



TOWARD A NATIONAL HEALTH INFORMATION INFRASTRUCTURE: A KEY STRATEGY FOR IMPROVING QUALITY IN LONG- TERM CARE

**U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy**

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EXECUTIVE SUMMARY

The availability of detailed and clinically relevant data is essential for clinical care decisions and essential for oversight groups making decisions related to the quality of that care. The Institute of Medicine has repeatedly emphasized that cost-effective, high quality health care is linked to the availability of information, and that computerized patient medical record information systems are an essential strategy in improving the quality of care. A National Health Information Infrastructure (NHII) has been identified by numerous advisory panels and experts as essential for improving patient safety and quality, controlling rising health care costs, and responding to health care crises (e.g., bioterrorist attacks). The technology to support the NHII is available. Implementation awaits a coordinated national effort, particularly around health information standards.

The purpose of the NHII is to share information and knowledge when and where needed. An essential building block of the NHII is adoption and use of agreed upon terminology and messaging standards. Terminology standards provide an unambiguous, machine-readable meaning of specific terms. Messaging standards permit the electronic exchange of information in a consistent format. Terminology and messaging standards will allow the inter-operable use and exchange of healthcare information. Much of the discussion about electronic health information standards has arisen within the acute care arena. In long-term care, there has been limited discussion related to electronic health information standards.

There were three objectives of this study. The first objective was to determine, as a pilot activity, whether leading terminology and classification systems provided content coverage to support clinical decision-making and quality of care oversight in nursing homes as recommended by clinical experts and as reflected in the literature. The three domain areas of pressure ulcers, chronic pain, and urinary incontinence provided the focus of this content coverage study. The second objective of this study was to examine the content of the federally required nursing home minimum data set (MDS) to determine whether it provides the information needed to understand quality of care in nursing homes in the three selected domains. Third, the study also examined the extent to which the content of MDS was captured by the three terminology systems described below.

Nursing homes are presently required to complete the nursing home MDS at numerous points during a resident's stay in a nursing facility. MDS data is used for several regulatory purposes including supporting the Medicare and sometimes Medicaid nursing facility payment methods and developing nursing home quality indicators and quality measures.

One formal terminology system and two classification systems were examined in this study: the Systematized Nomenclature of Medicine -- Clinical Terms (SNOMED CT),

International Classification of Functioning, Disability and Health (ICF), and International Classification of Nursing Practice (ICNP). SNOMED CT was developed specifically as a comprehensive, detailed clinical terminology system, and is structured in a way that takes advantage of new computer-based technologies for clinical information systems. SNOMED CT was selected for this study because it is considered to be the most comprehensive terminology system. Given the scope of clinical terms included in SNOMED CT and its acceptance by healthcare providers, the federal government is pursuing an agreement with the developers of this terminology that would make SNOMED CT widely available for use within the U.S. In contrast to SNOMED CT, ICF and ICNP were developed as classification systems, not detailed clinical terminologies. The ICF classifies many terms related to disability, an issue that many nursing home residents and that providers must address. The ICNP emphasizes the classification of terms relevant to nursing practice, a discipline very important to nursing home services.

The terms, data elements, and concepts needed to understand nursing home quality in the three domains were obtained through consultation with nationally recognized experts in each of the domains and a review of the literature.

Regarding the first objective, this report demonstrates that a comprehensive, internationally recognized formal terminology system such as SNOMED CT provides relatively complete coverage of terms suggested by the experts and the literature as needed to understand quality in the domains of pain, incontinence and pressure ulcers. Specifically, the study found the following complete match rates of terms in SNOMED CT and the terms recommended by experts: 77% for pressure ulcers, 92% for chronic pain, and 95% for urinary incontinence.

The ICF and the ICNP did not provide nearly as comprehensive coverage as SNOMED CT. The ICF was found to have the following complete match rates of the terms suggested by experts: 18%, 4%, and 4% for the domains of pressure ulcers, pain, and incontinence, respectively. The ICNP was found to perform equally poorly, with the following complete match rates of the terms suggested by experts: 16%, 3%, and 4% for the domains of pressure ulcers, pain, and incontinence, respectively. The differences between the content coverage provided by SNOMED CT and both ICF and ICNP illustrate why *comprehensive, detailed* clinical terminologies are essential components of the NHII. If clinically relevant data are captured at the point of care and encoded using a reference terminology system, algorithms can be written that enable the derivation of more use-specific classifications or reports (e.g., ICF, ICNP, or MDS). Perhaps more importantly, clinical data collected at the point of care can also be made available for “real time” applications such as automated alerts and clinical decision support systems, an important strategy for improving the quality of care. Clinical data, entered once at the point of care and encoded using a reference terminology system, are then said to be “re-usable” for multiple applications.

With respect to the second objective, the report indicates that the design and content of the MDS reflect the technology available at the time the MDS was originally developed. The report describes the MDS as an enumerated coding scheme that was designed to meet predefined needs for clinical data and information, and, as such, is not based on any standardized terminology system (i.e., a coding scheme that would permit the unambiguous exchange of information across the healthcare continuum).

The study found the nursing home MDS provided very limited coverage of terms suggested by experts as needed to understand nursing home quality in the domains of pain and incontinence. Overall, in the domains of incontinence and pain, fewer than 10% of the terms suggested by the clinical experts and literature as needed to understand nursing home quality had a complete match in the MDS. The MDS performed better with respect to pressure ulcers. The MDS provides an exact match for 70% of the pressure ulcer terms identified by the clinical experts and the literature needed to understand nursing home quality. Overall, this report concludes that the MDS does not capture information the experts said would be needed to measure nursing home quality in the three domains.

Finally regarding the third objective, most of the information collected using the MDS is not captured by SNOMED CT, ICF, or ICNP. Specifically, with respect to the extent to which SNOMED CT included any of the terms in the MDS, SNOMED CT was found to provide a complete match for 46% of the MDS terms. The ICF and ICNP were found to provide almost no coverage of the terms included on the MDS. Overall, a complete match rate of terms in the MDS and those in the ICF and ICNP was found 2% and 12% of the time, respectively.

Today, health information systems are expected to meet a variety of changing demands for data and information to support many purposes (e.g., automated alerts, decision support, quality monitoring, payment policy, and outcomes research). Standardized terminology systems are essential to permit the use and exchange of clinical data across applications and systems. Given point of care documentation, technology is now available to build electronic health information systems that will efficiently meet a variety of needs including: providing immediate feedback to care providers by, for example, issuing alerts related to relevant best practice guidelines, generating data needed for internal and external quality monitoring, exchanging critical patient information in a timely manner across the health care continuum, and reducing provider burden associated with current documentation requirements.

One of the most significant challenges to implementing electronic health information systems is the lack of standards for electronic patient medical record information, especially standards around the terminology that expresses clinical documentation. Achieving the promise of the NHII requires a coordinated national effort to adopt standardized terminologies, permitting the extension of inter-operable electronic health

information systems into long-term care. Efforts to develop payment and quality monitoring methods that are derived from clinical documentation systems in long-term care must be consistent with the underpinnings of the NHII. Failure to do so could only continue and exacerbate provider data collection burden and limit the scope, and, therefore, the utility of the NHII as a key strategy for improving the quality of care.

I. TOWARD A NATIONAL HEALTH INFORMATION INFRASTRUCTURE

There has been growing interest in the use of electronic health information systems. The Secretary of Health and Human Services (HHS), Tommy Thompson, has emphasized as one of his main priorities the use of information technology in healthcare. In November of 2001 the National Committee on Vital and Health Statistics (NCVHS) issued a report to Secretary of HHS that called for Federal leadership in establishing a National Health Information Infrastructure (NHII).¹ That report followed an 18-month period of hearings and consultations with consumers, providers, public health professionals, technology specialists, and policy makers. The first section of this paper provides an overview of the NCVHS report, and is followed by a discussion of the need for standards in order to achieve the goals of the NHII, the critical role of clinical terminologies in patient medical record information (PMRI) systems, and a discussion of the Minimum Data Set (MDS), a component of the Resident Assessment Instrument for Medicare and Medicaid certified nursing facilities in relation to NHII initiatives.

A. A National Health Information Infrastructure

Demands for readily available health care information have increased dramatically in recent years. Demographic changes such as an aging population with increased chronic illness and a more mobile population have created needs for larger volumes of health information and more easily transferable information. Most recently, concerns about bioterrorism have focused attention on the need for a public health information infrastructure with the capability of providing aggregated information on a real-time basis. The delivery of cost-effective, high quality health care in order to meet national goals for healthy people and healthy populations is now clearly linked to the availability of information.

The NCVHS is a public advisory committee authorized by statute to advise the Secretary of Health and Human Services on national health information policy. It concluded in its NHII report that "implementation of the NHII will have a dramatic impact on the effectiveness, efficiency, and overall quality of health and health care in the U.S." (p. 2). Presently, health information is typically maintained in paper records, in many locations for each patient, including: physician offices, laboratories, hospitals and departments within hospitals (e.g., radiology departments), and with post-acute care providers such as nursing homes and home health agencies. Paper medical records are difficult to read, poorly organized, and are frequently incomplete or unavailable. These problems are particularly pronounced for nursing home patients, who frequently have chronic health conditions and may be transferred to and from providers across the health care continuum.

The vision of the NHII is premised on a foundation of sharing relevant information and knowledge appropriately so that it is available to people when they need it to make the best possible health decisions. The argument put forward by the NCVHS was that with federal leadership as the cornerstone, human, institutional, and technological factors could be developed and brought together in way that enables many forms of communication and support for personal, provider, and public health concerns. The NCVHS report provided examples of how the NHII could improve the quality of health care:

For Consumers

- N Real time remote medical consultations wherever the person is located,
- N Online search for health information and looking for health care providers,
- N Management of one's own health care needs and their health care decision making;

For Providers

- N Providing access to more accurate and complete real-time patient data,
- N Using clinical guidelines and protocols concurrently with the patient care process,
- N Preventing adverse events by providing real time practice warnings to clinicians integrated with the patient care process,
- N Supporting continuous quality improvement processes by providing more complete and comprehensive clinical data for outcomes analysis;

For Public Health/Regulators

- N Improving the ability to identify, monitor, and respond to health problems,
- N Accessing and reporting data needed for public health,
- N Increasing the scope, effectiveness, and efficiency of clinical research.

Key characteristics of the NHII include data capture, storage, processing, and presentation of health information, all within secure, confidential environments. Examples of the desired functionality that would result from a fully implemented NHII include:

- Universal use of electronic medical records that capture all health information regardless of the setting in which a patient is receiving services;
- The ability to send and receive messages across health care settings and communities about a patient's health status whenever and wherever needed;
- Automatic electronic reporting to public health for early detection and response to unusual health patterns (such as bioterrorism);
- The provision of real-time clinical decision support (for example, about the efficacy of certain drug treatments or the effectiveness of particular interventions) to health care

professionals allowing more rapid widespread application of research findings in routine patient care;

- The ability to aggregate non-identified patient care information to rapidly provide evidence regarding the outcomes and efficacy of health interventions;
- The ability to more accurately and promptly monitor quality of health care services; and
- Reducing the administrative burden on health care practitioners associated with filling out forms, thus allowing providers to focus on delivery of services.

Key to achieving such functionality is point of service documentation in electronic record systems. For example, clinical decision support systems can be developed that “trigger” alerts related to needed assessments or suggest interventions that reflect best practices known to influence quality outcomes. But first, relevant data needs to be documented and coded in a uniform manner so that it can be mapped from the clinical data to an electronic knowledge base.

It is important to recognize that the NHII does not describe a centralized database of patient information. Rather, the vision is for *distributed* health information built on a framework within secure networks with strict confidentiality protections. Given this system architecture, health information could be stored in many locations: electronic record systems in provider offices and health care facilities, organizational databases, personal health cards, etc.

The rapid development and deployment of new information technologies enable data to be captured at the point of acquisition, and then stored, indexed, and retrieved in electronic formats for selective use as required across multiple settings, health care systems, and software applications. This means that if clinical data are carefully structured and encoded in a uniform manner, those data can be electronically transferred, shared, exchanged, and meaningfully used to support a variety of uses such as decision support, quality assessments, individual patient or population surveillance and outcomes analyses, or regulatory reporting. The vision is for the algorithmic retrieval, aggregation, and reuse of data from clinical records to meet multiple needs. Achieving such “interoperability” across systems and applications requires agreement on and adoption of standards for health information systems.

B. Health Information Standards for Interoperable Health Data

A major impediment to the development of the NHII is the lack of complete and comprehensive standards for electronic patient medical record information (PMRI). In its February 2002 letter to the Secretary of Health and Human Services the NCVHS wrote that “Standards for PMRI are important because they will facilitate significant improvements in the quality of patient care, promote patient safety, control rising healthcare costs, enhance the productivity of clinical research and strengthen the nation’s ability to detect and respond to healthcare emergencies. They are critical to the creation of a National Health Information Infrastructure.”²

Data interoperability, or the exchange of consistent and comparable data and information in electronic health information systems, can be accomplished only when developers and vendors adopt and use standards that allow one software program to communicate information to another and when the terms used mean the same thing. Compliance with standards assures that data and information are transmitted and received in a specific, structured form that enables data interoperability, comparability, and data quality. Congress demonstrated a commitment to this with the passage of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), requiring standards in connection with electronic payment, and the NCVHS is actively promoting data standards in conjunction with the broader goal of a national health information infrastructure.

