CONNECTING FOR HEALTH
COMMON FRAMEWORK

Resources for Implementing Private and
Secure Health Information Exchange

Learning What Works: IOM Roundtable on Evidence-Based Medicine
July 30, 2008

Carol C. Diamond MD, MPH
Managing Director, Markle Foundation
Chair, Connecting for Health

Where we are today

Learning What Works Best

IOM Roundtable on Evidence Based Medicine

IOM has clearly articulated the challenge…

Health care under-performs on many dimensions

- high cost
- poor performance,
- inconsistent delivery of evidence based
- large variations in care delivered unrelated to outcomes and unexplained by burden of illness, etc.
- large gaps in evidence
- long time lags research
- a chasm in applying results to clinical care and
- a rate of innovation in devices, biologics and procedures that outpaces research on comparative effectiveness generally…
- and on what works best for a particular individual (personalized medicine)

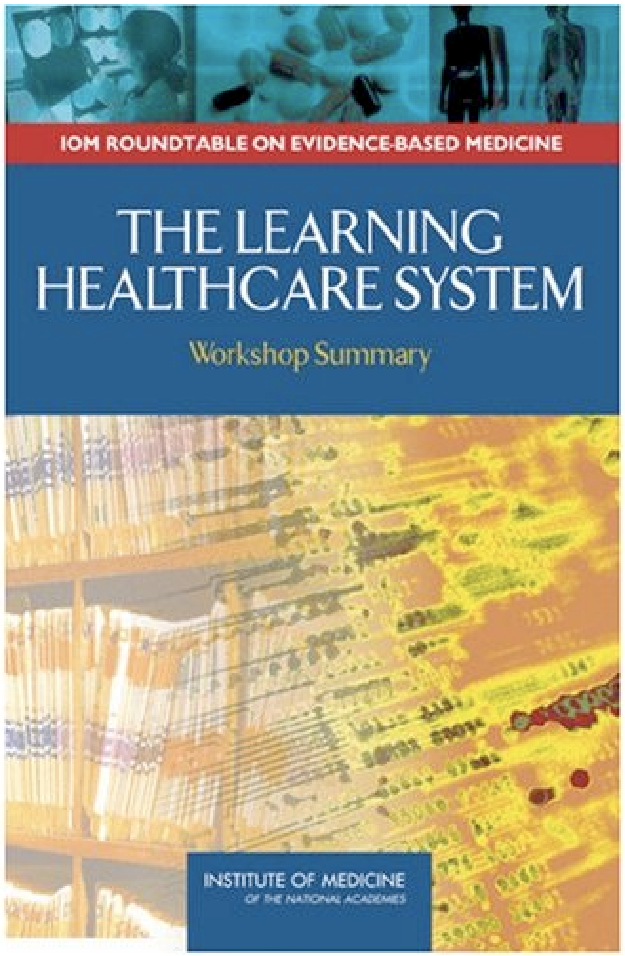
IOM has clearly articulated the challenge…

Health care under-performs on many dimensions

- Called for better information on the comparative effectiveness of diagnostic and therapeutic interventions
- To date, our methods, tools, investments and approaches to this problem have fallen short.

IOM has created the vision

a "Learning Healthcare System"



- Transformed by the availability and use of the best evidence for the collaborative health care choices of patient and provider;
- The process of discovery as a natural outgrowth of patient care; to ensure innovation, quality, safety, and value in health care.

Urgency!

"Rising health care costs represent the central fiscal challenge facing the country"

Peter Orzag, Director, CBO

What does a new center on comparative effectiveness require in the way of information networks?

- Success may be dependent on our ability to change our standard approaches to information collection and use.
    1. Clearly define the ultimate goal
    2. Be open to reset our definitions and assumptions about health data and research approaches
    3. Articulate new, broadly accepted working principles based on 21st century information paradigms
    4. Develop an information policy framework that broadly addresses public hopes and concerns

1. Clearly define the ultimate goal

Whose actions are you trying to impact with the information?

Lets be clear about the goal

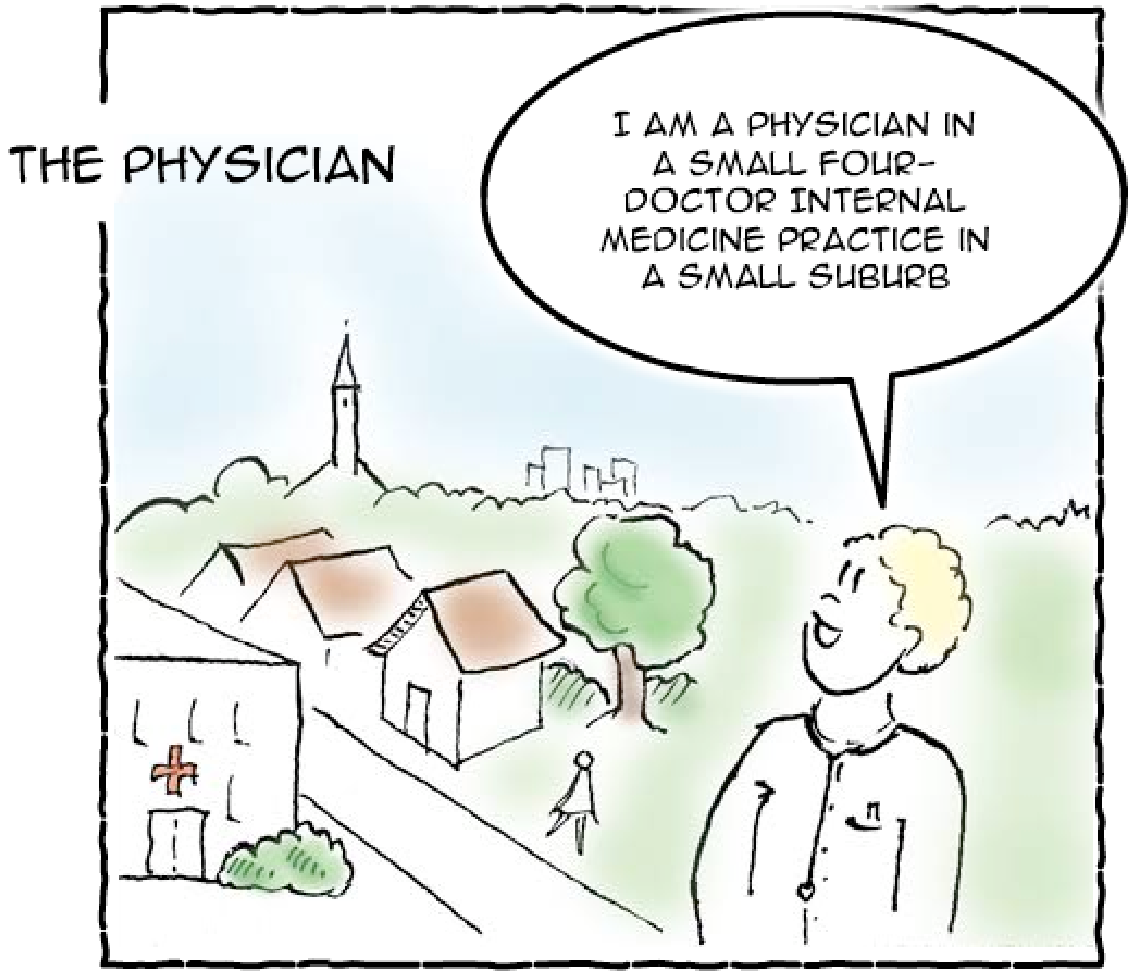
- Too often we let discussions about IT, data, standards, methods obscure our focus on the goal.
- Comparative effectiveness research is a tool
- Its ability to have impact on costs and outcomes depends on how it is used.
- Decision-makers should be more defined broadly than referring to those who need to develop guidelines or those who design benefits

The goal

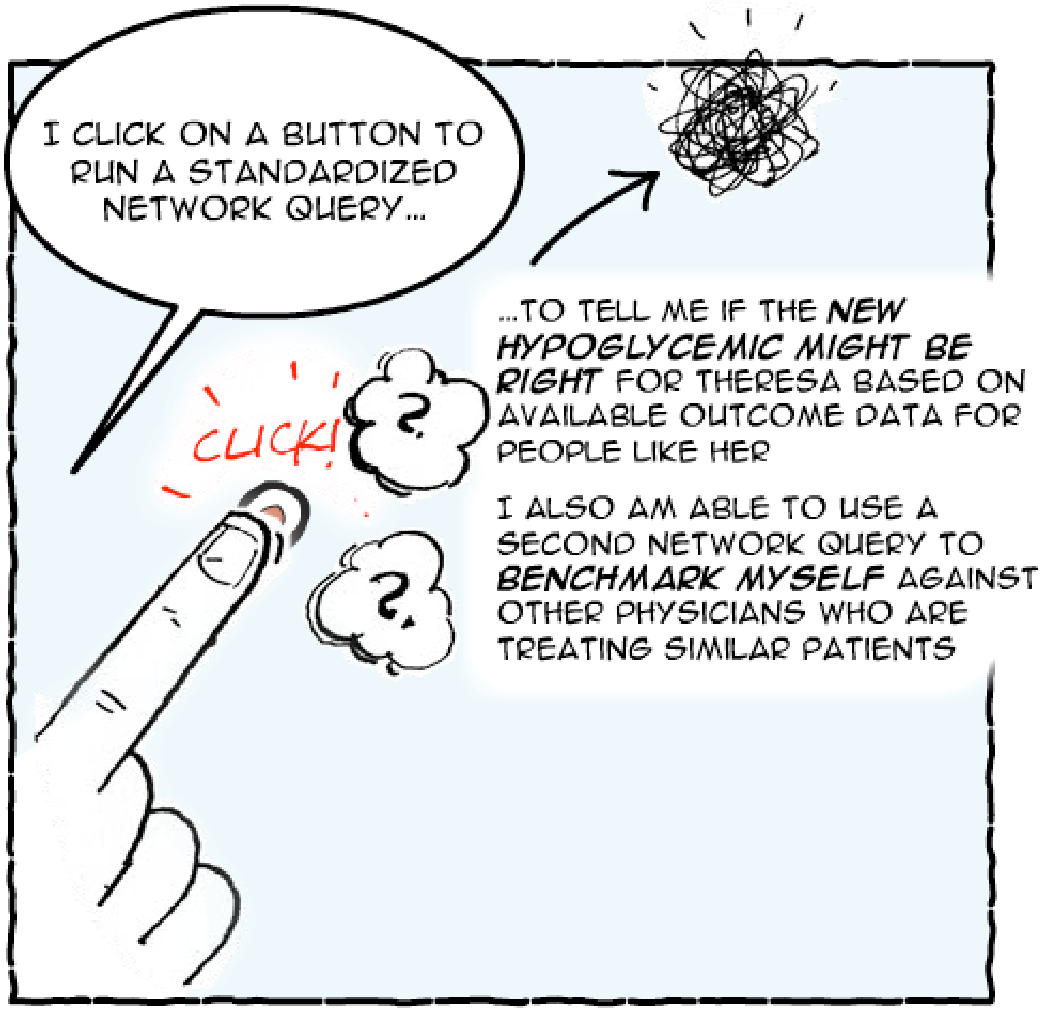
- Real transformation occurs when very clinical encounter is an opportunity to provide the right care to the right patient

