INTERNATIONAL TRACK

Open Data Initiatives

Hosted by Tim Kelsey
Telstra Health, Australia

Moderated by Elizabeth Kittrie
National Institutes of Health

HEALTH DATAPALOOZA® 2016
MAY 8 - 11, 2016 | GRAND HYATT | WASHINGTON, DC

AcademyHealth

Panelists

Emma Doyle
National Health Service (England)

Jay Barber
Public Health Agency of Canada

Wendy Thompson
Centre for Chronic Disease Prevention (Canada)

Damon Davis
US Department of Health and Human Services

Frank von Lennep
French Ministry of Health

Nir Yanovsky
Israel Ministry of Health

Ron Balicer
Clalit Health Services (Israel)

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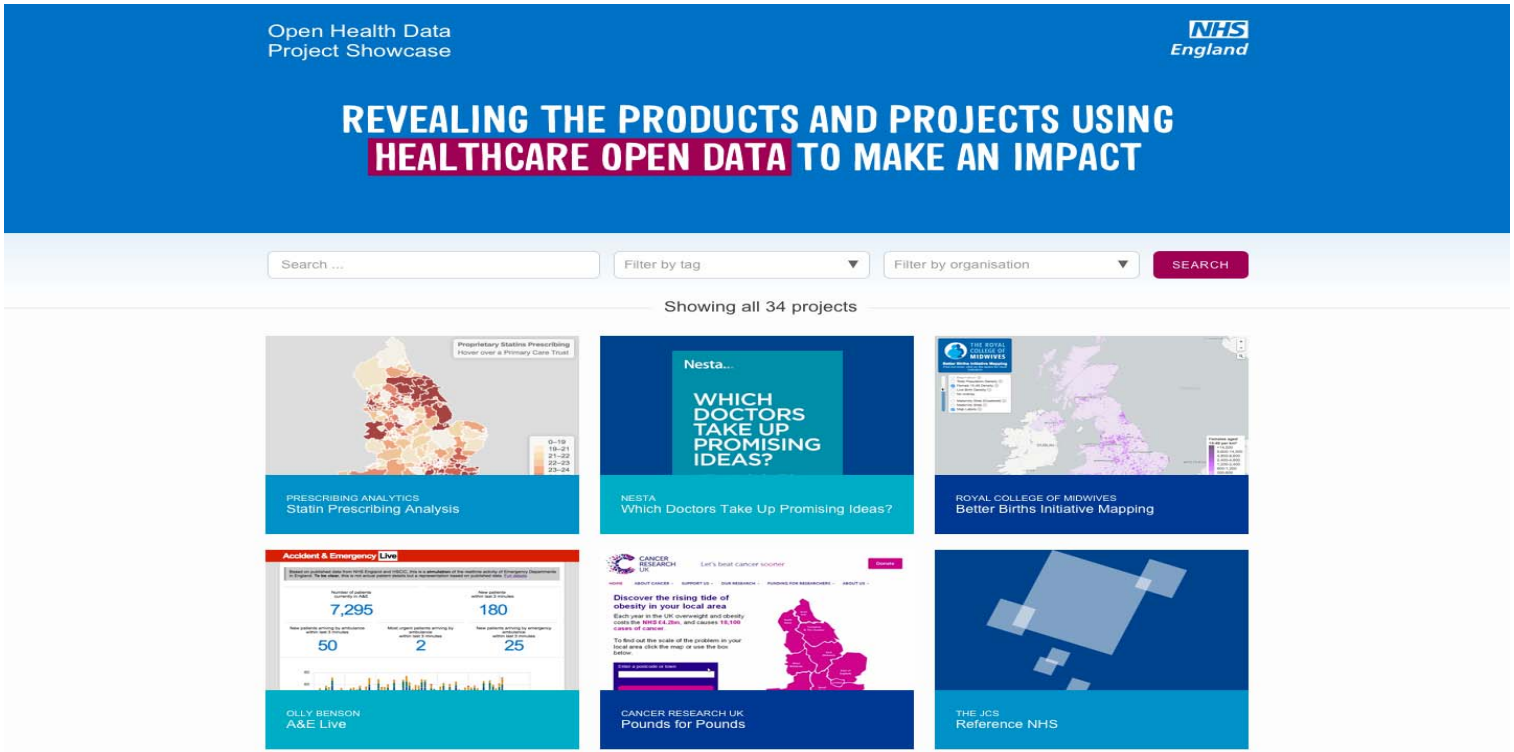
Open Health Data Directory