For health care information systems, several types of data standards are needed. The emphasis of this project is on terminology. However, a brief discussion of standards related to sending messages in electronic systems and standards related to clinical document architecture standards is provided to highlight the need for coordinated standards in several critical areas in order to ensure data interoperability.

Messaging Standards

The Health Level Seven (HL7) Messaging Standard Version 2.2 and higher was recommended to the Secretary of Health and Human Services by the NCVHS as the messaging format standards for the PMRI.² HL7 is a not-for-profit volunteer standards development organization that brings together developers, users, and vendors of electronic health record systems to develop standards that enable the exchange, or interoperability, of data and information across health care applications (www.hl7.org).

HL7 messaging standards specify the technical aspects of sending messages so that one software program can exchange information with another and have that information “understood” by the receiving machine. The format of the current version of the standard was developed for order entry, scheduling, medical record/image management, patient administration, observation reporting, financial management, and patient care transactions. An example of an HL7 ADT transaction message follows³:

```
OBX|2|ST|93000.1^VENTRICULAR RATE(EKG)|91|/MIN|60-100<cr>
```

This message is reporting an observation/result (OBX). Key fields in the message include the value type (string), the observation identifier (93000.1^ventricular rate (EKG)), the observation value (91), the units (beats/minute), and the reference or normal range for this test (60-100). It is important to recognize that HL7 messaging standards only provide for the structure of the message; they do not provide content for that message. The message standard is analogous to an envelope in which one can insert a letter; coded terminologies provide the content of the message.

The HL7 version 3 messaging standard currently under development is of particular interest because, in contrast to specifying the slots into which data and values are inserted as in the example above, version 3 will specify the complex data model (or information model) that carries the meaning or semantics of the data; HL7 version 3 will provide the syntax for messages that enables the vision of the NHII (i.e., make explicit the semantic and lexical connections that exist within the fields of HL7 messages). The terminologies provide the content of those messages. As a result, it will be technically possible to use data that was recorded at the point of care for multiple purposes, e.g., generating required patient assessment reports from clinical documentation systems.

Clinical Document Architecture Standard

The developing versions of the Clinical Document Architecture (CDA) standard highlight the need for coordinated approaches that will enable the electronic exchange of clinical documents (e.g., progress notes, histories). Also developed by HL7, the CDA standard is heavily dependent on, or leverages, the HL7 message formats mentioned above.

Essentially, a CDA standard is necessary to enable the algorithmic location of pertinent information within current documents, to logically organize documents in document management systems, to categorize information within the document according to a defined structure, and to display documents in electronic systems (including web-based and wireless systems). There is no uniform document structure for paper-based records in long-term care facilities. The lack of a uniform record structure presents significant constraints in deriving data from an electronic record to support reporting requirements such as the MDS.

Three releases of the CDA standard are planned and described by HL7. It is in the HL7 version 3 CDA standard that the format of the electronic medical record and clinical content of electronic documents will be formally specified and modeled using appropriately structured terminology coding systems (www.hl7.org).

Standards for Terminology Coding Systems

The phrase “terminology coding systems” refers to the continuum of approaches used to assure standardized recording and encoding of clinical data in electronic record systems. Such coded data is central to the efficient exchange of information in messages sent across documents, systems and applications. Various types of terminology coding systems exist on a continuum that ranges from human readable, enumerated coding schemes to formal terminologies that enable machine “understanding.”⁴

Enumerated coding schemes emphasize encoding *pre-coordinated phrases* that enable users to pick the most relevant terms from pre-defined lists. Typically, such systems provide a very limited coverage of clinical content, and focus only on the specific use for which those data are required. Such systems reflect the technology available 20 years ago and the constraints that were present in relation to coding data for computer based analysis. The MDS is an example of an enumerated coding scheme. The enormous collection of such single-purpose, stand-alone coding systems has created a situation often compared to the Tower of Babel (<http://www.tc215wg3.nhs.uk/pages/pdf/vocterm.pdf>), where different data sets and software applications are not able to meaningfully exchange or reuse data and information.

More recent research and development initiatives in electronic health records emphasize the use of formal terminologies. Formal terminology systems emphasize the indexing and retrieval of concepts and their associated terms, and the *post-coordination of phrases*.

Between the enumerated classification systems and formal terminologies that anchor this continuum are other types of terminology coding systems such as nomenclatures, classifications, and taxonomies. Each is differentiated by the nature of the organization of terms within the system and the concept orientation of the coding system. It is important to recognize that the development of more complex types of terminology systems is in large part enabled by the development of technologies that enable more complex data structures and the development and use of description logics based on first order logic as a foundation for the algorithms that enable the semantics or “machine understanding” of text.

The Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) is one of the most extensively developed terminologies of this type (<http://www.snomed.org/>). SNOMED CT is discussed more extensively below, but an example is provided here to clarify this discussion point. The pre-coordinated term “pneumonia due to *Klebsiella pneumoniae*” is equivalent to a phrase that could be post-coordinated using the following SNOMED CT codes: 56415008 “*Klebsiella pneumoniae*” and 233604007 “pneumonia”. A portion of the SNOMED CT hierarchy is presented below.⁵ SNOMED CT specifies that pneumonia:

Is-a disease of the lower respiratory tract
Finding_site lung structure

Onset (subacute, acute, insidious, sudden)
Severity (mild, moderate, severe)
Episodicity (first, new, ongoing, other)
Course (acute, acute diffuse, acute-on-chronic, etc.).

Similarly, SNOMED CT specifies that *Klebsiella pneumoniae*:

Is_a *Klebsiella*
 Is_a *enterobacteriaceae*
 Is_a *gram-negative bacillus*
 Is_a *gram-negative bacterium*
 Is_a *bacterium*
 Is_a *infectious agent*
 Is_a *microorganism*

The linkage concept “due_to” specifies the relationship between the two concepts of “pneumonia” and “*Klebsiella pneumoniae*.” More complex expressions are possible, and can be constructed at the point of care, reflecting the clinically relevant data. Encoding of patient information is then accomplished through the post-coordination of the terms “pneumonia” “due to” and “*Klebsiella pneumoniae*”, using a formalism such as description logics that function somewhat as an assembly language for expressing phrases.⁶

In this example, the goal is that in well-designed and standardized PMRI systems, all lab reports indicating the type of pneumonia would be located within a standard document architecture, a standard coding scheme would be used to name the pneumonia, and a message could be sent from the PMRI to a reporting document such as the MDS indicating the presence of pneumonia. With respect to pneumonia, the MDS only requires data on the presence or absence of pneumonia. That information could be “messed” from the PMRI and the MDS form could be sent only with information indicating pneumonia, excluding information on the biological agent that caused the pneumonia. However it is important to retain more detail in automated patient records in order to construct decision support systems that might, for example, suggest cost-effective antibiotics for specific types of pneumonia, detect any possible drug-drug interactions, or enable the reporting of another type of pneumonia, e.g., “pneumonia in anthrax” to appropriate public health agencies.

The relationship of messaging standards, document architecture, and coded terminology systems and formalisms is equivalent to thinking about the grammar that enables us to put words together in order to communicate ideas. Achieving the vision of the NHII requires finding the relevant data within a source document (most easily achieved by creating documents in a structured fashion), composing expressions that include varying degrees of detail, and then “populating” the data fields of an HL7 version 3 message format for transmission to another application. Uniform data structures and

encoding are required to accomplish this. All participants, from vendors supplying the software to providers to the government agencies providing oversight of quality, public health, and health policy, must adopt uniform data standards if the data are to be interoperable, or exchanged across applications and systems. The goal is similar to the use of an ATM card to deposit and withdraw cash at locations remote from one's bank; a major difference is that we all agree on the naming and value of monetary units while we do not agree on how to name our clinical data, or how to formally represent those data.

To date, the NCVHS has not recommended standards around terminology systems. However, desirable characteristics of formal terminologies are well described in the literature and are briefly summarized below.^{7,8,9}

Concept orientation: Tools that empower users to adapt "local terms" to reference terminologies are required when the concepts the terms represent are equivalent. For example, "pressure sores" may be the locally preferred term while "pressure ulcers" is the term in the reference terminology. Therefore well-formed terminologies must accommodate both synonymy and lexical variants, and a thesaurus must be available for automated identification of terms associated with concepts. A promising way to accomplish this is by assembling components into a dynamic terminology server, rather than presenting users with a laundry list of all possible terms.

Comprehensive and complete: Well-formed terminologies must provide the depth and breadth of content coverage relevant to specific domains. This means there must be a way to express all the clinical content required for a wide range of specified uses.

Atomic and compositional: Well-formed terminologies must ensure that "atomic" levels of data are available and that the meaning of atomic level data elements is preserved when combined or post-coordinated with other concepts. A closely related requirement is that concepts are organized within the framework of a reference terminology system that enables the assembly of atomic concepts into more complex expressions (as in the earlier pneumonia example).

Explicit formalism (e.g., description logic): Well-formed terminologies must have a formal logic or inference engine that enables the post-coordination of more complex expressions from atomic level data elements. Presently, description logics appear best suited to this task.

Multiple classifications: In order to support the reuse of clinical data across multiple special purpose classification systems, terminologies must enable concepts to be mapped to multiple "parents". For example, one MDS data element is "short-term memory," and the most similar SNOMED CT term is "uncompensated short term memory deficit." The short-term memory item in the MDS indicates that the patient "seems/appears to recall after 5 minutes." If using the SNOMED CT system for encoding

data, one would need to decide which of the following parent classifications represents the intended use of the data.

“Uncompensated short term memory deficit” is classified in SNOMED CT as

- Is_a
 - finding of memory performance
 - memory finding
 - functional finding
 - clinical history and observation finding
 - finding
 - SNOMED CT concept

“Uncompensated short term memory deficit” is also classified in SNOMED CT as

- Interprets
 - short-term memory performance
 - verbal short-term memory performance
 - ability to recall random address at five minutes
 - ability to recall five digit number at five minutes
 - visual short-term memory performance
 - ability to reproduce geometric figure at five minutes

Representation of context: Some experts in the field of electronic medical records believe that well-formed terminologies must be coordinated with structural models of clinical documents within the electronic record in order to disambiguate meaning from use (<http://www.hl7.de/cda2002>). For example, “History of heart disease” means something very different when recorded in a family history section of the record than when recorded in a past medical history section of the record.

Clearly, the needs for health care data and information reflect multiple and complex uses of that information, and the requirements for terminology systems are extensive. Without terminology standards that support the composition and de-composition of clinically relevant and detailed expressions, interoperability and reuse of patient data across applications and systems will be seriously constrained. Formal terminology coding systems are critical to the success of uniform coding in PMRI systems and to support the evolution of the NHII. This study focuses on three coding systems. Only SNOMED CT has been developed with the specific purpose of meeting the requirements of a reference terminology for PMRI systems. The other two coding systems, ICF and ICNP, are included because they are believed to include many of the definitions and classifications of terms in two subject areas that are particularly relevant to long-term care (functioning, disability and health; and nursing).

SNOMED CT

The Systematized Nomenclature of Medicine -- Clinical Terms (SNOMED CT) is one of the most extensive terminology systems available. Its development represents collaboration between the College of American Pathologists (CAP) and the United Kingdom's National Health Services. The development of SNOMED CT can be traced back to 1928 when the New York Academy of Medicine convened a forum to develop a new model for representing diseases and procedures.¹⁰ That multi-axial system eventually became the Standard Nomenclature of Diseases and Operations (SNDO) and provided the foundation for modern clinical terminologies. A consistent goal of all subsequent developers of the SNOMED works has been a terminology that is comprehensive enough for indexing the entire medical record.

SNOMED CT is structured in a way that emphasizes a computer readable format. A description logic based formalism supports navigation throughout the multiple hierarchies and allows for the composition of atomic level terms into more complex terms. The most recent version, SNOMED CT July 2002 Release, was used in this study and includes 330,000 concepts, 850,000 synonyms, and 50,000 semantic or defining relationships, for a total of over 1,000,000 terms. This terminology coding system is specifically designed to be embedded or enabled within computer based systems; a browser enables human navigation of the SNOMED CT hierarchies (www.snomed.org).

SNOMED CT was included in this study because it is a formal terminology and has the potential to serve as a convergent or reference terminology. The core data structure in which SNOMED CT is distributed includes a concepts table, a descriptions table, and a relationships table. SNOMED CT is available for use through an annual, renewable license and is distributed in a variety of electronic formats. There are ongoing discussions concerning between the federal government and CAP, that if ratified, would make SNOMED CT generally available for health care use in the U.S.

ICF

The International Classification of Functioning, Disability, and Health (ICF) is an example of a terminology coding system developed to meet a specific need. ICF is one of the families of classifications developed and maintained by the World Health Organization (<http://www.who.int>). The aims of the developers of the ICF were to provide a scientific basis for understanding the distribution and determinants of health and health-related states; establish a common language in order to improve communication among users of such data; permit comparisons on functioning, disability, and health across countries, providers, settings, and programs, and provide a coding scheme for health information systems.¹¹ ICF was included in this study because of its emphasis on functional status (an important concept at least in long-term care) and the potential applicability of this terminology to persons in nursing homes.

An example of how ICF codes might be used follows. The ICF code “d4500” refers to “walking short distances.” A performance qualifier can be added to this code by adding a fifth digit to the code. For example, “d4500.3” refers to “moderate restriction in performance of walking short distances.” A capacity qualifier could be added to this code by adding a sixth digit; for example “d4500._3” refers to “severe capacity limitation in walking short distances.”

