American Stroke Association: Evidence-based, quality improvement program**

The American Heart Association/American Stroke Association (AHA/ASA), the nation’s largest voluntary health organization, works with hospitals across the country to align their treatment of cardiovascular disease and stroke patients with evidence-based guidelines. Using patient-reported data, the organization is able to identify and recognize hospitals that provide quality care for these diseases. AHA/ASA is modifying its health impact goal to include the overall cardiovascular health of patients and expanding into the outpatient setting. The program will enable AHA/ASA to collect extensive data and conduct longitudinal studies on the effects of certain factors. “This is true comparative effectiveness research that the Obama Administration is talking about,” said Vincent Bufalino, MD, President and CEO of Midwest Heart Specialists. “We are developing the science for long-term, follow-up care.”

### **MedMining: Promoting healthcare research**

Geisinger Health System, a large integrated health system, created a company called MedMining, which de-identifies and licenses its data to promote healthcare research. Most major pharmaceutical companies and large biotech companies use MedMining's data to support their research in a process that is faster and less expensive than traditional clinical trials. "MedMining is enabling others beyond the four walls of Geisinger to engage in the type of research that is predicated on uniquely deep, longitudinal clinical and economic data. MedMining is a vehicle for Geisinger to help grow the research pie nationally as it relates to pharmaco-economic research, outcomes research, clinical effectiveness and drug safety," said Jim Peters, Managing Partner of Geisinger Ventures and CEO of MedMining.

### **Partners HealthCare: Post-market surveillance of drugs**

Partners HealthCare, a nonprofit integrated healthcare system, discovered that data mainly from its EHRs can identify trends in drug usage and clinical events, and now conducts post-market surveillance of drugs in an efficient, expeditious and cost-effective way. "There is serious potency here," said John Glaser, Vice President and CIO of Partners HealthCare System. "We'll be better off in lots of ways because of our ability to leverage the data."

### **WellPoint: An Integrated health record**

WellPoint, the largest health benefits company in the country, piloted an integrated health record for members of a large healthcare network, and demonstrated that claims data can be used to create an integrated clinical record that supports the delivery of care. "Taking transactional data such as lab orders and results, and being able to turn it into data that is clinically relevant and meaningful is a critical skill set," said Charles Kennedy, MD, Vice President of Health Information Technology for WellPoint.

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For a more complete description of these case studies, please visit  
[www.pwc.com/secondaryhealthdata](http://www.pwc.com/secondaryhealthdata)

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“Taking data from a system – a piece of data from system A to system B – is very analogous to a transaction, and that’s really not where we need to go. Where we need to go is to repurpose raw clinical transactional data into an electronic understanding of the patient that easily and quickly allows doctors and patients to make ideal care management decisions.”

Charles Kennedy, MD—WellPoint, Inc.

shared clinical and financial record for the patient and physician. WellPoint developed a process to ensure that the data is meaningful, accurate and useful by applying modeling and algorithms to the data to identify duplicate representations of the data. This process allows for a focused understanding of the patient’s clinical status and care to be obtained. “What we need is to take the current raw transactional data and re-purpose it into clinical information that represents an electronic understanding of the patient,” said Kennedy. “Once that is done, the electronic understanding of the patient can be used by the computer to advise doctors and patients on ideal care management decisions.”

WellPoint’s significant investments in health IT have enabled the health benefits company to engage in numerous initiatives that aggregate and analyze health data for such areas as clinical research and disease management. Aetna, a national diversified healthcare benefits company, has invested more than a billion dollars over the last five years to develop its IT platform. More than twenty percent of Aetna’s approximately 35,000-person workforce is either clinicians or IT specialists, according to Brian Kelly, MD, National Medical Director, National and International Business Solutions. Kelly believes that what Aetna is doing reflects the evolution of health plans to where health IT capabilities are a core competency.

Kelly noted that much of Aetna’s investment has been in data mapping, standardization and migration of standardized data into a data warehouse. Getting the data into reusable forms enables the organization to support empowering patients with information and tools to make the right

health care choices, strengthening provider-patient relationships, and driving more efficient business applications. While Aetna has been able to leverage the heavy lifting for multiple purposes, he acknowledged, “It’s a huge investment to bring these systems together.” Similarly, Geisinger Health System invested more than \$100 million in its EHR system, clinical decision information system and other supporting resources to enable the integration of all disparate data sources.

Yet for many healthcare organizations, the cost to build IT systems is prohibitive. This is particularly true with physician offices. Until EHR adoption grows—which the federal government hopes that the HITECH Act will foster—the data being generated by hospitals and integrated delivery networks will be moot in terms of providing a longitudinal computerized record of a patient’s care.

The American Heart Association/American Stroke Association (AHA/ASA) is trying to create a comprehensive view of the patient and continuum of care by linking inpatient and outpatient data. Linking both sets of data, however, requires systems integration, which was cited as one of the top two data-related problems encountered by more than 60 percent of the survey respondents.

