Bringing Big Data and Research to the Point of Care by Creating the "App Store" for Health

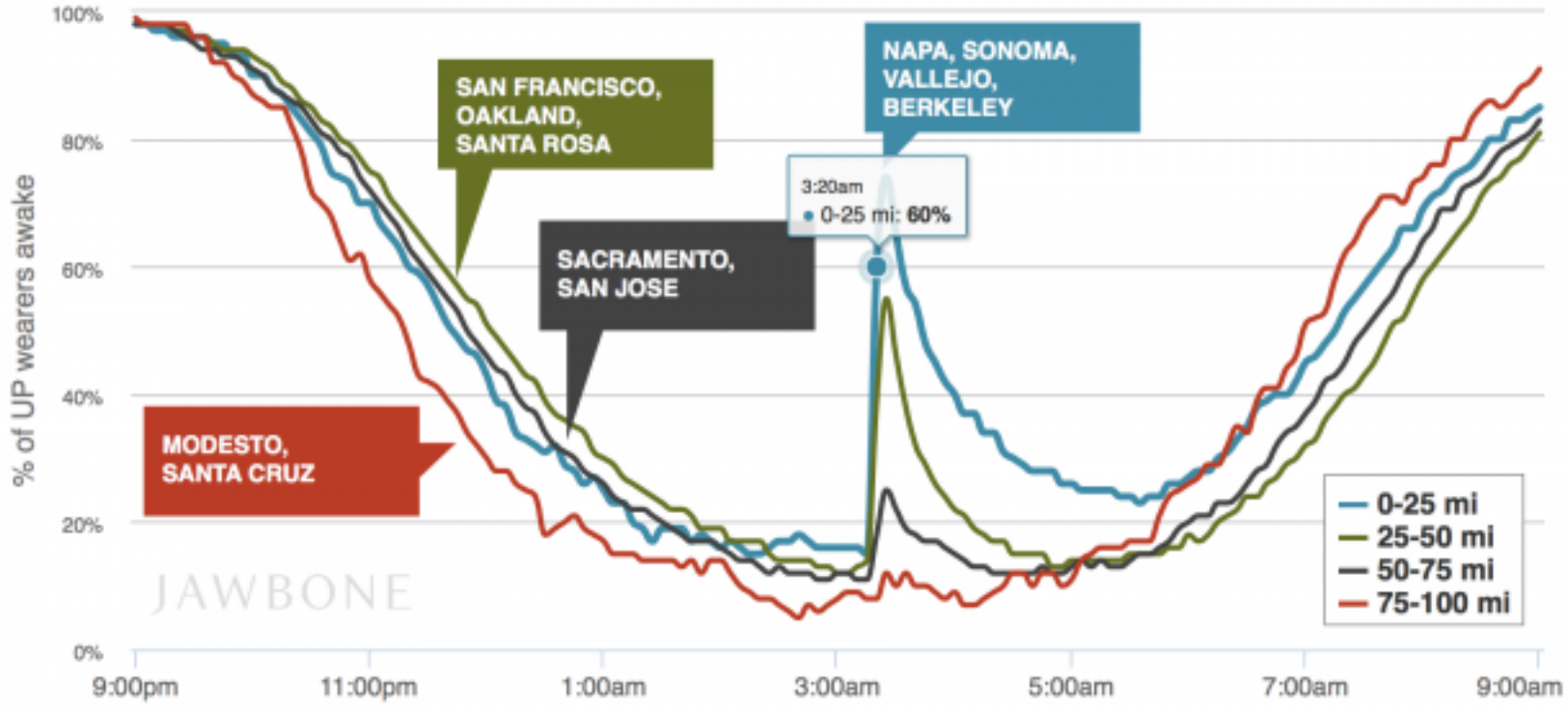
Kenneth D. Mandl, MD, MPH
Director, Computational Health Informatics Program
Boston Children's Hospital

Professor of Biomedical Informatics and of Pediatrics
Harvard Medical School

@mandl

www.chip.org

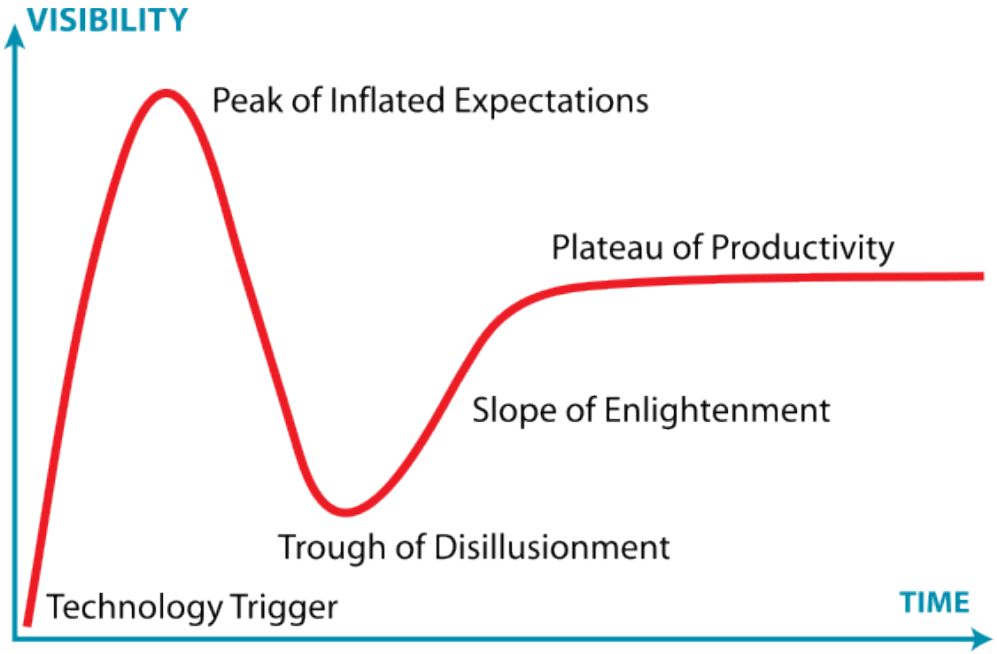
Virginia 2011



We wish all the people in the Bay Area who were affected by the earthquake a speedy recovery and a good night's sleep.

Hype Curve and HIT

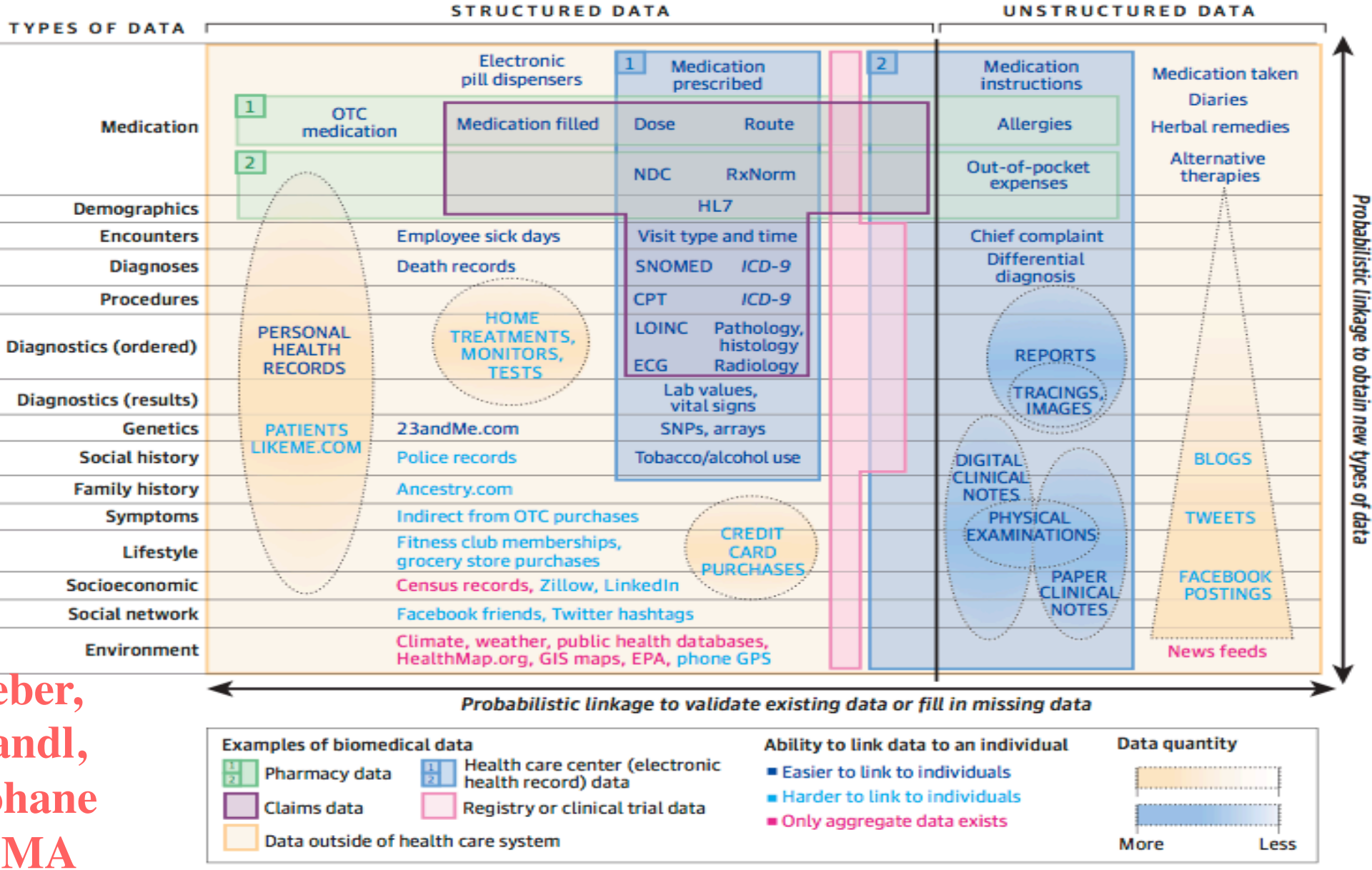
- $48B investment in HIT
- $1.4B at Partners
- North of $0.5T total