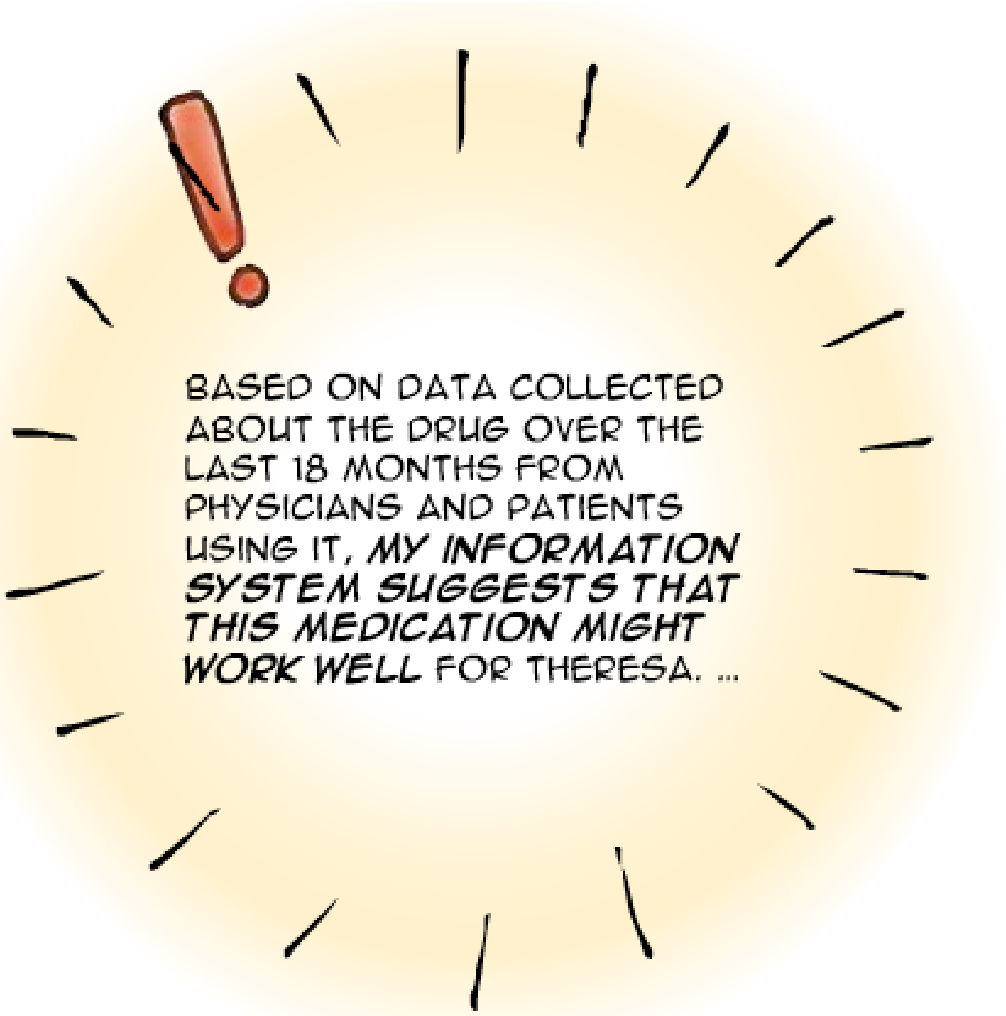
  A learning healthcare system is transformed by the availability and use of the best evidence for the collaborative health care choices of patient and provider

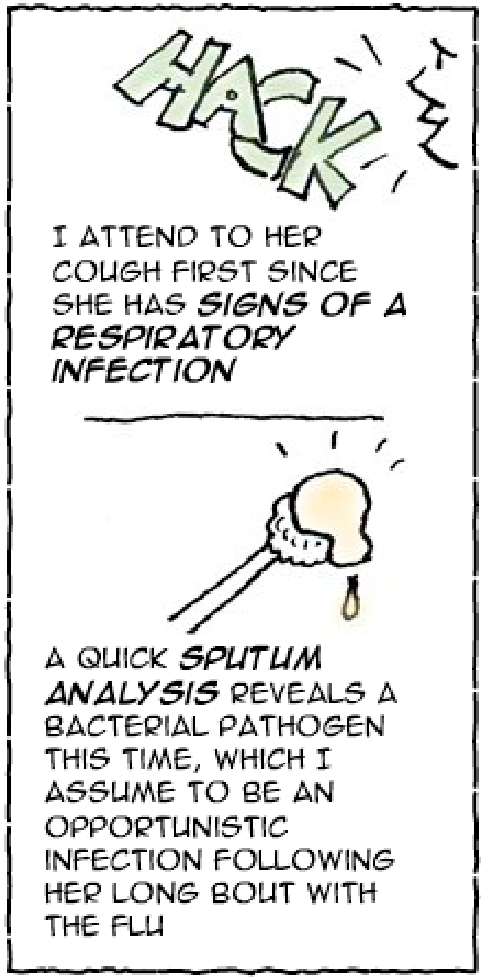
- A comprehensive approach to effectiveness research is inherently challenging today because of the lack of controlled environment for assessing therapeutic options and the heterogeneity of patient characteristics (never, always and "truth")
- This almost by definition requires thinking in terms of connectivity and networks rather than databases