The ICF is structured around a hierarchical classification of the domain of functioning, disability and health, grouping concepts and associated terms within the domain according to common characteristics or attributes. At the highest level are two broad classes, functioning and disability, and contextual factors. These two broad classes subsume other lower level classes. Qualifiers indicate the magnitude and/or direction of change in body function and structure, capacity and performance estimates related to activities and participation, and facilitators or barriers related to environmental factors. Users may combine terms across axes in order to create profiles of an individual’s functioning. While coding rules are published, there is no formal logic available to support such compositions.

In July 2001 the NCVHS reported to the Secretary of Health and Human Services on uniform coding for functional status.¹² NCVHS noted that while functional status information is recognized as essential for fostering the goals of healthy people and healthy populations, such information is often missing from clinical notes. The Committee further recommended the use of a uniform code set and classification system for concepts within the domain of functional status. The NCHS said that an internationally agreed upon classification and coding system was needed to support health care decision making, and that the ICF was the only viable code set presently available. However, the Committee also noted that intense work is needed to examine issues related to the ICF’s adequacy, reliability, and validity before any recommendations are adopted about its widespread implementation in PMRI systems. Presently, the ICF is distributed as a book or CD, and a browser is available on the web (<http://www3.who.int/icf/onlinebrowser/icf.cfm>). The WHO made an electronic copy of the ICF table available for this study.

ICNP

The International Council of Nurses developed the International Classification of Nursing Practice (ICNP) as a way to facilitate the cross mapping of terms and existing nursing vocabularies and classifications such as those recognized by the American Nurses Association (<http://www.nursingworld.org>). The ICNP was included in this study because of its focus on nursing care, an emphasis clearly related to the issue of quality in nursing homes.

Structurally, the ICNP exists as two multiaxial systems.¹³ At the highest level are the three classes of phenomena, actions, and outcomes. The axes associated with the

phenomena class are focus, judgment, frequency, duration, topology, body site, likelihood, and bearer. By combining terms from these axes, statements can be composed that reflect the aspect of health (or problem/diagnosis) that is relevant to the nursing care provided. The outcomes class is a serial measure of these same phenomena statements, i.e. outcomes representing changes in phenomena over time. The actions class includes the axes of action type, target, means, time, topology, location, routes, and beneficiary. In a similar fashion, the goal is to compose statements that reflect actions taken by nurses in response to the problem/diagnosis statements composed. As a result of this structure, the ICNP could potentially support aggregation into higher-level categories for summarization, review, research, or administration. However as with ICF, there is no formal logic system by which to accomplish this. As an example, “1A.1.1.2.2.1.1.8.9.2” refers to a nursing focus of “walking,” and a judgment of “1B.7.1.3” refers to “compromised to a high degree.” A more complex expression can be post-coordinated by combining “walking” and “compromised to a high degree.”

Across the multiple axes of the ICNP there is a somewhat uneven granularity of concepts. Most problematic from a computational perspective is that while some classes have clear hierarchical relationships among the terms in the axes, terms in other classes are arranged alphabetically. This is not problematic for human reading, but does create challenges for machine processing of the system. The ICNP is distributed as a book or CD, and a browser is available free of charge on the Web (www.icn.ch). Spreadsheets containing the ICNP axes were made available by the ICNP for this study.

C. Federal Support of Terminologies -- Consolidated Health Informatics Initiative

Given the federal government’s role in providing and paying for health care, the standards used by the federal government can significantly influence decisions on the standards used by health care providers and vendors. The Office of Management and Budget (OMB) identified the Consolidated Health Informatics (CHI) initiative as one of the 24 electronic government initiatives supporting the President’s Management Agenda (<http://www.jrfii.com/chi>). To accelerate the adoption and use of information standards and technology, the CHI will endorse, for future use in federal healthcare programs (i.e., HHS, VA, and DoD), clinical vocabularies and messaging standards that have widespread support and use within the private US health care community. The commitment of federal programs to use agreed upon clinical vocabularies and messaging standards will enable federal agencies to build interoperable federal health data systems, and will encourage the private sector to adopt electronic health information systems that will be compatible with those that federal government will employ, and vice versa. This federal leadership will help inform the private healthcare community’s investment decisions in electronic health information systems.

In March 2003, the Departments of HHS, Defense, and Veterans Affairs announced the first set of uniform standards for electronic exchange of clinical health information to be adopted across the federal government. As part of new systems developments, these Departments will adopt HL7 messaging standards, laboratory terminology standards (LOINC), digital imaging standards (DIACOM), and other standards.

D. The MDS: An Example of a Legacy Coding System

Assessment tools such as the MDS meet predefined needs for data and information. Additionally, these data sets reflect the limitations of the technology that was available when the assessment form was first developed; data storage was far more expensive than it is today, databases were largely limited to “flat files” and the internet did not exist. Typically, forms with specific questions and phrases that reflect the end-users’ need for data provide the structure by which persons record values that populate specific fields within the data set. In this approach to data entry, standardized terms, phrases, and sentences are presented in a highly structured format in order to encode concepts related to functioning and disability, thereby enabling consistent and comparable data. The recording of data is accomplished by people who complete the forms on paper and then enter the data into an electronic format, or by completing an electronic version of the form. Often the form provides a structure for organizing clinical data elements into categories that are later aggregated even further in order to meet the goals of various statistical classification and reporting requirements. The important point is that the person completing the form is presented with a limited set of terms and values and must understand the underlying purposes for which the data set was constructed in order to correctly complete the form. The amount and nature of information available for sharing and re-use for purposes such as automated alerts, decision support, quality monitoring, outcomes research and policy development is constrained by the limited scope of the data set.

In addition to the MDS, the Centers for Medicare and Medicaid Services (CMS) provides oversight of two other data sets that focus on the provision of post acute care services: the Outcome and Assessment Information Set (OASIS) for home care agencies, and the Inpatient Rehabilitation Facility Patient Assessment Instrument (IRF PAI) for rehabilitation units and hospitals. Each of these data sets was developed independently of the other. Consequently, different terms are used to describe similar clinical characteristics of beneficiaries, different rating scales are used, and the time periods in which assessments are completed differs, all limiting the comparability of the data. For example, the MDS requires that a value of 0-3 be entered into each of five data fields indicating over the course of seven days the frequency with which a resident exhibits a variety of behaviors classified as “behavioral symptoms”. One item concerns each of the following: wandering, verbally abusive behavior symptoms, physically abusive behavioral symptoms, socially inappropriate/disruptive behaviors, and resists care. Behavioral

symptoms are further classified as “Mood and behavior patterns.” The OASIS-B1 home care data set requires that a single item be checked indicating, over the course of one month, the “Frequency of behavior problems (e.g. wandering episodes, self abuse, verbal disruption, physical aggression, etc.)” These behavioral problems are further classified as “Neuro/emotional/behavioral status.” The developers of both data sets were likely interested in the same clinical data. If specific and detailed clinical descriptions were recorded and indexed within the patient’s medical record using standardized and uniform data standards, clinically relevant data could be and retrieved and aggregated for reporting requirements. The present situation seriously limits an analysis of the variation in patients and patient outcomes across post acute cares settings, and resulting in insufficient information on which to base policy decisions.¹⁴

This situation is not specific to post-acute care. The data sets on which most public health statistical reporting systems are based were similarly developed independent of each other, and are described as “a patchwork of data collection systems.”¹⁵ Among the goals of the NHII is that reporting requirements could be *derived from* patient medical record information, and given well-coordinated systems consistent and comparable expressions of clinical data would be enabled.

E. Summary

In summary, achieving the vision of the NHII put forward by the NCVHS requires a high level of coordination among messaging standards, clinical document architecture standards, and standards for terminology coding systems. It is terminologies that provide the content that must be included in messages in electronic health information systems. Although no terminology standards have yet been recommended by NCVHS or the CHI, the characteristics of terminologies that will enable interoperability in electronic patient record systems are well described.

II. THE MINIMUM DATA SET FOR NURSING FACILITIES

The following section briefly describes the development and multiple uses of the federally required patient assessment form -- the Minimum Data Set (MDS) for Medicare and Medicaid certified nursing facilities (NFs). The uses addressed include assessment and care planning, payment, quality indicators, and quality measures. In addition, this section provides a short description of how the MDS is completed and concerns about MDS data accuracy. This section concludes with a brief summary of these issues and a discussion of how refinement of this patient assessment instrument could facilitate more efficient and accurate patient assessment data collection, support the implementation of electronic medical records and information systems in nursing homes, and further the evolution of the NHII.

A. Assessment and Care Planning

The quality of long-term care has long been a concern among consumers, providers of care, policy makers, and payers. In 1986 the Institute of Medicine (IOM) issued a study entitled, "Improving the Quality of Care in Nursing Homes."¹⁶ The focus of the study was to examine ways to improve the regulation of nursing homes to improve quality of care. A core theme that emerged from that study was the need to standardize assessment and care planning for nursing home residents.

Congress subsequently passed a law in 1987 that required the development of the MDS to ensure that each nursing home resident receives, at regular specified intervals, a comprehensive assessment and care plan designed to meet his/her needs. CMS (formerly known as the Health Care Financing Administration (HCFA)) developed the MDS based on input from various disciplines. The MDS assessment includes more than 583 items that are used by facilities in performing comprehensive assessments of their residents. Thirteen domain areas are included in the MDS assessment: past medical history and medically defined conditions, medical status, functional status, physical and sensory impairments, nutritional status, special treatments or procedures, psychosocial status, discharge potential, dental condition, activities potential, rehabilitation potential, cognition, and drug therapy.¹⁷

Nationwide electronic collection of the MDS began in the 1990s. As required by statute for assessment and care planning, the MDS is required to be completed shortly after admission, annually, and quarterly thereafter. It is also required upon a significant change in the resident's condition. In most states, a shorter form is used for quarterly assessments than for the more comprehensive admission and annual assessments.

B. Payment

The MDS is also used in establishing Medicare skilled nursing facility (SNF) payment rates. Beginning in 1998, CMS began paying Medicare SNFs prospective payment rates adjusted using data from the MDS. CMS permits the use of yet another MDS form in calculating Medicare PPS payment rates. The MDS payment form is required to be completed at multiple points during a Medicare SNF stay. In addition, a number of States also use an MDS form to adjust Medicaid nursing facility payment rates.

C. Quality Indicators and Quality Measures

The NF quality is recognized as affecting a myriad of clinical outcomes that encompass functional, psychosocial and other aspects of resident health and well-being. In 2001 the IOM again published a report on the quality of long term care, emphasizing that “defining or evaluating quality of long-term care is fraught with problems, made more difficult by the unevenness of the available empirical evidence.... Opinions about what constitutes excellent, good, or poor quality also are changing and sometimes conflicting. Some of the available information is open to interpretation, and conclusions are sometimes based on personal and clinical experience rather than on empirical evidence.”¹⁸

Beginning in 1999, CMS began to use MDS data elements for the creation of “quality indicators” (QIs). These QIs are used in the nursing home survey process to indicate areas of potential quality problems which trigger more intensive review during a survey. A subset of these QIs are published on the CMS Nursing Home Compare Website as a source of public information about nursing home quality (<http://www.medicare.gov/NHCompare/Home.asp>). CMS believes that the quality indicators have been sufficiently validated to qualify as true measures of quality, although others question their validity.¹⁹ There has never been any published research on the relationship (validity) of these quality indicators to actual nursing home quality. A study of the validity of the more recently developed quality measures was completed (see discussion below). Although conceptually similar, the numerators and denominators within the ratios and the risk adjustments are constructed differently across the quality indicators and measures.

More recently, CMS embarked on an effort to develop “quality measures” (QMs) that could be used nationally to provide consumers with information about nursing home quality that would assist in their decision making process about nursing home placement. In an April 24, 2002 press release, Health and Human Services Secretary Tommy Thompson said, “A key step towards improving quality is getting consumers the information they need to make informed health care choices.... By generating and publishing quality data, we

are both helping consumers to make decisions that best meet their needs and creating market incentives for nursing homes to further improve quality."²⁰

CMS hired the National Quality Forum (NQF) to select, through a consensus process, measures of nursing home quality using MDS data elements. However, the NQF was unable to reach a consensus about which quality measures could be used in a national reporting effort and therefore delayed endorsing a nursing home measurement set. NQF members on various NQF councils were unable to approve all nursing home quality measures, particularly noting the need to review evidence of the validity of the proposed risk adjustment methods.²¹

Based on results from a study on the validity of nursing home quality measures, CMS determined that there was in fact sufficient information to select the new quality measures (derived from MDS data) and that those QMs that would be used in national reporting beginning in November 2002. Under contract to CMS, Abt Associates produced a report that, among other things, examined the inter-assessor agreement (a measure of reliability).²² The study found that all but one of the quality measures was reliable (i.e., a weighted kappa statistic value of .40 or higher).

