Testimony Vocabulary Task Force, Standards Committee,
Office of the National Coordinator
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11:00 p.m. September 1, 2010, Panel 2b: End Users, Clinicians, Hospitals, HIEs

INTRODUCTION

Good morning, as co-Chair for the Alliance for Nursing Informatics (ANI), I am pleased to provide testimony on nursing vocabularies. ANI believes that patient centric interdisciplinary care is required to effectively improve health care quality, safety and efficiency. Nurses are at the center of care coordination and technology should be an enabler, enhancing the communication between care providers throughout the continuum of care. Nursing data overlaps other health care disciplines, but also has unique phenomena represented by nursing vocabularies. Therefore, nursing terminologies and data sets are essential to meaningful use of electronic health records (EHRs), not only for provision of care but also reuse of data for quality improvement and research.

Nursing has over three decades of experience in developing vocabularies. There is a shift now from development to interoperability of data across the spectrum of health care settings.

The supplemental material provided describes a rich history of vocabulary development as well as the ANA criteria for national recognition of vocabularies. Key lessons learned from these experiences are:

1. Nursing vocabularies support codification of problems representing human responses to health and illness and should be linked to nursing interventions, and outcomes to support meaningful use of EHRs.
2. Multiple interface terminologies are useful for specific practices and settings and these should be retained, but mapped through a reference terminology.
3. Recognition of vocabularies using ISO standards ensures reliability, validity, and usefulness of terminologies and also supports appropriate ongoing maintenance.
4. Conceptual mapping is a first step toward interoperability; ongoing mapping of value is needed to improve semantic interoperability.

Nursing has successfully employed or is developing methods to improve process interoperability that can be of value this Task Force. These include the following with more details in the supplemental materials:

1. Association of periOperative Registered Nurses' (AORN) Standardized Patient Record,
2. The Omaha System Partnership for Knowledge Discovery and Health Care Quality,
3. International Classification for Nursing Practice' (ICNP) catalogues/ subset development,
4. Integrating the Healthcare Enterprise' (IHE) eNursing Summary Profile, and
5. Nursing vocabularies can be abstracted from EHR for quality metrics

Key lessons learned from these activities include:
1. Nursing vocabularies are useful to translate evidence-based practice guidelines for documentation of patient care.
2. Consistency in documentation can be simplified using subsets of terms from vocabularies
3. Software alone cannot assure interoperability, training on consistent use of terminologies in information systems is required. There is a cost associated with training that cannot be ignored.
4. A variety of multidisciplinary experts are needed to implement and manage value sets, subsets, and entire vocabularies as listed in the supplemental materials.

RECOMMENDATIONS FOR IMMEDIATE IMPLEMENTATION
1. All vocabularies to support meaningful use of EHRs should meet criteria similar to Table 1 in the Supplemental Material to assure reliability, validity and usefulness as well as appropriate ongoing maintenance.
2. Nursing terminologies should be incorporated into the continuity of care record including the data elements and value sets for of nursing diagnoses, interventions and outcomes to ensure semantic interoperability.
3. Include all stakeholders in the design, implementation, and meaningful use of vocabularies in EHRs to ensure semantic and process interoperability.
4. Terminologies can be used for quality metrics and not replaced by additional documentation requirements.

RECOMMENDATIONS FOR FUTURE IMPLEMENTATION
1. Improve process interoperability by requiring software vendors to integrate ANA recognized terminologies to support both semantic and process interoperability. We would recommend including this requirement in the certification criteria for achieving meaningful use.
2. A well funded central source is needed to support the ongoing growth, development, and proper use of nursing terminologies (that continue to be incorporated into SNOMED). To rapidly enable a central source that is a "one-stop" shop for vocabularies, subsets, and value sets should build on existing foundations to provide a web-enabled service. The NLM would be a good neutral organization that has the foundation, experience, and tools to serve this purpose; however, additional funding is necessary to provide this additional service.

SUMMARY
Nursing's vocabularies complement data from other health care disciplines and provide more complete details of the patient care experience and context that can be used to better describe patient safety, quality metrics, and outcomes linked with diagnoses and interventions.

Nursing has a long history of vocabulary development and experience in semantic and process interoperability that can be useful for the ONC Vocabulary Task Force to rapidly implement methods for meaningful use of EHRs.