HHS IDEA LAB

#HackRedTape

@damonldavis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This site is dedicated to making high value health data more accessible to entrepreneurs, researchers, and policy makers in the hopes of better health outcomes for all.
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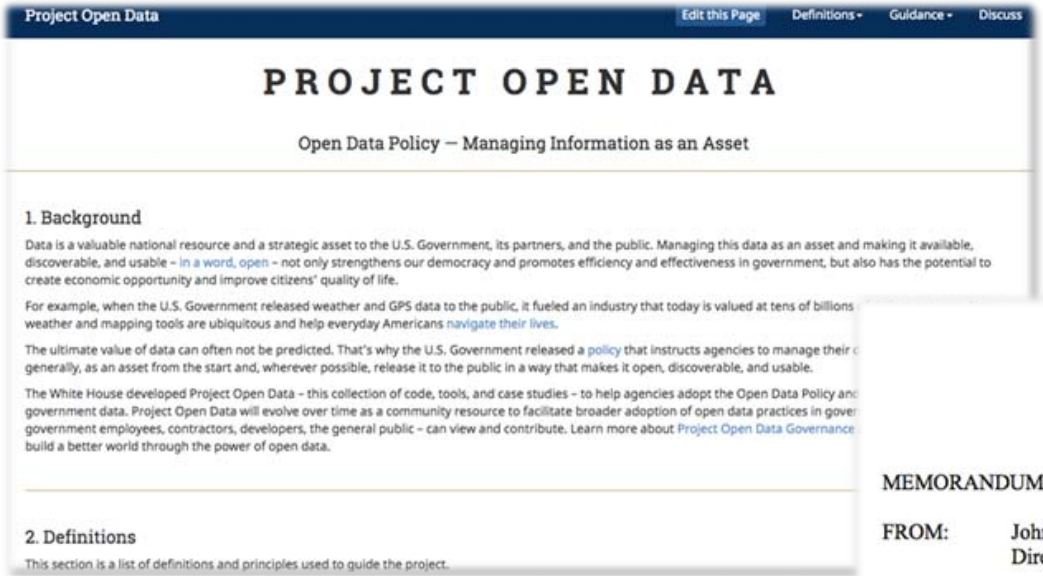
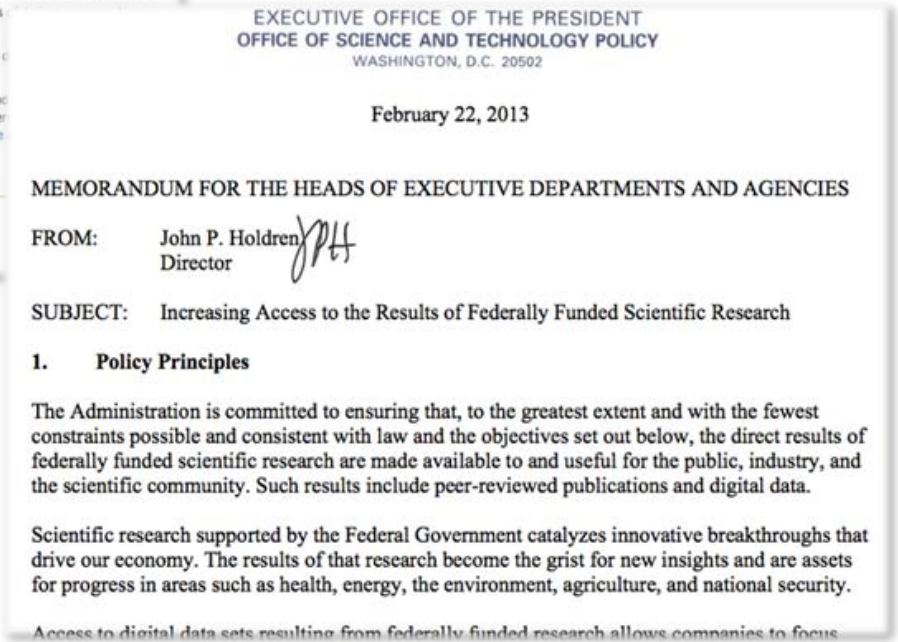
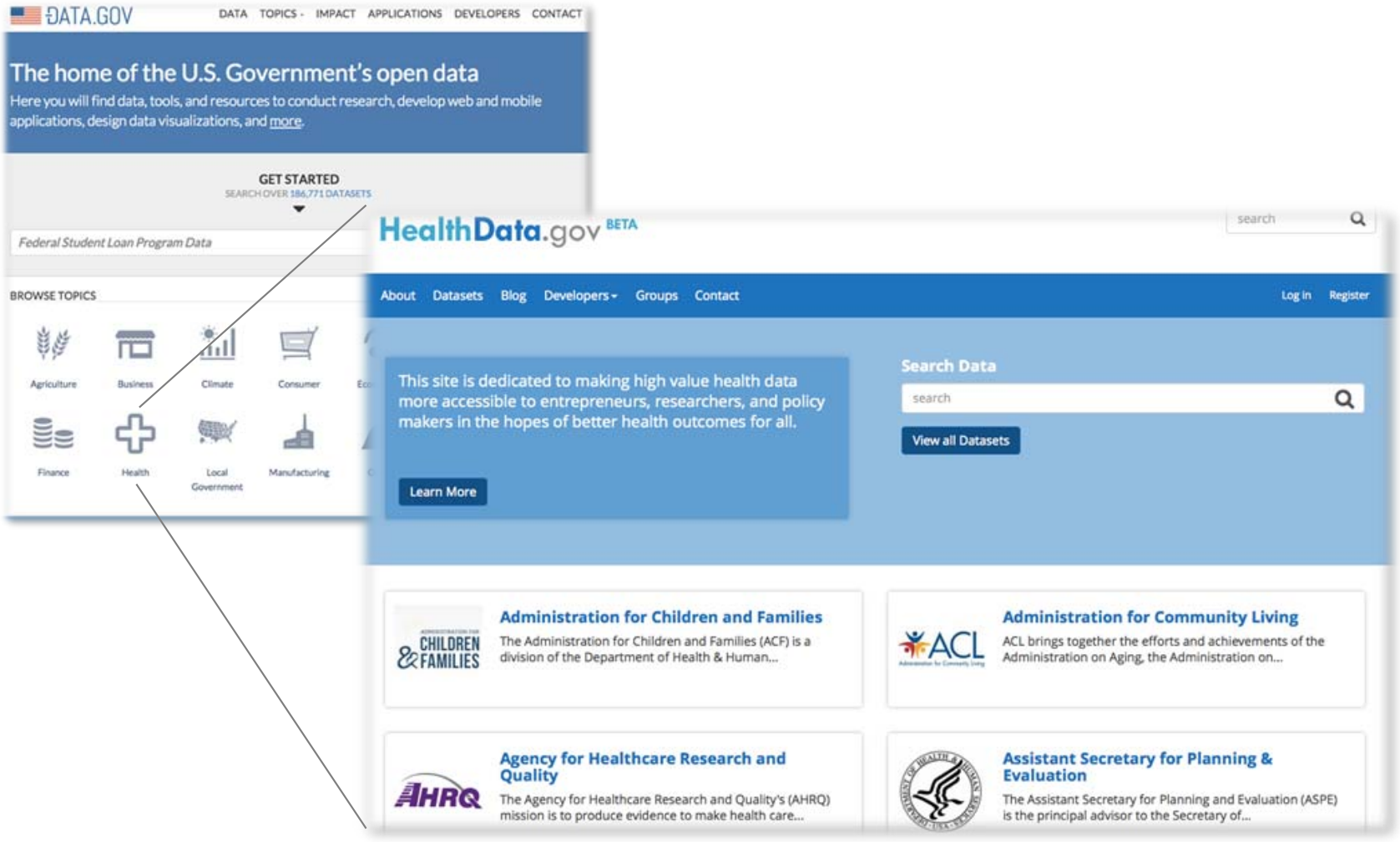