Controversy surrounds even the new quality measures; in particular there continues to be considerable criticism about the adequacy of the risk-adjustment of these new measures and whether a more rigorous validation study would find relationships between these measures and actual nursing home quality. For example, one of three risk-adjustment experts consulted by the NQF to provide recommendations to CMS about the use of the quality measures as a source of consumer information concluded that "...it would be irresponsible to report any of these quality indicators to the public" because there is insufficient information "that these risk-adjusted quality indicators accurately identify facilities with quality of care problems."²³ Similarly, the GAO recently concluded "although public reporting of quality indicators is a worthwhile goal, it is important for CMS to await and consider input ... to identify and evaluate appropriate quality indicators."²⁴

CMS responded, noting their intent to develop more refined measures: "As the process of choosing nursing home measures evolved, it became clear that the NQF needs adequate time to fully consider and discuss the Validation Report and to take into account any lessons learned from the Six-State Pilot Study. Once the NQF reaches consensus and delivers its recommendations, we expect to move to a timely implementation of the updated measures on Nursing Home Compare."²⁵

Clearly, significant challenges exist in providing useful and accurate information about quality in long-term care. Failure to reach agreement on a set of quality measures in nursing homes highlights one of the challenges in measuring nursing home quality. Nursing home quality is a multi-faceted concept. The continued use of the "QIs" in the survey process and as a source of consumer information on the Nursing Home Compare

website and the “QMs” as another type of consumer information and the mechanism to identify nursing homes in need of quality improvement underscores the uncertainty about how to measure nursing home quality. The number of QIs and QMs reflect a number of care domains that are of interest to different stakeholders. In addition, many believe that quality of life is at least equally important in understanding the quality of nursing home care,²⁶ but are included in either the QIs or QMs.

D. MDS Completion

Presently, nursing facilities do not typically use electronic medical records or robust electronic health information systems. To complete the MDS, NF staff abstract data from medical records, talk with staff, and observe nursing home residents to gather information required for the MDS. NF staff typically record this information on a paper record and at a later time electronically encode and transmit this information to State and Federal Governments. Abt Associates found that “MDS coordinators who complete each MDS independently were often not at all involved in resident care, and did not work as part of an interdisciplinary team with caregivers to fill out the MDS” and that nursing home providers describe the MDS as “an excessive paperwork burden.... and a time-consuming task that is difficult to manage in the face of inadequate staffing levels and high turn-over rates.”²⁷

E. MDS Accuracy

Several studies have identified serious accuracy problems with MDS data. The methods by which inaccuracies were determined varied across these studies but generally included either a review of whether medical record documentation contained information that supported the MDS findings and/or a comparison the nursing home’s MDS assessments with those completed by highly trained nurses. The Abt MDS Accuracy Study reported that MDS error rates average 11.6 percent for all MDS items.²⁷ That study reported the least accurate sections of the MDS included cognitive patterns (Section B), psychosocial well being (Section F), physical functioning (Section G), skin condition (Section M), and activity pursuit patterns (Section N). The study also noted problems with under-reporting in the areas of: vision, health conditions, pain, and falls; and over-reporting problems in the areas of: IV medication, intake and output, and physical, occupational and speech therapies. These areas of greatest disagreement generally require substantial periods of observation as well as resident or family interview in order to accurately assess.

Similarly, a study conducted by the Office of the Inspector General (OIG) of the MDS assessments completed for 640 nursing home residents, found errors on 17 percent of the MDS data elements (i.e., 17 percent of the MDS data elements were not supported by information in the medical record).²⁸

In a study on nursing home resident assessment, the GAO reported that 9 of the 11 States that had MDS accuracy review programs found MDS errors occurring most frequently in the following categories: mood and behaviors, nursing rehabilitation and restorative care, activities of daily living, therapy, physician visits or orders, toileting plans, and skin conditions.²⁹

F. The MDS in Relation to the NHII

There are few indications that the evolution of federally required documents such as the MDS is being discussed in the context of a national health information infrastructure development. As observed by the IOM in its report entitled, *Leadership by Example: Coordinating Government Roles in Improving Health Care Quality*, "Growing evidence supports the conclusion that automated clinical information and decision support systems are critical to addressing the nation's health care quality gap.... Although it may be possible in the short run ... to rely on medical record abstraction ... greater computerization of clinical information will be required over the long run to sustain performance measurement, apply it to a broader range of conditions, and decrease the associated administrative burden on providers."³⁰

G. Summary

In summary, the MDS is a paper and pencil assessment form that summarizes data from a variety of sources, may be completed by person who are not knowledgeable about the resident, and is eventually encoded and transmitted electronically to State and Federal governments. MDS forms are used for a variety of purposes:

- N Comprehensive assessment and care planning;
- N Medicare, and, in some States, Medicaid payments;
- N Construction of quality indicators used in the survey process and as a source of public information; and
- N Construction of quality measures used as a source of public information.

MDS data inaccuracies can have implications for accurately assessing nursing home residents' needs and developing appropriate care plans, paying appropriate Medicare and Medicaid nursing home payment rates, adequately and appropriately monitoring quality of care, and reporting useful and accurate information about nursing home quality. Deriving administrative data requirements from clinically relevant information collected and recorded at the point of care would significantly reduce the burden providers presently experience in completing the MDS and likely improve the accuracy of data needed to support administrative requirements (e.g., payment, quality monitoring, and public reporting requirements). Most importantly, introducing electronic medical records and

information systems to long-term care would support important enhancements to quality of care when automated alerts, decision support can be built into point of care systems. As emphasized earlier, uniform descriptions of clinical data are essential to the success of any such initiative.

III. A CONTENT COVERAGE STUDY

This section describes the purpose of the present study; why the conditions of pressure ulcers, pain, and incontinence were selected; identification of terms, terminology coding systems included in the study, and the methods and procedures used.

A. Purpose of the Study

The study had three objectives: The first objective was to determine, as a pilot activity, whether leading terminology and classification systems provided content coverage to support clinical decision-making and quality of care oversight in nursing homes as recommended by clinical experts and as reflected in the literature for three domains: pressure ulcers, chronic pain, and urinary incontinence. The second objective was to examine the content of the federally required nursing home minimum data set (MDS) to determine whether it provides the information needed to understand quality of care in nursing homes in the three selected domains. The third objective was to examine the extent to which the content of the MDS was captured by SNOMED CT, ICF, or ICNP.

Specifically, we set out to:

- Identify the concepts, terms, and data elements recommended by domain experts as needed for risk adjusted assessments of pressure ulcers, pain, and urinary incontinence in nursing homes;
- Determine the content coverage needed for these assessments provided by: (i) three terminology coding systems: SNOMED CT, ICF, and ICNP; and (ii) the MDS;
- Determine the extent to which the data elements of MDS are captured by SNOMED CT, ICF and ICNP.

This project was deliberately limited in scope to three clinical conditions in order to provide a focused, “pilot” study that examines the comprehensiveness of leading terminology code sets and the MDS with respect to clinically relevant data and concepts needed to measure quality for those three clinical conditions.

B. Selection of Study Focus Areas

The three conditions on which the study focused were selected because these conditions are frequently used in constructing measures of nursing home quality. However,

quality measures for each of these conditions presents a slightly different documentation challenge that relates to whether the condition is directly observable or not, the type of clinical data required, and the number of persons involved in recording relevant data in the record. The rationale for selecting these three conditions was, in part, based on the following:

Pressure Ulcers and Pressure Ulcer Risk

Pressure ulcers are areas of tissue damage or necrosis that develop due to pressure over a bony prominence; the reported incidence rate for pressure ulcers in long term care facilities varies from 0% to 31%.³¹ Severe pressure sores are a major source of morbidity and mortality in nursing home residents (including pain, infection, disfigurement, and interference with activities of daily living).¹⁸ The estimated costs of treating a pressure ulcer range from \$4000 to \$40,000 for newly developed ulcers. A specific goal of Healthy People 2010 is to reduce the prevalence of pressure ulcers in nursing homes by 50%.³²

Because pressure ulcers are directly observable, the documentation of pressure ulcers is relatively straightforward. Additionally, risk factors for the development of pressure ulcers are well described. Therefore, determination of quality of care based on pressure ulcer data can be related not just to the outcome of pressure ulcer development, but also to processes of care that are known to reduce the risk of pressure ulcer development.

Chronic Pain

Chronic pain is defined in a national clinical practice guideline as “unpleasant sensory or emotional experience that is persistent or recurrent.”³³ Estimates of the prevalence of chronic pain in long term care facilities range from 45 to 80%, but these rates are generally considered to be underestimates. In addition to the suffering associated with pain, untreated pain has been associated with increased occurrences of depression, social isolation, sleep disturbances, gait impairment, and increased use of health services.³⁴ Despite strong evidence that chronic pain can be ameliorated by appropriate use of medications, undiagnosed and untreated pain has been a widespread problem in nursing homes.

In part because of the highly subjective nature of chronic pain, assessment and subsequently documentation of an individual’s pain can be challenging. While self-report of pain is a “gold standard,” persons who are unable to provide an accurate self-report because of conditions such as cognitive or communication limitations are dependent on staff’s accurate interpretation of the non-verbal indicators of chronic pain (e.g., facial expressions such as grimacing and frowning, vocalizations such as yelling, groaning, moaning, or behaviors such as bracing, rubbing, and guarding).^{18,34} Documentation of

nonspecific signs and symptoms that may suggest the presence of chronic pain is necessary.

Urinary Incontinence

Urinary incontinence is defined as the involuntary loss of urine significant enough to be considered a problem.³⁵ Estimates are that 50% or more of persons in long-term care facilities are affected by incontinence, reflecting the role of incontinence as a cause of institutionalization. Incontinence is associated with skin breakdown, activity limitation, social isolation, and depression.³⁶ Because incontinence can be reversed or improved for up to half of nursing home residents, a high prevalence of incontinence suggests poor care.¹⁸

Because of the types of evaluations required in determining the cause of incontinence, relevant documentation is typically found in many different sections of clinical records (e.g., history and physical, nursing notes, laboratory reports), and those data are typically recorded by persons in a variety of health care disciplines.

C. Identification of Terms

Our primary goal was to examine the content coverage provided by select terminologies and the MDS for measuring quality of nursing home care with respect to the three selected conditions identified above. The study used the following methods to generate a list of relevant terms that served as the test set for examining the content coverage provided by three different coding systems.

ACOVE Indicators

First, the project team retrieved quality indicator data from recently published synthesis conferences on quality indicators for each of the selected conditions. A Task Force on Aging with members from the American College of Physicians and the American Society of Internal Medicine recently published a set of manuscripts concerning the assessment of quality of care for older persons, a project entitled “Assessing Care of Vulnerable Elders” (ACOVE).³⁷ Among the goals of the project was to develop a set of evidence-based, quality of care indicators relevant to vulnerable older persons, and to design a chart abstraction tool, interview instruments, and data analytic methods to implement a quality-of-care indicator system. Three of the manuscripts specifically addressed quality indicators for the domains of pain management, pressure ulcers, and urinary incontinence.^{32,34,36} Efforts that summarize the essential literature in specific areas, like the ACOVE initiative, are important for terminology work because they represent consensus among experts in the field on the key terms and concepts relevant to the knowledge base required for specific domains.

Although the ACOVE project focused on the identification of high-risk, community dwelling older persons, we chose to include the data elements put forward in these manuscripts for several reasons. First and most important for our purposes, there was a deliberate effort to develop the quality indicators considering information typically available in the medical record and administrative data. Second, each focused area included aspects of prevention, diagnosis, treatment and follow-up. Finally, the indicators were specifically developed for use in assessing the processes of care delivered to vulnerable older persons. See Appendix A for a listing of the ACOVE indicators for each of the three clinical conditions included in this study.

Domain Experts

Second, the project team identified one content expert for each domain based on their authorship of key citations retrieved from the literature review. The experts were asked to provide a listing of key literature related to their area of expertise, and of key clinical data they believed essential to making judgments of quality of care related to their specific area. This was felt to be necessary because literature synthesis by definition requires that content be summarized; and rarely includes a full complement of terms that are potentially relevant to any given focus area. In particular, we were interested in the types of clinical documentation terms that these reviewers identified.

Pressure Ulcers and Pressure Ulcer Risk: Nancy Bergstrom, Ph.D., RN, FAAN, is the Associate Director of Aging Research the Center on Aging at the University of Texas Health Sciences Center. Dr. Bergstrom was the chair of the AHCPH panel that developed the clinical practice guidelines for the prediction and prevention of pressure ulcers in adults. She has published numerous journal articles related to the assessment and treatment of pressure sore risk for nursing home residents and was the Principal Investigator for the 1988-1994 NIH study “Nursing Assessment of Pressure Sore Risk.”

Chronic Pain: Keela Herr, Ph.D., R.N. is Professor and Area Chair: Adult and Gerontology Nursing at the University of Iowa. The primary focus of her work and expertise is in the area of pain assessment in older adults. She has conducted NIH funded research to establish appropriate tools for evaluating pain intensity among the elderly population. She is currently working on the AHRQ sponsored research project, “Evidence-based Practice: From Book to Bedside: Acute Pain Management in the Elderly” that is examining interventions to improve adoption of clinical practice guidelines in health care organizations.

Urinary Incontinence: John F. Schnelle, Ph.D. is the Director of the Boren Center for Gerontologic Research at the UCLA/Jewish Home for the Aging. He has been the principal investigator on nine NIH clinical trial intervention grants designed to improve care and management in nursing homes. Dr. Schnelle has published numerous journal articles related to the assessment and treatment of urinary incontinence among nursing home

residents and was part of the AHCPH panel that developed the clinical practice guidelines for urinary incontinence. He is the author of the 1991 book “Managing Urinary Incontinence in the Elderly.”

The domain experts were asked, based on their expertise, to:

- Identify and refine the key terms and concepts needed to understand quality in their domain (i.e. data elements).
- Specify the quality inferences (and the data source(s)) that could be supported if all relevant data were available.
- Identify the data elements (and corresponding data source(s)) needed to risk adjust these estimates of quality.
- Provide a list of references related to their domain area.

Appendix B includes a list of the terms provided by each of the domain experts, and Appendix G a list of key literature citations provided by the domain experts.