SUPPLEMENTAL MATERIALS

Alliance for Nursing Informatics

The Alliance for Nursing Informatics (ANI) is a collaboration of organizations that enables a unified voice for nursing informatics. ANI represents more than 5,000 nurse informaticists and brings together over 27 distinct nursing informatics groups primarily in the United States. ANI crosses academia, practice, industry, and nursing specialty boundaries and works in collaboration with the nearly 3 million nurses in practice today. Nurses constitute the largest single group of healthcare workers, including experts that serve on national committees and interoperability initiatives focused on standards and terminology development, standards harmonization, and electronic health record (EHR) adoption, as well as certification of EHR systems. Further, nurses are active in the research, education, implementation, integration and optimization of information systems throughout the healthcare system.

American Nurses Association Recognized Terminologies

Nurses provide care for individuals, families, communities, and populations addressing health concerns ranging from health promotion, prevention, and treatment. The domains addressed by nurses include physiological, psychological, social, cultural, spiritual and environmental phenomena. Nurses provide health care in every setting and are key to engaging patients and families in their health care as well as responsible for information essential for care coordination across the spectrum of health care and home settings. The ANA is responsible for recognizing nursing datasets and terminologies based on ISO criteria, which are shown in Table 1 and approved by the ANA Congress on Nursing Practice and Economics in September 2008 (email communication, C. Bickford, ANA, 8/19/2010).

Table 1. ANA Recognition Criteria

1. The terminology supports one or more components of the nursing process.
2. The rationale for development supports this terminology as a new terminology itself or with a unique contribution to nursing / health care.
3. Characteristics of the terminology include:
   - Support of one or more of the nursing domains
   - Description of the data elements
   - Internal consistency
   - Testing of reliability, validity, sensitivity, and specificity
   - Utility in practice showing scope of use and user population
   - Coding using context-free unique identifier
4. Characteristics of the terminology development and maintenance process include:
   - The intended use of the terminology
   - The centricity of the content (patient, community, etc.)
   - Research based framework used for development
   - Open call for participation for initial and ongoing development
   - Systematic, defined ongoing process for development

- Relevance to nursing care and nursing science
- Collaborative partnerships
- Documentation of history of decisions
- Defined revision and version control mechanisms
- Defined maintenance program
- Long term plan for sustainability

5. Access and distribution mechanisms are defined.
6. Plans and strategies for future development are defined.

The two nursing data sets, seven interface nursing terminologies and three multidisciplinary terminologies recognized by ANA can be found on ANA's website (http://www.nursingworld.org/Terminologies). Nursing has a long history of terminology development beginning in the early 1970's. Federal funding supported the development of some terminologies, but most of the work to develop reliable and valid data sets and terminologies occurred through private funding and countless volunteer hours. All of the data sets and terminologies have research support to assure that they sufficiently represent the domains of concern to nursing and are sufficiently reliable and valid to include in meaningful use of EHRs and other information system.

The *seven nursing interface terminologies,* used to document care, differ based on the intended use for practice, the concepts included, and the organization of the concepts.
1. North American Nursing Diagnoses Association (NANDA) addresses nursing diagnoses
2. Nursing Intervention Classification (NIC)
3. Nursing Outcome Classification (NOC)
4. Clinical Care Classification (CCC)
5. Omaha System, and
6. Perioperative Nursing Data Set (PNDS), and
7. International Classification of Nursing Practice (ICNP)

The ICNP has been recognized by the World Health Organization (WHO) as one of the WHO Classifications, equivalent to ICD-10 or the International Classification of Functioning, Disability, and Health (ICF). All of the ANA recognized interface terminologies except ICNP are mapped through 2007 into SNOMED-CT to support interoperability. There is a harmonization agreement signed to map the ICNP into SNOMED-CT in the future.

METHODS TO IMPROVE PROCESS INTEROPERABILITY

SNOMED-CT Nursing Problem Subset

The SNOMED Nursing Working Group, has convened a group of nursing informaticists to create a nursing problem subset using SNOMED-CT. IHE and the NLM are participating in this effort. The goal is to create a nursing problem/diagnosis value sets by harmonizing the nursing diagnoses from the nursing terminologies to support semantic interoperability that assures the nursing problems.

AORN's Standardized Patient Record

The AORN developed the PNDS terminology. They since moved toward process interoperability by building software module that integrates the PNDS into standardized processes for surgical nursing.

> AORN has launched Syntegrity Standardized Perioperative Framework, software content for surgical care nurses that integrates into electronic health record (EHR) systems and nursing documentation systems. This is the first in a series of AORN offerings designed to improve patient outcomes and enhance operational performance. Syntegrity, which allows nurses to capture and identify critical patient care elements throughout all phases of perioperative care, is compatible with any commercially available or internally developed EHR and nursing documentation system. It meets all current interoperability and data standards set by the American National Standards Institute Health Level 7. The Framework will incorporate AORN's standardized nursing vocabulary, the Perioperative Nursing Data Set (PNDS), and align with clinical standards, accreditation specifications, and regulatory requirements to promote ongoing compliance and consistent patient care (AORN, Accessed 8/23/10).

