

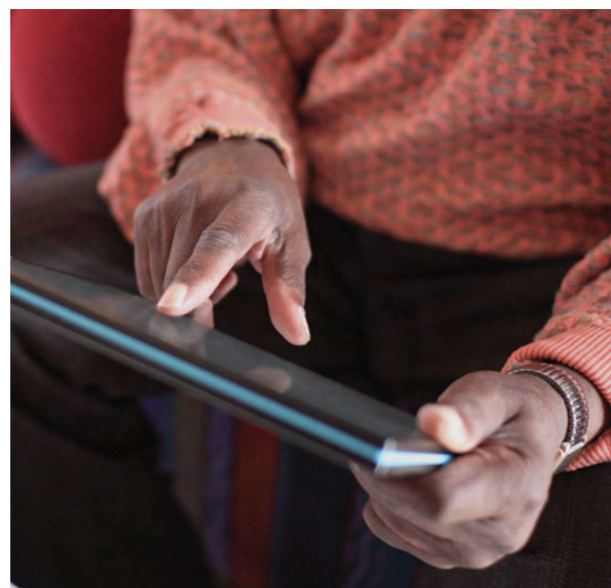
Data for Health

Learning What Works



Robert Wood Johnson
Foundation

A REPORT FROM THE DATA FOR HEALTH ADVISORY COMMITTEE



APRIL 2, 2015

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For more than 40 years the Robert Wood Johnson Foundation has worked to improve health and health care. We are striving to build a national Culture of Health that will enable all to live longer, healthier lives now and for generations to come. For more information, visit www.rwjf.org. Follow the Foundation on Twitter at www.rwjf.org/twitter or on Facebook at www.rwjf.org/facebook.

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A REPORT FROM THE DATA FOR HEALTH ADVISORY COMMITTEE

APRIL 2, 2015 | PREPARED BY VIRGINIA TECH



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“The sheer volume and velocity of data at our fingertips today is unprecedented... As we build a Culture of Health—a nation where everyone has the opportunity to live longer, healthier lives—it will be critical to ensure communities can effectively use and manage this information in ways that help people get healthy and stay healthy. The *Data for Health* initiative will be a starting point for identifying what infrastructure is needed to turn this information into an effective tool for improving health nationwide.”¹

—Risa Lavizzo-Mourey, MD, MBA, President and CEO, Robert Wood Johnson Foundation



Executive Summary

Data for Health: Learning What Works

The Robert Wood Johnson Foundation (RWJF) initiative, **Data for Health**, explores how data can be collected, shared, protected, and translated in ways that are useful to individuals, organizations and communities. With the opportunity of exponentially increasing amounts of data about almost every aspect of our lives, we face the challenge of how to effectively harness it, share it, and use it to guide public policy, as well as help efforts aimed at improving health.

Recognizing the vast opportunities to use data to improve health, RWJF charged an Advisory Committee, comprised of leading public health practitioners, physicians, health care researchers, health technology and informatics experts, consumers, and representatives of local government and health care systems, to investigate how individuals and communities are already using data to improve health, their aspirations for using health information, what new data they want to access, and how to collaborate to share and secure data.

RWJF and the Advisory Committee hosted a listening tour of five “*Learning What Works*” events in diverse cities across the country: Philadelphia; Phoenix; Des Moines, Iowa; San Francisco; and Charleston, South Carolina. A broad spectrum of individuals—from health care providers to researchers to community service providers to business leaders interested in using data to improve their health and the health of their communities—attended these five events. The forums generated key observations and examples, as well as many questions around using, exchanging, and protecting data and what individuals and communities want and need in order to improve health or foster connections between different sectors. These observations provided the basis for the Advisory Committee’s findings and recommendations, which are detailed in this report.

Learning What Works Participant Observations

Across the different cities, the Advisory Committee observed five significant themes:

- Using Data
- Exchanging Data
- Protecting Data
- What Individuals Want and Need
- What Communities Want and Need

Using Data

Now, more than ever, we know that an individual’s health is influenced by many things besides the care they receive, including: where that person lives, learns, works, plays, and worships.

More and more people understand that they can potentially use information technology and the data from this powerful technology to address health, both inside and outside the health care setting.

- **Health is More Than Health Care**—Individuals often think that their health is a direct result of the health care services they receive. However, individuals embrace a broader understanding when shown data linkages between the use and availability of social services and nonmedical data. Such linkages help people understand the social and behavioral determinants of health and how they can take action to improve their health.
- **Data Matter to Individuals**—It is not hard to get people to talk about the possibility of using data to help make health decisions. People are able to envision the many ways aggregated personal health information could inform actions that lead to improvements in health status within their communities.
- **Translating Data into Useful Information Remains a Challenge**—People expressed a need for guidance and tools that link data about their lives, including medical care, to help them make personal and family health decisions. Communities want to be proactive and expressed the need for timely data and information. Providers need information tools that assist their work, rather than detract by adding work to their day.
- **Generations and Cultures View Data Use Differently**—Age and cultural gaps exist in how people think about using personal health data. Some excel at digitally recording and accessing data about themselves and are open to broad use of their data to inform health decisions and health care options. Those who are less adept at using digital technologies are skeptical about the value of sharing their health information digitally. And there are groups who cannot participate due to having no access to digital technologies.

- **Data Use Does Not Equal Better Health Decisions**—Individuals do not necessarily act rationally, so simply having data or information available may not always promote positive changes in health.
- **Reimbursement and Funding Mechanisms Impact Data Use**—Doctors want and need better information about the populations they serve. Reimbursement mechanisms determine doctors' ability to have and use information. Funding mechanisms (e.g., grants and private funding) also drive research and collaborations that would provide new insights to improve population health management.

Exchanging Data

Health data is dynamic. It needs to be available at the right time and place to support both individual and community health.

- **Data Exchange Moves at the Speed of Trust**—Many individuals and community organizations support the use of aggregated personal health information to inform how to improve health, but demand more clearly stated value propositions supporting data exchange. People want to trust that their data will be used for important and helpful purposes, while also being protected from invasions of personal privacy and breaches in their personal information.
- **“Big Data” and “Long Data”**—People recognize the potential of “big data,” (e.g., aggregated sets of data that provide information about the livability and health of their community, access to services, and economic conditions), to support analytics that can inform practice and program development. People also want “long” data, data that tracks their individual health over time and allows them and their providers to see patterns and trends. They want their personal health data to move with them so that their providers can always access it when needed.
- **Infrastructure Competition**—Competition among private providers is a major barrier to sharing data at all levels and sectors, especially health care. This contributes to the lack of agreed-upon standards that would help share data across disparate information technology platforms.

Protecting Data

Digital services are needed to ensure that the data are securely stored and analyzed, that data can be drawn from multiple sources, and that it is possible for it to be shared.

- **Clinician to Community**—When community organizations, like social service agencies, ask clinicians for patient information, those clinicians are concerned about how to communicate that information back to community organizations securely.
- **Safety, Privacy, and Confidentiality Concerns Everyone**—Access to data is important. However, people should be able to choose when and how their data might be used. Fear of inappropriate use presents barriers to social consensus about where and how personal health data can be aggregated for use to inform individual, institutional, and community action.
- **Risk of Misuse**—At the community level, there are concerns about the risk of misuse of aggregated data, such as “data redlining,” (i.e., denial of services), or other harms that could come from broader access to health data about communities.

- **Legal Barriers**—Current laws, regulations and bureaucracies are an enormous impediment and barrier to data use and sharing. The absence of simply stated explanations limits the understanding and use of data privacy and security provisions already in law.



What Individuals Want and Need

Individuals want a “road map” that shows them their personal health information and guides them on what actions to take.

- **Lots of Data**—Individuals, including caregivers, need data to help them care for themselves and others. Yet, excessive amounts of information can be overwhelming. It is important to have the right amount of data when it is needed and interpretation when it is requested.
- **Caregivers Count**—Caregivers need data about their patients and the populations they serve to help care for them.
- **Health Data’s Split Personality**—People think differently about data when they think about using data for their individual health compared to using data for community health.

What Communities Want and Need

Community context is important. Data can be used to support neighborhood activism and help communities make wise decisions and investments in activities and actions that support the health and wellness of their citizens.

- **Partnerships Matter**—The strength of community partnerships is a pre-condition to the useful sharing of health data.
- **Community Data Infrastructure**—Many, if not most, communities lack the data infrastructures they need to use data for health.

- **Predictive Data Analytics**—To be proactive instead of reactive, communities need information on a broad range of data and predictive analytics on elements relevant to health, including the environment, safety, stress, and housing.
- **Data Stewards and Data Tutors**—Communities recognize that they need tools, such as digital tutors, to better understand how to gain access to and use data. And they need resources to turn data into information and information into action. In addition, communities want data stewardship through effective and legitimate data governance structures.

Learning What Works Adviser Findings and Recommendations

The listening tour at the core of the *Data for Health* Initiative generated in-depth conversations, shared observations, and concrete examples of successes and challenges that a broad range of players face in determining how data can be collected, shared, protected, and translated into actionable health information. The engaged discussions highlighted how people, communities and agencies are grappling with how to accelerate movement toward “making health information accessible when and where it is needed to improve and protect people’s health and well-being.”²

The observations from those sessions, along with individual advisers’ expertise, led the Advisory Committee to a set of findings and specific recommended actions across three areas:

- Establish the data exchange value proposition
- Build trust and community data competence
- Build community data infrastructures

Data for Health Advisory Committee Recommendations At-A-Glance

Listening Tour Themes	Data for Health Advisory Committee Recommendations
Establish the data exchange value proposition. Event participants emphasized that people do not have a clear understanding of why certain data should be shared or used.	<ol style="list-style-type: none"> 1. Launch a public awareness initiative on the value of data use and data exchange. (p. 6) 2. Establish a national health information dialogue. (p. 6)
Build trust and community data competence. The themes of trust and protecting data rang loudly across the country.	<ol style="list-style-type: none"> 1. Modernize policies governing health data. (p.7). 2. Strengthen data security and governance. (p.8). 3. Provide preparation for key stakeholders. (p. 8).
Build community data infrastructures. Communities have a greater chance of succeeding at health and well-being when organizations work together to create networks that integrate health with social and community services.	<ol style="list-style-type: none"> 1. Invest in data sharing. (p. 9) 2. Transform data into actionable behavior change. (p. 9) 3. Advocate for open state and local government <i>Data for Health</i> initiatives. (p. 9). 4. Access and use data generated by social media to demonstrate the value of health information. (p.9). 5. Launch a pilot Code for America data analytics program. (p. 9). 6. Address vulnerable populations. (p. 10). 7. Create and maintain a Community Resources Scorecard. (p. 10). 8. Create partnerships around <i>Data for Health</i>. (p. 10).

Establish the Data Exchange Value Proposition

Accelerating the use of data for improving health depends on helping individuals, communities and stakeholders see the benefits. Event participants emphasized that people do not have a clear understanding of why certain data should be shared or used. Across the country, attendees voiced strong desires to better understand the value of health data and how health information, central to them as individuals, is derived. There was consensus that context and issues must drive the collection and use of data.

FINDINGS

- **What's in it for me?** The public wants and needs an answer to this simple question.
- **Using the data.** Using data requires explaining why and how to use data. There is power in data for individual health and for community health, but it's challenging to spread that idea to the people and organizations that really need the information. Using data requires strong partnerships within a community—partnerships built upon trust.
- **Creating health information.** People want and need help translating their personal health data into useful, digestible information. They also need tools that help them interpret their data.
- **Constructing predictive analytics.** People want data to tell them more than just what has happened. They want help predicting what may happen to spark preventive health action and behavioral changes.
- **Broadening what people and communities think about health and well-being.** People often think only of health care when talking about their health and well-being. That limits thinking to curative medicine and often foregoes discussion of prevention and social determinants related to behaviors and the environment.

RECOMMENDATIONS

1. **Launch Public Awareness Initiative on the Value of Data Use and Data Exchange**—Detailed examples and use cases that explain how individuals and their communities benefit through the exchange and analysis of personal health information need to be shared. Philanthropic foundations, like RWJF, could host and disseminate a series of video stories showing patients, patient groups, researchers, and communities tell their stories of benefitting from data exchange and use.
2. **Establish a National Health Information Dialogue**—Health & Human Services (HHS) or philanthropic groups could engage a broad range of stakeholders as data use for health continues to evolve. The dialogue could serve as a platform for educating the public about ways in which data can be generated and used to make better health decisions, as well as health policies to improve the overall health of communities. The dialogue would promote the development of a national data infrastructure.

Build Trust and Community Data Competence

The themes of trust and protecting data rang loudly across the country. Data sharing is fundamental to realizing the Triple Aim goals of improving patient care, improving the health of populations, and reducing the per capita cost of health care. It is also central to achieving a Culture of Health where people understand that health is dependent on a multitude of factors that go beyond medical care.

FINDINGS

- **Mitigating concerns about privacy and security.** People have serious concerns about the security of private health data and the degree to which they can and should expect that their confidential health information will be kept private and secure.
- **Refreshing Privacy and Confidentiality Laws.** Many argue that we need smarter or next generation privacy and confidentiality laws at the federal and state levels.
- **Leveraging the digital self.** The use of personal devices that record, store and use health data is a growth market. Both public health and personal health should benefit. These data will impose additional privacy and security concerns.

RECOMMENDATIONS

1. **Modernize policies governing health data**—most of the federal and state statutes and regulations protecting the privacy of health data are years (and in some cases, decades) old. Policymakers should update these privacy protections in light of enormous changes in the ways technologies now influence and can be used to improve health. The Committee recommends policymakers modernize (and ideally harmonize across jurisdictions) these policies to reflect the interconnectedness of the health and social services delivery systems. They should also establish guidelines, rules and penalties needed to ensure secure data capture, storage, transmission and use. The Committee also finds that in many cases, simply changing or adjusting rules and guidelines will not be sufficient to meet society's health data use and infrastructure needs. In some cases, policymakers will need to modernize current privacy laws at both the federal and state levels.

Photo Credit: Mike Belleme/Getty Images



2. Strengthen Data Security and Governance

- **Strengthen the right of individuals to access and obtain their health data**—Today the law provides individuals with a right to access their health data, but the rights are not equal to the access enjoyed by others (e.g., health care providers and health plans). Frequently, individuals are treated as second-class citizens when they try to exercise these rights. Policies should establish clear, equal rights of an individual to obtain data about his or her health—akin to a Bill of Rights. Policies should empower individuals and enable them to make decisions about their own health and contribute to decisions that can improve the health of their communities.
- **Establish Laws for Consumer-Generated Data**—The United States needs a set of laws, policies and procedures governing devices that generate personal health information.
- **Accelerate Interoperability of Health Data**—HHS and particularly the Office of the National Coordinator for Health Information Technology (ONC) should create a national priority for accessing and exchanging electronic personal health information to improve population health. Achieving this will require accelerating sharing of lessons learned from Meaningful Use and other initiatives in order to spur people to push for an enhanced, interoperable health information infrastructure.

3. Provide Preparation for Key Stakeholders

- **Educate Health Professionals and Paraprofessionals**—Education is needed about the value and impact of social determinants of health and wellness as a step toward attaining the Triple Aim goals. Associations of health related schools—such as the American Association of Colleges of Nursing, American Association of Colleges of Pharmacy, American Dental Education Association, Association of American Medical Colleges, Association of Schools and Programs of Public Health, and the Physician Assistant Education Association—should ensure that curriculums integrate and emphasize learning about social and economic determinants of health.
- **Prepare Providers for Population Health Data Management**—Health professionals need access to data that support their ability to more effectively manage the populations that they serve. Incentives for key stakeholders to collect this data are needed. Tools need to be developed that provide data in formats that health professionals can use for population health management. Support for research to understand providers' needs and capacity is needed.

Photo Credit: Leo Kopelow/Getty Images



Build Community Data Infrastructures

Communities, broadly defined, have a greater chance of succeeding at improving health and well-being when organizations work together to create both formal and informal networks that integrate health with social and community services. Leadership, mutual respect, a shared vision, and common goals are essential to spurring these kinds of networks and systems.

FINDINGS

- **Creating health information technology platforms.** Communities need improved electronic health infrastructures to be able to use data for health.
- **Providing timely health data.** Data is needed at a useful geographic level or socio-demographic level for services (organizations) to better support the community.
- **Mediating the risks of data exchange.** Data exchange and data use initiatives are at risk of failing without agreement on the goals and value to the community.
- **Collaborating.** Organizations seem willing to collaborate, but are not always sure where to start. Sectors are working together for the first time and need to develop a common parlance around health information.

RECOMMENDATIONS

1. **Invest in Data Sharing**—To advance Triple Aim goals broadly, ONC, Centers for Disease Control (CDC), National Institutes of Health (NIH) and Patient-Centered Outcomes Research Institute (PCORI) and other interested funders should invest in data-sharing exemplars whereby cities and/or state agencies share data with health care partners, public health agencies and community groups. Resources should also be targeted to research that will generate better public understanding and support for data sharing.
2. **Transform Data Into Actionable Behavior Change**—Support partnerships between data scientists and health services researchers to understand how data can be utilized to nudge or influence behavior change, particularly in areas experiencing great health disparities. Private foundations such as RWJF, government (e.g., the NIH Precision Health initiative), private industry and academia should collaborate on these efforts.
3. **Advocate for Open State and Local Government Data For Health Initiatives**—Build on the open government data movement, focusing on data and reference information needed to help the public understand how to learn about and gain access to health services, like understanding insurance eligibility and social service quality and accessibility.
4. **Access and Use Data Generated by Social Media to Demonstrate the Value of Health Information**—Researchers and funders should promote the exploration of the potential of the many rich data sources coming from the enormous range of social media sources.
5. **Launch Pilot Code for America Data Analytics Program**—Provide opportunities for communities to develop ways to match people who need to understand the data with data analysis capacity. This could be as simple as building a community dashboard that mashes up data from existing government databases in ways that empower individuals to act on behalf of their own health. This initiative could include:

- Promoting a range of data “collaboratories” where people experiment with pilot sharing and accessing data, including social and human services data and information in every community;
 - Developing community data stewards (i.e., an accountable entity) known to all and committed to proper data use for health; this concept needs to link health care institutions with the communities they serve; and
 - Testing a parsimonious set of standardized measures that matter to the public for use on community dashboards and personal health comparisons.
6. **Address Vulnerable Populations**—Issues of digital health literacy need to be addressed by developing programs, educational tools and resources in health care settings to close the gap on digital health literacy among the diverse population at risk of experiencing health disparities (e.g., children, people living with a disability, minorities, elderly and rural populations). This work should be done through partnerships and collaborations between consumer advocacy groups, health care systems, payer, private industry and government agencies (local and state level).
- Discussions of vulnerable populations in this document do not by default include children or people living with a disability.
 - The role of individual health data for children is a unique situation as they are not in charge of the use of their health data. Parents who make decisions about access to their children’s data must take into consideration the future implications of its use. In addition, children with chronic medical conditions who will be required to manage their health data when developmentally appropriate must be a consideration in data health literacy education programs.
 - People with disabilities have very complex needs. Much of the technology that exists today is not customized for individual needs of this population. There is much to consider for next steps as we learn how to individualize data and keep vulnerable populations healthy.
7. **Create and Maintain Community Resource Scorecard**—Develop and promote a Community Resource Scorecard that provides information on how communities are being supported. The Scorecard would offer common indicators to facilitate comparisons across communities, but also be specific to sub-county or district levels to address their own concerns and interests. The scorecard could encourage HHS to adopt a core set of sentinel indicators to help align states, regions, and local communities in support of the nation’s goals for improving health.
8. **Create Partnerships Around Data for Health**—Create a partnership among ONC, NIH, PCORI and other relevant government agencies to galvanize stakeholders in the public, private, and academic communities around *Data for Health*, with a particular focus on vulnerable populations who may “fall through the cracks” of larger efforts.



I. Introduction

“The promise of improving health care through the digitization of patient information has drawn significant national attention and investment in health information technology in recent years, resulting in rapid implementation of electronic health records.

At the same time, an explosion of apps and devices that track fitness, mood and sleep, and of technologies that passively capture information as people communicate with one another on social networks, shop, work, or do any number of activities that leave “digital footprints,” are creating new forms of data relevant to health.

Secure, protected access to this wealth of information has the potential to help individuals, health care providers and communities make smarter, faster decisions that improve the health of the public and promote healthy lifestyles.” —*Robert Wood Johnson Foundation*³

A. Rationale and Goals for *Data for Health* Initiative

The Robert Wood Johnson Foundation (RWJF) designed the *Data for Health* initiative to explore the worries, hopes, and aspirations that people across the country have about health data and how people could turn that data into usable information to improve health—their own and that of their communities.

Rapid advances in technology have enabled the collection and use of large amounts of data that could help individuals, communities, organizations, and policymakers to make better decisions about how to improve health. These data, along with health information collected through public health surveys, electronic health records, clinical trials, insurance claims and other avenues outside of health can be

used to build a Culture of Health—a nation where everyone has the opportunity to live longer, healthier lives. To succeed, it will be critical to ensure individuals and communities can effectively use and manage data in ways that help people live, work, learn, and play in healthier communities.

Not that long ago most of the interest in health information technology focused on the adoption and use of electronic health records to improve health care. Health care is critically important; however, it is only one of many determinants that drive health and well-being. Many are beginning to use and think of health information technology and the data generated from that technology to address health outside of hospital and clinic walls; though this way of thinking is still somewhat new. For instance, currently most of that new thinking remains for now focused on consumer health and fitness devices.

“To succeed, it will be critical to ensure individuals and communities can effectively use and manage data in ways that help people live, work, learn, and play in healthier communities.”

The goal for the *Data for Health* initiative was to understand how individuals and communities think about using data from a wide range of sources to build a Culture of Health.

In the *Data for Health* initiative, RWJF hosted a series of *Learning What Works* events around the country to hear and learn from residents; patients, consumers; planners; public health departments; clinicians; social service providers; school districts; local businesses; housing and community developers; researchers and scientists about why health information is important to them and how they might use it to help people lead healthier lives. RWJF is grateful to the many participants who came to the events and shared their ideas.⁴ This report synthesizes the key ideas expressed at the *Learning What Works* events.