Quality Indicators and Quality Measures

Third, a list of the MDS data elements associated with the quality indicators and quality measures was compiled. Quality indicators derived from MDS data were described earlier in this paper. The pressure ulcer quality indicator is “Prevalence of stage 1-4 pressure ulcers” and is derived from the single MDS data element “pressure ulcer -- any lesion caused by pressure resulting in damage of underlying tissue.” Two quality indicators are relevant to incontinence: “Prevalence of bladder or bowel incontinence” and “Prevalence of occasional or frequent bladder or bowel incontinence with or without a toileting plan.” The respective MDS data element is “Control of urinary bladder function or continence programs, if employed.” This data element is then coded according to whether the individual is usually continent, occasionally incontinent, frequently incontinent, or incontinent all of the time. Appendix C includes examples of data from the MDS used to derive quality indicators related to pressure ulcers and incontinence. There is not a quality indicator for chronic pain.

The nursing home quality measures are derived from MDS data elements, as are the quality indicators. The quality measures of interest in this study are related to residents with pressure sores and pain. For the measure of prevalence of stage 1-4 pressure ulcers, the MDS data element is the same pressure ulcer data element listed above, with a risk adjustment factor based on the data elements “impaired transfer or bed mobility” or “comatose” or “malnutrition” or “end stage disease.” For the measure of inadequate pain management, the MDS data elements include “residents with moderate pain at least daily”

or “horrible/excruciating pain at any frequency.” This measure is covered by the MDS data elements “independence in decision making.” Appendix D includes examples of data from the MDS used to derive quality measures related to pressure ulcers and pain.

Terms Abstracted From the MDS

We also examined the content coverage provided by the three coding systems (i.e., SNOMED CT, ICF, and ICNP) for the entire MDS. This was necessary given the emphasis of the domain experts and ACOVE indicators on the identification of a range of factors beyond the occurrence of the pain, pressure ulcers, and urinary incontinence (e.g., risk factors, nonspecific signs and symptoms, and processes of care). That is, the MDS data elements used for QI and QM estimates are a subset of the entire MDS and only concern the presence of these conditions. Since the ACOVE indicators and the domain experts recommend considering factors beyond just the presence of the condition as an indicator of quality, we needed to examine the extent to which: (i) each of the three terminology coding systems provided content coverage of the entire MDS; and (ii) the entire MDS provided content coverage relevant to the ACOVE indicators and domain expert indicators.

This required that we carefully consider the way the structure of the MDS document because interpreting the meaning of specific data elements is tightly coupled to the hierarchy, or headings under which that item occurs in the document.

The MDS is organized into 18 sections, with a varying number of items in each section that specify a focused type of assessment.

- N Section A: Identification Information, Demographic Information, Customary Routine, and Face Sheet Signatures
- N Section B: Cognitive Patterns
- N Section C: Communication/Hearing Patterns
- N Section D: Vision Patterns
- N Section E: Mood and Behavior Patterns
- N Section F: Psychosocial Well-being
- N Section G: Physical Functioning and Structural Problems
- N Section H: Incontinence in Last 14 Days
- N Section I: Disease Diagnoses
- N Section J: Health Conditions
- N Section K: Oral/Nutritional Status
- N Section L: Oral/Dental Status
- N Section M: Skin Condition
- N Section N: Activity Pursuit Patterns
- N Section O: Medications
- N Section P: Special Treatments and Procedures

- N Section Q: Discharge Potential and Overall Status
- N Section R: Assessment Information

The MDS data elements that are actually encoded and stored are selected from pick-lists of responses to a number of items or questions within each of these sections. Many sections of the MDS are further subdivided with sub-headings that organize specific items.

For example, Section G: Physical Functioning and Structural Problems specifies a sub-heading of “bed mobility” which is defined as “how resident moves to and from lying position, turns side to side, and positions body when in bed”. The person completing the MDS form then records a value of 0, 1, 2, 3, 4, or 8 to describe the resident’s overall self-performance of bed mobility and a value of 0, 1, 2, 3, or 8 to indicate the support provided the resident in bed mobility. To completely express the meaning of the concepts, it is necessary to consider the text that explains the numeric coded value in association with the item, the sub-heading, and the section heading.

Another example is the concept of “weight change”. The term “weight change” is a sub-heading with the section of “oral/nutritional status”. A response of No or Yes is required for two separate items within this sub-heading. One item is “weight loss -- 5% or more in last 30 days or 10% or more in last 180 days” and the other item is “weight gain -- 5% or more in the last 30 days or 10% or more in the last 180 days”. In another section of the MDS, “health conditions”, there is a sub-heading of “problem conditions”, and a list of four items that are “indicators of fluid status”. One of those items is “weight gain or loss of 3 or more pounds within a 7 day period”. The person completing the form is instructed to check the associated data field if this applies. In the first example, the meaning of the MDS weight change item is related to nutritional status, while in the second example the meaning is related to conditions associated with fluid balance concerns, such as congestive heart failure. The point is that the terms that define the structure of the document contribute to the meaning or semantics of the data elements. These must be made explicit in computer based applications that process the *meaning* of coded data elements. The coded data elements of Yes or No do not carry any meaning related to the intent of the items with which they are associated.

The overall point to be made is that in order to complete a study of the extent to which various terminology systems provide content coverage for the MDS, it was necessary to include all of the terms in items, sub-headings, and sections that provide the context and meaning of a given data elements. Given that an intent of the study was to determine the content coverage of concepts within the MDS, all terms used within the MDS to label section headings, focused areas of assessment, and data elements were included. Duplicates were removed (e.g., “independent” was only included once). This resulted in a sample of 639 unique terms from the MDS. See Appendix F for a complete listing of these terms.

D. Terminology and Classification Coding Systems

One terminology coding system and two classification systems were included in this study: SNOMED CT (a large, comprehensive terminology system), and ICF and ICNP (small, domain specific classification systems). The systems were previously described, and only summary information is provided below. Investigators obtained electronic copies of each coding system from the developers, as well as permissions to use the coding systems in this project. See Appendix E for contact information for each coding system.

E. Coding Procedures

Terms from the ACOVE indicators, the domain experts, and the MDS data elements were entered into a spreadsheet, one element per row. As described above, each phrase within the MDS was considered a discrete data element for the purpose of the content coverage study, whether the phrase existed as a section header, item, or response option. Terms were then classified as administrative information, resident history, assessments, treatments, or other (terms referring to provider information, quantities (e.g., 1 to 500 cc/day) and miscellaneous activities) in order to facilitate analysis.

The terminology coding systems were imported into a database within the Mayo terminology services. This set of services is a compendium of tools that facilitate terminology indexing. There are two main divisions within the set of tools, corresponding to the server side and the client side. On the server side, there is a suite of terminology services that contain the core mechanisms for serving up and storing coded content. On the client side, there are graphical building blocks for searching and navigating the hierarchy of underlying terminologies, and for building complex coded expression if supported by the terminology system. Included within the Mayo terminology server is a basic spell checking service, a lexical variant generator (LVG), a synonym scheme, and a coding scheme service. Originally developed to support SNOMED RT, this suite of tools can be modified to accommodate other terminology coding systems.

A trained and experienced coder exhaustively searched for the best available concept or set of concepts that captured the clinical notions expressed by the target phrase from the ACOVE indicators, domain experts, and MDS. If no reasonable match was suggested by the coding tool, she further searched for matching terms from the terminology coding systems using common word processing techniques such as “find” functions. Results are presented in the next section of this paper.

IV. RESULTS

This section presents the results of the content coverage study. First, we compare the terms identified by the ACOVE documents, domain experts, and the MDS QI and QM metrics related to quality assessments of chronic pain, pressure ulcers, and urinary incontinence. Then, we summarize the content coverage provided by these terminology systems for the MDS overall.

A. Comparison of Terms: ACOVE Indicators, Domain Experts, and QIs/QMs

Table 1, Table 2, and Table 3 compare the terms we abstracted from three sources: the ACOVE indicators, the domain experts, and the MDS quality indicators and quality measures. To facilitate comparisons and analyses, we grouped data elements into the broad categories of targeted history and physical, treatments for condition, and assessments. It is important to remember that we asked the domain experts to suggest data elements that would be required to assess quality of care; therefore most of the terms from the domain experts reflect assessments. The relative lack of detail of terms related to treatments should not be interpreted as indicating the expert would not or could not recommend treatments. Our request to the domain experts emphasized a request for data elements that are associated with assessment indicators for each of the specific conditions.

It is striking to note that across these three tables, the number of terms dramatically diminishes as one moves from the domain experts and ACOVE indicators to the MDS data elements. This reflects the limited scope of the MDS, and subsequently the limited data available for making decisions related to the quality of care. The terms provided by the ACOVE indicators and the domain experts reflect the far more extensive data typically recorded (and available) in clinical records.

The difference in the number of terms also reflects an emphasis by the ACOVE documents and the domain experts that quality judgments must be associated with clinical decision-making, in contrast to summary measures of quality that are reflected in incidence and/or prevalence rates that emphasize counting events. The ACOVE groups and the domain experts emphasized that it is the failure to identify persons who might benefit from related processes of care and to then provide that care that is one of the most significant indicators of poor quality. The MDS quality indicators and measures emphasize the incidence and prevalence of events, i.e., the occurrence of pressure ulcers, pain, and incontinence -- not the timely detection and early intervention to prevent those events from occurring.

Given the limited coverage provided by the MDS quality indicators and quality measures for the targeted domains, we felt it was important to also examine the content coverage of the entire MDS in relation to the ACOVE indicators and domain expert terms in order to determine whether the indicators recommended by the ACOVE manuscripts and the domain experts could be derived from MDS data elements. This review is provided below in the section entitled, "Content Coverage for Domain Expert Terms." Unfortunately, even when examining the entire content of the MDS, the MDS does not provide much of the data content recommended by the ACOVE documents or the domain experts.

B. Content Coverage for Terms Provided by Domain Experts

After generating the lists of terms from the domain experts, we proceeded to code those terms using procedures described earlier. Table 4 compares the content coverage of the MDS and the three coding systems (SNOMED CT, ICF, ICNP) for the terms identified by the domain experts. As expected, SNOMED CT provided the most complete content coverage, consistent with the far more extensive compilation of terms within that terminology coding system. For the domains of chronic pain and urinary incontinence, SNOMED CT provided coverage for all the terms suggested by domain experts and a complete match was possible for the overwhelming majority of terms. For the domain of pressure ulcers, SNOMED CT provided a complete match with 80% coverage observed. The types of terms for which no SNOMED CT code could be identified included abbreviations (e.g., MR/DD, ADL, and a variety of qualifiers such as none of the above). The ICF and ICNP each provided either complete or partial content coverage for approximately half of the domain expert terms related to pressure ulcers and urinary incontinence, but only a small percentage of content coverage for the terms related to chronic pain.

Coverage provided by the MDS varied significantly across domains. The MDS provided a complete match on 70 percent of the pressure ulcer terms, but provided a complete match on only 8 percent of the terms recommended by the domain experts to assess of quality of care relate to pain and urinary incontinence. This is not an unexpected result, and is probably explained in part by the nature of three conditions selected for this review. As noted earlier, pressure ulcers are directly observable and were widely recognized as an issue of concern when the MDS was originally developed. Chronic pain is not directly observable and the presence of chronic pain is either directly reported by the person experiencing the pain or inferred by persons providing care to the person experiencing the pain. In the latter case, a correct inference requires that the provider observe for a wide variety of non-specific behaviors and then correctly interpret those behaviors as pain behaviors. This is the sort of information that should be recorded in clinical documentation systems (whether paper or electronic). Similarly for urinary incontinence, the results of diagnostic and evaluation tests such as laboratory work and

procedure results are typically recorded in clinical documentation systems. The MDS was not developed as a clinical documentation system.

Appendix G includes detailed lists of terms provided by the domain experts that do not have a complete “match” in either MDS or SNOMED CT (i.e., the “partial match” or “no match” columns of Table 4). It will be difficult to achieve the goal of “interoperable” or reusable data across applications without these terms.

For example, if a person has an existing pressure ulcer and is at known risk for the development of additional pressure ulcers, practice guidelines recommend that a skin inspection be completed at least once a day with particular attention to bony prominences and that either static or dynamic support surfaces be used depending on the person’s ability to assume a variety of positions without weight bearing. Terms related to the concept of “bony prominences” were not found in either the MDS or SNOMED CT. The MDS includes two items related to pressure relieving devices; one is “pressure relieving devices for chair” and the other, “pressure relieving devices for bed”. However our domain expert mentioned five more specific terms related to pressure relieving devices: air-fluidized beds, characteristics of support surfaces, dynamic support surface, low air-loss bed, and static support surface. SNOMED CT does provide terms related to these more specific concepts. The MDS use of the concept appears to be related to whether a pressure relieving device was used in a chair or a bed. More detailed information is needed in order to use the concept in an automated clinical decision support system (i.e., the type of pressure relieving device would need to be made explicit). Persons actually completing point of care clinical documentation would likely provide information at the more detailed level. A reporting interest in whether that device was used for a chair or bed could then be algorithmically derived from the more specific information within an electronic clinical documentation system.