Omaha System Partnership

The Omaha System Partnership for Knowledge Discovery and Health Care Quality (Monsen, director) consists of a scientific team skilled in outcomes research methods and affiliate members from five countries who contribute de-identified clinical data to an international Omaha System data warehouse housed at the University of Minnesota School of Nursing (http://omahasystemmn.org/links.htm). The scientific team and affiliate members collaborate to address relevant clinical questions and generate essential new knowledge discoveries to improve health care and population health outcomes. A major focus of this partnership is the dissemination and translation of evidence to practice settings through the development of standardized pathways that can be adopted within any EHR. This partnership has grown out of the Minnesota-based International Omaha System Users Group; a vital grass roots resource in which scholars and practitioners jointly address issues such as applications of interface terminology in the development of agency standards, EHR interoperability and data exchange, and data reliability.

ICNP Catalogue/ Subsets

The ICNP developed guidelines for creating subsets (catalogues) for use of the terminology in practice (http://www.icn.ch/pillarsprograms/icnpr-catalogues/). This allows nurses and developers to select terms that are most appropriate for addressing a specific health concerns or populations, thus streamlining the use of ICNP. To date, they have developed catalogues for "Palliative Care for Dignified Dying" and **"Partnering with Individuals and Families to Promote Adherence to Treatment."**

Patient Safety and Continuity of Care

The Joint Commission, in 2005, analyzed 3000 adverse events. Communication was the contributing factor in 70% of these events. Communication breakdowns during transitions of patient care accounted for a 50% error rate. This study in conjunction with the work of Institutes for Healthcare Improvement and other research, acknowledged the serious need for improvement.

Standardization work has been initiated by several standard development organizations as well as a new work from the European eNursing group calling for a summary tool which crosses the Healthcare Enterprise and provides a timely care transfer (Veenstra, 2010). The purpose of eNursing Summary Profile is to create an interoperable summary of nursing related data elements that communicates the ongoing patient care needs to another care provider. The data elements were determined by an international survey of 593 nurses. Use of the eNursing Summary tool by all clinicians in a care transition process may eliminate communication errors or contributing factors to communication breakdowns (http://www.ihe.net/Technical_Framework/index.cfm#pcc).

EHR Research Examples

Nursing terminologies are essential but insufficient to adequately represent nursing in EHRs and generate interoperable nursing data. The manner in which the terminologies are integrated into systems and then how these technical systems are implemented into practice also profoundly affect interoperability. Several research projects have carefully studied the related issues.

A research project called "HANDS" has been systematically studying the question of successful integration of ANA nursing terminology sets in electronic tools and implementation into practice for more than a decade. This work has been funded through multiple non-proprietary sources including the most recent multi-site study funded by AHRQ (2005- 2008 HIT support for safe nursing care - R01 HS015054). Specifically, through iterative studies that have used multiple research methods and tools, the HANDS research team has demonstrated how an ANA recognized terminologies can be successfully used to support continuity of care at handoffs and generate valid and reliable data for multiple secondary uses. The HANDS prototype electronic web deployed tool and processes of use have gone through numerous iterations and terminology updates over the past decade and now provides a well tested model for utilizing the ANA recognized terminology sets in the electronic health records. The model addresses each of the three levels of interoperability (technical, semantic, process) that are necessary to achieve the level of "meaningful" interoperability needed to support continuity of care at the point of care and generate valid data for secondary uses. The project is currently focused on demonstrating the valuable secondary uses of data collected using the model. (Keenan, Tschannen, & Wesley, 2008; Keenan, Yakel, & Tschannen, 2008).

Additional research exists to demonstrate the feasibility of integrating the Omaha system across vendors and settings (Westra, Oancea, Savik & Marek, 2010) as well as the reuse of the Omaha System EHR data across systems and vendors to demonstrate the influence of nursing interventions on outcomes (Westra, Delaney, Konicek, & Keenan, 2008; Westra et al., accepted 2009; Monsen,

Radosevich,, Kerr, & Fulkerson, accepted 2009). These examples provide evidence that quality indicators can be developed reusing nursing terminologies to support meaningful use of EHRs.