An advisory committee (see p.13) of public health practitioners, physicians, health care researchers, health technology and informatics experts, consumers, and representatives of local government and health care systems led and participated in the *Learning What Works* events and formulated the observations and recommendations in this report. The timing of the initiative was designed to provide organizations working in health information technology, personal health informatics, system interoperability, and related fields practical information to help support the Department of Health and Human Services [Office of the National Coordinator for Health Information Technology (ONC), 2015] planning efforts.⁵

The observations, findings, and recommendations from the *Data for Health* initiative are meant to stimulate conversation across stakeholder groups on how to best leverage health information technology in both traditional (health care) and new (health and wellness) ways. With the listening sessions, this initiative focused attention on the perspectives and values of diverse communities across the country. The feedback will inform future strategies for health information and health information technology. A collection of snapshots provides examples of programs underway in a variety of cities. In addition, the observations, findings, and recommendations should inform efforts to

design an infrastructure for collecting, sharing, and protecting data in ways that work best for individuals, communities, and organizations across the country.

B. Criteria for Selection of Cities for the *Learning What Works* Events

The cities chosen for the *Data for Health* events represent a mix of different regions, city size, ethnic and racial representation, readiness to use health data and technology, and political affiliations (Gallup, 2012; National Conference of State Legislatures, 2014; New York Times 2010 Census Map; Census, 2012). Twenty-two different cities that represented diversity in terms of those criteria were identified. From the 22 cities, based on the advisory committee's recommendations, five cities were selected: Philadelphia; Phoenix; Des Moines, Iowa; San Francisco; and Charleston, South Carolina.

Approximately 100–150 people were invited within each city from a diverse set of stakeholder sectors and perspectives:

- Businesses (private)
- Educators, researchers, technology innovators
- Government community services, such as public health, social service providers, urban and transportation planners, parks & recreation services
- Health care providers (private)
- Individuals and Individual advocates
- Non-government community services and nonprofits organizations, including places of worship, YMCAs, neighborhood organizations, and organizations that directly support community activities and research

Collectively, the invitees represented a mix of voices from traditional sectors, such as health care and public health, as well as new sectors, such as technology and other businesses. The invitees also represented diversity in terms of race, age, income level, sector, data usage and knowledge, and people who could speak to what their community wants.⁶

Data for Health Advisory Committee

Chairs

- Ivor Braden Horn, MD, MPH, *medical director*, Center for Diversity and Health Equity, Seattle Children's Hospital
- David A. Ross, ScD, *director*, Public Health Informatics Institute and *vice president*, The Task Force for Global Health

Advisers

- James J. Augustine, MD, *associate professor*, Wright State University
- David Blumenthal, MD, MPP, *president and CEO*, The Commonwealth Fund
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- Erin Moore, *family partner*, Cincinnati Children's Hospital
- Gilberto Salinas, MPA, *chief clinical officer*, Rancho Los Amigos National Rehabilitation Center
- Ida Sim, MD, PhD, *professor of medicine*, University of California, San Francisco and *co-founder*, Open mHealth
- Daniel Stein, MBA, *president*, Stewards of Change Institute
- David Whitlinger, *executive director*, New York eHealth Collaborative

Additional Data for Health Guidance

The following local organizations provided the team guidance in the selection of local venues, populating lists of invitees, and suggestions for local speakers and facilitators:

- Public Health Management Corporation
- Arizona Public Health Association
- Arizona Health-e Connection
- Telligen Community Health Initiative
- Public Health Institute
- South Carolina Institute of Medicine and Public Health



C. Definitions

The *Learning What Works* events illuminated the need for providing definitions and their context on the topic of health and health information technology. The context can change depending on the participant's perspective—for example, an individual participating as a patient will bring a different context and perspective than an individual participating as a public health official or health professional.

Definition of key report terms:

1. **What is health data?** Health data is data in all its forms derived from a wide range of sources that could become information to guide health and well-being for individuals, communities, and the population. This understanding includes raw data, aggregate data, summary data, and reference data. Although many people sometimes use the concepts of health data and health information interchangeably, this initiative parses the terms separately.
2. **What is health information?** Health data in its range of forms can, in certain instances, become information that people in turn could then use to inform actions that help improve individual or community health. Health data must be interpreted, analyzed and properly displayed in order for that data to become health information; otherwise health data is not necessarily health information. For instance raw data locked in enormous data sets are not yet health information.
3. **What is a Community?** The concept of community goes well beyond a geographically defined region. A community is where one lives, learns, works, and plays. Communities can be networks of people who have a common interest or need. Communities can include face-to-face and virtual networks.

What are the Perspectives on Population Health?

Population health can be defined from multiple perspectives, including perspectives from public health institutions, health care systems, and individuals. The population included in the definition will vary based on the underlying collection of individuals represented, such as a geographic region, a set of socio-demographic characteristics, or a disease.

- **Public Health perspective**—refers to the health of the public as a whole, whether they show up in electronic data or not. This focuses on understanding the determinants of the patterns of disease seen in populations and emphasizing actionable intervention, prevention and health promotion in whole communities.
- **Health care provider perspective**—refers to the health of the individuals they serve and involves understanding, measuring and improving the health of these individuals. Thus, health care providers serve populations but usually not all of the individuals within a geopolitical boundary.
- **Individuals' perspective**—refers to the health of the communities in which people live, work, learn, or play. These are not necessarily the geopolitical boundaries such as cities and counties.

What are Social Determinants of Health?

“Health” is defined broadly in this initiative and incorporates the social determinants of health, which can include economic stability, education, social community, health care access, physical environments, and social support (RWJF, 2014a). The Institute of Medicine (IOM) expands the idea of social determinants of health to include psychological and behavioral domains (IOM, 2014b and 2014c).

Social determinants of health encompass the definition of a community—a place where one lives, learns, works, and plays. It is an interconnected set of:

- **Social factors**—community safety, social support, education, food, recreation;
- **Economic factors**—employment, income, and demographic makeup; and
- **Physical environments**—air and water quality, housing, transit, access to health care, access to health information, including use of services, safety steps to take during an emergency, such as local outbreaks of illness.

Many of these factors are described for the five *Learning What Works* event cities (see Data Fact Sheets in Appendices C–G).



II. *Learning What Works* Events

A. The Events

The *Learning What Works* events followed a similar format in each city:

- Opening remarks describing the overarching purpose of the *Data for Health* initiative by the advisory committee co-chairs and leadership from RWJF and Department of Health and Human Services.
- Plenary session with three to four local and national leaders presenting their thoughts and activities related to uses for health information. The purpose of the plenary session was to provide multiple perspectives as a starting point for further discussion by attendees in the breakout sessions.
- Breakout sessions in which attendees each participated in two of the five sessions—one in the morning and one in the afternoon. The five breakout sessions were:
 1. Engaging People and Communities to Improve Everyone's Health
 2. Working Together and Sharing Information to Improve Health
 3. Enhancing Personal Health and Well-Being
 4. Improving Population Health
 5. Using Data to Create and Sustain Healthy Communities

The definition for each of the topics and questions discussed at each of the sessions are described in Appendix B.

An advisory committee co-chair summarized the key take-aways at each *Learning What Works* event in the closing remarks.

B. The Cities

The number of attendees in each city ranged from 85 to 122 people. The sector distribution of the attendees at each of the sessions is presented in Table 1. Representatives from the public health and health care sectors accounted for almost half to two-thirds of attendees at each of the events. A sizable share of attendees represented the technology sector at the San Francisco and Phoenix *Learning What Works* events.

Table 1. Percentage of attendees representing different sectors in each city

	Philadelphia	Phoenix	Des Moines	San Francisco	Charleston
Number of attendees	85	93	122	89	85
Public Health	43%	22%	19%	23%	35%
Health Care	19%	39%	28%	24%	24%
Technology	7%	14%	4%	19%	1%
Community Development	12%	2%	11%	9%	11%
Education	7%	10%	6%	3%	5%
Other	12%	12%	33%	20%	24%

In San Francisco and Charleston, the opening remarks and plenary sessions were live streamed and individuals could submit questions to the speakers via Twitter. Approximately 225 people around the country watched the San Francisco live stream and 150 watched the Charleston live stream.

Appendices C–G present: (1) a summary of the introductory and plenary speakers, the plenary discussion, and the closeout remarks for each *Learning What Works* event, and (2) a descriptive profile of each city (Data Fact Sheet).





III. *Learning What Works* Participant Observations

The observations below are based on comments attendees⁷ made during the *Learning What Works* events. The observations fall into five broad categories:

- Using Data
- Exchanging Data
- Protecting Data
- What Individuals Want and Need
- What Communities Want and Need

A. Using Data

Health Is More Than Health Care

“A living wage is fundamental to a Culture of Health.” —Tweet from plenary speaker at Data for Health event

“Your health data is not just what happened in the clinical setting, it’s about where you live, learn, work, and play.” —Tweet from Data for Health participant

Individuals frequently limit their definition of health as those services rendered by a medical practitioner. Although the concept of health was defined broadly throughout these events, **much of the health information technology dialogue tended to focus on fitness or health care versus**

health and social wellness. Attendees described how most individuals continue to see health as, “when I’m sick I go to the doctor” rather than a preventative holistic perspective of “I’m doing what I can to be healthy and live in a healthy community.” While fitness helps achieve physical health, it doesn’t necessarily address the social and human service aspects of overall health and wellness. Advisors cautioned that the focus on data and technology may over-emphasize health care and fitness above other health factors (e.g., access to healthy food and green spaces).

“Attendees described how most individuals continue to see health as, ‘when I’m sick I go to the doctor’ rather than a preventative holistic perspective of ‘I’m doing what I can to be healthy and live in a healthy community.’”

The RWJF Commission to Build a Healthier America (2014a) recommended “the nation must take a much more health-focused approach to health care financing and delivery. Broaden the mindset, mission, and incentives for health professionals and health care institutions beyond treating illness to helping people lead healthy lives.” **Individuals embraced a broader understanding when urged to consider how linkage with social services and nonmedical data, such as social and behavior determinant information, can be used to help inform actions that improve health. Moreover, communities wanted health care data to be broader and linked with nonmedical data, in order to make it more useful.**

The need to integrate health and social services was a theme heard in all the cities. Here are some examples that attendees discussed:

- Medical-legal partnerships that integrate the expertise of health care, public health, financial, and legal professionals to ensure patients have access to needed social services and to help them to access these services.⁸
- The Child Health Specialty Clinics in Iowa City that provide numerous services to children and their families,⁹ including health and disease management in which nurses and family navigators ensure that children and youth receive services they need without charge.
- The Care Coordination Institute¹⁰ in Greenville, S.C., is funded by the federal Agency for Healthcare Research and Quality initiative called Practice-Based Research Networks (PBRNs).¹¹ PBRNs answer community-based health care questions and translate research findings into practice to create an evidence-based culture focused on improving the health of the community.



Data for Health Snapshot

Photo Credit: Flickr.com/David McSpadden

Food Deserts and the North Charleston Chicora Place Community Garden

Community leaders in Charleston analyzed the percentage of people with diabetes and the food desert data and realized that the lack of access to healthy foods was causing health problems. The Fresh Future Farm was a solution to this problem. Food deserts are areas without ready access to fresh, healthy, and affordable food. Instead of supermarkets and grocery stores, only fast food

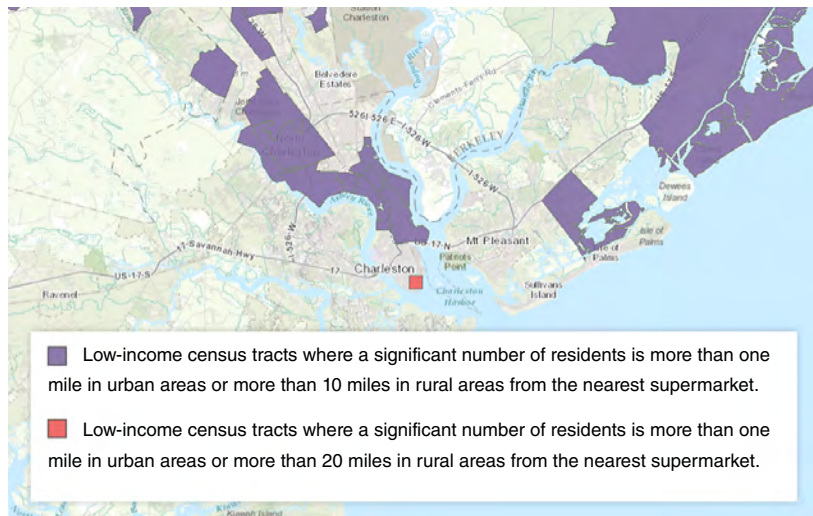
restaurants and convenience stores that offer very few healthy food options serve these communities. The U.S. Department of Agriculture designates low-income urban neighborhoods as food deserts if they are a mile or more to the nearest supermarket. In rural areas, where people are likely to have cars, it's 10 miles.

In 2011, volunteers started the Chicora Place Community Garden in North Charleston¹² to bring better food options to

residents and families in this historically underserved area and designated food desert. With support from South Carolina Community Loan Fund's Feeding Innovation Challenge, an urban farm is being built this year just a few blocks north of the garden at the site of a former elementary school. The Fresh Future Farm¹³ is planned to be more than just a place to grow fruits and vegetables, but will also serve as an entire community food operation, with an on-site store to sell produce and other groceries.

The farm, on almost an acre of land, will include beehives, a chicken coop, composting and areas for tours and demonstrations, in addition to more traditional crops.

A Map of Food Deserts in Charleston, South Carolina



Source: www.ers.usda.gov/data-products/food-access-research-atlas/go-to-the-atlas.aspx.

Observations from other studies support the notion that communities want standardized data, measures, and tools, such as community health indicators that encompass both health measures and social determinants of health (Ricciardi et al., 2013). Moreover, there has been a recent focus on building community-level health information infrastructures that would promote sustainable health care quality and efficiency (Des Jardins & Terrisca, 2014). This involves creating data warehouses and community-level, clinical data repositories. The need to connect clinical information with public health, commercial, and community information mirrors what has been said by many others (IOM, 2013; PCAST, 2010, 2014a; JASON, 2014a, 2014b). While social services and health care organizations are starting to work together, there is no current systematic way to track and assess the programs that affect the social determinants of health (RWJF, 2014b). **Moreover, many, if not most, communities lack the data infrastructures they need to use data for health.**

Data Matter to Individuals

“Data can help us build a Culture of Health by bridging the gap between knowledge & action.”—*Tweet from Data for Health participant*

It is not hard to get people to talk about the possibility of using data to help make health decisions. For the most part, attendees offered many different ways that they can envision using their personal health data to help them make better health decisions and can also envision many ways that aggregated personal health information could inform actions that lead to improvements in health status within their communities. One attendee spoke about how families may be willing to report their child’s asthma attacks to help track patterns of air quality when they know it will affect policies or decisions that would in turn affect the health of their child. For example, these parents might be more willing to share their child’s personal health data if this could result in public health officials making public announcements to keep children with asthma indoors on certain days.



Photo Credit: Tyrone Turner/Getty Images

Attendees also noted that capturing data about physical activity and diet would be valuable for community decision-making, especially since physical activity and eating a well-balanced diet have been found to protect against diseases like diabetes, cancer, and heart disease, as well as reduce mortality (Physical Activity Guidelines Advisory Committee, 2008; Powell et al., 2011; Salehi-Abargouei et al., 2013). This corresponds to other reports that have recommended that health systems gather information on individual social and behavioral factors that can influence health and disease (IOM, 2014b,c; RWJF, 2014b).

Attendees felt that incentives for sharing data should be personal and have tangible rewards, where people can see the direct benefit of sharing their information, such as building a new park or improving transportation to shorten commutes. As one attendee stated, “What people can share and what they will share depend heavily on how well people understand the value of the sharing to them.” **Thus, data can give individuals autonomy and power. Using data to improve individual health can be powerful but also challenging—even uncomfortable or scary.**

Translating Data into Useful Information Remains a Challenge

Big Data—We need to “collect it, share it, and use it.” —*Blog Post by Ivor Braden Horn, Co-Chair, Data for Health Advisory Committee*¹⁴

People can see both the promise and the current limitations in the ability to get at data to help make decisions. Attendees expressed a need for guidance and tools that link data about their lives, including their medical care, to help them make personal and family health decisions. They described the difficulty in sifting through massive amounts of data to find the most salient pieces of information in order to get the best outcomes. Many attendees said that they wanted access to information that is easy to use like what they find online with Amazon or Wikipedia. **Providers also need information tools that assist their work, rather than detract by adding an uncompensated time burden.**

“People will tweet that they are having an asthma attack as they are going through it. They need data at a time that they can actually take action.”

Communities also expressed the time value of information—that is, they want to be proactive and, therefore, need timely data and information. An attendee in Philadelphia echoed what has been noted in the literature (Balas & Boren, 2000)—that it can take as long as 17 years to translate data into clinical practice which then results in outdated practices that are based on old data. The value at the moment of care is contingent upon the timeliness and geographic detail of the data. As this attendee pointed out, “People will tweet that they are having an asthma attack as they are going through it. They need data at a time that they can actually take action.”

Beyond merely making data available, attendees strongly emphasized the need to translate data into information that could help drive action and policy. A common theme across all five cities was that



organizations have an obligation to assure from the very beginning that data collected becomes actionable information that impacts health and steers resources to areas of highest need. As one attendee said, “We need to press organizations at all levels to share data in a way that better shows the pathways to where we can more effectively intervene. We’re missing huge opportunities. We need to create algorithms to identify actual and potential return on investments and until we get that line connected, we are talking in circles.”

Communities are beginning to create useful information displays and dissemination tools to help people see how their communities are doing in terms of health. One example is the *County Health Rankings* report, produced by the University of Wisconsin Population Health

Institute and the Robert Wood Johnson Foundation.¹⁵ Additionally, RWJF made recommendations to “make public health analytical tools and information widely available to both public health agencies and clinical health care systems, to support collaborative data analysis and learning” (RWJF, 2014b). There are several civic technology movements, such as Code for America, that mobilize civic hackers to inform community issues through data.¹⁶

Generations and Cultures View Data Use Differently

“The complexities of people’s lives don’t always fit well in a drop-down box.”

—*Tweet from Data for Health participant*

Age and cultural gaps exist in how people think about using personal health data. Among those who are facile at digitally recording and accessing data about themselves, there is a desire to see broad use of their data to inform their health improvement and maintenance decisions and their health care options. Among those less facile in using digital technologies, there is shared skepticism about the value and benefits of “going digital” with their health information.

For instance, younger attendees were more likely to use portable health monitors¹⁷ (e.g., heart and blood pressure) and fitness trackers (e.g., Fitbit and Jawbone) to track their health behavior. Moreover, many of the younger attendees share this information on social media with their friends as a way of garnering support and reinforcing healthy behavior. One of the attendees said, “My 14-year-old son just expects that his data will be available for him when he wants it.”



Data for Health Snapshot

Photo Credit: Jed Conklin/Getty Images

Live Healthy Iowa, Annual 10-Week Wellness Challenge

Live Healthy Iowa is a fitness challenge where participants have access to a personal online dashboard to help them track progress toward healthy eating and physical fitness goals. Joining together with friends, colleagues, and family members in teams of 2-10, participants log their hours of personal activity and weight loss over a 10-week

period using the dashboard through the Live Healthy Iowa website, which can be synced with smartphone apps and wearable devices to help people track their progress daily. The program also helps motivate participants by offering healthy recipe ideas, suggested workouts, and other fitness resources. During the 10-week challenge in 2013, over 28,000 Iowa participants recorded almost 823,000 hours of activity and lost more than 82,000 pounds.¹⁸

Some older attendees used devices to monitor health conditions, often for chronic diseases like diabetes, and shared the information with their primary care provider. However, many attendees had serious doubts about sharing their personal health information with anyone beyond their doctor for fear of possible negative consequences for obtaining life insurance, getting a job, or other reasons. In addition, attendees expressed concerns about creating a digital divide where an abundance of data exists from young people using technology, but far less data exists from older generations who either don't use the technology or do not feel comfortable sharing their health information.

These observations correspond to research that finds certain populations, including disadvantaged, vulnerable, and elderly populations, tend not to access their electronic health records (EHRs) (de Lusignan et al., 2013; Turvey et al., 2014). In addition, while access to remote monitoring tools has dramatically increased in recent years and some health care organizations have incorporated the outputs into their recordkeeping, personal use of remote monitoring is still not widespread. A Pew survey found that only 9 percent of individuals who track their weight, diet, or exercise routine report using an online or app tool for this purpose (Pew, 2013).

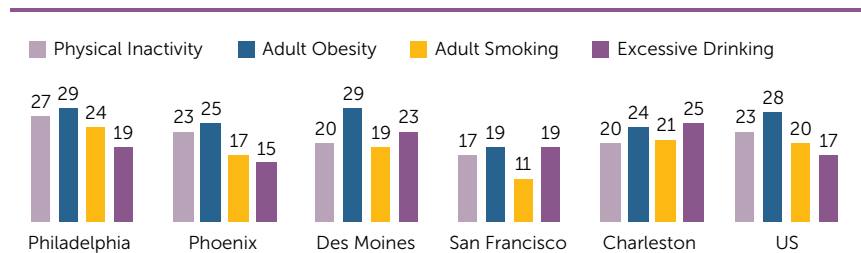
Data Use Does Not Equal Better Health Decisions

“We should not only ask others to share data but to share their stories.”