Point of Care is a Walled Garden

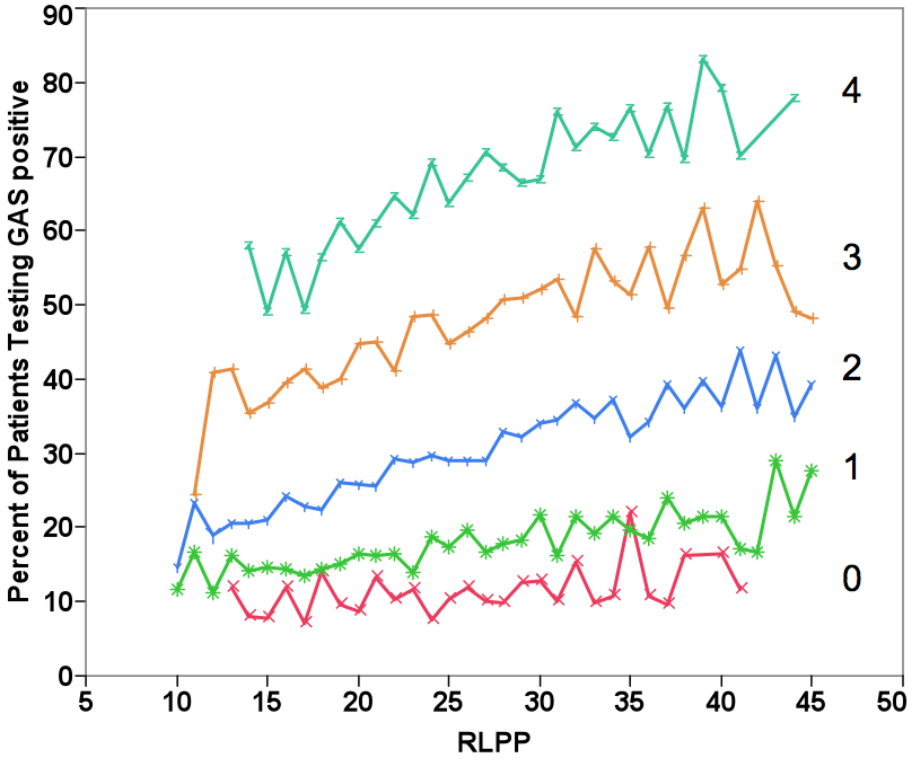
But 6 years later, we have an infrastructure that shows the clinician, one patient at a time, what he or she typed in in the past--a very narrow slice of big data

. The Tapestry of Potentially High-Value Information Sources That May be Linked to an Individual for Use in Health Care



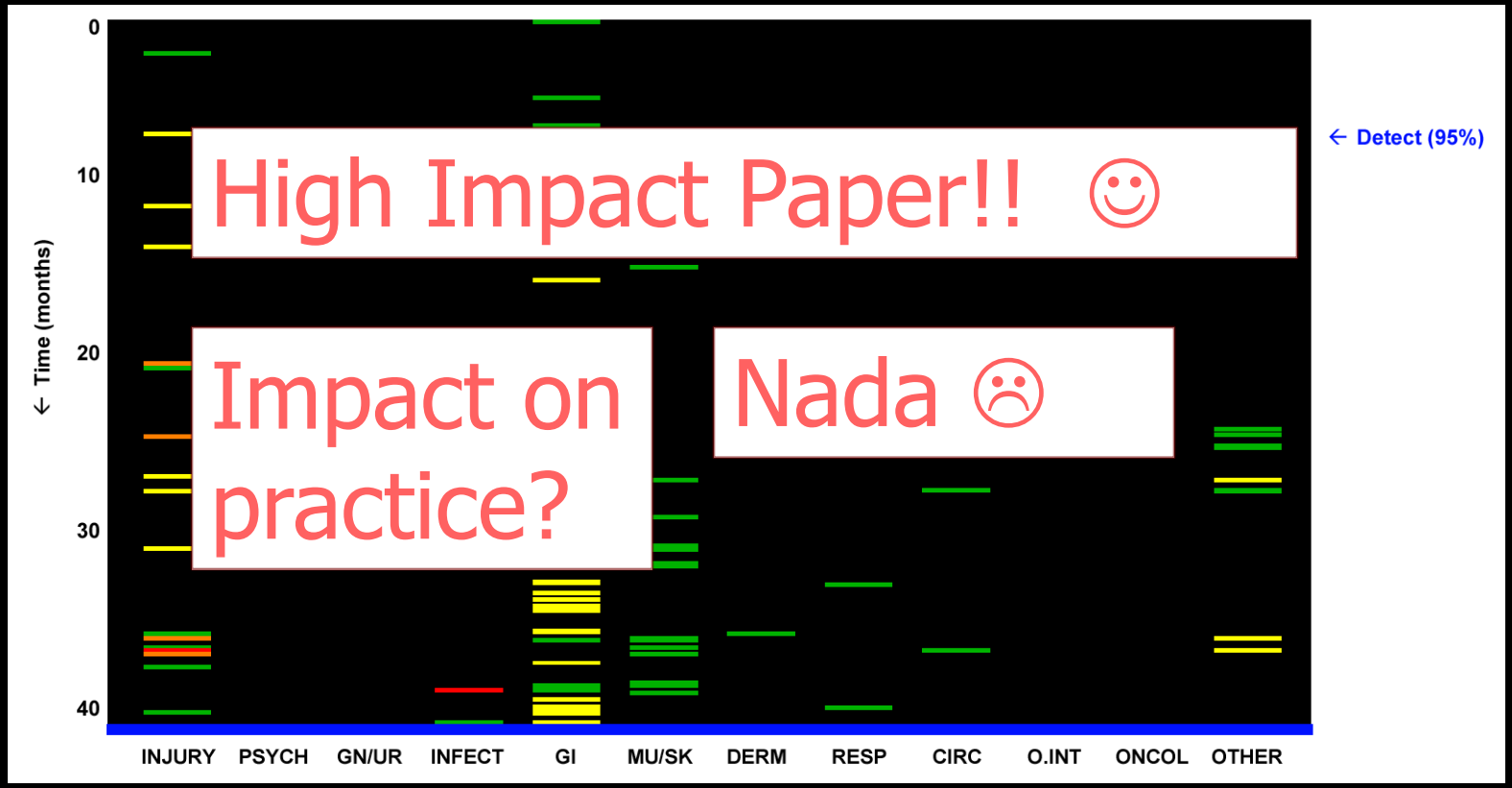
eber,
andl,
hane
MA

Adding Context is Powerful



Annals of Internal Med

Predictive Medicine: Domestic Violence



Reis, Kohane, Mandl BMJ

Turns out it Matters

JAMA The Journal of the American Medical Association

Viewpoint | October 20, 2014 FREE

PDF

Ebola in the United States: EHRs as a Public Health Tool at the Point of Care

Kenneth D. Mandl, MD, MPH

This Viewpoint discusses how health information technology and electronic health records (EHRs) could be transformed into platforms for public health responses to disease.

Topics: ebola virus; ebola virus disease; public health medicine; electronic medical records

JAMA. Published online October 20, 2014. doi:10.1001/jama.2014.15064

DATA ARE NOT INTEROPERABLE

Colombian
Fair Trade Select
ARTINSON
Pumpkin Pie
Tarte à la citrouille

The NEW ENGLAND JOURNAL of MEDICINE

No Small Change for the Health Information Economy

Kenneth D. Mandl, M.D., M.P.H., and Isaac S. Kohane, M.D., Ph.D.

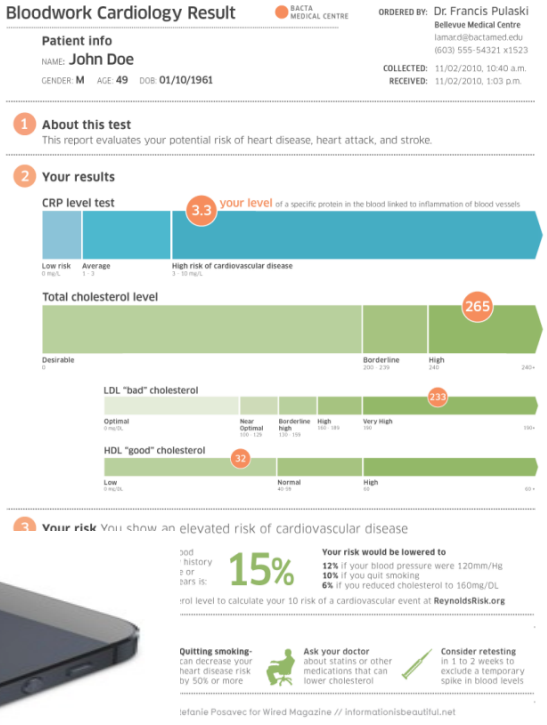
The economic stimulus package signed by President Barack Obama on February 17 included a $19 billion investment in health information technology. How can we best take advantage of this unprecedented opportunity to computerize health care and stimulate the health information economy while also stimulating the U.S. economy? A health care system adapting to the effects of an aging population, growing expenditures, and a diminishing primary care workforce needs the support of a flexible information infrastructure that facilitates innovation in wellness, health care, and public health.

Flexibility is critical, since the system will have to function under new policies and in the service of new health care delivery mechanisms, and it will need to incorporate emerging information technologies on an ongoing basis. As we seek to design a system that will constantly evolve and encourage innovation, we can glean lessons from large-scale information-technology successes in other fields. An essential first lesson is that ideally, system components should be not only interoperable but also substitutable.