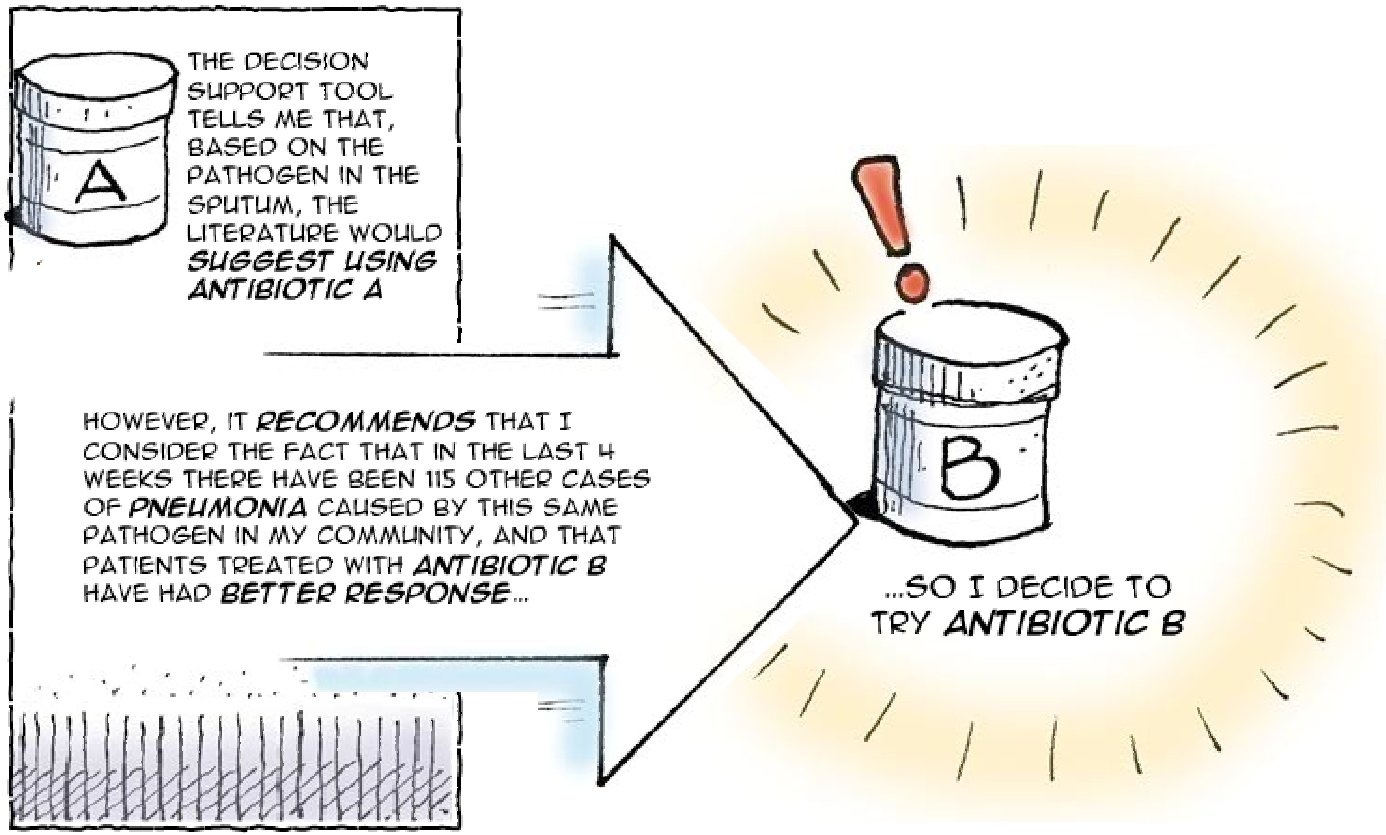

THE PHYSICIAN
I AM A PHYSICIAN IN A SMALL FOUR-DOCTOR INTERNAL MEDICINE PRACTICE IN A SMALL SUBURB

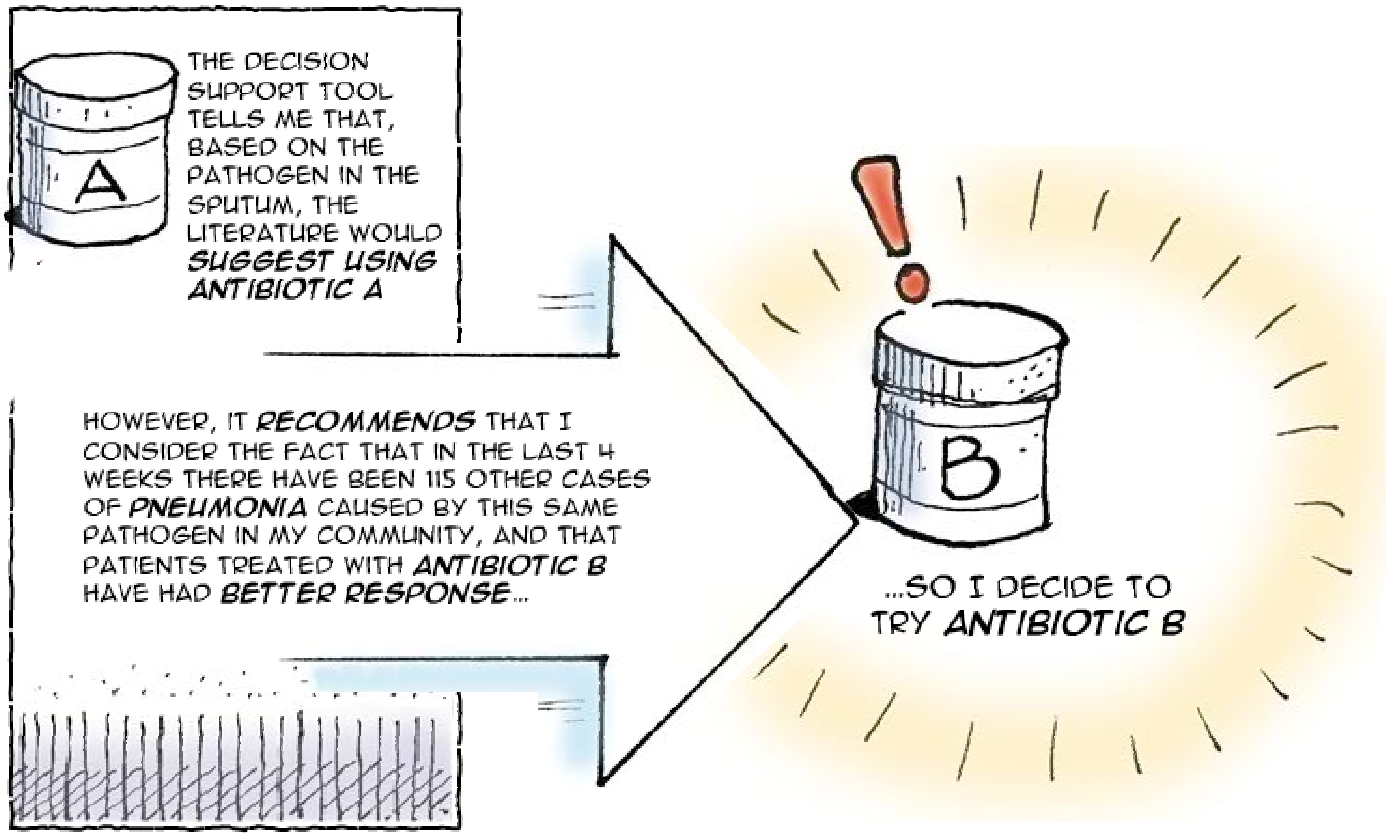
I CLICK ON A BUTTON TO RUN A STANDARDIZED NETWORK QUERY...


I CLICK ON A BUTTON TO RUN A STANDARDIZED NETWORK QUERY...
...TO TELL ME IF THE NEW HYPOGLYCEMIC MIGHT BE RIGHT FOR THERESA BASED ON AVAILABLE OUTCOME DATA FOR PEOPLE LIKE HER
I ALSO AM ABLE TO USE A SECOND NETWORK QUERY TO BENCHMARK MYSELF AGAINST OTHER PHYSICIANS WHO ARE TREATING SIMILAR PATIENTS
CLICK!
?
?


BASED ON DATA COLLECTED ABOUT THE DRUG OVER THE LAST 18 MONTHS FROM PHYSICIANS AND PATIENTS USING IT, MY INFORMATION SYSTEM SUGGESTS THAT THIS MEDICATION MIGHT WORK WELL FOR THERESA. ...


HACK
I ATTEND TO HER COUGH FIRST SINCE SHE HAS SIGNS OF A RESPIRATORY INFECTION
A QUICK SPUTUM ANALYSIS REVEALS A BACTERIAL PATHOGEN THIS TIME, WHICH I ASSUME TO BE AN OPPORTUNISTIC INFECTION FOLLOWING HER LONG BOUT WITH THE FLU


A
THE DECISION SUPPORT TOOL TELLS ME THAT, BASED ON THE PATHOGEN IN THE SPUTUM, THE LITERATURE WOULD SUGGEST USING ANTIBIOTIC A
HOWEVER, IT RECOMMENDS THAT I CONSIDER THE FACT THAT IN THE LAST 4 WEEKS THERE HAVE BEEN 115 OTHER CASES OF PNEUMONIA CAUSED BY THIS SAME PATHOGEN IN MY COMMUNITY, AND THAT PATIENTS TREATED WITH ANTIBIOTIC B HAVE HAD BETTER RESPONSE...
B
...SO I DECIDE TO TRY ANTIBIOTIC B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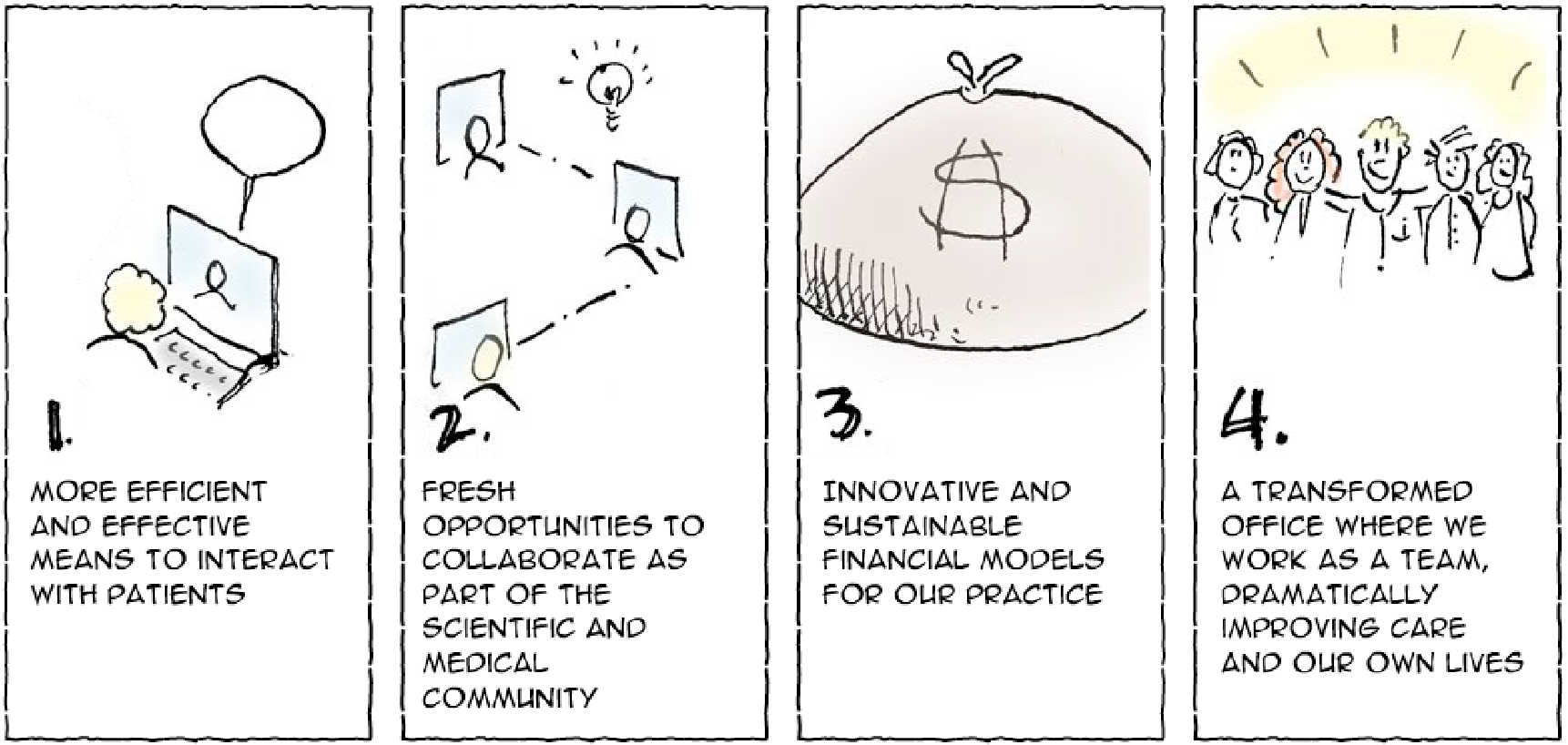
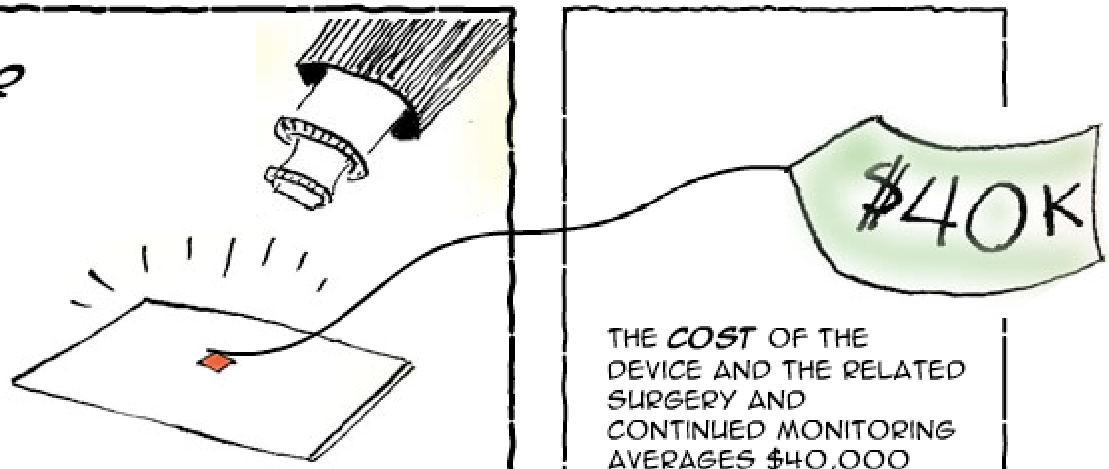