—*Tweet from Data for Health participant*

Individuals do not necessarily act rationally, so simply having data or information does not necessarily promote positive changes in health. As one attendee described, “Just because we have information doesn't mean we're going to use it to our benefit. We're weird human beings—we often react irrationally.” Attendees cited the example of people continuing to smoke despite the knowledge that it has negative health effects. This corresponds to research that 1 in 5 U.S. adults are smokers (see Figure 1) and approximately half did not meet the 2008 federal guidelines for aerobic or muscle-strengthening activities [Centers for Disease Control and Prevention (CDC), 2013] despite widespread knowledge regarding the health effects of smoking and exercise. Going back to at least the 1960s, economists and psychologists have discussed why people engage in what appears to be irrational (unhealthy) behavior but which may in fact be rational for them (Akerloff et al., 1987; Ariely, 2008; Becker, 1963; Kahneman, 1983). Figure 1 below presents data about health behaviors in each of the five cities.¹⁹

Figure 1. Health behaviors - Physical Activity, Obesity, Smoking, Drinking (Percent of Adult Population)



SOURCE: CDC Behavioral Risk Factor Surveillance System (2012).

Attendees emphasized the need to provide information about the value of health and to instill the value of health in people starting at a young age through education and the school system. They also emphasized the importance of understanding an individual's health goals and what they want to achieve by sharing and using their data. Understanding context is important for appreciating what may be hindering people from making healthy choices. As one attendee stated, “We need to more carefully listen to the stories behind the data. The data may help give us the

answers, but it's the stories that tell us which questions to ask.” Moreover, it's not enough to look at individual behavior; there are sometimes underlying structural and economic conditions in the way. This is especially true for vulnerable populations who work multiple jobs, live in communities that are not safe or where there are no sidewalks and there is little access to fresh food. These are obstacles that require data so communities can create change.

Reimbursement and Funding Mechanisms Affect Data Use

Doctors want and need better information about the populations they serve. Reimbursement mechanisms affect doctors' ability to have and use information. As one attendee described, "Use follows reimbursement, and we don't reimburse prevention, and so we don't get it." Many attendees felt that incentives were often misaligned between the data collector end and the data user end. Considering context is key to determining the right incentives, where people need to be asking, "Are the right incentives being employed in the right sectors?" This involves considering the value proposition for data exchanges and use for each sector. **Funding mechanisms (i.e., grants and private funding) also drive research and collaborations that would help providers understand population health management.**

"People want to trust that their data will be used for important and helpful purposes, while also being protected from invasions of personal privacy and breaches in their personal information."

B. Exchanging Data

"Ten-Year Agenda: The process of clinical trial recruitment, data collection, and analysis will be accelerated and automated. Retrospective analyses will allow for rapid inquiry around many aspects of public health, health care quality, outcomes, and efficiency. Public health surveillance will be dramatically improved through better outbreak detection and disease incidence and prevalence monitoring. Interoperable health IT will also help contain outbreaks and manage public health threats and disasters." (ONC, 2014)

Data Exchange Moves at the Speed of Trust

"Data is personal. Not because it is generated by a person. Because it is for the person."

— *Tweet from Data for Health participant*

Individuals and community organizations support the idea of using personal health information in its aggregate but demand more clearly stated value propositions supporting data exchange. Attendees emphasized that data and information flows need to be bi-directional, where the communities can communicate what they want and receive something of value in return. This requires involving communities before collecting data in order to ensure that the data helps to meet the community's goals. Many attendees felt that data exchange and data use projects would fail without a clear agreement on the goals and value for communities to share their information.

Moreover, people want to trust that their data will be used for important and helpful purposes, while also being protected from invasions of personal privacy and breaches in their personal information. Attendees pointed to the following concepts as key for building trust: leadership, mutual respect and understanding, and a shared vision and common goals. These three elements provide a road map for building trust with both individuals and communities. In addition, attendees emphasized the importance of speaking the language of the community (e.g., how the community talks about and defines health) as well as understanding the culture and education level of the individuals.

These observations correspond with other reports that community members want to participate in discussions around data use and collection and want to be asked permission to use their data [National Committee on Vital and Health Statistics (NCVHS), 2011]. However, a recent survey of health care, public health, early child care, education, human services, housing, transportation, and community development finance professionals found that leadership, mutual respect, and a shared vision were often missing in community collaborations (RWJF, 2013; IOM, 2014a).

“Big Data” and “Long Data”

People recognize the potential of “big data,” (e.g., aggregate data about the livability and health of the community, access to services, and economic conditions), to support analytics that can inform practice and program development.

People also want “long” data, data that tracks their individual health over time and allows them and their providers to see patterns and trends. They want their personal health data to move with them, whether it is across doctors’ offices, hospitals, or other caretaking settings. Attendees



Data for Health Snapshot

Photo Credit: Ed Kashi/Getty Images

Smart Patients

Smart Patients is an online community and information database where patients and caregivers learn from each other about treatments, clinical trials, and the latest science. The site empowers its users with an informed point of view about their condition and provides a support network for those who are struggling with their treatments and symptoms. The website builds a bridge between caregivers and patients, and also serves as a launch pad for further innovations in the health care sector, particularly in the way that the health care system can learn from

patients. Recently, Learn from Smart Patients launched as a separate space for doctors and clinicians to study the conversations in Smart Patients, which have been de-identified and used with individuals’ permission. Cancer Commons, a nonprofit, open science initiative linking cancer patients, physicians, and scientists in Rapid Learning Communities, are some of Smart Patients’ partners. “It’s critical to bring patient data as well as patient wisdom to our research teams, to accelerate the development of personalized cancer therapies,” said Sarah Greene, Executive Director of Cancer Commons. To listen to Stories of Survival, go to www.smartpatients.com/stories.

defined “long” data as data that tracks their health over time and allows them and their providers to see patterns and trends. **People want the assurance that when their provider needs access to their data he or she can access this data.**

Infrastructure Competition

Competition among private health providers is a major barrier to sharing data at all levels and sectors, especially health care. This contributes to the lack of agreed upon standards that would help share data across disparate information technology platforms (JASON 2014a, 2014b). Attendees described how there were many different types of systems being used within organizations and the incompatibility between these systems made integrating data difficult or impossible. Some attendees emphasized that the gold standard would be to create data infrastructures that can be customized but still useful across organizations and people. Attendees, particularly those with an information technology background said that creating interoperable systems is not difficult from a technology perspective.

Many discussions focused on the need to “break down firewalls” in order to facilitate accessing and sharing data across sectors. Aside from connecting data, attendees also wanted a way for their organization to connect with other organizations to solve problems together. Some attendees discussed the lack of awareness about other organizations in the area and the duplicative services that were being provided.

“We need to convert the data collection and sharing into a framework that our country and community values.”

However, attendees challenged the incentive for creating a data infrastructure and for sharing data. The value case has not been made in a way to have the public at large appreciate the value of a sound health data infrastructure that promotes holistic care at lower cost. Capturing data, transforming data into information, and making that information usable comes at a cost to someone. When personal data are aggregated for use at the population level, society may benefit, but often the providers of the data pay the cost and may not realize the value directly. The costs and benefits for each stakeholder and each sector need to be clearly articulated, including spillovers to other areas of the economy, such as economic development, education, employment and earning potential, and overall health care costs. “We need to convert the data collection and sharing into a framework that our country and community values. Until you can do that, you’re going to be leaving a lot of our decision-makers and public policy at the starting gate.”

The U.S. Health and Human Services Office of the National Coordinator for Health Information Technology (ONC) is aware of the barriers to integrating health data and is committed to a “range of activities to support existing governance initiatives and advance governance goals of nationwide health information exchange.” They recently released a road map, *Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap Draft Version 1.0*, which proposes actions needed in order to achieve interoperability over the next two years (ONC, 2015). This helps to answer concerns expressed in the listening events for a strong desire across communities to increase interoperability; increase trust among all attendees to mobilize trusted exchange to support patient health and care; and decrease the cost and complexity of exchange (Likumahuwa et al., 2013).

C. Protecting Data

Clinician to Community

“It’s about time to think about the ‘data prescription.’ This will require collaboration between provider and patient.” —*Tweet from Data for Health Adviser*

“ER Physician—I have the data, I don’t have the \$ to get it to the community.”
—*Tweet from Data for Health participant*

When community organizations ask clinicians for patient information, those clinicians are concerned about how to communicate that information back to community organizations securely. The Health Insurance Portability and Accountability Act (HIPAA), which protects the privacy of individually identifiable health information, came up in discussions at every event. Attendees expressed varying views on HIPAA as it relates to sharing information. Some felt that HIPAA was a necessary protection for individuals’ data and others felt that HIPAA was too restrictive and prevented sharing that could promote the common good. Many attendees felt that the lack of sharing between organizations was due to a lack of understanding about HIPAA and the legal ramifications of data sharing in general. Digital services are needed to ensure that the data are securely stored and analyzed, that data can be drawn from multiple sources, and that it is possible for primary care providers to share data. The vision for this system is to generate actionable information to maintain or improve health (Baird & Nowak, 2014; IOM, 2013).

Safety, Privacy, and Confidentiality Concerns Everyone

Privacy refers to the amount of personal information individuals allow others to access about themselves. Confidentiality is the process that data producers and researchers follow to keep individuals’ data private (National Research Council, 2007). More broadly, confidentiality procedures are designed to protect data on individual persons, households, companies, and other institutions (Schouten and Cigrang, 2003).

“People need to trust that the information they share will be used for their benefit rather than be used against them.”

“I’m worried once people can start identifying the outliers.” (Outliers are values that are outside most of the other values in a set of data; that is, the values are much smaller or larger, sometimes making their source more identifiable). Attendees expressed concerns that data could have unintended negative consequences for individuals and communities and be used in a harmful way, such as reinforcing negative stereotypes. People need to trust that the information they share will be used for their benefit rather than be used against them. This involves drawing attention to places that need resources without creating a stigma and considering context when interpreting the data. As one attendee asserted, “It’s about knowing that you’ll be honored as an individual and that you won’t be swindled.” Surveys and studies confirm what was heard at the *Learning What Works* sessions. One finding is that one out of eight patients do not seek treatment because of confidentiality concerns (McGraw, 2014).

Different data are subject to different permission rules. As one example, in Arizona opt-in and opt-out policies are both used, depending on the type of data. Patients must opt-in to share their behavior care data and do nothing to share their health care data; however, if they choose not to share their health care data, they have to exercise an opt-out option. These policies aim to protect privacy and build trust, however, some attendees described how this makes obtaining a comprehensive view of health for individuals very difficult and complicates aggregating data to obtain a community and population view.

Getting access to data is important, but people should be able to choose when and how their data might be used. Fear of inappropriate use presents barriers to social consensus about where and how personal health data can be aggregated for use to inform individual, institutional, and community action. At the community level, there are concerns about the risk of misuse of aggregated data such as “data redlining,” i.e., denial of services, or other harms that could come from broader access to health data about communities.

Attendees posed questions and comments such as: “How much information is enough? How much information is too much? If the information isn’t accurate or if no one is there to explain it, should we still have it and use it?” and “Just because we can collect the data doesn’t mean we should.” There were concerns about data being used to replace judgment. As one attendee put it, “If we blindly follow our GPS, we might drive off a cliff.”



Data for Health Snapshot

Photo Credit: iStock Photo

The Agile Science—Designing Health Lab

The Designing Health Lab at Arizona State University,²⁰ in partnership with Bob Evans at Google and *Jawbone*, is developing a process called Agile Science for creating smartphone and other mobile apps to promote healthy behavior change. Agile Science offers people access to an open source “prototyping platform,” which is an online resource where researchers and even individuals without any programming experience can design and evaluate personalized smartphone and Web programs to support behavior change, such as losing weight or improving sleep. This can involve tools such as smartphone apps, activity trackers, and home-based sensors.



Photo Credit: Leo Kopelow/Getty Images

Research over the past several years has found both favorable public opinions toward health information technology, as well as strong concerns about privacy and security (Ancker et al., 2013; Dimitropoulos et al., 2011; Udem, 2010). As indicated in the JASON reports (2014a and 2014b), there is a natural tension between safeguarding individual health information and making information available for both individual and public health. This sentiment was echoed at the *Learning What Works* events.

Legal Barriers

Current laws, regulations, and bureaucracies are an enormous impediment and barrier to information sharing. The absence of simple and clear language explanations limits understanding of and use of data privacy and security provisions already in law. Even if legal foundations are in place, people's lack of understanding leads to lack of use and enforcement. As one business attendee stated, "The reason we don't share data is because we're worried that we'll get sued."

Attendees brought up the idea of data ethics regarding the rights and responsibilities that come with data. The software architecture and practices for safeguarding individual health information are still evolving [Health Information Technology for Economic and Clinical Health (HITECH), 2014; McGraw, 2014; ONC, 2015]. "The adopted software architecture must have the flexibility to accommodate new data types that are generated by emerging technologies, the capacity to expand greatly in size, and the ability to balance the privacy implications of new data types with the societal benefits of biomedical research" (JASON, 2014a).

D. What Individuals Want and Need

"The complexities of people's lives don't always fit well in a drop-down box."

— *Tweet from Data for Health participant*

Lots of Data—The Right Amount of Data When They Need It

"Data is just a shadow of human experience. We still need to connect the dots."

— *Tweet from Data for Health participant*

Both individuals and caregivers need data to help them care for the individuals and the populations they serve. Yet, excessive amounts of information can be overwhelming. People expressed a need for information but also for help interpreting it. One attendee stated, "I want all the information—but I also want it when I need it. I don't want to have to interpret it. I'm not a doctor." Attendees described wanting a "road map" that not only tells them their personal health information, but also tells them what actions to take. In order to make the data actionable, it needs to be presented in a way that is understandable. Attendees differentiated between data and information, "Data isn't information, it's just what you produce. It doesn't tell you anything unless you analyze it and this requires storytelling skills that tie the information to the bigger picture."

Health literacy is a key component of these conversations. Health data should be communicated in a way that is easy for the individual to understand and act upon. As one attendee stated, "Sharing means in both directions: When I share my data I would like something back in return." Moreover, attendees highlighted the importance of paying attention to the language being used when asking individuals to share their data. They pointed out people often feel uncomfortable when asked to share their data due to distrust and the negative connotations around data sharing. However, if people are asked to share their story, then it provides a different frame and communicates a desire to understand the individual as a person.

Health Data's Split Personality

"Data: 'Not everything that matters is quantitative.'" —*Tweet from Data for Health participant*

People think differently about data for their individual health compared to community health. People believe that our society has the technical ability to share data and information to help improve health, but we just seem to lack the will. When people spoke about their individual health, they acknowledged that they did not always engage in healthy behaviors and at times felt blamed when this became the focus of their health. As one attendee described, "I don't just want devices and gadgets thrown at me that tell me to change my behavior. It's condescending and reinforces an idea of health as being only about personal behavior. It's very much victim-blaming."

However, when speaking about community health, attendees emphasized the importance of people taking responsibility for their own health. "We have a lot of social "dis-ease" (e.g., unease) [with taking responsibility for our own health and making use of health opportunities] that is leading to medical disease." Opportunities may exist for people to engage in healthy behaviors (for example, using accessible park space, biking to work when there are bike lanes), but people don't necessarily use them.

"The real question is not 'What data do you want to collect?' but rather 'What problem do you want to solve?'"

E. What Communities Want and Need

"Data can paint the picture of health in my community." —*Tweet from David Ross, Co-Chair, Data for Health Advisory Committee*

Community Context is Important

People recognized that data could be used to support neighborhood activism. Data are needed to help communities make wise investments in things that support health and wellness. Community support organizations want more basic information about people's situations (individual data such as from electronic health records or pharmacy or service providers) and about the community overall (such as from schools or transportation). Readily accessible comparative information would enable personal health decisions about quality of service and also about inequities associated with community resources.

Many attendees asked about the goals for sharing and using health information and expressed the need to go beyond data sharing to empowering change. They feel people need to have the power to act on the data and this involves social change. For example, GPS sensors on inhalers enable individuals and organizations to record the location of asthma incidences, but as attendees pointed out, individuals may not be able to avoid places with poor air quality since they may live or work in these areas.

The real question is not "What data do you want to collect?" but rather "What problem do you want to solve?" This is a question to be addressed at the individual and community levels through the use of the publically available data at the local, state, and federal level. Attendees noted that personalizing the information retrieval is one of the challenges to be addressed to make data useful to them.

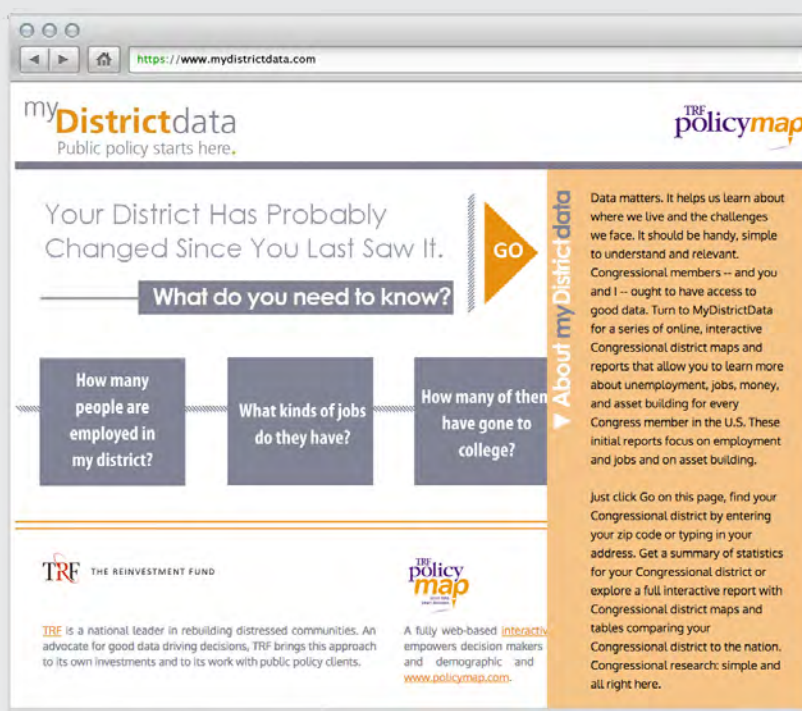


Data for Health Snapshot

Photo Credit: iStock Photo

PolicyMap

With access to more than 15,000 datasets from public and private sources, the *PolicyMap*²¹ Web tool is placing open data in the hands of citizens across the country, allowing them to visualize and explore issues ranging from consumer spending and crime rates to housing, education, health care, employment trends, and more. *PolicyMap* was created by The Reinvestment Fund, a Philadelphia-based organization that finances urban development, to give people a powerful way to explore data and trends in their neighborhood that are often overlooked. *PolicyMap* has helped researchers shed light on the food desert crisis in U.S. cities, mapped foreclosures in hard-hit neighborhoods, and makes it easy for anyone curious about issues in their community to have access to data at the local level. Recently, *PolicyMap* partnered with Citi Community Development to create *My District Data*, a first-of-its-kind tool that aggregates a range of data for each



Congressional district. Policymakers, constituents, and community groups alike now have a more complete picture of their region and a better understanding of the impact of federal policies at the district level.

Community Partnerships and Platforms

“Churches in marginalized communities can be a tremendous resource.”

— *Tweet from Data for Health participant*

When creating requirements and building a *Data for Health* information technology platform — a data science platform—**partnerships matter. The strength of community partnerships is a pre-condition to the useful sharing of health data.** Working together, **communities could use data to act proactively rather than only when reacting to problems. Communities need all kinds**

of information relevant to health, such as the environment, safety, stress, and housing. Creating a health information technology platform able to access, leverage and use all the data will be able to make use of **predictive analytics**, providing communities a window into their health.

Individuals and the communities in which they live, learn, work, and play need help being good stewards of health data and often need help (digital tutors) in understanding how to gain access to and use data. In addition, communities want data stewardship acting through effective and legitimate data governance structures. As attendees stated at all the *Learning What Works* events: “It is frustrating that there is so much data but it costs money to access. My organization is small—I do not have the resources to pay for accessing and using the data.” Attendees emphasized the need to get information about the needs and resources of the community in order to identify who and what could impact health within a community. Some described how the influence of a group of people within a community could create a tipping point to change health for that neighborhood. In addition, **communities want to use data to identify high-performing health systems.**

Though there is promise with all the new data, even if communities could get to it, they still would not be able to use it well. Communities are not set up to use data in smart ways.

Communities need resources to turn data into information and information into action. A major challenge heard across the cities was that small organizations lack resources, to use and share data. These organizations do not have the funding or staff to collect, obtain, or make use of the data that they have to coordinate and improve their care. “Even if I have the data, we still need personnel to be able to connect with individuals and do something based on the data, but we just lack the funding.” There is a need for stronger analytic capacities—both from staff and experts.



A review of the literature supports the observations that insufficient resources are allocated for training organizations in communities to access and utilize data. In previous studies, communities recognized the importance of collaborating with local academic or research institutes (Finkelstein et al., 2012; Feeley et al., 2011). However, there is currently no formal network for connecting sectors and utilizing existing technologies to encourage the regular exchange of information (RWJF, 2013).

Attendees suggested having crowd-funding or use of venture philanthropy for research where organizations and communities could submit their problems and researchers and local government could find relevant data and methods to act on these problems.

Venture philanthropists would support community data stewardship by focusing resources on meritorious problems that are identified and solved using better data. Organizations like Consano²² are starting to bring crowd-funding to medical research. In addition, there was a desire for best practices in terms of collecting and sharing data. Smaller organizations in particular seemed to be interested in having a model for successful local data sharing agreements, strategies for connecting with other organizations, and lessons learned. As attendees described, “Organizations may be willing to collaborate, but they’re not always sure where to start. Some sectors are working together for the first time and need interpreters initially between worlds.”



IV. *Learning What Works* Adviser Findings and Recommendations

Findings and Recommendations

The listening tour at the core of the *Data for Health* initiative generated in-depth conversations, shared observations, and concrete examples of successes and challenges that a broad range of players face in determining how data can be collected, shared, protected, and translated into actionable health information. The engaged discussion highlighted how people, communities and agencies are grappling with how to accelerate the country's movement toward embracing a vision of “making health information accessible when and where it is needed to improve and protect people's health and well-being.”²³

The information generated as part of those sessions, along with individual advisers' expertise, led the Advisory Committee to a set of findings and specific recommended actions across three areas:

- Establish the data exchange value proposition
- Build trust and community data competence
- Build community data infrastructures

Establish the Data Exchange Value Proposition

Accelerating the use of data for improving health depends on helping individuals, communities, and stakeholders see the benefits. Event participants raised over and over again the fact that people do not have a clear understanding of why certain data should be shared or used. Across the country, attendees voiced strong desires to better understand the value of health data and how health information, central to them as individuals, is derived. There was consensus that context and issues must drive the collection and use of data.

