Data Science for Health Datapalooza 2015

Story
Data Science for Health Datapalooza 2015
DataLab
RowdMap
Senior Government Leaders

Slides
Slide 1 Data Science for Health Datapalooza 2015
Slide 2 Overview
Slide 3 Data Culture at the NIH: MindTouch Knowledge Base and Data Science Data Publications for Dr. Philip Bourne
Slide 4 HDP 2015 Top 10
Slide 5 10 Tweets: Selfies and Self Congratulations
Slide 6 9 Exhibit: Handouts, Highlights & Business Cards
Slide 7 8 ESRI Book: GIS Tutorial for Health-Resources
Slide 8 8 ESRI Book: GIS Tutorial for Health-GDB-to-SHP
Slide 9 7 HDP 2015 Knowledge Base: Better Structure Than Conference Web Site
Slide 10 7 HDP 2015 Knowledge Base: Spreadsheet
Slide 11 7 HDP 2015 Knowledge Base: Spotfire
Slide 12 6 Data Science and Infrastructure Track: Six Sessions & BootCamp 1
Slide 13 6 Data Science and Infrastructure Track: Six Sessions & BootCamp 2
Slide 14 6 Data Science and Infrastructure Track: Six Sessions & BootCamp 3
Slide 15 6 Data Science and Infrastructure Track: Six Sessions & BootCamp 4
Slide 16 5 Demand Driven Open Data: Suggestions to GITHUB
Slide 17 4 DataLab: Table
Slide 18 3 General Session 4: Weather Scientist DJ Patil
Slide 19 2 The Precision Medicine Initiative: Natural Medicine for Disease & Wellness
Slide 20 Data Science Data Publication: Natural Medicine for Disease and Wellness-Semantic Medline
Slide 21 Policy Makers: Future of NLM - Report
Slide 22 Public: NLM - MedlinePlus
Slide 23 Public: NLM - MedlinePlus on Gluten
Slide 24 Researcher: Press Release - Glucan
Slide 25 Researcher: Slides - Glucan
Slide 26 Researcher: PubMed Search - Glucan
Slide 27 Data Scientist: Publication - Leukemia & Lymphoma
Slide 28 Data Science Data Publication Commons Examples: MindTouch Knowledge Base
Slide 29 Data Science Data Publication Commons Examples: Spotfire Knowledge Base
Slide 30 Semantic Medline: Context - For Each & Add More Data (Genomic & Nutrition)
Slide 31 Researchers: Have Examples - Data Scientists Help Them
Slide 32 Conclusions and Recommendations

Spotfire Dashboard
ESRI GIS Health - Spotfire
HDP 2015 DataLab - Spotfire
ACA - Spotfire

Research Notes
HealthData.gov Beta
Meeting of the President’s Council of Advisors on Science and Technology (PCAST)
Precision medicine stems from big data
Big health data project on new chief data scientist’s agenda
FACT SHEET: President Obama’s Precision Medicine Initiative

Health Datapalooza 2015
May 31
Registration
Welcome Reception
June 1
Opening General Session
Esther Dyson
General Session 1
App Demo Booth
Healthcare Transformer Showcase
App Expo Live Demos
DataLab
Applications of Transparency: From Visibility to Action
Transforming Local Health Data To Meaningful National Benchmarks
Innovation in Action: From Algorithms To Clinical Change
Patient Hackers: The #Wearenotwaiting Movement and the Way Forward For Open Device Data
Personalized Medicine: When Will We Get There? What’s the Path Forward?
Leveraging Big Data for Better Quality Measurements
The Future of Health Data Is On FHIR!
Insurer Perspectives: Health Plan Strategy and Investment
How Businesses Are Using Data To Select and Best Utilize Health Care Centers of Excellence
Using Data & Technology To Enable Better Patient Health, Support, and Care
How Do You Get Clinical Validation From Patient-Generated and Open Health Data in Obstetric Care?
Patient Reported Outcomes as Quality Indicators in the U.S. & U.K.: Issues and Opportunities
Using Open International Health Data in Decision-Making
Moving Beyond Sensational Outliers To Meaningful Anlaysis, Interpretation, and Application of Public Health Care Data
The Disruptive Social

June 2
General Session 2
  Bruce Broussard
General Session 3
  Andy Slavitt
  Aaron Levie
Data, Drugs, and Diversion: Hit Tools and the Prescription Drug Epidemic
App Demo Booth
App Expo Live Demos
Patient-Generated Health Data in the Real World
Using Open Data To Promote Entrepreneurship and Innovation in India
Open Data For Social Determinants of Health
Public Program Changes, Private Sector Benefits
No You Can't Always Get What You Want: Getting What You Need from HHS
A Delicate Balance: A Town Hall on Health Care Data Privacy and Security Issues
Role of Data in a Time of Massive Health Care Transformation
Democratizing Health Quality Improvement
Data & Technology Aren't Just for the Young: Supporting Aging Adults
Old School Data Sets, Rebooted, Repurposed and Creating Killer New Value
Centers For Medicare & Medicaid Services Data, Policies, Programs & Plans
Leveraging the Potential of Patient-Generated Data: Progress and Opportunities
Health Plans Collaborating with Providers
Value-Base Care: Going All In
Government Insights on Privacy Rules in the Health IT Teach Era
Direct-To-Consumer Data Structures and Scientists For Your Government Sponsored DTC Business
Healthcare Entrepreneurs Boot Camp: Matching Public Health Data With Real World Business Models
Turning Health Data Into Investigative Journalism
Clinical Transformation To Address Care Gaps and Improve Quality: Reflections On a Unique Platform
Iconquerms Patient-Powered Research: Kicking Butt and Taking No Names in the Fight Against Disease
Providers Operating Health Plans
Navigating the FDA Review Process For Health Innovators

June 3

General Session 4
Glyn Elwyn
Dr. DJ Patil

Innovative Value-Based Uses of Open Data
The Precision Medicine Initiative: Changing the Future of Health and Medicine
The Role of Retailers in the U.S. Healthcare System
Engaging Patients in Generating and Using Big Data
But What If I WantTo Share? Contributing Your Own Data To Foster Public Good
Challenges Facing Public Access to VA Health Data
Myths Vs. Reality: The Current State of Consumer Access and Use of Their Digital Health Data

Closing Luncheon
Steven Brill
Sylvia Mathews Burwell

Story

See Mini-Stories: Spotfire Dashboard

Data Science for Health Datapalooza 2015

The Health Data Consortium (HDC), the group organizing Health Datapalooza, encourages the creation of a health data “ecosystem” that promotes and accelerates the innovative use of health data. HDC is a collaboration among government, non-profit, and private sector organizations working to foster the availability and use of health data to drive innovations that improve health and health care. The Consortium advocates data best practices and information sharing with data providers, and works with businesses, entrepreneurs, and academia to help them understand how to use data to develop new products, services, apps, and research insights. Check out their main site to learn more.

Health Datapalooza is a national conference focused on liberating health data, and bringing together the companies, startups, academics, government agencies, and individuals with the newest and most innovative and effective uses of health data to improve patient outcomes.

The Health Datapalooza was originally launched as part of The Health Data Initiative (HDI). The author has participated in all of these events with stories and applications.

The 2010 Forum
National Academy of Sciences Building
Washington, DC
June 2, 2010
In March 2010, the IOM and HHS hosted a small gathering of leaders from the White House, federal agencies, academia, social sectors, public health communities, information technology firms, major businesses, and health care delivery systems to catalyze the formation of a new Community Health Data Initiative. On June 2, 2010, the IOM and HHS held *The Community Health Data Forum: Harnessing the Power of Information to Improve Health*. The purpose of this public forum was to further ongoing efforts of innovators using community-level health data, which would allow individuals and communities to make informed choices about their health.

View the agenda and a video clip from the inaugural HDI Forum.

**The 2011 Forum**  
**National Institutes of Health**  
**Bethesda, MD**  
**June 9, 2011**

As the types of available health data expanded beyond community data to include data on coverage, access, cost, quality, products and recalls, benefits, and more, the Community Health Data Initiative was rebranded as the Health Data Initiative (HDI).

On June 9, 2011, the *Health Data Initiative Forum II* expanded to include more than 50 applications that used data from HHS and other data suppliers. Community leaders, consumers, employers, providers, and others showcased ways that data could be used to spur health assessment, planning, and action.

Explore information on the 2011 Forum, including the agenda, list of presenters, and videos.

**The 2012 Forum**  
**Walter E. Washington Convention Center**  
**Washington, DC**  
**June 5-6, 2012**

The *Health Data Initiative Forum III: The Health Datapalooza* was held June 5 and 6, 2012 at the Walter E. Washington Convention Center in Washington, DC. The event brought together a diverse group of more than 1,500 data experts, technology developers, entrepreneurs, policy makers, health care system leaders, and community advocates to support innovative applications of health and health care data.

Explore information on the 2012 Forum including list of participants, and photos featuring HHS Secretary Kathleen Sebelius, US CTO Todd Park, Jon Bon Jovi, and many more.

**The 2013 Health Datapalooza**  
**Omni Shoreham Hotel**  
**Washington, DC**  
**June 2-4, 2013**

In 2013, the Health Datapalooza brought together more than 2,000 data experts, technology developers, entrepreneurs, policy makers, health care system leaders, and community advocates. The event included presentations, demos, keynotes, a code-a-palooza, and many more ways to interact with and discuss the future of health data.
The 2014 Health Datapalooza
Marriott Wardman Park
Washington, DC
June 1-3, 2014

In 2014, more than 2,000 technology experts, entrepreneurs, policy makers, health care system leaders, and community advocates convened in Washington, DC to unleash the power of health data. The 2014 event included exciting keynotes, a code-a-palooza, and best-in-class opportunities to network with industry elites. Check out the 2014 Program Guide for more information and view pictures from last year's event!

The agenda for this year's Health Datapalooza 2015 is structured below to facilitate your attendance.

Of particular interest to the Federal Big Data Working Group Meetup are the following:

Our April 20th Meetup: President's Chief Data Scientist and EPA Big Data Analytics featured DJ Patil's Precision Medicine Initiative and David Portnoy's Demand Driven Open Data Initiative, which will be Health Data Palooza sessions to get you excited about attending:

- June 3rd: General Session 4, The Precision Medicine Initiative: Changing the Future of Health and Medicine, and June 2nd: No You Can't Always Get What You Want: Getting What You Need from HHS, respectively.

Our July 20th Meetup: Data Science for ACA Data, is being co-organized by Lloyd Brodsky, Optum, which has two sessions of interest:

- June 1: Transforming Local Health Data To Meaningful National Benchmarks and Leveraging Big Data for Better Quality Measurements

As usual, the session of greatest interest to me in recent years will be June 1: DataLab, where we learn about new data sets and show their results before the end of the event. This year's description says:

In the DataLab you'll meet the people who collect and curate this trove of data assets as they serve up their data for your use. But if you still want inspiration, many of the data owners will co-present with creative, insightful, innovative users of their data to truly demonstrate its alternative value for positive disruptions in health, health care, and social services.

I will ask Damon Davis for advanced details about the new data sets so we could start work ASAP, if possible, to have results ready for June 1. In any event these new data will provide opportunities for future Meetups during 2015-2016, like the new ACA data for the July 20th Meetup.

The Panelists and their new data sets are:

<table>
<thead>
<tr>
<th>Panelist</th>
<th>Dataset or Other</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Natasha Alexeeva, CEO, Caretalia</td>
<td>This Web page is parked for FREE, courtesy of GoDaddy.com.</td>
<td>IBM Watson</td>
</tr>
</tbody>
</table>
A key question is do any of these new data sets support either the new Precision Medicine and/or Demand Driven Data Initiatives.

The most obvious would see to be: **Cancer Genomic Evidence-based Medicine Knowledge Base (CancerGEM KB)**


Updated: Wed, 18 Sep 2019 16:24:20 GMT
CancerGEM KB is an integrated, searchable knowledge base of cancer human genome epidemiology and genomic applications in cancer care and prevention. CancerGEM KB is a continuously updated searchable online resource that provides access to scientific information on the use of genomic information in cancer care and prevention.

