Urgent Call for Big Data & Nursing

NI 2016 June 28
Geneva, Switzerland
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Objective
To expand internationally a National Action Plan for sharable and comparable nursing data for quality improvement and big data science

• Vision of Big Data for Quality Improvement and Big Data Science

• Big Data/Data Science Initiative - Workgroups to Achieve the Vision

• Informatics and Leadership – Key to Success

• Engaging Vendors to Support Standard Data and Processes

• Opportunities and Challenges for an International Community
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National Action Plan for sharable and comparable nursing data for quality improvement and big data science

- Urgent need to assure that nursing has sharable and comparable data for quality improvement and big data science
- A national collaborative – Nursing Knowledge and Big Data Science – invites international collaboration
- Implement and use sharable and comparable nursing big data
- Share accomplishments and future plans toward international collaboration
Data-Enabled Science

- Volume
- Velocity
- Variety
- Veracity
- Value

- Analytics
- Visualization

- Genome
- Symptome
- Exposome
- Behavior
- ...and more

“...is not about analyzing small data sets that can be easily dealt with by using conventional statistics or even manually....the goal is to make sense of big data.”

Big Data Sources/Resources
(examples)

• Federal Agencies
  – CMS Claims Data
• Academic Repositories
• Commercial/Industry
  – Optum Labs
• Social Media
• Electronic Health Records
• Wearable Technologies

• National Institutes of Health Big Data to Knowledge (BD2K)
  (https://datascience.nih.gov)
  – 11 Centers of Excellence for Big Data Computing and two Centers that are collaborative projects with the NIH Common Fund LINCS program, the LINCS-BD2K Perturbation Data Coordination and Integration Center, and the Broad Institute LINCS Center for Transcriptomics.
  – Data Index: A data discovery index (DDI) prototype (https://biocaddie.org/)

• NSF created the Directorate for Computer & Information Science & Engineering (CISE)
Nursing Knowledge

Education
Workflow
Data Integration
Leadership
Health Policy

Nursing Big Data Science
Contexts for Big Data Science
- National & Global -

• Learning Health System (LHS)
• Quadruple aim
• Precision medicine and person-centric care
• Research: CTSA & PCORI initiatives
• Connected communities, local to global
Vision

A system that is designed to generate and apply the best evidence for the collaborative health care choices of each patient and provider; to drive the process of new discovery as a natural outgrowth of patient care; and to ensure innovation, quality, safety, and value in health care.

(Charter of the Institute of Medicine Roundtable on Value & Science-Driven Health Care)
Real-time access to knowledge

Digital capture of the care experience

Engaged, empowered patients

Full transparency
Digital Infrastructure for the Learning Health System: The Foundation for Continuous Improvement in Health and Health Care
Follow up Reports

• Leadership Commitments to Improve Value in Health Care: Finding Common Ground
• Evidence-Based Medicine and the Changing Nature of Health Care
• Redesigning the Clinical Effectiveness Research Paradigm: Innovation and Practice-Based Approaches
• Clinical Data as the Basic Staple of Healthcare Learning: Creating and Protecting a Public Good
• Engineering a Learning Healthcare System: A Look at the Future
• Learning What Works: Infrastructure Required for Comparative Effectiveness Research
• Value in Health Care: Accounting for Cost, Quality, Safety, Outcomes, and Innovation
• The Healthcare Imperative: Lowering Costs and Improving Outcomes
• Patients Charting the Course: Citizen Engagement and the Learning Health System
Quadruple Aim

- **Triple Aim**
  - better care
  - better health
  - lower costs

- **Quadruple Aim**: that emphasizes the original three goals plus the goal of improving caregivers' experiences
Precision Medicine/Health

an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person.


https://www.whitehouse.gov/the-press-office/2015/01/30/fact-sheet-president-obama-s-precision-medicine-initiative
ARE WE PREPARED TO CAPTURE AND USE SOCIAL DETERMINANTS OF HEALTH?
NIH Re-engineering Clinical Research

PCORnet: The National Patient-Centered Clinical Research Network
http://www.pcori.org/about-us

- **Clinical Data Research Networks (CDRNs) (N=11)**
  System-based networks that originate in healthcare systems, such as hospitals, health plans, or practice-based networks, and securely collect health information during the routine course of patient care.

- **Patient-Powered Research Networks (PPRNs) (N=18)**
  Networks operated and governed by groups of patients and their partners and are focused on a particular condition or population and whose members are interested in sharing health information and participating in research

**Coordinating Center** - Harvard Pilgrim Health Care Institute and Duke Clinical Research Institute - Provides technical and logistical support to the individual partner networks.

