



Big Data: Past, present, & future perspectives from an integrated delivery system— Group Health

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Key points

- What do we mean by Big Data?
- Big Data: *not* new. Larger-scale efforts and value: *new*.
- Most patients support sharing their data with some concerns.
- Big Data alone can't improve care or health
- Big Data: prone to misleading claims and reports.



What do we mean by Big Data?

- Broad (many people) &/or deep (many measurements per person)
- Structured (and unstructured) information from various sources:
 - Patients
 - Electronic medical records (EMRs)
 - Medical charts (natural language processing)
 - Administrative claims
 - Tests & results
 - Self-reported & self-collected data



Big Data in integrated care: Group Health



- Group Health, a pioneering nonprofit HMO, has had Big Data on a stable population **since mid-1970s**, when it computerized prescription refills, lab tests, & diagnoses.
- Advantages: Representative population, ready access to vast amounts of health care & health data with “complete” capture (HMO).
- Group Health’s Big Data: attractive to outside researchers. (GHRI established in 1983.)
- Data, research, & advances = Reputation for innovation & aspirational concept of learning health care system.



Our vision for Big Data: Learning health care system

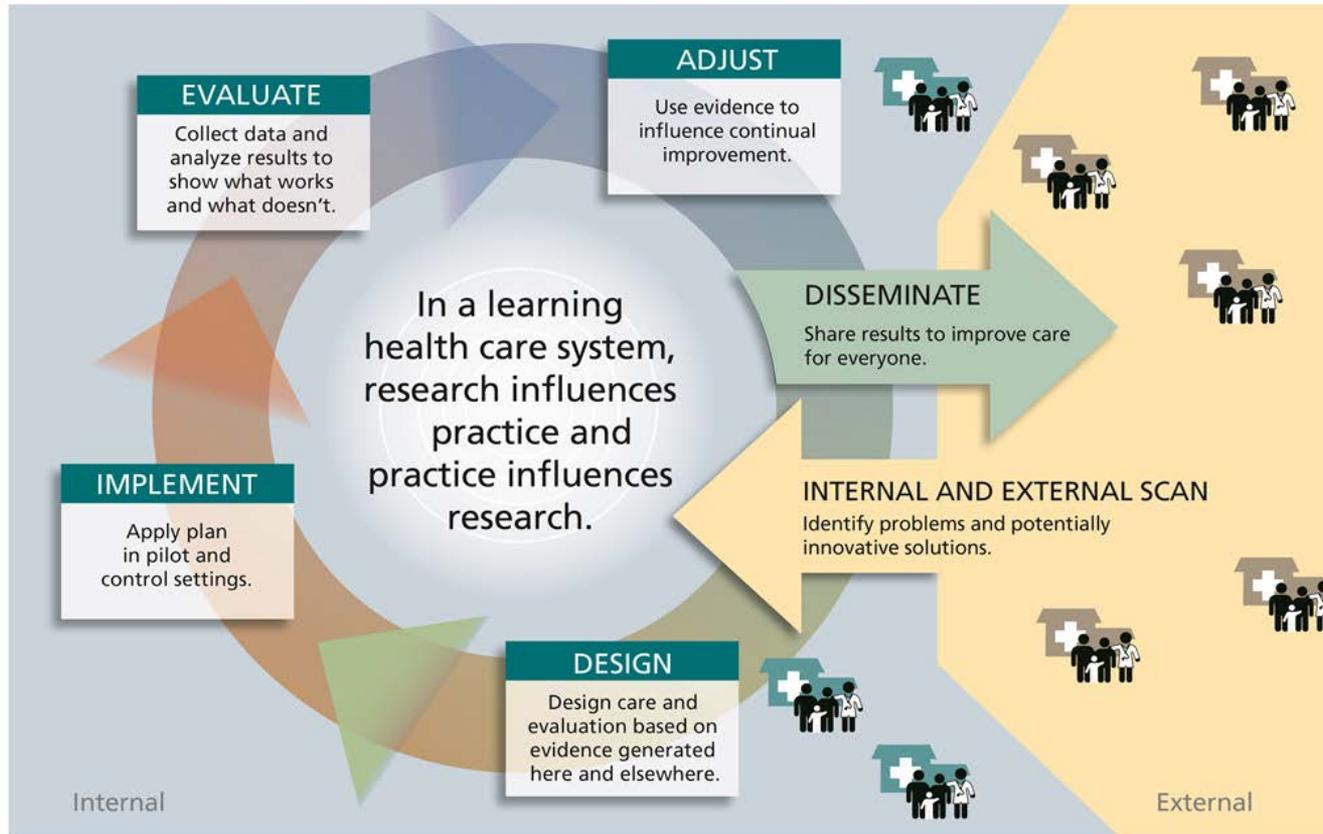


Figure from Group Health Research Institute, in Greene SM, et al. *Annals of Internal Medicine*, 2012.