1.
MORE EFFICIENT AND EFFECTIVE MEANS TO INTERACT WITH PATIENTS
2.
FRESH OPPORTUNITIES TO COLLABORATE AS PART OF THE SCIENTIFIC AND MEDICAL COMMUNITY
3.
INNOVATIVE AND SUSTAINABLE FINANCIAL MODELS FOR OUR PRACTICE
4.
A TRANSFORMED OFFICE WHERE WE WORK AS A TEAM, DRAMATICALLY IMPROVING CARE AND OUR OWN LIVES

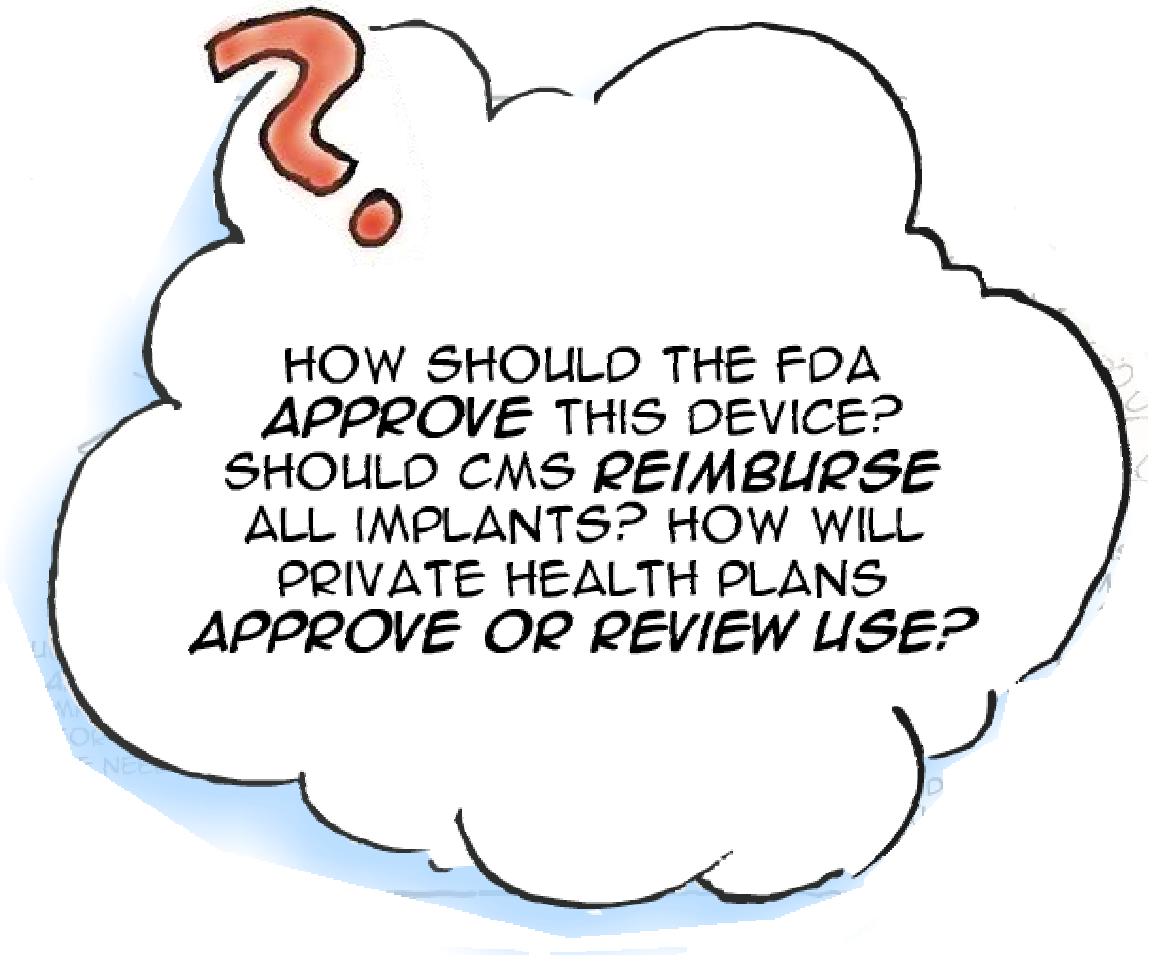
THE POLICY-MAKER

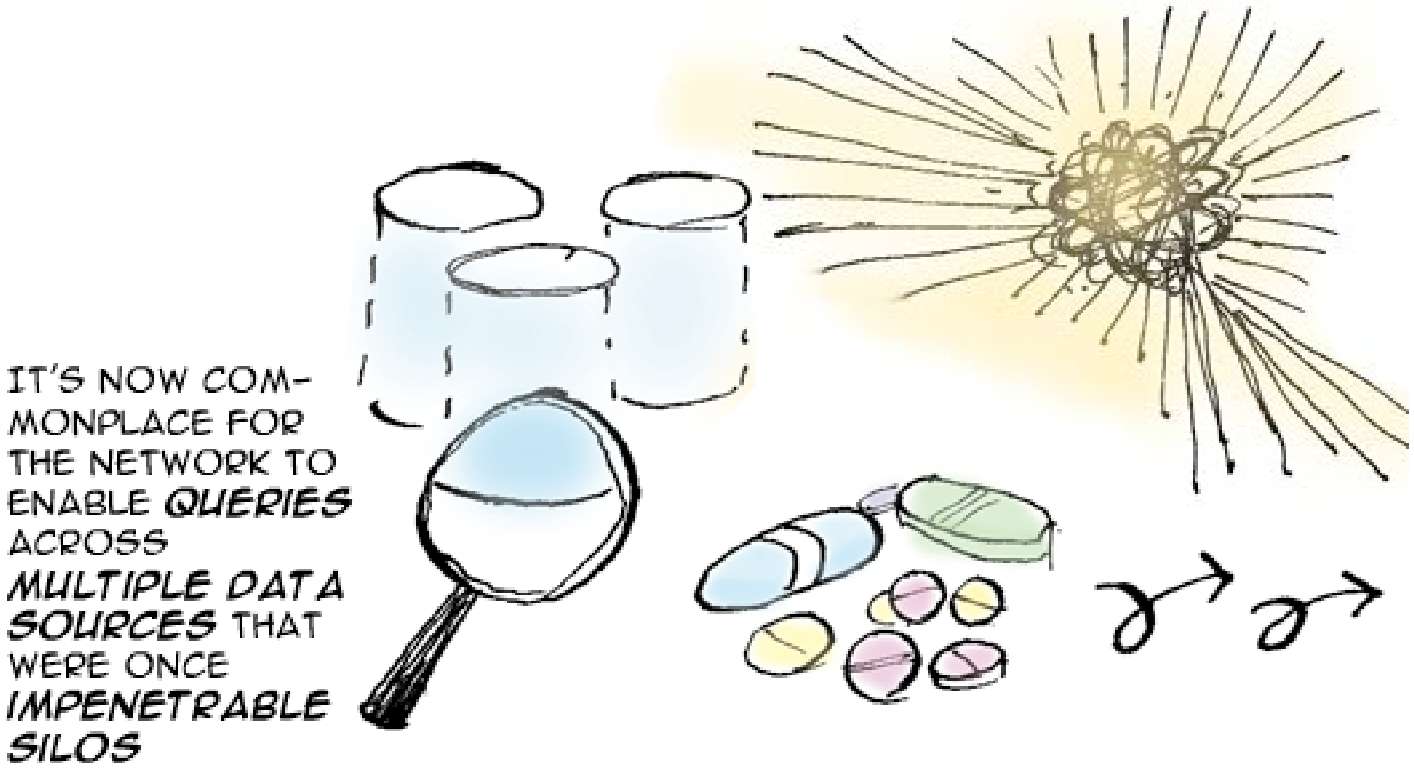


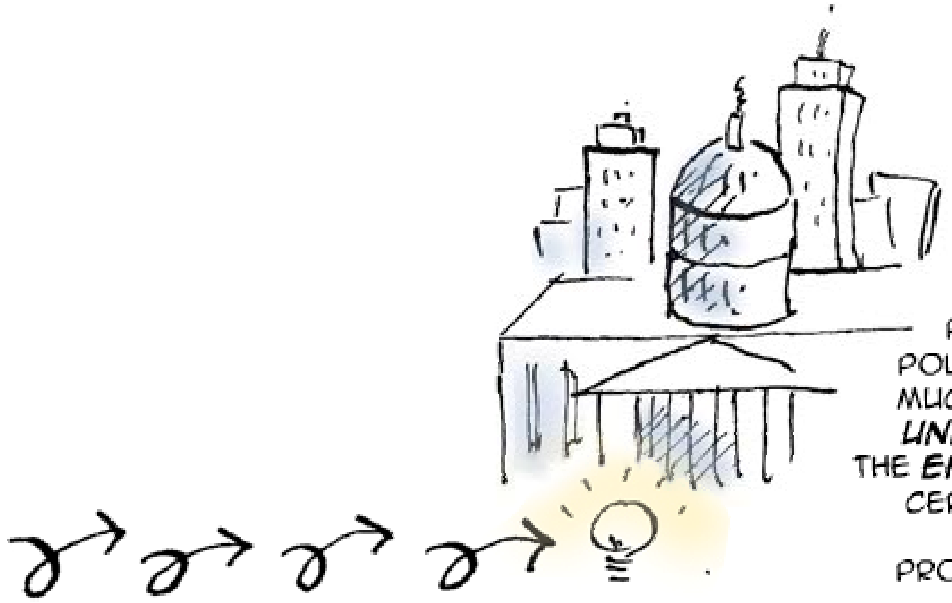
HEALTH PLANS BOTH PUBLIC AND PRIVATE WANT TO ANALYZE A ***NEW, IMPLANTABLE RENAL NANO-DEVICE*** THAT HAS RECENTLY COMPLETED CLINICAL TRIALS AND SHOWN GREAT BENEFIT FOR MANY PATIENTS WITH KIDNEY FAILURE, ***PREVENTING*** THE NEED FOR ***DIALYSIS OR KIDNEY TRANSPLANT.***

THE ***COST*** OF THE DEVICE AND THE RELATED SURGERY AND CONTINUED MONITORING AVERAGES $40,000 PER PATIENT PER YEAR,

AND PATIENTS MUST ***REMAIN COMPLIANT*** WITH A NEW ORAL MEDICATION TO AVOID SERIOUS COMPLICATIONS


?
HOW SHOULD THE FDA APPROVE THIS DEVICE? SHOULD CMS REIMBURSE ALL IMPLANTS? HOW WILL PRIVATE HEALTH PLANS APPROVE OR REVIEW USE?


