

Beyond the EMR: Disease Registries

Better Health Greater Cleveland Learning Collaborative
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Anil Jain, MD, FACP

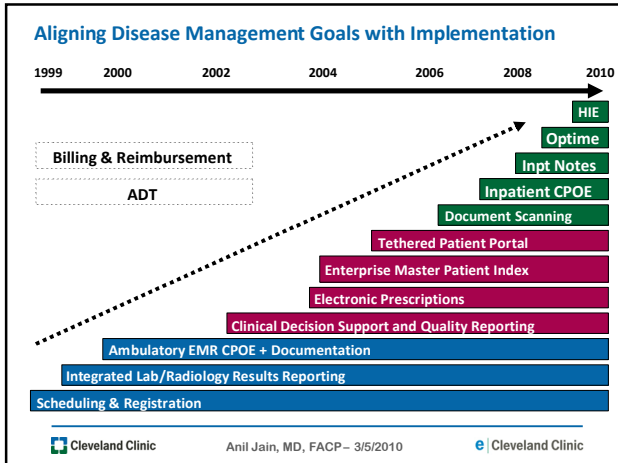
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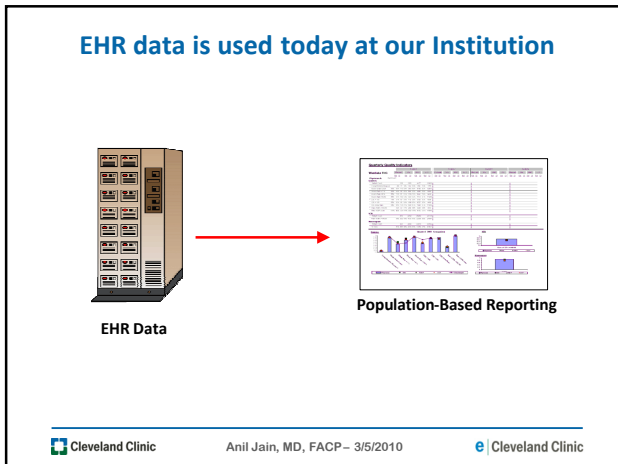
Objectives

- Define Disease Registries and give some examples
- Discuss the relationship between the Electronic Medical Records and Disease Registries
- Review the opportunities and challenges with using EMR to auto-populate registries
- Propose a governance model to support disease registries at an institution
- Discussion

What are disease registries?

- List of patients with a specific chronic disease.
- Include clinical information and/or demographic information
- Used to improve the care of individuals and populations
- Can facilitate clinical, quality, research and education missions





- EMR Based Performance Measurement & Reporting**
- **Health Wellness and Prevention**
 - Immunizations, Osteoporosis, Diabetes and Cancer screening
 - **Disease-based Reporting**
 - Diabetes, Hypertension, Heart Failure, Asthma
 - **Patient Safety**
 - Adverse Drug Events and sentinel events
 - FDA Public Health Advisories (e.g., Vioxx® and Ortho-Evra®)
 - Local Consensus (e.g., Avandia® notification)
 - **Public Reporting**
 - Pediatric Immunizations (SIRS), Communicable Diseases, process measures and quality indicators (JCAHO, HEDIS, CMS, etc.)
 - **Operational Reporting**
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Populating Registries with EHR data

- Identifying data sources
- Standardization
- Making Decisions on Definitions
- Technical Process
- Challenges and Reliability Issues

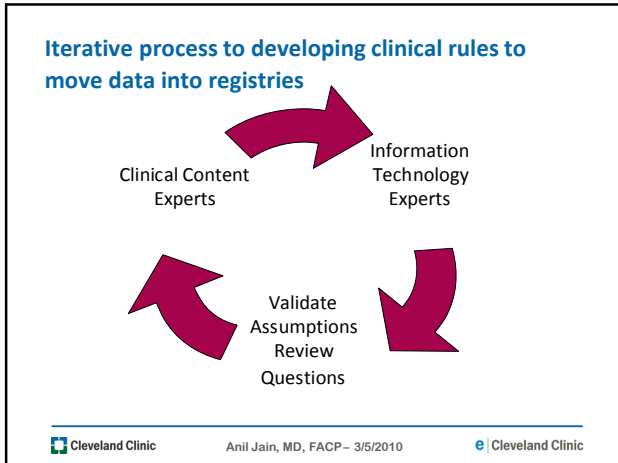
Data Sources – Available electronically in EMR?