Project Open Data
Edit this Page
Definitions
Guidance
Discuss
PROJECT OPEN DATA
Open Data Policy — Managing Information as an Asset
1. Background
Data is a valuable national resource and a strategic asset to the U.S. Government, its partners, and the public. Managing this data as an asset and making it available, discoverable, and usable – in a word, open – not only strengthens our democracy and promotes efficiency and effectiveness in government, but also has the potential to create economic opportunity and improve citizens' quality of life.
For example, when the U.S. Government released weather and GPS data to the public, it fueled an industry that today is valued at tens of billions
weather and mapping tools are ubiquitous and help everyday Americans navigate their lives.
The ultimate value of data can often not be predicted. That's why the U.S. Government released a policy that instructs agencies to manage their
generally, as an asset from the start and, wherever possible, release it to the public in a way that makes it open, discoverable, and usable.
The White House developed Project Open Data – this collection of code, tools, and case studies – to help agencies adopt the Open Data Policy and
government data. Project Open Data will evolve over time as a community resource to facilitate broader adoption of open data practices in gover
government employees, contractors, developers, the general public – can view and contribute. Learn more about Project Open Data Governance
build a better world through the power of open data.
2. Definitions
This section is a list of definitions and principles used to guide the project.


EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF SCIENCE AND TECHNOLOGY POLICY
WASHINGTON, D.C. 20502
February 22, 2013
MEMORANDUM FOR THE HEADS OF EXECUTIVE DEPARTMENTS AND AGENCIES
FROM: John P. Holdren
Director
SUBJECT: Increasing Access to the Results of Federally Funded Scientific Research
1. Policy Principles
The Administration is committed to ensuring that, to the greatest extent and with the fewest constraints possible and consistent with law and the objectives set out below, the direct results of federally funded scientific research are made available to and useful for the public, industry, and the scientific community. Such results include peer-reviewed publications and digital data.
Scientific research supported by the Federal Government catalyzes innovative breakthroughs that drive our economy. The results of that research become the grist for new insights and are assets for progress in areas such as health, energy, the environment, agriculture, and national security.
Access to digital data sets resulting from federally funded research allows companies to focus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DATA TOPICS - IMPACT APPLICATIONS DEVELOPERS CONTACT
The home of the U.S. Government's open data
Here you will find data, tools, and resources to conduct research, develop web and mobile applications, design data visualizations, and more.
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This site is dedicated to making high value health data more accessible to entrepreneurs, researchers, and policy makers in the hopes of better health outcomes for all.
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Administration for Children and Families
The Administration for Children and Families (ACF) is a division of the Department of Health & Human...
Administration for Community Living
ACL brings together the efforts and achievements of the Administration on Aging, the Administration on...
Agency for Healthcare Research and Quality
The Agency for Healthcare Research and Quality's (AHRQ) mission is to produce evidence to make health care...
Assistant Secretary for Planning & Evaluation
The Assistant Secretary for Planning and Evaluation (ASPE) is the principal advisor to the Secretary of...

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DEPARTMENT OF HEALTH & HUMAN SERVICES · USA

NHS England

OBESITY DATA CHALLENGE WINNERS!