Human Resources to Implement Vocabularies
For a developer of a component of the EHR that utilizes nursing terminologies (implementing and managing value sets and updates) requires the following specialty expertise:
1. Data-modeling and architecture knowledge for initial program development that will incorporate data elements that utilize specified value sets--Purposes: To ensure a) data base supports the relationships needed among the elements captured using value sets so that questions of interest can be answered. (e.g., if database doesn't store the relationship between a diagnosis and the treatment assigned to it, there will be no way to establish this in queries of the database) b) to build architectures that are sustainable (easily upgradeable with new versions of value sets).
2. Database development & management (including networking) to make sure the actual database is built according to the architecture and that the value sets are entered and updated within the database properly.
3. Application programmers, usability experts to ensure the application that utilizes values sets are built to support clinicians who must use the terminology at the point of care.
4. Terminology experts (informaticists) – clinicians and researchers who understand the terminologies and appropriate use of them. Because of their domain knowledge, these experts must lead 1), 2), and 3) to build and properly test products to ensure the achievement of the intended outcomes.
5. Training specialists - clinicians who create and update training that creates competent users of applications that contain nursing value sets.

SUMMARY
Nursing's vocabularies complement other health care vocabularies and provide more complete details of the patient care experience and context that can be used to better describe patient safety, quality metrics, and outcomes linked with diagnoses and interventions. Nursing has a long history of vocabulary development and experience in semantic and process interoperability that can be useful for the ONC Vocabulary Task Force to rapidly implement methods for meaningful use of EHRs.

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About the ONC Vocabulary Task Force

The HIT Standards Committee's Clinical Operations Workgroup set up a **Vocabulary Task Force** to address vocabulary subsets and value sets as facilitators and enablers of "meaningful use." The Vocabulary Task Force meets monthly under the auspices of the parent Workgroup."

Specific Charge

- To identify gaps, issues and needs for clinical and administrative vocabulary solutions within the scope of the HIT Standards Committee; to develop recommendations to the HIT Standards Committee for methods, actions, and/or programs to mitigate, manage, or solve these vocabulary concerns.

Member List

- Jamie Ferguson, Chair, Kaiser Permanente
- Betsey Humphreys, Co-Chair, National Library of Medicine
- Donald Bechtel Accredited Standards Organization X12
- Chris Brancato HHS/ONC
- Lisa Carnehan NIST
- Christopher Chute Mayo Clinic
- Bob Dolin HL7
- Greg Downing HHS
- Floyd Eisenberg National Quality Forum
- Doug Fridsma HHS/ONC
- Marjorie Greenberg HHS/CDC
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- Amy Gruber CMS
- John Halamka Harvard Medical School
- Stan Huff Intermountain Healthcare
- John Klimek NCPDP
- Clem McDonald National Library of Medicine
- Stuart Nelson National Library of Medicine
- Marc Overhage Regenstrief Institute
- Marjorie Rallins American Medical Association
- Dan Vreeman Regenstrief Institute
- Jim Walker Geisinger
- Andrew Wiesenthal IHTSDO (SNOMED)

All previous testimony and meeting materials is available on the ONC website at:
http://healthit.hhs.gov/portal/server.pt?open=512&mode=2&objID=3004&PageID=20395

The Alliance for Nursing Informatics (ANI)
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ANI Member organizations*

- Alabama Society for Clinical Informatics (ASCI)
- American Medical Informatics Association (AMIA)
- ANIA – CARING
- Association of periOperative Registered Nurses (AORN)
- Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN)
- Center for Nursing Classification and Clinical Effectiveness (CNC)
- Central Savannah River Area Clinical Informatics Network (CSRA - CIN)
- Cerner Nursing Advisory Board
- Connecticut Healthcare Informatics Network (CHIN)
- Croatia Nursing Informatics Association (CroNIA)
- Delaware Valley Nursing Computer Network (DVNCN)
- Health Informatics of New Jersey (HINJ)
- Healthcare Information and Management Systems Society (HIMSS)
- Informatics Nurses From Ohio (INFO)
- MEDITECH Nurse Informatics program
- Midwest Nursing Research Society - NI Research Section (MNRS)
- Minnesota Nursing Informatics Group (MINING)
- NANDA International
- New England Nursing Informatics Consortium (NENIC)
- North Carolina State Nurses Association Council on NI (NCNA CONI)
- Omaha System
- Perinatal Information Systems User Group (PISUG)
- Puget Sound Nursing Informatics (PSNI)
- SNOMED CT Nursing Working Group
- South Carolina Informatics Nursing Network (SCINN)
- Utah Nursing Informatics Network (UNIN)

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*as of September 1, 2010