FINDINGS

- **What's in it for me?** The public wants and needs an answer to this simple question.
- **Using the data.** Using data means explaining why and how to use data. There is power in data for individual health and for community health, but it's challenging to spread that idea to the people and organizations that really need the information. Using data requires strong partnerships within a community, partnerships built upon trust.
- **Creating health information.** People want and need help translating their personal health data into useful, digestible information. They also need tools that help them interpret their data.
- **Constructing predictive analytics.** People want data to tell them more than just what has happened. They want help predicting what may happen to spark preventive health action and behavioral changes.
- **Broadening what people and communities think about health and well-being.** People often think only of health care when talking about their health and well-being, thereby limiting their thinking to curative medicine and eliminating discussion of prevention and social determinants related to behaviors and the environment.

“Accelerating the use of data for improving health depends on helping individuals, communities, and stakeholders see the benefits.”

RECOMMENDATIONS

1. **Launch Public Awareness Initiative on the Value of Data Use and Data Exchange**—Detailed examples, use cases, that explain how individuals and their communities benefit through the exchange and analysis of personal health information need to be shared. Philanthropic foundations, like RWJF, could host and disseminate a series of video stories showing patients, patient groups, researchers, and communities tell their stories of benefitting from data exchange and use. TEDMED could be another avenue for explaining these use cases and examples of real life benefit.
2. **Establish a National Health Information Dialogue**—Engage a broad range of stakeholders as data use for health continues to evolve. The dialogue could serve as a platform for educating the public about ways in which data can be generated and used to make better health decisions, as well as health policies to improve the overall health of communities. The dialogue would promote the development of a national data infrastructure. To do this will require leaders to:
 - Directly address the public's concerns about the privacy and confidentiality of their data;
 - Explicitly address the current ambiguities about the rights of individuals to manage their own data; and
 - Promote efforts to help people interpret their individual and community data in order to facilitate action from that new information.The next step will be to establish trust in communities and among individuals in communities before attempting large-scale sharing and use of data. To do this, leaders must:

- Leverage the fact that people are interested and concerned about the data they are creating about their lives and how they and their communities might use it to help inform their decisions about their health;
- Establish programs, educational efforts and community communications to reposition health as inclusive of human services; modify clinical medical and social work educational curricula to reflect this broader definition of health; and
- Find ways to ensure that there is value for individuals when they share their data for health.

Build Trust and Community Data Competence

The themes of trust and protecting data rang loudly across the country. Data sharing is fundamental to realizing the Triple Aim goals of improving patient care, improving the health of populations, and reducing the per capita cost of health care. It is also central to achieving a Culture of Health where people understand that health is dependent on a multitude of factors that go beyond medical care.

FINDINGS

- **Mitigating concerns about privacy and security.** People have serious concerns about the security of private health data and the degree to which they can and should expect that their confidential health information will be kept private and secure.
- **Refreshing Privacy and Confidentiality Laws.** Many argue that we need smarter or next generation privacy and confidentiality laws at the federal and state levels.
- **Leveraging the digital self.** The use of personal devices that record, store and use health data is a growth market. Both public health and personal health should benefit. These data will impose additional privacy and security concerns.

RECOMMENDATIONS

1. **Modernize policies governing health data**—most of the federal and state statutes and regulations protecting the privacy of health data are years (and in some cases, decades) old. Policymakers should update these privacy protections in light of enormous changes in the ways technologies now influence and can be used to improve health. The Committee recommends policymakers modernize (and ideally harmonize across jurisdictions) these policies to reflect the interconnectedness of the health and social services delivery systems. They should also establish guidelines, rules, and penalties needed to ensure secure data capture, storage, transmission, and use. The Committee also finds that in many cases, simply changing or adjusting rules and guidelines will not be sufficient to meet the society's health data use and infrastructure needs. In some cases, policymakers will need to consider modernizing current privacy laws at both the federal and state levels.
2. **Strengthen Data Security and Governance**
 - **Strengthen the right of individuals to access and obtain their health data**—Today the law provides individuals with a right to access their health data, but the rights are not equal to the access enjoyed by others (e.g., health care providers and health plans). Frequently individuals are treated as second-class citizens when they try to exercise their rights. Policies should establish clear, equal rights of an individual to obtain data about his or her health—akin to a Bill of Rights. Policies should empower individuals and enable them to make decisions about their own health and contribute to decisions that can improve the health of their communities.
 - **Establish Laws for Consumer-Generated Data**—The United States needs a set of laws,



policies and procedures governing devices that generate personal health information.

- **Accelerate Interoperability of Health Data**—Create a national priority for accessing and exchanging electronic personal health information to improve population health. Achieving this will require accelerating sharing of lessons learned from Meaningful Use and other initiatives in order to spur people to push for an enhanced, interoperable health information infrastructure.

3. Provide Preparation for Key Stakeholders

- **Educate Health Professionals and Paraprofessionals**—Education is needed about the value and impact of social determinants of health and wellness as a step toward attaining the Triple Aim goals. Associations of health-related schools such as the American Association of Colleges of Nursing, American Association of Colleges of Pharmacy, American Dental Education Association, Association of American Medical Colleges, Association of Schools and Programs of Public Health, and the Physician Assistant Education Association should ensure that curriculums integrate and emphasize learning about social and economic determinants of health.
- **Prepare Providers for Population Health Data Management.** Providers need access to data that supports their ability to more effectively manage the populations that they serve. Incentives for key stakeholders to collect this data are needed. Tools need to be developed that provide data in formats that providers can use for population health management. Support for research to understand providers' needs and capacity is needed.

Build Community Data Infrastructures

Communities, broadly defined, have a greater chance of succeeding at improving health and well-being when organizations work together to create both formal and informal networks that integrate health with social and community services. Leadership, mutual respect, a shared vision, and common goals are essential to spurring these kinds of networks and systems.

FINDINGS

- **Creating health information technology platforms.** Communities need improved electronic health infrastructures to be able to use data for health.
- **Providing timely health data.** Data is needed at a useful geographic level or socio-demographic level for services (organizations) to better support the community.
- **Mediating the risks of data exchange.** Data exchange and data use initiatives are at risk of failing without agreement on the goals and value to the community.
- **Collaborating.** Organizations seem willing to collaborate, but are not always sure where to start. Sectors are working together for the first time and need to develop a common parlance around health information.

RECOMMENDATIONS

1. **Invest in Data Sharing**—To advance Triple Aim goals broadly, ONC, CDC, NIH, and PCORI should invest in data sharing exemplars, whereby cities and state agencies share data with health care partners, public health agencies and community groups. Resources should also be targeted to research that will generate better public understanding and support for data sharing.
2. **Transform Data into Actionable Behavior Change**—Support for partnerships between data scientists and health services researchers to understand how data can be utilized to nudge or influence behavior change, particularly in areas experiencing great health disparities. Private foundations such as RWJF, government (e.g., the NIH Precision Health initiative), private industry, and academia should collaborate on these efforts. Request for research projects, code-a-thons, and other calls to action are needed to stimulate these efforts.
3. **Advocate for Open State and Local Government Data For Health Initiatives**—Build on the open government data movement, focusing on data and reference information needed to help the public understand how to learn about and gain access to health services, like understanding insurance eligibility and social service quality and accessibility.



Photo Credit: Lynn Johnson/Getty Images

4. **Access and Use Data Generated by Social Media to Demonstrate the Value of Health**

Information—Researchers and funders should promote the exploration of the potential of the many rich data sources coming from the enormous range of social media sources. (ONC’s *Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap*²⁴ may contain directives to explore information blocking barriers presented by providers and developers).

5. **Launch Pilot Code for America Data Analytics Program**—Provide opportunities for communities to develop ways to match people who need to understand the data with data analysis capacity. This could be as simple as building a community dashboard that mashes up data from existing government databases in ways that empower individuals to act on behalf of their own health. This initiative could include:

- Promoting a range of data “collaboratories” where people experiment with pilot sharing and accessing data, including social and human services data and information in every community;
- Developing community data stewards (i.e., an accountable entity) known to all and committed to proper data use for health; this concept needs to link health care institutions with the communities they serve; and
- Testing a parsimonious set of standardized measures that matter to the public for use on community dashboards and personal health comparisons.

6. **Address Vulnerable Populations**—Issues of digital health literacy need to be addressed by developing programs, educational tools, and resources in health care settings to close the gap on digital health literacy among the diverse population at risk of experiencing health disparities (e.g., children, people living with a disability, minorities, elderly, and rural populations). This work should be done through partnerships and collaborations between consumer advocacy groups, health care systems, payer, private industry, and government agencies (local and state level).

- Discussions of vulnerable populations in this document do not by default include children or people living with a disability.
- The role of individual health data for children is a unique situation as they are not in charge of the use of their health data. Parents who make decisions about access to their children’s data must take into consideration the future implications of its use. In addition, children with chronic medical conditions who will be required to manage their health data when developmentally appropriate must be a consideration in data health literacy education programs.
- People with disabilities have very complex needs. Much of the technology that exists today is not customized for individual needs of this population. There is much to consider for next steps as we learn how to individualize data and keep vulnerable populations healthy.

7. **Create and Maintain Community Resource Scorecard**—Develop and promote a Community Resource Scorecard that provides information on how our communities are being supported. The Scorecard would offer common indicators to facilitate comparisons across communities, but also be specific to sub-county or district levels to address their own concerns and interests. Done correctly, the scorecard would encourage HHS to adopt a core set of sentinel indicators to help align states, regions, and local communities in support of the nation’s goals for improving health.

8. **Create Partnerships Around Data for Health**—Create a partnership between ONC, NIH, PCORI and other relevant government agencies to galvanize stakeholders in the public, private, and academic communities around *Data for Health*, with a particular focus on vulnerable populations who may “fall through the cracks” of larger efforts.



V. Conclusions and Next Steps

The explosion of health data has created excitement about the possibilities of turning all that data into helpful information that people could use to improve health and wellness. Data from multiple sources (including electronic medical records, wearable monitoring devices, the emerging Internet of Things, and social media) could provide vast amounts of extremely useful information about both, individual and community health.

“The explosion of health data has created excitement about the possibilities of turning all that data into helpful information that people could use to improve health and wellness.

However, in addition to the many technical challenges for that vision that this report does not address, there remain significant “people-related” barriers and concerns as well. All these new, promising data sets coming from an increasing number and variety of devices and sources may one day become useful, helpful information that many can use to improve health. That will only happen, though, when people both can access the data and even more importantly trust they can do that with confidence.

The RWJF *Data for Health* initiative has begun a conversation across the country to help accelerate the design and implementation of an infrastructure for collecting, sharing, and, protecting data that could be useful to individuals, communities, and organizations. The advisory committee encourages public, private, and not-for-profit organizations to continue this conversation to help our nation realize a promising vision of using data to help build our future Culture of Health.

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- National Network of Public Health Institutes provided overall coordination, arranged for the logistics in each city, and led facilitation of the events;
- Burness oversaw public relations and final publication of materials; and
- Virginia Tech conducted the background research and drafted the report.

Thanks also go to the advisers, plenary speakers, and attendees who participated in the *Data for Health* events and contributed their insights and knowledge, which were critical input to the findings and recommendations. (See agendas in Appendices C–G for list of plenary speakers).

Appendix A: Health Information Concepts and Definitions

Creating a Culture of Health in the United States requires data and information that can be accessed and used by individuals and communities to learn about and understand their own health and the health of their community. To ensure a common understanding of terms, this fact sheet provides definitions of terms and describes tensions in making data available to achieve societal benefits (the common good) while ensuring the privacy of individuals.

Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.²⁵ **Health Care** is the diagnosis, prevention and treatment of disease, primarily focused on individual patients, using best practice medical care. **Health Information** is data in all its forms that guides and drives health and well-being for individuals, communities, and the population.

A robust health information technology (HIT) infrastructure must address all aspects of privacy and security while allowing broad access across data for clinical practice, public health and research purposes. The privacy and security considerations in an HIT infrastructure are as follows.

- **Privacy considerations** apply to access and use of individual health records.
- **Security considerations** apply to data storage and transport.

Individual Health Information²⁶

Electronic Health Records (EHRs) are a digital version of a patient's paper chart that provide real-time information instantly and securely to authorized users. EHRs capture information that is entered by clinicians involved in the patient's care. EHRs are managed and curated by authorized medical providers. The use and security of EHRs must abide by Health Insurance Portability and Accountability Act of 1996 (HIPAA) regulations to protect the privacy of the patient.²⁷

The **HIPAA Privacy Rule** establishes national standards to protect individuals' medical records and other personal health information and applies to health plans, health care clearinghouses, and health care providers. The Privacy Rule:

- requires safeguards to protect the privacy of personal health information, and sets limits and conditions on the uses and disclosures that may be made of such information without patient authorization
- gives patients rights over their health information, including rights to examine and obtain a copy of their health records, and to request corrections

Personal Health Records (PHRs) are similar to EHRs but the individual manages the content. Individuals can maintain and manage their PHRs in a private, secure, and confidential environment. Examples of PHRs are data collected and maintained by individuals such as recording data for diet plans or from home monitoring systems, as well as patient contact information, diagnosis lists, medication lists, allergy lists, immunization histories, personal monitoring and wearable devices.

Population Health Information

Population Health, a subdiscipline of public health, focuses on understanding the determinants of the patterns of disease seen in populations and emphasizing actionable intervention, prevention and health promotion in whole communities. Population health incorporates a spectrum of health determinants and disciplines, from the biological (genetics) to the social (economic drivers of health disparities).

There is a natural tension between the sensitivity of an individual's data and the use of health information for population health, such as scientific, medical, community, and economic purposes. Health information can provide a much needed and very novel approach for enabling the prevention of disease and promotion of healthy living. Examples of different types of data include immunization registries, electronic laboratory reporting, and surveillance data of health information through a variety of sources. Through aggregation and analysis, community and population health information can be used to define the health outcomes of a group of individuals, including the distribution of such outcomes within the group. This information allows for the development of new approaches to address health equity, such as more effective and sustainable community-based programs and health systems, especially in communities with a greater burden of disease. Moreover, this information can be used to understand how an individual compares to the population or subgroup of the population and how treatments and interventions could improve individual's health and wellness. Overall these data can then be used to monitor, prevent, and manage disease as well as promote wellness.

Appendix B. Topics, Definitions, and Questions Discussed at Each of the Five Breakout Sessions

The *Learning What Works* sessions followed a similar format in each city. The event began with opening remarks describing the overarching purpose of the *Data for Health* initiative by one of the adviser committee co-chairs from RWJF and the Office of the National Coordinator. This was followed by the session and discussion where three to four local and national leaders presented their thoughts and activities related to health information technology (HIT). The purpose of the plenary session was to provide multiple perspectives as a starting point for further discussion by attendees in the breakout sessions. Attendees each attended two of the five breakout sessions—one in the morning and one in the afternoon. The day ended with a wrap-up session by a committee co-chair.

The breakout sessions, definitions, and questions discussed are described below.

Engaging People and Communities to Improve Everyone's Health

Definition: Catalyzing consumer engagement in health is the level of effort, concentration, and involvement to health and health-related concerns at the individual, community, and population levels. At the individual level, this involves staying informed, making good lifestyle choices, seeking medical care as needed, following medical advice, and balancing privacy with the sharing of health information for the social good. At the community level, this involves collaboration with social and civic organizations, and with businesses, schools and universities, and transportation providers to increase community well being, resilience, and overall health.

The large group discussed the following questions:

1. What information do you track about individual's health and wellness?
2. What information do you track about the health of the community?
3. Who do you share that information with?
4. How could data from individuals or communities help your organization improve everyone's health?

The small group discussed the following questions:

1. What data or information do you wish you had to help you take care of your health or the health of your friends and family?
2. What data or information do you wish your organization had to create a substantially healthier community?
3. What health information and technology would facilitate better collaboration? What incentives would be needed for collaboration?
4. What are the costs versus benefits of sharing data?

Working Together and Sharing Information to Improve Health

Definition: Working together and sharing data to improve health involves collaboration and interaction among individuals and their personal social network, collaborative networks, community organizations,

and health care teams about health and wellness. Communication involves sharing what has been learned through education and collaboration. Education and collaboration can occur through the use of products (e.g., education materials, medical devices), services, and in-person or virtual encounters. Education, collaboration, and communication processes occur at the individual, community, and population system levels.

The large group discussed the following questions:

1. What health information do you share with others (either as an individual or as an organization)?
2. What is the value proposition (business case) for data exchanges and use for each stakeholder?
What are the costs and benefits for each stakeholder?
3. What information would you like to access as you work to improve health?
4. What can be done to improve access to health information?

The small group discussed the following questions:

1. How do you use data or information to collaborate for better community health? What do you collaborate to do to promote a Culture of Health?
2. What are the incentives and barriers in information, technology or systems for working together?
3. What is the value proposition (business case) for data exchanges and use for each stakeholder?
What are the costs and benefits for each stakeholder?

Enhancing Personal Health and Well-being

Definition: To enhance personal health and well-being, individuals need information to track and manage their overall health. An individual's overall health and well-being is defined by their: 1) Physical condition (e.g., illness, injury, functional ability); 2) Mental condition (e.g., mental illness, emotional state); 3) Social condition (e.g., social support, relationship quality); and 4) Behaviors that impact these conditions (e.g., diet, exercise).

The large group discussed the following questions:

1. What data or information do you use to understand your own health?
2. How could sharing your data with others help us improve health overall?
3. What information do you think you, your friends, and family need to make better decisions about your health and health care?
4. What can be done to improve access to that information?

The small group discussed the following questions:

1. How would individuals in your community use health information to enhance their personal health and well-being?
2. How could health care providers use community health information to support their patients' personal health and well-being?
3. How would organizations in your community such as businesses, schools, civic organizations and others use health information to enhance the individual health and well-being of their residents?

Improving Population Health

Definition: Population health is concerned with the distribution and drivers of health outcomes for populations where a population is defined by some grouping of people, such as a neighborhood, socioeconomic class, occupational class, or gender, and the drivers include the built environment, residential mobility, access to health care, and health behaviors.

The large group discussed the following questions:

1. What health care information could help us better understand the health of our community?
2. What information could individuals share about their health to help us understand and improve population health?
3. What other sources of data could help us make decisions about how to improve population health? (For example, data on access to healthy food, traffic congestion and air quality)
4. How can we improve access to this information?

The small group discussed the following questions:

1. What health information do you think you or your friends and family would be willing to share for the benefit of a healthier population?
2. What incentives would support or motivate you and your friends and family? What are the costs that would deter your friends and family? How does one balance the costs and benefits—what is the value proposition?
3. How would you use this information?
4. How do you think your family or neighbors or colleagues in other organizations use this information?

Using Data to Create and Sustain Healthy Communities

Definition: A community is where one lives, learns, works, and plays. It is an interconnected set of: 1) Social factors (e.g., community safety, social support, education, food, recreation); 2) Economic factors (e.g., employment, income); and 3) Physical environments (e.g., air and water quality, housing, transit, access to health care, access to health information including use of services, safety steps to take during an emergency such as local outbreaks of illness).

Understanding and engaging with and within the community can lead to improved health behaviors, quality of health care, and health and well-being.

The large group discussed the following questions:

1. What information about our neighborhood could help us improve the health of residents? (For example, how could knowing that your community has a very poor air quality rating or many food deserts help us improve individual or community health?)
2. What kinds of information about individuals and their health could help us design healthier places to live? (For example, how they commute to work, or where they exercise).
3. What information do schools, businesses, local governments and others need to promote better health and wellness?
4. How can we encourage sharing of data? What are the costs versus benefits of sharing data?

The small group discussed the following questions:

1. What are the strategies for sharing data to help communities be a healthier place?
What are some incentives that would encourage sharing information?
2. What are the barriers?
3. What are the costs versus benefits of sharing data?
4. What do you wish organizations would have in the future?

Appendix C. Philadelphia— October 30, 2014

Data for Health—Summary of the Learning What Works Event

Welcome and Opening Remarks

David A. Ross, ScD, co-chair, Data for Health Advisory Committee, introduced the Philadelphia *Data For Health* meeting with a call to action to use information to build a Culture of Health. He gave an example of presenting obesity data to organizations and businesses within a community. He shared how that created a collective epiphany for those organizations and businesses about the importance of sharing data and creating action plans based on that data. Each organization realized they had data that the other could use and needed—the awareness of each other helping the other through sharing of data has led to solutions. He encouraged discussion about the ethical, legal, medical, and cultural barriers that must be resolved before data sharing can occur in a seamless way, claiming it will require everyone's involvement.

Michael Painter, JD, MD, senior program officer, Robert Wood Johnson Foundation, highlighted that “Data creation is on an escalation curve.” He noted everyone has devices bristling with sensors to track information from cell phones to personal monitoring devices to other devices that we carry with us all the time. “We are human sensors—we carry terabytes of information with us.” He gave an example where Portland, Ore., bought GPS bicycle-riding data recorded from Strava²⁸ that tracks the routes and times of the bike riders. They used the data to improve the city's bicycling routes and design new routes. This saved time and money as it prevented the city from having to conduct an independent survey that would have taken years to complete.

