Meeting Proceedings

On June 25, 2013, the Bipartisan Policy Center (BPC) held a policy forum in collaboration with Intel to explore the potential that “big data” holds to improve both the delivery of care and the health and wellness of individuals. Following a welcome from BPC President Jason Grumet and opening remarks from U.S. Senator Ron Wyden (D-OR) and Intel’s Eric Dishman, a panel of more than 35 leaders across the health care industry engaged in an interactive discussion on the promise, challenges, and key policy issues associated with the use of big data to improve health and health care in the United States.

Leading experts with a diverse range of perspectives provided opening insights to spur discussion on three key areas: the opportunities and the challenges of big data, how to operationalize its use, and effective ways to manage privacy and security. Insights offered by the participants during this interactive discussion are summarized in this report.

Panel discussion with:

- Khaled El-Emam
  Canada Research Chair in Electronic Health Information, University of Ottawa; Chief Executive Officer, Privacy Analytics

- Joe Gray, Ph.D.
  Associate Director for Translational Research, Knight Cancer Institute and Chair, Department of Biomedical Engineering, Oregon Health and Science University

- Mary Grealy
  President, Healthcare Leadership Council

- Mark Hogle
  Chief Technology Officer, Centers for Medicare and Medicaid Services

- Leonard Lichtenfeld, M.D.
  Deputy Chief Medical Officer, American Cancer Society

- Deven McGraw
  Director, Health Privacy Project, Center for Democracy & Technology

- J. Marc Overhage, M.D., Ph.D.
  Chief Medical Informatics Officer, Health Services, Siemens Healthcare

- Nirav Shah, M.D., MPH
  Commissioner of Health, State of New York

Moderated by:

- Janet Marchibroda
  Director, Health Innovation Initiative, Bipartisan Policy Center

Featuring remarks from:

- The Honorable Ron Wyden (D-OR)
  U.S. Senate

- Eric Dishman
  Intel Fellow, General Manager, Health Strategy and Solutions, Intel Corporation

- Jason Grumet
  President, Bipartisan Policy Center
Overarching Themes

Data is the next great natural resource. Big data has the power to transform lives. In health care it can reveal the factors that influence health, help target appropriate care for individuals or populations, enable new discoveries, shape outcomes, and reduce costs.

Opportunities for big data bring new challenges. To fully realize the promise of big data, more work is needed to address common challenges, including improving data standardization and interoperability, promoting information sharing, engaging individuals and establishing strong data governance, improving upon analytical methods, developing workforce capabilities, and exploring ways to bring the value of big data to individuals and clinicians at the point of care.

Enhanced privacy and security are enablers for big data. Building awareness of the benefits of big data for improving health and health care among individuals, and allowing those individuals to participate with strong assurances about privacy and security, further enables big data to realize its promise.

What is Big Data?

From the dawn of time until 2003, the world generated an estimated 5 quintillion bytes (or 5 exabytes) of digital data. Now we generate that much data every two days. The digital universe currently includes about 2.72 zettabytes (ZB) of data, a figure predicted to double every two years.¹ As recently as the year 2000, only 25 percent of the world’s information was stored digitally. Today, that number is 98 percent.²

That’s “big data.”

In a broad sense, big data refers to enormous data sets that are large, complex, and not easily processed using traditional methods. Analysis of big data can lead to improved safety and security, tailored information and products, breakthroughs in understanding our environment on Earth and in space, and better health care outcomes. Big data is fueling not only an information revolution, but an innovation economy as well.

The U.S. health care system is increasingly becoming digitized, due in part to significant federal investments in the use of electronic health records (EHRs) by providers across the United States. Adoption of at least a basic EHR system among office-based physicians increased from 17 percent in 2008 to 40 percent in 2012.³ The share of hospitals that have adopted at least a basic EHR system increased from 9 percent in 2008 to 44 percent in 2012.⁴ Authorized by the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, nearly $16.6 billion in incentives have been paid through October 31, 2013, to 4,149 hospitals and 320,975 eligible professionals that are “meaningfully using” health IT, through the Centers for Medicare and Medicaid Services’ (CMS) Medicare and Medicaid EHR Incentive Programs.⁵

“I think that America is at a transformational moment in the debate about health care, a moment where access to the most significant information about health care services becomes easily accessible to American consumers.”