IT'S NOW COM-
MONPLACE FOR
THE NETWORK TO
ENABLE QUERIES
ACROSS
MULTIPLE DATA
SOURCES THAT
WERE ONCE
IMPENETRABLE
SILOS



PAYERS AND PUBLIC POLICYMAKERS HAVE A MUCH MORE GRANULAR ***UNDERSTANDING*** OF THE ***EFFECTIVENESS*** OF CERTAIN TREATMENTS, AND CAN ***TARGET*** PROVIDER AND PATIENT EDUCATION ***INTERVENTIONS*** MUCH MORE ***EFFECTIVELY***

THE ***INNOVATION CYCLE*** HAS QUICKENED – PROMISING NEW USES ARE QUICKLY DIFFUSED THROUGH THE REAL-TIME ONLINE CHANNELS. AT THE SAME TIME, WE QUICKLY STAMP OUT SPURIOUS AND UNFOUNDED OFF-LABEL USES. THE PHARMACEUTICAL AND DEVICE INDUSTRY, ALONG WITH THEIR CLINICAL PARTNERS, DEVELOP ***FASTER, BETTER AND CHEAPER*** NEW TECHNOLOGIES AND CREATIVE USES OF EXISTING TECHNOLOGIES.

2. An effort to address capacity for clinical and comparative effectiveness research should be open to reset our definitions and assumptions about health data and research approaches

Kenneth Buetow, National Cancer Institute

- The current world of biomedicine is best characterized as information "islands"
- Information dissemination uses methods recognizable to Gutenberg

Presentation to AHIC July 29, 2008

http://www.hhs.gov/healthit/documents/m20080729/06c_buetow_files/800x600/slide5.html

Albert Einstein said, “Insanity is doing the same thing over and over again and expecting different results” ...

The Way We Do it Today

- Most of the effort in trying to collect, clean and then "silo" data from a decentralized and fragmented system.
- Places a huge burden on data "providers" to submit the (same) information repeatedly to different repositories
- Creates separate repositories for each specific purpose at great cost in money and time
- Poorly adaptable and therefore "success" is elusive
- Creates privacy and security vulnerabilities
- Lacks connectivity, feedback, and broad USE for better decision-making
- Does not include the consumer (and often not the provider) as a key and active participant

Its not just about data

- An explosion of data
- 450,000 peer-reviewed medical journal articles are published each year. David Adams, "Information Overload", December 8, 2005 – Available at http://www.smh.com.au/articles/2005/12/06/1133829599706.html
- But, we have slow and uneven distribution of innovation and information

Where has the typical gap between clinical research and care delivery been most successfully overcome?

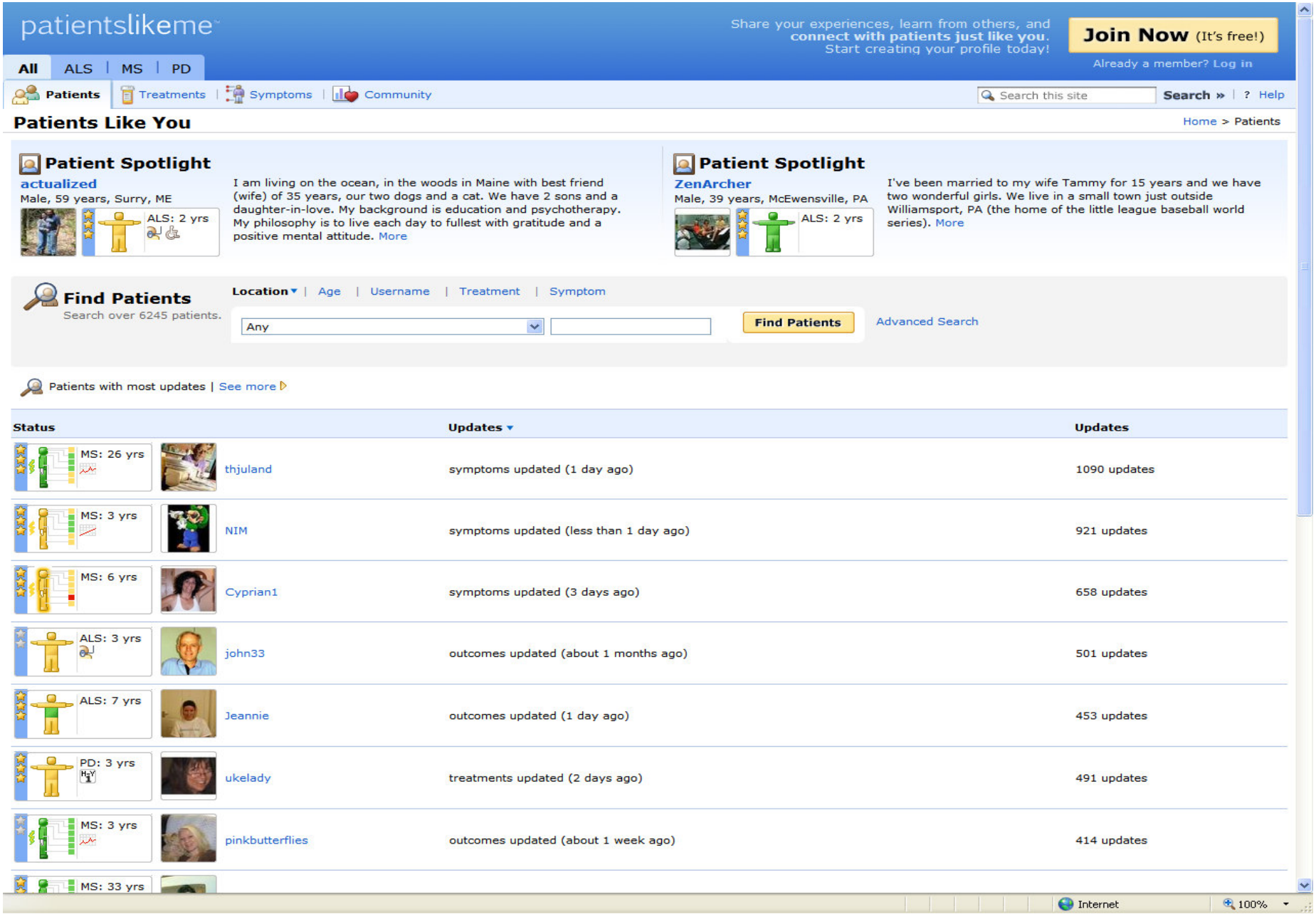
- Childhood cancer is an often used example of an area where the silos of clinical care and clinical research have been "connected"
- The result has been dramatic improvement in survival over the last 20-30 years
- Clinicians and researchers are part of a unique community that has been able to utilize clinical data continuously to evaluate outcomes to improve protocols and treatments
- This was not accomplished because of a special network or early EHR adoption

A networked society has already begun to change traditional research paradigms

"We believe that the Internet can democratize patient data and accelerate research like never before"

"PatientsLikeMe was built to… accelerate the transfer of knowledge about what works and what does not. Today, PatientsLikeMe has data on the progression and history of more than 1600 ALS patients - twice the number in the largest ALS trial in history. Even before the trial results were published, 50 patients worldwide who had elected to start taking lithium, in collaboration with their doctors, have been tracking their progression and blood levels on PatientslikeMe. This is more than twice the number of patients participating in the trial itself! We have data on historical forced vital capacity, the ALS Functional Rating scale, and a full symptom battery for most of the patients who have started, as well as for all the other non-lithium users in our system."

(from http://blog.patientslikeme.com/)


