The Future of Awesome!

Informatics Opportunities in Research

First International Conference on Research Methods for Standardized Terminologies
Minneapolis, MN
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• School of Nursing
  – Center for Nursing Informatics
    Omaha System Partnership
Opportunity

Societal revolution of communication and information technologies and informatics
Societal revolution in health care
Societal revolution in research & scholarship infrastructure
Redefine meaningful health knowledge within an environment of information overload
Institute of Medicine (IOM) and the Information Technology (IT) Revolution
Institute of Medicine (IOM) and the Information Technology (IT) Revolution

2009

2011

2011

2012
Federal Health IT Strategic Plan
2011 - 2015

**Goal I:** Achieve Adoption and Information Exchange through Meaningful Use of Health IT

**Goal II:** Improve Care, Improve Population Health, and Reduce Health Care Costs through the Use of Health IT

**Goal III:** Inspire Confidence and Trust in Health IT

**Goal IV:** Empower Individuals with Health IT to Improve their Health and the Health Care System

**Goal V:** Achieve Rapid Learning and Technological Advancement
BioMedical Health Informatics

- Microscopic
- Macroscopic

bioinformatics
imaging informatics
clinical informatics
public health informatics

Human Health & Disease
[translational bioinformatics]

Clinical Research Informatics

Consumer Health Informatics

- Molecular and cellular processes
- Tissues & organs
- Individual patients
- Populations
Informatics Sub-specialties

Algorithms, Models & Systems
- Information retrieval
- Natural language processing
- Data mining
- Modeling
- Data privacy, de-identification and re-identification
- Machine learning & discovery systems
- Scientific visualization/imaging informatics
- Decision models & expert systems

Information Structure & Semantic Relationships
- Database architecture
- Terminology architecture
- Knowledge architecture
- System architecture

Workflow Fit & Evaluation
- Organizational development
- Design & requirements
- Human factors & safety
- Utility & effectiveness assessment
Scientific breakthroughs will be:
powered by advanced computing capabilities
researchers manipulate/explore massive datasets

Speed at which any given scientific discipline advances will depend on:
researchers collaboration
partnership with technologists
in areas of eScience
databases
workflow management
visualization
cloud computing

What is the CTSI?

CTSI is part of a national Clinical and Translational Science Award (CTSA) consortium created to accelerate laboratory discoveries into treatments for patients. The CTSA program is led by the National Institutes of Health's National Center for Research Resources.
Currently, 60 medical research institutions in 30 states and the District of Columbia are active members of the CTSA consortium. These institutions are working together to speed the translation of research discovery into improved patient care.
Biomedical Informatics

Informatics

Regulatory Oversight

Inputs to TIDE
- Bench-findings
- Research
- EMRs
- Registries
- Public Data
- Bio-data
- ODAT

Use of Data
- Research
- Publications
- Community Partners
- University
  - Policy decision-makers
  - CTSA
- Healthcare delivery
- Training

CDelaney 2013
Big Data

Knowledge discovery through analysis of big data is key to improving health care quality and population health

Big data use

- increasingly common in many disciplines as indicated in a recent survey of 1700 peer reviewers for Science Magazine
- 20% of respondents identified that they regularly use data sets that range from over 100 gigabytes to data exceeding 1 terabyte (Science, 2011)
- EHR data converging with other data streams
NINR Strategic Plan: Innovation

NINR will invest in research that:

• Develops new technologies and informatics-based solutions that promote health, including comprehensive high-throughput technologies

• Develops and creatively applies new and existing knowledge to the implementation of health information technology, including electronic health records

• Expands knowledge and application of health care technologies to facilitate decision support, self-management, and access to health care

• Uses genetic and genomic technologies to advance knowledge of the “symptome,” including the biological underpinnings of symptoms associated with chronic illness

• Encourages risk-taking, innovation, re-invention, and creativity, including high-risk/high-return concepts
Nursing informatics agenda for 2008–18 must expand users of interest to:

- Include interdisciplinary researchers
- Build upon the knowledge gained in nursing concept representation to address genomic and environmental data
- Guide the reengineering of nursing practice
- Harness new technologies to empower patients and their caregivers for collaborative knowledge development
- Develop user configurable software approaches that support complex data visualization, analysis, and predictive modeling
- Facilitate the development of middle-range nursing informatics theories
- Encourage innovative evaluation methodologies that attend to human-computer interface factors and organizational context