Cautionary tale: Big Data can mislead

An early lesson:

- Spermicide “use” associated with birth defects & spontaneous abortion (1981).
- Babies with defects from *planned* pregnancies—with no exposure to spermicides (1986). Definitive study disproved original finding (1987).
- Outside researchers knew only “data.”
- Familiarity with data & local practice can be critical to avoid mistakes.



Local & global: Big Data @ Group Health



Broader data networks developed, e.g.:

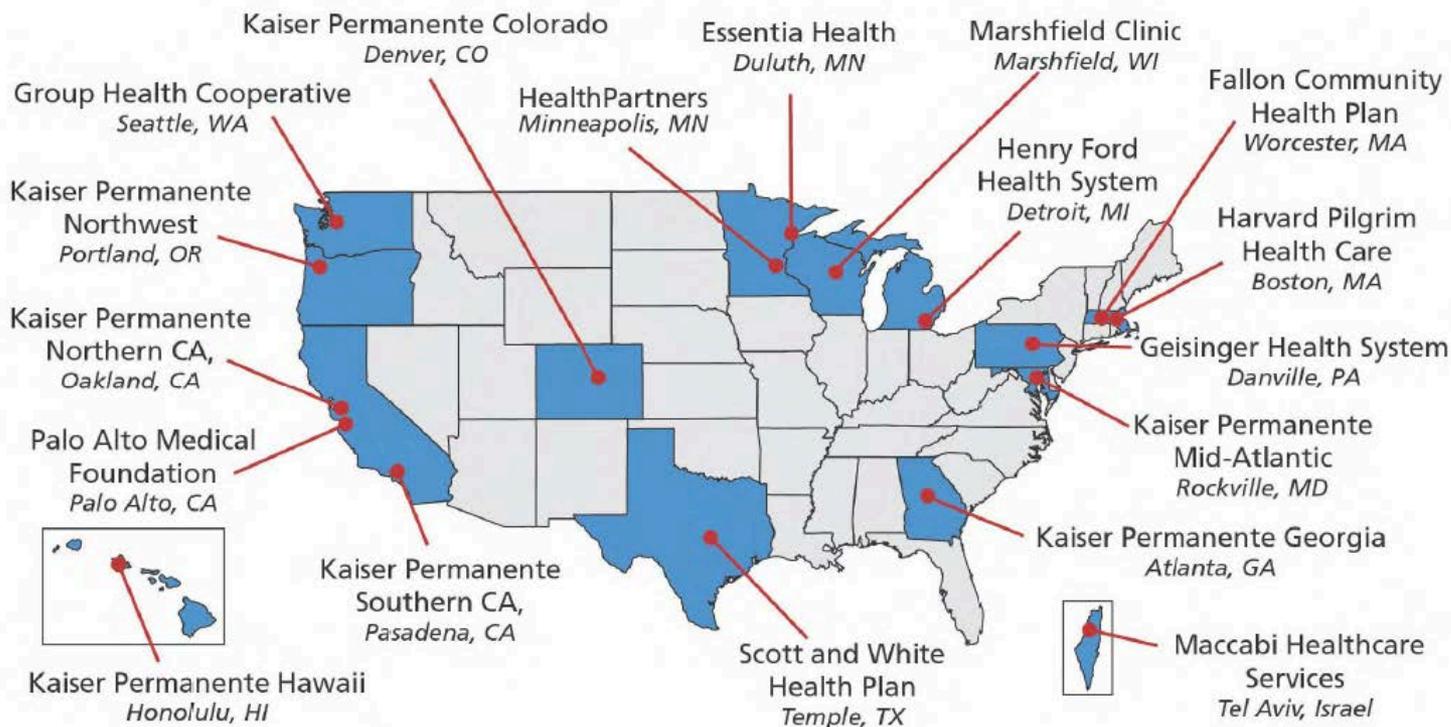
NCI's Cancer Research Network & CDC's **Vaccine Safety Datalink**:

- Integrated systems share data
- Solution: a **“federated” data model**, not centralized model.
- Virtual Data Warehouse (**VDW**): Data stay local, and programs written to extract “de-identified” data.



Similar current activities

- HMO Research Network (**HMORN**)
 - 20 health systems combine information on diverse population of 15 million people for statistical power to answer pressing questions





Similar current activities, cont.