patientslikeme
Share your experiences, learn from others, and connect with patients just like you. Start creating your profile today!
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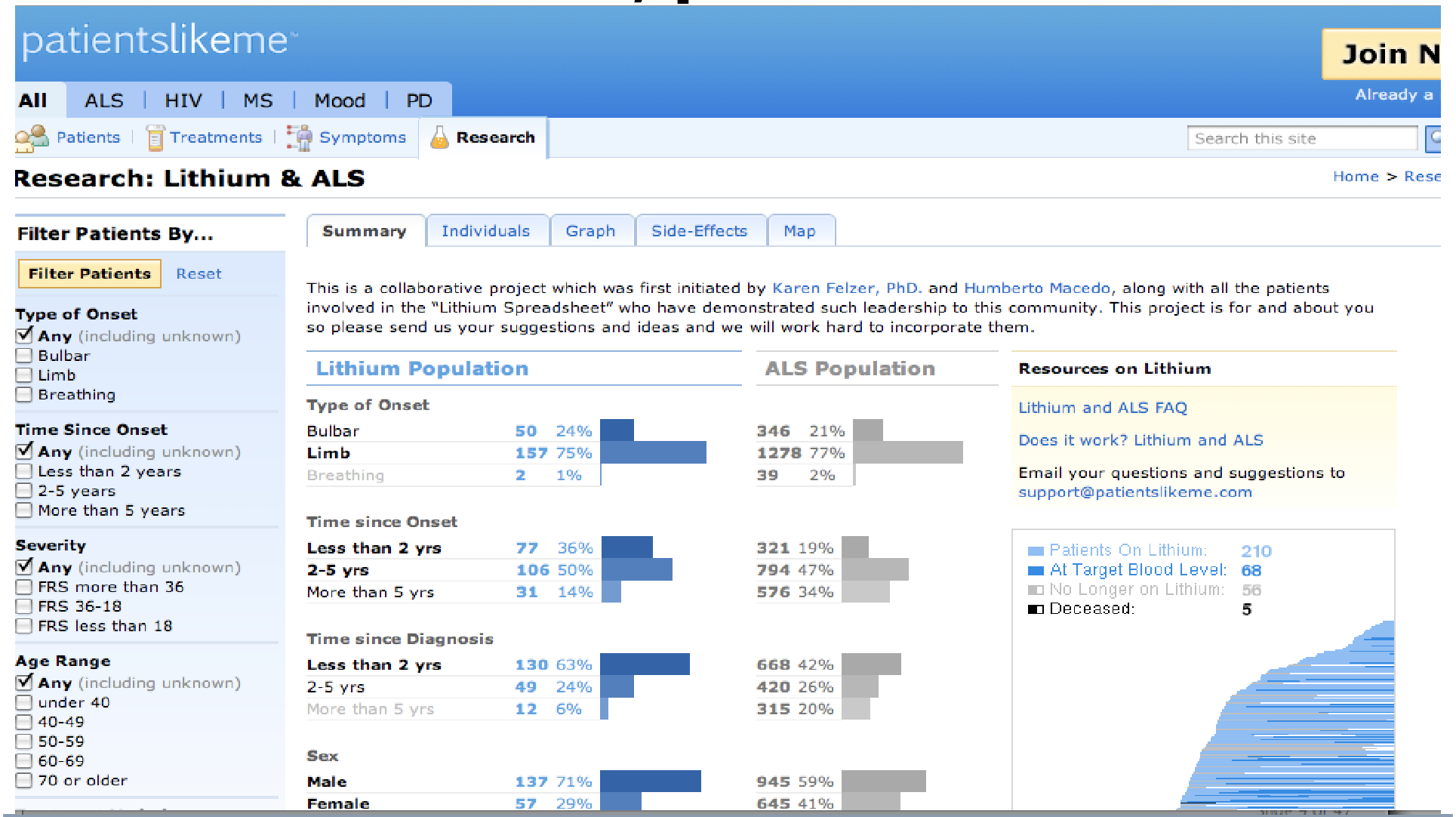
Already a member? Log in
All | ALS | MS | PD
Patients | Treatments | Symptoms | Community
Search this site
Search » | ? Help
Patients Like You
Home > Patients
Patient Spotlight
actualized
Male, 59 years, Surry, ME
ALS: 2 yrs
I am living on the ocean, in the woods in Maine with best friend (wife) of 35 years, our two dogs and a cat. We have 2 sons and a daughter-in-love. My background is education and psychotherapy. My philosophy is to live each day to fullest with gratitude and a positive mental attitude. More
Patient Spotlight
ZenArcher
Male, 39 years, McEwensville, PA
ALS: 2 yrs
I've been married to my wife Tammy for 15 years and we have two wonderful girls. We live in a small town just outside Williamsport, PA (the home of the little league baseball world series). More
Find Patients
Search over 6245 patients.
Location | Age | Username | Treatment | Symptom
Any
Find Patients
Advanced Search
Patients with most updates | See more
Status
Updates
Updates
MS: 26 yrs
thjuland
symptoms updated (1 day ago)
1090 updates
MS: 3 yrs
NIM
symptoms updated (less than 1 day ago)
921 updates
MS: 6 yrs
Cyprian1
symptoms updated (3 days ago)
658 updates
ALS: 3 yrs
john33
outcomes updated (about 1 months ago)
501 updates
ALS: 7 yrs
Jeannie
outcomes updated (1 day ago)
453 updates
PD: 3 yrs
ukelady
treatments updated (2 days ago)
491 updates
MS: 3 yrs
pinkbutterflies
outcomes updated (about 1 week ago)
414 updates
MS: 33 yrs
Internet
100%

"the first real-time, real-world, open and non-blinded, patient-driven trial".



3. Articulate new, broadly accepted working principles based on 21st century information paradigms

The 21st century Health care environment

- Increasingly distributed needs for sharing and accessing information about what works best
- Increasingly sophisticated "nodes" capable of analytics
- Seeing research as occurring in a connected environment, not a database ("connecting silos into a community)
- Clinicians as researchers and researchers as clinicians
- Embracing consumers as key producers, users and potentially managers of clinical data and partners in the research process
- A networked and distributed approach to information sharing and evidence creation
- Tolerance for incremental progress

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Columnists: John Drescher | Dennis Rogers | Barry Saunders | Ruth Sheehan | Road Worrier

Published: Feb 21, 2008
Modified: Feb 21, 2008

State hacking through worst of flu season

This year's vaccination is a flawed match for current viruses it should fight

MANDY LOCKE AND LORENZO PEREZ, Staff Writers

Your son can't shake his cough. At work, you're doing the tasks of three while your colleagues are home in bed. Grandma waited five hours to be seen at the hospital's emergency department last night.

Sound familiar? North Carolina is smack dab in the worst of the seasonal flu. We're at the top of a two-week peak that's forced long lines at pharmacies, long waits at doctors' offices and toppled even those smart enough to get the flu vaccine this year.

Is it the worst flu season in recent years? The ailing would declare it so. But public health officials are reluctant to say that, mai
receive from health provi
are not consistent year to
always think it's the wors
the middle of it.

Still, there are reasons w
bad:

* The vaccine missed the
antibodies didn't match th
year, said Jeff Engel, the
Health epidemiologist. Th

Story Tools

Printer Friendly | Email to a Friend

Enlarge Font | Decrease Font

BOOKMARK | Buzz up!

COLD OR FLU

Here's a guide to determining whether the flu i
responsible for your sniffles:

SymptomsCOLDFLU

Is it the worst flu season in recent years? The ailing would declare it so. But public health officials are reluctant to say that, mainly because reports they receive from health providers come voluntarily and are not consistent year to year. Doctors insist we

Syndromic.org

DiSTRIBuTE for Flu Surveillance

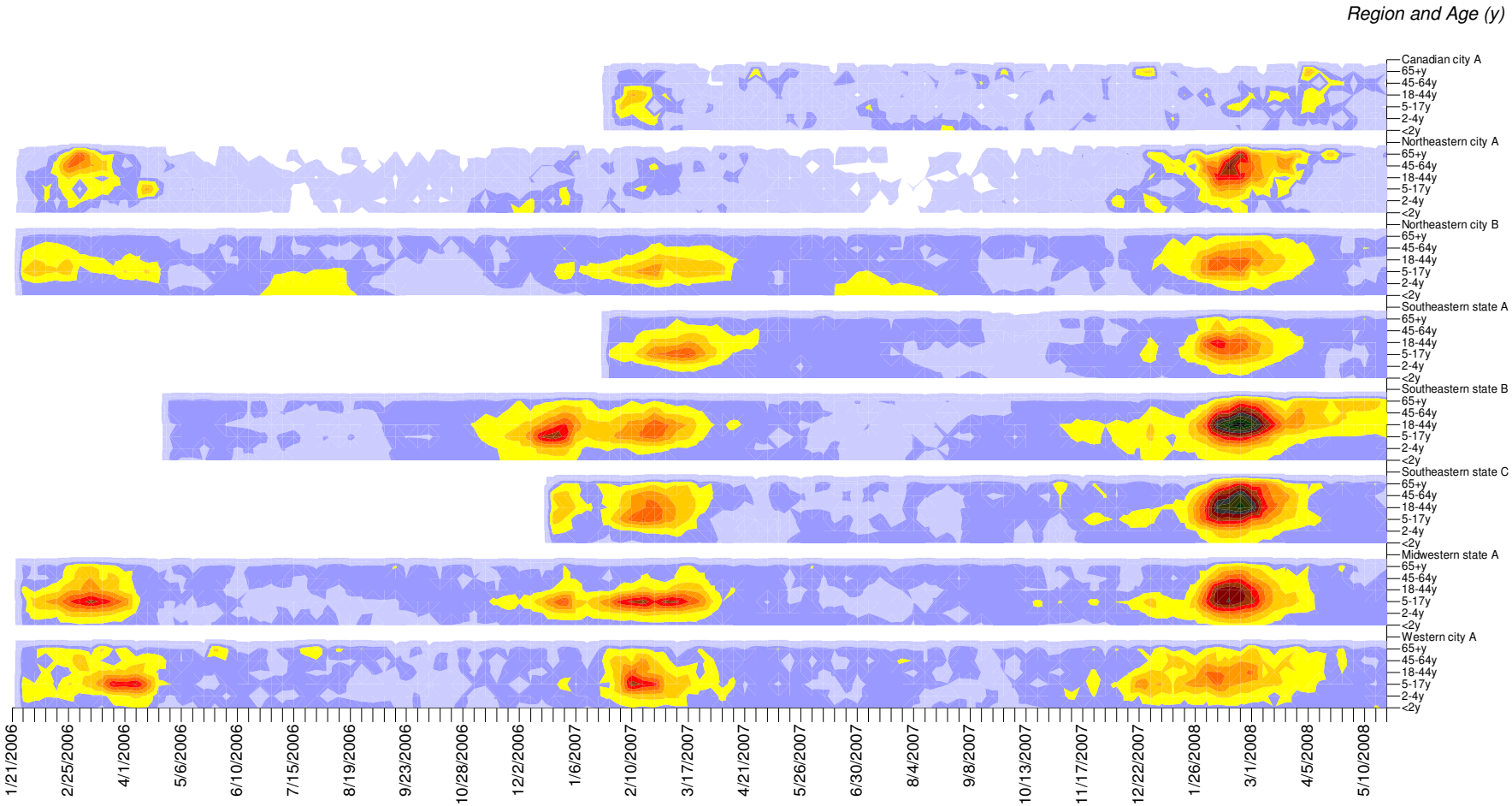
http://www.syndromic.org

- Uses summarized counts of influenza-like-illness (ILI) syndrome reported by age group from existing syndromic surveillance systems.
- The data is visualized and used to provide public health practitioners with age-specific weekly trends in influenza morbidity.
- The DiSTRIBuTE approach changes the traditional surveillance paradigm from central data collection and analysis to one of distributed data collection and analysis with central monitoring of summary information.
- By limiting the data request to the information that is truly the minimum required (summarized counts), the system has retained the ability to demonstrate meaningful flu trending data quickly and cost effectively.

International Society
For Disease Surveillance

DiSTRIBuTE Visualizations - Week 2008-21 (ending Saturday, May 24, 2008)

Surface plots depict relative increase in ED syndrome visits as observed / baseline by jurisdiction and age.