Karen DeSalvo, MD, MPH, MSc, acting assistant secretary for health and national coordinator for health information technology, U.S. Department of Health and Human Services, lived, worked, and played in New Orleans, before coming to Washington, D.C. She used Hurricane Katrina as an example of how a lack of access to data makes it difficult to take measured actions and develop effective policies. She pointed out most available data are from users of health care, specifically people with phones, which leaves out community members that are not in traditional databases. She pointed out most available data are from users of health care, specifically people with phones, which leaves out community members that are not in traditional databases. She shared the Office of the National Coordinator's forthcoming strategic plan²⁹ is about health beyond health care and health information technology beyond electronic health records, noting it brings together the federal government in this effort to be a better partner to the community to help advance health information technology. She is a believer in collective action describing this with a metaphor of making gumbo—“You don't need to have all the ingredients, other people have different ingredients that they can share to make a really delicious gumbo. The same is true for building a Culture of Health—Everyone contributes something to the Culture of Health.”

Plenary Speakers

James W. Buehler, MD, health commissioner, Philadelphia Department of Public Health, noted that a population health perspective requires asking two questions: (1) what do we know about the health of population we are serving? and (2) how well are we doing our job in serving these populations? He highlighted there are currently three types of data systems that have the potential

to answer these questions and a fourth emerging. These include data about health care services; population health surveys; and data from other sources, primarily federally collected survey data. They are looking into a fourth category—data from Internet sources. “We need to be mindful of the connections across programs. Technology should not drive the choice of problems to solve. First ask what are the questions that need to be answered; then ask, what data are needed?”

Donald Hinkle-Brown, CEO, The Reinvestment Fund (TRF), described his nonprofit organization, which is a community development financial institution. TRF helps connect the financial industry with communities that have been disconnected from finances by organizing people, money, capacity, and data to implement investments. Their investment decisions have been guided by analysis of data and supported by 850 socially motivated investors. “Data can be much more impactful when you combine it with financial resources.” One of their successes is the creation of *PolicyMap*, which is an online data and mapping tool that allows policymakers, individuals, researchers, and others to access data about communities across the United States (see Snapshot, p.32).

Susannah Fox, entrepreneur-in-residence, Robert Wood Johnson Foundation, talked about results from a recent Pew Research Internet Project that presents findings about the approaches people use to track their own data, from tracking in their head, to keeping pieces of paper on the fridge, to a notebook, to technology. All of these approaches should count as health data tracking.³⁰ She pointed out the group most likely to be tracking their health is those living with chronic conditions. There are opportunities with cellphones and other devices to start to track health formally. Formal trackers are more likely to do it on a regular basis and share their data. She claimed that about one-third of trackers share their data. She pointed out the need to start a conversation with people about their willingness to share their data.

Plenary Discussion

Comments were offered regarding how to be inclusive, such as marshaling resources from all sectors, such as public safety and transportation, not just public health. This will require a better job of wrapping policy around people to create change. Technology was claimed to be an equalizer, a leveler, and an opportunity to bring equity.

Interoperability was presented as “pay to play.” If you want to share data, you must pay to build interfaces, create data sharing agreements, and initiate systems. It was noted that this favors big systems, not the smaller clinics and health care providers with less resources. Culture change was also discussed as being critical. Consensus was shared around building trust as being key to sharing data. This is important, as concern was expressed about the unintended consequences of sharing data, both at the individual and community levels.

Wrap-up

David A. Ross, ScD, co-chair, Data for Health Advisory Committee, ended the event by summarizing some of the key points that came up throughout the *Learning What Works* events. These included the importance of building trust when it comes to sharing and collecting data, the need for timely data that is relevant to people’s current needs, and the need for information on the social determinants of health so that communities can enact change.

Philadelphia's Health and Well-being— From Multiple Perspectives

“There is no better time than now to renew our focus on a nationwide, interoperable health IT infrastructure – one in which all individuals, their families, and their health care providers have appropriate access to health information that facilitates informed decision-making, supports coordinated health management, allows patients to be active partners in their health and care, and improves the overall health of our population. This is not just a technology challenge.”¹

This handout paints a picture of the health of Philadelphia. It sets the stage for seeking community input about what information individuals, communities, researchers, and other interested parties would find useful for monitoring and increasing their health and well-being. The Philadelphia population is compared to the populations of Pennsylvania and the United States with a focus on health outcomes and behaviors, the social and economic environment, and quality of and access to health care.

I. Health Behaviors and Outcomes

Health outcomes refer to how people feel physically and mentally and include factors that can influence conditions of health.

- Philadelphians have more physically unhealthy days per month (4.4) as compared to people in Pennsylvania (3.5) and the US (3.7). Philadelphians also have more mentally unhealthy days per month (4.6) as compared to Pennsylvania (3.6) and the US (3.5).²
- More Philadelphians (1 in 5) report fair or poor health compared to people in Pennsylvania (1 in 6) and across the US (1 in 6).³
- In Philadelphia, more babies have low birthweight (1 out of 9 babies) compared with babies born in Pennsylvania and the US (1 out of 13 babies).⁴
- Certain behaviors, like smoking and drinking, can influence health and mortality.⁵ Philadelphia has some similarities and some differences to Pennsylvania and the US on behaviors that affect health (see Chart 1, p.53).⁶

II. Social and Economic Environment

“A population's health is a function of the combination of many factors. These include genetic predisposition, but also social circumstances, behavioral patterns, health care, and environmental exposure.”⁷

Overall health is affected by individuals' social and economic environment, which includes family situations and income, educational opportunity, and employment opportunity (see Table 1, p.53).⁸

Social support, housing quality, and neighborhood safety affect the health of individuals and the community (see Chart 2, p.53).

Access to public transportation (see Chart 3, p.54), quality food, and recreation affect overall health and well-being.

The built environment includes the quality of housing, water, air, and access to healthy foods and recreation facilities. Philadelphia has 66 farmers' markets, 654 healthy corner stores, 12,000 acres of parks, and 133 recreation centers. The map below shows the distribution of healthy food retailers, parks, and recreation centers in Philadelphia.⁹

- One survey finds that all Philadelphians have adequate access to locations for physical activity compared to three-fourths of the US population. However, even this can vary depending on where one lives in Philadelphia. Philadelphians have increased their usage of these recreational facilities from 35 percent to 42 percent between 2004 and 2010.¹⁰
- One out of five Philadelphians have limited access to health food. The number of food establishments that comply with food safety regulations has increased 8 percent to 39 percent between 2010 and 2012.¹¹

III. Access to and Quality of Health Care

The overall health of the community can be measured by both the length and quality of people's lives, which is partially influenced by access to health care.

- Philadelphians lose 10,500 years of potential life before age 75 (per 100,000 population) compared to almost 7,000 years for the Pennsylvania and US populations.¹²

Philadelphia has 5 medical schools, 45 federally qualified health centers, and 43 hospitals and medical treatment centers.¹³

- There is a growing use of electronic health records associated with patient care in the US. In the US, 48 percent of office-based doctors are using electronic records, up from 11 percent in 2006. In Pennsylvania, 41 percent of office-based doctors are using electronic health records.¹⁴

Individuals need Internet access in order to obtain their health information electronically.

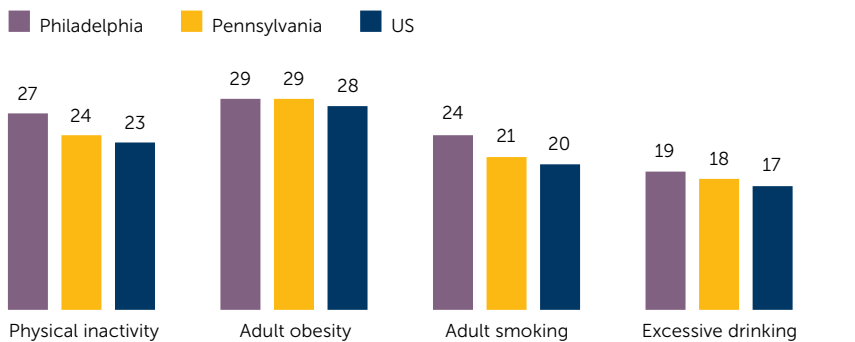
- Almost four out of five of Philadelphia households have a computer (78%) and two out of three have broadband internet access (65%). This is slightly lower than computer ownership for households in Pennsylvania and the US (82% and 84%) and broadband Internet access (72% and 73%).¹⁵

Table 1. Social and Economic Characteristics, 2013

Demographics	Philadelphia	Pennsylvania	United States
Total population	1,553,165	12,773,801	316,128,839
Median age	33.7	40.6	37.5
Percent white	43.4%	83.4%	76.2%
Percent black	44.7%	12.2%	13.8%
Percent Hispanic	13.3%	6.3%	17.1%
Percent living alone	41.1%	30.1%	27.7%
Economic			
Median household income	\$36,836	\$52,007	\$52,250
Mean household income	\$54,615	\$71,597	\$73,767
Percent unemployed	8.2%	5.2%	5.3%
Education			
Percent high school graduate only	34.2%	36.4%	27.8%
Percent of adults with some college or higher	47.9%	52.8%	58.8%

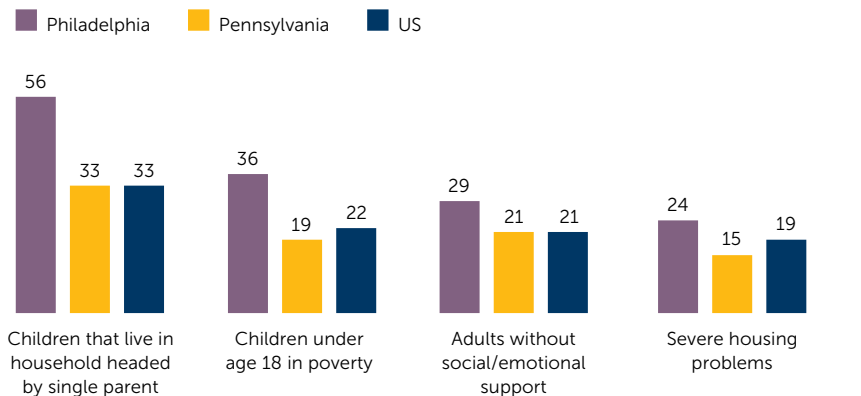
Source: Census Bureau, American Community Survey, 2013.

Chart 1. Health Behaviors—Physical Inactivity, Obesity, Smoking, Drinking (Percent)



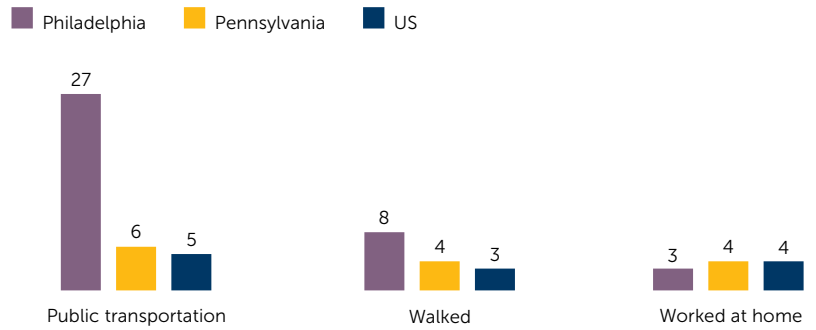
SOURCE: CDC Behavioral Risk Factor Surveillance System (2012)

Chart 2. Children and Adults with Possible Need for Social Support (Percent)



SOURCE: Census Bureau, American Community Survey, 2013, CDC Behavioral Risk Factor Surveillance System (2006-2012), and Housing and Urban Development (HUD) Comprehensive Housing Affordability Strategy (CHAS) (2007-2011)

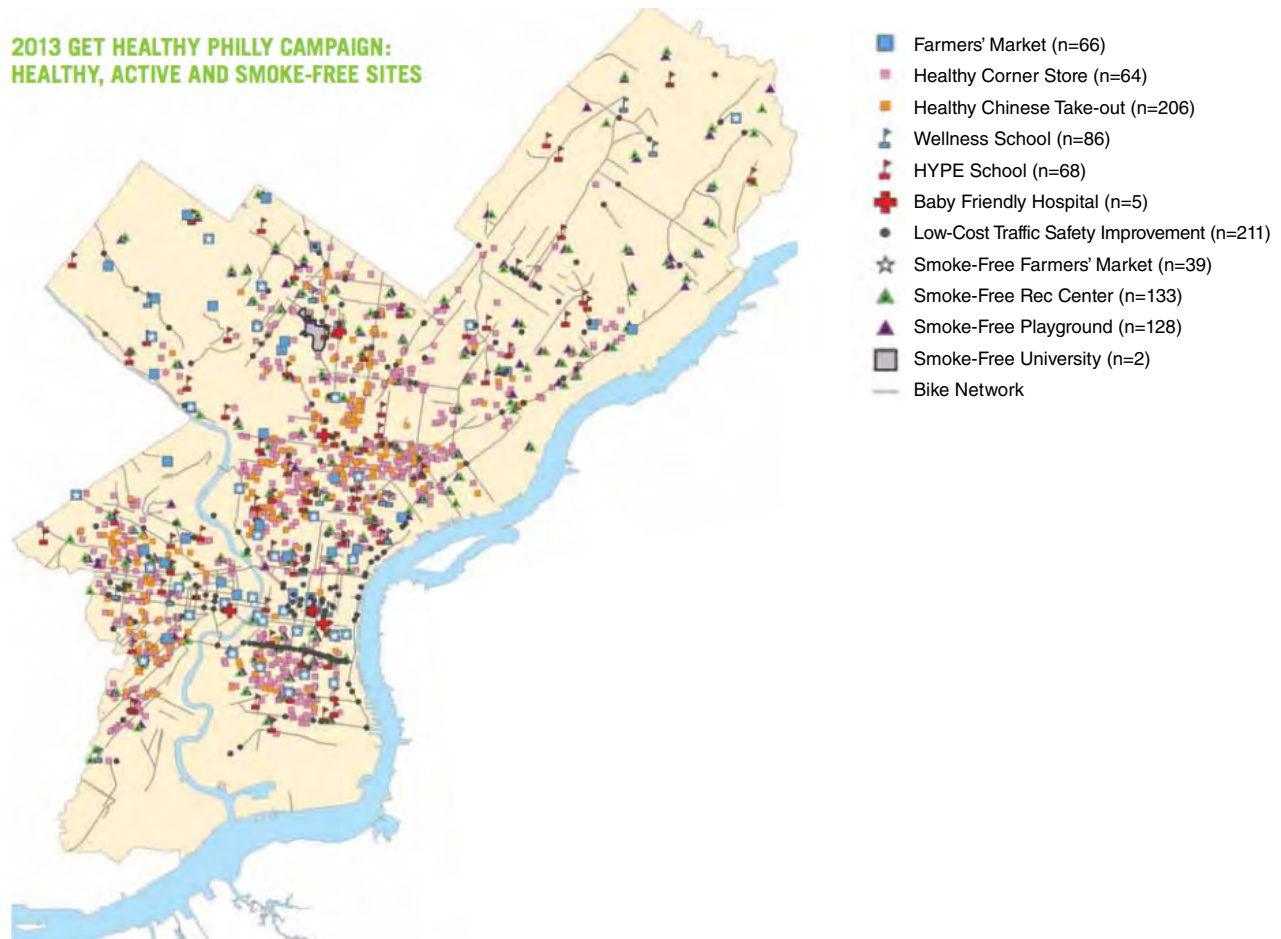
Chart 3. Means of Transportation to Work (Percent)



SOURCE: Census Bureau, American Community Survey, 2013

Map 1. Healthy Food Retail, Parks, and Recreation Centers in Philadelphia

(PHILADELPHIA DEPARTMENT OF PUBLIC HEALTH, 2013)



Endnotes

- 1 Office of the National Coordinator for Health Information Technology. (2014). Connecting Health and Care for the Nation: A 10-Year Vision to Achieve an Interoperable Health IT Infrastructure. <http://www.healthit.gov/sites/default/files/ONC10yearInteroperabilityConceptPaper.pdf>
- 2 Robert Wood Johnson Foundation County Health Rankings. <http://www.countyhealthrankings.org/>
Centers for Disease Control and Prevention (CDC) Behavioral Risk Factor Surveillance System 2006-2012. <http://www.cdc.gov/brfss/>
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- 4 Robert Wood Johnson Foundation County Health Rankings. <http://www.countyhealthrankings.org/>
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- 5 Mokdad, A. H., Marks, J. S., Stroup, D. F., & Gerberding, J. L. (2004). Actual causes of death in the United States, 2000. *Jama*, 291(10), 1238-1245.
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- 10 Robert Wood Johnson Foundation County Health Rankings, <http://www.countyhealthrankings.org/>
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- 14 Hsiao C-J, Hing E. (2014). Use and characteristics of electronic health record systems among office-based physician practices. United States, 2001–2013. NCHS data brief, no. 143. Hyattsville, MD: National Center for Health Statistics. <http://www.cdc.gov/nchs/data/databriefs/db143.pdf>
- 15 Census Bureau, American Community Survey, 2013. <http://www.census.gov/acs/www/>

The above endnotes pertain to this Data Fact Sheet only.

Appendix D. Phoenix— November 6, 2014

Data for Health—Summary of the Learning What Works Event

Welcome and Opening Remarks

Ivor Braden Horn, MD, MPH, co-chair, Data for Health Advisory Committee, introduced the *Data for Health* event in Phoenix and encouraged attendees to be candid and future-oriented. She told the story about her father, a Korean War veteran, who had traumatic brain injury and seizures. Having access to her father's health records through Blue Button³¹ fundamentally changed the way she and her family interacted with her father's health care team.

Michael Painter, JD, MD, senior program officer, Robert Wood Johnson Foundation, described how we live in exciting times where data are at our fingertips that open the door for a grand human experiment. For the first time in history we are collecting data about all aspects of our lives. He highlighted how we own many devices that have sensors—like GPS, accelerometers, health monitors, and many more. For example, the Google self-driving car collects and generates a detailed 3D map of its environment, combines them with high-resolution maps of the world, and produces different types of data models that allow it to drive itself. The ultimate goal for the self-driving car is to reduce congestion, accidents, and fuel consumption—all of which would help improve our health.

Karen DeSalvo, MD, MPH, MSc,³² acting assistant secretary for health and national coordinator for health information technology, U.S. Department of Health and Human Services, explained how the Office of the National Coordinator (ONC) creates and updates the federal health IT strategic plan. She described the mission of ONC, which is to determine how federal agencies will work together to efficiently collaborate on advancing Health IT. ONC is currently drafting the strategic plan³³ with the goal to translate health IT into advancing knowledge and information. Karen described how interoperability across health records could eliminate the need for one large data repository for the country. However, she acknowledged that to achieve this will require a culture change and the viewing of Health Information Technology (HIT) as not only a system of electronic health records, but as a bigger ecosystem that requires metadata, governance, and standards.

Plenary Speakers

Joe Pringle, MS, director of health, Socrata, said that they help organizations get more value out of their data so the organizations can share it more effectively to inform health policy and consumer choice. Some government health organizations publish machine-readable data and application programming interfaces (APIs) that allow researchers and developers to create data visualizations and dashboards to explain complex health issues to policymakers. The Socrata health team has helped many organizations use open data to improve their services. He gave the examples of *Castlight Health* which helps buyers of health care compare and shop for health services, the *Chicago Health Atlas* which allows users to view citywide information about health trends and take action to improve their health, and *Yelp* which provides restaurant health inspection scores on their website for each restaurant in San Francisco, New York, and other cities. He described how sharing data is a transaction with costs and, when this cost lacks standards or incentives, it discourages sharing and creates friction. He emphasized the need for an Amazon-like health care system to make the health data marketplace more efficient by reducing time accessing and transforming data and more time using data to improve health and health care.

Larry Aldrich, JD, executive director and chair of the board, Employers Health Alliance of Arizona described this newly formed, employer-driven, non-profit membership organization. It focuses on helping employers manage the cost of health care while producing better health outcomes for employees and their families. Arizona expanded Medicaid before the Affordable Care Act was passed into law. He emphasized the need to look ahead 10 years to ensure that data can be converted to information and actionable knowledge. Larry described how this will require development of technology so that individuals have the tools and knowledge to help improve health and so companies know which systems improve health and which don't. His goal is for all "to be rigorously accountable to health outcomes."

Eric Hekler, PhD, director, Designing Health Lab, School of Nutrition and Health Promotion at Arizona State University, focuses on how to use new and emerging technologies (e.g., smartphones, cloud computing, big data) to promote health behavior change, particularly physical activity and healthful eating. He emphasized the importance of thinking about the intersection of technology and people at the same time and to ask questions, such as, "What is the information that each person needs? How do you build systems so that the data are actionable and useful? What if you had more active choice about what data you want to share and how it will be used? What are incentives for people to share their data?" He stated, "We are data rich but information poor. We need to figure out how to communicate so we get what we need." (See Snapshot on Agile Science—Designing Health Lab, p.29)

Erin Moore, family partner, Cincinnati Children's Hospital, described how keeping her son's health information allows her to work with doctors to make better decisions about his Cystic Fibrosis. She highlighted the need for health information to be as easy to access as making a purchase from Amazon or the Push For Pizza app. "It's not about the technology, it's about the human use of the technology."

Plenary Discussion

The question was posed, "**How do we move the health system from asking 'what's the matter?' to 'what matters?'**" Responses included building models bottom up to focus on individuals, combining qualitative knowledge with quantitative data, and having conversations about individual and community goals. There was emphasis that the goal is not mathematical truth but truth for you (as an individual) and the need to move from $n = 400$ to $n = 1 \text{ times } 400$. "I am more interested in Long data, not Big data. Long data are those that track my health over time."

There was also discussion around how to increase health literacy. Solutions included involving people in asking the questions, learning about their priorities, and working to address those priorities—rather than assuming you know what those priorities might be. This involves asking questions such as, "What is the information you need right now? And what are the decisions you don't feel confident in making now due to lack of data?"

The question was also posed, "What data are we missing to get at the full denominator (including folks who don't touch the system)?" Comments were offered about how tribal health data is not high-quality and sample sizes are too small. There was concern that these data cannot be used to drive decision-making. Consensus was shared around the need to think of health more broadly by taking into account the social determinants of health—economic stability, education, social and community context, neighborhood and built environment—as well as health care.

