



## *Data for Health, Learning What Works* Report Themes and Recommendations

### Overview

Never before has so much information been shared on such a vast scale—from wearable monitoring devices to an explosion of apps that track everything from how many steps we take to our sleep patterns. Secure access to this wealth of information has the potential to transform how we improve health in ways we can't even imagine.

Recognizing a unique opportunity to improve health, the Robert Wood Johnson Foundation (RWJF) launched its *Data for Health* initiative to learn how data can be harnessed to spur innovations and greater sharing of data. *Data for Health* is led by an advisory committee of public health practitioners, physicians, health care researchers, health technology and informatics experts, consumers, and representatives of local government and health care systems.

During a five-city listening tour, the *Data for Health* Advisory Committee heard from community leaders across the country about their hopes, fears, and ideas for how data can be shared, protected, and used. The report, *Data for Health, Learning What Works*, gives an overview of findings from the listening tour. It also includes recommendations offered by the *Data for Health* Advisory Committee, based on what they heard, for how to better harness data to build a Culture of Health.

### Themes and Recommendations At-A-Glance

The Advisory Committee's recommendations, summarized below, are organized under three themes that emerged during the listening tour. For a more detailed explanation of the themes, findings, and recommendations from the report, visit <http://www.rwjf.org/en/library/research/2015/04/data-for-health-initiative.html>.

#### Listening Tour Themes

Establish the data exchange value proposition. There are significant health benefits in capturing and sharing health data, but people do not have a clear understanding of why certain data should be shared or used.

#### *Data for Health* Advisory Committee Recommendations

1. **Launch a public awareness initiative on the value of data use and exchange** to educate people about the benefits of widespread adoption and use of data to improve health. Philanthropic groups, like RWJF, could host and share a series of video stories where patients, patient groups, researchers, and communities tell their stories of benefitting from data exchange and use.
2. **Establish a national health information dialogue** to engage a broad range of stakeholders on how to establish and promote a national data infrastructure. The U.S. Department of Health and Human Services or philanthropies could lead these efforts, and the dialogue could serve as a platform for educating the public.

# Data for Health

## Learning What Works



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Build trust and community data competence. Individuals and communities have serious concerns about the security of private health data.

1. **Modernize policies governing health data** to protect personal health information, account for new technologies, and implement policies that address new security risks as they arise. Most of the laws protecting the privacy of health data are years, and in some cases, decades old. U.S. policymakers should update these privacy protections.
2. **Strengthen data security and governance** for individuals who wish to access their own personal health data. Policies should establish clear, equal rights for individuals—akin to a Bill of Rights—so people can obtain their health records and are empowered to make better health decisions for themselves and contribute to health decisions about their communities.
3. **Provide preparation for key stakeholders.** This includes educating and training health professionals about the role of social factors that influence health and preparing and supporting providers in the collection and management of population health data.

Build community data infrastructures that integrate information on health with social and community services, and support collaboration across sectors. A local data infrastructure is one of the most effective tools for monitoring and improving health across communities.

1. **Invest in data sharing.** The Office of the National Coordinator for Health Information Technology (ONC), the Centers for Disease Control and Prevention, or other health leaders could invest in data sharing exemplars, whereby cities and states share data with health care partners, public health agencies, and community groups.
2. **Transform data into actionable behavior change** through research partnerships focused on how data can be used to encourage healthy behaviors, especially in areas with poor health outcomes. Private foundations, government, private industry, and academia can collaborate on these efforts.
3. **Advocate for open state and local government Data for Health initiatives** to make health information more readily available and transparent. This will make it easier for people to access health services and make more informed decisions about their health.
4. **Access and use data generated by social media to demonstrate the value of health information** to reveal local and national health trends and improve health. Researchers and funders should promote the use of social media as a rich data source.
5. **Launch a pilot Code for America data analytics program** that creates open-source applications for cities and municipalities to promote greater transparency in public health data. This could be as simple as building a community dashboard that combines data from existing government databases.
6. **Address vulnerable populations** by developing programs, educational tools, and resources in health care settings to close the gap on digital health literacy in populations experiencing higher rates of health disparities. Consumer advocacy groups, health care systems, private industry, and local and state governments should collaborate toward this end.
7. **Create and maintain a Community Resources Scorecard** that provides information on how communities are being supported to improve health. The Scorecard would offer common indicators to facilitate comparisons across communities, as well as more granular sub-county and district level data to address their own concerns and interests.
8. **Create partnerships around Data for Health** among government agencies, such as ONC and the National Institutes of Health, to promote using data for health and galvanize other stakeholders. These efforts would focus on reaching vulnerable populations.