—U.S. Senator Ron Wyden

With 85 percent of Americans using the Internet and 56 percent owning a smartphone, individuals are increasingly going online for their health and health care to gather information, assist with self-monitoring or tracking, and share their experiences with others.⁶,⁷ Seventy-two percent of Internet users have looked online for health information.⁸ About one-fifth of the 69 percent of adults who track a health indicator like weight, diet, exercise, or symptoms, use some form of technology to do so.⁹ Sixteen percent of online health information seekers have tried to find others who might share the same health concerns.¹⁰

In health care, big data encompasses a whole range of data types, including the following:

- Clinical data derived from electronic records within physician offices, hospitals, imaging centers, laboratories, pharmacies, and other settings in which care and services are delivered;
- Claims and cost data derived from those who pay for and manage care;
Biometric data derived from devices and other remote tools that monitor such things as weight, blood pressure, blood glucose levels, etc.;

- Data input by individuals, including preferences, satisfaction levels, health status, and self-tracking information on food intake, exercise, sleep, etc.;
- Genomic information, which is showing significant reductions in the time and cost associated with genetic sequencing;
- Data on other determinants of health, such as those related to socioeconomic factors and the environment; and
- Social media data.

“There is no doubt that big data and the analytics of big data and the discoveries that it will enable are a fundamental pillar of enabling personal health for all.”

—Eric Dishman, Intel

Only an estimated 10 to 15 percent of health is determined by medical care delivery. The remaining 85 to 90 percent of health is determined by other factors, which include healthy behaviors, genetics, and the socioeconomic and physical environment (e.g., access to education and job opportunities, housing, public safety, availability of places to exercise, healthy food choices, and other environmental factors). Introducing clinical information with data from sources that reside outside of the health care system through big data initiatives offers significant opportunities to improve health and health care.

Discussion Summary

Using Big Data to Drive Improvements: Opportunities and Challenges

Analysis of big data can help clinicians and organizations deliver higher-quality, more cost-effective care. Big data can lead to the development of an anticipatory health care system, where providers can create personalized evidence-based medicine, tailored to patients’ personal prevention profiles, social determinants of health, and even preferences for how, where, and when they want to receive care. It can help to identify both public health threats and safety issues. Big data can help researchers understand more than ever before about health and the many factors that affect it, as well as determine what treatments are most effective for particular conditions. Most importantly, it can help patients better understand their own health and more effectively navigate and access the health care system.

Using big data, analysts can use predictive models—statistical methods that use data to predict risk or trends—to help health care providers target care in ways that improve outcomes and save money. Some health care organizations are already using predictive models to help customize care in ways that improve outcomes and prevent unnecessary utilization. For example, Mt. Sinai Medical Center in New York has used a predictive model to effectively target high-risk patients to reduce its 30-day readmission rate from 30 percent to 12 percent and decrease...
Operationalizing the Use of Big Data

A great deal of health data is stored in silos by the organization or entity that collected it, and there is very little sharing of that information across organizations. Even for health systems that wish to share data, the lack of interoperability between and among information systems is a common and often high barrier. Reliable, sustainable, and effective infrastructure for health information exchange is not broadly deployed. In addition, there is a lack of adoption of many of the standards required for interoperability and exchange.

Integrating and analyzing data from disparate sources requires the ability to accurately match data associated with an individual patient. Currently there is considerable
variation in the approaches used to link patient data, and there are no universally accepted standards for conducting matching processes or for evaluating their effectiveness.

Variable quality in the data derived from different sources has an impact on its usefulness and usability. Data is often collected for one purpose (e.g., for paying claims) without any anticipation that it may be used for other purposes in the future (e.g., assessment of quality of care delivered or evaluation of safety risk). Additional challenges to operationalizing data include the volume and variety of data, and the rapid pace at which the available data and the needs for sharing it are growing.