The Apple iPhone, for example, uses a software platform with a published interface that allows software developers outside Apple to create applications; there are now nearly 10,000 applications that consumers can download and use with the common phone interface. The platform separates the system from the functional-

Designing the App Store for Health

SMART



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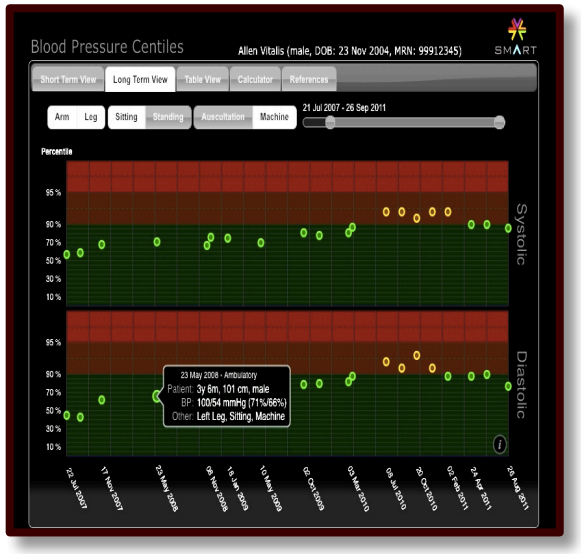


'API'

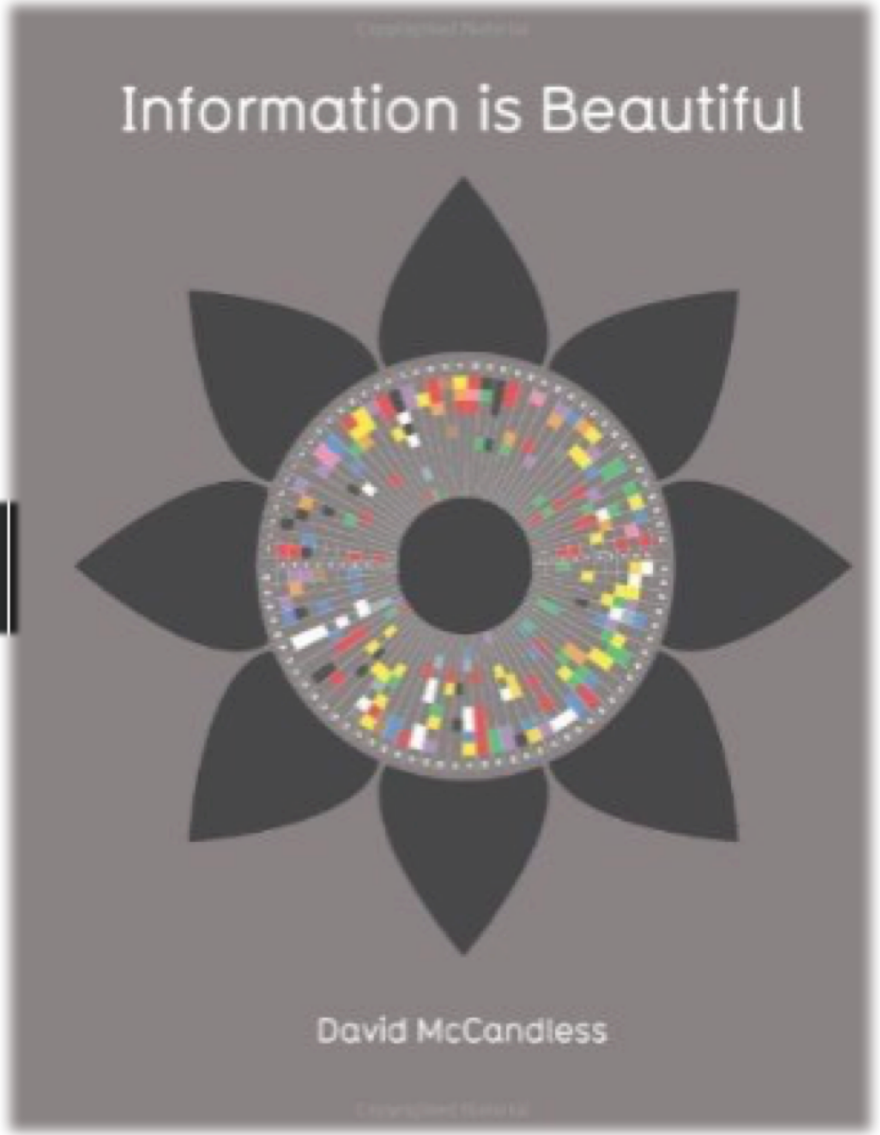
Can EMRs behave like iPhones or Androids in that innovators readily create and widely distribute SUBSTITUTABLE apps across thousands of installs?

Inspired by a

WIRED

18.12 Issue

Design Challenge



State-of-the-Art ???

SIGN HERE [X]

SEND TO:

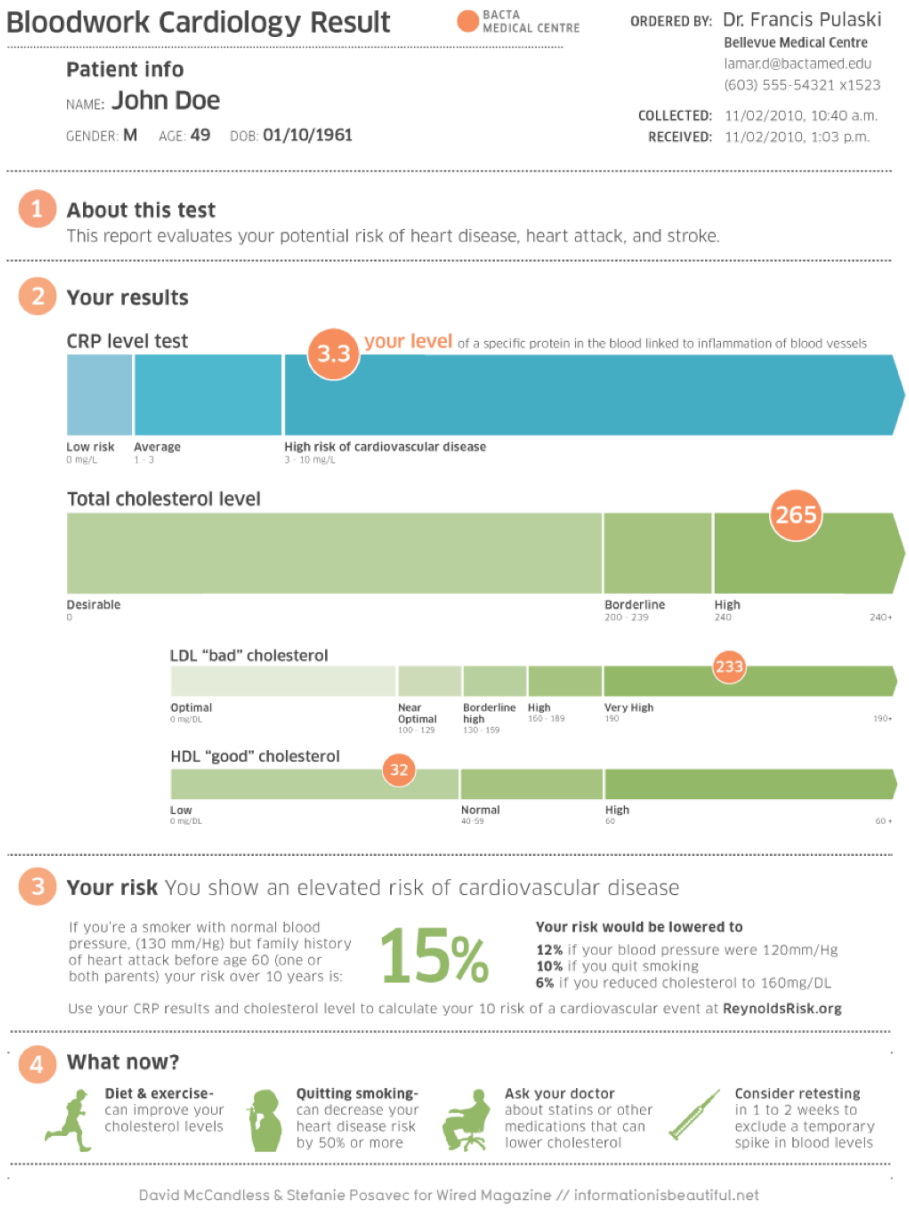
PATIENT NAME				PATIENT ID NO.		DATE	TIME
DOE, JOE				NOT GIVEN		COLLECTED 06/11/2010	NOT GIVEN
ACCESSION NO.	BIRTH DATE	GENDER	SAMPLE ID NO.	OTHER ID NO.		RECEIVED 06/11/2010	09:41
36904447	55	MALE	NOT GIVEN			REPORTED 06/11/2010	10:00
REMARKS: SAMPLE REPORT, NO SAMPLE SENT				REFERRING PHYSICIAN		STATUS FINAL	

TEST	RESULT (* = OUT OF RANGE)	UNITS	REFERENCE RANGE
Cardio CRP	0.4	mg/L	

For Ages > 17 Years:

CCRP mg/L	Risk According to AHA/CDC Guidelines
<1.0	Lower Relative Cardiovascular Risk.
1.0-3.0	Average Relative Cardiovascular Risk
3.1-10.0	Higher Relative Cardiovascular Risk. Consider retesting in 1 to 2 weeks to exclude a benign transient elevation in the baseline CRP value secondary to infection or inflammation.
>10.0	Persistent elevations upon retesting, may be associated with infection and inflammation.

An Inspired Design from Dave McCandless (cc license)



Bloodwork Cardiology Result

BACTA MEDICAL CENTRE

ORDERED BY: Dr. Francis Pulaski
Bellevue Medical Centre
lamar.d@bactamed.edu
(603) 555-54321 x1523

COLLECTED: 11/02/2010, 10:40 a.m.
RECEIVED: 11/02/2010, 1:03 p.m.

Patient info
NAME: John Doe
GENDER: M AGE: 49 DOB: 01/10/1961

1 About this test
This report evaluates your potential risk of heart disease, heart attack, and stroke.

2 Your results

CRP level test — 3.3 your level of a specific protein in the blood linked to inflammation of blood vessels
Low risk 0 mg/L · Average 1 - 3 · High risk of cardiovascular disease 3 - 10 mg/L

Total cholesterol level — 265
Desirable 0 · Borderline 200 - 239 · High 240 · 240+

LDL "bad" cholesterol — 233
Optimal 0 mg/DL · Near Optimal 100 - 129 · Borderline high 130 - 159 · High 160 - 189 · Very High 190 · 190+

HDL "good" cholesterol — 32
Low 0 mg/DL · Normal 40-59 · High 60 · 60+

3 Your risk You show an elevated risk of cardiovascular disease

If you're a smoker with normal blood pressure, (130 mm/Hg) but family history of heart attack before age 60 (one or both parents) your risk over 10 years is: **15%**

Your risk would be lowered to
12% if your blood pressure were 120mm/Hg
10% if you quit smoking
6% if you reduced cholesterol to 160mg/DL

Use your CRP results and cholesterol level to calculate your 10 risk of a cardiovascular event at **ReynoldsRisk.org**

