Learning from Health Care:
One Infrastructure, Many Uses for Better Evidence

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Learning from patient care data is essential for improving health care and reducing costs

- We need more and better data to improve quality and lower costs
  - Reduced duplication
  - More personalized care
  - **Quality improvement in patient care**

- Better data provides foundation of evidence for improving care for groups or populations of patients
  - Treatments received
  - Outcomes: adverse events, complications, experience with care
  - Resource use / costs

- Institute of Medicine: "Learning Health Care System"
  - Generate and apply the best evidence for the collaborative health care choices of patients and providers
  - Drive the process of discovery as a natural outgrowth of patient care; and
  - Ensure innovation, quality, safety, and value in health care

- Data being used for better evidence now
  - Drug safety surveillance
  - Quality measurement and reporting
  - Comparative effectiveness
  - Public health and other uses

Examples of evidence to improve health care developed from data used in delivering care

Quality Measurement and Reporting	Medical Product Safety Surveillance	Comparative Effectiveness Research
How do my doctors' performance compare to others in the region?	Does Vioxx increase the risk of heart attack?	Is "virtual" colonoscopy better than invasive colonoscopy?
Where are the best opportunities for our institution to improve performance?	Is the H1N1 vaccine safe for adults and children?	Does the "medical home" improve outcomes and reduce costs vs. usual care?

How can emerging electronic information systems support all these uses effectively and securely?

What "infrastructure" is needed?

Data needs for these different uses are similar

Safety
- Accurate measurement of exposure, clinical outcomes, and potential confounders in a ***defined sample*** of patients exposed to a medical product

Effectiveness
- Accurate measurement of exposure, clinical outcomes, and potential confounders in a defined sample of patients exposed to the intervention ***with alternative treatments***

Quality
- Accurate measurement of care processes, resource use, clinical outcomes and risk adjustment data on ***virtually all patients*** of a given provider

Much of the needed data can come from data systems used for patient care

Payer Claims and Other Data
- Defined population for which everything paid for is known
- Includes claims from physicians, hospitals, pharmacies, and labs
- Linked at patient level – and including more clinical data

Health Care Provider Systems
- Detailed accounting of inpatient or outpatient services not otherwise captured in claims
- Ideally linked to payer and other provider data

Electronic Medical Records (EMRs)
- Detailed clinical data such as lab values, radiology results, etc
- Ideally reflects patient data from multiple sources

Registries
- Information on groups of patients with data integrated from multiple sources

Patient-level data can be summarized (aggregated) for developing better evidence

Treatments
- Filled prescriptions
- Inpatient products
- Medical procedures
- Enrollment in a program

Clinical outcomes
- Medical diagnoses
- Medical procedures
- Laboratory values
- Mortality

Potential confounders
- Age
- Sex
- Disease severity
- Comorbid conditions

Resource use / costs
- Physician
- Hospital
- Pharmacy
- Lab

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Most evidence needed to improve health care involves summary data, not "identified" patients

De-identified data for evidence

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When "identifiable" data is collected for patient care, it remains behind local firewalls

	Quality Measurement and Reporting	**Medical Product Safety Surveillance**	**Comparative Effectiveness Research**
De-identified data for evidence	How do my doctors' performance compare to others in the region?	Does Vioxx increase the risk of heart attack?	Is "virtual" colonoscopy better than invasive colonoscopy?
	Where are the best opportunities for our institution to improve performance?	Is the H1N1 vaccine safe for adults and children?	Does the "medical home" improve outcomes and reduce costs vs. usual care?
Identified data for patient care	Which patients need intervention to achieve better diabetes control?	Does this person really have Guillain-Barré syndrome ?	What are the patient's preferences?
	Quality Improvement	**Case Validation**	**Patient Reported Outcomes**

Improving health care while improving patient care does not generally require sharing identifiable data

- Wires, boxes, and clouds bring together identifiable data for patient care

- Common models for organizing and summarizing data can bring together experiences of many groups of patients

  - Standard terminology for queries and results
  - Site-level analytic capacity

Current approaches to learning from health care data lack coordination and consistency

- Large projects involving data pooling face multiple obstacles
  - Organizations (and individuals) may not contribute data because of concerns about confidentiality
  - Different data sources may lack consistency
  - "Central" data pooling requires central infrastructure
  - Difficult to apply to multiple uses

- "Distributed networks" avoid sharing identifiable data, but often work on particular uses and are not well coordinated
  - Considerable resources are being spent on different data resources doing similar things
  - Separate efforts are less powerful (less precise quality measures, less certain "safety signals,") and may produce inconsistent results due to differences in methods

- Can these efforts be better coordinated, leading to more compelling results?

More effective use of data from health care delivery faces multiple obstacles

- **Access to Data Network**
  - who can obtain summary information
  - what information
  - what uses
  - under what conditions

- **Privacy and Security**

- **Incentives and Sustainable Financial Support**

- **Consistent Methods for Reaching Conclusions**

- **Avoiding Biases in Results**

Learning from Health Care Data – Towards a Common Infrastructure

- Define the evidence questions – and their common elements across uses

- Identify sources ("environments") of needed data for multiple uses

- Apply consistent methods where possible for summarizing and analyzing de-identified data

- Align incentives and support for improving patient care (e.g., health IT payments) with incentives and support for improving evidence (e.g., paying for better quality in health care reform)

- Step by step progress – limited steps toward multiple uses can build up to longer-term progress

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One Infrastructure with Many Uses