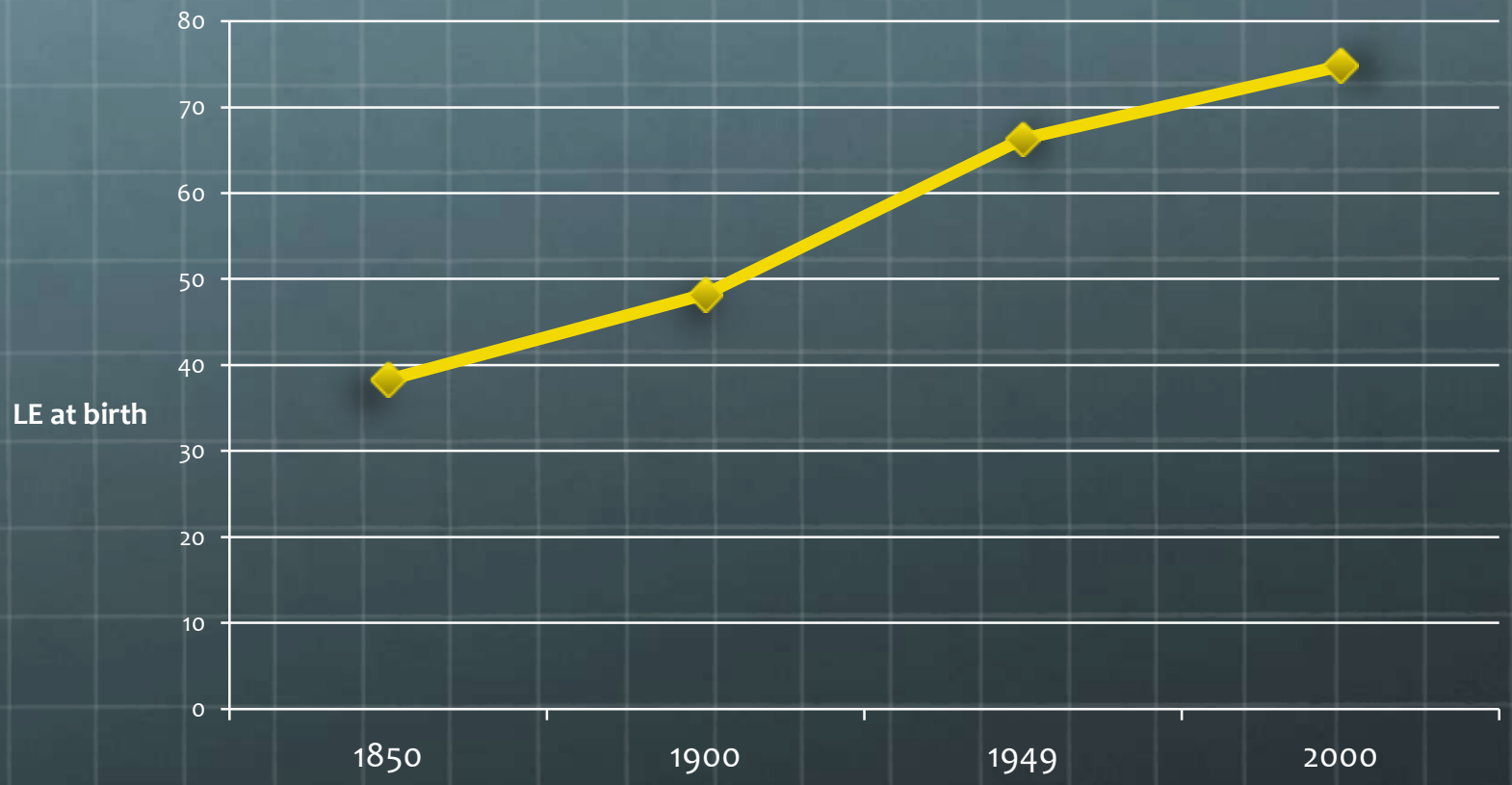
Evidence Generating Medicine and the Data Promise

