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The Emerging Revolution in Health Care

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INTRODUCTION

Health care is in a time of major transition. Eighty percent of doctors now have deployed electronic health records. Health information exchanges are starting to share data and undertake analysis that helps people learn in real-time. And patients are getting more engaged with their medical treatment through Internet searches, medical chatrooms, and social media conversations.

There clearly are substantial opportunities to move health care into an evidence-based model using health information technology, social collaboration, and advanced data analytics. Yet there remain a number of challenges in order to gain the benefits of the information revolution. We need to address problems in terms of interoperability, privacy, and security to make necessary progress.

Recently, we held a dinner discussion at Brookings with leading health experts from government, business, and academia. We talked about new advances in consumer access, data sharing, and infrastructure development and ways to modernize our health care system. In this paper, we summarize key ideas that came out of that conversation and ideas that we believe are important for the future of health care.

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OPPORTUNITIES FOR PATIENT ENGAGEMENT AND DATA SHARING

Several current trends have the potential to transform medical treatment. One is the rise of patient engagement in prevention, wellness, and treatment. Patients often supplement information from health providers with electronic sources and conversations with friends or family members. Digital technology gives people the capacity to broaden their searches and consult with a wide range of people. Patients get access to the most up-to-date information and this helps them make informed choices about their treatment. Educating patients and encouraging them to actively engage with care providers in the process of the medical decision making is the first step toward patient-centered care.[1]

Second, greater numbers of patients and health care providers are engaging in collaborative activities. At the consumer level, patients are sharing their symptoms and treatments online and getting advice and reactions from other people. Recent studies[2] show that such online platforms are playing an important role in educating patients and even reducing their need for inpatient care. Moreover, these online communities provide an abundance of patient-reported data that can be a valuable resource for evidence based medical research.[3]

These data sources will potentially reduce the high costs of conducting medical research. There are listservs for people suffering from certain illnesses, and patients can compare notes on diagnosis and treatment. Sharing similar experiences with others will help the patients and their families to better cope with the emotional burdens of their medical situation. Among providers, collaboration takes the form of formalized consultation. The more serious the illness is, the greater the number of health providers who are likely to be involved. In those situations, information-sharing is vital in order to make sure there are no drug interactions or therapies that are inappropriate for the various diseases being treated. New solutions such as Health Information Exchange platforms enable care providers to have access to a more comprehensive medical history of their patients. This will not only enable them to provide better care to their patients, but also helps them to avoid unnecessary medical tests and procedures which results in considerable savings in health care costs.[4]

Finally, regulators are paying greater attention to health outcomes. Governments have started penalizing hospitals for high readmissions rates. Those with rates above average have to provide an explanation and develop plans to improve their performance. Functioning information systems help providers track patient outcomes and ensure that patients receive treatments that have positive patient results.

CHALLENGES

In an era of data sharing and data analytics, one of the most important questions is who hosts medical data. There are a range of organizations that collect health data, from doctors and hospitals to insurers, pharmacies, and patients themselves. The diversity of information collectors makes it difficult to assemble the different pieces of the information ecosystem in a single system. Companies recognize that health information has great value, and it often is difficult to get them to share data. Building trust between different stakeholders and creating sustainable business models is a critical and missing element in the smooth exchange of health data.[5]

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[1] Barry, Michael J., and Susan Edgman-Levitan. "Shared decision making—the pinnacle of patient-centered care." *New England Journal of Medicine* 366.9 (2012): 780-781.

[2] Wicks, Paul, et al. "Sharing health data for better outcomes on PatientsLikeMe." *Journal of medical Internet research* 12.2 (2010).

[3] Frost, Jeana, et al. "Patient-reported outcomes as a source of evidence in off-label prescribing: analysis of data from PatientsLikeMe." *Journal of medical Internet research* 13.1 (2011).

[4] Frisse, Mark E., et al. "The Financial Impact of Health Information Exchange on Emergency Department Care." *Journal of the American Medical Informatics Association* 19.3 (2012): 328–33.

[5] Vest, Joshua R., and Larry D. Gamm. "Health Information Exchange: Persistent Challenges and New Strategies." *Journal of the American Medical Informatics Association* 17.3 (2010): 288–94.

Even if providers cooperate on data sharing, interoperability remains a big challenge in many parts of the system. Although stakeholders have long known the crucial role of interoperability,[6] it is still difficult to get different information systems to exchange data with each other. Providers use systems with varying technical specifications, language, and semantics. Some progress has been made through "meaningful use" requirements by the federal government. Standards have been set that have helped manufacturers and software designers build more compatible systems.

In an interconnected world, patients want to know how medical professionals are using their data. Even with de-identified personal information, respecting privacy is crucial. As more and more information is included in people's medical records, it becomes even more important to safeguard the confidentiality of health information. The combination of medical records, geolocation data, and consumer spending decisions creates a network of information that is rather comprehensive.

Data may include records, everything from diseases and prescriptions to consumer purchases, lifestyle choices, and personal circumstances. As compared with personal and financial data, medical data is highly sensitive and data leaks could have severe consequences for patients. Unlike financial data sharing systems, there are no third parties to ensure the security of storage and exchange of medical data in the event of a breach, or to provide compensation to the patients. The unique risks associated with health data may discourage patients to share it liberally.

With the creation of data sharing networks, there are questions about how to make sure information is used for positive purposes. The creation of large data sets may tempt criminals or fraudsters who want to steal the identities of patients, gain access to credit card data, or obtain information that could be used to embarrass or even blackmail patients. While the security technology in sectors such as banking and e-commerce is mature enough to ensure that customers' data are sufficiently protected, there are still many opportunities for improving this technology in health care sector.