Advancing the interoperability of data will require more consistent use of existing standards, concerted efforts to break down data silos, continued standards development, and an acceptance of some level of variability. Agreement on and execution of common methods for more accurately linking patient data will be needed. Moving from encounter-centric data to longitudinal data about patients will render data more actionable and a more effective tool to shape interventions that will improve health and processes of care.

As the amount and diversity of available data continue to grow, so will the needs for enhanced analytical methods. Traditional scientific models, which depend on expert opinions and best practices will over time be replaced with more data-driven and evidence-based approaches. New analytical approaches will be needed as sample sizes increase. More work must be done to make methods transparent as well as to evaluate, compare, and improve analytical approaches as big data takes hold.

Being able to access and analyze the data is only one part of the challenge. Converting insights gleaned from the

Lessons From the Human Genome Project

Joe Gray, Ph.D., Oregon Health and Science University, highlighted the Human Genome Project as “the first successful biomedical big data program” in the nation. Some of the factors that helped it to succeed include:

1. A national objective was clearly articulated.
2. A new culture of sharing rather than guarding data was defined and promoted within the scientific community.
3. The program fostered the development of data standardization, archiving, and distribution processes.
4. The program included incentives to make the data easily, widely, and quickly available.
5. Project funders built many of these steps into their requirements.

As a result of this project, the number of human disorders for which the molecular basis is now known grew from about 60 to almost 5,000. This has directly influenced the development of more than 100 drugs. Genomic data has been used to develop molecular markers to define subtypes of the major cancer types, leading to commercially available diagnostics and new therapies. This research has resulted in the discovery of more than 1,800 disease genes and has reduced the time it takes to find a gene suspected of causing an inherited disease from years to days.
data into understandable tools that are integrated into a clinician’s workflow are yet another. Making information understandable and actionable by consumers can also be a challenge. Considerable attention must be paid to making the results of the analysis useful and valuable to both individuals and clinicians at the point of care, so that the benefits of big data can be fully realized.

Finally, the vast increase in the amount, diversity, and complexity of data will require new capabilities within the workforce. One study suggests that the nation will be short two million workers with the required knowledge and expertise in big data by the year 2018. Workforce development programs—sponsored by both the public and private sectors—can help, along with incentives to attract individuals with expertise in math, statistics, data science, and related fields to health care.

**Addressing Privacy and Security**

Concerns about privacy and security are sometimes cited as barriers to further progress on the use and exchange of big data. While the Health Insurance Portability and Accountability Act of 1996 (HIPAA) is designed to safeguard patient privacy, it is often misunderstood, misapplied, and over-applied in ways that may inhibit information sharing unnecessarily. Additionally, a great deal of data about individuals falls outside the purview of HIPAA, such as consumer-generated data that might be posted on social networks, stored in apps, or shared through other online sources. HIPAA specifies how data should be de-identified, but there is considerable variability in the practice of anonymization and no existing standards to govern it. Additionally, some data, such as genomic data, is difficult to adequately anonymize.

Seeking consent from patients to use their data for clinical trials or observational research can help mitigate concerns about privacy, but there is evidence that using “opt-in” or “opt-out” patient data results in bias.

Trust plays a critical role in the use of big data and data governance is needed. The use of big data in health care typically requires the multiple organizations in which various data sets reside to work together and negotiate agreed-upon policies and technical methods for information sharing based on trust. Fair information practices can be leveraged to support common policies for information sharing.

Robust security also plays a role in building trust. The use of multilayered approaches, combined with other safeguards—such as encryption, tokenization, and access controls—can play a critical role in addressing privacy and security risks, enabling sharing of data, and supporting research that requires more than fully de-identified data.
Policy Considerations

Based on insights shared by meeting participants and previous policy work, BPC offers the following.

- **Standards: Promoting Adoption of Current Standards and Developing New Ones**
  Effective standards, policies, and best practices for data capture, analysis, and sharing must be in place for big data to serve its potential. Use of common standards and policies should be incentivized. Processes for agreement on and adoption of new standards for data content and transport should continue within a long-term data and standards strategy that addresses broad health and health care needs.