- National Patient-Centered Clinical Research Network (**PCORnet**): Patient-Centered Outcomes Research Institute (PCORI)
- FDA's **Sentinel** Initiative
 - Rapid-response electronic safety-surveillance system monitors drugs, devices, and vaccines in 120 million people
- Electronic Medical Records and Genomics (**eMERGE**) Network:
 - National Human Genome Research Institute (NHGRI) project with 10 institutions
 - Links genomic data from existing biobanks to EMR data to discover genetic causes of disease
 - Uses VDW approach but with standardized download of limited data to public Big Data repository: database of Genotypes and Phenotypes (dbGaP)



The importance of trust

- **Current Examples:** FDA's Sentinel & NIH's Health Care Systems Research Collaboratory using rapidly conducted pragmatic clinical trials
- **Problem:** Overly burdensome "research" oversight
- **Solution:** "Building Trust in the Power of Big Data: Research to Serve the Public Good"

"Routinely collected data provide great potential for extracting useful knowledge to achieve the triple aim in health care."

—2013 IOM Clinical Effectiveness Research Innovation Collaborative (CERIC) report



Patients' perspectives on Big Data

- Most engaged patients are **enthusiastic** about sharing their data—but have some **concerns**.
- **Trust** matters.
- **Local** trust, relationships, & engagement help.
- One prominent concern expressed: **Profit making**



How to build trust in using routine health care records data

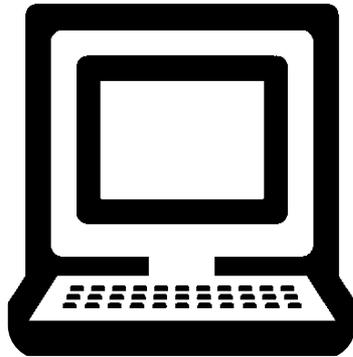
- Local control (VDW) & patient engagement
- Restricted virtual and physical access: “need-to-know principle”
- Culture and policies that respect patient privacy
- Commitment that research serves the public good

“Consider how the consent process could foster respectful engagement rather than merely mitigate risk.”

—Trinidad et al., *Science* 2011, etc.



Efficient use of available data will speed discovery & translation



Use of electronic health records (EHRs)

- EHRs allow efficient and cost-effective, recruitment, data collection, & participant communication, monitoring, & follow-up.



Randomize treatment alternatives based on normal health care operations

- This sometimes mean randomizing at clinic or provider level (“cluster randomization”).



Synchronize your watches

- Increased availability of routine health care data speeds research up.
- Studies that once required decades of data collection can now be accomplished in just months.
- Goal: *quick*—but not *dirty*.





But Big Data will not automatically improve health & health care

Big Data must be transformed into usable and actionable information that **can be used to improve health—& health care's quality and safety.**

- Clinicians need 24/7 decision support based on high-quality, generalizable science from representative populations.
- Patients & general public will also increasingly have that decision support directly at hand.
- Process will involve shared decision making & support behavior changes.



How will we distinguish *responsible* decision support providers from vast amount of bogus material in cyberspace today?





Misleading report: Alzheimer's: even small rise in risk creates fear

- January 2015 paper went around world in hours: United Kingdom front-page news, sensationalizing findings, unleashing panic.
- National Health Service created factsheet to correct misimpressions created by sensationalistic press coverage.
- No dangerous anticholinergics in Benadryl in UK.



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How to declutter your brain - and think better **2** Keeping the pound has saved us from disaster Ed Conway, page 27



Welcome to the fold The Right Rev Libby Lane, the first woman bishop, with the Archbishop of Canterbury yesterday after her historic consecration in York. Page 7

Labour MPs inspired by left's victory in Greece

Lucy Fisher Political Correspondent
Charles Bremner Europe Editor

Labour MPs have hept on the success of a radical left-leaning party in the Greek elections by demanding that Ed Miliband reject austerity.

A former cabinet minister backed the group, which released a signed statement aimed at persuading the Labour leader to pledge significant state investment in the economy and jobs, instead of backing swingeing public cuts.

Among their other demands were calls for the railways to be renationalised once their franchises expire and for trade unions to play an enhanced role in order to combat "excessive corporate power".

The late intervention, led by Michael Meacher and including Diane Abbott, the London mayoral hopeful, came on the eve of the final 100 days of the election campaign.

The MPs were fuelled by optimism after the success of Syriza, the populist anti-austerity party that yesterday formed a governing coalition in Athens. Mr Miliband sought to put distance between Syriza's policies and Labour's commitment to lowering the deficit by reiterating his commitment to "balance the books".

The Labour leader released a muted statement in response to the victory of Alexis Tsipras's party. "It is up to each country to choose its own path on how to deal with the economic and social challenges they face," he said. "We have set out our path for Britain to make sure our country is fairer and more prosperous and balance the books."