4 What now?

Diet & exercise- can improve your cholesterol levels

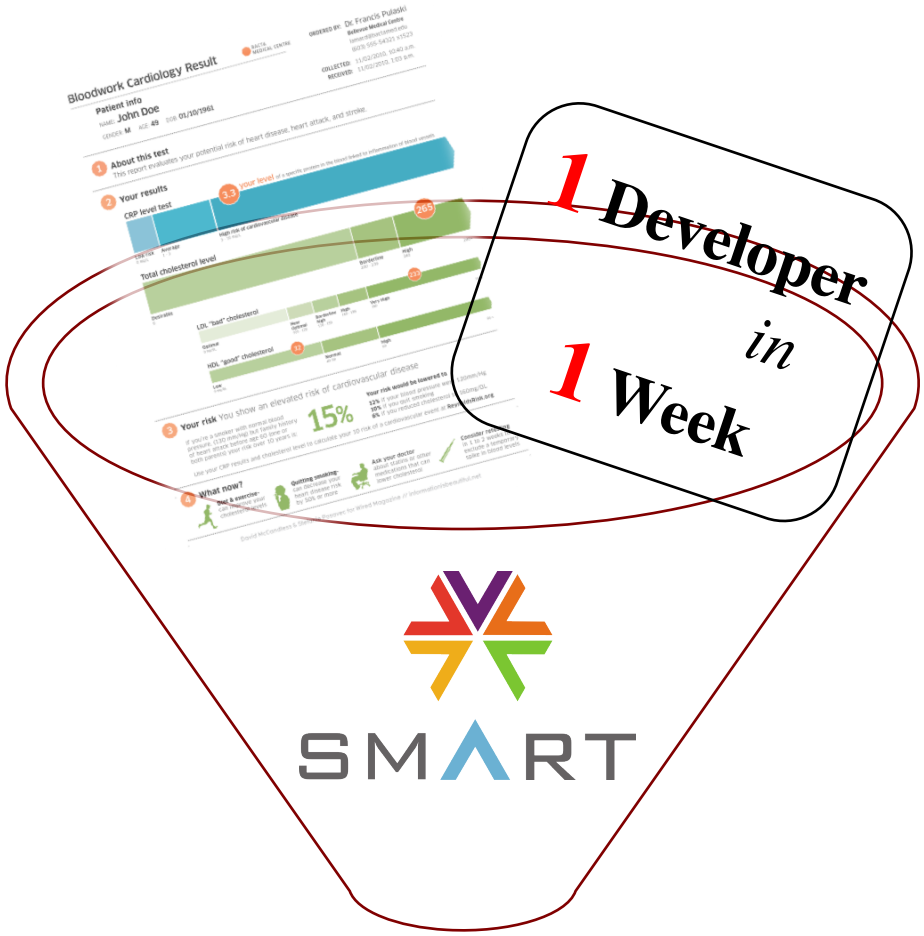
Quitting smoking- can decrease your heart disease risk by 50% or more

Ask your doctor about statins or other medications that can lower cholesterol

Consider retesting in 1 to 2 weeks to exclude a temporary spike in blood levels

David McCandless & Stefanie Posavec for Wired Magazine // informationisbeautiful.net