PUBLIC HEALTH INSTITUTE

LiveStories

RTI INTERNATIONAL

Community Health Solutions of America

GeoHealth Innovations
Changing the View on Public Health

HEARTSMARTkids

U.S. Obesity and Healthy Living Locator

Open Data Initiatives and the Public Health Agency of Canada

The Experience in Healthy Living and Injury Surveillance in Canada

Jay Barber and Wendy Thompson

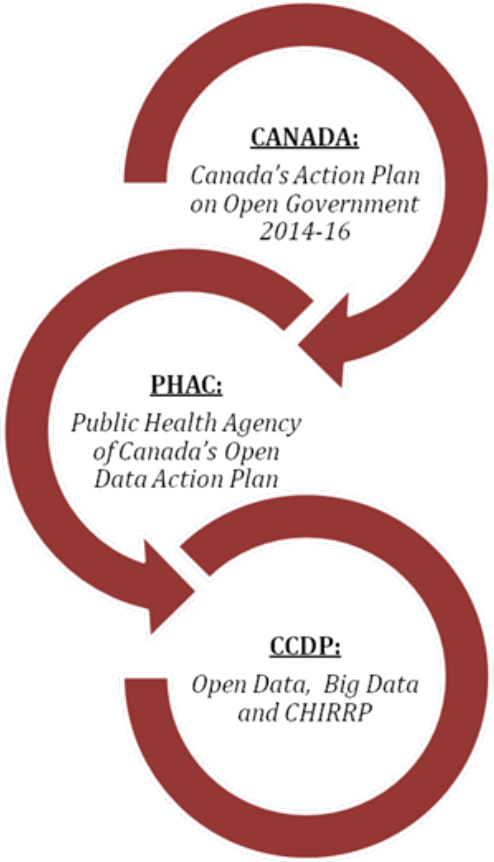
Health Datapalooza, May 2016

Setting the Context

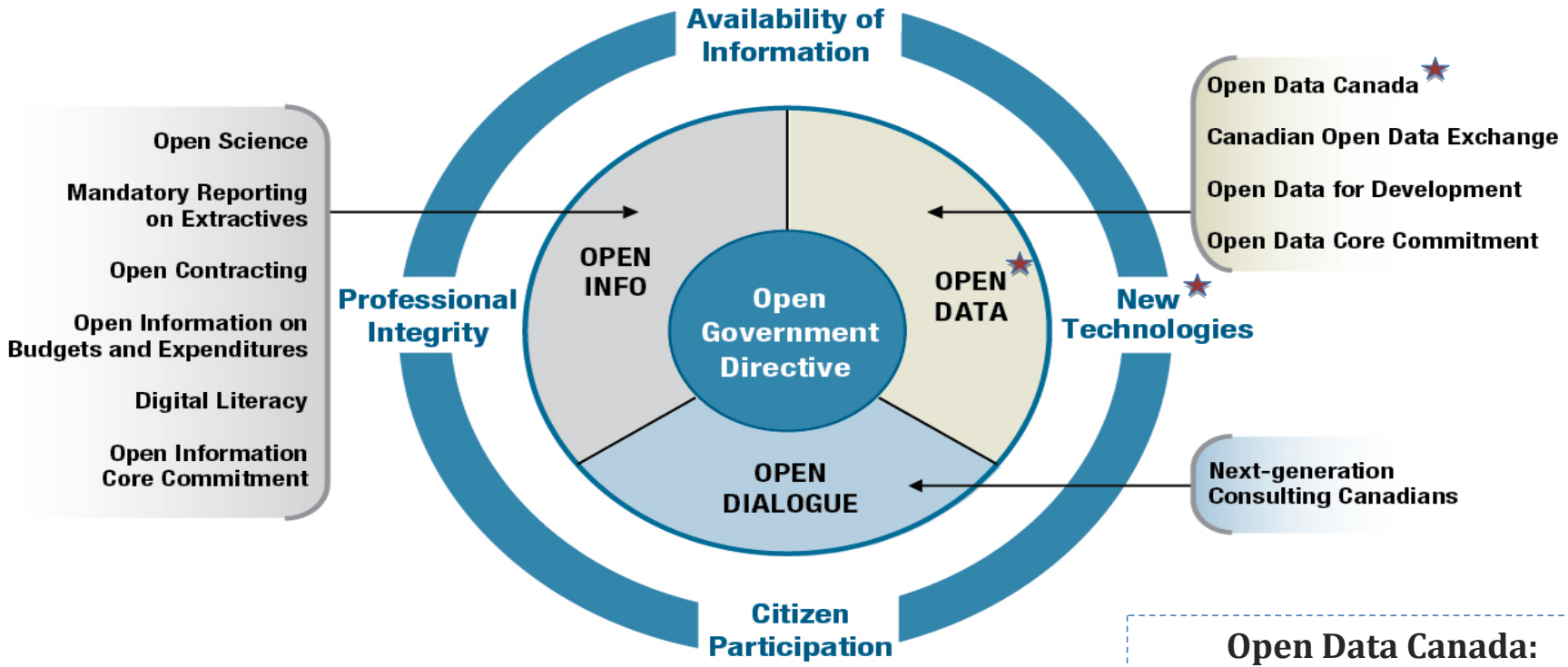
1. **Open Data in Canada- The Big Picture**

2. **Open Data at PHAC- Who We Are? Situating Chronic Disease Surveillance**

3. **Open Data in Practice at the CCDP- Open Data & Big Data and the Canadian Hospitals Injury Reporting and Prevention Program (CHIRRP)**



Open Data in Canada: The Big Picture



Open Data Canada:
http://open.canada.ca

Open Data in Practice: CHIRPP

Canadian Hospitals Injury Reporting and Prevention Program (CHIRPP)

•A near-real time injury and poisoning surveillance system that collects information from patients, caregivers and hospital staff on injuries and poisonings that present at the emergency department of 17 participating hospitals across Canada - 11 paediatric and 6 general hospitals

•CHIRPP is a unique, richly detailed database of "pre-event" injury information- database provides information for summary reports on injury occurrence and may also be used for more detailed research

•CHIRPP's ultimate goal: to reduce the number and severity of injuries in Canada.

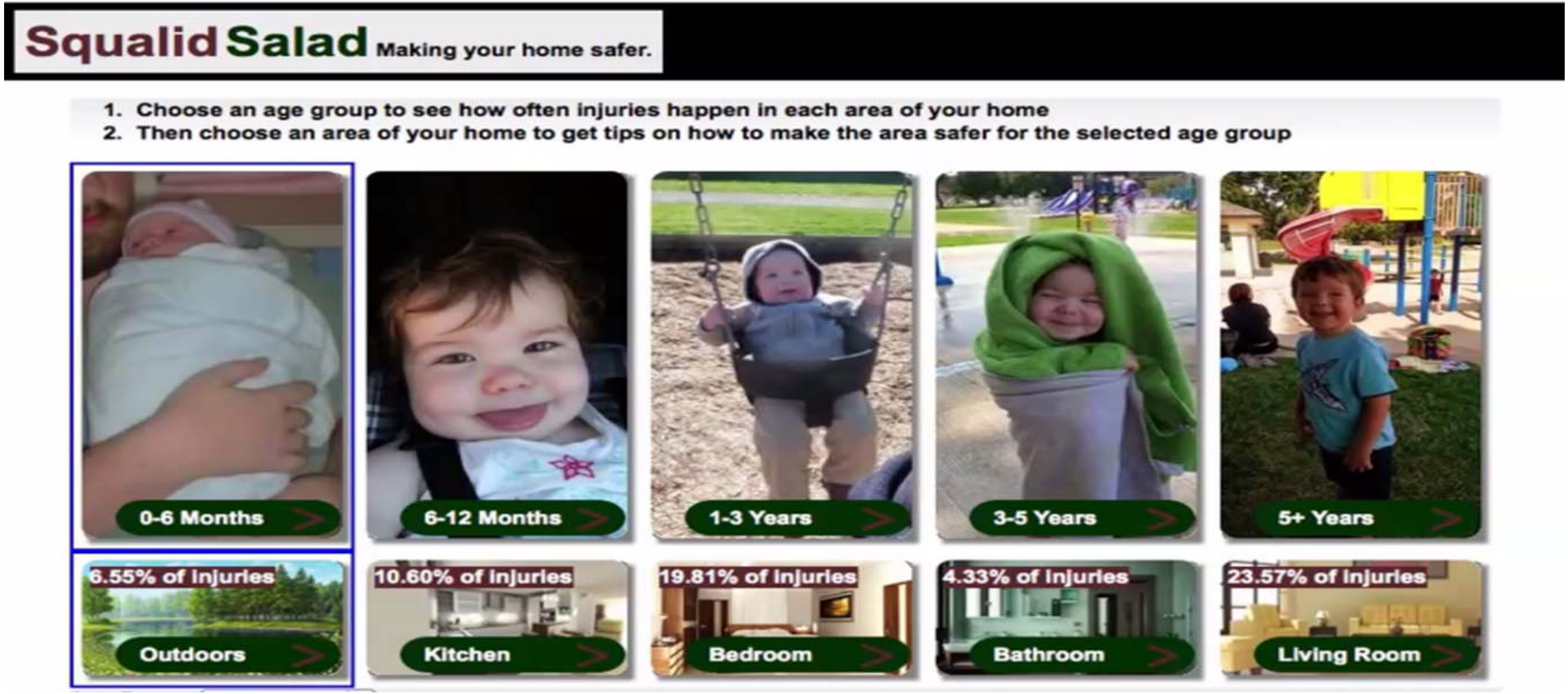
CODE 2014, (**Canadian Open Data Experience**) one of top 15 apps used CHIRPP data for injury prevention

•**Team: DemoFirst**

•**Description: Squalid Salad** informs parents of the likelihood of injuries to children, by age group, in different areas of the home, and provides age-appropriate suggestions for making the home safer.