### **Privacy and security concerns**

Across the board, the vast majority (over 80 percent) of survey respondents cited privacy, legal implications, and public relations ramifications as concerns (see Exhibit 7). “But interestingly these issues were less likely to be mentioned as an actual barrier to secondary data use. (Rather, not having access to electronic health data was the top



Charles Kennedy, MD, WellPoint

“We determined that getting into this area of leveraging secondary data was supportive of our mission. In fact, to not start this business would not have been in the best interest of our patients and healthcare in general.”

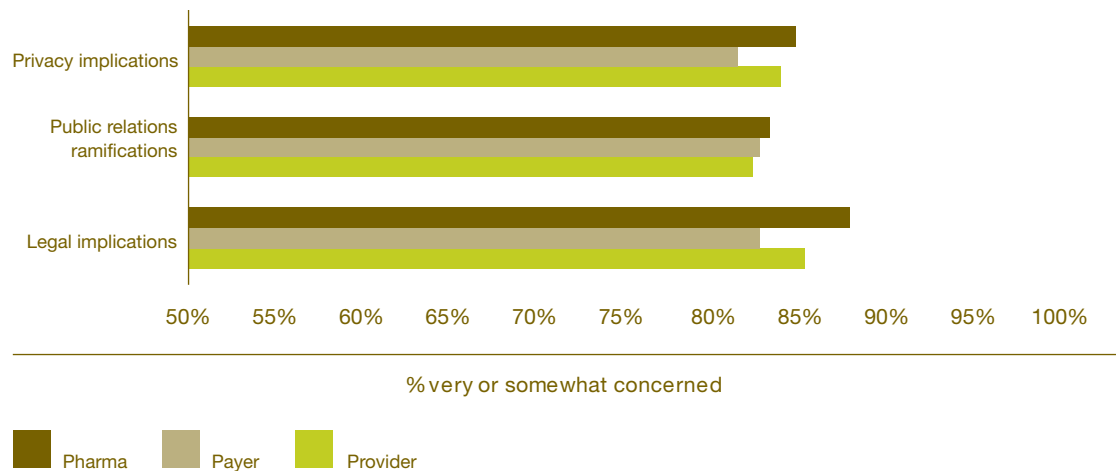
Jim Peters, MedMining—a Geisinger Health System business

barrier) (see Exhibit 8). This indicates that, for most organizations, these are issues that can be managed effectively, rather than insurmountable barriers. When Geisinger Health System established MedMining, CEO Jim Peters said that the health system had the same concerns regarding secondary use of data, but these concerns were not a barrier. On the contrary, Peters said, “We determined that getting into this area of leveraging secondary data to promote healthcare research was supportive of our mission. In fact, we felt it would be against our mission—and the best interests of our patients and healthcare in general—to take the path of least resistance and not start this business.”

MedMining went above and beyond HIPAA compliance to develop a “belt, suspenders, Velcro and glue approach” to patient privacy and information security, Peters said. It made its data processes transparent and created multiple levels of separation between the data and the end customer, including employing a formal Honest Broker system, an Information Security function, and a Privacy Office that collectively serve as process review checkpoints for data exchanges to ensure the data are appropriately encrypted and completely de-identified, and that neither MedMining nor its customers ever sees protected health information.

### Exhibit 7: Privacy, PR, and legal implications are common concerns

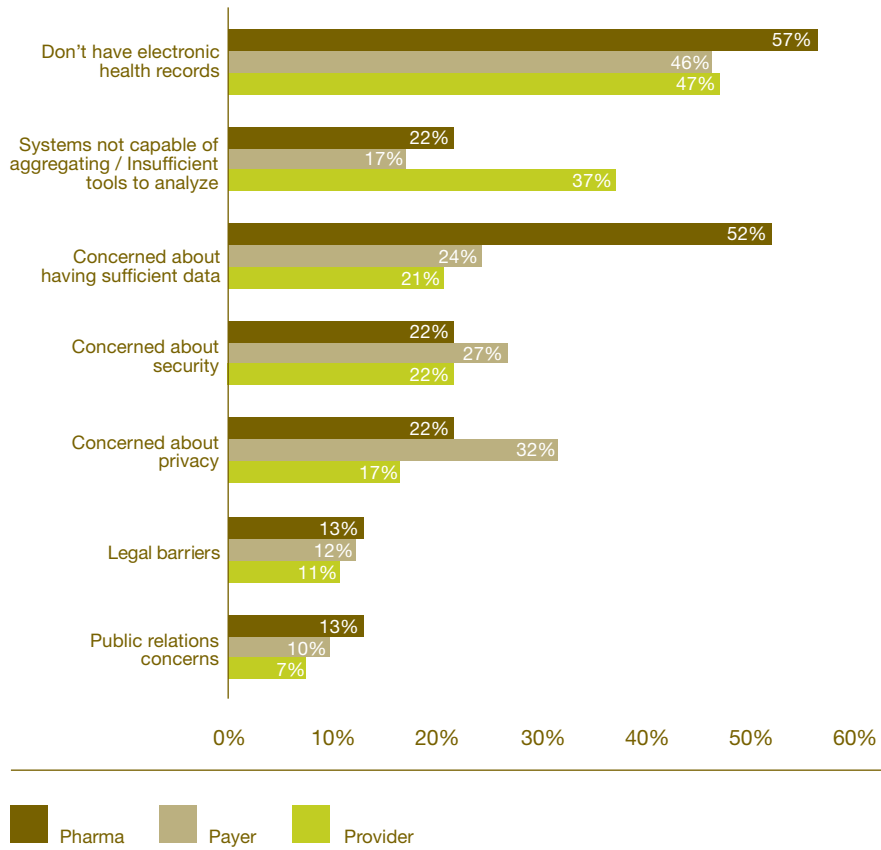
Do you have concerns about secondary data use?