Another example illustrating the need for terminology completeness relates to the names of specific clinical assessment scales. SNOMED CT includes names of many scales used in health care. For example, the McGill Pain Questionnaire and the FACES pain scale are terms within SNOMED CT, however neither the Braden Scale nor the Norton Scale were included in SNOMED CT at the time of this review, nor is pressure ulcer risk quantified in the MDS. Automated clinical alerts when critical values of the Braden Scale or Norton Scale are observed would likely result in the earlier deployment of preventive interventions (such as pressure relieving devices) and therefore a reduction in the incidence of new pressure ulcers. This means that the concept of a Braden Scale score or a Norton Scale score must be available within a given system. The developers of SNOMED CT have a defined procedure for updating the content of this terminology. Researchers at Mayo will submit the terms that were found to not have a complete match in SNOMED CT to the developers of SNOMED for their consideration as terms that should be added to SNOMED.

In the present analysis we included only the specific name of the clinical assessment scale recommended by the domain expert. We did not retrieve specific content within any given scale and further determine the content coverage of that scale. Readers should not

automatically assume that because the name of the scale is missing that the content of scale is missing. Researchers at Mayo Clinic are working to apply natural language processing techniques to discover “kernel concepts” in such clinical scales, and will focus future content coverage studies on identifying the terms that may be lacking in clinical terminology systems.

C. Content Coverage Provided for Terms Within the Minimum Data Set

Table 5 compares the content coverage of SNOMED CT, ICF, and ICNP for all terms within the MDS. Again, as expected SNOMED CT provided the most complete coverage of the three coding systems reviewed in this study.

A few comparisons are of particular interest. First ICNP provided relatively complete coverage of interventions compared to ICF. This is very consistent with the focus of the ICF on providing a profile of functioning and disability, while the emphasis of the ICNP is on interventions provided by nurses as well as patient assessments. Similarly, the content coverage of administrative terms is more extensive in the ICNP than in the ICF.

TABLE 1. A Comparison of Recommended Data Elements to Infer Quality of Care for Persons with Pressure Ulcers/At Risk for Pressure Ulcers

	Pressure Ulcers: ACOVE	Pressure Ulcers: Domain Expert	Pressure Ulcers: MDS Quality Measure
Targeted history and physical	Risk assessment	Risk for decreased tissue perfusion: Tobacco use and CABG procedure Radiation treatment History of ulcers History of hospital stays Surgical treatments: Surgical flap At risk for developing pressure ulcers High risk for pressure ulcers Risk assessment tools Braden scale Norton scale Skin inspection	
Treatment for condition	Preventive interventions Nutritional interventions Management Debridement Cleansing Topical dressing Management If at risk, then repositioning and pressure reduction for tissue loads If at risk and malnourished, then nutritional intervention If \geq stage 2, no topical antiseptic If full thickness sacral or trochanteric with necrotic debris or eschar, then debride If clean full-thickness or partial-thickness, then topical dressing If s/s of infection with no other cause, then debride within 12 hours, tissue biopsy or needle aspiration for culture and sensitivity within 12 hours	Ulcer care plan Application of dressings Clean dry dressings Dressings that keep ulcer bed continuously moist Protective dressings Cleanse wound Mild cleansing agent Whirlpool treatment Wet to dry dressings Debridement Topical debriding agents Autolytic debridement Enzymatic debridement Mechanical debridement Wound irrigation Foam Gel Growth factors Hormones Hyperbaric oxygen Infrared ultraviolet Hydrotherapy Normal saline Topical agents Topical aminoglycoside treatment Topical antibiotics Topical treatment with iodine containing agents Avoid massage over bony prominences Moisturizers Luricants (corn starch and cream) Electrical stimulation therapy Low energy laser irradiation Assisted oral feeding Oral supplements Devices that totally relieve pressure Distribution of weight Proper postural alignment Characteristics of support surfaces	

	Pressure Ulcers: ACOVE	Pressure Ulcers: Domain Expert	Pressure Ulcers: MDS Quality Measure
		Dynamic support surface Low air loss bed Pressure relief Pressure reducing beds Pressure reducing mattresses Pressure reducing overlays Maintain position in bed or chair Nutritional management Aggressive nutritional interventions Air fluidized beds Plan of nutritional support Patient education Repositioning schedule Surgical flap Postoperative viability of the surgical site Evaluate adequacy of treatment	

	Pressure Ulcers: ACOVE	Pressure Ulcers: Domain Expert	Pressure Ulcers: MDS Quality Measure
Assessments	<p>Risk assessment Evaluation If unable to reposition self, then risk assessment for pressure ulcers If pressure ulcer, assess for location, depth, stage, size, presence of necrotic tissue If partial thickness pressure ulcer and no improvement after 2 weeks then assess appropriateness of tx plan</p>	<p>Age, gender Cognition: Comatose, Cognitive skill, Distracted, Awareness, Restlessness, Lethargy, Mental function, Altered level of consciousness, Depression score, Mental status Speech, Verbal responses Ability to move: Bed mobility, Bed bound, Chair bound, Transfer ability, Walking ability, Locomotion, Dressing ability, Motion of: neck, arm, hand, leg, foot; ADL function, Activities of daily living, Restraint use, Body control, Mobility device, Difficulty with repositioning, Impaired ability to reposition, Immobility, Spinal cord injury, Physical status Nutrition: Eating ability, Nutritional intake, Oral/nutritional status, Oral problems, Oral nutritional supplements, Enteral feeding, Modular products, Vitamin/mineral supplements, Weight loss, BMI, Poor meal intake, Dietary intake, Albumin, Nitrogen balance, Nutritional status, Dietary intake of protein, Dietary intake of calories, Malnutrition, Nutrition screening, Nutritional assessment Risk for moisture exposure: Toilet use, personal hygiene, bathing, bowel incontinence, bladder incontinence, Toilet use, Briefs, Protective padding, Underpads, Skin hydration Recurrence of pressure ulcer Location of pressure ulcer Stage of pressure ulcer Ulcer healing Friction injuries Bed linen to move Lifting devices Minimize force and friction Positioning devices Transferring support Turning techniques Risk for delayed healing Bony prominences Infections</p>	<p>Pressure ulcer Risk adjustment: Impaired transfer or bed mobility OR Risk adjustment: Comatose Malnutrition End stage disease</p>

TABLE 2. A Comparison of Recommended Data Elements to Infer Quality of Care for Persons with Chronic Pain

	Chronic Pain Management: ACOVE	Chronic Pain: Domain Expert	Chronic Pain: MDS Quality Measure
Targeted history and physical	<p>If newly reported chronic pain condition then history and physical within 1 month</p> <p>If treated with NSAIDs, check history to peptic ulcer disease</p> <p>If history of peptic ulcer disease, justify NSAID use</p> <p>If treatment with opioids, then bowel regimen/treatment</p>	<p>Presence of diagnoses known to be painful: osteoarthritis, low back pain, fibromyalgia, spinal stenosis, post-herpetic neuralgia, peripheral neuropathy, myofascial pain syndromes, vasogenic claudication, phantom limb pain, headaches, vasculitic pain syndromes, osteoporosis with fractures, cancer, contractures, peripheral vascular disease, rheumatoid arthritis</p> <p>When starts, what started it, what makes it better, what makes it worse</p>	
Treatment for condition	<p>If newly reported chronic pain condition then offer treatment</p> <p>Acetaminophen for OA</p> <p>NSAIDs for OA</p> <p>Opioids</p> <p>Avoid meperidine</p>	<p>Pain intensity monitoring</p> <p>Appropriate use of medications</p> <p>Appropriate use of non-pharmacologic interventions</p> <p>Acetaminophen for OA</p> <p>NSAIDs for OA</p> <p>Opioids</p> <p>Avoid meperidine</p>	

	Chronic Pain Management: ACOVE	Chronic Pain: Domain Expert	Chronic Pain: MDS Quality Measure
Assessments	<p>If treated, then assess for response within 6 months</p> <p>Depression</p> <p>Palliative care</p> <p>Side effects of new medications</p> <p>Education concerning medication side effects</p> <p>Osteoarthritis</p>	<p>Dementia</p> <p>Delirium</p> <p>Pain Scales: Numeric estimate (0-100); Verbal descriptors: no pain, moderate, severe, excruciating, worst pain possible, most intense pain imaginable; Faces pain scale; Pain map; McGill pain questionnaire</p> <p>Pain Behaviors: Facial (wrinkled forehead, tightly closed eyes, grimacing, frowning); Nonverbal behavior (bracing, rubbing, guarding); Vocalizations (crying, yelling, groaning, moaning)</p> <p>Nonverbal indicators of discomfort: Aggressive, crying, fearful, negative vocalization, noisy respirations, pacing, repetitive, restlessness, rocking, confusion</p> <p>irritability, increased activity, withdrawal, tense, calling out, grunting, knees pulled up; Other changes in usual activities or behavior patterns/routines</p> <p>Impact of pain on quality of life outcomes</p> <p>Physical function, sleep, appetite, interpersonal relationships/interactions with others, mood (anxiety, depression), mental status (ability to think clearly/concentration/confusion), energy/fatigue</p>	<p>Moderate pain at least daily</p> <p>Horrible/excruciating pain at any frequency</p> <p>Independence in decision making</p>

TABLE 3. A Comparison of Recommended Data Elements to Infer Quality of Care for Persons with Urinary Incontinence

	Urinary Incontinence: ACOVE	Urinary Incontinence: Domain Expert	Urinary Incontinence: MDS Quality Measure
Targeted history and physical	<p>If new or persists ≥ 1 month, then targeted hx: Voiding characteristics; Ability to get to toilet; Previous tx for incontinence; Importance of problem to pt.; Mental status</p> <p>If new or persists ≥ 1 month, then target physical: Rectal exam; Genital system exam</p> <p>If new or persists ≥ 1 month, then dipstick ua and post-void residual</p> <p>If newly discovered overflow incontinence and indwelling catheter used, documentation, that not candidate for other interventions as result of physical or mental impairments or tx preference</p>	<p>Characteristics of voiding and non-invasive bladder diagnosis</p> <p>Ability to toilet</p> <p>Prior treatment for incontinence</p> <p>Importance of problem to patient</p> <p>Mental status exam</p> <p>Rectal exam to exclude fecal impaction</p> <p>Skin exam to evaluate skin problems associated with urinary incontinence</p> <p>Genital system exam to identify physical abnormalities that may explain incontinence (e.g., pelvic prolapse)</p>	
Treatment for condition	<p>If cognitively intact without hematuria or high post void residual, then behavioral therapy</p> <p>If surgery or periurethral injections, then cystometry before procedure</p> <p>If female with stress incontinence caused by sphincter deficiency, then surgery is sling or artificial sphincter procedure</p> <p>Behavioral therapies</p>	<p>Prompted toileting</p> <p>Prompted voiding</p> <p>Scheduled toileting</p> <p>Timed voiding</p>	
Assessments		<p>MDS recal scale, MDS item B3, or Cognitive performance scale derived from MDS items</p> <p>Frequency of incontinence</p> <p>Status of incontinence: day and night</p> <p>Symptoms on urination</p> <p>Symptoms to distinguish between urge incontinence (short interval between sensation to void and bladder contraction) and stress incontinence (urine loss during physical movements)</p> <p>Mobility problems on MDS and provider notes</p> <p>Toileting responsiveness assessments: How often person voids when prompted on a routine basis</p> <p>Voiding record</p> <p>Non-invasive diagnoses of bladder function</p> <p>Urodynamic analyses of bladder functioning (for select diagnoses)</p> <p>Lab reports</p> <p>Primary care notes</p>	<p>Control of urinary bladder function or continence programs, if employed</p> <p>Risk adjustment: Severe cognitive impairment</p> <p>Totally ADL dependent in mobility</p> <p>Total dependence in ADL self-performance</p>

TABLE 4. Content Coverage Provided by Selected Coding Systems for Terms Related to Three Domains of Quality: Chronic Pain, Pressure Ulcers, and Urinary Incontinence

Terms Provided by Domain Experts	MDS Coverage of Terms			SNOMED CT Coverage of Terms			ICF Coverage of Terms			ICNP Coverage of Terms		
	Complete Match ¹	Partial Match ²	No Match	Complete Match ¹	Partial Match ²	No Match	Complete Match ¹	Partial Match ²	No Match	Complete Match ¹	Partial Match ²	No Match
PRESSURE ULCERS (n=179 terms)	70%	—	30%	77%	10%	13%	18%	37%	47%	16%	24%	60%
Administrative Information (n=5 terms)	100%	—	—	100%	—	—	—	20%	—	—	—	100%
Resident History (n=10 terms)	80%	—	20%	80%	—	20%	—	10%	90%	20%	40%	40%
Assessments (n=82 terms)	75%	—	25%	85%	13%	2%	12%	50%	38%	21%	28%	50%
Treatments (n=82 terms)	50%	21%	29%	90%	10%	—	—	—	—	25%	40%	35%
CHRONIC PAIN (n=79 terms)	8%	8%	84%	92%	8%	—	4%	9%	87%	3%	5%	96%
Administrative Information												
Resident History (n=19 terms)	26%	16%	58%	94%	5%	—	—	26%	73%	5%	10%	84%
Assessments (n=53 terms)	9%	13%	77%	84%	16%	—	6%	17%	77%	2%	2%	96%
Treatments (n=7 terms)	—	—	100%	100%	—	—	—	—	100%	15%	—	85%
URINARY INCONTINENCE (n=28 terms)	8%	8%	84%	95%	5%	—	4%	50%	46%	4%	46%	50%
Administrative Information (n=5 terms)												
Resident History (n=2 terms)	—	—	100%	100%	—	—	—	50%	50%	—	50%	50%
Assessments (n=20 terms)	15%	15%	70%	85%	15%	—	5%	50%	45%	5%	50%	45%
Treatments (n=6 terms)	—	15%	85%	100%	—	—	—	50%	50%	—	—	100%

1. Complete match indicates a lexical match and/or synonyms (e.g. “ability to toilet” and “ability to use toilet”)
2. Partial match includes either of the following
 - S terms with a broader or narrower conceptual meaning (e.g., the ICF code of “Weight maintenance function” has a broader conceptual meaning than the domain expert term of “weight loss”)
 - S coverage of some but not all concepts in the target term (e.g., the ICNP code of “nursing home” provides partial coverage of the MDS term “prior stay at this nursing home”)

TABLE 5. Content Coverage Provided by Selected Coding Systems for All Terms Within the Minimum Data Set (MDS)

Terms Within the MDS	SNOMED CT Coverage of Terms		ICF Coverage of Terms		ICNP Coverage of Terms	
	Complete Match ¹	Partial Match ²	Complete Match ¹	Partial Match ²	Complete Match ¹	Partial Match ²
(n=628 terms)	46%	45%	2%	39%	12%	50%
Administrative Information (n=87)	20%	71%	—	8%	1%	38%
Resident History (n=143)	89%	7%	—	40%	1%	53%
Assessments (n=262)	29%	66%	4%	58%	20%	53%
Treatments (n=93)	63%	33%	—	31%	20%	57%
Other ³ (n=43)	40%	37%	—	7%	2%	38%

1. Complete match indicates a lexical match and/or synonyms (e.g. “ability to toilet” and “ability to use toilet”)
2. Partial match includes either of the following
 - S terms with a broader or narrower conceptual meaning (e.g., the ICF code of “Weight maintenance function” has a broader conceptual meaning than the domain expert term of “weight loss”)
 - S coverage of some but not all concepts in the target term (e.g., the ICNP code of “nursing home” provides partial coverage of the MDS term “prior stay at this nursing home”)
3. “Other” includes terms such as provider information (e.g., signature), quantities (e.g., 1 to 500 cc/day), and available activities (e.g., cards/other games)

A discussion of these results follows in the next section.