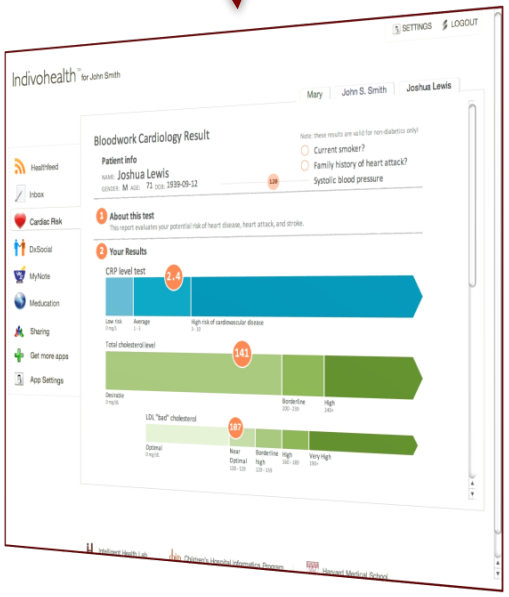
1 Design + 1 Developer + 1 Week

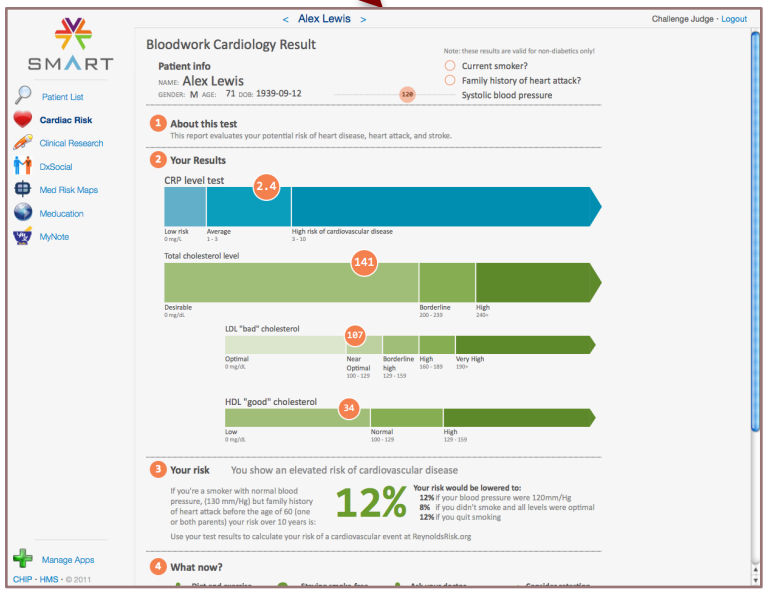


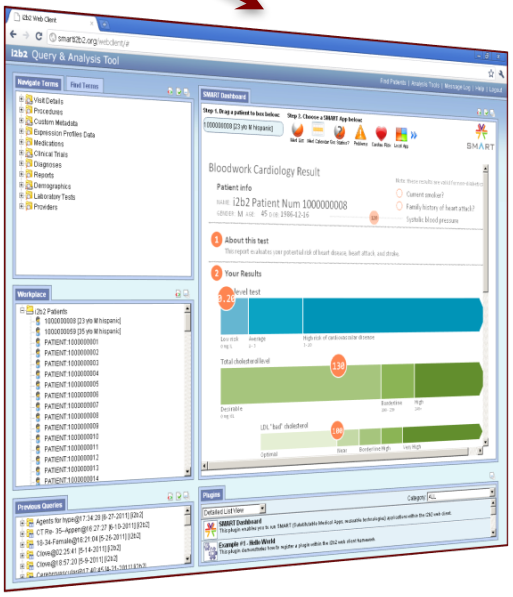
SMART *Cardiac Risk* App

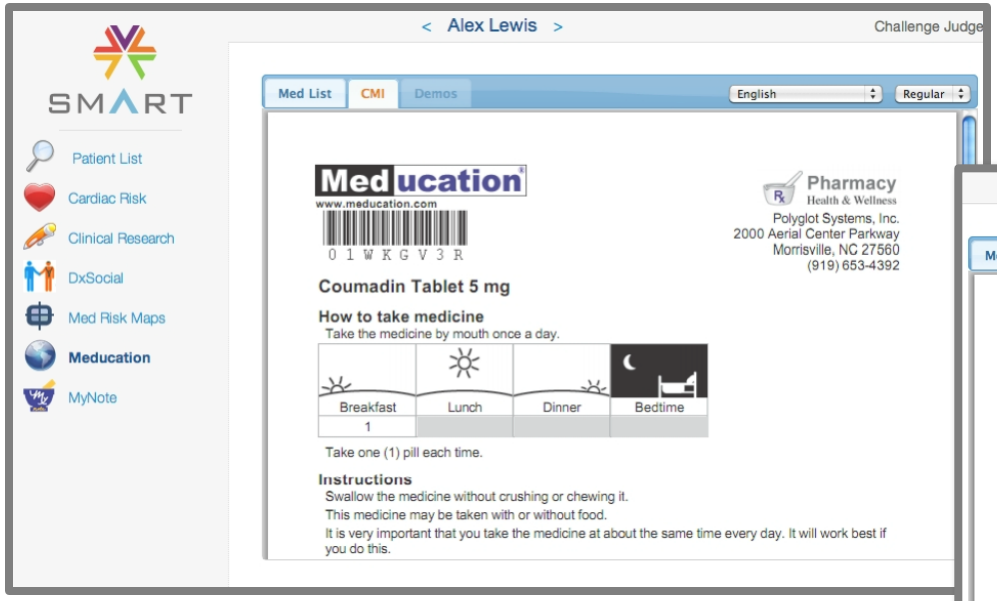
1 SMART App in 3 SMART Systems

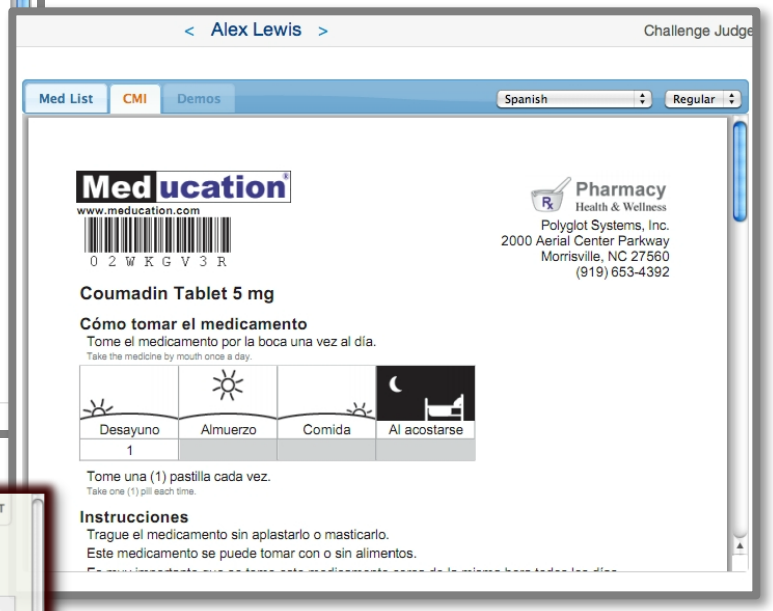
SMART Cardiac Risk App








SMART
< Alex Lewis >
Challenge Judge
Patient List
Cardiac Risk
Clinical Research
DxSocial
Med Risk Maps
Meducation
MyNote
Med List
CMI
Demos
English
Regular
Meducation
www.meducation.com
0 1 W K G V 3 R
Pharmacy
Health & Wellness
Polyglot Systems, Inc.
2000 Aerial Center Parkway
Morrisville, NC 27560
(919) 653-4392
Coumadin Tablet 5 mg
How to take medicine
Take the medicine by mouth once a day.
Breakfast
Lunch
Dinner
Bedtime
1
Take one (1) pill each time.
Instructions
Swallow the medicine without crushing or chewing it.
This medicine may be taken with or without food.
It is very important that you take the medicine at about the same time every day. It will work best if you do this.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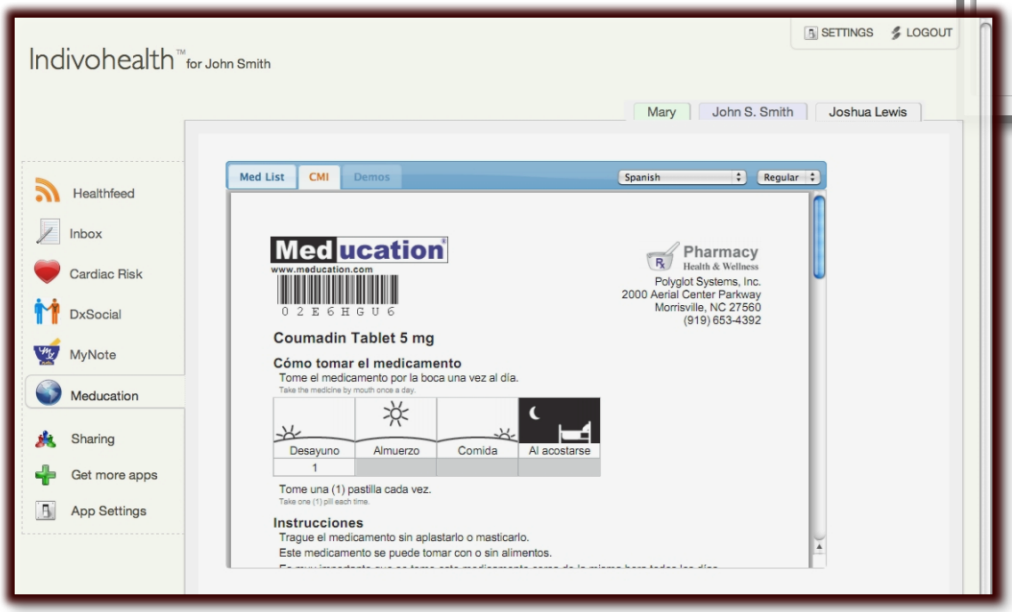
2000 Aerial Center Parkway
Morrisville, NC 27560
(919) 653-4392
Coumadin Tablet 5 mg
Cómo tomar el medicamento
Tome el medicamento por la boca una vez al día.
Take the medicine by mouth once a day.
Desayuno
Almuerzo
Comida
Al acostarse
1
Tome una (1) pastilla cada vez.
Take one (1) pill each time.
Instrucciones
Trague el medicamento sin aplastarlo o masticarlo.
Este medicamento se puede tomar con o sin alimentos.


Indivohealth™ for John Smith
SETTINGS
LOGOUT
Mary
John S. Smith
Joshua Lewis
Healthfeed
Inbox
Cardiac Risk
DxSocial
MyNote
Meducation
Sharing
Get more apps
App Settings
Med List
CMI
Demos
Spanish
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0 2 E 6 H G U 6
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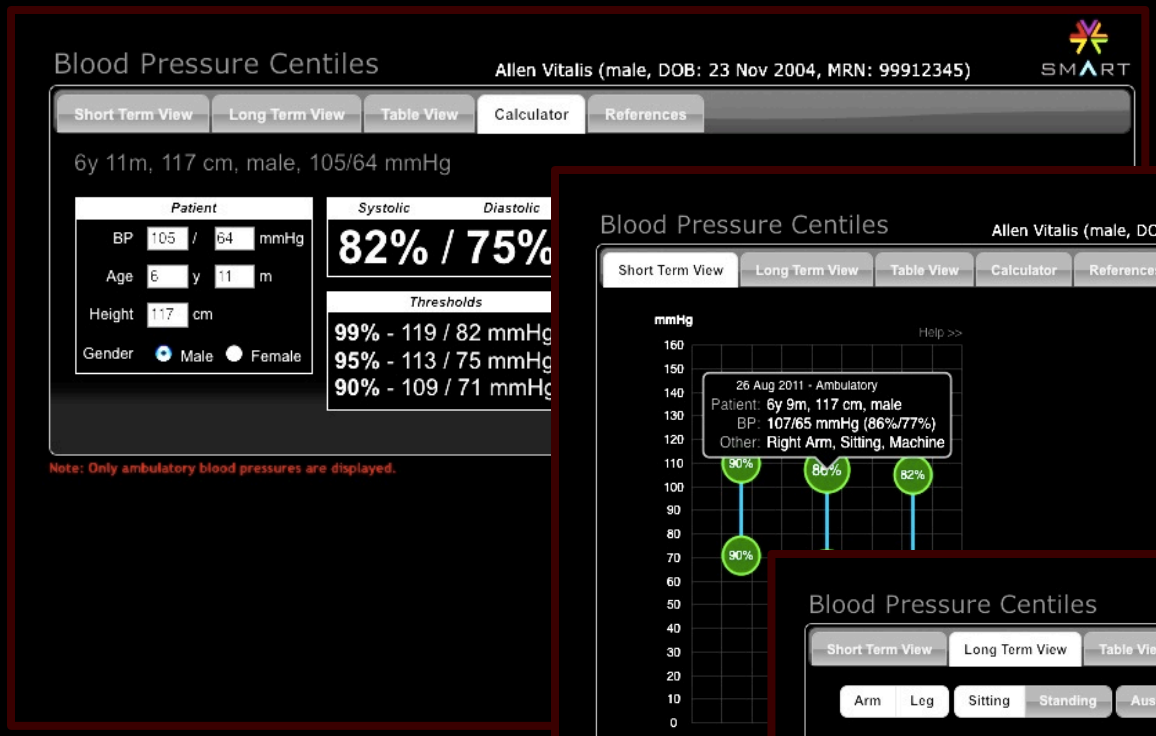
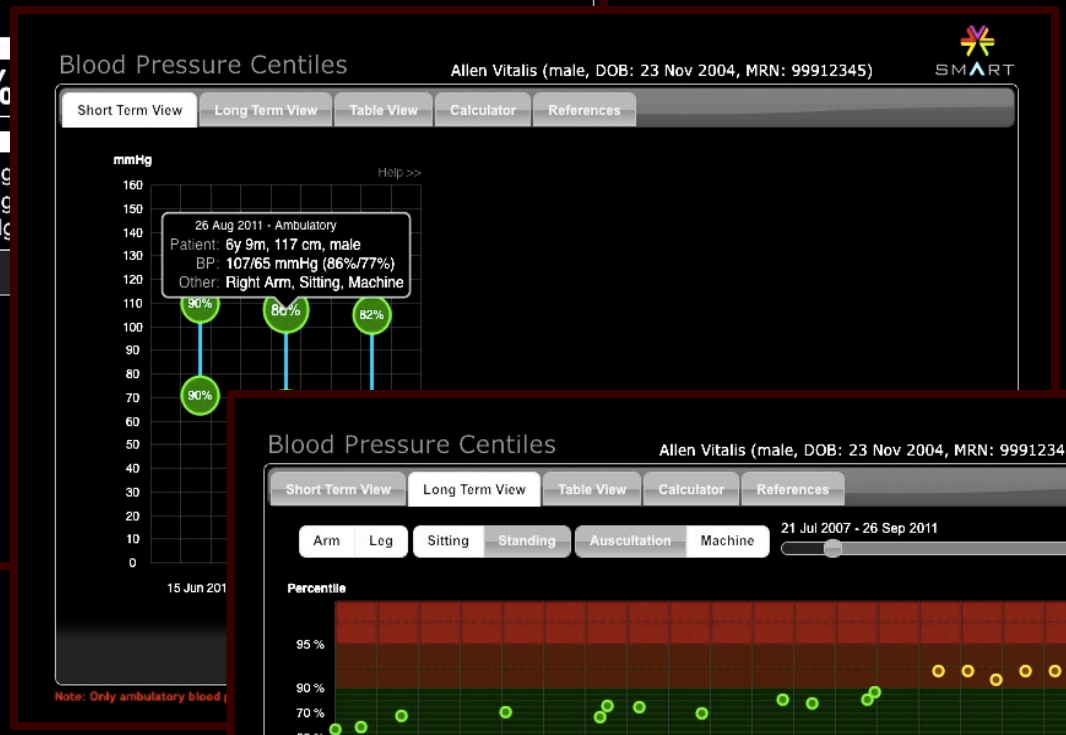
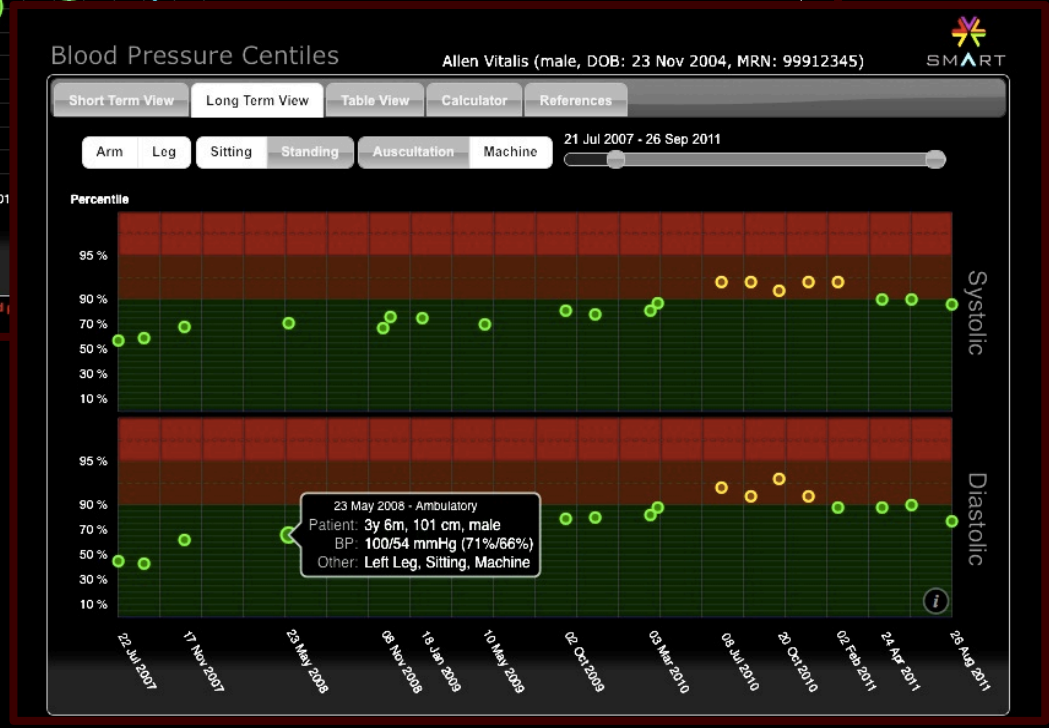
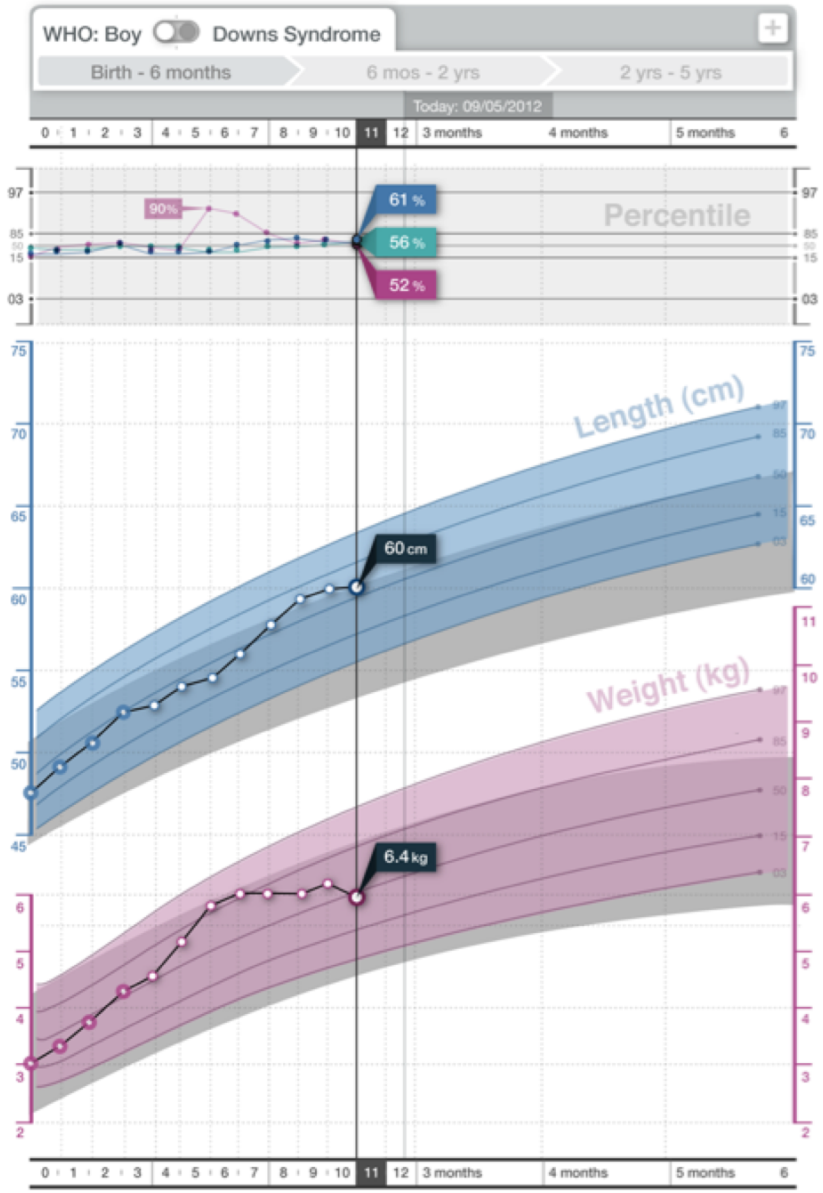
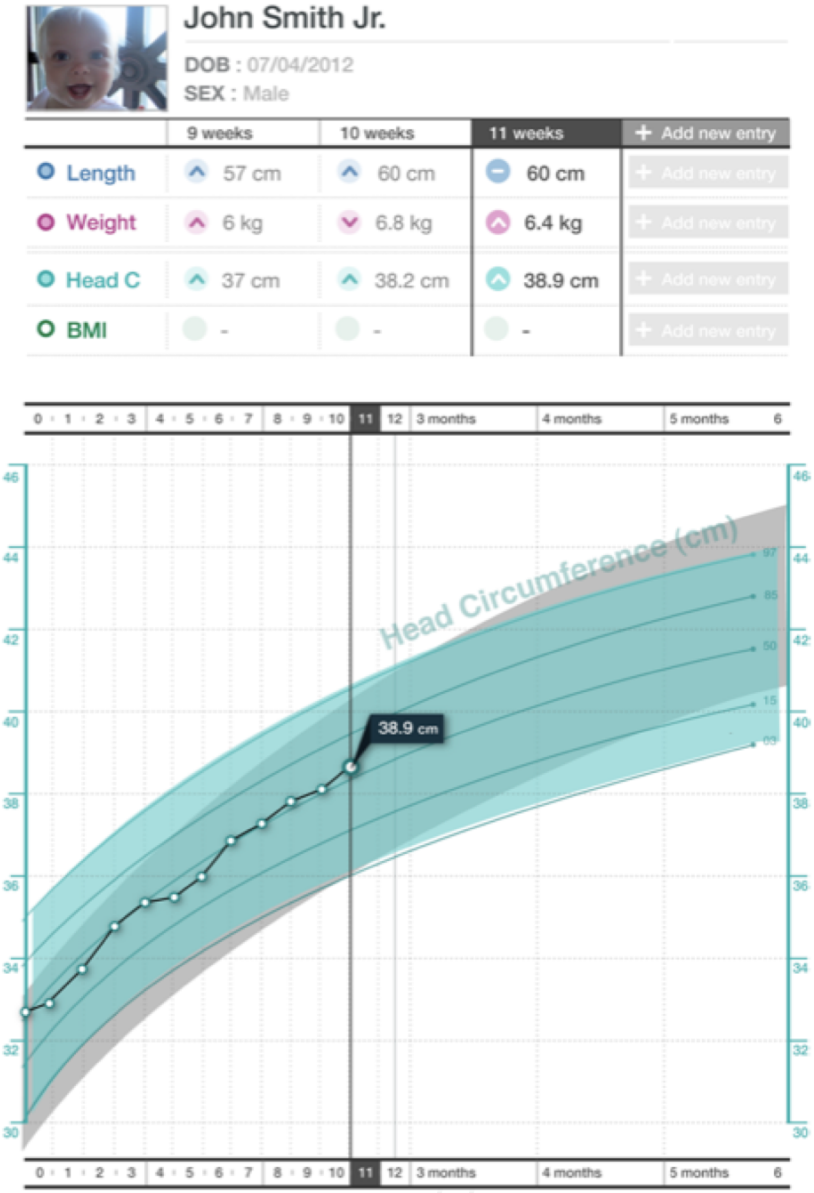