Source: PricewaterhouseCoopers survey.

**Exhibit 8: As EHRs increase, a major barrier to secondary data could be removed, but others may remain for each stakeholder**

Why aren't you using secondary data?



Source: PricewaterhouseCoopers survey.

## In search of data standards

Managing and deciphering the terabytes of data coming out of health IT systems will be a huge challenge with the expected increase in EHR implementations. “We assume that every megabyte and individual gigapixel that we generate in the healthcare industry somehow needs to be aggregated and reported to everybody in a useful way,” said Allan Korn, MD, CMO and Senior Vice President for Clinical Affairs for BlueCross BlueShield Association (BCBSA) and a Roundtable attendee. “If we just abandon this hundred gazillion gigabyte project, and look at the handful of things that are truly meaningful and useful, like they did at MasterCard 25 years ago—the most important thing is make the card work when you’re at the store—we’d make a lot more progress,” he said.

Dennis Liotta, MD, Senior Medical Director of EmblemHealth and a Roundtable attendee, agreed, saying, “We’ve got so much data we don’t know where to begin.” Liotta suggested “going back to the basics” and defining some standards for the combined (payer, provider and pharma) industry at large. “We have to first sit down and talk to each other and ask, ‘What are each of our needs and uses for collecting this (secondary) data?’. We then need to come to a commonality about what data is really necessary and how to use it effectively,” he said.

But finding that commonality is extremely difficult when you look at the multiple stakeholders in the healthcare ecosystem. Peggy O’Kane, President of the National Committee for Quality Assurance (NCQA), noted that the path is clear for organizations

that have a lot of data and also have an enterprise with common goals and the capability to make use of the data. The larger question is whether some of the attributes of an enterprise can be created for those—namely the small physician practices around the country—who don’t have common goals. While physician distrust in the hospital-created network that reaches out to its physician community demands an alternative model, O’Kane said, “The jury is really out on whether we can create a model that works for all these different players.”

The industry needs to construct the use of data around general health guidelines and provide the best type of patient care for such things as chronic conditions and end of life, said Vincent Bufalino, MD, President and CEO of Midwest Heart Specialists. The data he would like to measure are those that show how well the industry is taking care of patients. Within the last 40 years, the U.S. has seen a 10-fold reduction in mortality for heart attacks, Bufalino pointed out. These are quality goals that would resonate with all stakeholders.

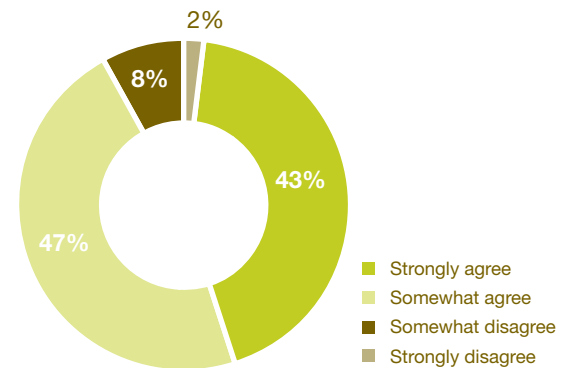
Once consensus is formed over what minimal set of high-use, high-value subsets of data to collect, the next standards-based issue is finding a common format in which the data resides. Steven Labkoff, MD, Senior Director, Team Leader National Accounts — Corporate and Government Customer Medical Division for Pfizer, sees benefits in secondary use of data for drug safety and research and development in the pharmaceutical market. Labkoff said that it would be helpful to get data in a standardized format that promotes ease of usability and interpretability.

## Industry guidelines and the role of government

One of the obstacles MedMining encountered when the company was being formed was not having an accepted industry standard for secondary use of data. Thus, in the absence of such guidance, the company took the initiative to attempt to create “the gold standard for the industry.” He told the Roundtable attendees, “We would be happy to contribute our process and to join others around the table to develop a set of commonly accepted guidelines that reflect a common sense view of what is best for patients.” Not only was there consensus on the need for standards among the Roundtable attendees, but many of the survey participants also wanted more guidance (see Exhibit 9).

“What can’t happen is a government-imposed process that says this is how it will be because I think those types of models don’t work well here in the United States,” said Midwest Heart Specialists’ Bufalino. Roundtable attendees all agreed that government should not mandate standards. Rather, standards should come from the market, said Peters. “We are ready for a national body to define those standards,” said Hartford Hospital’s O’Neill. Roundtable attendees also agreed that guidelines need to be aligned with incentives and payment reform.