RowdMap

I have received one response so far from RowdMap with the the major data sources they will be referencing in my presentation:

- **Referrals:** [http://1.usa.gov/1FzoEOV](http://1.usa.gov/1FzoEOV)

- **Variation:** [http://go.cms.gov/1D8j7LE](http://go.cms.gov/1D8j7LE)
  - [http://www.cms.gov/Research-Statisti...on/GV_PUF.html](http://www.cms.gov/Research-Statisti...on/GV_PUF.html) MULTIPLE PDFS

- **Shared Savings:** [http://go.cms.gov/1Hh8vx0](http://go.cms.gov/1Hh8vx0)
  - [http://www.cms.gov/Research-Statisti...SP_ACO_PUF.zip](http://www.cms.gov/Research-Statisti...SP_ACO_PUF.zip)

- **Medicare FFS Part B:** [http://go.cms.gov/OCmyoy](http://go.cms.gov/OCmyoy)
  - [http://www.cms.gov/Research-Statisti...-Supplier.html](http://www.cms.gov/Research-Statisti...-Supplier.html)
  - [http://www.cms.gov/Research-Statisti...plier2013.html](http://www.cms.gov/Research-Statisti...plier2013.html)

- **Medicare FFS Part D:** [http://bit.ly/1mGyBx](http://bit.ly/1mGyBx)
  - Sorry, the website ap73c.tk cannot be found

- **Medicaid:** [http://go.cms.gov/1z7b5ic](http://go.cms.gov/1z7b5ic)
  - [http://www.cms.gov/Research-Statisti...MIS/index.html](http://www.cms.gov/Research-Statisti...MIS/index.html)

  - [http://www.dartmouthatlas.org/downlo...data_2012.xls](http://www.dartmouthatlas.org/downlo...data_2012.xls)

- **Behaviors:** [http://1.usa.gov/1PzcisT](http://1.usa.gov/1PzcisT)
  - [http://www.cdc.gov/brfss/gis/gis_maps.htm](http://www.cdc.gov/brfss/gis/gis_maps.htm)

  - [http://allstars.healthdataconsortium...bout-all-stars](http://allstars.healthdataconsortium...bout-all-stars)

A slide deck (PDF) that provides a sample of sources (slide 2) with links and a basic approach of how to organize them and make meaning from them. They have used this successfully at Harvard, Hopkins and MIT as well as open to the
public events. They suggested that if I am interested in seeing how people use the data to create things people want to actually use, either to foster public good or to create market value, participate in the Healthcare Entrepreneurs' BootCamp which will have many of the same participants and work through many of the same sources you'll see at the datalab, but in a much broader context.

The June 2nd Session: No You Can't Always Get What You Want: Getting What You Need from HHS, facilitator and panelists reminded me of the Data Science Data Publications I have done for each of them as summarized in the table below. This is essentially an HHS Data Science MOOC like the USDA Data Science MOOC we did recently.

### Senior Government Leaders

<table>
<thead>
<tr>
<th>Senior Government Leader</th>
<th>Data Science Data Publication</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Damon Davis, U.S. Department of Health &amp; Human Services</td>
<td>Data Science for the HHS IDEALAB</td>
<td>George Thomas Post Graduate Fellowship</td>
</tr>
<tr>
<td>Phil Bourne, National Institute of Health (NIH)</td>
<td>Data Culture at the NIH</td>
<td>NLM Data Science Data Publication Pilot</td>
</tr>
<tr>
<td>Niall Brennan, Centers for Medicare &amp; Medicaid Services</td>
<td>CMS Data Navigator</td>
<td>3rd Annual Data Liberators Award</td>
</tr>
<tr>
<td>Jim Craver, MMA, Centers for Disease Control &amp; Prevention</td>
<td>Data Science for Health United States 2013</td>
<td>Does this persuade me that the claims and evidence are true?</td>
</tr>
<tr>
<td>Taha Kass-Hout, Food &amp; Drug Administration</td>
<td>Data Science for Open FDA</td>
<td>Recent In-house event.</td>
</tr>
<tr>
<td>Brian Lee, MPH, Centers for Disease Control &amp; Prevention</td>
<td></td>
<td>I thought I did something else for CDC but cannot find it right now</td>
</tr>
<tr>
<td>David Portnoy, MBA, U.S. Department of Health &amp; Human Services</td>
<td>Data Science for HealthData.gov Developers</td>
<td></td>
</tr>
</tbody>
</table>

MORE TO FOLLOW DURING AND AFTER THE CONFERENCE

### Slides

[Slides](https://semanticommunity.info/Data_Science/Data_Science_for_Health_Datapalooza_2015)
Slide 1 Data Science for Health Datapalooza 2015

Semantic Community

Data Science

Data Science for Health Datapalooza 2015

Dr. Brand Niemann  
Director and Senior Data Scientist/Data Journalist  
Semantic Community  
Data Science  
June 5, 2015

Slide 2 Overview

http://semanticommunity.info/#Health_Data


http://semanticommunity.info/Data_Science/Data_Culture_at_the_NIH

Overview

• History:  
  • http://semanticommunity.info/#Health_Data
• Health Datapalooza 2015 Knowledge Base:  
  • http://semanticommunity.info/Data_Science/Data_Science_for_Health_Datapalooza_2015
• HDP 2015 Top 10:  
  • See Slide 4
• Data Culture at NIH:  
  • http://semanticommunity.info/Data_Science/Data_Culture_at_the_NIH
• NLM Data Science Data Publications Commons Pilot:  
  • See Slide 20

Slide 3 Data Culture at the NIH: MindTouch Knowledge Base and Data Science Data Publications for Dr. Philip Bourne

Semantic Community Data Science Data Culture at the NIH
Slide 4 HDP 2015 Top 10

HDP 2015 Top 10

- 10 Tweets: Selfies and Self Congratulations
- 9 Exhibit: Handouts, Highlights & Business Cards
- 8 ESRI Book: GIS Tutorial for Health-Resources & GDB to SHP
- 7 HDP 2015 Knowledge Base: Better Structure Than Conference Web Site
- 6 Data Science and Infrastructure Track: Six Sessions & BootCamp
- 5 Demand Driven Open Data: Suggestions to GITHUB
- 4 Datatlab: Table
- 3 General Session 4: Weather Scientist DJ Patil
- 2 The Precision Medicine Initiative: Natural Medicine for Disease & Wellness
- 1 Data Science Data Publication: Natural Medicine for Disease and Wellness-SemanticMedline

Slide 5 10 Tweets: Selfies and Self Congratulations

https://twitter.com/hashtag/hdpalooza?src=hash

10 Tweets: Selfies and Self Congratulations

https://twitter.com/hashtag/hdpalooza?src=hash
Slide 6 9 Exhibit: Handouts, Highlights & Business Cards

9 Exhibit: Handouts, Highlights & Business Cards

- ESRI Book: GIS Tutorial for Health-Resources and Human Health and Climate Change App Challenge-$17,000
- FastStats-NCHS Mobile App
- Improving Personal Health Device Communications Through Consensus Building-IEEE Standards Association
- US Obesity Data Challenge and England’s Obesity Challenge Rewired State-$40,000
- US News & World Report Best Hospitals Dashboard and Hospital of Tomorrow Conference, October 18-20, 2015, Washington, DC
- CVS-HHS Online Personalized Preventative Car Recommendations
- NHS England Test Bed Programme-Expressions of Interest Due June 12th
- Catapult Your Research Career Using Public Data Sets, June 28-30, Bethesda, MD
- Nutrition: Verified Nutrition Database from the Cloud - Find and calculate the nutrition information for all of your favorite foods

Slide 7 8 ESRI Book: GIS Tutorial for Health-Resources


Slide 8 8 ESRI Book: GIS Tutorial for Health-GDB-to-SHP

http://www.safe.com/
Slide 9 7 HDP 2015 Knowledge Base: Better Structure Than Conference Web Site

Semantic Community Data Science Data Science for Health Datapalooza 2015

Slide 10 7 HDP 2015 Knowledge Base: Spreadsheet

HDP2015.xlsx

Slide 11 7 HDP 2015 Knowledge Base: Spotfire

Web Player
Slide 12 6 Data Science and Infrastructure Track: Six Sessions & BootCamp 1

6 Data Science and Infrastructure Track: Six Sessions & BootCamp 1

- Transforming Local Health Data To Meaningful National Benchmarks:
  - Moderator: Scott Howell, MD, Optum; Amy Nguyen Howell, MD, MBA, FAAFP, CAPG
  - Panelists: Craig Brammer, The Health Collaborative; Jim Chase, MHA, Minnesota Community Measurement; Jonathan Mathieu, PhD, Center for Improving Value in Health Care
- Moving Beyond Sensational Outliers To Meaningful Analysis, Interpretation, and Application of Public Health Data:
  - Moderator: Joshua Rosenthal, PhD, RowdMap, Inc.
  - Panelists: Tom McGinty, The Wall Street Journal; Charles Ornstein, ProPublica; Jennifer Schneider, MD, MS, Castlight Health

Slide 13 6 Data Science and Infrastructure Track: Six Sessions & BootCamp 2

6 Data Science and Infrastructure Track: Six Sessions & BootCamp 2

- No You Can’t Always Get What You Want: Getting What You Need from HHS:
  - Moderator: Damon Davis, U.S. Department of Health & Human Services
  - Panelists: Phil Bourne, National Institute of Health (NIH); Niall Brennan, Centers for Medicare & Medicaid Services; Jim Craver, MMA, Centers for Disease Control & Prevention; Chris Dynek, EdD, U.S. Department of Health & Human Services; Tahia Kess-Houri, Food & Drug Administration; Brian Lee, MPH, Centers for Disease Control & Prevention; David Portnoy, MBA, U.S. Department of Health & Human Services
- Old School Data Sets, Rebooted, Repurposed and Creating Killer New Value:
  - Moderator: Michael Painter, MD, Robert Wood Johnson Foundation
  - Panelists: Jessica Kahn, MPH, Centers for Medicare & Medicaid Services; Raman Martinez, Pan American Health Organization; David Wennberg, MD, MPH, NNEACC

Slide 14 6 Data Science and Infrastructure Track: Six Sessions & BootCamp 3

6 Data Science and Infrastructure Track: Six Sessions & BootCamp 3

- Direct-To-Consumer Data Structures and Scientists For Your Government Sponsored DTC Business:
  - Moderator: Fred Trotter, DocGraph/CareSet
  - Panelists: Ben Coleman, Moravian College; Andres Colubi, PhD, Broad Institute of MIT and Harvard; Sreenivas Rangan Sukumar, PhD, Oak Ridge National Laboratory
- But What If I Want To Share? Contributing Your Own Data To Foster Public Good:
  - Moderator: Niall Brennan, Centers for Medicare & Medicaid Services
  - Panelists: Geraldine Gueron, PhD, The Welllife Foundation; Aaron Selb, National Association for Trusted Exchange; Maksim Tsetovat, OpenHealth

Updated: Wed, 18 Sep 2019 16:24:20 GMT
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Slide 15 6 Data Science and Infrastructure Track: Six Sessions & BootCamp 4

6 Data Science and Infrastructure Track: Six Sessions & BootCamp 4

- Healthcare Entrepreneurs BootCamp: Matching Public Health Data With Real World Business Models
  - Speakers: Sujata Bhatia, MD, Harvard University; Neil Brennan, Chief Data Officer, Centers for Medicare & Medicaid Services; Mark Hurd, SVP, Partners HealthCare Ventures and NHIN; Cargill Group; Andrew Recknorth, PhD, RedMap; Marli Witter, Lengend Health Solutions
  - Panelists: Michael Bates, MD, Emory University; Gail Huestis, Chief Information Officer, Centers for Medicare & Medicaid Services; Christopher Carver, Chief Privacy Officer, Centers for Medicare & Medicaid Services; and Paul Sabatier, Department of Health and Human Services

- DataLab: Table
  - Story

- 4 DataLab: Table

Slide 16 5 Demand Driven Open Data: Suggestions to GITHUB

http://www.meetup.com/Federal-Big-Data-Working-Group/events/221457264/

https://github.com/demand-driven-open-data/ddod-intake/issues/36

5 Demand Driven Open Data: Suggestions to GITHUB

- Provide Health.data.gov and cms.data.gov data catalogs in spreadsheet format with web links to metadata, data, and data dictionary; and
- Participate in our Federal Big Data Working Group Meetups to provide feedback to agencies and OMB on data science results (e.g. our USDA Data Science MOOC is our more recent best practice example):
  - Response from David Portnoy: Thank you for your entry. Will process shortly.

https://github.com/demand-driven-open-data/ddod-intake/issues/36

Slide 17 4 DataLab: Table
3 General Session 4: Weather Scientist DJ Patil

- Situation: Day 103, Amazing Talent, & Amazing Things Happen in the 4th Quarter.
- Precision Medicine: Gene sequencing costs decreasing, data scientists, new sensors, and next generation medicine.
- Use Case Design & Product Spec: What do patients want? how do you know? design like you write-write like you are wrong, & iterate on pilots to get seamless user experience of app interoperability.
- ESRI & Whitehouse Announcement: Climate Change and Health Effects
- Jeff Weiner: Trust is consistency over time
- DJ Patil: Here to fill the cracks.