Relative increase (observed/linear-baseline).

CONNECTING FOR HEALTH COMMON FRAMEWORK

Results from the 2007/2008 Influenza Season

- During 2007/08 season, over 300,000 encounters were reported per week from eight participating sites in the DiSTRIBuTE network- a number equivalent to the weekly total collected from all sites in the current national manual reporting system.
- By limiting the data request to the information that is truly the minimum required (summarized counts), the system has retained the ability to demonstrate meaningful flu trending quickly and cost effectively.

4. An information policy

What are the network requirements?

Motive, standards, methods and rules—that's how you get leverage

Americans recognize the "upside"… and the "downside"…

- Significant concern about privacy and security
  - 85% say protecting confidentiality absolutely essential
  - FACCT survey: 91% "very concerned" (barrier for 1/4)
  - Strong desire to "control" who sees health information
- Fear of misuses
  - 52% believe employer uses medical info to affect personnel or insurance benefits (CHCF Survey 2005)
  - 85% believe if genetic test results known to insurers, would refuse policies or charge more (Genetics and Public Policy Center Survey 2007)
- Three-quarters of Americans are willing to share their personal information to help public officials look for disease outbreaks and research ways to improve the quality of health care if they have safeguards to protect their identity (Markle Survey 2006).

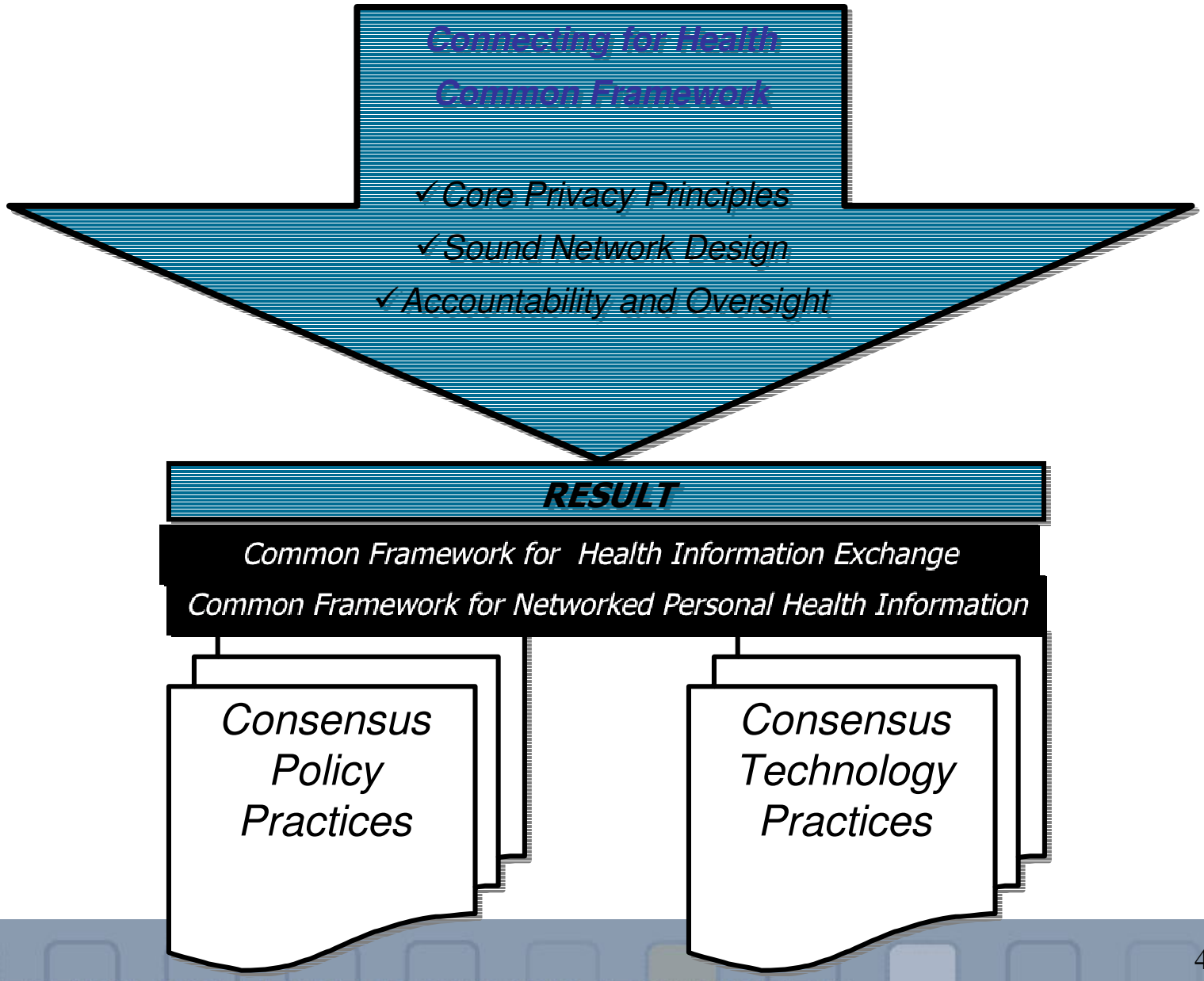
Connecting for Health…*A Public Private Collaborative*

- Convened and operated by the Markle Foundation since 2002, additional support from the RWJF
- Brings together private, public, and not-for-profit groups
- Works to accelerate the development of a health information-sharing environment to improve the quality and cost effectiveness of health care while protecting privacy
- Our approach is rooted in looking at technical AND policy issues together!
- http://www.connectingforhealth.org

Connecting for Health

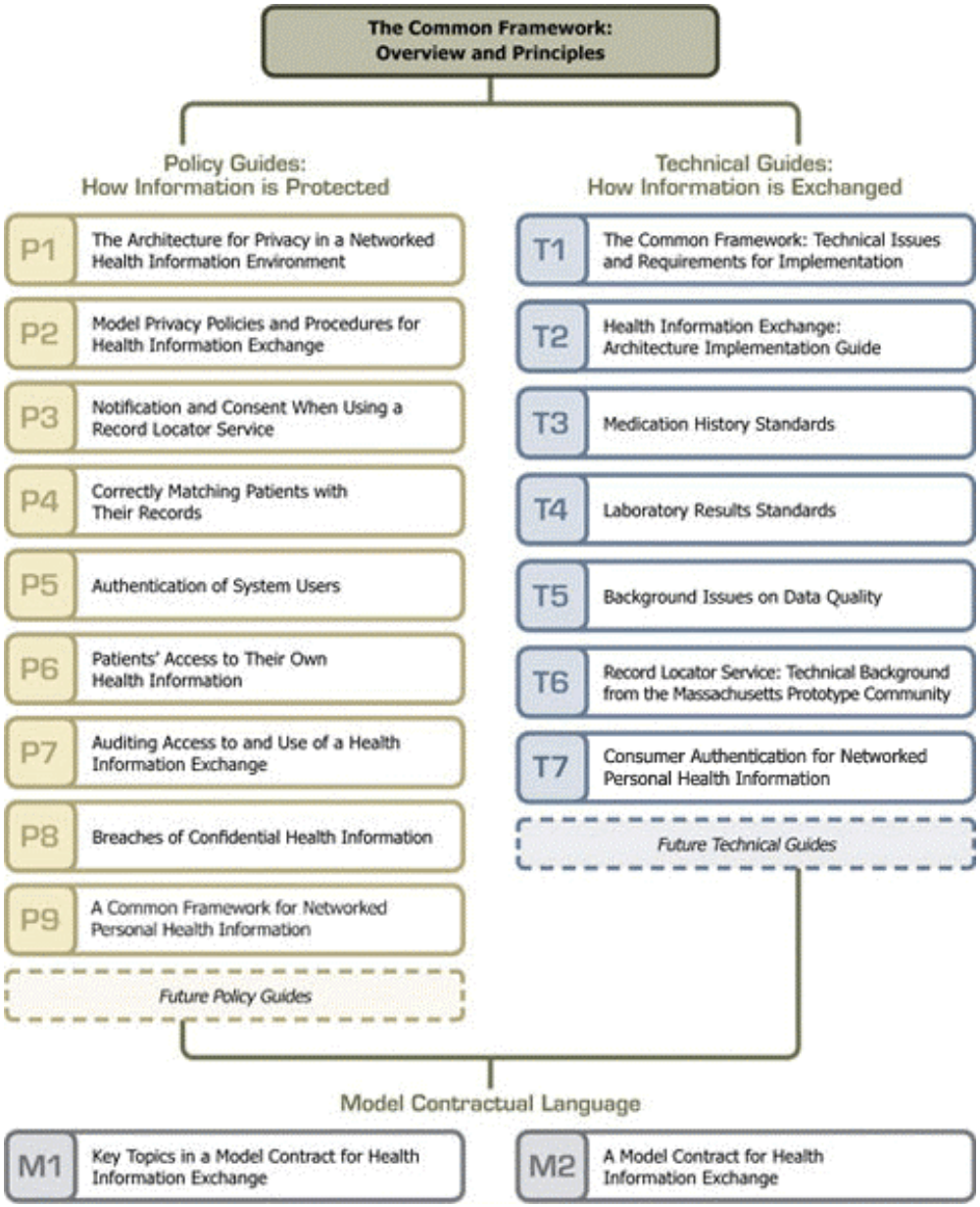
- **Connecting Professionals**: Common Framework for Health Information Exchange (released April 2006)
- **Connecting Consumers**: Common Framework for Networked Personal Health Information (full compendium to be released 2nd quarter 2008)
- **Connecting All Health Decision Makers**: Current work…how can the Common Framework support the nation's goals of improving the health of entire populations?
  - Bolstering **research** capabilities and enabling clinical practice to fully participate in and make use of scientific evidence
  - Increasing the effectiveness of our **public health system**
  - Empowering consumers and professionals with information about **cost, quality, and outcomes**