## Exhibit 9: The healthcare industry needs to have better guidelines on how secondary data should be used and shared



Source: PricewaterhouseCoopers survey.

“Until physicians are appropriately reimbursed, particularly primary care doctors, for taking the time to put in the important data, we will never get past this problem. Payment reform is going to be fundamental to any true lasting progress we’ll make in secondary use.”

Brian Kelly, MD—Aetna

### **Aligning incentives with quality and value**

Alignment of incentives for the clinical community and payment reform to collect, share and use data are paramount to expanding secondary use of data. “I think it really all comes down to payment reform and aligning incentives to get physicians and health care professionals to input the important data that lets you measure quality, cost and access in a meaningful way,” said Aetna’s Kelly. “Until physicians are appropriately reimbursed, particularly primary care doctors, for taking the time to put in the important data, we will not be able to maximize the opportunity afforded technology. Payment reform is going to be fundamental to any true lasting progress we’ll make in secondary use.” NCQA’s O’Kane agreed, saying, “Until financial goals are aligned through payment reform, I think we’re always going to be struggling.”

Ultimately, O’Neill said, “We need new incentives that are patient-centric and realigned around quality and value.” AHA/ASA’s Get With the Guidelines (GWTG) program, which is one of the case studies, exemplifies that model. GWTG helps hospitals align the care that they provide to coronary artery disease, stroke and heart failure patients with the latest scientific guidelines. The long-term goal of using secondary data is to define a care model that really makes sense to people and is centered around the patient, said Midwest Heart Specialists’ Bufalino.

Hartford Hospital’s O’Neill insisted, “If you focus on the people, and don’t worry about the special interests or the hospitals or the docs or the payers—focus on the people and the care that they need—I think we have a much better starting point for whatever we talk about doing with IT here in this industry.” BCBSA’s Korn agreed, saying, “The ultimate measure is more health per dollar.”



Brian Kelly, MD, Aetna

What it means for your business

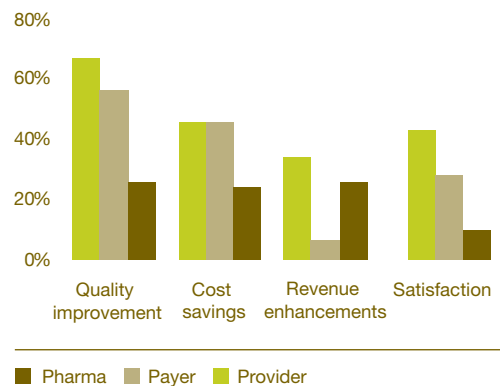
Industry stakeholders  
are calling for a  
framework to define  
public and private  
sector roles in  
secondary data use.

# Opportunities for industry stakeholders

Most organizations are currently using secondary data for quality monitoring and reporting, and for identifying areas that need quality improvement. With EHR and other health IT implementations projected to grow, we can expect innovation in how data will be used in the near and long-term future to flourish. While results from secondary data use have been fairly limited to date, over 90 percent of industry respondents believe that it has potential to significantly improve patient care, and offers the promise of greater benefits in the future. The variety of stakeholders' needs will drive the private markets to create new models, such as financial management and fraud detection for payers; disease, case and care management for providers; and market and sales development and treatment efficacy testing for pharmaceutical companies; and even public health protection and enhancement for government entities (see Exhibits 10 and 11).

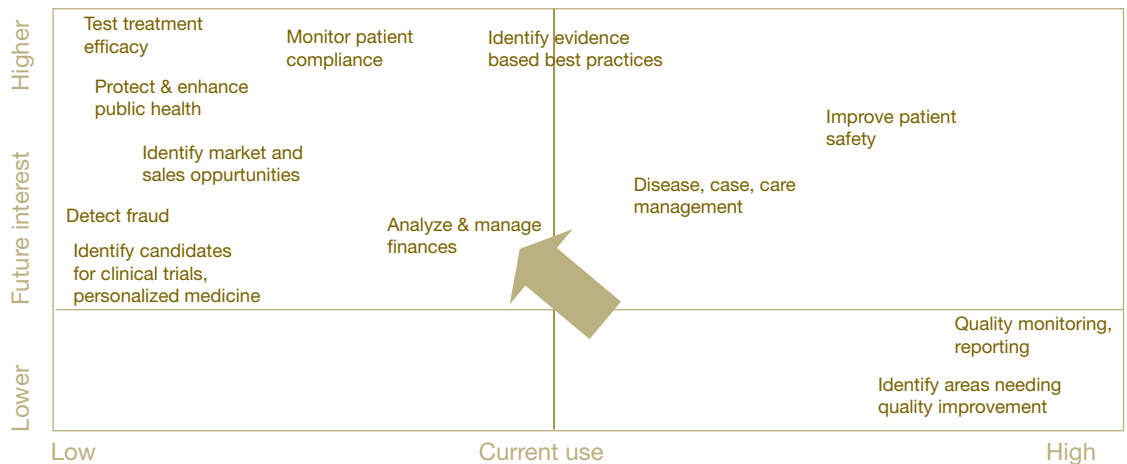
**Exhibit 10: Though quality improvement is the overriding benefit, the types and magnitude of results vary by stakeholder**

Where have you achieved desired results from secondary use of data?