July, 21, 2015, PCORI’s Board of Governors approved funding for 34 individual data networks that will comprise Phase II
Synergy – Collaboration
Digital Infrastructure

CTSA
https://ctsacentral.org/

PCORI
http://www.pcori.org/
6977 Airports Spanning Globe

OpenFlights Airports Database
01/2012

http://openflights.org/data.html

Top 15 Most Popular Social Networking Sites | March 2016

Top 15 Most Popular Social Networking Sites as derived from our eBizMBA Rank which is a continually updated average of each website's Alexa Global Traffic Rank, and U.S. Traffic Rank from both Compete and Quantcast. "**#**" Denotes an estimate for sites with limited data.

http://www.ebizmba.com/articles/social-networking-websites

1,100,000,000 + 310,000,000 + 255,000,000 + 120,000,000
Optum Labs: Building A Novel Node In The Learning Health Care System

Abstract
Unprecedented change in the US health care system is being driven by the rapid uptake of health information technology and national investments in multi-institution research networks comprising academic centers, health care delivery systems, and other health system components. An example of this changing landscape is Optum Labs, a novel network “node” that is bringing together new partners, data, and analytic techniques to implement research findings in health care practice.

Partners
- Mayo Clinic
- AARP
- AMGA
- Boston Scientific
- Boston University
- Lehigh Valley
- Pfizer Inc.
- Rensselaer Polytechnic
- Tufts Medical Center
- University of Minnesota School of Nursing
- Harvard Medical School
- Medica Research Institute
- Merck
- University of Maryland
- The Brown University School of Public Health
- Johns Hopkins Bloomberg School of Public Health
- MIT Sloan School of Management
- Novartis Pharmaceuticals Corporation
- ResMed
Vision for health

The Nexus

Education

Practice

Leading to partnerships

Producing positive impact on Triple Aim outcomes

NCDR

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Workgroups

Nursing Knowledge

Education    Workflow   Data Integration    Leadership   Health Policy

Nursing Big Data Science
Nursing Knowledge: Big Data Science

Workgroups
Care Coordination

• Co-leaders: Jean Scholz, Laura Heerman Langford
  – New leaders: Mary Hook and Lori Popejoy

• Purpose
  – To identify nursing implications related to “big data” associated with “care coordination”

• Major achievement
  – Collaborated with ANA for consensus model for care coordination and strategic agenda

• Main activity plan
  – To determine the essential elements in predictive and management nursing big data science
Clinical Data Analytics

- Co-leaders: Connie W. Delaney, Bonnie L. Westra
  - New leaders: Bonnie L. Westra, Martha Sylvia

- Purpose
  - to demonstrate the value of sharable and comparable nursing-generated data to support practice and translational research for transforming health care and improving patient quality and safety

- Major achievement
  - Integrated 6 organizations in nursing information models validation for flowsheet data and developed applied big data science literature review. Co-editing special issue on WJNR about nursing big data research

- Main activity plan
  - Population health analytics, and foster information models validation across settings
Connecting Emerging and experts Nurse Informatics Leaders

• Co-leaders: Kari Ballou, Anne LaFlamme
  – New leaders: Kali Ballou, Lynn Choromaski

• Purpose
  – To provide a platform for emerging and expert informatics nurses to connect and discuss opportunities to enhance nursing knowledge

• Major achievement
  – Collected content for communication and posting, and collected new ideas to attend “connection” between emerging and experts needs

• Main activity plan
  – ANIA connections and other organizations to share their vision into their system
Context of Care

• Co-leaders: Amy Gracia, Barbara Caspers
  – Co-leaders: Amber Oliver, Barbara Caspers, Dan Robert

• Purpose
  – To develop a NMMDS dissemination plan working group, and to design a comparative study to compare the NMMDS and to the Minimum Data Sets used by the National Forum of State Workforce Centers

• Major achievement
  – Developed an initial detailed clinical model and test kitchen methodologies for nursing data sets, including NMMDS

• Main activity plan
  – Propose a national integration framework for nursing data sets, including NMMDS
Education

- Co-leaders: Thomas Clancy, Judy Warren
  - New leader: Marisa Wilson

- Purpose
  - Develop a crosswalk between the AACN Essentials for Information Management and the Application of Patient Care Technology, QSEN KSA’s for Nursing Informatics and the TIGER competencies for clinical nurses and nursing students. Investigate the development of a course curriculum that incorporates these competencies.