Despite all of the benefits of information technology and big data analytics in the medical field, over reliance on them may obstruct the important relationship between physicians and patients. Replacing these innovations with personal and face-to-face exchange of information between doctors and patients hampers the emotional and human element of medical treatment. Patients may feel ignored and not heard. In this situation, they could lose their trust in their physicians, which will ultimately hamper their treatment.

The initial costs for providers deploying big data systems present acute challenges for certain providers. Ongoing maintenance and upgrading expenses also present important barriers. It is also critical that big data systems save money in other areas and improve overall efficiency. The Many hospitals and clinics have decided for now to not use these advanced tools because of the challenges. The precise measurement of the impact of implementing big data solutions in health care sector remains unclear.

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[6] Brailer, David J. "Interoperability: the key to the future health care system. "*Health Affairs* 24(2005):W5.

RECOMMENDATIONS

In order to encourage evidenced-based medicine and better consumer engagement, there are several steps that should be undertaken. Having data on what works and doesn't work is vital for making informed choices. This is true both for patients as well as health care providers. Establishing proofs of concept will go a long ways towards furthering value-based health care. Data represents an important way to empower patients and put them in charge of their medical care. We need computer architecture that integrates health information and clinical care into the work flows of people's overall lives. Having people-centered systems increases the odds that patients will incorporate technology into their real-time decision-making.

Physicians remain a critical part of the health system. They are the most trusted and authoritative source for many patients. They are the ones who make treatment recommendations and offer patients advice on wellness and prevention protocols. We need to make sure that there are enough incentives for them to adopt health information technology and incorporate the latest evidence in their decision-making. The reforms to insurance payment plans in which the quality and value rather than volume of the medical services is rewarded will incentivize medical providers to enhance their use of computerized decision support software and do a better job in treating patients.

USEFUL BIG DATA TOOLS

Rapid-learning models analyze data and generate recommendations for researchers and providers in real-time. Each patient's individual experience is an essential part of effective treatment. Rather than only performing expensive clinical trials on small numbers of patients over a period of several years, it is valuable to have data on large numbers of patients. This allows databases to be stratified and randomized, and helps researchers identify patterns, even for those who suffer from rare diseases. Speeding up the research process is vital for the future development of medicine.

INTEROPERABILITY

Tracking patients across health care systems is also critical. There now are data sharing networks within particular organizations, but it still is a challenge to connect different groups and diverse geographic areas. Having identification mechanisms that match patients across systems will facilitate the integration of information from different sources. In addition, promoting the compatibility between different medical information systems and compliance with universal standards of information exchange such as HL7 will significantly enhance our ability to track patients and share their medical data between different entities.

Medical imaging is an area that already has high interoperability. Standards assure that different systems can read information produced elsewhere. Encouraging physicians to share data and ensure that relevant parties have access to patient information will improve treatment options and improve health outcomes. Accountable care organizations need a 360 degree outlook on patient conditions so they can see the full range of factors that impinge on health.

CONSUMER EDUCATION

Improving consumer education and access to information is vital to producing change. Empowered patients do the best job of protecting their interests and making sure that their treatment plans are appropriate. It is important to make sure that underserved populations have access to electronic systems and quality medical care. Both patients and physicians should be provided with tools that have an intuitive design and are easy to use. The quality of interface design and user friendliness of medical applications of hand held devices can encourage patients and physicians to increase their level of use.

DIVERSE SETS OF RECORDS

Electronic health records provide a narrow view into a patient's health. They include only data from doctors' visits and in lab tests, but not information on what happens outside of those medical facilities. Using nominally "non-medical" would help providers determine the effectiveness of treatments and identify aspects of people's behavior that complicate their wellness regimes. Patient centered health records systems in which the patient has online access to his or her medical records could also improve diagnoses. A well-designed health records system would enable patients to electronically record, store, monitor, and share many different kinds of health related data such as diet, exercise level, and blood pressure. This information would serve as a useful supplement to clinical records and would improve the quality of medical services provided to the patients.

ENSURING PRIVACY

As medical information gets aggregated and consolidated, we need to make sure that data are not used against people. In the financial area, for example, some institutions engage in illegal redlining in which lenders refuse to make loans or charge higher interest rates based on perceptions of risk in certain areas. If a similar situation played out with health records then a claims processor could potentially penalize a diabetes patients who purchased a doughnut.

These possibilities raise ethical questions for the system as a whole. Avoiding unintended consequences of data sharing and technological innovation are important to the long-term success of these systems. In certain respects, our technology is ahead of the culture, and this poses certain risks in how we handle consumer information. Unwarranted use of medical data in other sectors may lead to discrimination and unfair social treatment of citizens. New policies and regulations should be set to make sure that the medical data is only used for their intended purpose upon the consent of the patients.

THIRD PARTY CONSULTATIONS

As medical care gets more complicated, patients may turn to third parties for health advice. The growing complexity of information systems and health treatments may lead them to rely on others outside their medical providers for consultation. This raises the question of who will police these third parties and make sure they offer fair and reasonable recommendations. In new models of medical care, consumers should be provided with enough information to educate themselves about risks arising from new players and practices.

Finally, as more medical data is accumulated and integrated with personal, financial, and geospatial data, the consequences of compromising it become more disastrous and the risks of privacy intrusion elevate. Special effort should be made to fully integrate all of the health information systems with appropriate security technology and ensure that the patient records remain safe and protected.

GOVERNANCE STUDIES

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