Slide 19 2 The Precision Medicine Initiative: Natural Medicine for Disease & Wellness

- The Precision Medicine Initiative: Changing the Future of Health and Medicine:
  - The Precision Medicine initiative, announced by the President in January, is a bold new research project to revolutionize how we improve health and treat disease. The initiative will build on recent advances in biomedical research to create a personalized approach to healthcare. It will allow us to take advantage of new advances in biomedical discoveries and provide clinicians with new tools, knowledge, and therapies to select which treatments will work best for which patients. Translating initial successes to a larger scale will require a coordinated and sustained national effort. To get there, we need to incorporate many different types of data including genetic information, personal device and sensor data, and medical records collected by health-care providers and by patients themselves. Success will require that health information can be easily shared between providers, researchers, and most importantly, patients and research participants.
- Speakers:

Slide 20 Data Science Data Publication: Natural Medicine for Disease and Wellness-Semantic Medline

- Policy Makers: Future of NLM - Report
- Public: NLM MedlinePlus - Gluten
- Data Scientist: Publication - Leukemia & Lymphoma
- Semantic Medline: Context - For Each & Add More Data (Genomic & Nutrition)
- Researchers: Have Examples - Data Scientists Help Them

Slide 21 Policy Makers: Future of NLM - Report
Policy Makers: Future of NLM - Report

- Report of the NLM Working Group of the Advisory Committee to the NIH Director, June 11 at 11:15 am ET
- From NLM Acting Director Betsy L. Humphreys:
  - The NLM Working Group of the Advisory Committee to the Director of NIH (ACD) will present its vision and recommendations for an expansive and exciting future for NLM to the full ACD on June 11, 2015.
  - The presentation is scheduled to begin at 11:15 am. You will find the full agenda for the ACD meeting at [http://acd.od.nih.gov/meetings/nlm](http://acd.od.nih.gov/meetings/nlm).
  - The meeting will be broadcast live and also archived so you will be able to watch it at [http://cdm.nih.gov/](http://cdm.nih.gov/).
  - The text of the report will be posted on the ACD website soon after the meeting. Recruitment for a new permanent NLM Director will begin shortly thereafter, too.

Source: [Blog](http://www.nlm.nih.gov/)

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**Slide 22 Public: NLM - MedlinePlus**


**Slide 23 Public: NLM - MedlinePlus on Gluten**


**Slide 24 Researcher: Press Release - Glucan**

Researcher: Press Release - Glucan

- Youngevity (YGY) Announces Acquisition of Restart Your Life:
  - A.J. Langan, Co-Founder of Restart Your Life said, "Since 1996, I have been working to develop Beta 1, 3-D Glucan as the most relevant immune support compound in the world. Countless peer reviewed medical articles have attested to its safety and benefits. I am a big believer that network marketing is a proper channel to help rapidly advance this type of product. I look forward to working with the corporate staff, the tremendously talented field force and the most important asset, the great customers that I expect will enjoy good health and have an opportunity for great financial success. I would encourage all to avail themselves of the vast reservoir of knowledge available to make sure they reach their goals. I want to give special recognition to Dr. Joel Wallach. He has blazed a trail as a pioneer in this field and it is my honor to assist him to accomplish his dreams for a better world."

Source: Press Release

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Slide 25 Researcher: Slides - Glucan

Slides

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Slide 26 Researcher: PubMed Search - Glucan

PubMed Search

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Slide 27 Data Scientist: Publication - Leukemia & Lymphoma

Data Scientist: Publication - Leukemia & Lymphoma

http://informaticshealthcare.com/de/de/0/03.09/0/02/8136.2015.104892

Slide 28 Data Science Data Publication Commons Examples: MindTouch Knowledge Base

Semantic Community Data Science Data Science for Health Datapalooza 2015 NLM - Semantic Medline Data Science Data Publication

Slide 29 Data Science Data Publication Commons Examples: Spotfire Knowledge Base

Data Science Data Publication Commons Examples: Spotfire Knowledge Base
Semantic Medline: Context - For Each & Add More Data (Genomic & Nutrition)

- Semantic Medline provides context for each of these examples and justifies need to add more data (genomic and nutrition), like Clinical Trials, and pilots the use of Semantic Insights and Tarr.
- Semantic Medline presents query results for glucan at our July 20th Meetup that have been found to be useful:
  - glucan
  - glucan immune
  - glucan cancer
  - glucan immune cancer
  - glucan "interleukin-2"

Researchers: Have Examples - Data Scientists Help Them

- The new NLM has a Data Science Data Publication Commons so researchers can see examples of what they need to do to publish their data as part of their papers and what data scientists can do to help them.
- This supports the new NIH Data Science and Big Data to Knowledge to implement FAIR (findable, accessible, interoperable, and reusable) and the Commons (an open digital ecosystem).
- This can be crowdsourced using communities of data scientists, like the Federal Big Data Working Group Meetup that need NIH subject matter expertise, and NIH scientists in turn benefit from scarce data scientist manpower.

Conclusions and Recommendations

- Health Datapalooza 2015 was both amazing and confusing to attend and digest and distill its content.
- My HDP 2015 Top 10 is an attempt to digest and distill its content for additional data science data publications for all six events for 2010-2015 and organize Federal Big Data Working Group Meetups between now and HDP 2016.
- The President’s Precision Medicine Initiative and our Natural Medicine for Disease & Wellness Initiative are complimentary and fit with the new NLM vision and role of Semantic Medline.
- The purpose of our Data Science Data Publication Commons Examples are so researchers can see examples of what they need to do to publish their data as part of their papers and what data scientists can do to help them.

Spotfire Dashboard
ESRI GIS Health - Spotfire

An ESRI GIS Tutorial for Health in Spotfire

As a Data Scientist / Data Journalist, I was invited to attend the recent Health Datapalooza 2015 Conference and write Data Stories about it as I have done with all the previous conferences from 2010 - 2015.

My principal interest was in the DataLab Session where the newest government health data sets are released and described. I am always eager to get these and try them in Spotfire.

I build the broader context for my Spotfire analytics and visualization into a Wiki Knowledge Base and Federal Big Data Working Group Meetup.

At the HDP 2015 Exhibit I was given a free copy of the ESRI GIS Tutorial for Health 5th Edition which contained a link to 90 GDB files (about 1 GB) that I converted to 90 shape files (about 0.6 GB) using the FME Workbench from Safe Software.

The 90 shp files were grouped in 10 categories corresponding to the chapters and exercises in the book. I imported them into Spotfire with a separate Tab for each and noted the file size, number of rows and columns, and data column elements in a spreadsheet table that provides an overview of the data ecosystem to prioritize further analyses. I used this to select one shp file in each of the 10 categories for more in-depth analytic and visualizations. I found that some of the shp files selected (usually the largest in size in term of rows, etc.) did not have geometry, so I displayed them as scatterplots.

The Knowledge Base Index and ESRI GIS Tutorial for Health shp file inventory in spreadsheet tables for used for the Spotfire Cover Page.

When I published the ESRIGISHealth-Spotfire file (304 MB) to the Web Player, I used the email option to send the following message to my fellow Spotfire Data Scientists:

Title: ESRIGISHealth-Spotfire
Location: https://spotfire.cloud.tibco.com/spo...c-ce786c21fb51
Web Player location: https://spotfire.cloud.tibco.com/spo...ealth-Spotfire
Path: /users/bniemann/Public/ESRIGISHealth-Spotfire
Author: bniemann

This blog shows that a data scientist can repurpose an entire set of ESRI GIS training files into a Spotfire Guided Analysis for others to learn ESRI GIS and Spotfire skills.

Updated: Wed, 18 Sep 2019 16:24:20 GMT
Powered by MindTouch
I am currently working on another Health Data Ecosystem in Spotfire from the HDP 2015 Data Lab Session where I built an inventory of 20 of the most prominent health data sets from Health & Human Services for Medicare and the new Affordable Care Act Data in preparation for a Federal Big Data Working Group Meetup on July 20th. I intend to submit that as a blog as well so stay tuned.

Dr. Brand Niemann  
Director and Senior Data Scientist/Data Journalist  
Semantic Community  
http://semanticommunity.info/  
http://semanticommunity.info/Data_Sc...g_Group_Meetup http://www.meetup.com/Federal-Big-Data-Working-Group/

For Internet Explorer Users and Those Wanting Full Screen Display Use: Web Player Get Spotfire for iPad App

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HDP 2015 DataLab - Spotfire

The Health Datapalooza 2015 DataLab in Spotfire

In my previous Blog on "An ESRI GIS Tutorial for Health in Spotfire," I mentioned that was working on another Health Data Ecosystem in Spotfire from the Health Datapalooza 2015 Data Lab Session where I built an inventory of 20 of the most prominent and large (6.6 GB, 84 Million Rows, and 654 Columns) health data sets from Health & Human Services for Medicare and the new Affordable Care Act Data in preparation for a Federal Big Data Working Group Meetup on July 20th.

I have learned to Data Mine and Prepare Data Sets for Spotfire by starting with a seed URL, in this case a press release from HHS/CMS at HDP 2015 and the DataLab Session presentations and drill down from there. My steps are documented below for anyone who would like to reproduce and/or learn from them.

The results of downloading, unzipping, opening in Spotfire and documenting the size, and number of rows and columns is documented in my spreadsheet inventory which is also in the Spotfire Cover Page.

I selected 9 of the largest and most interesting TXT, CSV, and Excel files to import into Spotfire. The initial results are in the Spotfire Cover Page and 6 Tabs. Many more Spotfire analytics and visualizations are possible now that the Data Ming and Data Preparation work have been done. This demonstrates the important role of data scientists who know how to use Spotfire in facilitating the greater use and understanding of the major health databases. The HDP2015DataLab-Spotfire Guided Analysis file can be viewed in the Web Player.

My Spotfire work with the new Affordable Care Act Data Sets will be described in a final blog in this series for the upcoming Data Science for ACA Data & Semantic Medline Precision Medicine Meetup on July 29th. I hope that you can participate in-person or remotely.

Dr. Brand Niemann
Director and Senior Data Scientist/Data Journalist
Semantic Community
http://semanticommunity.info/
http://www.meetup.com/Federal-Big-Data-Working-Group/

Appendix: Data Mining Steps
http://www.cms.gov/Newsroom/MediaRel...015-06-01.html
RESULTS

http://www.cms.gov/Newsroom/MediaRel...015-06-01.html
http://www.cms.gov/Newsroom/MediaRel...5-06-01-2.html
RESULTS
http://www.cms.gov/Research-Statistics_Supplier.html
DONE

End User Point and Click Agreement:
CPT codes, descriptions and other data only are copyright 1995 - 2014 American Medical Association. All rights reserved. CPT is a registered trademark of the American Medical Association (AMA).


http://www.cms.gov/Research-Statistics_Supplier.html
DONE

http://www.cms.gov/Newsroom/MediaRel...015-04-30.html
http://cms.gov/Newsroom/MediaRelease...015-04-30.html
RESULTS
http://download.cms.gov/Research-Sta...PI_DRUG_13.zip
NEW

For Internet Explorer Users and Those Wanting Full Screen Display Use: Web Player Get Spotfire for iPad App

Media, iframe, embed and object tags are not supported inside of a PDF.
Research Notes

HealthData.gov Beta

http://www.healthdata.gov/

It's Health Datapalooza time!
If this isn't related to that, I'll have to get back to you.

http://www.hhs.gov/open/initiatives/hdi/index.html Does Not Work

Where is TYCHO, and the other originally featured data projects (FDA, HDI, and NIH)?

http://www.tycho.pitt.edu/

What is Format Type: 1181 with 10 Data Sets?

You can get a complete dump of Level 1 and Level 2 Version 1.0.0 Project Tycho® data from HealthData.gov. Level 2 data is also available via an API for those users who wish to retrieve the data directly from their scripts or software. No data dump is available for Level 3 data; instead, level 3 datasets may be requested using the Level 3 data request form.

http://healthdata.gov/data/dataset/p...m-level-1-data PAGE NOT FOUND

http://www.healthdata.gov/data/datas...m-level-2-data PAGE NOT FOUND

http://www.healthdata.gov/data/dataset/search/tycho
TYCHO NOT FOUND, BUT WHEN SEARCH FOR "TYCHO" I GET

http://www.healthdata.gov/data/dataset/se...ort_order=DESC

http://www.healthdata.gov/data/dataset/pr...m-level-1-data
http://project-tycho.s3-website-us-e...cho_Level1.zip

http://www.healthdata.gov/data/dataset/pr...m-level-2-data
The TYCHO Level 1 and 2 CSV Files Are Actually TSV Files That Need to Be Opened and Saved As Text Files

TSV is a file extension for a tab-delimited file used with spreadsheet software. TSV stands for Tab Separated Values. TSV files are used for raw data and can be imported into and exported from spreadsheet software. TSV files are essentially text files, and the raw data can be viewed by text editors, though they are often used when moving raw data between spreadsheets.