- Major achievement
  - Workshops, conferences, webinars, seminars – Deep Dive Program – thousands of nurses attended. New appointments in key national programs to advance nursing informatics

- Main activity plan
  - To focus on graduate nurse population at the master and entry level, developing training resources, tools, and framework
Encoding/Modeling Workgroup

• Co-leaders: Susan Matney, Tess Settergren

• Purpose
  – To develop and Disseminate Logical Observation Identifiers Names and Codes (LOINC®) and Systematized Nomenclature of Medicine - Clinical Terms (SNOMED CT®) for Electronic Health Record (EHR) Nursing Assessments and incorporate them into a framework and repository for dissemination

• Major achievement
  – Publications, completed medical/surgical assessment LOINC submission, and started SNOMED CT submission. Additional work on describing peripheral intravenous and central venous catheter properties

• Main activity plan
  – Communication, implementation, and creation of model development for nursing data
Engage and Equip all Nurses in Health IT Policy

- Co-leaders: Joyce Sensmeier, Kelly Cochran
- Purpose
  - To better engage all nurses in health IT policy efforts; To provide nurses with the education, tools and resources to equip them as knowledgeable advocates for policy efforts that are important to nursing
- Major achievement
  - Collected relevant health IT policy-related educational tools and resources and made them available through a resource library
- Main activity plan
  - To increase library resources, collaborate in policy efforts, and leverage relevant policy positions for advocacy efforts
mHealth (Connected Health)

• Co-leaders: Victoria L. Tiase, Robin R. Austin
  – New leaders: Christie Martin, Lily Tunby

• Purpose
  – To explore the use of mobile health tools and data by nurses including both nursing generated data and patient generated data.

• Major achievement
  – Definitions and identification of use case examples for mhealth

• Main activity plan
  – To collect use cases and examples for dissemination
Nursing Value

• Co-leaders: Ellen Harper, John Welton
• Purpose
  – To develop a national consensus model to measure patient level nursing intensity and costs per patient in multiple care settings to support the continuum of care and to produce objective measures of nursing value
• Major achievement
  – Several publications and presentations, including the Nursing Value Data Model Version 20 in Nursing Economic$ as public domain
• Main activity plan
  – To request a national nursing provider identifier number, to develop use cases/stories and data dictionary, and detect gaps in current work
Social Behavioural Determinants of Health (SBDOH)

• Co-leaders: Erin Maughan, Susan Hull

• Purpose
  – Develop a toolkit of resources to support the inclusion of Social and Behavioral Determinants of Health (SBDOH) into electronic health records, including expected requirements for the CMS Meaningful Use Programs

• Major achievement
  – Established foundational review of existing work

• Main activity plan
  – To develop knowledge, data, and information models for SDBOH
Transform documentation

• Co-leaders: Ann O’Brien, Charlotte Weaver

• Purpose
  – To support the recommendations from the IOM Report: Best Care at Lower Cost - The Path to Continuous Learning Healthcare in America to “accelerate the integration of best clinical knowledge into care decisions”.

• Major achievement
  – Toward a Central Repository for Sharing Nursing Informatics’ Best Practices. Judith Effken, RN, PhD, FACMI, FAAN, Charlotte Weaver, RN, PhD, FAAN, Kelly Cochran, MS, RN, Ida Androwich, PhD, RN, Ann O’Brien, RN, MSN, CPHIMS (CIN, 2016)

• Main activity plan
  – To move from silos of documentation and incorporate across the continuum of care with the creation of a data repository
Questions and resources

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#NursingandBigData
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Informatics and Leadership – Key to Success

• Collaboration is the Key
• More than 100 unique organizations participated in the 2016 Big Data Conference
• Unique collaboration of individuals and groups
  – Professional societies
  – Academia
  – Industry
  – Healthcare provider organizations
  – Government agencies
Diversity of Roles

• Academia
  – Deans, professors, faculty, staff

• Industry
  – CEOs, vice presidents, directors, managers, associates

• Healthcare provider organizations
  – CNOs, CIOs, directors, managers, staff

• Government agencies
  – CNOs, directors, fellows, coordinators

• Professional societies
  – CEOs, vice presidents, directors, managers
Power in Collaboration

• Provided insight and collaboration with ANA on strategic agenda for care coordination.

• Validate flowsheet information models for extending interprofessional common data models.

• Published American Academy of Nursing Policy Brief and call for action.