Source: PricewaterhouseCoopers survey.

**Exhibit 11: While data often is, and will be, used for quality monitoring and improvement, there are a variety of other needs**



Source: PricewaterhouseCoopers survey.

All stakeholders can benefit from deploying secondary use of data, but the key is to develop a comprehensive roadmap that identifies business needs, addresses barriers, develops opportunities and partnerships, and analyzes results for return on investment (ROI), refinement of best practices and next steps.

#### **Providers: Hospitals and health systems**

Hospitals typically rely on internal sources for their secondary data. They most frequently use the data for patient-centered initiatives, and quality improvement and reporting activities. However, they often lack sufficient data aggregation and analysis tools. To achieve greater benefit from secondary data in the future, Roundtable attendees agreed that providers should:

- **Implement an interoperable, standards-based EHR system.** The recession has hammered hospitals and health systems, forcing many of them to reduce their IT capital and/or operating expenses in 2009 and into 2010. Visionary hospital leaders, however, understand that health IT brings value across departments and will deliver ROI in the long run in the form of improved clinical and operational services. The federal stimulus funds provide a tangible, timely incentive for hospitals to implement EHRs now. Geisinger Health System and Partners HealthCare are ahead of the market because they can harvest years of data from their mature EHR systems. Not implementing an interoperable, standards-based EHR system, however, will result in a market handicap, especially when many hospitals take advantage of the federal stimulus funds.

- **Participate in quality-improvement programs.** Participating in quality-improvement programs, such as AHA/ASA's GWTG, provides a competitive edge. AHA/ASA has achieved a high rate of adoption among hospitals in large measure because being formally recognized in U.S. News and World Report's "America's Best Hospitals" edition every July is a "great marketing tool" for hospitals, said Midwest Heart Specialists' Bufalino. National, state and local recognition for quality care creates market differentiation and loyalty.
- **Reach out to the physician community.** The relaxation of the Stark Law should make it easier for hospitals to connect local physician practices to their IT systems.

#### **Providers: Physicians**

- **Implement an interoperable, standards-based EHR system.** Survey respondents who are providers indicated that they lack sufficient data aggregation and analysis tools. Recognizing the long-term value and business opportunities, physicians need to take advantage of the federal stimulus funds and adopt health IT.
- **Partner with local hospitals or health systems to leverage their IT systems.** If upfront cost is prohibitive, physician offices can save money by connecting to large provider systems, which would promote data sharing and the ability to deliver continuity of care for patients who access both the physician office and hospital.

- **Deploy mobile technologies to gather data.** Physicians should take advantage of mobile devices as another source of data collection. Enabling data entered into mobile devices to be captured in IT systems will create an efficient, user-friendly and unobtrusive workflow for physicians, which will drive adoption.
- **Focus on patient wellness.** Roundtable attendees admitted that physicians are the hardest to incentivize to collect data. While payers may be the drivers to incentivize physicians, physicians should collect data when they focus on the wellness of their patients instead of sickness, which is an overall trend in the healthcare industry and a consumer demand.

## Payers

According to PricewaterhouseCoopers' survey, payers are able to access data from a wide variety of sources, but have the lowest use of secondary data of all health industry stakeholders. They are widely concerned about privacy issues, but do not see cost as a barrier. While they have seen limited revenue enhancement benefits from secondary data to date, they are likely to use the data for quality improvement; disease, case and care management, and to support evidence-based medicine. For example, Aetna conducted a number of studies on its secondary use of data to determine the return on investment (ROI) from its health IT. Its care management capabilities produced an ROI in the form of higher rates of compliance with evidence-based medicine guidelines, indicating that members are getting more appropriate care. Greater compliance over time will result in reduced medical cost and better clinical

outcomes. To drive greater benefits in the future, Roundtable attendees agreed that payers should:

- **Invest in health IT to derive long-term clinical and administrative benefits.** Payers should prioritize their IT investments around ensuring data accuracy and data mapping. A healthier membership and automated processes will result in higher satisfaction rates with members and providers, respectively, which in turn will drive loyalty and market competitiveness and differentiation. While it may seem counter-intuitive to invest, now is the time. Some of the federal stimulus funds are earmarked for health information exchanges (HIEs), which already involve a number of payers. Payers who put a system in place before the incentives kick in will be in better shape than those who wait until the economy recovers.
- **Leverage health IT investments for other uses.** Payers can leverage their health IT investments for secondary use of data beyond quality improvement and reporting, and patient compliance monitoring. These investments can be used across departments for such things as fraud detection, business modeling and financial analysis and management.
- **Bolster workforce with clinicians and IT specialists.** Some payers are evolving into health IT organizations. Payers are no longer simply claims processors; they are in the business of ensuring health and wellness for their members and deploying health IT to that end. Payers should hire a workforce that reflects this evolution of mission and goals.