Difference Between Dataset Tag and Search Numbers-Why?

Tag national is 302
http://www.healthdata.gov/dataset?f...eld_tags%3A176
But search for national is 549
http://healthdatagovstg.prod.acquia-...ort_order=DESC

Meeting of the President’s Council of Advisors on Science and Technology (PCAST)

https://www.whitehouse.gov/sites/def...a_may_2015.pdf

My Note: See The President’s Precision Medicine Initiative

DATE: Friday, May 15, 2015

TIME: 9:00 a.m. until approximately 12:00 p.m. LOCATION:
National Academy of Sciences, Lecture Room
2101 Constitution Avenue, NW, Washington, DC
(Nearest Metro station: Foggy Bottom)

PRIMARY TOPICS:
• Quadrennial Energy Review
• Precision Medicine Initiative
• Reimagining Capitalism: Business & the Big Problems

Precision Medicine Initiative

• Tania Simoncelli, Assistant Director, Forensic Science and Biomedical Innovation, Office of Science and Technology Policy (OSTP)
• George D. Yancopoulos, President and Chief Scientific Officer, Regeneron Laboratories
• Richard Lifton, Sterling Professor of Genetics and Internal Medicine, Chair at the Department of Genetics and Investigator at the Howard Hughes Medical Institute, School of Medicine, Yale University
• Todd Golub, Founding Core Member, Chief Scientific Officer, and Director, Cancer Program, The Broad Institute, MIT, Harvard University

REGISTRATION: To attend in-person, please register online, here.
WEBCAST: This event will be live-streamed on the web, here. No registration is required to watch the live-stream.

For full agenda (subject to change), visit: http://www.whitehouse.gov/ostp/pcast/meetings.

For more information, visit: http://www.whitehouse.gov/ostp

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**Precision medicine stems from big data**

Source: [http://healthdatapalooza.org/open-da...h-datapalooza/](http://healthdatapalooza.org/open-da...h-datapalooza/)

Boone, a believer in big data’s potential to transform healthcare, also sees freer availability of health data as a key tool for precision, or personalized, medicine.

While genomic and specialized biological data are the building blocks for the individually targeted approach of precision medicine, one perhaps overlooked aspect of this emerging field is using big data to account for environmental issues, such as poverty and its often-attendant problems of poor childhood nutrition and lack of exercise, Boone said.

“The ability to look at individual variability is critical,” he said.

Boone divides his time between his hometown of Dallas and Washington, D.C., where the consortium and its small full-time staff of four is based.

The consortium’s more than two dozen organizational members form an eclectic group. They include tech giants such as Hewlett-Packard; EHR vendors such NextGen Healthcare Information Systems LLC; the Robert Wood Johnson Foundation; the American Health Information Management Association; and Boone’s previous employer, the health consultancy Avalere Health LLC.

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**Big health data project on new chief data scientist’s agenda**

Source: [http://fedscoop.com/big-health-data--...tists-agenda-2](http://fedscoop.com/big-health-data--...tists-agenda-2)

DJ Patil will work on the administration’s Precision Medicine Initiative, which the president announced in his State of the Union address.

In his new job as the federal chief data scientist, DJ Patil will be working on a new Obama administration project to use big data to improve patient care, the White House said.

The Precision Medicine Initiative is an effort to test and eventually use “precision medicine” — that is, treatment plans that factor in differences from patient to patient — to help treat cancer and other diseases.

As part of the plan, researchers hope to bring together 1 million or more volunteers to participate in a research cohort. Participants would share genomic data, lifestyle information and biological samples, and that information would be linked to their electronic medical records, National Institutes of Health Director Dr. Francis Collins said during a two-day workshop on the program last week. Researchers then ideally would analyze that information to improve medical treatments.
"We have a lot of work to do to take what has emerged as a nascent, compelling, exciting, promising idea and turn it into something that we can actually push for," Collins said at the event.

He also said there would be major challenges surrounding the data sets that would be created for the research.

"This is going to require huge investments to make sure we come up with the right structures and the ability to mine them," Collins said.

Tailoring health care treatments to patients isn't new, he said. Indeed, patients use prescriptions for eyeglasses and receive blood transfusions based on their blood type. But things like electronic medical records, big data, mobile health applications and other advances could allow for greater precision, Collins said.

FACT SHEET: President Obama’s Precision Medicine Initiative

Source: https://www.whitehouse.gov/the-press...ine-initiative

January 30, 2015

Building on President Obama’s announcement in his State of the Union Address, today the Administration is unveiling details about the Precision Medicine Initiative, a bold new research effort to revolutionize how we improve health and treat disease. Launched with a $215 million investment in the President’s 2016 Budget, the Precision Medicine Initiative will pioneer a new model of patient-powered research that promises to accelerate biomedical discoveries and provide clinicians with new tools, knowledge, and therapies to select which treatments will work best for which patients.

Most medical treatments have been designed for the “average patient.” As a result of this “one-size-fits-all-approach,” treatments can be very successful for some patients but not for others. This is changing with the emergence of precision medicine, an innovative approach to disease prevention and treatment that takes into account individual differences in people’s genes, environments, and lifestyles. Precision medicine gives clinicians tools to better understand the complex mechanisms underlying a patient’s health, disease, or condition, and to better predict which treatments will be most effective.

Advances in precision medicine have already led to powerful new discoveries and several new treatments that are tailored to specific characteristics of individuals, such as a person’s genetic makeup, or the genetic profile of an individual’s tumor. This is leading to a transformation in the way we can treat diseases such as cancer. Patients with breast, lung, and colorectal cancers, as well as melanomas and leukemias, for instance, routinely undergo molecular testing as part of patient care, enabling physicians to select treatments that improve chances of survival and reduce exposure to adverse effects.

The potential for precision medicine to improve care and speed the development of new treatments has only just begun to be tapped. Translating initial successes to a larger scale will require a coordinated and sustained national effort. Through collaborative public and private efforts, the Precision Medicine Initiative will leverage advances in genomics, emerging methods for managing and analyzing large data sets while protecting privacy, and health information technology to accelerate biomedical discoveries. The Initiative will also engage a million or more Americans to volunteer to contribute their health data to improve health outcomes, fuel the development of new treatments, and catalyze a new era of data-based and more precise medical treatment.
Key Investments to Launch the Precision Medicine Initiative:

Complementing robust investments to broadly support research, development, and innovation, the President’s 2016 Budget will provide a $215 million investment for the National Institutes of Health (NIH), together with the Food and Drug Administration (FDA), and the Office of the National Coordinator for Health Information Technology (ONC) to support this effort, including:

- $130 million to NIH for development of a voluntary national research cohort of a million or more volunteers to propel our understanding of health and disease and set the foundation for a new way of doing research through engaged participants and open, responsible data sharing.
- $70 million to the National Cancer Institute (NCI), part of NIH, to scale up efforts to identify genomic drivers in cancer and apply that knowledge in the development of more effective approaches to cancer treatment.
- $10 million to FDA to acquire additional expertise and advance the development of high quality, curated databases to support the regulatory structure needed to advance innovation in precision medicine and protect public health.
- $5 million to ONC to support the development of interoperability standards and requirements that address privacy and enable secure exchange of data across systems.

Objectives of the Precision Medicine Initiative:

- More and better treatments for cancer: NCI will accelerate the design and testing of effective, tailored treatments for cancer by expanding genetically based clinical cancer trials, exploring fundamental aspects of cancer biology, and establishing a national "cancer knowledge network" that will generate and share new knowledge to fuel scientific discovery and guide treatment decisions.
- Creation of a voluntary national research cohort: NIH, in collaboration with other agencies and stakeholders, will launch a national, patient-powered research cohort of one million or more Americans who volunteer to participate in research. Participants will be involved in the design of the Initiative and will have the opportunity to contribute diverse sources of data—including medical records; profiles of the patient’s genes, metabolites (chemical makeup), and microorganisms in and on the body; environmental and lifestyle data; patient-generated information; and personal device and sensor data. Privacy will be rigorously protected. This ambitious project will leverage existing research and clinical networks and build on innovative research models that enable patients to be active participants and partners. The cohort will be broadly accessible to qualified researchers and will have the potential to inspire scientists from multiple disciplines to join the effort and apply their creative thinking to generate new insights. The ONC will develop interoperability standards and requirements to ensure secure data exchange with patients’ consent, to empower patients and clinicians and advance individual, community, and population health.
- Commitment to protecting privacy: To ensure from the start that this Initiative adheres to rigorous privacy protections, the White House will launch a multi-stakeholder process with HHS and other Federal agencies to solicit input from patient groups, bioethicists, privacy, and civil liberties advocates, technologists, and other experts in order to identify and address any legal and technical issues related to the privacy and security of data in the context of precision medicine.
- Regulatory modernization: The Initiative will include reviewing the current regulatory landscape to determine whether changes are needed to support the development of this new research and care model, including its critical privacy and participant protection framework. As part of this effort, the FDA will develop a new approach for evaluating Next Generation Sequencing technologies — tests that rapidly sequence large segments of a person’s DNA, or even their entire genome. The new approach will facilitate the generation of knowledge about which genetic changes are important to patient care and foster innovation in genetic sequencing technology, while ensuring that the tests are accurate and reliable.
- Public-private partnerships: The Obama Administration will forge strong partnerships with existing research cohorts, patient groups, and the private sector to develop the infrastructure that will be needed to expand cancer genomics, and to launch a voluntary million-person cohort. The Administration will call on academic medical
centers, researchers, foundations, privacy experts, medical ethicists, and medical product innovators to lay the foundation for this effort, including developing new approaches to patient participation and empowerment. The Administration will carefully consider and develop an approach to precision medicine, including appropriate regulatory frameworks, that ensures consumers have access to their own health data – and to the applications and services that can safely and accurately analyze it – so that in addition to treating disease, we can empower individuals and families to invest in and manage their health.

Health Datapalooza 2015

Source: http://healthdatapalooza.org/detailed-agenda/

May 31

Registration

Welcome Reception

June 1

Opening General Session

Featuring: Christopher Boone, Chief Executive Officer, Health Data Consortium; David Knott, Chair, Health Datapalooza Steering Committee, Senior Partner, McKinsey & Company

Main Stage Emcee: Thomas Goetz, Co-Founder, Iodine

Keynote Speaker: Esther Dyson, Founder, HICcup

App Demo: Sensentia

Panel: Big Changes from Big Data in Healthcare

Moderator: Ceci Connolly, Managing Director, Health Research Institute, PricewaterhouseCoopers

Panelists: Bob Kocher, MD, Partner, Venrock; Farzad Mostashari, MD, Founder, Aledade; Ed Park, Executive Vice President & COO, Athenahealth

Challenge Announcement

Esther Dyson

Founder, HICcup

Esther Dyson (@edyson on Twitter) is the founder of HICcup.co, for Health Initiative Coordinating Council. HICcup runs The Way to Wellville (@WaytoWellville), an open-source, evidence-generating project devoted to defining and testing
models for producing health (not health care) that will return profits to investors and health to participants. Dyson spends her time nurturing start-ups. On the health side, she is an investor in 23andMe (also a director), Applied Proteomics, Eligible API, Genomera, GeriJoy, Health Loop, HealthTap, i2Dx, Keas (advisor), Medivo, mEquilibrium, Omada Health, Organized Wisdom, PatientsLikeMe, PatientsKnowBest (UK), Resilient, Sleepio (UK), StartupHealth, Tocagen, Valkee (Finland), VitaPortal (Russia, advisor), Voxiva (director) and Zipongo. Dyson also sits on the boards of the Sunlight Foundation and the Personal Genome Foundation. (And, full disclosure, she is an investor in Brave New Talent, which has a contract to deliver the Greater Wellville knowledge platform.)