•**Datasets used:** Unintentional injuries in Canada 2010 – PHAC

Open Data in Practice: CHIRPP & Squalid Salad



Open Data in Practice: CCDP's Infobase

Head Injuries in Children and Youth – The Invisible Epidemic

You might have noticed that head injuries in sport have received a lot of attention lately, and this type of injury is now recognized as a public health problem. In some sports, head injuries are common and their potential short- and long-term consequences can be severe. The Minister of Health has committed to support a national strategy to raise…

View

CHRONIC DISEASE AND INJURY INDICATOR FRAMEWORK

QUICK STATS, 2015 EDITION

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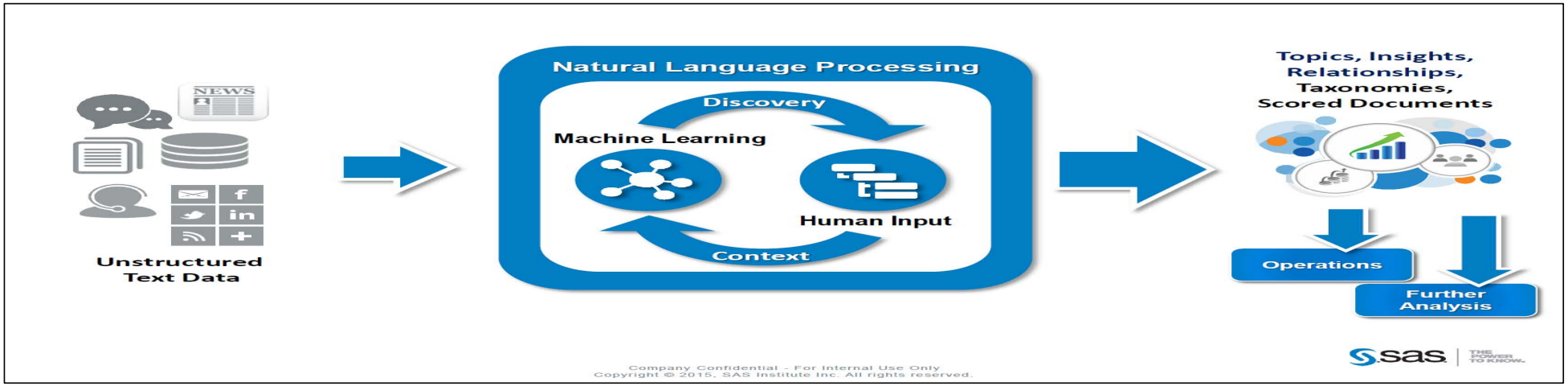
INDICATOR GROUP	INDICATOR MEASURE(S)	LATEST DATA[a]	DATA SOURCE (YEAR)
SOCIAL AND ENVIRONMENTAL DETERMINANTS			
Education	% of population with less than a high school education, population aged 20+ years	12.8%	CCHS (2014)
Income	% of population living below low-income cut-offs, after tax, total population	9.7%	CIS (2013)
Employment	Average annual unemployment rate (% of labour force that was unemployed during reference period), population aged 15+ years	6.8%	LFS (2015)
EARLY LIFE/CHILDHOOD RISK AND PROTECTIVE FACTORS			
Breastfeeding	% of women who reported exclusive breastfeeding of their child for at least the first 6 months of life, women aged 15+ years	26.2%	CCHS (2012)
Birth weight	% of live births with a low birth weight	6.1%	CVS (2011)
Exposure to second-hand smoke	% of households with children aged less than 12 years regularly exposed to environmental tobacco smoke at home	3.1%	CTADS 2013
Family violence	% of population that experienced any of three types of child abuse [physical abuse, sexual abuse or exposure to intimate partner violence] before the age of 16 (NEW)	32.3%	CCHS-MH (2012)
BEHAVIOURAL RISK AND PROTECTIVE FACTORS			
Physical activity	% of children and youth who met physical activity guidelines by accumulating at least 60 minutes of moderate-to-vigorous physical activity per day, population aged 5–17 years (NEW)	9.3%	CHMS (2012–2013)
	% of adults who met physical activity guidelines by accumulating at least 150 minutes of moderate-to-vigorous physical activity each week, in bouts of 10 minutes or more, population aged 18+ years (NEW)	22.2%	CHMS (2012–2013)
Sedentary behaviour	% children and youth who reported exceeding sedentary behaviour guidelines by spending more than …er day watching television or using computers during leisure-time, population aged 5–17 years	72.7%	CHMS (2012–2013)
	…amount of time per day spent sedentary, excluding sleep time, population aged 5–17 years (NEW)	8.5 hours	CHMS (2012–2013)
	…amount of time per day spent sedentary, excluding sleep time, population aged 18+ years (NEW)	9.8 hours	CHMS (2012–2013)
	…ulation that reported consuming fruit and vegetables at least 5 times/day, population aged 12+ years	39.7%	CCHS (2014)
	…ren and youth who reported drinking sugar-sweetened beverages daily, population aged 5–17 years	17.2%	CHMS (2012–2013)
	…ren and youth who reported obtaining adequate daily sleep (10–13 hours for those aged 5 years, …rs for ages 6–13 years and 8–10 hours for ages 14–17 years), population aged 5–17 years (NEW)	74.6%	CHMS (2012–2013)
	…ulation that reported a high level of coping, population aged 18+ years (NEW)	56.9%	CCHS-MH (2012)
	…ulation that reported life to be "quite a bit" or "extremely" stressful most days in the last …s, population aged 12+ years	22.4%	CCHS (2014)
	…ulation that exceeds low risk alcohol drinking guidelines for chronic drinking, population aged 15+ years	15.7%	CTADS 2013
	…ulation that reported being current smokers (daily or occasional), population aged 15+ years	14.6%	CTADS 2013
	…ulation that reports being current smokers (daily), population aged 15+ years	10.9%	CTADS 2013