- **Form community partnerships.** Payers should form partnerships in the community to expand their reach for data integration and exchange, as well as create trust and collaboration among competitors and historical antagonists. For example, WellPoint is looking to expand the infrastructure it created for the Dayton HealthKonnnect pilot to other regions by partnering with other payers and local physician groups and hospital systems.
- **Make data collection a P4P metric.** Payers should take on the responsibility of incentivizing network physicians to collect data by including it as a measure for their pay-for-performance (P4P) program. BCBSA's Korn highlighted a Blues P4P program that replaces board recertification audits with meeting quality measures. "Since we reward people every year, it capitalizes the practice and makes it worth their while to engage in this process," he said. "For the first time ever, a doctor is rewarded not for how well he takes a test but for what he does in the real world. And he's acknowledged by his or her peers. That's trust. That's a good collaboration."
- **Mandate or incentivize PHR use.** Payers should also consider incentivizing providers and members to use PHRs to provide data and continuously update their records.
- **Create incentives for pharmaceutical companies.** BCBSA demonstrated in one state using one product in limited production that when the field force incentive compensation was switched from gross sales to patient adherence, adherence and bonuses went up, while

healthcare costs began to decrease. While the field force initially fought the initiative, it ultimately worked. With a P4P program in place for physicians based on adherence, everybody came out a winner – patient, physician, payer and pharmaceutical company.

### Pharmaceutical companies

As revealed by the survey responses, pharmaceutical companies typically use secondary data for product research and development, analysis of trends across populations, efficacy testing of specific treatments, identification of markets and sales opportunities and competitive intelligence. Although the pharmaceutical companies are most supportive of data commercialization among the health industry stakeholders, the survey also revealed that they have limited access to data and knowledge of how to use it.

Payers and providers have reported that attempts to partner with pharmaceutical companies in order to share data have been unsuccessful largely because of conflicting business interests. Whereas providers and payers focus on the breadth of the data, pharmaceutical companies are focused on specific diseases or data sets. To address barriers and achieve greater benefit in the future, Roundtable attendees agreed that pharmaceutical companies should:

- **Partner with health systems and payers.** Given its limitations, pharmaceutical companies should partner with health systems and payers to leverage their IT infrastructure, data and IT expertise.

## Collaborative opportunities for healthcare industry stakeholders

As secondary use of data grows, stakeholders will discover myriad opportunities to collaborate with one another:

- According to PricewaterhouseCoopers' survey, more than 70 percent of respondents agreed that national stewardship over secondary data use should be regulated. Independent third parties, custodians or "honest brokers" should be delegated to help protect the privacy of patient health information and keep data processes transparent.
- Once the industry collectively defines a standard data set, the data set could be commoditized, resulting in a lower-cost, less-complex EHR. Multiple custodians—for example, Google or Microsoft, or even hospital or payer—could compete for the business, not unlike 401K plan managers.
- As data accumulates exponentially, healthcare organizations can share repositories to split management and resource costs or store data for others in a utility model, which would provide a revenue stream.
- Healthcare organizations with clinical informatics and analytics expertise can leverage those resources to analyze data for others, creating a revenue stream and an incentive for data collection.
- A hybrid, or shared, model would allow payers to embed their rules into an EHR, which would eliminate administrative costs for physicians, recently estimated at \$70,000 per physician annually, according to WellPoint's Kennedy.

- **Partner with industry groups.** Pharmaceutical companies should also partner with industry organizations, foundations and collaborations such as the eHealth Initiative Foundation's Connecting for Drug Safety Collaboration, which is engaged in post-market surveillance of drugs. In this particular

collaboration, pharmaceutical companies would be able to access EHR data and call on the collaboration's resources to interpret the data. Collaborating with data partners could potentially result in support for pricing, new products, enhanced reputation and savings through lower costs for clinical trials and more efficient, shortened time to market.



Left to Right: Jim Peters, MedMining & Geisinger Ventures, Joseph Alban, PricewaterhouseCoopers

- **Deploy a neutral third party to facilitate partnerships.** Pharmaceutical companies should acknowledge upfront all conflicting business interests and issues, such as who will pay for the data, who owns the data and how will the data be used, with potential partners. Bringing in a neutral facilitator can help all parties find common ground for successful collaborations.
- **Expand the data focus.** While it makes business sense to focus on specific diseases or data sets, pharmaceutical companies should broaden the data they collect and shares. Being a broad-based data partner will create more opportunities for collaboration, which will ultimately provide benefits to all parties, including pharmaceutical companies.
- **Create an infrastructure that lets patients collect data via mobile technologies and social networking sites.** Some stakeholders in the industry believe that personal, mobile collection of data is key to conditional approval at the Food and Drug Administration (FDA) and for risk management for post-market surveillance of drugs.

#### Health IT vendors

- **Focus on healthcare reform, patients.** Despite accusations of self-interest, health IT vendors must focus above all else on healthcare reform and keeping the patient in the center.
- **Build a new data architecture in a collaborative process.** The market for secondary use of data requires a new data architecture focused on quality

and outcomes rather than transactions. Roundtable attendees agreed that government policies and standards should not dictate vendors' architecture. Rather, the public market is better equipped to foster collaboration, interoperability and innovation in IT systems. Health IT vendors need to partner with an industry consortium comprising clinical and IT experts to determine stakeholder needs and a migration path, and to build the new infrastructure.