**General Session 1**

**Keynote:** George Freeman MP, Parliamentary Under Secretary of State for Life Sciences, UK Department for Business, Innovation and Skills and the Department of Health

**Panel:** The Power of Transparency and Data to Remake Health Care

**Moderator:** Sarah Kliff, Senior Editor, Vox

**Panelists:** Niall Brennan, Chief Data Officer, Centers for Medicare and Medicaid Services; Bernard Lo, MD, President, Greenwall Foundation; Nick Sinai, Venture Partner, Insight Venture Partners

**App Demo:** The Advisory Board Company

**App Demo Booth**

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<tr>
<th>Time</th>
<th>Company 1</th>
<th>Company 2</th>
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<tr>
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<td>DocSpot</td>
<td>FindTheBest</td>
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<td>Sensentia</td>
<td>The Advisory Board Company</td>
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<td>1:30 pm</td>
<td>Health&amp;Code Software Solutions</td>
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<tr>
<td>2:00 pm</td>
<td>Amida Technology Solutions</td>
<td>Carevoyance</td>
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<td>Dimensional Dosing Systems, Inc.</td>
<td>Tapasvi Clin-MolBio Solutions, Inc.</td>
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<tr>
<td>3:00 pm</td>
<td>MobiDox Health Technologies, Inc.</td>
<td>The Ohio State University</td>
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<td>3:30 pm</td>
<td>Klio Health</td>
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</table>
4:00 pm Healthy Me Mobile Solutions

4:30 pm HealthLabs

5:00 pm Partnership of UNC Chapel Hill and Crohn’s & Colitis Foundation of America

5:30 pm Esri

6:00 pm Avhana Health

Healthcare Transformer Showcase

The Healthcare Transformer Showcase is an opportunity to experience breakthrough digital health innovations and meet the entrepreneurs transforming the space. The event will include a fireside chat with key innovation stakeholders, StartUp Health entrepreneurs pitching their innovations, and structured networking for HDP attendees to make meaningful connections with the entrepreneurs and fellow attendees.

App Expo Live Demos

1:00 pm – Welcome
1:05 pm – HealthLucid
1:17 pm – Wellth
1:29 pm – 3M Health Information Systems
1:41 pm – Gather Health
1:53 pm – Ostonics
2:05 pm – Mana Health
2:17 pm – Allscripts
2:29 pm – My Clinical Outcomes
2:41 pm – Symptify Inc.
2:53 pm – Mental Affect
3:05 pm – AEGIS.net, Inc.
3:17 pm – Personal Air Quality Systems Pvt Ltd.
3:29 pm – Break
5:17 pm – DocSpot
5:29 pm – FindTheBest
5:41 pm – Health&Code Sftware Solutions
5:53 pm – MobiDox Health Technologies, Inc.

Updated: Wed, 18 Sep 2019 16:24:20 GMT
Powered by Mindtouch
6:05 pm – The Ohio State University
6:17 pm – Closing

DataLab

HHS has so much data! Medicare, substance abuse and mental health, social services and disease prevention are only some of the MANY topical domains where HHS provides huge amounts of free data for public consumption. It’s all there on HealthData.gov! Don’t know how the data might be useful for you? In the DataLab you’ll meet the people who collect and curate this trove of data assets as they serve up their data for your use. But if you still want inspiration, many of the data owners will co-present with creative, insightful, innovative users of their data to truly demonstrate its alternative value for positive disruptions in health, health care, and social services.

**Moderator:** Damon Davis, U.S. Department of Health & Human Services

**Panelists:** Natasha Alexeeva, Caretalia; Christina Bethell, PhD, MBA, MPH, Johns Hopkins; Lily Chen, PhD, National Center for Health Statistics; Steve Cohen, Agency for Healthcare Research & Quality; Manuel Figallo, Sas; Reem Ghandour, DrPH, MPA, Maternal and Child Health Bureau; Jennifer King, U.S. Department of Health & Human Services; Jennie Larkin, PhD, National Institutes of Health; Brooklyn Lupari, Substance Abuse & Mental Health Services Administration; Rick Moser, PhD, National Cancer Institute; David Portnoy, MBA, U.S. Department of Health & Human Services; Chris Powers, PharmD, Centers for Medicare and Medicaid Services; Elizabeth Young, RowdMap.

Applications of Transparency: From Visibility to Action

As transparency in health care has emerged as a crucial enabler towards achieving the Triple Aim, myriad sources and types of information have become available in the last few years. Join this session to learn new ways of understanding the behaviors of patients and providers, and novel approaches to payment and delivery already underway.

**Moderator:** Ben Harder, *U.S. News & World Report*

**Panelists:** Elizabeth Mitchell, NRHI; Jeanne Pinder, ClearHealthCosts; Josh Rosenthal, PhD, RowdMap, Inc.

Transforming Local Health Data To Meaningful National Benchmarks

Like gambling, hard liquor, and other supply-sensitive economies, healthcare is local. Academics talk of access to care, price, cost, and even supply driving demand – all things that happen in a local context driven by geography. The problem is that different communities want different things, do different things, and keep data on different things in different ways. But we need geographic benchmarks to make sense of the particularities of my community’s data. As the Data Liberation movement matures, it faces a major challenge in tying all of these different things together to create national benchmarks. This session explores the work; best practices; case studies; and hits, misses, and challenges from the Center for Healthcare Transparency, a Robert Wood Johnson recipient whose network of regional data entities is on track to produce provider performance information for 50% of the U.S. by 2020... dark hollers and deep cities included.

**Moderator:** Scott Howell, Optum; Amy Nguyen Howell, MD, MBA, FAAFP, CAPG

**Panelists:** Craig Brammer, The Health Collaborative; Jim Chase, MHA, Minnesota Community Measurement; Jonathan...
Mathieu, PhD, Center for Improving Value in Health Care

**Innovation in Action: From Algorithms To Clinical Change**

This session will explore how advanced data analytics can lead to change at a clinical level. First, attendees will hear from an actual innovation center that deals with the intersection of entrepreneurs and clinicians. Then, we will hear about novel uses of data and clinical information to advance sepsis care. Finally, we will understand how big data can better identify practical solutions for payers and providers.

**Moderator:** Nick Dawson, MHA, Johns Hopkins Sibley Innovation Hub

**Panelists:** Sean Benson, Wolters Kluwer; Basit Chaudhry, IBM

**Patient Hackers: The #Wearenotwaiting Movement and the Way Forward For Open Device Data**

Diabetes patients are digital health natives. Daily life is constantly calibrated based on streams of medical device data, but integrating the relevant data streams is difficult. Medical device companies have been slow to act, so patients and caregivers have found ways to ‘hack’ their devices to access and integrate data and create tools that enable them to better manage their health. At the same time, diabetes patients worked with FDA to raise concerns and recommend changes to regulations governing medical device data access and interoperability. In turn, FDA has embraced this patient input working with—rather than against—the patient hackers. While diabetes patients may be leading the charge, more data-generating medical devices are being developed to manage and monitor a range of chronic illnesses. This panel will feature leaders in the patient hacker movement discussing the tools they’ve developed, lessons they’ve learned and how they envision this movement developing.

**Moderator:** Anna McCollister-Slipp, Galileo Analytics

**Panelists:** Doug Kanter, Databetes; Howard Look, Tidepool; Bakul Patel, Food & Drug Administration, Centers for Devices & Radiological Health; Ken Stack, Perceptus.org

**Personalized Medicine: When Will We Get There? What's the Path Forward?**

This session will move past the hype of wearables. It will feature innovators who are taking these new data sources and making them actionable, via implementation in care settings, integration into the medical record, and really doing something with the data that changes healthcare outcomes.

**Moderator:** Jodi Daniel, JD, MPH, U.S. Department of Health & Human Services

**Panelists:** Seth Bokser, MD, MPH, UCSF Benioff Children’s Hospital and Moore Women’s Hospital; Rajiv Kumar, Stanford Children’s Health; Jafar Shenasa, Proteus Digital Health

**Leveraging Big Data for Better Quality Measurements**

Clinicians and hospitals are increasingly being paid based on their measured quality, with HHS recently announcing that it will have 85% of Medicare payments tied to quality or value by 2016. However, quality measurement is still largely calculated from healthcare claims data, which limits the scope and quality of the results. New data sources, such as
patient registries, mobile devices, or repositories of clinical and claims data, can provide for new insights and better assessments of quality. This panel will explore some of these new data innovations, their potential benefits, and strategies for leveraging them further.

**Moderator:** Christine Cassel, MD, National Quality Forum

**Panelists:** Tony Hussain; Aaron McKethan, RxAnte; Paul Wallace, MD, Optum Labs

**The Future of Health Data Is On FHIR!**

You have probably been hearing a lot in the news about HL7’s most recent standard, FHIR (Fast Healthcare Interoperability Resources). This session is designed to shed light on the next generation standards framework that leverages the latest web standards and applies a tight focus on implementation. FHIR represents a significant advance in accessing and delivering data while offering enormous flexibility. In December 2014, in an effort to address the recommendations of the JASON Task Force, HL7 launched the Argonaut Project in collaboration with leading health care IT vendors and providers to accelerate the development and adoption of FHIR. This session will help the audience better understand the FHIR adoption trajectory as well as the future promise of what this standard makes possible to improve patient care.

**Presenter:** Charles Jaffe, MD, PhD, Health Level 7

**Insurer Perspectives: Health Plan Strategy and Investment**

As new approaches to the collection and use of data change the way we deliver and pay for health care, they also change the business of investing in health care. Join this session to learn how health plans fund entrepreneurs and diversify their own businesses.

**Moderator:** Terry Stone, MBD, Oliver Wyman

**Panelists:** Sander Duncan, North Shore Ventures; Kent Marquardt, Premera Blue Cross; Bjorn Thaler, Aetna

**How Businesses Are Using Data To Select and Best Utilize Health Care Centers of Excellence**

Join us to explore the next frontier of data and analytics being used to improve healthcare quality and reduce cost. We will have a discussion with leading industry innovators who will describe their processes for using data to select Centers of Excellence and will discuss how they are using employee data and Center of Excellence outcome data to drive care and cost decision making. This is a session we don’t want any of our self-insured business partners to miss.

**Moderator:** E.J. Holland, U.S. Department of Health & Human Services

**Panelists:** Mary Bourland, MD, Sisters of Mercy; Rick Chelko, EdisonHealth Network; Tom Emerick, Emerick Consulting LLC; Remy Szykier, Aegis Health Security

**Using Data & Technology To Enable Better Patient Health, Support, and Care**

Patient, provider, and caregiver access to health data is increasingly viewed as essential to the delivery of quality care, improving health, and enabling innovation. This panel will share insights from ongoing initiatives to connect patients and
consumers with their health data via mobile and other technologies to support health and wellness goals, such as
treatment adherence and diabetes management.

**Moderator:** Joe Greenwood, MBA, MaRS Discovery District

**Panelists:** Mischa Dick, Healthcare Excellence Institute, LLC; Jaffie Rajan, Merck; Jason Victor, Merck

**How Do You Get Clinical Validation From Patient-Generated and Open Health Data in Obstetric Care?**

This presentation will be two pronged. First, it will include a brief overview of our initial study at George Washington
University and its results. Second will be a panel featuring Doctors Kathryn Marko, Jill Krapf, and Andrew Meltzer,
clinicians at the George Washington University, who were the principal investigators. In our study, more than 150
expectant mothers were recruited for the program and subsets of those patients were provided with the full Babyscripts
experience that included connected devices. We found that Babyscripts enhances patient satisfaction with their prenatal
care, improves patient compliance, and engagement and could potentially decrease healthcare costs by avoiding
unnecessary visits for low-risk patients. Our goal for this session is to demonstrate the active collaboration that is
required between clinicians, entrepreneurs, and technologists to leverage this new paradigm of health data in clinical
care and commercialize digital healthcare solutions.

**Moderator:** Anish Sebastian, Babyscripts

**Panelists:** Jill Krapf, MD, The George Washington University; Katie Marko, MD, FACOG, The George Washington
University School of Medicine and Health Sciences; Andrew Meltz, MD, 1EQ

**Patient Reported Outcomes as Quality Indicators in the U.S. & U.K.: Issues and Opportunities**

The use of data within health has grown exponentially in the past five years. Whilst it often gives pointers to the care
process, the predicted growth in whole scale change in pathways hasn’t followed. This has been partly because of
untapped data, lack of customer feedback and triangulation with other health systems. Three years ago the U.S. and
U.K. governments came together, initially to promote transparency of data and latterly to address this void. A joint
concordant has enabled close working of the NHS and HHS and sharing of data items.

The session will demonstrate how copyright issues can and have been addressed in relation to Patient Reported
Outcome Measures (PROMs), giving access to the largest repository of ‘customer outcome data’ within health care. The
session will also demonstrate the use of simple data to turn into knowledge with respect to the most common joint
replacement surgery performed in both countries and its relation to obesity.

