Genetic Research at Intermountain Healthcare

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Objectives

- Describe research philosophy at Intermountain
- Goals of genetics in research at Intermountain
- Decision-making and barriers
- Future challenges

Who Are We?

- LDS church had hospitals beginning in 1882
- Church sold all health care properties in 1975 to not-for-profit entity Intermountain Healthcare
- Largest health care system in Utah
- Only integrated system in Utah

LDS Hospital 1905

Intermountain Healthcare

- Over 1 million patients Utah and Southern Idaho
- 20+ Hospitals
- Over 1000 employed physicians
- SelectHealth insurance
- Home care, pharmacy, hospice, etc.
- Inpatient and outpatient electronic health record

Intermountain Medical Center
2007

History of research

- Informatics research began in late 1950s
- Institute for Healthcare Delivery Research 1986
- Academic medical faculty established in 1960s
  - Cardiovascular
  - Pulmonary/Critical Care
  - Maternal fetal medicine
- Modest internal funding through Deseret Foundation
- No overall vision for research until 2 years ago

Research Mission

- Excellence in clinical and translational research resulting in improved clinical care within the Intermountain Healthcare system

Research Vision at Intermountain

- Improves patient care and well being for many
- Encourages expertise
- Effectively communicates accomplishments
- Is financially responsible
- Is effectively resourced and optimally efficient
- Complies with all applicable rules and regulations

Research Priorities

- Retain focus in areas of traditional strength
- Support clinicians in any area with good research ideas
- Use research to better support clinical program goals/objectives
- Establishing genetics and genomics as a research strength recognized across specialties

Rationale for Genomics

- Genomics will impact care across many clinical areas in near future
- Intermountain's information system positions us to make important contribution
- Recognition we can't do this alone—need to combine unique assets with partners (academic, commercial, public health)
  - Recently completed master research agreement with University of Utah
  - Part of University of Utah's CTSA

Current Genomic Research

- Within existing specialty research
  - Cardiovascular
    - Biorepository
    - Genealogy
    - Genome discovery
    - Pharmacogenomics
  - Pulmonary/Critical Care
    - Primary Pulmonary Hypertension (*BMPR2*)
  - Maternal Fetal Medicine
    - Genetic factors for premature birth
    - Partnership with University of Utah

Clinical Genetics Institute

- Convinced Intermountain leadership of risk to system if not done correctly
- Identified need to have a central core of experts that worked across the Intermountain system
- CGI board and strategic planning done in 2002-3
- CGI staff hiring 2004-5
- Started January 2005

Clinical Genetics Institute

- Primary objective is to move evidence-based genetic medicine into clinical practice
- Recognition that this will require novel mechanisms
  - Leveraging expertise in informatics and health care delivery research
  - Committed to work with provider focus
- Commitment to research
  - Define and measure outcomes of interventions
  - Communicate results to broad audience
  - Create processes that can be disseminated

CGI Research Decision-making

- Positives
  - Expertise in genetics, healthcare delivery, quality improvement, informatics, technology assessment
  - Clear internal vision of goals
  - Some strong supporters
- Negatives
  - No shared institutional vision until recently
  - Beyond personnel no discretionary resources
  - Large capital projects decreasing resource pool for all researchers

Research Strategy

- Identify partners
- Quick wins
- Targets of opportunity
- Alignment with clinical efforts
- Methods consistent with Intermountain core values
- Measure outcomes important to institution

Overview Current Research Activity

Current Research Activity

- Rapid technology assessment of emerging genetic tests
- Family History
  - How primary care physicians use FH
  - Developing tool in Patient Portal
    - Assess consumer use of tool
    - Study moving information into EHR environment
  - Screening for high risk Breast/Ovarian cancer in mammography
- Economics of genetic services
- Epidemiologic research using Intermountain clinical data
  - Utah Population Database
  - National Children's Study

Current Research Activity

- Informatics
  - Point of care genetic education in EHR (infobuttons)
  - Coding and messaging of cytogenetic results
  - Electronic communication of genetic test results
  - Clinical decision support
    - Family History
    - Genetic test results

Current Research Activity

- Health Services Research
  - Quality improvement in Down syndrome
  - Duplicate genetic testing
  - Patient satisfaction with genetic services
  - Identification of genetic disease using Clinical Data Repository
  - Implementation of tumor based screening for Lynch syndrome
    - Modeling of process for Intermountain
    - Partnering with relevant clinical services to define work process
    - Define outcomes of interest
    - Create system to measure outcomes
    - Report results

Barriers and Challenges

- Internal
  - Unified vision of genomic research
    - Varying maturity of different research entities within Intermountain regarding genetics/genomics
  - Adequate resources
    - Financial
    - Personnel
    - Laboratory
  - Tension between primary mission of clinical care and relevance of research to this mission
  - Identification and establishment of equitable partnerships between Intermountain and outside entities

Barriers and Challenges

- External
  - Vision and funding of translational research
    - Less than 3% of federal dollars to research beyond basic discovery
  - Competition for awards
    - Non-traditional research environment
    - Health care delivery research (real-world) vs. tightly controlled hypothesis based research
    - Criticism of narrow applicability due to unique resources
  - Current environment
    - Healthcare delivery and reform
    - Economic

The Future

- Bush administration foci:
  - Personalized Medicine
  - Electronic Health Record
  - Likely continued emphasis in Obama administration
- Funds available through CDC NOPHG and AHRQ to fund health services research aligning with Intermountain strategy
- Potential for shift in NIH funding
- CTSA emphasis on partnership between academic medical centers and private entities
- Public/private partnerships to broker information

Questions