Lisa Schilling, MD, MSPH
U of Colorado School of Medicine

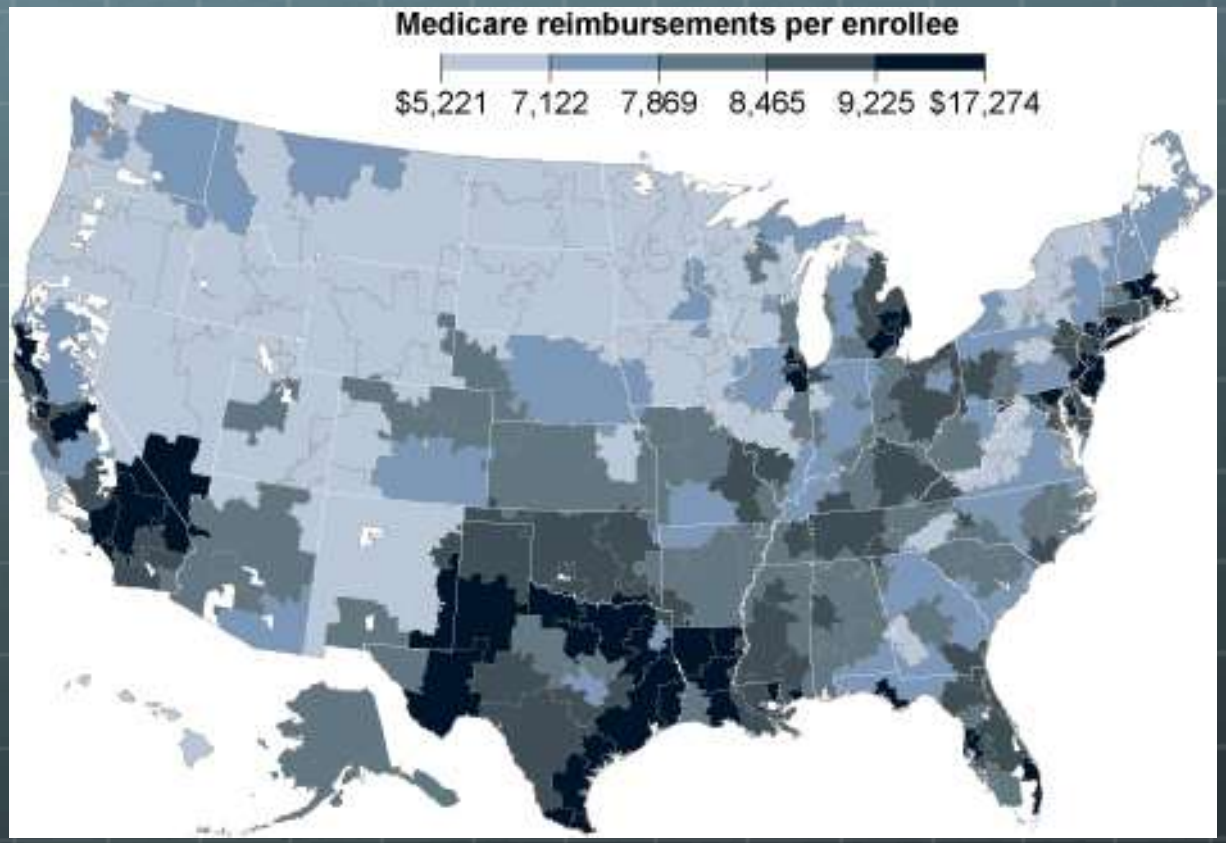
Life Expectancy @ birth



44,000 to 90,000 die yearly…

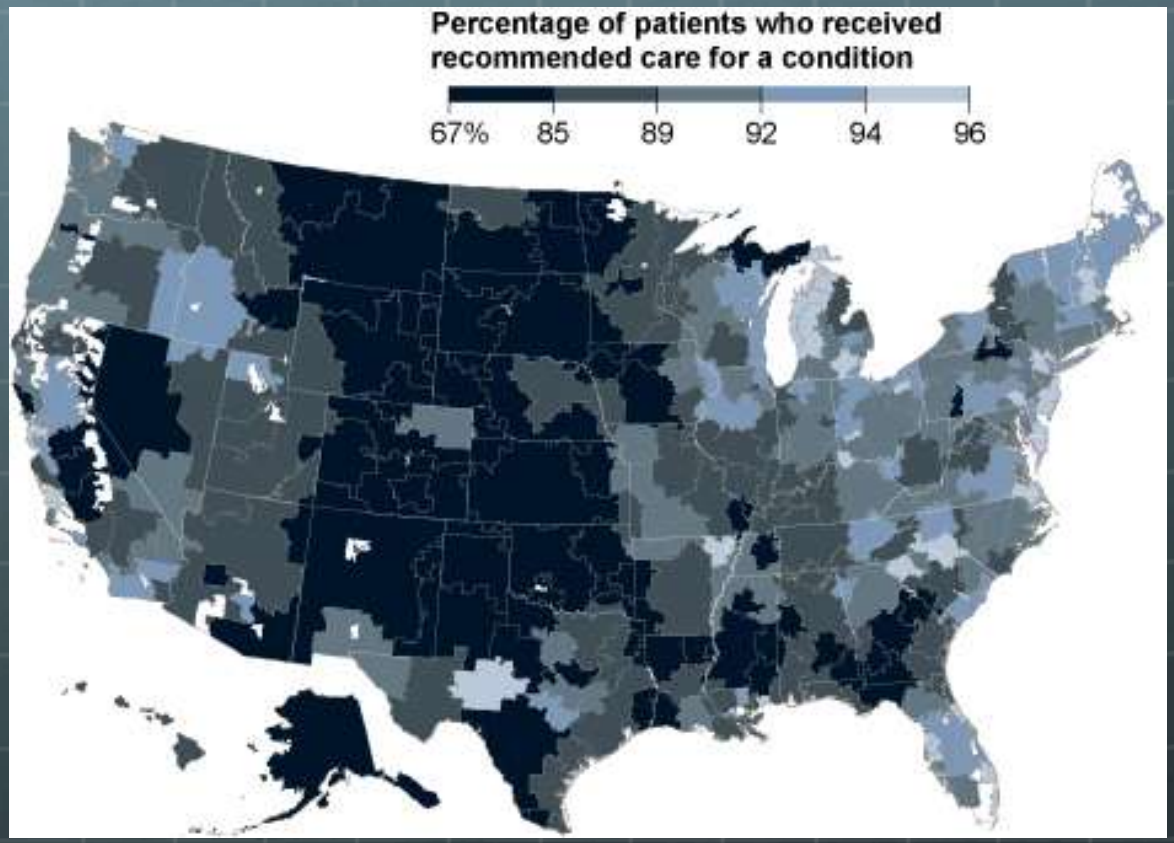
due to care received in hospitals!

Medicare Reimbursement per Enrollee



Dartmouth Atlas

% Receiving Recommended Care



Dartmouth Atlas

Variation in practice –

- Best Practice -15-25% of the time, we have this information, (RCT, strong obs, expert consensus opinion)
- PLOS Med – 75 RCT and 11 Systematic Review per day
  - John Williamson -17 to 20 years for findings with evidence of benefit to make it into practice
- Innate Recall – used to be good enough, now to complex – too many estimations, too biased
- Expert mind (1956 Miller, magic # 7+- 2 factors to consider)- but often there are very more factors to consider –antibiotics choice, vent settings

What are the barriers?

- Lack of evidence/uncertainty
- Lack of clinical knowledge- doubling time is 8 years
- Reliance on recall (dominated by anecdotes, notoriously poor when estimating results over time and across groups)
- Limitation of the expert mind – Eddy "The complexity of modern medicine exceeds the capacity of the unaided human mind"