The group of 15 leftist MPs were given a boost by Peter Hain, the veteran Labour MP and party granee, who made a separate intervention yesterday that echoed their sentiments. Mr Hain said that the capitalism that dominates today "requires" far more radical responses than the neoliberal, right-wing orthodoxy that has been tanking "crisis-era could ever provide".

Rejecting calls for "more cuts to cure the deficit stigma", the former Northern Ireland and work and pensions secretary also tweeted his support for Syriza. "Welcome, historic Greek voter. How to austerity also boost for anti-austerity case in Britain."

The response to the result from EU

Continued on page 5, col 1

Routine drugs for elderly 'raise risk of dementia'

Well-known brands may increase danger level by 50%, says study

Kat Lay Health Correspondent

Drugs taken by more than half of those aged over 65 in Britain have been linked to an increased risk of dementia.

A large study found that common over-the-counter and prescription medications used to treat heart problems, sleeping difficulties and allergies could mean that users are 50 per cent more likely to develop the disease.

The drugs — which include the brands Nyctel, Benadryl and Piriton — are taken regularly by more than five million over-65s each year. More than 300,000 Britons a year have dementia

diagnosed, and at that rate by 2025 one million people will be living with the disease.

Last night experts urged doctors to review older patients' medications to ensure that the drugs they were taking were necessary.

The study by the University of Washington, published in JAMA Internal Medicine, suggested that the risk of dementia linked to the drugs remained years after people stopped taking them.

The researchers followed 3,414 people aged 65 or older who did not have dementia at the start of the study. More than 600 developed Alzheimer's disease and 160 other forms of dementia. The study examined drugs known as "anticholinergics", which block a chemical transmitter in the nervous system called acetylcholine.

The drugs are also used as anti-depressants and treatments for incontinence and Parkinson's.

People who took a daily dose more than 1,095 times over ten years had a 54 per cent higher risk of developing dementia, and people who took between 366 and 1,095 doses had a 23 per cent higher risk, the study found.

One of the drugs, amitriptyline, can be used to relieve chronic pain, and an arthritis sufferer could be put on a long-term dose of 75mg per day.

Another of the drugs likely to be used longterm is warfarin, which helps to thin blood. Patients who have had a clot occur spontaneously are at high risk of it happening again, so may need to take the drug for the rest of their life.

A major British study of over-65s four years ago found that half its 11,000 participants were taking drugs with potential anticholinergic properties.

Chris Fox, of the University of East Anglia, who led that research, said clinicians should review their use. "Some

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Association of Health Care Journalists: Help!

- Big Data & Internet have tremendous persuasive power.
- Too much self-promoting advice & products—from private & public (including academic) sectors
- Overdiagnosis, overtreatment, & medicalization of everyday life = huge threat.
- Honest brokers are needed, so quick Big Data don't lead to quick & dirty hype.

“Improving public understanding of health and health care”

—AHCJ tagline is ideal for this task



Thank you.

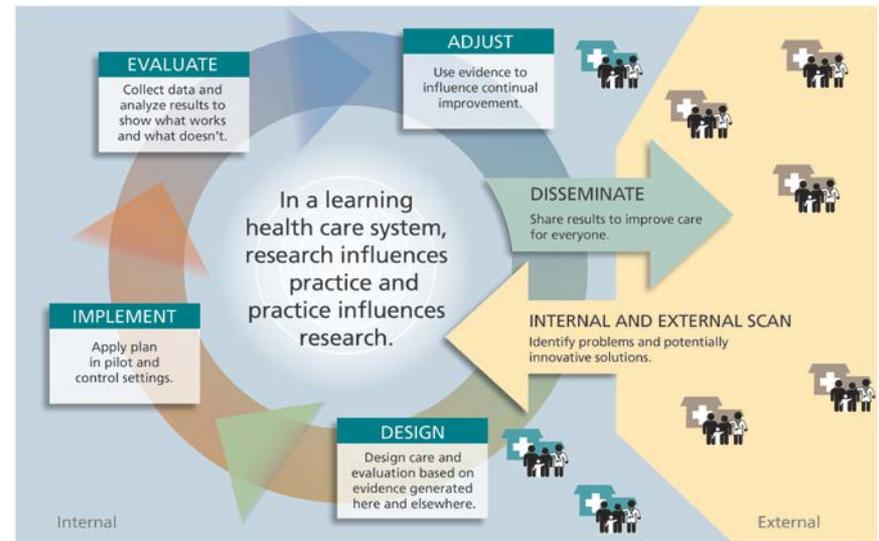
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