http://infobase.phac-aspc.gc.ca/index-en.html

Open Data: Some Final Observations



- **Open Data Within the Federal Public Health Infrastructure in Canada-**Privacy and security, data interpretation, and timeliness challenges rem (P/T approvals, data cycles)
- **Innovation of Open Data in CCDP & CHIRPP-** Further examination of injury syndromics (early warning rules), predictive modelling, text mining, mobile data collection for real-time surveillance
- **Building the Technological and Methodological Innovation and Capacity-** Autocoding, machine language learning, data visualizations
- **Open Data Exploration & Integration-** Smart exploration of non-traditional open data sources (social media data, wearable data, unstructured data) to tell a more complete public health surveillance story
- **Continue to build our technological and innovative capacity-** Identify our data needs, challenges & optimise ***"open data out and smart integration of open/ big data in"***

Questions:

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Twitter @jayjbarber

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PHAC, CCDP Infobase & CHIRPP:
www.phac-aspc.gc.ca
http://infobase.phac-aspc.gc.ca/index-en.html
www.phac-aspc.gc.ca/injury-bles/chirpp/index-eng.php

OPENING ACCESS TO THE NATION-WIDE HEALTH DATABASE IN FRANCE FOR RESEARCH AND INNOVATION

Health Datapalooza – International open data panel

Franck von Lennep, Ministry of Health, France

The National Health Data System

Mainly composed of three paired national administrative databases covering 66 M people:

- National health insurance database (outpatient data only: complete history medical consultations and prescriptions, sick leaves…)
- National hospital discharge database
- Medical certificates of cause of death

=> deidentified data

Does not contain information such as:

- results of clinical exams, blood pressure, BMI, results of laboratory tests…
- smoking, alcohol use, exercise, diet, family history, …

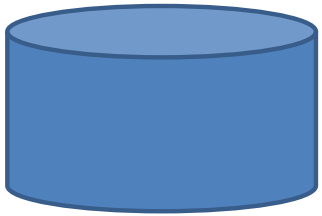
The conditions of access were defined in consultation with health data producers and users

- Demands from civil society to make access to the databases easier, faster and wider :
  - Each database had its own access rules & processes
  - 1-year delay on average to access the databases
  - Access was restricted to non-profit organizations, in practice only researchers and public institutions were using the databases
- Consultation launched in 2014 through a multi-stakeholder « commission on open data in health »
- Report published in July 2014, with recommendations :
  - Facilitate access to more health data to any project advancing public interest
  - Establish a coherent, transparent and participatory governance of these databases
  - Expand open data initiatives
  - Facilitate pairing with other datasets (cohorts, surveys)
- Theses recommendations were translated into law (article 193 in the Health Law adopted in January 2016)

The new rules to access the national health database : 3 levels of risks => 3 access rules

National health data system

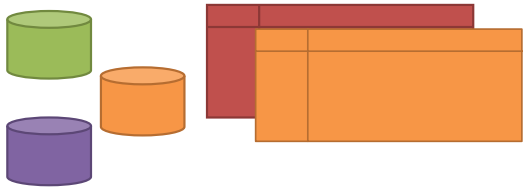
National databases paired together, composed of de-identified individual-level data ; easy to re-identify individuals



- Project assessed by an independent scientific advisory committee
- Only if advances public interest
- Authorized by the Data Protection Authority
- Security rules (traceability => remote access)

Datamarts and low-risk datasets

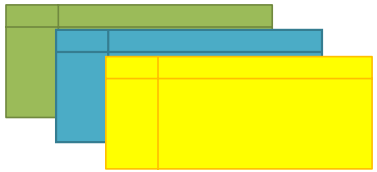
Datamarts & datasets with low-sensitivity or low re-identification risks



- Authorized by the National Health Data Institute
- Only if advances public interest
- Security rules (traceability => remote access)

Open data

Datasets with non-sensitive, aggregate or trunkated data with no re-identification risk



- Open access
- Public or private interest

What's next ?

- Set up the new governance framework (National Health Data Institute as a consortium of public and private stakeholders)
- Design the « business model »: what access payments, to cover which costs?
- More work on anonymization and reidentification
- Hackathons
- Support collaborative production of the metadata in French and English
- Working group with all stakeholders to facilitate linkage with cohorts and surveys
- On going discussion on Big Data and on a French Blue Button