- **Present relevant data where it's needed.** The consortium would advise health IT vendors where meaningful information can be interjected into the healthcare delivery process, and its corresponding IT system, to impact quality and outcomes. Clinical information on a patient can be added at eligibility check and inserted in either a paper or electronic chart for review by the physician at the point of care. While not ideal because of the additional work, physicians can add information into the EMR at the point of care, and information on what service was provided can also be input when the patient is discharged. Also important are evidence-based information and continual feedback to the patient for better decision making and self-management, and providing that data in a single view for both patient and physician. Health IT vendors who can integrate data and present the data in one view will serve healthcare organizations desiring this capability.
- **Work with payer and provider champions of PHRs for uptake and expansion.** While PHR uptake is low across the industry, both Aetna and WellPoint deploy PHRs and believe in the

value they add to the patients' longitudinal record. PHR vendors should look to the national health benefits company and the large integrated delivery networks as models for PHR adoption and expansion.

- **Court small, mid-size payers with cost-effective health IT solutions.** Health IT vendors with expertise in data integration, predictive analytics, and platforms based on evidence-based medicine should court payers who don't have these capabilities. While Aetna and WellPoint acquired these IT capabilities to improve the health and wellness of their members through real-time decision support, there are many more small to mid-size, regional payers who don't have significant IT budgets.
- **The market for emerging, innovative health IT applications is wide open.** As advanced in IT capabilities as Aetna and WellPoint are, these health benefits companies are continuing to explore how they can work with other technologies and HIEs and regional health information organizations (RHIOs).
- **Interoperability is king.** Given the federal stimulus funds allotted for HIE activity, health IT vendors with data-exchange platforms or interfaces that enable interoperability among IT systems should find a growing market for secondary use of data in this area.
- **Target healthcare communities wanting health information exchange.** In addition to payers, health systems are also looking to connect to HIEs and RHIOs. Hartford Health Care Corp. is working with 16 of Connecticut's 32 hospitals to create an HIE for the state of Connecticut. The HIE would enable critical data-sharing among providers and impact individual and population healthcare, said Hartford Hospital's O'Neill. In addition to expanding its research capabilities, UK HealthCare, the clinical arm of the University of Kentucky, is also positioning to link with regional HIEs, said CIO Timothy Tarnowski.
- **Deliver data exchange and integration capabilities.** AHA/ASA's Get With The Guidelines – Outpatient, the next evolution of its GWTG program to be released later this year, aims to improve clinical data flow between inpatient and outpatient systems. GWTG – Outpatient will leverage growing EHR adoption and emerging health IT to create a model that harvests data directly through the EHR system, providing participating outpatient clinicians performance feedback reports to help identify patients who are not being managed to the goal. The goal is to ultimately impact 30-day readmission rates. Roundtable attendees agreed that a longitudinal computerized record of a patient is compromised, resulting in gaps in care, when inpatient and outpatient data are not shared. MedMining's Peters argues for getting data, not simply across the care continuum, but also from provider, payer, pharmacy and patient. The market is wide open for health IT vendors that can demonstrate this capability.
- **Hire the best and the brightest data experts.** In addition to the technology itself, the healthcare industry will need expert data management teams to study the data and determine how stakeholders can most effectively use it. Data experts from other industries hit by the economic

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## Establishing the necessary standards

An industry consortium comprising respected, high-level decision makers representing provider, payer, pharmaceutical and patient organizations, is the best type of entity to develop standards around what data to collect and share, defining data quality elements and identifying minimal initial data sets.

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downturn should find an attractive market across all stakeholders in the healthcare industry. Small- and mid-size physician offices with new EHR systems will need to call on IT experts whose fees are commensurate with their budgets. Community colleges are an ideal venue for training a new workforce in IT, business process change and physician office operations to support those physicians.

### Industry consortium and national industry body

- **Form an inclusive industry consortium to establish standards.** An industry consortium comprising respected, high-level decision makers representing provider, payer, pharmaceutical and patient organizations, is the best type of entity to develop standards around what data to collect and share, defining data quality elements and identifying minimal initial data sets. Already, Roundtable attendees have come up with their preferred list of high-use/high value data based on their own clinical needs. They agreed in the value of all the data “necessary for the ongoing management of the patient,” but not all the data that was generated by the inpatient stay. For example, the primary care physician treating a patient who was admitted to a hospital with a heart attack would not want blood pressure data that has been recorded on a regular basis; he would be better served with the medication list the patient was discharged on. Aetna’s Kelly noted that different stakeholders want different sets of data, but said, “I do believe in incremental building.” If providers were given demographic data across systems, a list of chronic conditions, a medication list, basic biometric and lab data, providers would have between 80 to 90 percent of what they would need to take care of their patient, he said. “That would be a huge step,” Kelly said.
- **Attract a national industry body to provide governance, leadership.** Some of the Roundtable attendees want the Certification Commission for Healthcare Information Technology (CCHIT), Healthcare Information Technology Standards Panel (HITSP) or Health Level Seven (HL7) to provide some governance and leadership around how to deploy secondary use of data initiatives.
- **Educate and advise stakeholders on the critical issues regarding health IT certification.** Many industry executives are concerned that the federal

## Empowering the patient

Roundtable attendees agree that the patient should always be the focus of any secondary use of data. In fact, the patient is the most important stakeholder in all initiatives. They are also a vital collection source. It is incumbent upon the public sector, providers, payers, pharmaceutical companies, health IT vendors and other participants to encourage patients to collect and share their healthcare data with their physicians and other trusted partners.

