Creating a Public Good for the Public’s Health

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Key Points for an **Action Agenda**

1. Be open to reset our definitions and assumptions about health data and research approaches

2. Articulate new, broadly accepted working principles based on 21\(^{st}\) century information paradigms

3. Develop an information policy framework that broadly addresses public hopes and concerns
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
- Our approach is rooted in looking at technical AND policy issues together!

- [http://www.connectingforhealth.org](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
In extensive interviews with our leadership group serious concerns and frustrations with current approach to population health and data collection from each sector.

Yet a shared vision …
What We Heard...

“Research should be a normative part of health care...every intervention with a patient is a chance to learn something”

“The data must be incorporated with decision support and re-measurement not an episodic hiccup of a data dump”

“I have been saying this for 20 years...where is the feedback loop folks?”

“The only way to improve a process is to extract information from that process and send it back to the person”
The Vision: What COULD it be like?

In this new vision, the **decisions** of providers, consumers, payers and policy-makers are grounded on reliable evidence.

Imagine if.....
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 hyperglycemic 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.
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. ...
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.
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...

So I decide to try antibiotic B.
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 CONSUMER

ANGELA MORENO LIVES IN DAYTON, OHIO, WITH HER 9-YEAR OLD SON, MARTIN

MARTIN HAS MODERATE TO SEVERE ASTHMA, WHICH HAS BEEN HARD TO CONTROL. IT INTERFERES WITH HIS SCHOOL PERFORMANCE AND, OFTEN, HIS ABILITY TO SLEEP. HE SKIPS SPORTS.
Based on her weighted preferences, the system provides her with an ordered list of ten physicians and a button to "schedule initial appointment."
She selects a doctor who best meets Martin’s needs, and after their first visit, is invited to return to the website to rate the visit on a variety of measurements. She consents to allowing Martin’s peak-flow readings to be pooled with other patients on a de-identified basis.
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 COMMONPLACE 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.
This roundtable has outlined a vision for a learning healthcare system, in which clinical data are a staple resource.

We share this vision.

And recognize the critical importance of clinical data as a key resource.
But it is unlikely that we can achieve this vision using our historical approaches for collecting and analyzing these data.
“In the past 50 years we have made substantial progress in understanding the biology of disease and in devising new ways to prevent or treat it. However, there has been a substantial lag in applying what we know to actual patient care.”

Claude Lenfant
Clinical Research to Clinical Practice -- Lost in Translation?
1. An **Action Agenda** should be open to reset our definitions and assumptions about health data and research approaches.
The Way We Do it Today

• Most of the effort in trying to collect, clean and then “hoard” data.

• 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
Swarms of Data Requests to a Single Care Delivery Organization

Local Requests
- IRB Projects
- JCAHO Reporting
- IM Reporting
- CQ Reporting
- Teaching requests
- Commercial plans

State Requests
- Cancer registry
- Genetic screening
- Public Health
- Quality/ AQA pilots
- Peri-natal
- UB92

National Requests
- AHRQ
- Leapfrog
- NCQA
- Biosense
- PB Project
- NACRI
- UHC
- CMS
- DAWN

CONNECTING FOR HEALTH COMMON FRAMEWORK
The Temptation

- Gaps in data, knowledge and evidence
- It is tempting to try to solve the problem by focusing on bigger centralized data collection repositories
- But this approach is not practical and has not proven to be effective to date
- Many reasons…
We can’t replace the swarms with one 800-pound gorilla!
The goal is better decisions by many, not more data for the few

- It is tempting to focus our efforts on amassing data for better research
- But the thornier and more important question is how to truly improve decision-making – and what role information plays in this process
The “Mountain”

“You send your data to the mountain but the mountain rarely gives you something useful back”
2. An **Action Agenda** needs to articulate new, broadly accepted working principles based on 21\textsuperscript{st} century information paradigms
21st Century *Thinking*

- Whereas businesses of earlier centuries thrived on command and control paradigms
- 21st century enterprises depend on the ideas and initiative of many
- They succeed by distributing decision-making authority, incentives, and information tools to the edges
The 21st century
Health care environment

Characterized by:

• Increasingly distributed needs for sharing and accessing information about what works best

• Increasingly sophisticated “nodes”

• 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
Caveats

• This is not a matter of centralizing an analytic function

• There is a compelling need to embed analysis, decision-support, and feedback loops throughout the health care system

• We cannot predict exactly who the future information users will be, or what questions they will bring to the data – needs will change
The challenge is to create alternative models that take into account...

A wide variety of distributed information users

Multiple and growing data sources

A new approach to research and evidence-creation taking advantage of 21\textsuperscript{st} century information paradigms

(the evolution of the global information economy as a whole vs. traditional exceptionalism of health care)
“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/)
Let’s Start with First Principles…
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 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.
3. An Action Agenda needs to develop an information policy framework that broadly addresses public hopes and concerns.
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).
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
These Principles are Interdependent

- Openness
- Purpose Specification
- Use Limitation
- Collection Limitation
- Data Integrity
- Security
- Remedies
- Accountability

Individual Participation and Control

CONNECTING FOR HEALTH COMMON FRAMEWORK
Why A Policy Framework Matters

• “Post-hoc” policy is rarely easy to implement technically and can only mitigate risk, never eliminate it.

• We create a comprehensive set of criteria as opposed to piece-meal “fixes” and we lower the likelihood of gaps (collection).

• We are less likely to take on unnecessary risks (better matching between risk and benefit)

• There is a lot at stake if we lose the trust of the public
DiSTRI BuTE 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 DiSTRI BuTE 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.
Draft DiSTRIBuTE Visualizations - week ending 02/09/08
Jurisdiction specific graphs depict ED visits (% fever/total)

USA: North East

USA: Midwest

Visualization accessed 2/22/08 at:
http://www.syndromic.org/projects/DiSTRIBuTE2008_02_09.doc
What if..

• We created a climate of trust with a policy framework that enabled information liquidity
• We engaged stakeholders in constructive, forward-looking process towards a shared vision that prioritized creating value for all participants
• We embraced alternatives that involve and reward consumers
• We focused on the infrastructure requirements to push the questions to the data rather than trying to bring all the data to every question
• We set our sights on a collective effort to address a small set of high priority public good objectives using this new approach and enjoyed some rapid learning
“As the Markle Foundation puts it...........This goes to the very heart of the matter. For even though it is fine to start hoping for the day when interoperable electronic health records create vast pools of medical information that could be used to find new cures and battle epidemics in real time, their ultimate purpose is to make one simple and shockingly overdue change: to enable individuals, at last, to have access to, and possession of, information about their own health.”