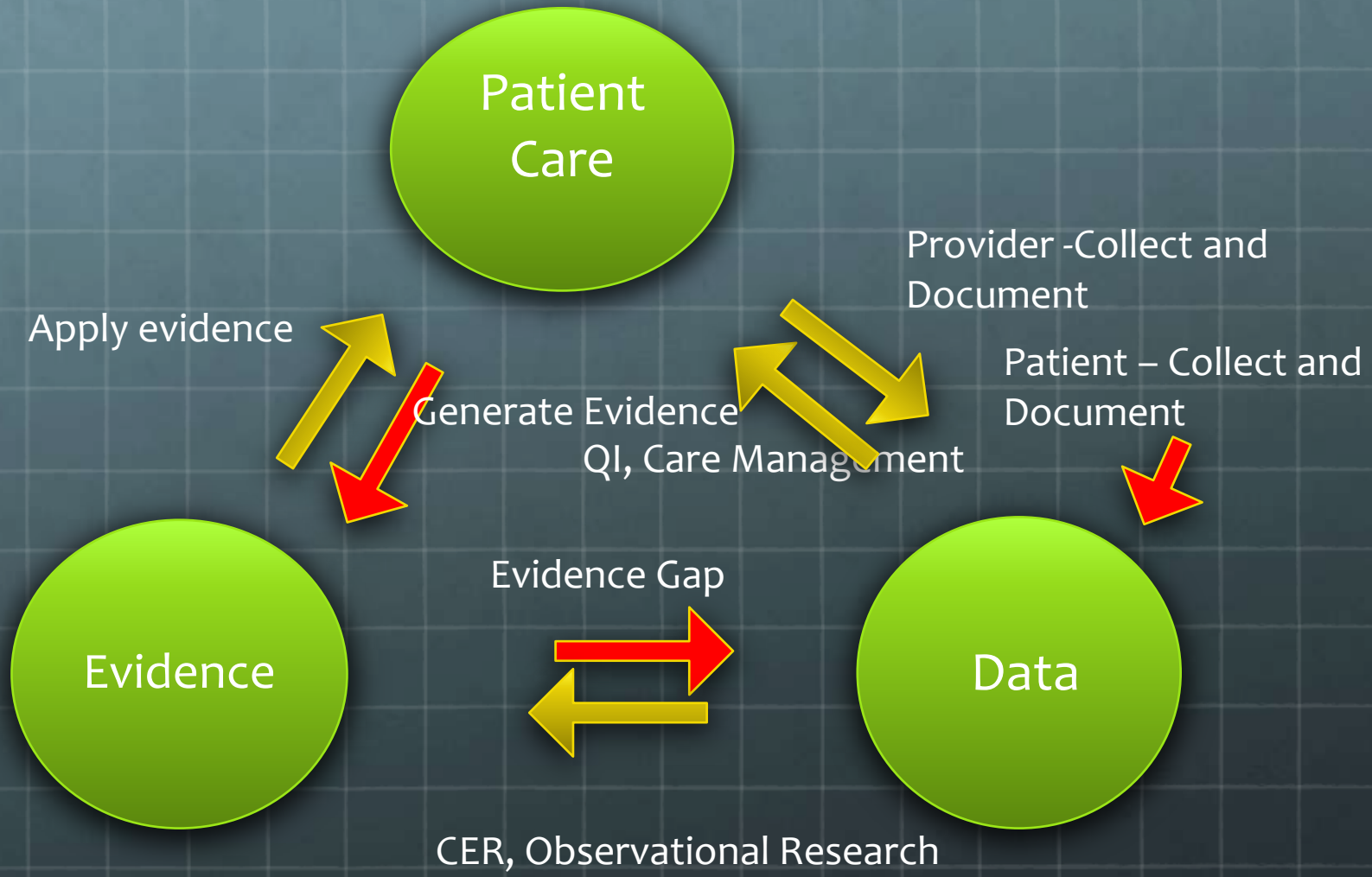
What's the goal?

- Doing the right thing 90% of the time
- Solve the uncertainties
- Assimilate data to generate required information
- Provide the right knowledge at the right time to providers and patients

Now -Future

- Evidence generating medicine
- Learning health care systems
- Big data and health analytics
  - Personalized medicine
  - Clinical decision support
  - Efficient systems
- Collecting patient information
  - mHealth, Internet, quantified self
- Visualizing information

Evidence Generating Medicine



Evidence Generating Medicine

- What evidence do we need to generate?
  - Specific populations/sub-groups
  - Impact of different delivery systems
- What and how do we document?
- How do we enhance collection of information from patients – family hx, occupational exposure

EGM

- VA – Point –of – Care trials (active)
  - Creating infrastructure for enrollment, randomization, and longitudinal data collection all integrated into electronic health record systems
- Collecting information that matters
- Using/Collecting/storing meaningful patient outcomes

Learning Healthcare System

- Adaptation to the pace of change
- Stronger synchrony of efforts
- Culture of shared responsibility
- New clinical research paradigm
- Clinical decision support systems
- Universal electronic health records
- Tools for database linkage, mining, and use
- Notion of clinical data as a public good
- Incentives aligned for practice-based evidence
- Public engagement
- Trusted scientific broker

Meaningful Outcomes

Computerized Adaptive Testing

PROMIS®

Dynamic Tools to Measure Health Outcomes from the Patient Perspective

Home | About PROMIS® | Measures | Science | Software | What's New | Related Resources | PROMIS® For You | Search