Wrap-up

Ivor Braden Horn, MD, MPH, co-chair, Data for Health Advisory Committee, ended the event by describing some of the key themes heard throughout the day. The themes included the need for incentives for individuals to be healthier and use their data as part of their care, the importance of building trust and ensuring that the data would not be used in a way that could be harmful, and the need to develop strategies that make data useful and available.

Phoenix and Maricopa County's Health and Well-being— From Multiple Perspectives

“There is no better time than now to renew our focus on a nationwide, interoperable health IT infrastructure – one in which all individuals, their families, and their health care providers have appropriate access to health information that facilitates informed decision-making, supports coordinated health management, allows patients to be active partners in their health and care, and improves the overall health of our population. This is not just a technology challenge.”¹

This handout paints a picture of the health of Phoenix and the rest of Maricopa County. It sets the stage for seeking community input about what information individuals, communities, researchers, and other interested parties would find useful for monitoring and increasing their health and well-being. The Maricopa County population is compared to the populations of Arizona and the United States with a focus on health outcomes and behaviors, the social and economic environment, and quality of and access to health care.

I. Health Behaviors and Outcomes

Health outcomes refer to how people feel physically and mentally and include factors that can influence conditions of health.

- The Maricopa County population has fewer physically unhealthy days per month (3.2) as compared to people in Arizona (3.5) and the US (3.7), and fewer mentally unhealthy days per month (3.2) as compared to Arizona (3.4) and the US (3.5).²
- The percentage of those in Maricopa County reporting fair or poor health (17%) is similar to people in Arizona (18%) and the US population (17%).³
- In Maricopa County, fewer babies have low birth weight (7%) as compared with babies born in the US (8%).⁴
- Certain behaviors, like smoking and drinking, can influence health and mortality.⁵ Maricopa County has some similarities and some differences to Arizona and the US on behaviors that affect health (see Chart 1, p.60).⁶

II. Social and Economic Environment

“Decades of research have demonstrated that citizens’ health is determined by much more than their level of knowledge and health behavior choices. Beyond race and gender, one’s opportunity and environment are strong predictors in terms of health status and outcomes.” (Maricopa County Department of Public Health, 2012)⁷

Overall health is affected by individuals' social and economic environment, which includes family situations and income, educational opportunity and employment opportunity (see Table 1, p.60).⁸

Social support, housing quality, and neighborhood safety affect the health of individuals and the community (see Chart 2, p.60).

Access to public transportation (see Chart 3, p.61), quality food, and recreation affect overall health and well-being.

The built environment includes the quality of housing, water, air, and access to healthy foods and recreation facilities.

- One survey found that 81.8 percent of people in Maricopa County have parks, playgrounds, or open spaces within walking distance of their home and less than a quarter eat the minimum required daily servings of fruits and vegetables.⁹
- In Maricopa County, the number of recreation and fitness facilities has decreased by 12 percent between 2007 and 2011, and the number of farmers markets has increased by 10 percent between 2009 and 2013. Approximately 1 in 8 Maricopa County residents do not have easy access to a grocery store.¹⁰

III. Access to and Quality of Health Care

The overall health of the community can be measured by both the length and quality of people's lives, which is partially influenced by access to health care.

- People in Maricopa County lose 6,247 years of potential life before age 75 (per 100,000 population) compared to almost 7,000 years for the Arizona and US populations.¹¹

Maricopa County has 5 federally qualified health centers with approximately 45 sites.¹²

- There is a growing use of electronic health records associated with patient care in the US. In the US, 48 percent of office-based doctors are using electronic records, up from 11 percent in 2006. In Arizona, 51 percent of office-based doctors are using electronic health records.¹³

Individuals need Internet access in order to obtain their health information electronically.

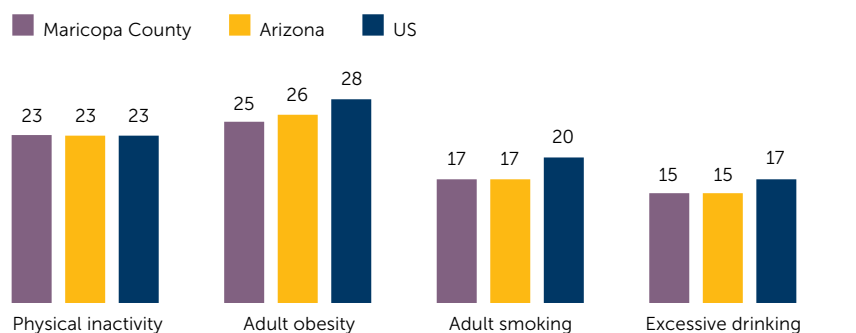
- Almost 9 out of 10 Maricopa County households (86%) have a computer and 76 percent have broadband internet access. This is slightly higher than computer ownership for households in Arizona and the US (both 84%) and broadband Internet access (74% and 73%, respectively).¹⁴

Table 1. Social and Economic Characteristics, 2013

Demographics	Maricopa County	Arizona	United States
Total population	4,009,412	6,626,624	316,128,839
Median age	35.6	36.8	37.5
Percent white	82.6%	81.7%	76.2%
Percent black	6.2%	5.2%	13.8%
Percent Hispanic	30.0%	30.3%	17.1%
Percent living alone	27.1%	27.6%	27.7%
Economic			
Median household income	\$52,045	\$48,510	\$52,250
Mean household income	\$72,078	\$66,389	\$73,767
Percent unemployed	4.7%	5.3%	5.3%
Education			
Percent high school graduate only	23.4%	24.8%	27.8%
Percent of adults with some college or higher	63.2%	61.1%	58.8%

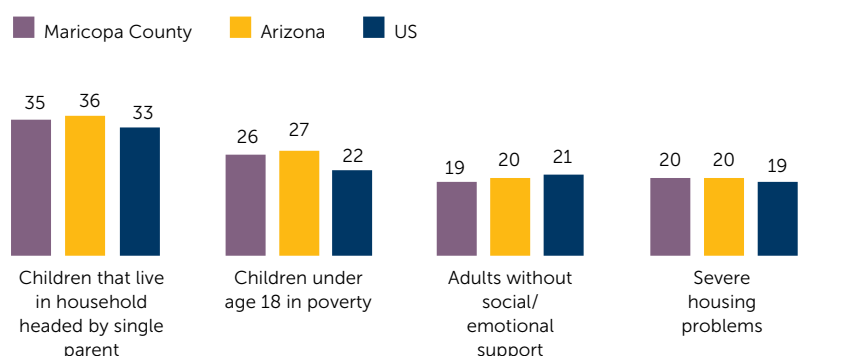
Source: Census Bureau, American Community Survey, 2013.

Chart 1. Health Behaviors—Physical Inactivity, Obesity, Smoking, Drinking (Percent)



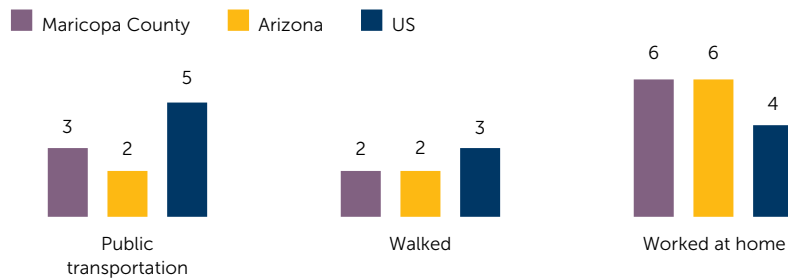
SOURCE: CDC Behavioral Risk Factor Surveillance System (2012)

Chart 2. Children and Adults with Possible Need for Social Support (Percent)



SOURCE: Census Bureau, American Community Survey, 2013, CDC Behavioral Risk Factor Surveillance System (2006-2012), and Housing and Urban Development (HUD) Comprehensive Housing Affordability Strategy (CHAS) (2007-2011)

Chart 3. Means of Transportation to Work (Percent)



SOURCE: Census Bureau, American Community Survey, 2013

Endnotes

- 1 Office of the National Coordinator for Health Information Technology. (2014). Connecting Health and Care for the Nation: A 10-Year Vision to Achieve an Interoperable Health IT Infrastructure. <http://www.healthit.gov/sites/default/files/ONC10yearInteroperabilityConceptPaper.pdf>
- 2 Robert Wood Johnson Foundation County Health Rankings. <http://www.countyhealthrankings.org/>
- 3 Centers for Disease Control and Prevention (CDC) Behavioral Risk Factor Surveillance System 2006-2012. <http://www.cdc.gov/brfss/>
- 4 Robert Wood Johnson Foundation County Health Rankings. <http://www.countyhealthrankings.org/>
- 5 Mokdad, A. H., Marks, J. S., Stroup, D. F., & Gerberding, J. L. (2004). Actual causes of death in the United States, 2000. *JAMA*, 291(10), 1238-1245.
- 6 Centers for Disease Control and Prevention (CDC) Behavioral Risk Factor Surveillance System 2012. <http://www.cdc.gov/brfss/>
- 7 Maricopa County Community Health Assessment, 2012. <http://www.maricopa.gov/PublicHealth/programs/OPI/pdf/CHA-2012.pdf>
- 8 Census Bureau, American Community Survey, 2013. <http://www.census.gov/acs/www/>
- 9 Maricopa County Community Health Assessment, 2012. <http://www.maricopa.gov/PublicHealth/programs/OPI/pdf/CHA-2012.pdf>
- 10 US Department of Agriculture, Food Environment Atlas, 2014. <http://ers.usda.gov/data-products/food-environment-atlas/data-access-and-documentation-downloads.aspx#.VD6EDivF98w>
- 11 Robert Wood Johnson Foundation County Health Rankings. <http://www.countyhealthrankings.org/>
- 12 Maricopa County Community Health Assessment, 2012. <http://www.maricopa.gov/PublicHealth/programs/OPI/pdf/CHA-2012.pdf>
- 13 Hsiao C-J, Hing E. (2014). Use and characteristics of electronic health record systems among office-based physician practices. United States, 2001–2013. NCHS data brief, no. 143. Hyattsville, MD: National Center for Health Statistics. <http://www.cdc.gov/nchs/data/databriefs/db143.pdf>
- 14 Census Bureau, American Community Survey, 2013. <http://www.census.gov/acs/www/>

The above endnotes pertain to this Data Fact Sheet only.

Appendix E. Des Moines— November 10, 2014

Data for Health—Summary of the Learning What Works Event

Welcome and Opening Remarks

David A. Ross, ScD, co-chair, Data for Health Advisory Committee, introduced the *Data for Health* event in Des Moines. He described how building a Culture of Health requires data to paint the picture of the health of a community, which would then allow communities to hold the data up and assess if they like what we see. If they don't like what they see, they can use the data to guide change. He asked the audience three questions: 1) have you used data to improve health in your community? 2) What type of data would you like to use to improve people's health? 3) Who would you like to collaborate with? The audience responded by noting the importance of real-time data access and analysis, especially access and analysis at the local level. They noted that most health falls outside the health care system. They expressed concerns about lack of data for vulnerable populations, data about patients who have the potential to become high risk, and data for policy analysis.

Michael Painter, JD, MD, senior program officer, Robert Wood Johnson Foundation, noted that information is an important aspect for building a Culture of Health and using that information for making decisions. He described how we don't currently have the ability to turn the information into actions and decisions and this is not a hardware or software problem but a cultural problem. "In an ideal world, a Culture of Health means everyone would have a realistic opportunity to be healthy."

Karen DeSalvo, MD, MPH, MSc, acting assistant secretary for health and national coordinator for health information technology, U.S. Department of Health and Human Services, described the role of The Office of the National Coordinator (ONC) in creating the federal health IT strategic plan through collaborations with all federal agencies and outreach to communities.³⁴ She gave the example of the Health Information Technology for Economic and Clinical Health (HITECH) Act, signed into law in 2009, which promoted the adoption and meaningful use of health information technology, resulting in more than 90 percent of hospitals adopting a system of electronic health records. She described how we are information-rich for people who have insurance and are identifiable in the system, but information-poor for people who are invisible to the health care system. She shared her goal of creating an empowering environment that defines health beyond health care in a way that respects privacy and achieves societal good.

Plenary Speakers

Jeff Chungath, MS, CEO, Telligen, explained how Telligen focuses on improving health through providers and members. They look for patterns in the data at a facility level to improve care and to reward quality outcomes. They are starting to break down the data silos by looking for patterns in the data that would help reduce re-admissions, such as access to primary care and transportation, ability to follow through on doctor's recommendations, and access to community resources to stay healthy. He described how Telligen looks at health broadly and with an eye toward informing public policy to encourage optimal location of grocery stores, parks, walking trails, and other infrastructure that a community needs to get and stay healthy. He shared that communities need real-time information to drive decisions and policies.

Troy Vincent, director, Live Healthy America, provides technology to community-based programs, such as Live Healthy Iowa. They develop health and wellness programs that provide a mechanism for communities to help change individual behavior, build healthy environments, and forge health initiative policy. They connect the data scientists (what he calls the thinkers) with the doers (the providers) to nudge and connect people and to make them more social. (See Snapshot on Live Healthy Iowa, p.23.)

Erin Drinnin, MS, community impact officer, Health, United Way of Central Iowa, described how United Way of Central Iowa (UWCI) works to have the greatest collective impact. Currently, UWCI acts as a convener, funder, advocate, and educator to have the community identify and solve its challenges. The community set goals for 2020 around education, income, and health.³⁵ She gave the example of a UWCI Project called Connections that puts family support specialists inside pediatric clinics to work with families to address nonhealth needs, such as housing, food, transportation, and child care and provides other services. She described how helping families meet basic needs promotes health within the family.³⁶ She highlighted the key challenges of finding timely data with enough detail to describe the health and characteristics of central Iowa residents.

Plenary Discussion

There was discussion around how children are the key to future prosperity yet many children live in poverty and need care beyond health care to improve their social and environment conditions. Consensus was shared that health is where we live, learn, work and play and health is more than health care encounters. For example, if there's a school where children have more asthma attacks, this information can be used to identify policies to change the environment. Comments included that to achieve equity we need to invest money in the determinants that are really affecting health.

There was discussion around The White House's report on big data and the concerns it raised about discrimination and privacy.³⁷ Karen DeSalvo described how the Office of the National Coordinator (ONC) has included the topic of privacy in the forthcoming ONC strategic plan. Concerns were voiced about data being used appropriately and with consent. There was a discussion about how big data are not protected by HIPAA³⁸ and it is not clear that people understand and appreciate this. There was recognition that big data have the potential to transform health beyond health care and it makes it easier if people will consent to sharing their data in a way that does not violate their confidentiality.

Wrap-up

David A. Ross, ScD, co-chair, Data for Health Advisory Committee, ended the event by describing the key themes that were heard throughout the day—the importance of interoperability and data integration, the need to instill in people the value of health, and the need to gather and share information on the social determinants of health.

Des Moines and Polk County's Health and Well-being— From Multiple Perspectives

“There is no better time than now to renew our focus on a nationwide, interoperable health IT infrastructure – one in which all individuals, their families, and their health care providers have appropriate access to health information that facilitates informed decision-making, supports coordinated health management, allows patients to be active partners in their health and care, and improves the overall health of our population. This is not just a technology challenge.”¹

This handout paints a picture of the health of Des Moines and the rest of Polk County. It sets the stage for seeking community input about what information individuals, communities, researchers, and other interested parties would find useful for monitoring and increasing their health and well-being. The Polk County population is compared to the populations of Iowa and the United States with a focus on health outcomes and behaviors, the social and economic environment, and quality of and access to health care.

I. Health Behaviors and Outcomes

Health outcomes refer to how people feel physically and mentally and include factors that can influence conditions of health.

- The Polk County and Iowa populations have fewer physically unhealthy days per month (both 2.8) as compared to people in the US (3.7), and fewer mentally unhealthy days per month (2.8 and 2.6, respectively) as compared to the US (3.5).²
- The percentage of those in Polk County reporting fair or poor health (13%) is similar to people in Iowa (14%) and lower than the US population (17%).³
- In Polk County, fewer babies have low birth weight (7%) as compared with babies born in the US (8%).⁴
- Certain behaviors, like smoking and drinking, can influence health and mortality.⁵ Polk County has some similarities and some differences to Iowa and the US on behaviors that affect health (see Chart 1, p.66).⁶

II. Social and Economic Environment

“Our health is primarily a reflection of the behavior and choices we make. And these choices are made in the context of our social, political and physical environments.” (Polk County Health Department Annual Report, 2011/2012)⁷

Overall health is affected by individuals' social and economic environment, which includes family situations and income, educational opportunity and employment opportunity (see Table 1).⁸

Social support, housing quality, and neighborhood safety affect the health of individuals and the community (see Chart 2, p.66).

Access to public transportation (see Chart 3, p.66), quality food, and recreation affect overall health and well-being.

The built environment includes the quality of housing, water, air, and access to healthy foods and recreation facilities.

- In Polk County, the number of recreation and fitness facilities increased by 22 percent and the number of fast food restaurants decreased by 3 percent between 2007 and 2011. Approximately 1 in 5 Polk County residents do not have easy access to a grocery store.⁹

III. Access to and Quality of Health Care

The overall health of the community can be measured by both the length and quality of people's lives, which is partially influenced by access to health care.

- People in Polk County lose approximately 6,300 years of potential life before age 75 (per 100,000 population) compared to almost 6,000 years in Iowa and 7,000 years for the US population.¹⁰
- There is a growing use of electronic health records associated with patient care in the US. In the US, 48 percent of office-based doctors are using electronic records, up from 11 percent in 2006. In Iowa, 66 percent of office-based doctors are using electronic health records.¹¹

Individuals need Internet access in order to obtain their health information electronically.

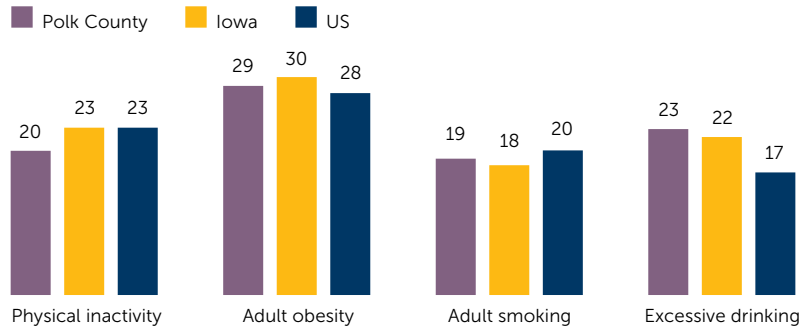
- Almost 9 out of 10 Polk County households have a computer (88%) and 78 percent have broadband internet access. This is higher than computer ownership for households in Iowa and the US (83% and 84%, respectively) and broadband Internet access (72% and 73%, respectively).¹²

Table 1. Social and Economic Characteristics, 2013

Demographics	Polk County	Iowa	United States
Total population	451,677	3,090,416	316,128,839
Median age	35.0	38.0	37.5
Percent white	87.5%	93.0%	76.2%
Percent black	7.7%	4.1%	13.8%
Percent Hispanic	8.0%	5.4%	17.1%
Percent living alone	27.8%	29.0%	27.7%
Economic			
Median household income	\$59,328	\$52,229	\$52,250
Mean household income	\$78,810	\$68,075	\$73,767
Percent unemployed	4.1%	3.3%	5.3%
Education			
Percent high school graduate only	26.1%	32.7%	27.8%
Percent of adults with some college or higher	66.6%	59.0%	58.8%

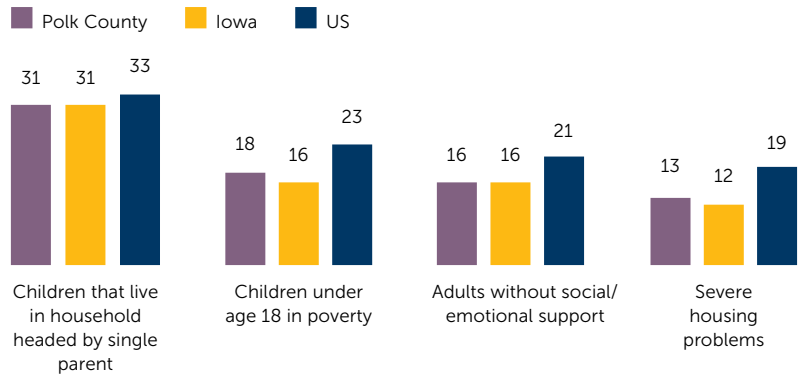
Source: Census Bureau, American Community Survey, 2013.