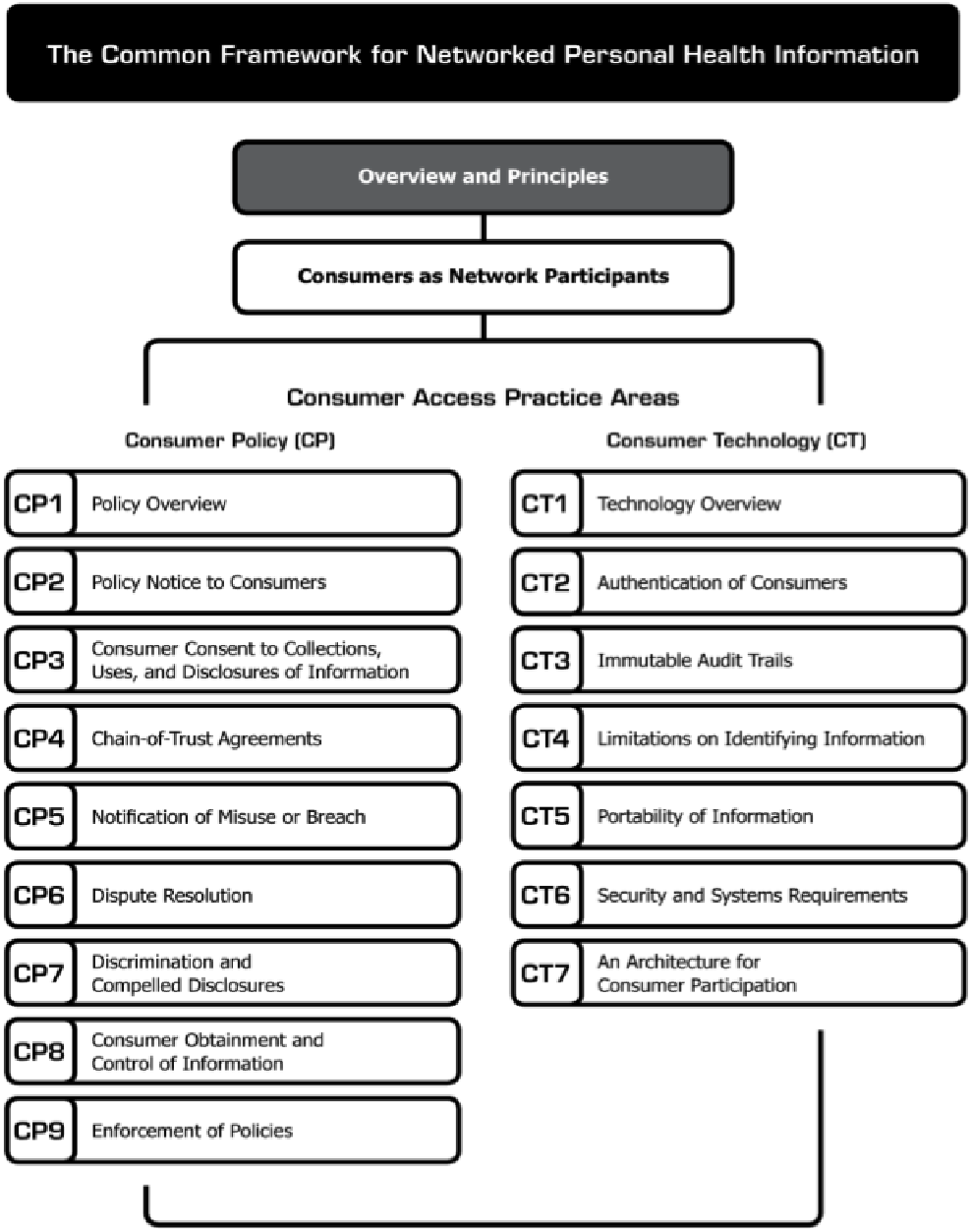
Our Approach



Architecture for Privacy in a Networked Health Information Environment

1. Openness and Transparency
2. Purpose Specification and Minimization
3. Collection Limitation
4. Use Limitation
5. Individual Participation and Control
6. Data Integrity and Quality
7. Security Safeguards and Controls
8. Accountability and Oversight
9. Remedies


The Common Framework:
Overview and Principles
Policy Guides:
How Information is Protected
P1
The Architecture for Privacy in a Networked Health Information Environment
P2
Model Privacy Policies and Procedures for Health Information Exchange
P3
Notification and Consent When Using a Record Locator Service
P4
Correctly Matching Patients with Their Records
P5
Authentication of System Users
P6
Patients' Access to Their Own Health Information
P7
Auditing Access to and Use of a Health Information Exchange
P8
Breaches of Confidential Health Information
P9
A Common Framework for Networked Personal Health Information
Future Policy Guides
Technical Guides:
How Information is Exchanged
T1
The Common Framework: Technical Issues and Requirements for Implementation
T2
Health Information Exchange: Architecture Implementation Guide
T3
Medication History Standards
T4
Laboratory Results Standards
T5
Background Issues on Data Quality
T6
Record Locator Service: Technical Background from the Massachusetts Prototype Community
T7
Consumer Authentication for Networked Personal Health Information
Future Technical Guides
Model Contractual Language
M1
Key Topics in a Model Contract for Health Information Exchange
M2
A Model Contract for Health Information Exchange


The Common Framework for Networked Personal Health Information
Overview and Principles
Consumers as Network Participants
Consumer Access Practice Areas
Consumer Policy (CP)
CP1 Policy Overview
CP2 Policy Notice to Consumers
CP3 Consumer Consent to Collections, Uses, and Disclosures of Information
CP4 Chain-of-Trust Agreements
CP5 Notification of Misuse or Breach
CP6 Dispute Resolution
CP7 Discrimination and Compelled Disclosures
CP8 Consumer Obtainment and Control of Information
CP9 Enforcement of Policies
Consumer Technology (CT)
CT1 Technology Overview
CT2 Authentication of Consumers
CT3 Immutable Audit Trails
CT4 Limitations on Identifying Information
CT5 Portability of Information
CT6 Security and Systems Requirements
CT7 An Architecture for Consumer Participation

Endorsers of the First Detailed, Consensus-Based Framework for Networking Personal Health Records

AARP

Aetna

American Academy of Family Physicians

Association of Online Cancer Resources (ACOR.org)

America's Health Insurance Plans

BlueCross BlueShield Association

CapMed

Center for Democracy and Technology

Center on Medical Record Rights and Privacy

Cisco Systems Inc.

Consumers Union

Dossia

FollowMe

Google

Geisinger Health System

Health Care For All

InterComponentWare Inc.

Intuit Inc.

MedicAlert

Microsoft Corp.

National Breast Cancer Coalition

National Partnership for Women and Families

NewYork-Presbyterian Hospital

Pacific Business Group on Health

Palo Alto Medical Foundation

Partners Healthcare System

RxHub

SureScripts

U.S. Department of Veterans Affairs

Vanderbilt Center for Better Health

WebMD

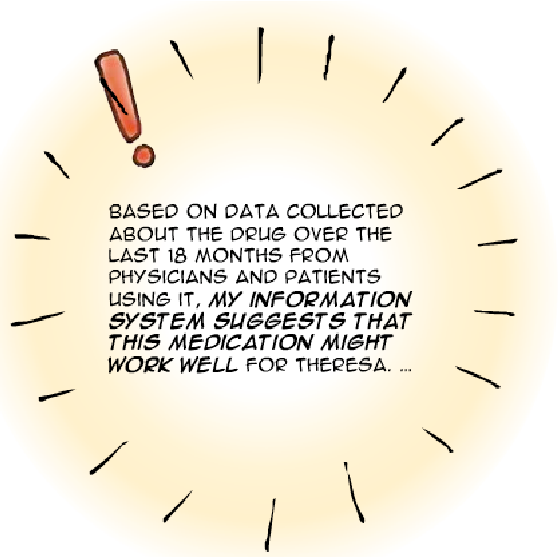
Last year we worked on a set of consensus based "First Principles for Population Health"

www.connectingforhealth.org

Response to an AHRQ RFI on a National Data Stewardship Entity

1. Designed for Decisions

A 21st century health information environment will focus on improving the decision-making ability of the many actors in the health sector.

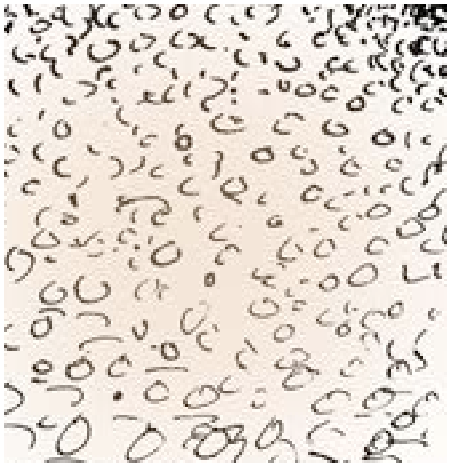


2. Designed for Many

A 21st century health information environment should empower a rich variety of users.

3. Shaped by Public Policy Goals and Values

A 21st century health information environment should achieve society's goals and values –
e.g.: improve the health, safety, and efficiency; reduce threats to public health, etc.



4. Boldly Led, Broadly Implemented

A 21st century health information environment should be guided both by bold leadership and strong user participation. The network's value expands dramatically with the number of needs it can meet and the number of participants it can satisfy.

5. Possible, Responsive and Effective

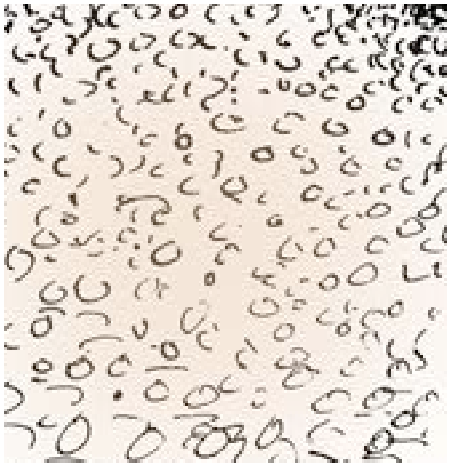
A 21st century health information environment should grow through realistic steps.

6. Distributed but Coordinated and Queriable

A 21st century health information environment should be comprised of a large network of distributed data sources.

7. Trusted through Safeguards and Transparency

A 21st century health information environment should earn and keep the trust of the public through policies that provide safeguards and transparency.



8. Layers of Protection

A 21st century health information environment should protect patient confidentiality by emphasizing the easy movement of queries and responses, rather than of raw data.

9. Accountability and Enforcement of Good Network Citizenship

A 21st century health information environment should encourage and enforce good network citizenship by all participants.

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