### Informatics Support of the Research Lifecycle

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<thead>
<tr>
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<th>PRE AWARD</th>
<th>STUDY CONDUCT</th>
<th>CLOSE-OUT</th>
<th>IMPACT</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Capture</strong></td>
<td>Grant Prep (EGMS)</td>
<td>Visit Calendar Setup (OnCore, TASCs)</td>
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<td>Protocol Development</td>
<td>Data Collection and Management</td>
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<td>Committee Applications (CTSI Portal, SIRC)</td>
<td>Clinical visit/participant (REDCap, OnCore, CTSI Portal, TASCS)</td>
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<tr>
<td></td>
<td>Federal Applications (ERA Commons, electronic applications)</td>
<td>Specimen Collection and Tracking (CaTissue, CaBig, Freezer Mgmt, BioBank)</td>
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<td><strong>Use Data</strong></td>
<td>Participants (Profiles)</td>
<td>Recruitment and Accrual (clinicaltrials.gov, OnCore, Fairview database)</td>
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<td>Researchers (Research Central, SHRINE)</td>
<td>Regulatory Monitoring and Reporting (SIRIC, OnCore)</td>
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<td></td>
<td>Use Data (researchmatch.org)</td>
<td>Specimen Collection and Tracking (CaTissue, CaBig, Freezer Mgmt, BioBank)</td>
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<tr>
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<td>Use Data (i2b2)</td>
<td>Adverse Event Reporting</td>
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**Legend:** (Available tools)

- **i2b2:** Informatics for Integrating Biology & the Bedside
- **researchmatch:** A National Center for Biomedical Computing
- **SciVal:** Shared Health Research Information Network (SHRINE)

**EBP – Clinical Guidelines**
The Omaha System Partnership

In 2010, I invited our Center for Nursing Informatics to initiate the Omaha System Partnership to advance our capacity to use Big Data for knowledge discovery.

The Partnership has three components:

- **multidisciplinary scientific teams of researchers** with experience in advanced data analysis and data mining techniques.
- **a group of affiliate members from many countries** who contribute clinical Omaha System data, suggest important clinical questions, and work together with the scientific team on research and evaluation projects.
- **a warehouse of de-identified clinical Omaha System data** including client problems, signs/symptoms, interventions, and knowledge, behavior, and status outcomes.
Why This Works

Information Infrastructure

- the type of data
- methods of standardizing the data for comparison
- organization of data to represent information and discover knowledge
Three minimum data sets represent nursing and the context of nursing care

- USA Nursing Minimum Data Set (NMDS)
- USA Nursing Management Minimum Data Set (NMMDS)
- International Nursing Minimum Data Set (iNMDS)
16 data high level elements divided into three categories

- nursing care
- patient or client demographics
- service
18 data elements divided into three categories describing the context of care

• environment
• nursing resources
• financial resources
Interface Terminologies

North American Nursing Diagnoses Association (NANDA)
Nursing Intervention Classification (NIC)
Nursing Outcome Classification (NOC)
Omaha System
Clinical Care Classification (CCC)
Peri-operative Nursing Data Set (PNDS)
International Classification of Nursing Practice (ICNP)
Data from 15 home care agencies were extracted from their electronic health records (EHRs) and integrated into a single database

• 2,072 episodes of care
  – 1,793 adults
  
  Outcome and Assessment Information (OASIS) data required by CMS (including demographics)
  
  651,000 Omaha System interventions

Knowledge, Behavior, and Status Outcomes
Methods

Logistic regression
Data mining
  • K Means
  • Estimation maximization
  • Decision trees
New Knowledge

How should intervention data sets be managed?

Can data from multiple agencies and vendors be integrated?

Can urinary and bowel incontinence improvement be predicted?

Can interventions and outcomes be linked?
Synergy

Big data +
Data infrastructure +
Clinical experts +
Researchers +

Synergistic environment+

… New partners …
Next step: Clinical Data Repository

Clinical Translational Science Award (CTSAs) funded Centers develop clinical data repositories (CDR) to accelerate translational and clinical research

- Essential information infrastructure for clinical and translational research
  - Reflects the health continuum
  - Reflects the health care continuum
  - Reflects emphasis on patient-centered care coordination

  Health care (medical) homes
  Accountable Care Organizations
Biomedical Informatics
Evaluation

Community partners using six unique EHRs for home care and public health were interviewed. The three data sets in community-based EHRs cover 80% of the of the CCD sections for home care and 46.7% for public health. Additional data are included in these systems, that likely address other CCD components.

- All six vendors include data for the Outcome Assessment Information Set (OASIS) and the 485 Plan of Care.
- The Omaha System assessments, problem lists, interventions, and goals/ outcomes for home care and public health were included or planned in 4 of the 6 EHRs.
Conclusions

The UMN AHC Information Exchange Platform

CDR will include OASIS and Omaha System data sets from home care and public health EHRs

- Expand the capacity for translational research across the continuum of care
- Data describe a period of care that is not apparent in other data warehouses nor represented in other terminologies-vocabularies
- Expand T1 - T4 research to develop new practice-based research designs and discover implications from EHR data for improving practice and the health of populations across the continuum of care.
As a TEAM, we are equipped to Lead

Practice + Science + Big Data + .... YOU!

<Your Study Here>

Keep collaborating – growing – learning!
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