Connecting Dots: How Open Data, Payment Reform, and Consumer APIs will Accelerate Precision Medicine

@aneeshchopra
www.innovativestate.com
Agenda for Discussion

1. Connecting Dots ~ Payment Reform, Open Data
2. The Emerging “Connected Apps” Era
3. Implications for Precision Medicine
David Van Sickle collaborates with Mayor Fisher (Louisville) to micro-target air quality improvement opportunities; patient inhaler GPS data informs action to lower particulate matter 10%; results in 27% reduction in asthma risk area
Democratize Government Data via Open APIs
From Jefferson to Health Datapalooza

On July 4, 1776, the weather in Philly was clear and mild with a high of 76 degrees

CSV

rows.csv?accessType=DOWNLOAD

Source: http://celebrating200years.noaa.gov/foundations/climate_data/image1.html; healthdata.gov; iTriage
Connecting the Dots on Care Delivery Reform

“Million Hearts” campaign invokes open data, connected apps, pmt reform

Medicare Reporting Coverage

CMS EHR Incentive Program 2011-2013


ASCVD Risk Estimator

10-Year ASCVD Risk
59.9% calculated risk
7.8% risk with optimal risk factors

Life Time ASCVD Risk

HDL - Cholesterol
46 (mg/dL)

Systolic Blood Pressure
150

Recommendation Based On Calcul...

Medicare Program Reveals The Challenge Ahead
ACOs incentivized, but not wired up to close feedback loops

~40% of hypertensive patients (~4500 in one Medicare ACO) received their last E&M visit of the year at an out-of-network provider

Source: NavHealth

Widespread variation across physician practices in the percent of hypertensive patients with the last visit of 2015 out of network
The Emerging “Connected Apps” Era
PG&E’s CIO leads industry adoption, scaling through national movement

“Chevrolet Volt...led to his developing the app...in...three months...his electric bill reduced an average 20 percent;”
one of 50 registered apps with open access to customer energy data without fees or IP constraint
After dramatic reduction in aircraft manufacturing following WWI, then-Secretary Hoover encourages industry collaboration on engine, wing standards, commercialized on popular DC-3, Boeing 247
“All-in” Embrace of Open APIs for Data Exchange

Regulations, industry response aligned on technical capability

Section 1561 of the Affordable Care Act
Technical Recommendations (2010)

“...a system in which the consumer has access to his or her own information in a format that can be used and re-used, ... may be the highest-value approach to transferring account... information from one Exchange to another.”

“The purpose... is to rapidly develop a first-generation FHIR-based API and Core Data Services specification... based on Internet standards and architectural patterns and styles.”

Opening Up While Locking Down

“API-First” approach adds security protection by monitoring use

API vs. “Point to Point”

1. API-first approach to facilitate controlled access to data
2. Single point of “truth” for connected mobile, web apps
3. Real-time analytics to monitor use vs. shipping “blind” flat files

“Built-in” Security–APIs enforce a consistent protection mechanism across all channels with built-in authentication, authorization, and threat protection.

Entering the “Burger King” Era – Have it Your Way!
Hackensack Meridian tests many digital paths for patient data access
Implications for Precision Medicine
Enable consumers to assemble their health data regardless of care setting

“MeTree” Assessment Tool: Duke Center for Applied Genomics and Precision Medicine expands the traditional “data model” by running deeper on family history, among other topics, to better understand risk
“All of Us” Initiative: Health systems contracted by NIH to enroll 10,000 participants – inclusive of EHR, claims, assessment data; emphasis on the entire HIPAA-regulated “designated record set”
Encouraging New (Digital) Services
ClinVar collaboration model enables lower time, cost to insight

ClinVar submissions

This page summarizes submissions and properties of submissions (assertion criteria, genes, unique variation records), represented in ClinVar.

Follow this link to review all submitters and the summary of their contributions. We acknowledge their support.

Submission overview

<table>
<thead>
<tr>
<th>Category of analysis</th>
<th>Current total (Feb 13, 2017)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Records submitted</td>
<td>405668</td>
</tr>
<tr>
<td>Records with assertion criteria</td>
<td>315613</td>
</tr>
<tr>
<td>Records with an interpretation</td>
<td>368513</td>
</tr>
<tr>
<td>Total genes represented</td>
<td>27545</td>
</tr>
<tr>
<td>Unique variation records</td>
<td>268824</td>
</tr>
<tr>
<td>Unique variation records with interpretations</td>
<td>256824</td>
</tr>
<tr>
<td>Unique variation records with assertion criteria</td>
<td>208399</td>
</tr>
<tr>
<td>Unique variation records with practice guidelines (4 stars)</td>
<td>23</td>
</tr>
<tr>
<td>Unique variation records from expert panels (3 stars)</td>
<td>7608</td>
</tr>
<tr>
<td>Unique variation records with assertion criteria, multiple submitters, and no conflicts (2 stars)</td>
<td>24191</td>
</tr>
<tr>
<td>Unique variation records with assertion criteria (1 star)</td>
<td>167658</td>
</tr>
<tr>
<td>Unique variation records with assertion criteria and a conflict (1 star)</td>
<td>8829</td>
</tr>
<tr>
<td>Unique variation records with conflicting interpretations</td>
<td>8972</td>
</tr>
<tr>
<td>Genes with variants specific to one gene</td>
<td>5134</td>
</tr>
<tr>
<td>Genes with variants specific to one protein-coding gene</td>
<td>5042</td>
</tr>
<tr>
<td>Genes included in a variant spanning more than one gene</td>
<td>27478</td>
</tr>
<tr>
<td>Variants affecting overlapping genes</td>
<td>9654</td>
</tr>
<tr>
<td>Total submitters</td>
<td>660</td>
</tr>
</tbody>
</table>

QC and Analysis

Sample 3245  Pan cancer panel

Mutations with approved drugs

<table>
<thead>
<tr>
<th>Gene</th>
<th>Mutation</th>
<th>Known association</th>
<th>Known drugs</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>BRAF</td>
<td>p.V600E</td>
<td>Melanoma, Thyroid cancer</td>
<td>Sorafenib (Block)</td>
<td>Report</td>
</tr>
</tbody>
</table>

Mutations without approved drugs

People are increasingly asking why the technologies that enable us to get directions, or transfer money are unable to help guide us through the maze of the American health care system.”