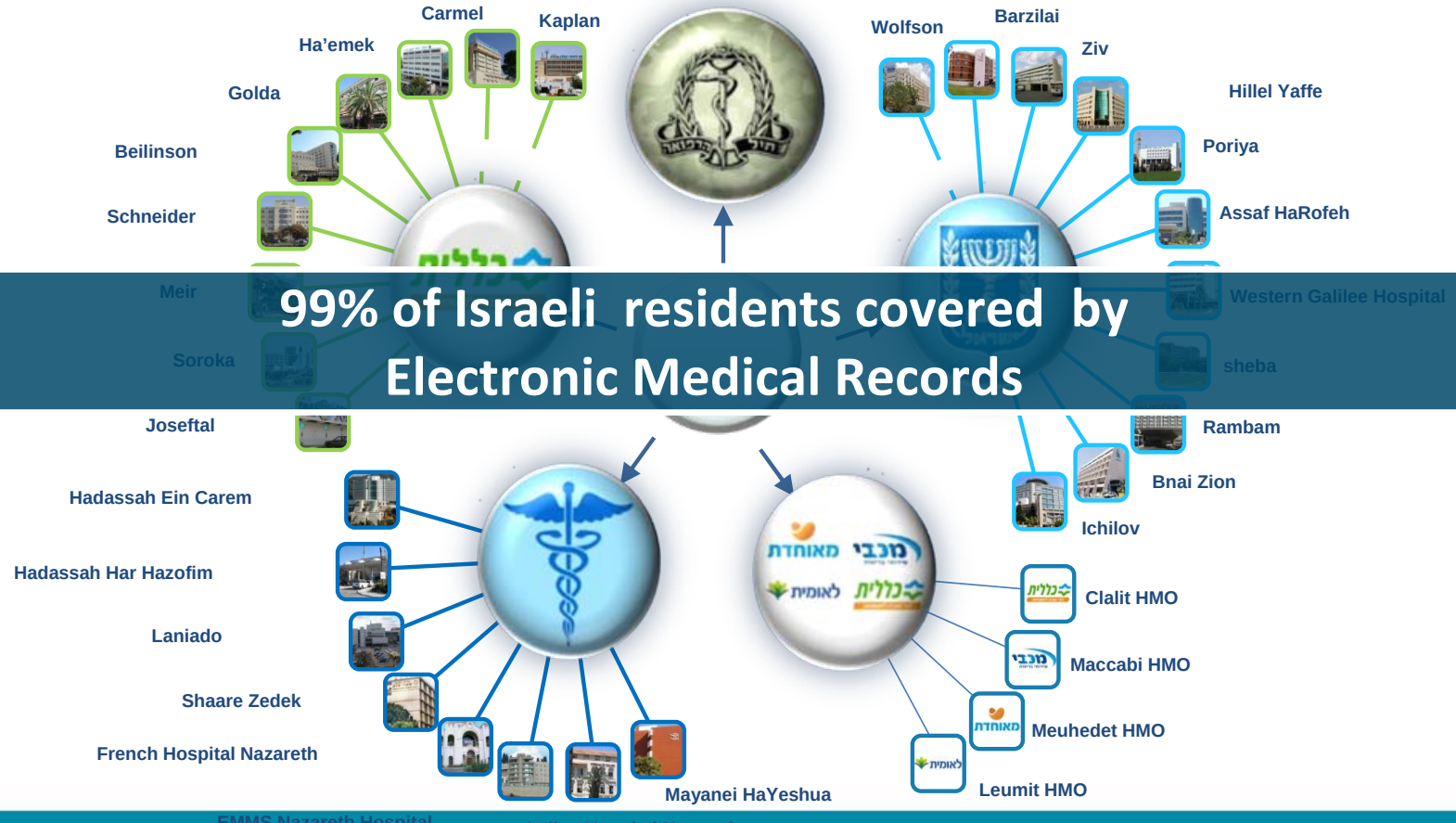
Israel's National Big Data Initiative:
Constructing Data Highways for 21st Century Healthcare

Nir Yanovsky
Digital Health Implementation Manager, Ministry of Health, Israel

MINISTRY OF HEALTH

May 9th 2016

Israel National EMR Distribution



99% of Israeli residents covered by Electronic Medical Records

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The Role of Data in Israel's Digital Health Strategy




Transformations Enabled by Digital Heath

- Personalized Medicine
- Health Promotion Preventive, Predictive, Proactive
- Patient Centered, Participatory Care
- Sustainable Health
- Online Health

Information as the Lifeline

Continuous Care Based on HIE | Health Big Data Platform

Information at every Patient Interaction : EMR Everywhere

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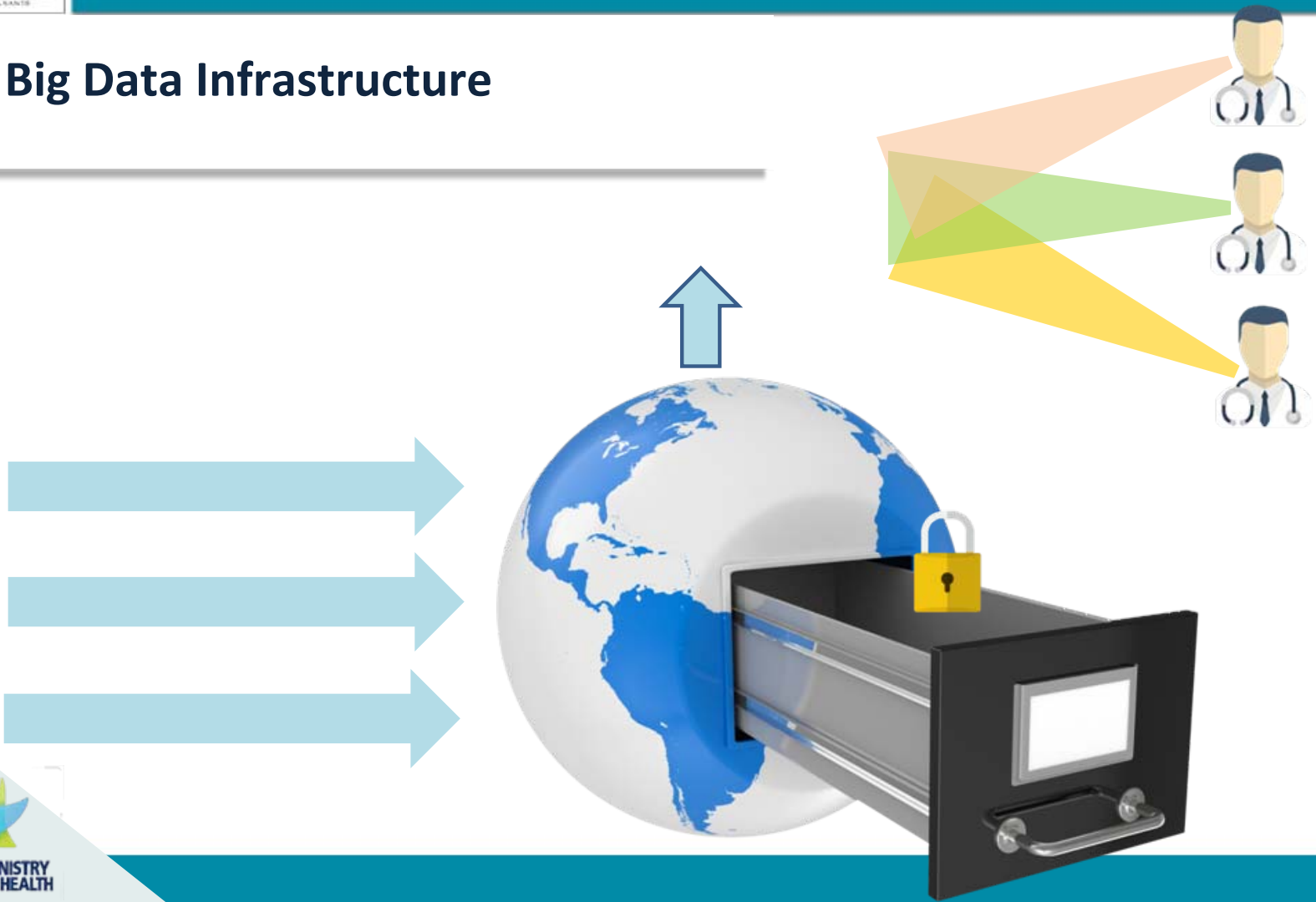
Big Data Infrastructure