SMART BP Centiles App Running on Cerner


WHO: Boy
Downs Syndrome
Birth - 6 months
6 mos - 2 yrs
2 yrs - 5 yrs
Today: 09/05/2012
Percentile
90%
61 %
56 %
52 %
Length (cm)
60 cm
Weight (kg)
6.4 kg
3 months
4 months
5 months


John Smith Jr.
DOB : 07/04/2012
SEX : Male
9 weeks
10 weeks
11 weeks
Add new entry
Length
57 cm
60 cm
60 cm
Weight
6 kg
6.8 kg
6.4 kg
Head C
37 cm
38.2 cm
38.9 cm
BMI
Head Circumference (cm)
38.9 cm
3 months
4 months
5 months

Trial Eligibility

Trial Eligibility

Female | Male | 43 y

Boston, MA

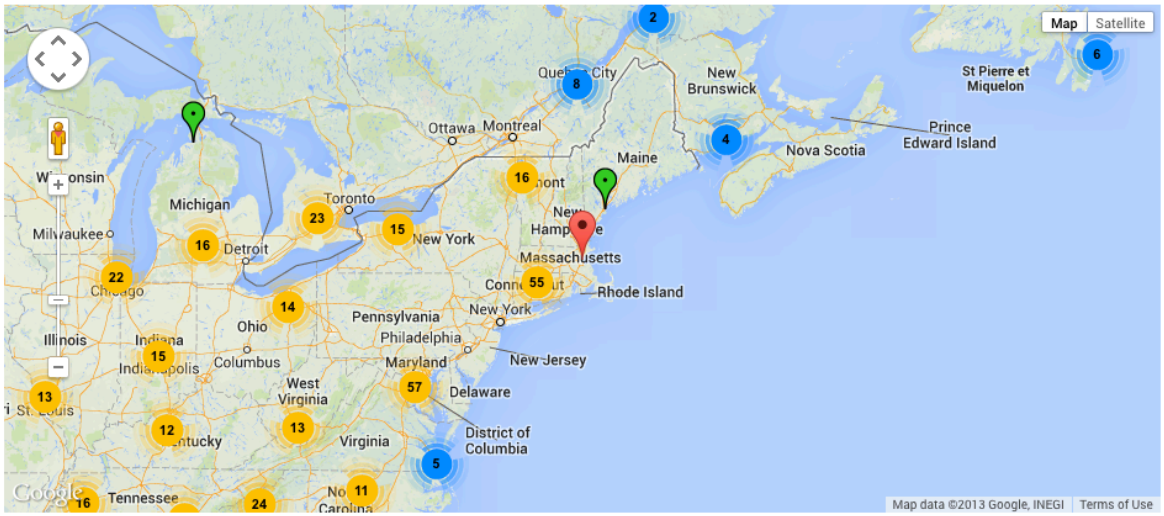
rheumatoid arthritis +methotrexate | Cancel | Refresh