Chart 1. Health Behaviors—Physical Inactivity, Obesity, Smoking, Drinking (Percent)



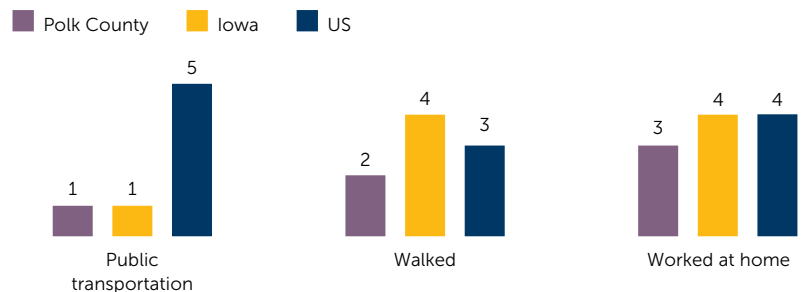
SOURCE: CDC Behavioral Risk Factor Surveillance System (2012)

Chart 2. Children and Adults with Possible Need for Social Support (Percent)



SOURCE: Census Bureau, American Community Survey, 2013, CDC Behavioral Risk Factor Surveillance System (2006-2012), and Housing and Urban Development (HUD) Comprehensive Housing Affordability Strategy (CHAS) (2007-2011)

Chart 3. Means of Transportation to Work (Percent)



SOURCE: Census Bureau, American Community Survey, 2013

Endnotes

- 1 Office of the National Coordinator for Health Information Technology. (2014). Connecting Health and Care for the Nation: A 10-Year Vision to Achieve an Interoperable Health IT Infrastructure. <http://www.healthit.gov/sites/default/files/ONC10yearInteroperabilityConceptPaper.pdf>
- 2 Robert Wood Johnson Foundation County Health Rankings. <http://www.countyhealthrankings.org/>
Centers for Disease Control and Prevention (CDC) Behavioral Risk Factor Surveillance System 2006-2012. <http://www.cdc.gov/brfss/>
- 3 Centers for Disease Control and Prevention (CDC) Behavioral Risk Factor Surveillance System 2012. <http://www.cdc.gov/brfss/>
- 4 Robert Wood Johnson Foundation County Health Rankings. <http://www.countyhealthrankings.org/>
CDC National Center for Health Statistics (NCHS), National Vital Statistics Reports. <http://www.cdc.gov/nchs/products/nvsr.htm>
- 5 Mokdad, A. H., Marks, J. S., Stroup, D. F., & Gerberding, J. L. (2004). Actual causes of death in the United States, 2000. *JAMA*, 291(10), 1238-1245.
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- 7 Polk County Health Department Annual Report 2011/2012. <http://www.polkcountyiowa.gov/media/112598/2012annualreport.pdf>
- 8 Census Bureau, American Community Survey, 2013. <http://www.census.gov/acs/www/>
- 9 US Department of Agriculture, Food Environment Atlas, 2014. <http://ers.usda.gov/data-products/food-environment-atlas/data-access-and-documentation-downloads.aspx#.VD6EDlvF98w>
- 10 Robert Wood Johnson Foundation County Health Rankings. <http://www.countyhealthrankings.org/>
CDC National Center for Health Statistics (NCHS), Mortality Data, 2008-2010. <http://www.cdc.gov/nchs/deaths.htm>
- 11 Hsiao C-J, Hing E. (2014). Use and characteristics of electronic health record systems among office-based physician practices. United States, 2001–2013. NCHS data brief, no. 143. Hyattsville, MD: National Center for Health Statistics. <http://www.cdc.gov/nchs/data/databriefs/db143.pdf>
- 12 Census Bureau, American Community Survey, 2013. <http://www.census.gov/acs/www/>

The above endnotes pertain to this Data Fact Sheet only.

Appendix F. San Francisco— December 4, 2014

Data for Health—Summary of the Learning What Works Event

Welcome and Opening Remarks

Ivor Braden Horn, MD, MPH, co-chair, Data for Health Advisory Committee, introduced the *Data for Health* event in San Francisco and described the goal of learning how communities can use data to improve health. She pointed out that people don't often have the chance to sit in the room together and have a conversation about collecting and sharing health information. That is what makes the *Learning What Works* events so powerful.

Michael Painter, JD, MD, senior program officer, Robert Wood Johnson Foundation, shared RWJF's vision to build a Culture of Health that goes beyond health care. He described how realizing this vision would allow all of us to have the opportunity to live a healthy life and access the care we need when we need it. While there are many pieces that go into a Culture of Health, he emphasized the importance of information. "We have all of this data, but the problem is turning this data into information that we can use." He emphasized that this isn't a hardware or software issue, but a people issue. As he pointed out, each of us collects data through our transactions and our daily activities as well as through our electronics. He described how to create a strategy requires listening to what communities want to know and would and could do with data.

Karen DeSalvo, MD, MPH, MSc, acting assistant secretary for health and national coordinator for health information technology, U.S. Department of Health and Human Services,³⁹ said that the *Learning What Works* events have allowed the Office of the National Coordinator (ONC) to stay engaged with communities across the United States and to gain perspective as they update the Health Information Technology Strategic Plan.⁴⁰ She described how there is a paradigm shift to move people to better health. She stated that many people today don't have the choice to be healthy and it's ONC's job to determine how we can use health information to solve this problem. "Envision an interoperable health system where information can be collected, shared, and used to inform health not just in the health care system, but in communities as well." She posed the questions, "How can information be used to promote good health for everyone? How can we make info available when and where it matters?" She described how we all have a role to play in designing a system that looks at the picture of health beyond health care.

Plenary Speakers

Andrew Rosenthal, MBA, chief strategy officer, Jawbone, turns quantitative health data into qualitative recommendations regarding health behaviors. He described how *Jawbone* is a wearable monitor that has been around for about 14 years and measures everything from heart rate to hydration through a computer that you wear on your wrist. "*Jawbone* disrupts technology through design which is not a new trend." He gave the example of John Snow who was an anesthesiologist in 1854 when Cholera was breaking out in his community. John Snow built a map and labeled where there were instances of Cholera in his neighborhood to figure out if there was an explanation for the location of the outbreaks. Andrew linked what John Snow was doing in 1854 to what is happening today with

companies using health data to inform choices. He demonstrated how *Jawbone* sleep data reflected Napa Valley's 6.0 earthquake in August 2014, and they could see in the data that almost half of *Jawbone* wearers did not go back to sleep after the 3:30 a.m. earthquake.⁴¹ He suggested that the information can be used by employers and school leaders to delay school or the work day, recognizing that people do not perform as well if they are sleep deprived.

Roni Zeiger, MD, MS, CEO, Smart Patients, and former Chief Health Strategist at Google, where he led efforts ranging from *Google Flu Trends* to *Symptom Search*. In 2012, he and Gilles Frydman founded Smart Patients in order to amplify the knowledge created by networks of engaged patients. He described how he went into medicine and discovered his interest in making sense of the massive amounts of data produced each day at his medical center. He studied Google searches for medical conditions, and realized the data collected from the searches told stories of people that could be used to gain insight. He emphasized the need for more data and better access to the data but also the need to listen more carefully to the stories behind the data. "The data may give us the answers, but it's the stories that tell us which questions to ask." (See Snapshot on Smart Patients, p. 26)

Gary Wolf, MA, director and co-founder, Quantified Self, said that his company is a collaboration of users and toolmakers who share an interest in gaining self-knowledge through self-tracking. Their goal is to help people get meaning out of their personal data. He described how using data to build a Culture of Health changes the way we think about data. He gave the example of how data are useful for scientists, but also useful for self-care, self-discovering, and self-expression—sharing with others. While big data are useful to do big science, he emphasized the importance of OUR data—personal data. "If we're going to build a Culture of Health we have to pay attention to the democratic and personal aspirations for using these data." He described how access to data is a problem as there is no consensus that access to your data is desirables or even useful.

Plenary Discussion

Comments were offered regarding the goal of translating information from data to knowledge, as well as how the flow of personal information can be aggregated to create new knowledge. There was discussion around how many people are invisible to the health care system and don't use apps or fitness trackers. Individuals described the need to increase to scope to include more than hospitals and those that use electronics to track health, but also those organizations and individuals that contribute to the Culture of Health, such as places of worship in communities.

Comments were offered about the need to serve communities who don't have resources or access to data. Concerns were voiced about the patchwork of regulations and laws that aren't consistent across organizations and social services. Individuals described how the data are created within silos and regulated in silos. Although there are new ways and better designs for obtaining these data, there has to be a willingness to do this.

Wrap-up

Ivor Braden Horn, MD, MPH, co-chair, Data for Health Advisory Committee, ended the event by describing the key points that were heard throughout the day. The key points included the need for data ethics and the responsible use of data, the importance of creating a conversation around data sharing so that people understand the benefits of sharing and how their data will be used, and the idea that sharing data is not enough to create a Culture of Health, but that using data in an actionable way needs to be the focus.

San Francisco's Health and Well-being—From Multiple Perspectives

“There is no better time than now to renew our focus on a nationwide, interoperable health IT infrastructure – one in which all individuals, their families, and their health care providers have appropriate access to health information that facilitates informed decision-making, supports coordinated health management, allows patients to be active partners in their health and care, and improves the overall health of our population. This is not just a technology challenge.”¹

This handout paints a picture of the health of the City and County of San Francisco. It sets the stage for seeking community input about what information individuals, communities, researchers, and other interested parties would find useful for monitoring and increasing their health and well-being. The San Francisco population is compared to the populations of California and the United States with a focus on health outcomes and behaviors, the social and economic environment, and quality of and access to health care.

I. Health Behaviors and Outcomes

Health outcomes refer to how people feel physically and mentally and include factors that can influence conditions of health.

- The San Francisco population has fewer physically unhealthy days per month (3.1) as compared to people in California (3.7) and the US (3.7), and fewer mentally unhealthy days per month (3.1) as compared to California (3.6) and the US (3.5).²
- The percentage of those in San Francisco reporting fair or poor health (13%) is lower than the percentage of people in California (18%) and the US population (17%).³
- In San Francisco, fewer babies have low birth weight (7%) as compared with babies born in the US (8%).⁴
- Certain behaviors, like smoking and drinking, can influence health and mortality.⁵ San Francisco has some similarities and some differences to California and the US on behaviors that affect health (see Chart 1, p.72).⁶

II. Social and Economic Environment

“Quality of life factors affect a person’s perception of whether s/he is in good health and able to engage with the community as indicated by attending school, exercising and playing, recreating outdoors, and accessing nutritious food and other necessities.”⁷

Overall health is affected by individuals' social and economic environment, which includes family situations and income, educational opportunity and employment opportunity (see Table 1, p.72).⁸

Social support, housing quality, and neighborhood safety affect the health of individuals and the community (see Chart 2, p.72).

Access to public transportation (see Chart 3, p. 73), quality food, and recreation affect overall health and well-being.

The built environment includes the quality of housing, water, air, and access to healthy foods and recreation facilities.

- Access to open spaces for outdoor activities combined with outreach and education lead to increase in the frequency of physical activity (see Figure 1, p.73).
- In San Francisco, the number of farmers markets increased from 14 in 2009 to 28 in 2013.⁹
- About 3 percent of San Francisco residents do not have easy access to a grocery store.¹⁰

III. Access to and Quality of Health Care

The overall health of the community can be measured by both the length and quality of people's lives, which is partially influenced by access to health care.

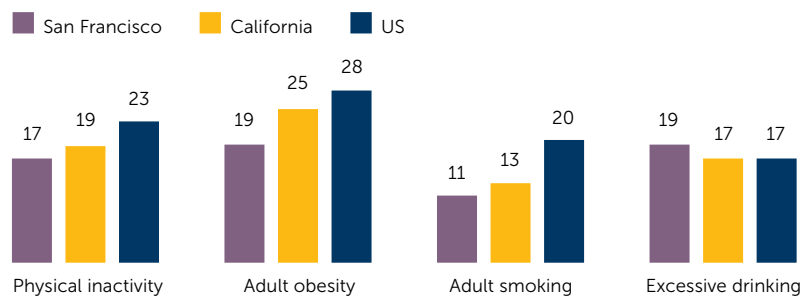
- People in San Francisco County lose fewer years of potential life before age 75 (5,244 per 100,000 population) compared to 5,570 for California and almost 7,000 years for the US population.¹²
- San Francisco has about 55 primary care health centers. The map below shows the quarter mile radius around each center, which is considered a reasonable distance for a typical resident to walk or bike to obtain medical care (see Figure 2, p.74).¹³
- There is a growing use of electronic health records associated with patient care in the US. In the US, 48 percent of office-based doctors are using electronic records, up from 11 percent in 2006. In California, 54 percent of office-based doctors are using electronic health records.¹⁴
- Individuals need Internet access in order to obtain their health information electronically. Almost 9 out of 10 San Francisco households (88%) have a computer and 82 percent have broadband Internet access. This is slightly higher than computer ownership for households in California and the US (87% and 84%) and broadband Internet access (78% and 73%, respectively).¹⁵

Table 1. Social and Economic Characteristics, 2013

Demographics	San Francisco	California	United States
Total population	837,442	38,332,521	316,128,839
Median age	38.7	35.7	37.5
Percent white	52.1%	65.6%	76.2%
Percent black	6.7%	7.1%	13.8%
Percent Hispanic	15.3%	38.4%	17.1%
Percent living alone	27.8%	29.0%	27.7%
Economic			
Median household income	\$77,485	\$60,190	\$52,250
Mean household income	\$117,255	\$85,707	\$73,767
Percent unemployed	5.1%	6.3%	5.3%
Education			
Percent high school graduate only	12.6%	20.8%	27.8%
Percent of adults with some college or higher	74.2%	60.9%	58.8%

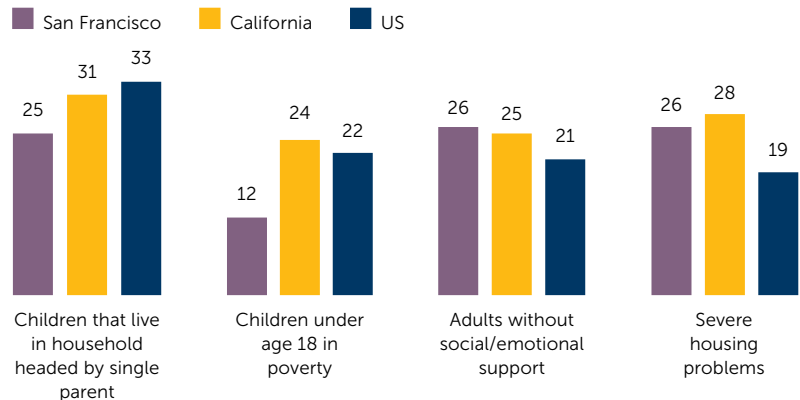
Source: Census Bureau, American Community Survey, 2013.

Chart 1. Health Behaviors—Physical Inactivity, Obesity, Smoking, Drinking (Percent)



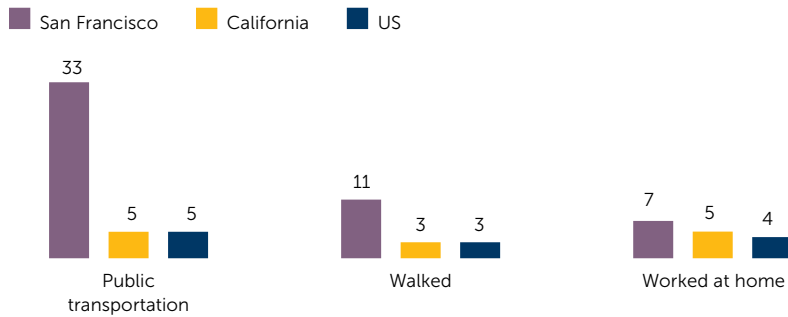
SOURCE: CDC Behavioral Risk Factor Surveillance System (2012)

Chart 2. Children and Adults with Possible Need for Social Support (Percent)



SOURCE: Census Bureau, American Community Survey, 2013, CDC Behavioral Risk Factor Surveillance System (2006-2012), and Housing and Urban Development (HUD) Comprehensive Housing Affordability Strategy (CHAS) (2007-2011)

Chart 3. Means of Transportation to Work (Percent)



SOURCE: Census Bureau, American Community Survey, 2013

Figure 1. The relative measure of the number of acres of public recreation space within two miles, weighted by distance.¹¹

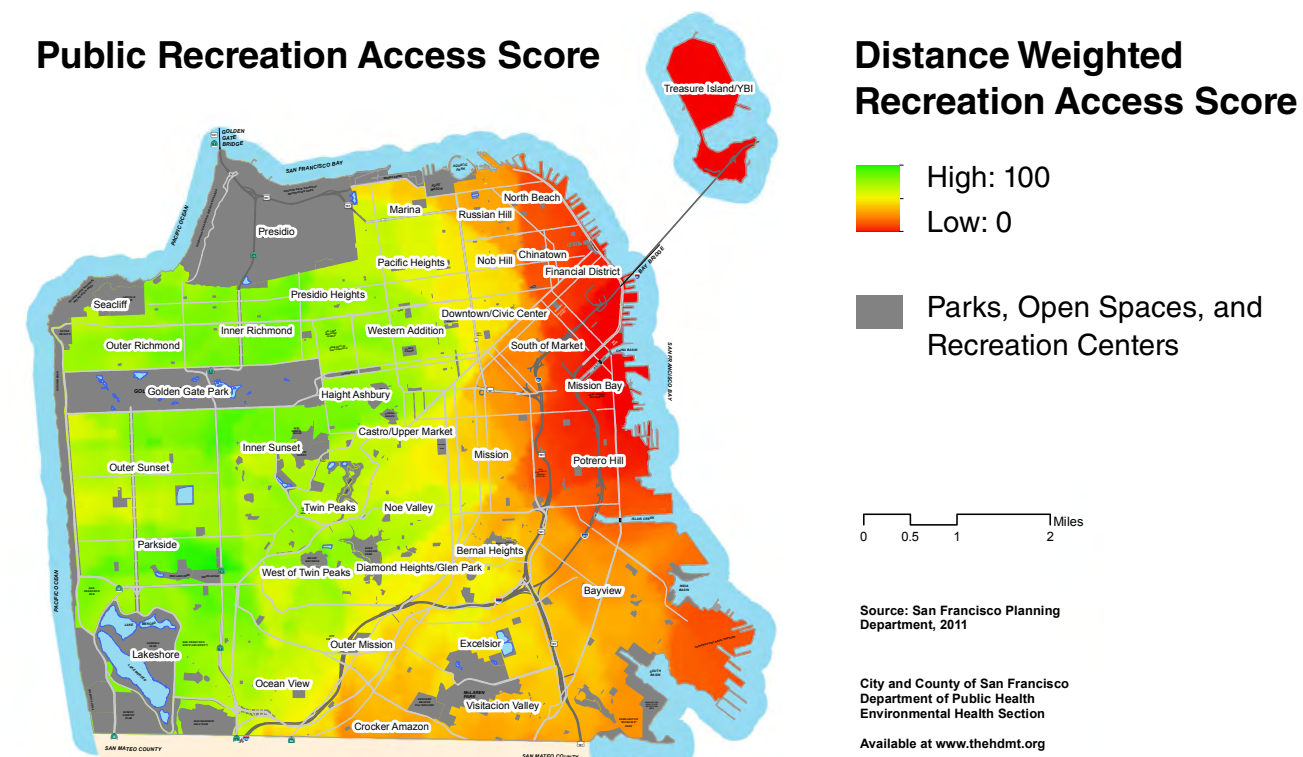
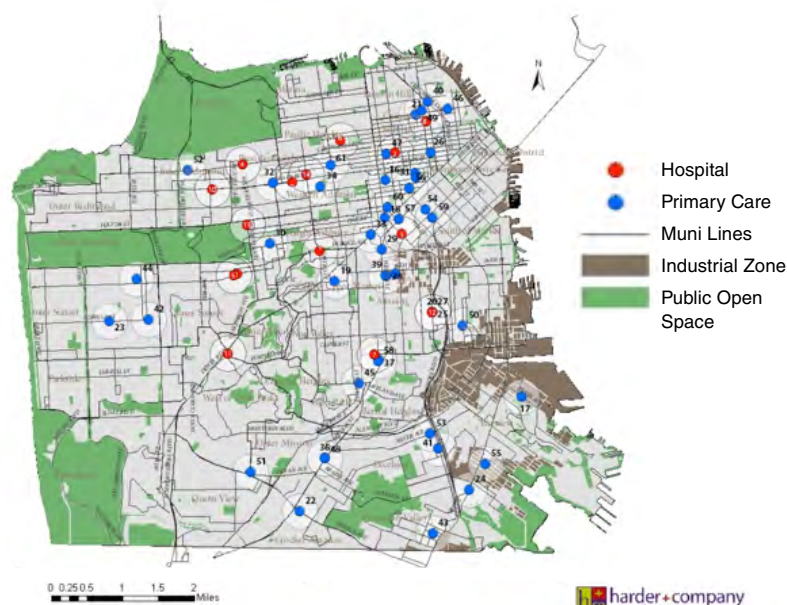


Figure 2. Geographic proximity to health care as indicated by quarter mile radius surrounding select primary care health centers and all hospitals.¹⁶



Endnotes

- 1 Office of the National Coordinator for Health Information Technology. (2014). Connecting Health and Care for the Nation: A 10-Year Vision to Achieve an Interoperable Health IT Infrastructure. <http://www.healthit.gov/sites/default/files/ONC10yearInteroperabilityConceptPaper.pdf>
- 2 Robert Wood Johnson Foundation County Health Rankings. <http://www.countyhealthrankings.org/>
Centers for Disease Control and Prevention (CDC) Behavioral Risk Factor Surveillance System 2006-2012. <http://www.cdc.gov/brfss/>
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CDC National Center for Health Statistics (NCHS), National Vital Statistics Reports. <http://www.cdc.gov/nchs/products/nvsr.htm>
- 5 Mokdad, A. H., Marks, J. S., Stroup, D. F., & Gerberding, J. L. (2004). Actual causes of death in the United States, 2000. *JAMA*, 291(10), 1238-1245.
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- 11 Sustainable Communities Index, San Francisco Department of Public Health, 2011. (A distance of < 0.5 miles is given a score of 1, while distances between 0.5-0.1 miles are given a score of 0.75 and distances >1 mile are given a score of 0.5.) <http://www.sustainablecommunitiesindex.org/indicators/view/91>
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CDC National Center for Health Statistics, Mortality Data, 2008-2010. <http://www.cdc.gov/nchs/deaths.htm>
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- 16 Community Health Status Assessment: City and County of San Francisco, Harder+Company Community Research, 2012. <http://www.sfdph.org/dph/files/chip/CommunityHealthStatusAssessment.pdf>

The above endnotes pertain to this Data Fact Sheet only.

Appendix G. Charleston— December 10, 2014

Data for Health—Summary of the Learning What Works Event

Welcome and Opening Remarks

Ivor Braden Horn, MD, MPH, co-chair, Data for Health Advisory Committee, introduced the Charleston *Data for Health* meeting. She highlighted the goal is to learn how communities are using data to improve health, to encourage communities to think about their future health data needs, and how to prepare for that future. She discussed *Blue Button*,⁴² which allows individuals the ability to access and save their health care data electronically. She described the potential for these data to be anonymously aggregated across a community and combined with other data so that the health of a community could be known. She also highlighted uses for these data, such as policymakers using it to allocate taxpayer dollars more efficiently to create a healthier environment; hospitals and clinics anticipating health needs to inform health care and encourage healthier lifestyles; schools using these data to educate students about their overall health and support a more active student body; and places of worship and other organizations creating activities and improving support to help those in need and at the same time improving the overall health of their members.