V. DISCUSSION

In this section we first discuss the comparison of data elements on which inferences of quality are based, and the content coverage provided by three different coding systems for those data elements. We then discuss potential implications of this study in relation to continuing initiatives around an information infrastructure of health care.

A. Essential Data Elements for Inferring Quality

The data elements suggested by the domain experts, ACOVE indicators, and MDS quality measure reflect differing perspectives related to the essential data on which to infer quality of care. There is clearly a different emphasis on the type of information needed to understand quality between the clinical experts (both the individual domain experts and the ACOVE panels) and the MDS quality measures. The clinical experts emphasized assessments that identify persons with actual or potential problems, and then link those assessments and judgments to processes of care. A repeating theme in the ACOVE panels is that it is the failure to identify persons who would benefit from specific care processes that is an indicator of quality, not merely the occurrence of the event.

The focus of the MDS quality indicators and quality measures is on the prevalence of the three conditions, reflecting in part the nature of data within the MDS but also perhaps a public demand for prevalence and outcomes data. However, as experts in the measurement of quality emphasize, such data are extremely difficult to interpret accurately, particularly in the absence of information needed to adequately risk adjust and the absence of information about the processes of care associated with those outcomes. This suggests that the MDS quality measures may not be the most relevant indicators of quality for inferring quality.

The construction of quality indicators and quality measures from MDS data elements is constrained by the availability of data within the MDS; the availability of data within the MDS is constrained by the limited clinical content within the MDS. The difference in the extent to which the MDS provided acceptable pressure ulcer data compared to chronic pain and urinary incontinence data suggests that the MDS be examined carefully for the completeness with which quality inferences can be made. A highly coordinated and structured NHII would enable reporting data for quality oversight functions to be derived from a patient medical record information system. In addition, and perhaps more important to improving quality in long-term care facilities, automated decision support systems could be built within that patient medical record information (PMRI) system thereby providing alerts and reminders at the point-of-care.

B. Content Coverage Provided by Terminology Coding Systems

The results in the previous section clearly indicate that a large, comprehensive terminology coding system (SNOMED CT) provided a more complete coverage of desired terms than either of the two focused coding systems (ICF and ICNP). However there are important caveats to this statement. First, the ICF and ICNP are both classification systems, not formal terminologies. The coded terms within both systems reflect a high-level grouping of data, not an exhaustive list of all possible terms that could be classified into specific groups. Of note, both the ICF and ICNP were developed with intent to expand their content over time. Second, both the ICF and the ICNP classification systems provide textual definitions of each coded term. If the definitions within the ICF and ICNP were formally expressed and coded, a more extensive content coverage would have been evident. SNOMED CT does not provide textual definitions of terms. The meaning of terms must be inferred based on the placement of the term within the SNOMED CT hierarchies. This presents an obvious source of potential error in any content coverage study.

As yet, there is no recommendation from the NCVHS on the use of single, comprehensive health care terminology such as SNOMED CT or on an alternative federated approach with many different systems providing terms. Should the NCVHS recommend a single comprehensive reference terminology (for example, SNOMED CT), classification systems such as the ICF and ICNP could be rolled into such a terminology system in ways that retain the intent and focus of those classification systems. This will require significant development work for both the ICF and the ICNP in order to formally express their structure in a manner that is compatible with the reference terminology system. Alternatively, should the NCVHS recommend a federated approach whereby multiple large and small scale systems are used, similar development work will be required in order to integrate and assure interoperability of various coding systems within and across electronic health information systems.

C. Implications Related to Patient Medical Record Information System Developments

A standards-based information infrastructure is needed for long-term care PMRI systems, just as such an infrastructure is needed in other areas of health care. In particular, the presence of a uniform data system for expressing terminological data would enable quality reporting as a “by-product” of care. More importantly, such a terminology system is critical in order to build automated alerts and decision support systems that would enable enhancements to the care provided. The convergence of “best practices” with information systems requires a highly coordinated approach between terminology

systems, documentation systems, and the standards of care suggested in the literature such as the ACOVE indicators that point to best practices. Electronic point of service documentation using a terminology system that is recognized by all of the software applications that interface with that documentation would enable, for example, prompts to be issued as reminders to care providers around practice guidelines such as those published by ACOVE. Further, failure to use standardized terminologies in electronic health information systems will increase costs and slow the adoption of interoperable PMRI systems.

Moving forward towards the NHII model for long-term care requires that standards for encoding clinical data, sending messages, and document architecture be adopted.

Experts in the development of health information systems agree that achieving the vision of the NHII requires Federal and private partnerships around the development, maintenance and dissemination of clinical terminologies. Among the recommendations made by the NCVHS to the Secretary of HHS is federal involvement in the selection of standards for patient medical record information, early adoption of PMRI standards by the Federal government, conformance testing and licensure of clinically specific terminologies, and funding for demonstration projects and research on improved clinical data capture (<http://ncvhs.hhs.gov/reptrecs>). Long-term care is an area of health care where there would likely be immediate benefits from the development of electronic health information systems.

To facilitate the evolution of the NHII first requires commitment to and adoption of standards by system developers, vendors, and purchasers; reaching consensus on the role of the federal government as a facilitator; continuing standards development, and providing financial resources. Until recently, standards development was seen largely as an industry responsibility because no federal funding has been allocated for this purpose. After standards are fully developed, subsequent efforts will be required that emphasize collaborations and implementations.

Sufficient progress has been achieved in our understanding of functioning characteristics, achievable reporting goals, information systems standards, and formal logics to permit the formation and defense of the vision proposed. However, many gaps exist in our underlying patient record model, standards specifications, and terminology logics. Each of these gaps defines a body of cross-cutting research to close them. Harmonization of this research, to ensure the comparability and interoperability of the patient data elements, would afford obvious efficiencies.

D. Implications for the MDS

A reference terminology such as SNOMED CT is an essential underpinning of the NHII. An evolution from stand-alone reports such as the MDS to reports that are derived from clinical documentation systems requires close attention to terminology and other NHII related standards that will enable the re-use of clinical data across *multiple* applications (e.g., clinical decision support, alerts, quality monitoring, and reimbursement). The development and implementation of electronic patient medical record information systems that adhere to data standards required to achieve the NHII vision is a critical strategy for improving the quality of care in nursing homes.

This means that the development of an electronic clinical record for nursing homes and the derivation of quality monitoring and reporting from those clinical records must evolve in a fashion that is highly coordinated with the standards that will enable the NHII vision. The standards around clinical terminology systems that will allow the NHII vision to become a reality are particularly important to embrace. Failure to do so will only continue and exacerbate provider data collection burden and limit the scope, and, therefore, utility of the NHII for improving the quality of care in nursing homes.

E. Summary

The IOM report on computer based patient records concluded “computerized clinical data [are] a prerequisite for the safe provision of quality care.”³⁸ Similarly, in its report on the quality of long-term care the IOM suggests that the development of computer based record systems is an essential strategy in improving the quality of care.¹⁸ Underlying this is the basic understanding that key documentation systems are not separate and removed from persons providing care. This report has illustrated that: (1) current nursing home reporting requirements do not completely reflect the information needed at the point of care to deliver quality of care or to subsequently monitor nursing home quality; and (2) work is needed to extend clinical terminologies so that they reflect the essential data elements required for delivering quality care.

Point of care clinical data captured in an integrated electronic health information system needs to be seen as a business imperative, both as a means of reducing documentation burden and improving accuracy, and, most importantly, as a means of supporting improvements in the quality of care. Although patient medical record information systems are not yet widely implemented in long-term care facilities, the IOM and others have identified the need for such initiatives as a way to substantially contribute to quality of care enhancements across the healthcare continuum. Development of electronic information systems will be slowed without public policy that supports and encourages the adoption of standards for messages, clinical document architecture, and terminologies.

The technology required to support the NHII vision of a distributed health information system is available, representing dramatic developments in the technical infrastructure of health care systems since the MDS was first developed. We can now support through technology assistance a patient and practice-centered approach that was the goal of the MDS efforts in the first place.

However achieving the vision awaits a concerted and coordinated national effort, including public and private efforts to support the adoption of standardized terminology systems, and research and demonstration efforts needed to extend inter-operable electronic clinical information systems into long-term care. In addition, work will be needed to build federal and state payment and quality monitoring policies using a well-developed terminology system that is a part of the NHII.

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APPENDIX A.

ACOVE Indicators

Pressure Ulcers	
Risk Assessment	IF a vulnerable elder is admitted to an intensive care unit or a medical or surgical unit of a hospital and cannot reposition himself or herself or has limited ability to do so, THEN risk assessment to pressure ulcers should be done on admission.
Preventive Intervention	IF a vulnerable elder is identified as at risk for pressure ulcer development or a pressure ulcer risk assessment score indicates that the person is at risk. THEN a preventive intervention addressing repositioning needs and pressure reduction (or management of tissue loads) must be instituted within 12 hours.
Nutritional Intervention	IF a vulnerable elder is identified as at risk for pressure ulcer development and has malnutrition (involuntary weight loss of >10% over 1 year or low albumin or prealbumin levels,) THEN nutritional intervention or dietary consultation should be instituted.
Evaluation	IF vulnerable elder presents with a pressure ulcer, THEN the pressure ulcer should be assessed for location, depth, and stage, size, and presence of necrotic tissue.
Management	<p>IF a vulnerable elder presents with a clean full-thickness pressure ulcer and has no improvement after 4 weeks of treatment, THEN the appropriateness of the treatment plan and the presence of cellulitis or osteomyelitis should be assessed.</p> <p>IF a vulnerable elder presents with a partial-thickness pressure ulcer and has no improvement after 2 weeks of treatment, THEN the appropriateness of the treatment plan should be assessed.</p>
Debridement	IF a vulnerable elder presents with a full-thickness sacral or trochanteric pressure ulcer covered with necrotic debris or eschar, THEN debridement by using sharp, mechanical, enzymatic, or autolytic procedures should be done within 3 days of diagnosis.
Cleaning	IF a vulnerable elder has a stage 2 or greater pressure ulcer, THEN topical antiseptic should not be used on the wound.
Systemic Infection	<p>IF a vulnerable elder with a full-thickness pressure ulcer presents with systemic signs and symptoms of infection, such as elevated temperature, leukocytosis, confusion, and agitation, and these signs and symptoms do not have another identified cause, THEN the ulcer should be debrided of necrotic tissue within 12 hours</p> <p>IF a vulnerable elder with a full-thickness pressure ulcer presents with systemic signs and symptoms of infection, such as elevated temperature, leukocytosis confusion, and agitation, and these signs and symptoms do not have another identified cause, THEN a tissue biopsy or needle aspiration sample should be obtained and sent for culture and sensitivity testing within 12 hours.</p>

Topical Dressing	IF vulnerable elder presents with a clean full-thickness or a partial-thickness pressure ulcer, THEN a moist-healing environment should be provided with a topical dressing.
Pain Management	
Screening for Pain	<p>ALL vulnerable elders should be screened for chronic pain during initial evaluation period.</p> <p>ALL vulnerable adults should be screened for chronic pain every 2 years.</p>
Target History and Physical Examination	IF a vulnerable adult has a newly reported chronic pain condition, THEN a targeted history and physical examination should be initiated within 1 month.
Addressing Risks of NSAIDs	IF a vulnerable adult has been prescribed a cyclooxygenase nonselective NSAID for the treatment of chronic pain, THEN the medical record should indicate whether he or she has a history of peptic ulcer disease and, if a history is present, justification of the NSAID should be documented.
Constipation with Opioid Use	IF a vulnerable elder with chronic pain is treated with opioids, THEN he or she should be offered a bowel regimen, or the medical record should document the potential for constipation or explain why bowel treatment is not needed.
Treating Pain	IF a vulnerable elder has a newly reported chronic painful condition, THEN treatment should be offered.
Reassessment of Pain Control	IF a vulnerable elder is treated for a chronic painful condition, THEN he or she should be assessed for a response within 6 months.
Related Indicators	<p>Evaluate depression in patients with chronic pain.</p> <p>Palliative care.</p> <p>Educate concerning side effects of new medication.</p> <p>Avoid meperidine.</p> <p>Assess pain and function annually for osteoarthritis.</p> <p>Acetaminophen use for osteoarthritis.</p> <p>NSAID use for osteoarthritis.</p>