Intervention / Observation

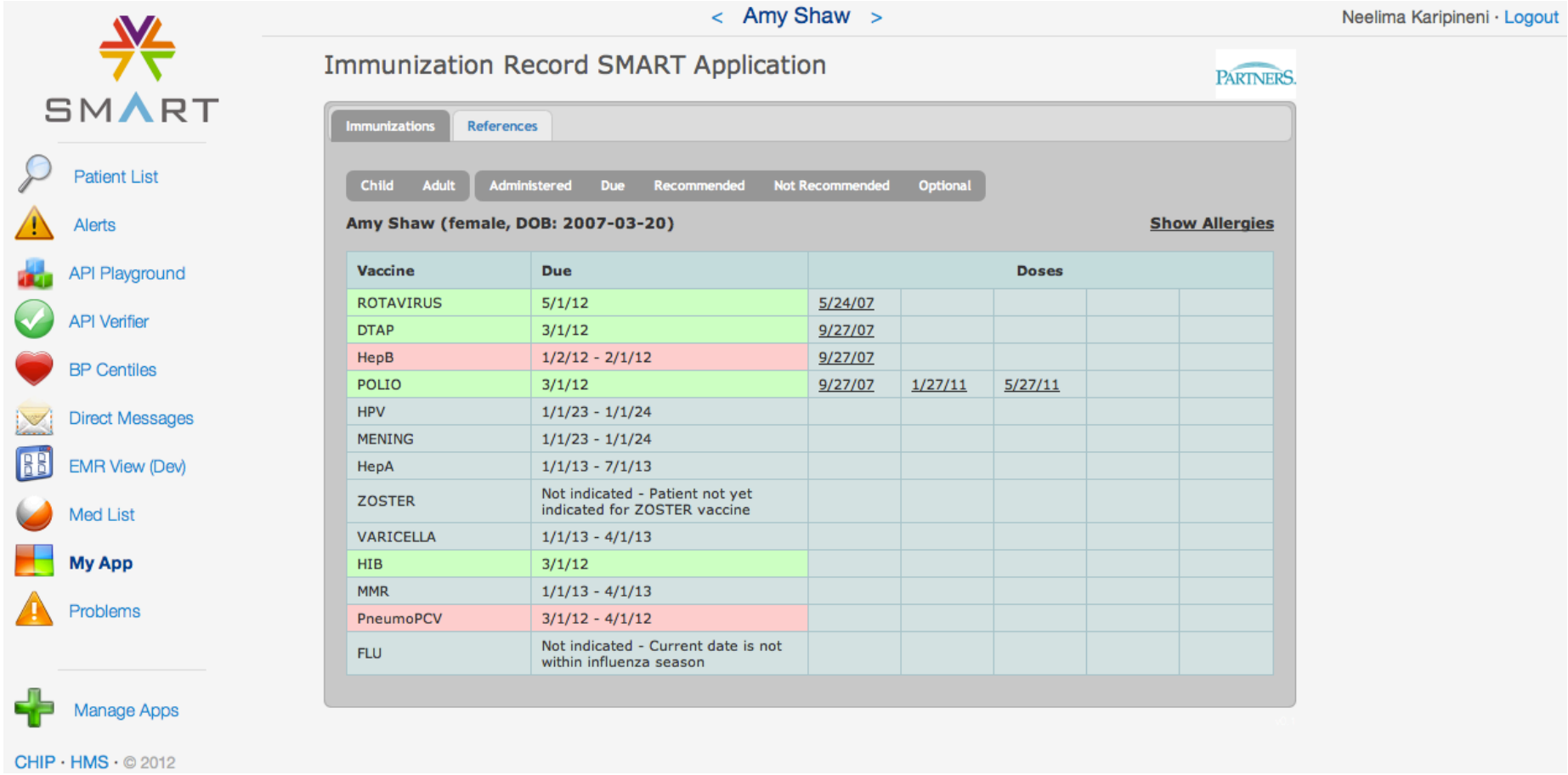
- [x] **Biological (14)**
- [ ] Device (1)
- [ ] Dietary Supplement (1)
- [x] **Drug (69)**
- [ ] Observational (14)
- [ ] Other (4)
- [ ] Procedure (1)

Trial phase

- [x] **N/A (8)**
- [x] **Phase 1 (8)**
- [x] **Phase 2 (23)**
- [x] **Phase 3 (17)**
- [x] **Phase 4 (26)**

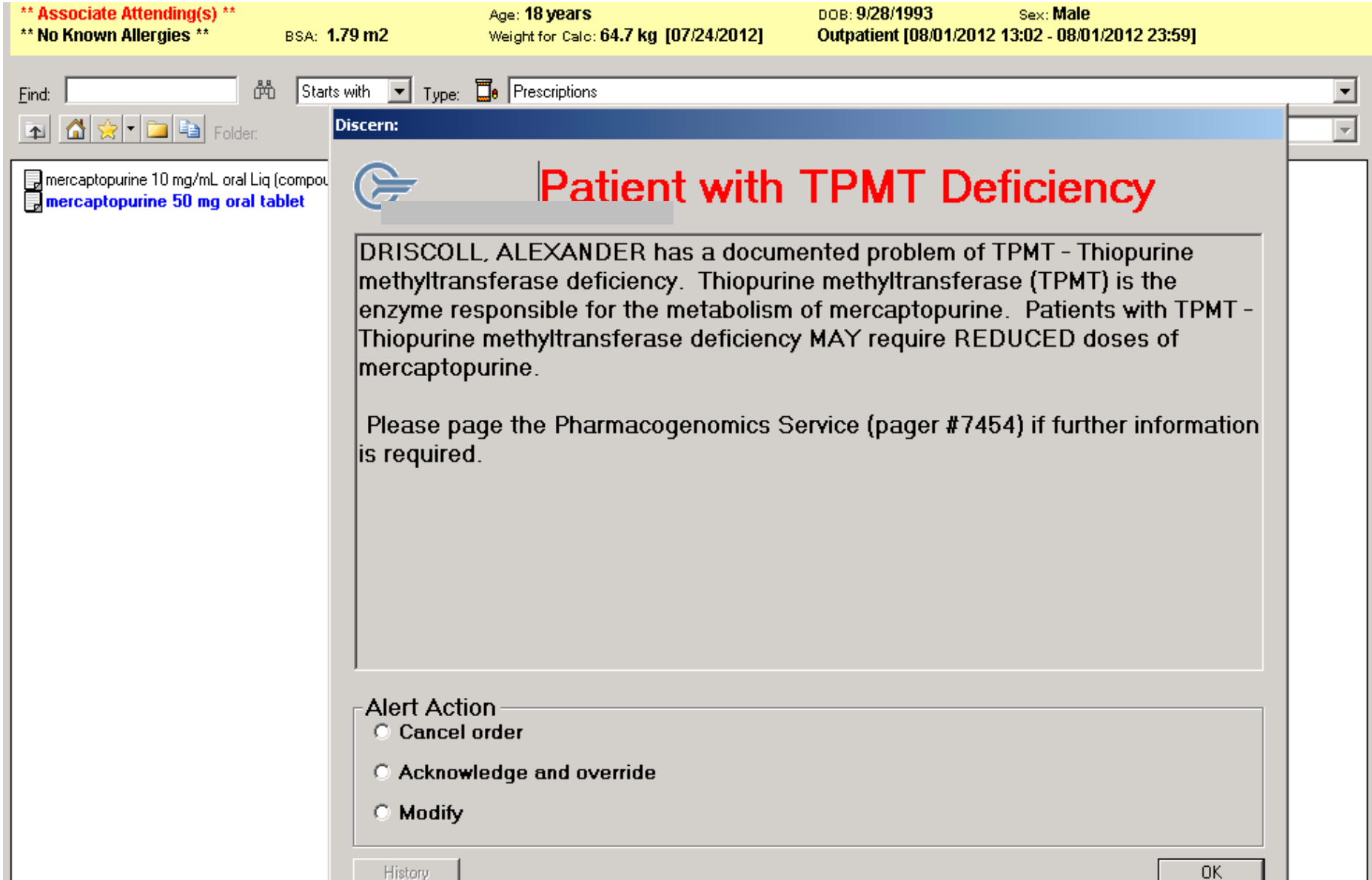


Decision Support Integration
e.g., Immunization Forecasting



Vaccine	Due	Doses				
ROTAVIRUS	5/1/12	5/24/07				
DTAP	3/1/12	9/27/07				
HepB	1/2/12 - 2/1/12	9/27/07				
POLIO	3/1/12	9/27/07	1/27/11	5/27/11		
HPV	1/1/23 - 1/1/24					
MENING	1/1/23 - 1/1/24					
HepA	1/1/13 - 7/1/13					
ZOSTER	Not indicated - Patient not yet indicated for ZOSTER vaccine					
VARICELLA	1/1/13 - 4/1/13					
HIB	3/1/12					
MMR	1/1/13 - 4/1/13					
PneumoPCV	3/1/12 - 4/1/12					
FLU	Not indicated - Current date is not within influenza season					

Personalization of Therapy



CDS Hooks Demo | Rx View | Patient View | Change Patient | + Quick Add | Reset | Configure Hooks

Context

Rx View

Patient: Daniel X. Adams **ID:** 1288992

Treating:

Choose a problem

Medication:

Search for a drug...

mercaptopurine 10 MG Oral Tablet

Take 1 **pill by mouth** daily

Start date ☑ 2016-11-27

End date ☑ 2016-12-27

TPMT - Thiopurine methyltransferase deficiency

Daniel X. Adams has a documented problem of Thiopurine Methyltransferase (TPMT) deficiency. TPMT is the enzyme responsible for the metabolism of mercaptopurine. Patients with TPMT deficiency MAY require REDUCED doses of mercaptopurine.

Please page the Pharmacogenomics Service (pager #7454) if further information is required.

iPad
11:01 AM
83%
MRN Search
SMART™
Genomics: Precision Cancer Medicine
Enter an MRN number below
Search
Powered by VANDERBILT
This work was supported by grant ONC 90TR0001/01. The funder had no direct role in application design, software development, or decision to publish.
Copyright © Vanderbilt-Ingram Cancer Center
SMART™
FHIR™
MRN Search
Patient Search
About

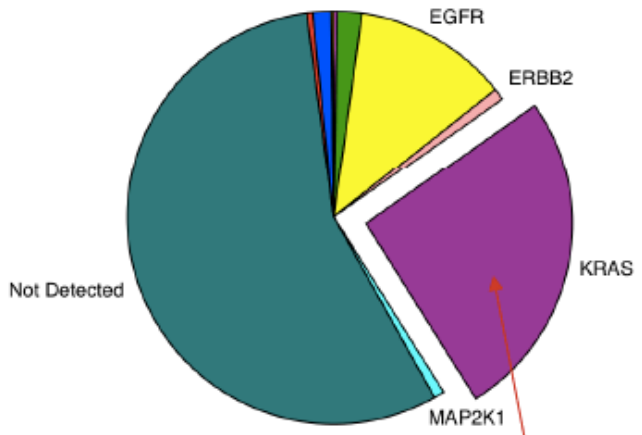
iPad 11:03 AM 83%

Patient Search [redacted]

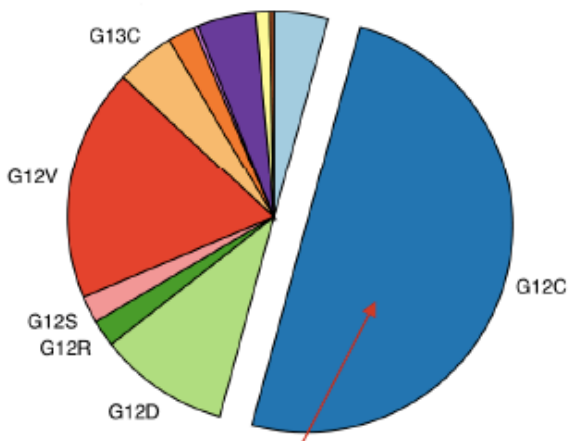
[redacted] (MRN: [redacted])

Male, [redacted]
Diagnosis: Lung Cancer
Mutation: KRAS G12C

Mutated Genes Observed in Lung Cancer



Observed Variants in Lung Cancer Patients with KRAS Mutation



A gene mutation was detected in this patient, so variant level information is also provided. They have the most common variant of KRAS seen in the ***lung cancer*** population.