**Moderator:** Kevin Larsen, MD, Office of the National Coordinator of Health IT

**Panelists:** Do Dewji, National Health Service England; Patricia Franklin, MD, MBA, MPH, University of Massachusetts;
Ellen Makar, MSN,RN-BC, CCM, CPHIMS, CENP, U.S. Department of Health & Human Services; Sohail Mirza, MD,
MPH, Dartmouth Hitchcock Medical Center
Using Open International Health Data in Decision-Making

A wealth of healthcare data exists, but often this data is not widely disseminated or used to their maximal benefit. In this workshop, we will explore how open international health data can be repurposed to promote accountability and data-driven decision making. We will discuss policies and projects that increase access to health data, such as the USAID-funded MEASURE Evaluation Dataverse; how these data can be used to evaluate development projects; and challenges and lessons learned in publicly sharing data.

**Moderator:** Brandon Pustejovsky, USAID

**Panelist:** Eran Bendavid, MD, MS, Stanford University; Jon Crabtree, Odum Institute University of North Carolina Chapel Hill; Irum Zaidi, Office of the U.S. Global AIDS Coordinator & Health Diplomacy

Moving Beyond Sensational Outliers To Meaningful Analysis, Interpretation, and Application of Public Health Care Data

HHS just backed up the data truck, dumping boatloads of Medicare data after decades of Freedom of Information Act requests. When it first hit, the media went wild and outliers from fraud, waste, and abuse made headlines. As the Data Liberation movement matures, one of its chief challenges comes from communicating the value of the public data beyond sounds bites and sensational stories to meaningful inputs. This session has the best of the journalists in the heart of this story. Charles Ornstein is a Pulitzer Prize winner. Tom McGinty is with the Wall Street Journal, the media organization that broke the story. And Jennifer Schneider of Castlight Health is at the forefront of the next wave of work, mining the data for meaning and application in a post-reform world. This session will showcase some finds, share cools stories, do a bit of reflection around the nature of reporting and the popular appetite for specific stories, and sketch out the path forward from sound bite to sound practice.

**Moderator:** Joshua Rosenthal, PhD, RowdMap, Inc.

**Panelists:** Tom McGinty, The Wall Street Journal; Charles Ornstein, ProPublica; Jennifer Schneider, MD, MS, Castlight Health

The Disruptive Social

Featured Speaker: Todd Park, Technology Advisor, Executive Office of the President, The White House

**June 2**

General Session 2

**Main Stage Emcee:** Kavita Patel, MD, MS, Managing Director of Clinical Transformation, Brookings Institution

**Fireside Chat:** Bruce Broussard, President and Chief Executive Officer, Humana

**Moderator:** Kavita Patel, MD, MS, Managing Director of Clinical Transformation, Brookings Institution

**App Demo:** Healthy Communities Institute
Panel: Rethinking Healthcare Delivery with 21st Century Data

Moderator: Susan Dentzer, Senior Policy Advisor, Robert Wood Johnson Foundation

Panelists: Patrick Conway, Deputy Administrator for Innovation & Quality, CMS Chief Medical Officer, Centers for Medicare & Medicaid Services; Karen DeSalvo, Acting Assistant Secretary for Health, National Coordinator for Health Information Technology, U.S. Department of Health & Human Services; Tim Kelsey, National Director for Patients & Information, NHS England; Todd Park, Technology Advisor, Executive Office of the President, The White House; Joe Selby, Executive Director, Patient-Centered Outcomes Research Institute

Panel: Data Independence Day: Consumer Demand Will Unlock Health Data

Presenters: Christine Bechtel, Vice President, National Partnership for Women & Families; Chris Boone, Chief Executive Officer, Health Data Consortium; Rebecca Coelius, Director of Health, Code for America; Farzad Mostashari, Chief Executive Officer, Aledade; Sharon Terry, President and CEO of Genetic Alliance

Bruce Broussard

President and Chief Executive Officer, Humana

Bruce Broussard became Humana’s President and Chief Executive Officer on January 1, 2013, after completing a year-long transition to the CEO role. Prior to joining Humana in December 2011, Broussard was CEO of McKesson Specialty/US Oncology, Inc. At US Oncology, which McKesson purchased in 2010, Broussard served in several roles, including Chief Financial Officer, President, CEO and Board Chairman. Broussard also plays a leadership role in key business advocacy organizations. He is a member of the Business Roundtable and a member of the Board of Directors of America’s Health Insurance Plans (AHIP), also serving on AHIP’s Executive Committee.

Moderated by: Kavita Patel, MDMS, Managing Director of Clinical Transformation, Brookings Institute

General Session 3

Keynote Speaker: Andy Slavitt, Acting Administrator, Centers for Medicare & Medicaid Services

Fireside Chat: Aaron Levie, Co-Founder, Box

Moderator: Aneesh Chopra, Co-Founder and Executive Vice President, Hunch Analytics

App Demo: HealthLabs

Andy Slavitt

Acting Administrator, Centers for Medicare & Medicaid Services

Andy Slavitt is the Acting Administrator for the Centers for Medicare & Medicaid Services. As Acting Administrator, Slavitt is responsible for cross cutting policy and operational coordination for the agency’s Medicare, Medicaid, CHIP, and Marketplace programs including efforts to expand access to health coverage; combat health care fraud; reform health care delivery; and improve health outcomes. Slavitt joined CMS after spending more than 20 years in the private sector. Most recently he served as Group Executive Vice President for Optum. Slavitt was the top day-to-day executive
leading the systems integration work and tech surge to fix HealthCare.gov. Prior to his role at Optum, Slavitt was CEO of OptumInsight from 2006 through 2011. He was also founder and CEO of Health Allies, which was acquired by UnitedHealth Group in 2003, and has worked as a strategy consultant with McKinsey & Company as well as an investment banker with Goldman Sachs.

Aaron Levie
Co-Founder, Box

Aaron Levie co-founded Box with friend and Box CFO Dylan Smith in 2005. The Box mission is to provide businesses and individuals with the simplest solution to share, access and manage their information. Levie is the visionary behind Box’s product and platform strategy, which is focused on incorporating the best of traditional content management with an elegant, easy-to-use user experience suited to the way people collaborate and work today. Box is one of the fastest growing companies in enterprise software, used by more than 27 million individuals and 240,000 businesses worldwide. For healthcare, Box supports HIPAA compliant file sharing and sells to providers, payors, and life science companies around the world.

Moderated by: Aneesh Chopra, Co-Founder, Executive Vice President, Hunch Analytics

Data, Drugs, and Diversion: Hit Tools and the Prescription Drug Epidemic

A key goal of the HITECH Act was to create digital tools for solving public health problems. This session will address HIT solutions for a public health problem that the CDC has declared a national epidemic: abuse, overdose, and death from prescription painkillers. As the volume of prescriptions for opioids has exploded over the past decade, so has the incidence of overdose and death from the misuse of these powerful drugs. Over the past five years, pharmacy and law enforcement regulators at the federal and state levels have collaborated to legalize electronic prescribing of controlled substances (EPCS) so that public health, law enforcement, and the provider community can flag suspicious patient and prescriber behavior and intervene to prevent high-risk dispensing. Today, most pharmacies are prepared to receive digital prescription orders for controlled substances. With EPCS now legal in nearly every state, we are poised to deploy a technology that has the potential to reduce deaths.

Moderator: Susan Dentzer, Robert Wood Johnson Foundation

Panelists: Justin Berhaupt, Malkin & Ross; Miya Gray, Surescripts; Tricia Wilkins, PharmD, MS, PhD, Office of Clinical Quality and Safety

App Demo Booth

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**App Expo Live Demos**

- 12:25 pm – Welcome
- 12:30 pm – Partnership of UNC Chapel Hill and Crohn’s & Colitis Foundation of America
- 12:42 pm – Esri
- 12:54 pm – @Point of Care
- 1:06 pm – CVOffice, LLC
- 1:18 pm – Intrigma, Inc.
- 1:30 pm – Audacious Inquiry for CRISP
- 1:42 pm – Break
- 1:54 pm – Caremerge
- 2:06 pm – Noblis
- 2:18 pm – Avhana Health
- 2:30 pm – Caspio, Inc.
- 2:42 pm – Klio Health
- 2:54 pm – realFIT, Inc.
- 3:06 pm – Break
- 3:42 pm – Healthy Me Mobile Solutions
- 3:54 pm – Carevoyance
- 4:06 pm – Tapasvi Clin-MolBio Solutions, Inc.
- 4:18 pm – Amida Technology Solutions
- 4:30 pm – Dimensional Dosing Systems, Inc.
- 4:42 pm – Closing

**Patient-Generated Health Data in the Real World**

Patients, from the worried well to those with chronic conditions, are tracking their health more and more as devices and tools appear on GooglePlay and the AppStore, or are crowd-built on sites like Github. Sharing that data – from symptom
trackers, activity monitors, blood pressure cuffs, WiFi-enabled scales – with medical providers is problematic, making much of that data invisible to the patient’s clinical team. Moderated by a healthcare journalist and blogger who is also an e-patient, the panel will talk about the gaps and opportunities presented by patient generated data – how it might be incorporated into patient medical records, how it could inform care in and out of the medical office or hospital, where it might disrupt standard testing and diagnostic models, and how it might empower patients as primary stakeholders in their health outcomes.

**Moderator:** Casey Quinlan, Mighty Casey Media  
**Panelists:** Mandi Bishop, Dell; Greg Meyer, Cerner Corp.; Danny Sands, MD, MPH, Society for Participatory Medicine; Scott Strange, Scott Strange, LLC

### Using Open Data To Promote Entrepreneurship and Innovation in India

Access to data is a barrier to health innovation globally. With 800 million mobile phone users and a growing community of technology entrepreneurs, India is poised for major growth in health IT innovation. This panel, which includes representatives from the Office of the Registrar General in India (which oversees the collection of vital statistics) and U.S. experts, will explore how increasing access to open data can encourage entrepreneurship and support the development of low cost applications and services to promote health in India and the U.S. Possible opportunities for U.S.-India collaboration will also be discussed.

**Chair:** Indu Subaiya, Co-Chairman and CEO, Health 2.0

**Speakers from the Government of India:** Rohit Bhardwaj, Deputy Registrar General, Office of the Registrar General of India, Ministry of Home Affairs, Central Government of India; Rajeev Kumar, Deputy Director, Office of the Registrar General of India, Ministry of Home Affairs, Central Government of India

**Reaction From US experts:** Rushika Fernandopulle, CEO, Iora Health; Ramesh Kolluru, Vice President of Research at University of Louisiana at Lafayette

### Open Data For Social Determinants of Health

This session will focus on combining different datasets to reach vulnerable and low-income patients. We will bring a different perspective to the conversation about open health data by focusing on organizations and companies working to ensure that everyone has the chance to benefit from health technology and open data, including those in underserved populations. We’ll also highlight the many ways in which creative uses of open data can empower physicians and social workers to do their jobs more efficiently and in partnership.

**Moderator:** Farzad Mostashari, Aledade, Inc  
**Panelists:** Rebecca Coelius, MD, Code for America; Joseph Flesh, Purple Binder; Stacy Lindau, MD, MAPP, University of Chicago; Rishi Manchanda, MD, MPH, HealthBegin

### Public Program Changes, Private Sector Benefits

Many government agencies have recently implemented significant changes or launched new programs in response to budget pressures and regulatory reforms. Join this session to learn how these have led to new services and information sources that reduce government cost and improve opportunities for private sector collaboration.
Moderator: Shawn Bishop, MPP, SB Health Policy Consulting
Panelists: Barbara Gage, Brookings Institution; COL John S. Scott, Clinical Informatics Policy, Office of the Asst. Secretary of Defense; Kitt Winter, CPA, MBA, Social Security Administration

No You Can’t Always Get What You Want: Getting What You Need from HHS

While more data is better than less, pushing out any ol’ data isn’t good enough. As the Data Liberation movement matures, the folks releasing the data face a major challenge in determining what’s the most valuable stuff to put out. How do they move from smorgasbord to intentionally curated data releases prioritizing the highest-value data? Folks at HHS are wrestling with this, going out of their way to make sure they understand what you want and ensure you get the yummy data goodies you’re craving. Learn how HHS is using your requests and feedback to share data differently.

This session explores the HHS new initiative the Demand-Driven Open Data (DDOD): The lean startup approach to public-private collaboration. A new initiative out of HHS IDEA Lab, DDOD is bold and ambitious, intending to change the fundamental data sharing mindset throughout HHS agencies — from quantity of datasets published to actual value delivered.