Hillary Heishman, MPH, program officer, Robert Wood Johnson Foundation, defined *Data for Health* as an initiative to use health and other data to create a Culture of Health. She described data as a powerful tool for building a Culture of Health, but acknowledged that to achieve this vision, many conversations are needed to learn about and understand individual and community needs for data and their concerns about privacy and trust. She indicated that these *Learning What Works* events are meant to start these conversations and provide specific recommendations for moving this agenda forward.

Karen DeSalvo, MD, MPH, MSc, acting assistant secretary for health and national coordinator for health information technology, U.S. Department of Health and Human Services, noted that we are creating an infrastructure and policy framework that allows your data to wrap around you and uses sources beyond the electronic health records. She described how this is about creating a person-centered and community-centered plan and approach. She notified everyone of the new Federal Health IT strategic plan⁴³ and asked people to provide their comments.

Plenary Speakers

Ida Sim, MD, PhD, professor of medicine, University of California, and Co-Founder, Open mHealth, cautioned that the focus on data and technology creates an environment called “healthism”—a lifestyle that prioritizes health and fitness above thinking about all aspects of health. In addition, she noted that our health care system focuses on eliminating disease and infirmity rather than on creating a healthy environment, a state of complete physical, mental, and social well being. She indicated that the more important question is what are the health outcomes that we want to achieve?

David Blumenthal, MD, MPP, president and CEO, The Commonwealth Fund, noted that many people are collecting health data through monitoring devices but that the data are only useful if they have a purpose. He identified the current challenges for digital health as incorporating mobile data into electronic health records, privacy and security, the need for evidence of efficacy of applications, algorithms to translate big data to information and action, and tools to allow the overwhelmed clinician to use data easily and without additional burden.

Lisa Wear-Ellington, CEO, South Carolina Business Coalition on Health, said that the focus has always been on driving down the health care fee schedule, but that the main problem is how to use data to understand how patients access and move through the health care system. She noted that there are many holes in the data and described her data wish list as having the ability to combine data into a common data base at the state or community level, achieving price transparency; creating provider payments based on outcomes; and utilizing data analytics that produce pathways to potential solutions. Her health outcomes wish list is a fee for performance instead of fee for service system.

Bernie Mazyck, president and CEO, South Carolina Association for Community Economic Development (SCACED), said their mission is to improve the quality of life for low-wealth families and communities by advancing community economic development in every county in South Carolina. He described data as important for building community capacity to identify and address issues of importance in their communities. He gave the example of how his organization identified diabetes as a main issue in communities and linked diabetes with food deserts—areas with low access to grocery stores and healthy food. As a result, his organization helped create a network of farmers to increase healthy food hubs and to increase local farming to provide healthy food in order to enhance the health of the community.

Plenary Discussion

There was consensus that efficient ways exist for monitoring and collecting health data. The focus now needs to be translating these data to information and action for all people from the young and fit to the older population with chronic conditions.

There was discussion about the value in combining and benchmarking health data as well as the need for public-private partnerships to build systems that individuals and communities can use. Places of Worship were cited as an example of a starting place for these collaborations.

Attendees described the need for data citizenship (rights to your data) and public dialogue about what privacy/security means in age of global health and globalization. There were concerns that we don't have federal regulations about how organizations access, protect, and use people's private data beyond their electronic health data.

It was also acknowledged that most of the data we have available is very health care centric and the focus should be broader to include social and physical determinants of health including economic stability, education, social and community context, health and health care, and the neighborhood and built environment.

Attendees described the need to understand the data. "I have access to my health care data but I do not know what it means." Identifying the health and social problems first was proposed as the key to developing data systems to address these problems.

Wrap-up

Ivor Braden Horn, MD, MPH, co-chair, Data for Health Advisory Committee, concluded the event by describing some of the key points heard throughout the day. These included the idea of motivating people to make changes and be healthier, the need for more resources to access data—especially for small organizations and health providers, and the need to communicate the goal for sharing and ensuring that the data is not only collected, but used in a way that can benefit the community.

Charleston County's Health and Well-being—From Multiple Perspectives

“There is no better time than now to renew our focus on a nationwide, interoperable health IT infrastructure – one in which all individuals, their families, and their health care providers have appropriate access to health information that facilitates informed decision-making, supports coordinated health management, allows patients to be active partners in their health and care, and improves the overall health of our population. This is not just a technology challenge.”¹

This handout paints a picture of the health of Charleston County. It sets the stage for seeking community input about what information individuals, communities, researchers, and other interested parties would find useful for monitoring and increasing their health and well-being. The Charleston County population is compared to the populations of South Carolina and the United States with a focus on health outcomes and behaviors, the social and economic environment, and quality of and access to health care.

I. Health Behaviors and Outcomes

Health outcomes refer to how people feel physically and mentally and include factors that can influence conditions of health.

- The Charleston County population has fewer physically unhealthy days per month (2.9) as compared to people in South Carolina and the US (3.6 and 3.7, respectively) and fewer mentally unhealthy days per month (3.2) as compared to South Carolina and the US (3.7 and 3.5).²
- The percentage of those in Charleston County reporting fair or poor health (15%) is lower than people in South Carolina (19%) and the US population (17%).³
- In Charleston County and South Carolina, more babies have low birth weight (both 10%) as compared with babies born in the US (8%).⁴
- Certain behaviors, like smoking and drinking, can influence health and mortality.⁵
- Charleston County has some similarities and some differences to South Carolina and the US on behaviors that affect health (see Chart 1, p.79).⁶

II. Social and Economic Environment

“Fortunately, people are broadening their perspective on health to include not only absence of disease and access to quality medical care, but also the importance of living in healthy and environmentally sound communities.”⁷

Overall health is affected by individuals' social and economic environment, which includes family situations and income, educational opportunity and employment opportunity (see Table 1, p.79).⁸

Social support, housing quality, and neighborhood safety affect the health of individuals and the community (see Chart 2, p.79).

Access to public transportation (see Chart 3, p. 80), quality food, and recreation affect overall health and well-being.

The built environment includes the quality of housing, water, air, and access to healthy foods and recreation facilities.

- In Charleston County, the number of farmers' markets has increased from 7 in 2009 to 12 in 2013. The number of recreation and fitness facilities has decreased by 17 percent. The number of fast food restaurants increased by 22 percent between 2007 and 2011. Approximately 1 in 5 Charleston County residents do not have easy access to a grocery store.⁹

III. Access to and Quality of Health Care

The overall health of the community can be measured by both the length and quality of people's lives, which is partially influenced by access to health care.

- People in Charleston County lose approximately 7,800 years of potential life before age 75 (per 100,000 population) compared to almost 8,500 years in South Carolina and 7,000 years for the US population.¹⁰
- There is a growing use of electronic health records associated with patient care in the US. In South Carolina, 39 percent of office-based doctors are using electronic health records. In the US, 48 percent of office-based doctors are using electronic records, up from 11 percent in 2006¹¹

Individuals need Internet access in order to obtain their health information electronically.

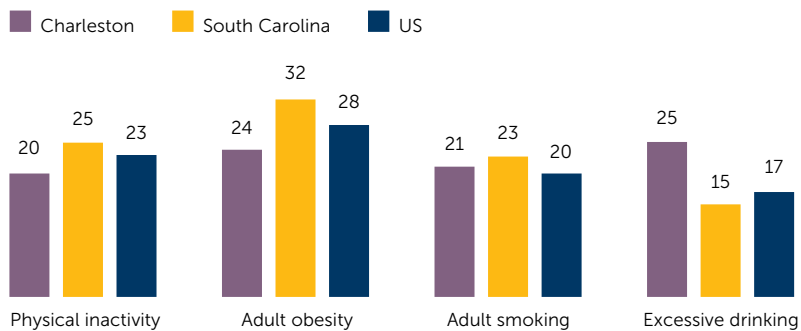
- In Charleston County, 85 percent of households have a computer which is slightly higher than computer ownership for households in South Carolina and the US (80% and 84%, respectively). Broadband Internet access is 71 percent in Charleston County, falling between access in South Carolina and the US (67% and 73%, respectively).¹²

Table 1. Social and Economic Characteristics, 2013

Demographics	Charleston County	South Carolina	United States
Total population	372,803	4,774,839	316,128,839
Median age	36.0	38.6	37.5
Percent white	68.8%	68.8%	76.2%
Percent black	29.6%	28.7%	13.8%
Percent Hispanic	5.2%	5.3%	17.1%
Percent living alone	32.5%	28.0%	27.7%
Economic			
Median household income	\$51,694	\$44,163	\$52,250
Mean household income	\$75,291	\$59,927	\$73,767
Percent unemployed	5.1%	5.7%	5.3%
Education			
Percent high school graduate only	21.2%	29.4%	27.8%
Percent of adults with some college or higher	68.8%	56.3%	58.8%

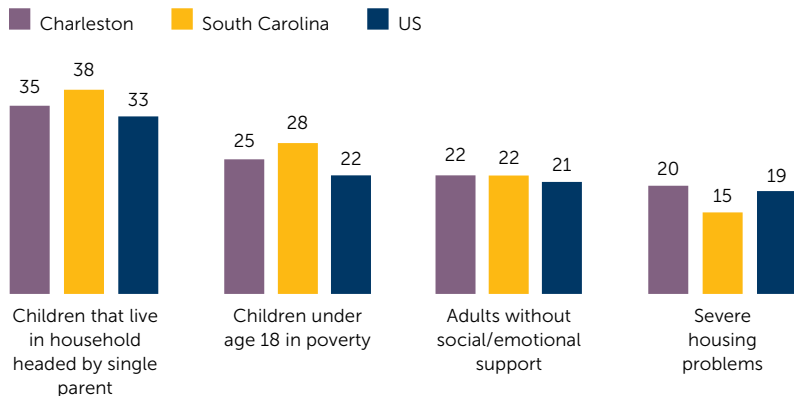
Source: Census Bureau, American Community Survey, 2013.

Chart 1. Health Behaviors—Physical Inactivity, Obesity, Smoking, Drinking (Percent)



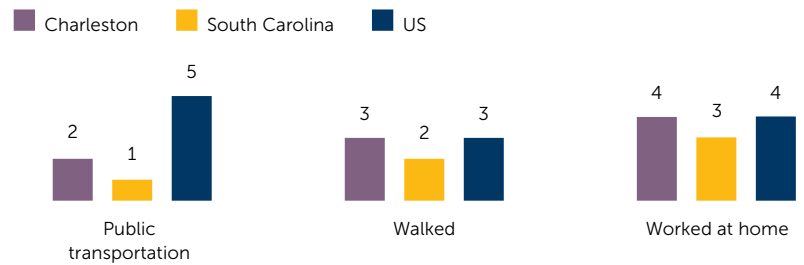
SOURCE: CDC Behavioral Risk Factor Surveillance System (2012)

Chart 2. Children and Adults with Possible Need for Social Support (Percent)



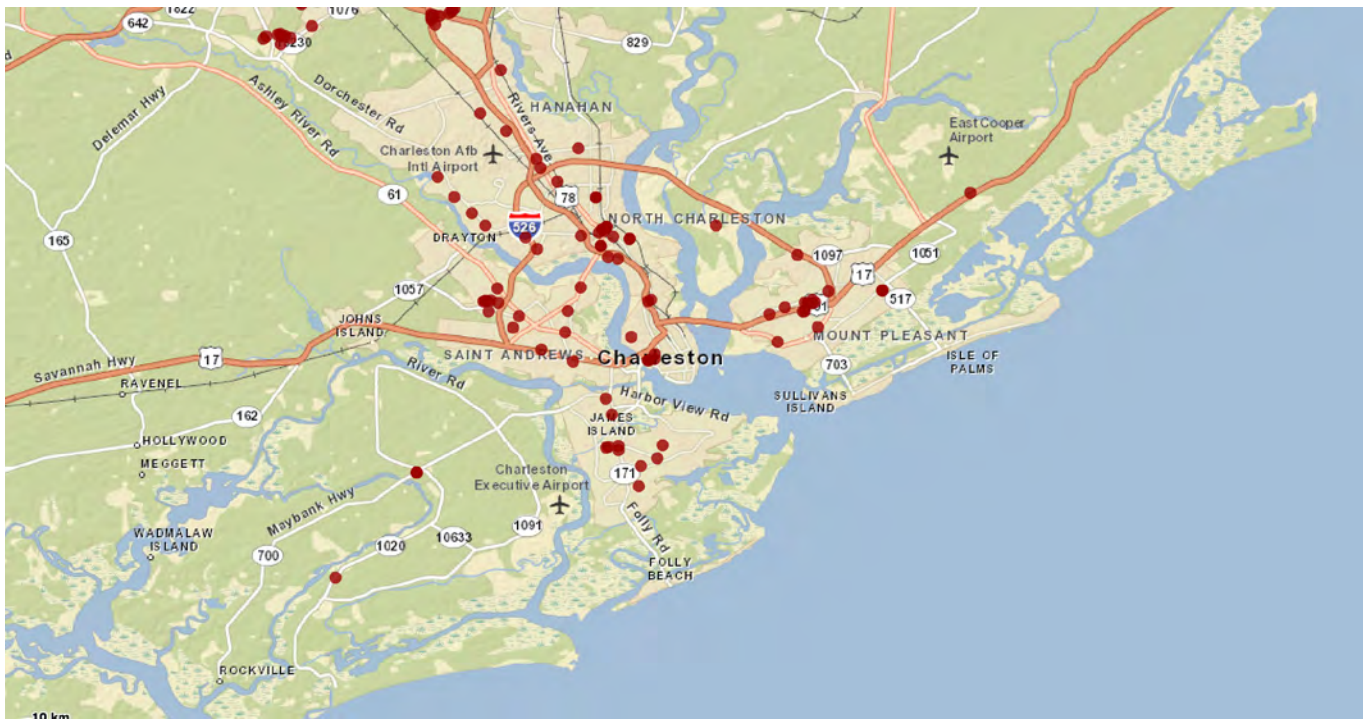
SOURCE: Census Bureau, American Community Survey, 2013, CDC Behavioral Risk Factor Surveillance System (2006-2012), and Housing and Urban Development (HUD) Comprehensive Housing Affordability Strategy (CHAS) (2007-2011)

Chart 3. Means of Transportation to Work (Percent)



SOURCE: Census Bureau, American Community Survey, 2013

Figure 1. The location of health facilities in Charleston County¹³



Endnotes

- 1 Office of the National Coordinator for Health Information Technology. (2014). Connecting Health and Care for the Nation: A 10-Year Vision to Achieve an Interoperable Health IT Infrastructure. <http://www.healthit.gov/sites/default/files/ONC10yearInteroperabilityConceptPaper.pdf>
- 2 Robert Wood Johnson Foundation County Health Rankings. <http://www.countyhealthrankings.org/>
- 3 Centers for Disease Control and Prevention (CDC) Behavioral Risk Factor Surveillance System, 2006-2012. <http://www.cdc.gov/brfss/>
- 4 Robert Wood Johnson Foundation County Health Rankings. <http://www.countyhealthrankings.org/>
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- 5 Mokdad, A. H., Marks, J. S., Stroup, D. F., & Gerberding, J. L. (2004). Actual causes of death in the United States, 2000. *JAMA*, 291(10), 1238-1245.
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- 8 Census Bureau, American Community Survey, 2013. <http://www.census.gov/acs/www/>
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- 10 Robert Wood Johnson Foundation County Health Rankings, <http://www.countyhealthrankings.org/>
CDC National Center for Health Statistics, Mortality Data, 2008-2010. <http://www.cdc.gov/nchs/deaths.htm>
- 11 Hsiao C-J, Hing E. (2014). Use and characteristics of electronic health record systems among office-based physician practices. United States, 2001–2013. NCHS data brief, no. 143. Hyattsville, MD: National Center of Health Statistics. <http://www.cdc.gov/nchs/data/databriefs/db143.pdf>
- 12 Census Bureau, American Community Survey, 2013. <http://www.census.gov/acs/www/>
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The above endnotes pertain to this Data Fact Sheet only.

Endnotes

- 1 Robert Wood Johnson Foundation. *Robert Wood Johnson Foundation Launches Initiative to Assess How Data Can Be Used to Improve Health*, <http://www.rwjf.org/en/about-rwjf/newsroom/newsroom-content/2014/10/RWJFLaunchesInitiativeToAssessHowDataCanBeUsedToImproveHealth.html> Accessed Mar 4, 2015.
- 2 Office of National Coordinator for Health Information Technology U.S. Dept. of Health and Human Services. *Federal Health IT Strategic Plan 2015–2020*, www.healthit.gov/sites/default/files/federal-healthit-strategic-plan-2014.pdf. Accessed Mar 4, 2015.
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- 4 See Acknowledgments section for statement of appreciation to attendees and local partners.
- 5 Office of National Coordinator for Health Information Technology U.S. Dept. of Health and Human Services. *Interoperability Roadmap*, www.healthit.gov/policy-researchers-implementers/interoperability. Accessed Mar 4, 2015.
- 6 See Acknowledgements section for list of local partners and appreciation of contributions for the success of the Data for Health Learning What Works events.
- 7 We use the word ‘attendee’ throughout to represent people who attended the Learning What Works events. We use the word ‘participant’ for acknowledging the Tweets, since not all of the people who wrote Tweets attended the Learning What Works events.
- 8 See <http://medical-legalpartnership.org/mlp-response/> These are also described in Teufel et al. (2009, 2012, 2014),
- 9 United Way 2-1-1 Resource Directory. *Child Health Specialty Clinics—Iowa City*, <http://fcfhiowa.bowmansystems.com/index.php/component/cpx/?task=resource&id=672577&tab=1>. Accessed Mar 4, 2015.
- 10 See Care Coordination Institute, www.ccihealth.org/ Accessed Mar 4, 2015.
- 11 See Practice-Based Research Networks, <http://pbrn.ahrq.gov/>. PBRNs are groups of primary care clinicians and practices across the country. As of January 28, 2015, there are 151 registered PBRNs.
- 12 American Community Gardening Association. *Chicora Place Community Garden*, <https://communitygarden.org/find-a-garden/gardens/chicora-place-community-garden/> Accessed Mar 4, 2015.
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- 17 US News & World Report Health. *There’s a Giant Job Ahead for Big Data: Can Analytics Produce Better Outcomes?* <http://health.usnews.com/health-news/hospital-of-tomorrow/articles/2014/10/03/theres-a-giant-job-ahead-for-big-data>. Accessed Mar 4, 2015.
- 18 See Live Healthy Iowa, www.livehealthyiowa.org/ and *Live Healthy America’s 2013 10-Week Wellness Challenge Gets More Than 70,000 People Moving*, <http://globenewswire.com/news-release/2013/05/28/550251/10034245/en/Live-Healthy-America-s-2013-10-Week-Wellness-Challenge-Gets-More-Than-70-000-People-Moving.html> Accessed Mar 4, 2015.
- 19 This same information is presented for each city in comparison to their state and the United States in each of the factsheets in Appendixes B–F.
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- 21 The Reinvestment Fund. *TRF Policymap*, www.policymap.com, Accessed Mar 4, 2015.
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- 26 Office of National Coordinator. *What is An Electronic Health Record?* www.healthit.gov/providers-professionals/faqs/what-electronic-health-record-ehr. Accessed Mar 4, 2015.
- 27 HIPAA Privacy Rule, www.hhs.gov/ocr/privacy/hipaa/administrative/privacyrule/index.html.
- 28 Strava, Inc, www.strava.com/. Accessed Mar 4, 2015. Also see news story about this: www.theverge.com/2014/10/8/6938041/portland-enlists-big-data-to-make-biking-safer
- 29 At the time of DeSalvo’s presentation the plan had not been released. It has since been released: www.healthit.gov/policy-researchers-implementers/health-it-strategic-planning. Accessed Mar 4, 2015.
- 30 Pew Research Center. *Health Fact Sheet*, www.pewinternet.org/fact-sheets/health-fact-sheet/. Accessed Mar 4, 2015.
- 31 U.S. Dept of Veterans Affairs. *VA Blue Button*, www.va.gov/BUEBUTTON/. Accessed Mar 4, 2015.
- 32 In Phoenix, Dr. DeSalvo spoke after lunch, but her notes are included in the opening session here for symmetry with the notes from the other sessions.
- 33 See note 29.
- 34 See note 29.
- 35 United Way of Central Iowa. *Health Strategy Map*, http://www.unitedwaydm.org/UserDocs/Health_strategy_map2013.pdf and <http://www.unitedwaydm.org/asp/health.aspx?n1id=7> Accessed Mar 4, 2015.
- 36 United Way 2-1-1 Resource Directory. See one example at <http://fcfhiowa.bowmansystems.com/index.php/component/cpx/?task=resource&id=672577&tab=1>.
- 37 Executive Office of the President, President’s Council of Advisors on Science and Technology. Report to the President: Big Data and Privacy—A Technological Perspective. Washington; May 2014, https://www.whitehouse.gov/sites/default/files/microsites/ostp/PCAST/pcast_big_data_and_privacy_-_may_2014.pdf Accessed Mar 4, 2015.
- 38 HIPAA—the Health Insurance Portability and Accountability Act of 1996 regulations protect the privacy of patient data.
- 39 For this event, Karent DeSalvo spoke via a pre-taped video.
- 40 See note 29.
- 41 Jawbone has more sleep data than world-class sleep labs have. The sleep lab data are more precise, but maybe not as realistic because it’s in a lab. Jawbone data are messier. Researchers are learning to work with these non-traditional data to extract patterns and insights.
- 42 U.S. Dept of Veterans Affairs. *VA Blue Button*, <http://www.va.gov/BUEBUTTON/> Accessed Mar 4, 2015
- 43 See note 29.

Data for Health Advisory Committee

Chairs

- Ivor Braden Horn, MD, MPH, *medical director*, Center for Diversity and Health Equity, Seattle Children's Hospital
- David A. Ross, ScD, *director*, Public Health Informatics Institute and *vice president*, The Task Force for Global Health

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