- Assessment Center
- Software Demonstration
- Sample Questions

Home >> Software >> Software Demonstration

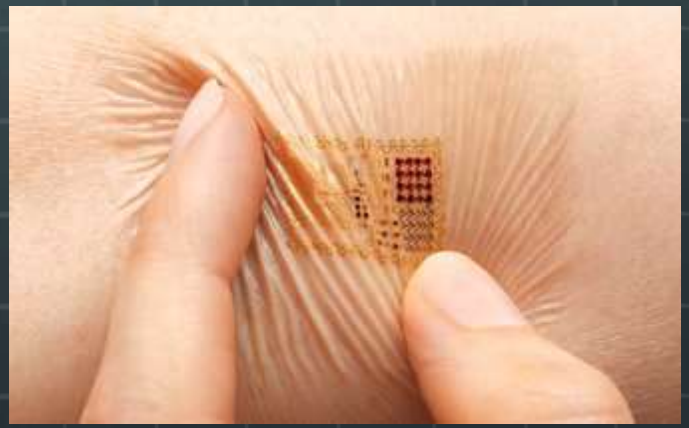
Software Demonstration

The PROMIS® Computer Adaptive Test (CAT) provides an instant personal health status report on up to nine different areas (or domains) of health. The CAT works by choosing the questions in each area that are best for you based on your answers to earlier questions. Each area only takes 1–2 minutes to complete. After you are done with all the questions, the CAT will show you how your health compares to the general public and people who are similar to you in age and gender.

Try a demonstration of the PROMIS CAT.

Big Data- Analytics

- Use of multiple data sources
- Clinical decision support
- Predictive analytics
- Personalized medicine
- Personalized CME
- Data standardization
- Entity- vs. patient-centered data
- Shortage of people with deep analytic skills



Personalized Use

- Genomics
- Adverse drug reactions
- Predict who, what, when will benefit from an intervention
  - Risk-
  - Impact
  - Timing/receptivity
  - Adherence
  - Affecting behaviors

Informing Uncertainty

- When the existing literature and a survey of colleagues was insufficient to guide the clinical care of a patient, Frankovich *et al* applied trend analysis to the EMR data from 98 patients to 'learn' a data-driven guideline on how to provide care for a 13-year-old girl with systemic lupus erythematosus.

Evidence-based medicine in the EMR era. *Frankovich J, Longhurst CA, Sutherland SMN Engl J Med. 2011 Nov 10; 365(19):1758-9.*

Using the data captured in our institution's electronic medical record (EMR) and an innovative research data warehouse. The platform, called the Stanford Translational Research Integrated Database Environment (STRIDE), acquires and stores all patient data contained in the EMR

Results of Electronic Search of Patient Medical Records (for a Cohort of 98 Pediatric Patients with Lupus) Focused on Risk Factors for Thrombosis Relevant to Our 13-Year-Old Patient with Systemic Lupus Erythematosus.*

Outcome or Risk Factor	Keywords Used to Conduct Expedited Electronic Search	Prevalence of Thrombosis	Relative Risk (95% CI)
		no./total no (%)	
Outcome — thrombosis	"Thrombus," "Thrombosis," "Blood clot"	10/98 (10)	Not applicable
Thrombosis risk factor			
Heavy proteinuria (>2.5 g per deciliter)			
Present at any time	"Nephrosis," "Nephrotic," "Proteinuria"	8/36 (22)	7.8 (1.7–50)
Present >60 days	"Urine protein"	7/23 (30)	14.7 (3.3–96)
Pancreatitis	"Pancreatitis," "Lipase"	5/8 (63)	11.8 (3.8–27)
Antiphospholipid antibodies	"Aspirin"	6/51 (12)	1.0 (0.3–3.7)

* In all cases, the sentences surrounding the keywords were manually reviewed to determine their relevance to our patient. Pancreatitis was defined as an elevated lipase level (twice the upper limit of normal) coexisting with abdominal pain. We used the word "aspirin" as a proxy for antiphospholipid antibodies, since it is standard practice at our institution to give all patients with these

Dashboards - Displays

- Effective visual displays – what matters most!
- Relevant, reliable & actionable information - Real-time data
  - Purpose – quality, case management
- Multi-disciplinary teams
- Allows comparison to local or national data sets
- Time to focus on not doing too much!
  - Antibiotics and URIs
  - DEXAs
  - Imaging

Assimilating and Displaying

- Difficult for clinicians to find, aggregate and confidently visualize all of the clinical information that is pertinent to a given encounter.
- Geisinger: rheumatologists estimated that even with a fully-functional EHR, it would take an average of 15 minutes to fully review patient data to ensure that a treatment decision was optimal; on average, physicians have 2 to 3 minutes.
- Temporal profiles that link health status, symptoms, lab results and facilitate clinical care and decision making

Questions/Conversation

- Learning Health Care System
- Evidence generating medicine
- Optimizing and transforming data

Conatact Lisa.schilling@ucdenver.edu