MRN Search Patient Search About

Big Data Mashups: e.g., Personalized Medicine

- Linkage to external decision support services
  - ✓ Pharmacogenomic rule sets
  - ✓ Decision support for doctors

Nicole Fisher
Contributor

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health policy expert covering health innovation, outcomes & justice

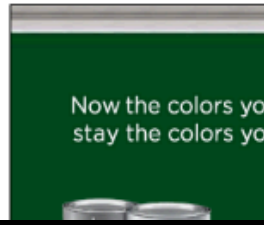
full bio →

PHARMA & HEALTHCARE 5/29/2014 @ 4:43AM | 3,417 views

Who's Who Of Health Care Join Forces For SMART Technology

+ Comment Now + Follow Comments

In the new app-driven health economy, ease of use of IT for providers and patients is a must. Equally important is a sound technical approach and business plan for application creators looking for success, sustainability, and a large market for their innovations. Under the leadership of Boston Children's Hospital's Drs. Kenneth Mandl, Isaac Kohane, Joshua Mandel and an advisory



- Clayton Christensen, HBS
- American Medical Association
- The Advisory Board Company
- AARP
- Blue Cross Blue Shield Association
- BMJ
- Canadian Institutes of Health Research
- CMS
- HCA
- Lily
- MyHealthBook
- Polyglot Systems
- Premier
- Surescripts
- UK NHS
- Quest

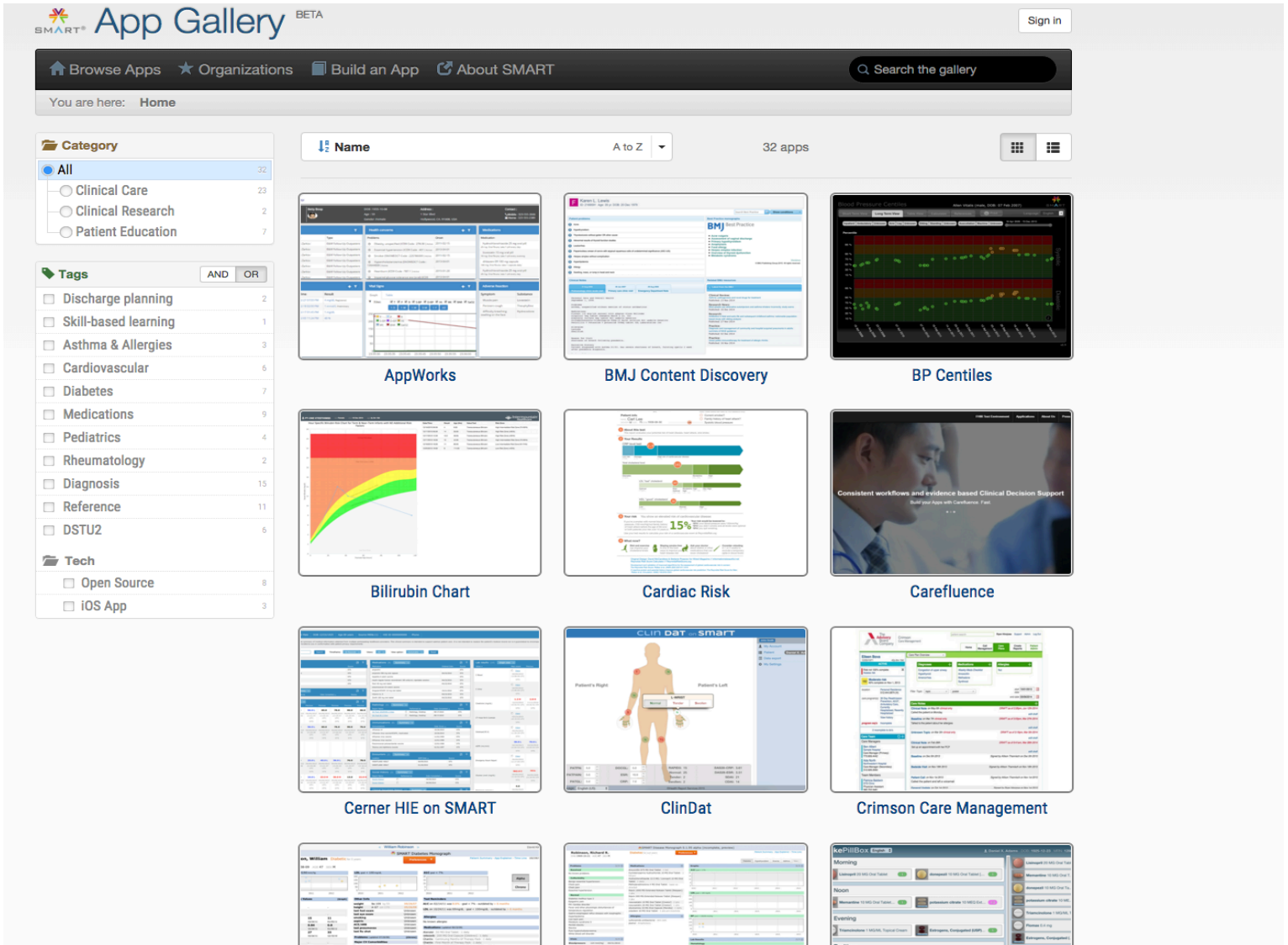
Perfect Storm for SMART Adoption

- EHR Vendors Implementing SMART API
- Health systems standardizing on SMART
- MU3 Policy requiring apps for patients
- Vendor implementation of S4S—patient access
- ONC/CMS Imprimatur and $ for Gallery
- Decision Support Model
- SMART Genomics (PMI)

SMART Strongholds

- Boston Children's Hospital
- Duke Medical Center
- Intermountain
- Geisenger
- ?Partners?

gallery.smarthealthit.org



The NEW ENGLAND JOURNAL of MEDICINE

Perspective

Time for a Patient-Driven Health Information Economy?

Kenneth D. Mandl, M.D., M.P.H., and Isaac S. Kohane, M.D., Ph.D.

N Engl J Med 2016; 374:205-208 | January 21, 2016 | DOI: 10.1056/NEJMp1512142

As patients strive to manage their own health and illnesses, many wonder how to get a copy of their health data to share with their physicians, load into apps, donate to researchers, link to their genomic data, or have on hand just in case. To seek diagnosis or better care (see table), many patients are taking steps outside traditional doctor–patient relationships. Some join 23andMe to obtain genetic information. Others bring data to the Undiagnosed Diseases Network at the National Institutes of Health (NIH). Patients are coalescing with others with the same disease in what the Patient Centered Outcomes Research Institute calls patient-powered research networks. But such patients have found no easy way to get copies of their electronic health records (EHRs).

Selected Reasons for Pursuing Patient-Controlled Data.

Sync for Science http://syncfor.science

Goal: helping patients share EHR data w/researchers

- PMI is one early S4S "customer" (research study). There will be lots more, if we're successful.
- Approach: SMART, FHIR, Argonaut, and MU3 API certification requirements
- Collaborators: Government (NIH, ONC, OSTP), EHR vendors (Allscripts, athenahealth, Cerner, drchrono, eClinicalWorks, Epic, McKesson)
- Timeline: testing vendor implementations Q3 2016, deploying to

A Foundation for Discovering Clinical Health IT Applications

June 1, 2016, 11:00 am / Karen B. DeSalvo, Former National Coordinator for Health IT, and Andy Slavitt / Acting Administrator, CMS

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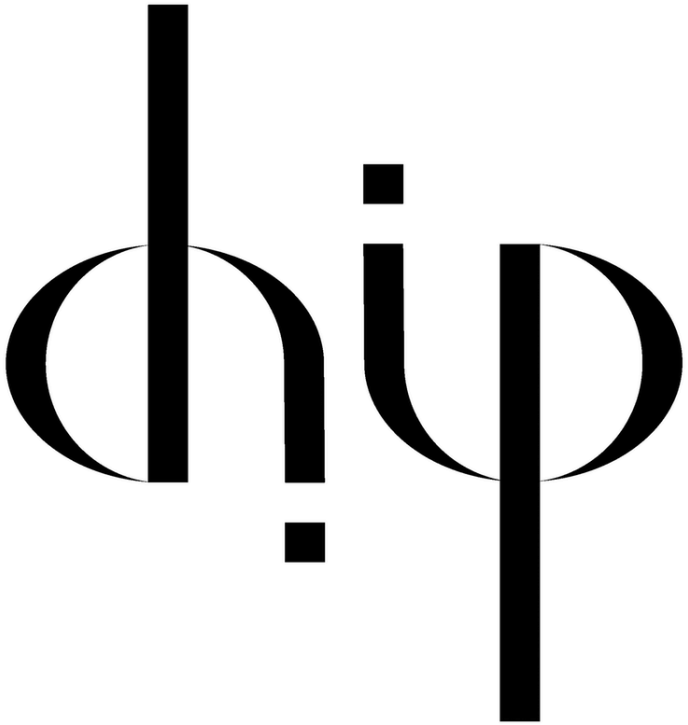
Every day across America, health information technology (health IT) professionals and development teams are creating interoperability solutions using application programming interfaces (APIs). As this surge of innovation grows with each passing year, the likelihood that teams across the nation are creating similar or duplicative health IT applications is also increasing. Unfortunately, our capability to search for, discover, compare, and test existing applications has been limited and this lack of available information may contribute to a lag in the diffusion of innovation across the health IT application ecosystem.

Earlier this year, the Office of the National Coordinator for Health Information Technology (ONC) announced its vision for Connecting and Accelerating a Fast Healthcare Interoperability Resources (FHIR) App Ecosystem, with a total of $625,000 in funding support. This strategy expressed three complementary goals: 1) help consumers get and use their data; 2) improve user-experience for providers; and 3) coordinate open information about market-ready electronic health record (EHR) app solutions.

Today, we are excited to announce that Boston Children's Hospital, has been awarded approximately $275,000 to address our stated third goal of coordinating open information about market-ready EHR app solutions. This new cooperative agreement will support the development of

https://www.healthit.gov/buzz-blog/from-the-onc-desk/foundation-discovering-clinical-health-applications/

Establish your independent research program at Harvard and Boston Children's



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