- **Advancing Information Sharing**
  Despite the significant growth in electronic health information, for the most part, data continues to reside in silos—inaccessible for purposes of improving health as well as the quality, cost, and patient experience of care. Public and private sector incentives are needed to accelerate information sharing across (and discourage information blocking among) clinician practices, hospitals and health systems, health plans, laboratories, pharmacies, imaging centers, and other settings in which care and services are delivered. Sharing of best practices for the conversion of data analytics to useful interfaces for both clinicians and consumers should be supported and encouraged.

- **Engaging Individuals**
  Individuals have the most to gain from big data, including the movement toward more personalized care based on genomics, environment, and medical history; better evidence about the effectiveness of alternative treatments; development of new therapies designed to cure disease; and improvements in the quality and cost of care. The integration of patient-generated information in analysis promises to accelerate both discovery and improvement. Current efforts associated with exploring the technical and policy aspects of integrating patient-generated information within electronic health records should continue and accelerate. Engagement of individuals in planning, executing, and improving big data efforts can play a big role in their success. In addition, the development of policies and technical methods to enable individuals to electronically access information in their health records should continue and accelerate.

- **Building Workforce Capabilities**
  Methods for expanding the capabilities of the workforce to help address new demands for data scientists should be explored.

- **Improving Analytical Methods**
  Federally funded collaborative research efforts should promote and support transparency of analytical methods, evaluation of their usefulness, development of new methods that meet new data demands, and best practices.

- **Ensuring Privacy and Security**
  The explosive growth of technology and data brings with it new challenges in understanding how to apply current policies associated with privacy and security. Providing more clarity regarding the application of existing federal and state privacy laws will help organizations meet the challenge of effectively collecting, using, and protecting information from so many sources to improve health and health care. Supporting best practices and common policies within collaborative big data efforts will help build trust and improve the likelihood of success. In addition, the development of policies and technical methods to enable individuals to electronically access information in their health records should continue and accelerate.

**Conclusion**

Big data has the potential to transform health care and significantly improve health outcomes in the United States. The promise that big data represents—dramatically improving the delivery of care and the health of populations and individuals—is significant, yet there are challenges to realizing this promise. Health care and information technology leaders and policymakers must continue the kind of rich dialogue that this forum fostered, moving our nation forward toward better care and better health for all its citizens.

*See http://bipartisanpolicy.org/events/2013/06/innovation-economy-information-revolution-transforming-health-care-through-big-data for the video archive of the entire meeting.*
Endnotes


June 2013 Meeting Participants

Justin Barnes
Vice President of Industry and Government Affairs, Greenway Medical

Hunt Blair
Principal Advisor, State Health-IT Enabled Care Transformation, Office of the National Coordinator for Health IT

George Bo-Linn
Chief Program Officer, George and Betty Moore Foundation

Alice Borrelli
Director, Global Healthcare Policy, Intel Corporation

Sharon Canner
Senior Director, Public Policy, College of Health Information Executives

James Crawford, M.D., Ph.D.
Senior Vice President, Laboratory Services, North Shore-LIJ Health System

Damon Davis
Director, Health Data Initiative, U.S. Department of Health and Human Services

Eric Dishman
Intel Fellow, General Manager, Health Strategy and Solutions, Intel Corporation

Gregory Downing
Executive Director for Innovation, U.S. Department of Health and Human Services

Khaled El Emam
Canada Research Chair in Electronic Health Information, University of Ottawa; Chief Executive Officer, Privacy Analytics

Kevin Fickenscher, M.D.
Chief Executive Officer, American Medical Informatics Association

Tina Grande
Senior Vice President, Policy, Healthcare Leadership Council

Joe Gray, Ph.D.
Associate Director for Translational Research, Knight Cancer Institute; Chair, Department of Biomedical Engineering, Oregon Health and Science University

Mary Grealy
President, Healthcare Leadership Council

David Hoffman
Director of Security Policy and Global Privacy Officer, Intel Corporation

Mark Hogle
Chief Technology Officer, Centers for Medicare and Medicaid Services

John Iglehart
National Correspondent, New England Journal of Medicine; Founding Editor, Health Affairs

Angela Jeansson
Assistant Director, American Osteopathic Association

Josh Lemieux
Health Strategy and Solutions Group, Intel Corporation

Jeffrey Lerner
President and Chief Executive Officer, ECRI Institute

Leonard Lichtenfeld, M.D.
Deputy Chief Medical Officer, American Cancer Society

Andrew Litt, M.D.
Chief Medical Officer, Healthcare and Life Sciences, Dell Inc.