Moderator: Damon Davis, U.S. Department of Health & Human Services
Panelists: Phil Bourne, National Institute of Health (NIH); Niall Brennan, Centers for Medicare & Medicaid Services; Jim Craver, MMA, Centers for Disease Control & Prevention; Chris Dymek, EdD, U.S. Department of Health & Human Services; Taha Kass-Hout, Food & Drug Administration; Brian Lee, MPH, Centers for Disease Control & Prevention; David Portnoy, MBA, U.S. Department of Health & Human Services

A Delicate Balance: A Town Hall on Health Care Data Privacy and Security Issues

Improving how our healthcare system uses data holds great promise to advance research and patient care. Many across the healthcare community are working hard to find ways to achieve this potential. But the sensitive and personal nature of these data demands careful, thoughtful, inclusive deliberations about ownership, stewardship, and “terms of use” in pursuing laudable goals. This Town Hall, organized by the Patient-Centered Outcomes Research Institute (PCORI), presents one such opportunity. Representatives of patients, researchers, clinicians, and experts in ethical, legal and social issues in data use, a number of whom are working with PCORI on developing a new patient-centered clinical research network, will discuss the considerations that must be addressed if we are to realize our hopes for a patient-centered, learning healthcare system.

Moderator: Deven McGraw, JD, MPH, Partner, Manatt, Phelps & Phillips. Former director, Health Privacy Project, Center for Democracy & Technology
Panelists: Michael Kappelman, MD, Associate Professor of Pediatrics, UNC Chapel Hill; Sally Okun, RN, Vice President, Advocacy, Policy and Patient Safety, PatientsLikeMe; Sharon Terry, MA, President and CEO, Genetic Alliance

Role of Data in a Time of Massive Health Care Transformation

This session will introduce concepts of big data but will help attendees drill down on priorities for venture investments, innovative health systems, and other researchers.
Moderator: Sandeep Pulim, MD, @Point of Care
Panelists: Mayank Sharma, PhD, IBM Research; Anand Veeravagu, MD, Stanford University School of Medicine

Democratizing Health Quality Improvement

Quality improvement is the cornerstone of the health system. It empowers health enterprises to report and monitor against targets, compare each other, and continually improve. In the health industry today, there are a dazzling array of measures and data sets. Unfortunately, measures are all too often implemented in silos, locked into back-office systems, with little standardization or ability to be shared. They can take years to implement and months of effort to update and maintain. In this presentation we propose and discuss a revolutionary approach that connects quality improvement to the heart of the new generation health organization. This approach is being piloted at the Mayo Clinic. It empowers a large community of leading quality and safety improvement executives to author, publish, and share standardized quality measure with unparalleled ease. Professionals everywhere can then connect their data and use them in practice, where they have greatest impact on patient outcomes.

Moderator: Paul Magelli, Apervita, Inc.
Panelists: Floyd Eisenberg, MD, MPH, FACP, iParsimony, LLC; Jim Frankfort, MD, IMS Health; Brad Ryan, MD, Apervita, Inc.; Craig Stancl, Mayo Clinic

Data & Technology Aren't Just for the Young: Supporting Aging Adults

The United States is an aging society—and it is positive that people are living longer, healthier lives. There are now new technologies that can support aging adults and help them remain active and independent for as long as possible. This session will consider where technologies could help with better aging, what prevents new technologies for aging adults from emerging, and where technologies could do more in the future.

Moderator: Susan Dentzer, Senior Policy Advisor, Robert Wood Johnson Foundation
Panelists: Christine Cassel, MD, President, National Quality Forum; Charlotte Yeh, Chief Medical Officer, AARP

Old School Data Sets, Rebooted, Repurposed and Creating Killer New Value

As the Data Liberation movement matures, one of the challenges it faces is using current data sets in new and creative ways, applying decades of research to create new value propositions in both Fee-for-Service and Pay-for-Value arenas. This session explores the limits of current data systems and statistical models by using alternative traditional gold-standard data sets, either as-is or rebooted. David Wennberg uses social determinants and health behaviors to lay out the framework for a population-health approach to reform, while Jessica Kahn showcases the new Transformed Medicaid Statistical Information System. Ramon Martinez puts our national benchmarks in global perspective using data from World Health Organization and the Institute of Health Metrics and Evaluation, showing you easy ways to access and understand tried-and-true data sets. We walk through a couple of case studies and ensure the audience has access to the old dogs and knows how to teach them new tricks.

Moderator: Michael Painter, Robert Wood Johnson Foundation
Panelists: Jessica Kahn, MPH, Centers for Medicare & Medicaid Services; Ramon Martinez, Pan American Health Organization; David Wennberg, MD, MPH, NNEACC
Centers For Medicare & Medicaid Services Data, Policies, Programs & Plans

CMS will present information on new and updated data and information products of interest to health researchers, policymakers, and data innovators. Panelists will present on: new policies and mechanisms for access to CMS data, public release of provider utilization and payment data, new/updated information visualization tools, and other publicly available data files.

**Moderator:** Niall Brennan, Centers for Medicare & Medicaid Services

**Panelists:** Christine Cox, Centers for Medicare & Medicaid Services; Allison Oelschlaeger, Centers for Medicare & Medicaid Services; Chris Powers, PharmD, Centers for Medicare & Medicaid Services; Debbie Pusateri, Centers for Medicare and Medicaid Services; Andrew Shatto, Centers for Medicare and Medicaid Services

Leveraging the Potential of Patient-Generated Data: Progress and Opportunities

Consumer-facing technologies and new initiatives to collect and sequence genetic information are dramatically expanding the variety and volume of data available to drive improvements in health and care, and foster a learning health system. Despite the proliferation of such data through these new sources, it is highly fragmented and often not fully leveraged for important uses, such as quality improvement and research. In this session, panelists will share examples of how patient generated health data are informing and improving care, democratizing and accelerating the research process, and generating new insights about the impact of genetic variants on health.

**Moderator:** Alison Rein, MS, AcademyHealth

**Panelists:** Kathy Hudson, PhD, National Institutes of Health (NIH); Joshua Mann, SHARE For Cures; Drew Schiller, Validic

Health Plans Collaborating with Providers

Health plans are changing the way they collaborate with providers to manage the quality and cost of health care delivered to beneficiaries sponsored by employers and the government. Join this session to learn about how payment and delivery models are changing, the challenges ahead, and the role information technology is playing in facilitating the transition.

**Moderator:** Jack Lewin, MD, Cardiovascular Research Foundation

**Panelists:** Charles Kennedy, Aetna; Stuart Levine, BlueShield of California; David Sperling, CareMore

Value-Base Care: Going All In

Primary care providers are embracing new models of payment that focus on value rather than volume. As we focus on better care for individuals and populations, we need to leverage data to better understand both where we are and where we need to go next. The speaker will review their organization’s success in aggregating data and using analytics to improve the health of communities.

**Presenters:** Aneesh Chopra, Hunch Analytics; Rushika Fernandopulle, MD, MPP, Iora Health
Government Insights on Privacy Rules in the Health IT Teach Era

Join us for this discussion between HHS’ Office of Civil Rights and Office of the National Coordinator on how a regulatory agency can best do its job, ensure appropriate guidance to the rapidly developing business of mHealth and consumer-generated health tools, and promote compliance with the Privacy and Security Rules. Topics covered will include OCR’s role as the regulator responsible for HIPAA policy, including guidance and enforcement and how the health data developer community can provide information to OCR and ONC to inform relevant and appropriate guidance and support an emerging economic sector.

Moderator: Gus Mutscher, PricewaterhouseCoopers

Panelists: Jocelyn Samuels, JD, HHS Office for Civil Rights; Lucia Savage, JD, U.S. Department of Health & Human Services

Direct-To-Consumer Data Structures and Scientists For Your Government Sponsored DTC Business

The Harvard Business Review just named data scientist as the “Sexiest job for the 21st century.” Data science is even making its way into historically un-Silicon Valley healthcare, but it looks different – more Direct-to-Consumer (DTC). As the Data Liberation movement matures, one of the challenges it faces is recognizing, embracing and even mastering DTC data structures and data science and cultivating next-gen open health data scientists. In this session, we look at what happens when you take something like Facebook’s social graph structures and then apply it to healthcare data. In this case, Bam!, you’ve got DocGraph. This session explores some classic hypothesis-led, hypothesis-generating visualization and how undergrads take to these DTC structures in healthcare. Then we cap it off by taking high-end data scientists and turning them loose in an effort to apply classic healthcare data to the DTC of healthcare reform.

Moderator: Fred Trotter, DocGraph/CareSet

Panelists: Ben Coleman, Moravian College; Andres Colubri, PhD, Broad Institute of MIT and Harvard; Sreenivas Rangan Sukumar, PhD, Oak Ridge National Laboratory

Healthcare Entrepreneurs Boot Camp: Matching Public Health Data With Real World Business Models

If you’ve ever considered starting something using health data, whether a product, service, or offering in an existing business, or a start-up company to take over the world this is something you won’t want to miss. In this highly-interactive, games-based brew-ha, we pack the room full of flat-out gurus to get an understanding of what it takes to be a healthcare entrepreneur. Your guides will come from finance and investment; clinical research and medical management; sales and marketing; technology and information services; operations and strategy; analytics and data science; government and policy; business, product, and line owners from payers and providers; and some successful entrepreneurs who have been there and done it for good measure. We’ll take your idea from the back of a napkin and give you the know-how to make it a reality!

Orchestrators: Sujata Bhatia, MD, PhD, Harvard University; Niall Brennan, Chief Data Officer, Centers for Medicare & Medicaid Services; Mohit Kaushal, MD, Partner Aberdare Ventures and NCHVS Data Group; Joshua Rosenthal, PhD, RowdMap Inc., NACHVS Data Group; Marshall Votta, Leverage Health Solutions
Panelists: Michael Abate, JD, Dinsmore & Shohl LLP; Stephen Aguilar, Zaffre Investments; Chris Boone, PhD, Health Data Consortium; Craig Brammer, The Health Collaborative; John Burich, Passport Health Plan; Jim Chase, MHA, Minnesota Community Measurement; Arnaub Chatterjee, Merck; Henriette Coetzer, MD, RowdMap; Jim Craver, MAA, Center for Disease Control; Michelle De Mooy, Center for Democracy and Technology; Gregory Downing, PhD, U.S. Department of Health & Human Services; Chris Dugan, Evolent Health; Margo Edmunds, PhD, AcademyHealth; Douglas Frisda, MD, PhD, American Medical Informatics Association; Tina Grande, MHS, Healthcare Leadership Council; Mina Hsiang, US Digital Services; Jessica Kahn, Center for Medicare & Medicaid Services; Brian Lee, MPH, Center for Disease Control; David Portnoy, MB, U.S. Department of Health & Human Services; Aaron Seib, National Association for Trusted Exchange; Maksim Tsvetovat, OpenHealth; David Wennberg, MD, The Dartmouth Institute; Niam Yarahgi, PhD, Brookings Institute; Jean-Ezra Yeung, Ayasdi

Organizers: Sujata Bhatia, MD, PhD, Harvard University; Niall Brennan, Chief Data Officer, Centers for Medicare & Medicaid Services; Mohit Kaushal, MD, Partner Aberdare Ventures and NCHVS Data Group; Joshua Rosenthal, PhD, RowdMap Inc. and NACHVS Data Group Marshall Votta, Leverage Health Solutions

Turning Health Data Into Investigative Journalism

Data analysis is a key element of investigative journalism. In reforming the health care system, journalists play key roles in identifying inequities and fraud, as well as documenting what works and what doesn’t work. Data has made this job easier. The release of large healthcare data sets within the past two years has allowed reporters to compare variation at the doctor level and create tools that translate this information for consumers. This session will be a roundtable discussion on techniques, insights, and the importance of open data in journalism.

Moderator: Charles Ornstein, ProPublica

Clinical Transformation To Address Care Gaps and Improve Quality: Reflections On a Unique Platform

The MedConcert Fracture Liaison Service (FLS) platform provides a unique opportunity to address the nearly 80% post-fracture care gap means for practices and hospitals to automate, benchmark, and improve their performance around selected osteoporosis/post-fracture quality measures and patient care, and create a registry that can collect and report on each site.