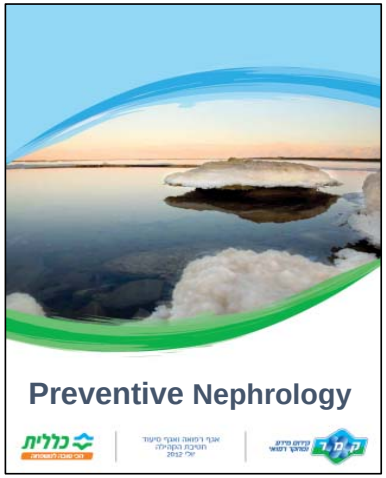
Data driven innovation in practice

Prof. Ran Balicer
Director, Health Policy Planning & Director, Research Institute.
Clalit Health Services. Israel

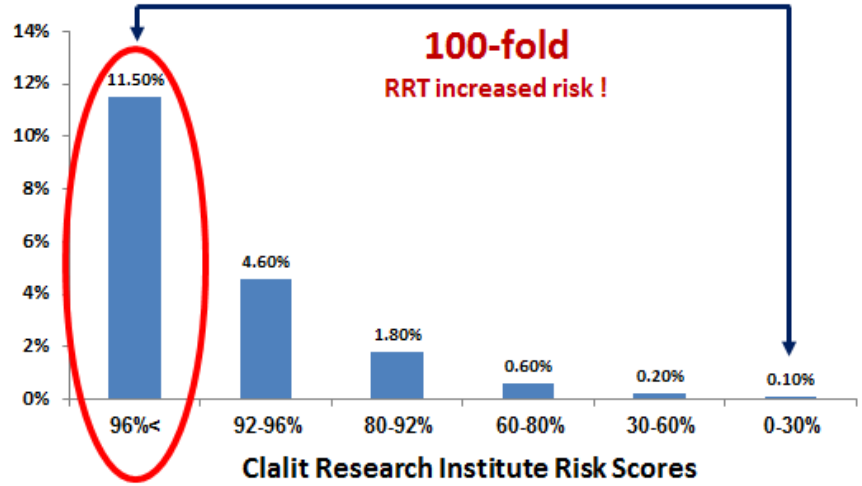
May 9th 2016

Predictive proactive care

Clalit Research Institute

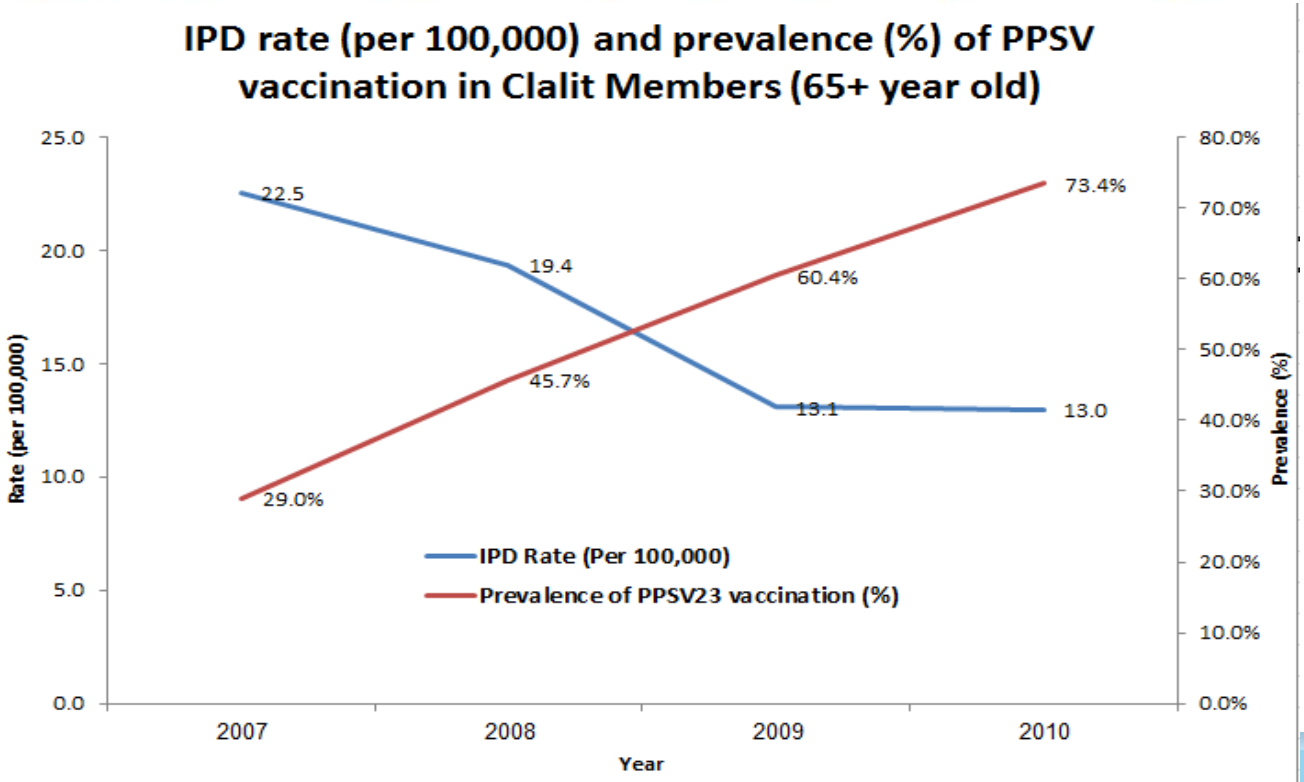


5-year deterioration rates to RRT among CKD stage 3 patients, Clalit



Real-World Outcomes

- Are we barking at the right tree? Is the vaccine effective?



Population proactive management

Generation of a list of patients that performed poorly on a measure, not achieved control