Lisa Malloy
Director, Policy Communications, Intel Corporation

Janet Marchibroda
Director, Health Innovation Initiative, Bipartisan Policy Center

Kerry McDermott
Senior Director, Healthcare Technology Policy, West Health Institute

Deven McGraw
Director, Health Privacy Project, Center for Democracy and Technology

J. Marc Overhage, M.D., Ph.D.
Chief Medical Informatics Officer, Health Services, Siemens Healthcare

Steve Phillips
Senior Director, Global Health Policy, Johnson & Johnson

Matt Quinn
Director of Health Care Initiatives, Federal Communications Commission

Darryl Roberts
Senior Policy Fellow, American Nurses Association

Mark Savage
Director of Health IT Policy and Programs, National Partnership for Women and Families

Mark Segal, Ph.D.
Vice President, Government and Industry Affairs, GE Healthcare

Nirav Shah, M.D., MPH
Commissioner of Health, State of New York

Paul Uhrig
Chief Administrative and Legal Officer, Chief Privacy Officer, Surescripts

Steve Waldren, M.D.
Senior Advisor, American Academy of Family Physicians

Claudia Williams
Senior Advisor, Health IT, White House Office of Science and Technology Policy

The Honorable Ron Wyden
U.S. Senate (D-OR)

Stephanie Zaremba
Senior Manager of Government and Regulatory Affairs, athenahealth
About the BPC Health Innovation Initiative

BPC’s Health Innovation Initiative conducts research and collaborates with experts and stakeholders across every sector of health care to develop recommendations that promote innovation and the use of IT to support improvements in the cost, quality, and patient experience of care.

About the Innovation Economy Series

The Bipartisan Policy Center hosted two forums in collaboration with Intel to explore the potential for big data innovation to advance efforts in the areas of health care and homeland security. Discussions focused on the promise of big data, current and future challenges to overcome, and policy issues that must be addressed to encourage innovation while safeguarding privacy and security in our increasingly connected society.

This event is part of a broader 2013 “Innovation Economy: Information Revolution” series of roundtable and public forums convened in parallel by the Aspen Institute and the Bipartisan Policy Center, in collaboration with Intel. The Innovation Economy conversation was convened by Intel in 2009 to focus on the vital role of innovation in sustaining and building upon U.S. competitiveness in the global economy.

Acknowledgements

BPC would like to thank and acknowledge the meeting panelists and participants for contributing their time and expertise to the interactive policy discussion. BPC would also like to acknowledge Janet Marchibroda, director of BPC’s Health Innovation Initiative; Ann Gordon, writer and editor; and Kelly Isom, administrative assistant of BPC’s Health Innovation Initiative and Health Project, for their contributions to this report. BPC extends special thanks to the Intel Corporation for their support of this meeting and the production of this report.

Disclaimer

This report is a product of the BPC Health Innovation Initiative. This meeting summary was prepared by BPC staff and consultants as a factual summary of discussions that occurred during the meeting hosted by the BPC Health Innovation Initiative in collaboration with Intel. The statements made are those of the authors or individual meeting participants and do not necessarily represent the views of all of the meeting participants.

Also, the findings and recommendations expressed herein do not necessarily represent the views or opinions of the Bipartisan Policy Center, its founders, or its board of directors.
Founded in 2007 by former Senate Majority Leaders Howard Baker, Tom Daschle, Bob Dole and George Mitchell, the Bipartisan Policy Center (BPC) is a non-profit organization that drives principled solutions through rigorous analysis, reasoned negotiation and respectful dialogue. With projects in multiple issue areas, BPC combines politically balanced policymaking with strong, proactive advocacy and outreach.