• ANA position statement “Inclusion of Recognized Terminologies Supporting Nursing Practice within Electronic Health Records and Other Health Information Technology Solutions”

• Began development of a test Big Data set - Test Kitchen - and Detailed Clinical Model (DCM)
Power in Collaboration

- **Appointment** of Connie Delaney to the AMIA Advanced Interprofessional Informatics Certification Work Group.
- LOINC and SNOMED-CT concept updates
- Considered recommendation for collaboration on a sustainable, public-facing health IT-focused policy resource library for nurses
- Identify and log use cases examples of mhealth data/patient reported data use via mobile technologies
- Used Agile Project Management Method to Develop a User Story Template
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Engage Vendors in Key Initiatives

• Deliberately invite key decision-makers from major vendors

• Involve Vendor Reps in work product development

• Include Vendor Reps in publications

• Bring Policy, Legislative and Vendors into work through press and publications
Example 1: Report of the AMIA EHR 2020 Task Force on the Status & Future Direction of EHRs

JAMIA, May 28, 2015

Five Goals
Ten Recommendations

• Heavily cited
• Adopted by Legislative Committees
• Used by HIT Policy Groups
• Physician Focused

http://jamia.oxfordjournals.org/
AMIA EHR 2020 Task Force Recommendations

I. SIMPLIFY & SPEED DOCUMENTATION
1. Decrease data entry burden (all team members)
2. Separate data entry from data reporting
3. Enable systematics learning & research at POC

II. REFOCUS REGULATION
4. Clarify & simplify certification & MU regulations
   – improving data exchange & interoperability
   – need for re-entering data & prioritizing pt outcomes
   – Vendors & providers streamline workflows!
5. New regulations should support innovation in EHR systems
AMIA EHR 2020 Task Force Recommendations

III. INCREASE TRANSPARENCY & STREAMLINE CERTIFICATION

6. how vendors satisfy certification criterion should be flexible & transparent

7. health care organizations, providers, & vendors should be fully transparent about:
   – unintended consequences
   – new safety risks introduced by health IT
   – best practices for mitigating risks

IV. FOSTER INNOVATION

8. Vendors should use APIs & data standards that enable EHRs to be open to innovators, researchers, & patients.
AMIA EHR 2020 Task Force
Recommendations

V. EHR of 2020 MUST SUPPORT PERSON-CENTERED DELIVERY

9. Promote integration of EHRs into full social context of care
10. Improve interface designs to support how people think
   – (e.g. cognitive-support design)

Individual actions sought:
• input into RFPs & purchasing decisions
• inform proposed regulations & legislation
• guide research
Example 2: University of Minnesota’s Big Data and Nursing

Working Group #10

- Published 1st year’s work in Nursing Admin Quarterly Journal as specific recommendations
- Lead by CNIO’s from major health systems
- Involved health policy and vendor stakeholders
- Adopted by ONC, AHRQ and National Academy of Medicine as required reading for Task Forces

http://journals.lww.com/naqjournal/toc/2015/10000
LAS VEGAS—HHS' Office of the National Coordinator for Health Information Technology is pushing nurses across the nation to use common language in electronic health records.

ONC’s CNO, Rebecca Freeman, is promoting the use of the LOINC (Logical Observation Identifiers Names and Codes) and SnoMed (Systematized Nomenclature of Medicine) codes for nursing documentation.

http://www.modernhealthcare.com/article/20160301/NEWS/160309988
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International Community Challenges and Opportunities

1. eHealth initiatives in Europe and elsewhere
   - Different health care systems
   - Fragmentation influences data
   - Languages

2. Standardization
   **Objective: Increase adoption of terminologies in nursing**
   - Academic programs - Nursing curriculum
     - Informatics in nursing curricula
     - Teaching nurses what they are and how to use them
   - Accuracy of diagnoses, interventions -> accuracy of data
   - Clinical placements – role models
   - Faculty preparation
     - New data analytics
   - Translations between languages
Challenges and Opportunities

3. Value of nursing data for practice, research, quality improvements, cost

Objective: Increase the impact of nursing data in health care by increasing quality of the data and the demand

- Standardization
- Structured, consistent documentation in clinical practice
- Storage of data, linkages between data elements
- Data standards & information structures, retrieval of data
Challenges and Opportunities

4. Collaboration with International Organizations

Objective: Facilitate nurses engagement in developing health information policy

- IMIA
- IMIA NISIG
- Association for Common European Nursing Diagnoses, Interventions and Outcomes (ACENDIO)
- EFN
- HIMSS
- ICN
- WHO
Challenges and Opportunities

5. Data access and privacy issues
   – Rules, regulations and law
Discussion

• What are the challenges for contributing sharable and comparable nursing data for big data science?

• What activities and resources already exist for conducting nursing big data science?

• Where is there congruence for conducting comparative effectiveness research across health systems and countries?
Discussion

• What health policies and leadership strategies have been successful for standardizing data and process for comparative data?

• What initiatives are embedding Nursing Data into Research, Quality, and Finances internationally?

• How can we support, partner, and share political advice for Integrating Nursing Data into Health Policy with international leaders?