Moderator: Mitesh Rao, MD, MHS, Northwestern Medicine
Panelist: Simone Karp, RPh, CECity; David Lee, MPA, National Bone Health Alliance; Debbie Zeldow, MBA, Ostonics

Iconquerms Patient-Powered Research: Kicking Butt and Taking No Names in the Fight Against Disease

Engaged consumers are no longer satisfied with traditional models of research that place patients in the passive role of guinea pig. Patients are eager to share information and contribute their health data to solve medical mysteries. Driven by increasing consumer demand for knowledge, an innovative new model for the collection, integration, aggregation, and analysis of data has emerged in which the patient is both participant and research collaborator. With an award from the Patient-Centered Outcomes Research Institute (PCORI), the Accelerated Cure Project for Multiple Sclerosis, in
collaboration with its members and partners, has launched iConquerMS™, a patient-driven, patient-governed national initiative to facilitate the use of health data from 20,000 enrolled participants to speed and enhance research that matters most to MS patients. As it evolves, iConquerMS™ can be the model by which other communities of patients conquer disease utilizing Big Data.

**Moderator:** Lisa Emrich, MM, BME, iConquerMS™ Initiative of Accelerated Cure Project  
**Panelists:** Kenneth Buetow, PhD, Arizona State University; Marcia Kean, Feinstein Kean Healthcare; Robert McBurney, PhD, Accelerated Cure Project for MS

### Providers Operating Health Plans

Health systems across the country are moving beyond collaborating with health plans... and offering their own insurance products. Join this session to hear how providers are applying clinical data sources and best practices to manage customers both as patients and plan members.

**Moderator:** Ryan Stewart, TripleTree  
**Panelists:** Alan Murray, North Shore LIJ-CareConnect Insurance Company; Pamela Peele, PhD, UPMC Health Plan

### Navigating the FDA Review Process For Health Innovators

Understanding how to approach the FDA 510k process is a daunting prospect for many early stage companies developing products for health and health care. Confusion still exists around which class a device or application falls under, and how to best structure the application before the 90-day review period. In this panel, speakers will discuss the 510K process, the new MMS guidance, and valuable lessons learned from companies that have successfully gone through the process.

**Moderator:** Robert Jarrin, JD, Qualcomm Incorporated  
**Panelists:** Anand Iyer, PhD, MBA, WellDoc, Inc.; Corinna Lathan, PhD, PE, AnthroTronix; Jennifer Leib, ScM, CGC, CRD Associates; Bakul Patel, Food & Drug Administration, Centers for Devices & Radiological Health

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**June 3**

### General Session 4

**Main Stage Emcee:** Bryan Sivak, Former Chief Technology Officer, U.S. Department of Health and Human Services  
**Fireside Chat:** Dhanurjay “D’J” Patil, PhD, Chief Data Scientist and Deputy Chief Technology Officer for Data Policy, White House Office of Science and Technology Policy  
**Moderator:** Alyssa Bereznak, National Correspondent, Yahoo News  
**Keynote Speaker:** Glyn Elwyn, BA, MD, MSc, PhD, Physician-Researcher, The Dartmouth Institute for Health & Clinical Practice
App Demo: Kuveda, Inc.

Panel: How Leading Healthcare Companies Are Powering Their Businesses with Big Data

Moderator: David Knott, Senior Partner, McKinsey & Company

Panelists: Tim Ferris, MD, Senior Vice President, Massachusetts General Hospital and Partners HealthCare; Eric Perakslis, Executive Director, Center for Biomedical Informatics, Harvard; David Watson, CEO, Cal INDEX

Glyn Elwyn

Physician-Researcher, The Dartmouth Institute for Health & Clinical Practice

Glyn Elwyn, BA, MD, MSc, PhD, is a physician-researcher at The Dartmouth Institute for Health Policy and Clinical Practice. He qualified in medicine in the United Kingdom completing his doctorate with Professor Richard Grol in the Netherlands. Twitter: @glynelwyn. He leads an interdisciplinary team examining the implementation of shared decision making into routine settings. His current focus is on the development and impact of Option Grids, tools to stimulate better conversations based on best evidence. He co-chairs the International Patient Decision Aids Standards Collaboration. He has developed the Observer OPTION and CollaboRATE tools to measure shared decision making. He is the lead editor of Shared Decision-Making in Health Care: Achieving Evidence-Based Patient Choice (Oxford University Press, 2016). He holds the following positions: Honorary Research Chair at Cardiff University, UK, and Visiting Chair at the Scientific Institute for Quality of Healthcare, Radboud University Nijmegen Medical Centre, Netherlands.

Dr. DJ Patil

Chief Data Scientist and Deputy Chief Technology Officer for Data Policy, White House Office of Science and Technology Policy

DJ Patil joined the White House Office of Science and Technology Policy (OSTP) in February 2015, where he advises on policies and practices to maintain U.S. leadership in technology and innovation, fosters partnerships to maximize the Nation’s return on its investment in data, and helps to attract and retain the best minds in data science to serve the public.

Since joining OSTP, Dr. Patil has collaborated with colleagues across the government as part of the Administration’s commitment to open data and data science. He is leading data science efforts related to the Precision Medicine Initiative, which focuses on utilizing advances in data and health care to provide clinicians with new tools, knowledge and therapies to select which treatments will work best for which patients, while protecting patient privacy.

Dr. Patil joins the White House following an incredible career as a data scientist — a term he helped coin — in the public and private sectors, and in academia. Most recently, he served as the Vice President of Product at RelateIQ, which was acquired by Salesforce. Dr. Patil also previously held positions at LinkedIn, Greylock Partners, and eBay Inc.

Moderated by: Alyssa Bereznak, National Correspondent, Yahoo News

Innovative Value-Based Uses of Open Data

This session will feature unique uses of government and private sector open data sources that are contributing to better consumer decision making and value based care. These exciting initiatives include unique, community-sourced guides to health care costs, revealing patterns of purchasing by consumers and creating deeper community engagement around cost transparency and the only free data set and API for information about individual medications, pill images,
and drug identification.

**Moderator:** Bryan Sivak, Former Chief Technology Officer, U.S. Department of Health & Human Services

**Panelists:** Charles Gellman, MSHI, Qwalcare; Dale Hale, National Institutes of Health; Jeanne Pinder, ClearHealthCosts

**The Precision Medicine Initiative: Changing the Future of Health and Medicine**

The Precision Medicine Initiative, announced by the President in January, is a bold new research project to revolutionize how we improve health and treat disease. The initiative will pioneer a new model of participant-centered research that promises to accelerate biomedical discoveries and provide clinicians with new tools, knowledge, and therapies to select which treatments will work best for which patients. Translating initial successes to a larger scale will require a coordinated and sustained national effort. To get there, we need to incorporate many different types of data including genetic information, personal device and sensor data, and medical records collected by health care providers and by patients themselves. Success will require that health information can be easily shared between providers, researchers, and most importantly, patients and research participants.

**Speakers:** Mina Hsiang, U.S. Digital Service, The White House; Kathy Hudson, PhD, Deputy Director for Science, Outreach, and Policy, National Institutes of Health; Claudia Williams, Senior Advisor for Health Innovation and Technology, The White House

**The Role of Retailers in the U.S. Healthcare System**

Retailers are developing and expanding healthcare products and services, some as a new core focus, and others to complement their traditional businesses. Join this session to learn what industry leaders understand about their customers and how that informs their strategies to help people live healthier lives.

**Moderator:** Maureen O’Connor, JD, Mosaic Health Solutions

**Panelists:** Brian Bobby, PharmD, Rite Aid; Brad Fluegel, Walgreen Co.; Alex Hurd, WalMart

**Engaging Patients in Generating and Using Big Data**

Clinical research requires patients to share their data, which makes it critical to engage them about privacy, security, and evidence-based care. Moreover, patients can be important for identifying what data is important about their life and their health, as well as what research questions they want answered. This session will highlight examples where patients have been engaged in generating big data resources and how big data has been applied to generate new healthcare knowledge.

**Moderator:** Kym Martin, MBA, CNC, CFT, Cancer Catharsis, LLC

**Panelists:** David Muntz, CHCIO, FCHIME, LCHIME, FHIMSS, GetWellNetwork; Sally Okun, RN, MMHS, PatientsLikeMe; Doris Peter, PhD, Consumer Reports; Lygeia Ricciardi, EdM, Clear Voice Consulting, LLC
But What If I Want To Share? Contributing Your Own Data To Foster Public Good

If you want your own health data, you can hit the Blue Button and it’s yours to do with as you see fit. The Blue Button project is a stunning success story with about 8 gajillion people (give or take) downloading their personal medical histories. But what if you want to share your data? As the Data Liberation movement matures, it faces a number of challenges around developing open data. How can folks participate in open data if they don’t have six Masters degrees in data science, but simply want to share and help others? How can we protect and secure individuals’ privacy by creating data that meets research needs — by allowing people to opt in or otherwise? Finally, how do we best collect and analyze new sources of data from personal life streams and connect this unstructured data to the health care system?

Moderator: Niall Brennan, Centers for Medicare & Medicaid Services (CMS)

Panelists: Geraldine Gueron, PhD, The Wikilife Foundation; Aaron Seib, National Association for Trusted Exchange; Maksim Tsvetovat, OpenHealth

Challenges Facing Public Access to VA Health Data

The VA provides health care to 8.7 million veterans on an annual basis and collects data through its electronic health record system. Most of the data collected during health care is available throughout the VA for operations and for research. Open access to health data poses challenges from ensuring patient privacy to implementing solutions that provide data without the need for manual preparation. The VA, a federal partner with the Federal Health Architecture, recognizes how these challenges impact the effective collection, use, and sharing of key data and is working to improve public access to specific data sets. In this presentation, the VA will discuss the current methods being used to share data with requestors, the challenges of these methods, and how the agency is working to improve open access to VA data.

Presenter: Rachel Harrison-Gordon, U.S. Department of Veterans Affairs

Myths Vs. Reality: The Current State of Consumer Access and Use of Their Digital Health Data

Join the Office of Consumer eHealth from the Office of the National Coordinator for Health IT (ONC), for a first look at results from its 2014 Consumer Survey. This annual survey reveals key insights around consumer attitudes, experiences, and expectations accessing their health data online and using health IT. Find out the myths vs. reality about how consumers are using their health data, trends in consumer engagement with their health data, and health IT and consumer expectations for engaging with their providers. We’ll also discuss the federal strategy for increasing patient engagement with their health data and how you can get involved in the Blue Button Initiative. Attendees will leave with resources to guide consumers in finding and using their health data and what else is needed.

Moderator: Erin Siminerio, MPH, Department of Health & Human Services

Panelists: Erin MacKay, MPH, National Partnership for Women & Families; Vaishali Patel, PhD, Office for the National Coordinator for Health IT
Closing Luncheon

Health Data Consortium Overview

Health Data Liberators Award

**Keynote Speaker:** Steven Brill, Founder, Court TV and *The American Lawyer*, Author

**Moderator:** Zeke Miller, Political Reporter, *TIME Magazine*

**Panel:** How State and Local Governments are Using Big Data to Transform Their Healthcare Systems

**Moderator:** Karen DeSalvo, MD, MPH, MSc, National Coordinator for Health Information Technology, U.S. Department of Health and Human Services

**Panelists:** Greg Moody, Director, Ohio Office of Healthcare Transformation; Michael Nutter, Mayor, City of Philadelphia

**Announcements**

**Keynote Speaker:** Sylvia Mathews Burwell, Secretary, U.S. Department of Health & Human Services

**Steven Brill**

**Founder, Court TV and The American Lawyer**

**Author,** *America’s Bitter Pill: Money, Politics, Backroom Deals, and the Fight to Fix Our Broken Healthcare System*

Steven Brill is a longtime journalist and is the founder of Court TV and in 1979 launched the monthly magazine *The American Lawyer*, which is still in publication. He has written for *The New Yorker, The New York Times Magazine, Esquire* and *TIME*. A graduate of Yale College and Yale Law School, Brill’s special report in *TIME* on medical costs won the 2014 National Magazine Award. His new book, *America’s Bitter Pill: Money, Politics, Backroom Deals, and the Fight to Fix Our Broken Healthcare System*, instantly became a best-seller when it was published in January 2015.

**Moderated by:** Zeke Miller, Political Reporter, *TIME Magazine*

**Sylvia Mathews Burwell**

**Secretary of the U.S. Department of Health & Human Services**

Sylvia Mathews Burwell was sworn in as the 22nd Secretary of Health & Human Services (HHS) on June 9, 2014. A results-driven manager, Secretary Burwell has led large and complex organizations across the public and private sectors. As the Secretary of HHS, Burwell oversees more than 77,000 employees, in work that touches the lives of Americans at every age, from every background, in every part of our country. She is committed to the mission of ensuring that every American has access to the building blocks of healthy and productive lives. Prior to serving in the Administration, Burwell served as President of the Walmart Foundation in Bentonville, Arkansas, where she led efforts to fight hunger in America, empower women around the world, and leverage Walmart’s presence in local communities to reach millions of people. During her tenure, the Foundation surpassed $1 billion in total giving.