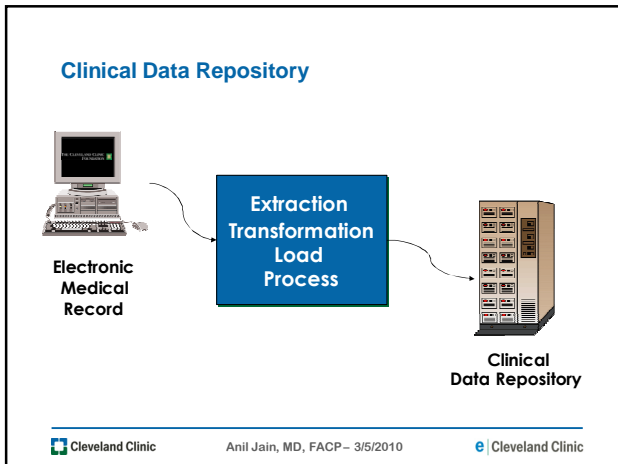
- Rand Corporation review of the Quality Assessment Tools system
- Approximately only a third of the indicators would be readily accessible from EHR data.
- Barriers include
 - complexity of required data elements
 - provider documentation habits
 - EHR variability
 - Accurately identifying eligible cases for quality assessment

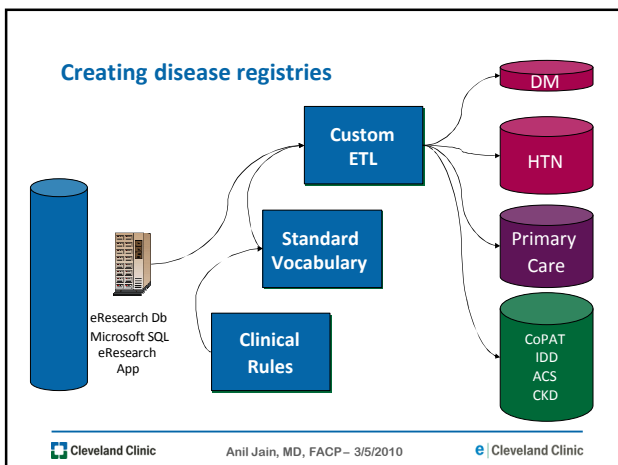
Roth et al, 2009.

Ontology & Vocabulary

Information	Standard Vocabulary
Diagnoses	<ul style="list-style-type: none"> • ICD9 Codes • SNOMED Mapping
Medications	<ul style="list-style-type: none"> • Local • First Data Bank / NDDF+ / Medispan • National Drug Code • RxNorm (thru cross-walk)
Laboratory	<ul style="list-style-type: none"> • Local Codes • LOINC Mapping (thru cross-walk via RELMA tool)
Allergies	<ul style="list-style-type: none"> • Local
Family History	<ul style="list-style-type: none"> • Local
Procedures	<ul style="list-style-type: none"> • CPT™







Less Reliable

- **Current** prescription medications actually taken by patient
- Over-the-counter medications
- Non-antibiotic allergies (often intolerances classified as allergies)
- Family history
- Surgical history

Validation of Clinical Data

- Extraction and then manual chart review to determine accuracy of extracted data
 - Accounts for variability in workflow – e.g., vitals signs not documented in structured flowsheet but entered as free text
 - Are structured elements missing from the data extraction
- Basic statistical Analysis of Data
 - “missing values” (how many)
 - “nonsense values” (what do these values signify)
 - Visual histogram inspection (is this the expected result)
- Comparison with data from other sources

Governance of the Disease Registry

- Develop a transparent governance structure with leadership from clinical, quality and information technology teams.
- Creating a timeline with achievable goals and milestones aligned with internal and external needs
- Monitor milestones, establish accountability and regularly update key stakeholders, i.e., leadership, physicians, nurses, quality personnel and IT Staff
- Determine Data Governance

Sustainability & Growth

- Survey the landscape to find sources of funding
 - Institutional – Quality, Med Ops, etc.
 - Public – CMS (e.g. PQRI), Medicaid, etc.
 - Payor – ?Medical Home
 - Grants & Demonstration projects
 - Community & Philanthropy
- Establish collaborations and partnerships to help share infrastructure cost (e.g., NSQIP, ACS, STS)

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Approach to Choosing a Registry

- Overall disease management or research strategy
- Direct v. indirect costs
- Data sources (in EMR or not?)
- If you are choosing an EMR vendor, discuss disease-registries as a requirement.
- If you already have an EMR, explore if registry functionality already is supported
- What about while you wait to implement?

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Features to consider

- | | |
|-------------------------------|--------------------------------|
| • Medical condition(s) | • Patient versus Disease focus |
| • Client server vs. web based | • Market penetration |
| • Security of Data | • Sustainability of vendor |
| • Data export and import | • Ease of use |
| • Point of care tools | • Customizable |
| • Patient outreach tools | • Ease of set up |
| • Reporting capabilities | • Scalability |
| | • Cost |

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Creating a Registry

- Personnel
 - Database Administrator
 - Web Programmer
 - Report Writer
 - Clinical Analyst
 - Project Management Oversight
- Hardware/Software
 - Database License/Server
 - Web Server

Final Thoughts

- Registries are critical to achieving incremental value from health IT investments including the EMR.
- EMR data can be used to auto-populate registries after careful validation by subject matter experts and informatics personnel but will often require supplementation from other sources
- A transparent governance model for supporting the disease registry is required for adoption and use
- Assessing sustainability of the disease registry should be addressed immediately

“Not everything that can be counted counts, and not everything that counts can be counted.”

-Sign hanging on Albert Einstein’s Princeton University Office

Questions?

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