Collecting data is a challenge, but stakeholders can create an environment that promotes and keeps patients engaged to maintain this activity:

- **Educate patients** that providing quality healthcare requires the existence of a comprehensive, longitudinal clinical record about them, which includes self-reported health information.
- **Develop a solid relationship and engender trust with patients** by sharing information with them and making it transparent and accessible.
- Stress that **data collection and sharing empowers patients** to take control of their health and healthcare decisions.

- **Encourage technology-savvy patients to deploy their mobile devices to aggregate data**, which will enable sharing and help them manage their conditions. For example, applications for mobile devices such as the iPhone allow patients to record readings and tests such as glucose levels.
- Encourage patients to **collect and share their data via social networking sites** such as *www.patientslikeme.com*. These sites foster a sense of community, which drives adoption and compliance.
- Make patients aware of entities that have initiatives on self-reported data collection and sharing. Share those resources with other stakeholders. For instance, the MIT Media Lab has a project in which patients collect and share data publicly in order to perform their own clinical trials.

Empowering the patient creates trust and ensures that patients are engaged in the process of collecting and sharing data for the benefit of their quality of care and the quality of care for everyone in the healthcare system.

stimulus funds for health IT adoption will be useless unless EHR packages are certified. The federal health IT certification decision-making and rulemaking process has been constantly evolving, with recommendations flowing from appointed committees and workgroups, as well as from the public. As of September 2009, in addition to the Certification Commission for Health Information Technology (CCHIT) certification, the Department of Health and Human Services (HHS) will provide its own preliminary certification, which will focus on health IT functionalities that would help providers qualify for the stimulus funds under ARRA. Providers need to understand the difference between the two certifications. In addition, the Meaningful Use Workgroup of the Health IT Policy Committee has recommended to HHS the expansion of certification entities to some 10 or 12 bodies. The proposed national industry body should be tasked with educating providers should this recommendation be included in the final rulemaking. Regardless of how many certification bodies exist and who those bodies may be, the proposed national industry body should strongly advise providers to implement fully certified systems, rather than simply implement health IT that meets the minimum requirements to qualify for the federal stimulus funds. All decision makers – from the federal level to physicians – need to be focused on the fact that the end game of adopting EHR systems and other health IT is to create better clinical outcomes, which will help transform and reform the healthcare industry.

## The Role of government

- **Government should act as sponsor, communicator and champion.** Roundtable attendees all agreed that government has an important role – but not as an entity mandating standards. Government should sponsor the industry consortium and be a champion of secondary use of data, communicating and promoting opportunities and benefits, not just risks. They agreed that the government has a critical role in communicating best practice guidelines.
- **Collaborate with various industry stakeholders.** Government should also be a collaborator. According to John Glaser, Vice President and CIO of Partners HealthCare, “There are ways to work with the life-sciences companies but also to work with the federal government in exploring the use of this for an ongoing and complementary post-market surveillance.” Partners HealthCare, whose work on secondary use of data is one of the case studies, is collaborating with the Department of Defense as part of the eHealth Initiative Foundation’s Connecting for Drug Safety Collaboration. The collaboration was created, among other reasons, to support the FDA’s Sentinel Initiative. The FDA is also an advisor to the Collaboration. “I don’t know that we’ll get as much specificity as might be needed to really challenge whether a drug ought to be in a market, but I also think it’s fairly clear that you can be much faster and involve much less fewer funds, frankly, to do what we would call the ‘canary in the mine,’” Glaser said.

With healthcare reform on the national agenda this year and health IT seen as central to the overall solution, ONC's (Office of the National Coordinator for Health IT) actions will be felt from the federal level to the consumer. Industry leaders and stakeholders across the healthcare ecosystem who came together to put forth these recommendations on the secondary use of data are pushing for a similar impact.

Decades ago, all data that the healthcare industry generated was paper based. Knowledge exchange was, and still is to some extent, a laborious practice. Today, data is capable of being accessed in real or near-real time and at the point of care, and best practices are being shared. This,

however, is the tip of the iceberg. The healthcare industry can and should do more. Secondary use of data has the potential to transform how we deliver healthcare. Imagine a time in the future when a physician eschews standard treatment for a patient's chronic disease because of the patient's genetic makeup. Or imagine a drug's time to market being shortened without compromising patient safety, which in turn would reduce the medication's cost, because of the broad and deep data available for clinical trials. That time will come sooner rather than later when all stakeholders embrace secondary use of data and work together to build an infrastructure to support it.

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