Urinary Incontinence	
Initial Evaluation	ALL vulnerable elders should have documentation of the presence or absence of urinary incontinence during the initial evaluation.
Annual Evaluation	ALL vulnerable elders should have annual documentation of the presence or absence of urinary incontinence.
Targeted History	IF a vulnerable elder has a new urinary incontinence that persists for more than 1 month or urinary incontinence at the time of a new evaluation, THEN a targeted history should be obtained that documents each of the following: (1) characteristics of voiding, (2) ability to get to the toilet, (3) previous treatment for urinary incontinence, (4) importance of the problem to the patient, and (5) mental status.
Targeted Physical Examination	IF a vulnerable elder has new urinary incontinence that persists for more than 1 month or urinary incontinence at the time of a new evaluation, THEN a targeted physical examination should be performed that documents (1) rectal examination (2) a genital system examination (including a pelvic examination for women).
Diagnostic Tests	IF a vulnerable elder has a new urinary incontinence that persists for more than 1 month or urinary incontinence at the time of a new evaluation, THEN a dipstick urinalysis and post-void residual should be obtained.
Discussion of Treatment Options	IF a vulnerable elder has a new urinary incontinence or urinary incontinence at the time of a new evaluation, THEN treatment options should be discussed.
Behaviorial Therapy	IF a cognitively intact vulnerable elder who is capable independent toileting has documented stress, urge, or mixed incontinence without evidence of hematuria or high post-void residual, THEN behavioral treatment should be offered.
Urodynamic Testing	IF a vulnerable elder undergoes surgery or periurethral injections for urinary incontinence, THEN subtracted cystometry should be performed before the procedure.
Surgery for Stress Incontinence	IF a female vulnerable elder has documented stress urinary incontinence caused by isolated intrinsic sphincter deficiency or intrinsic sphincter deficiency with coexistent hypermobility, and she undergoes surgical correction, THEN a sling or artificial procedure should be used.
Catheter Use	IF a vulnerable elder has clinically significant newly discovered overflow urinary incontinence and indwelling urethral catheterization is used, THEN there should be documentation that the patient is not a candidate for alternative interventions as a result of severe physical or mental impairments or does not want to alternative interventions.

APPENDIX B.

Terms Abstracted from Domain Experts Reports

DOMAIN FOCUS: Pressure Ulcer Risk	
Purpose for Which Term Provides Information	Term
Provider Information	NA, RN, LPN
Patient Tracking Information	
Patient Information	Age Gender
Pressure Ulcer	Assess for recurrence of pressure ulcer Location of pressure ulcer Stage of pressure ulcer Ulcer healing
Risk Status	At risk for developing pressure ulcers High risk for pressure ulcers Risk assessment tools Braden scale Norton scale Skin inspection Periodic reassessment
Cognition/Mental Status	Comatose Cognitive skill Distracted Awareness Restlessness Lethargy Mental function Altered level of consciousness Depression score Mental status
Can Request Help	Speech Verbal responses

Purpose for Which Term Provides Information	Term
Ability to Move Activity Mobility	Bed mobility Bed bound Chair bound Transfer ability Walking ability Locomotion Dressing ability Motion of: neck, arm, hand, leg, foot ADL function Activities of daily living Restraint use Body control Mobility device Difficulty with repositioning Impaired ability to reposition
Ability to Move Activity Mobility (continued)	Immobility Spinal cord injury Physical status
Nutrition	Eating ability Nutritional intake Oral/nutritional status Oral problems Oral nutritional supplements Enteral feeding Modular products Vitamin/mineral supplements Weight loss BMI Poor meal intake Dietary intake Albumin Nitrogen balance Nutritional status Dietary intake of protein Dietary intake of calories Malnutrition Nutrition screening Nutritional assessment

Purpose for Which Term Provides Information	Term
Risk for Moisture Exposure Moisture	Toilet use Personal hygiene Bathing Bowel incontinence Bladder incontinence Briefs Protective padding Underpads Skin hydration
Pressure	Bony prominence
Risk for Delaying Healing	Infections
Outcome and Risk Factor	History of ulcers Hospital stays
Risk for Decreased Tissue Perfusion	Skin pliability Tobacco use CABG
Treatment for Pressure Ulcers	Ulcer care plan Application of dressings Clean dry dressings Dressings that keep ulcer bed continuously moist Protective dressings Cleanse wound

Purpose for Which Term Provides Information	Term
Treatment for Pressure Ulcers (continued)	Mild cleansing agent Whirlpool treatment Wet to dry dressings Debridement Topical debriding agents Autolytic debridement Enzymatic debridement Mechanical debridement Wound irrigation Foam Gel Growth factors Hormones Hyperbaric oxygen Infrared ultraviolet Hydrotherapy Normal saline Topical agents Topical amioglycoside treatment Topical antibiotics Topical treatment with iodine containing agents Avoid massage over bony prominences Moisturizers Lubricants (corn starch and cream) Electrical stimulation therapy Low energy laser irradiation Assisted oral feeding Oral supplements Devices that totally relieve pressure Distribution of weight Proper postural alignment Characteristics of support surfaces Dynamic support surface Low air loss bed Pressure relief Pressure reducing beds Pressure reducing mattresses Pressure reducing overlays Maintain position in bed or chair Nutritional management Aggressive nutritional interventions Air fluidized beds Plan of nutritional support Patient education Repositioning schedule Surgical flap Postoperative viability of the surgical site Evaluate adequacy of treatment

Purpose for Which Term Provides Information	Term
Condition Factors	Radiation treatment
Fiction/Shear	Friction injuries Bed linen to move Lifting devices Minimize force and friction Positioning devices Transferring support Turning techniques

DOMAIN FOCUS: Chronic Pain	
Purpose for Which Term Provides Information	Terms
Risk Factors for Chronic Pain in Long-Term Care Facilities	Presence of diagnoses known to be painful: osteoarthritis, low back pain, fibromyalgia, spinal stenosis, post-herpetic neuralgia, peripheral neuropathy, myofascial pain syndromes, vasogenic claudication, phantom limb pain, headaches, vasculitic pain syndromes, osteoporosis with fractures, cancer, contractures, peripheral vascular disease, rheumatoid arthritis
Risk of Unrecognized and Thus Untreated Pain	Dementia Delirium
Location	Pain map Drawing Description
Intensity or Severity of Pain	Numeric estimate (0-100) Verbal descriptors scale: no pain, moderate, severe, excruciating, worst pain possible, most intense pain imaginable Faces pain scale
Quality	Terms within McGill pain questionnaire
Duration	Intermittent, continuous, lasting minutes or hours
Pattern	When starts, what started it, what makes it better, what makes it worse
Pain Behaviors	Facial (wrinkled forehead, tightly closed eyes, grimacing, frowning) Nonverbal behavior (bracing, rubbing, guarding) Vocalizations (crying, yelling, groaning, moaning)
Nonverbal Indicators of Discomfort	Aggressive, crying, fearful, negative vocalization, noisy respirations, pacing, repetitive, restlessness, rocking, confusion irritability, increased activity, withdrawal, tense, calling out, grunting, knees pulled up. Other changes in usual activities or behavior patterns/ routines.
Impact of Pain on Quality of Life Outcomes	Physical function, sleep, appetite, interpersonal relationship/interactions with others, mood (anxiety, depression), mental status (ability to think clearly/ concentration/confusion), energy/fatigue
Treatments	Pain intensity monitoring Appropriate use of medications Appropriate use of non-pharmacologic interventions

DOMAIN FOCUS: Urinary Incontinence	
Purpose for Which Term Provides Information	Terms
Target History Mental Status Characteristics of Voiding and Non-Invasive Bladder Diagnosis Ability to Toilet Prior Treatment for Incontinence Importance of Problem to Resident	MDS recall scale, MDS item B3, or Cognitive performance scale derived from MDS items Frequency of incontinence Status of incontinence: day and night Symptoms on urination Symptoms to distinguish between urge incontinence (short interval between sensation to void and bladder contraction) and stress incontinence (urine loss during physical movements) Mobility problems on MDS and provider notes
Targeted Physical	Rectal exam to exclude fecal impaction Skin exam to evaluate skin problems associated with urinary incontinence Genital system exam to identify physical abnormalities that may explain incontinence (e.g., pelvic prolapse)
Factors Associated with UI	Lab reports Primary care provider notes
Toileting Responsiveness Assessments	How often person voids when prompted on a routine basis Voiding record Non-invasive diagnoses of bladder function
Urodynamic Analyses of Bladder Functioning	
Intervention	Prompted toileting Prompted voiding Scheduled toileting Timed voiding

APPENDIX C.

Examples of MDS- Derived Quality Indicators

Prevalence of Stage 1-4 Pressure Ulcer	
Numerator	Residents with pressure ulcers (Stage 1-4) on most recent assessment.
Denominator	All residents on most recent assessment.
MDS 2.0 Quarterly Variable Definition	Pressure ulcer (M2a > 0, or 13 = ICD-9 CM 707.0)
Risk Adjustment	High Risk: Impaired transfer or bed mobility (G1a or b = 3 or 4-Box A) OR comatose (B1 = 1) OR malnutrition (13 = ICD-9 CM 260,261, 262, 263.0, 263.1, 263.2, 263.8, or 263.9) OR end stage disease (J5c is checked) most recent assessment
	Low Risk: All others at most recent assessment.

Prevalence of Bowel or Bladder Incontinence	
Numerator	Residents who were frequently incontinent or incontinent on most recent assessment.
Denominator	All residents, except as noted in exclusion. Exclude: Residents who are comatose residents (B1 = 1) OR have indwelling catheter (H3d is checked) OR have an ostomy (H3i is checked) at most recent assessment
MDS 2.0 Quarterly Variable Definition	Bladder incontinence (H1b = 3 or 4) Bowel incontinence (H1a = 3 or 4)
Risk Adjustment	High Risk: Severe cognitive impairment AND short-term memory problems (B4 = 3 and B2a = 1) OR Totally ADL dependent in mobility ADLs (G1a, b, e-Box A self-performance = 4 in all areas) at most recent assessment
	Low Risk: All others at most recent assessment.

APPENDIX D.

Examples of MDS- Derived Quality Measures

Percent of Residents with Pressure Sores with Additional Level of Risk Adjustments (A QM for Long-Stay Residents)	
Numerator	Number of residents with pressure ulcers (stage 1-4) on full or quarterly assessment (M2A > 0 or I3a-e = 707.0)
Denominator	All residents with valid full (AA8a = 01, 02, 03, 04) or quarterly assessment (AA8a = 05 10) Exclusions: Most recent assessment is the admission assessment (AA8a = 01); the QM is not triggered (resident is not included numerator) AND the value of M2a is missing on the target assessment.
<p>Resident is a facility with a chronic care sample size =0 (i.e., over the last 12 months no residents with a non-PPS assessment - AA8a= 01 and AA8b=blank or 6)</p> <p><i>Facility Admission Profile</i> <i>Considers prevalence of stage 1-4 PU (M2a>0 OR I3a-e=707.0 among admissions (AA8a=01) occurring over the previous 12 months</i></p> <p><i>Numerator: admission assessments (AA8a=01) w/ M2A.0 OR I3a-e=707.0</i> <i>Denominator: all admission assessments (AA8a=01)</i> <i>Exclusions: admission assessments (AA8a=01) that do not satisfy the numerator conditions AND have missing data on M2a.</i></p>	

Percent of Short-Stay Residents with Pain (A QM for Short-Stay Residents)	
Numerator	Number of residents who experience moderate pain at least daily (J2a = 2 and J2b = 2) OR horrible excruciating pain at any frequency (J2b = 3) as noted on the SNF PPS 14 day
Denominator	All residents with valid SNF PPS 14 day assessment (AA8b = 7) Exclusions: J2a or J2b missing from SNF PPS 14 day assessment; J2a or J2b inconsistent on the SNF PPS 14 day assessment (e.g., coding pain frequency as "no pain" while simultaneously coding intensity of pain as "moderate"); resident is in a facility with a post-acute care sample size =0 (i.e., SNF PPS 5 day assessment AA8b=1 over the last 12 months).
<p>Uses SNF PPS 14 day assessment (AA8b=7) with valid preceding 5 day SNF PPS assessment (AA8b=1)</p>	

APPENDIX E.

Contact Information, Terminology Coding Systems

SNOMED CT	
Purpose Reported by Developers	Terminology system that facilitates coding and retrieval of clinically relevant information.
Copyright	SNOMED International, a division of the College of American Pathologists (CAP)
Contact Information	SNOMED International 325 Waukegan Road Northfield, IL 60093-2750 Phone: (800) 323-4040 ext. 7700 U.S. (847) 832-7700 Canada E-mail: snomed@cap.org

ICF	
Purpose Reported by Developers	A classification of health and health related domains that describe body functions and structures, activities and participation.
Copyright	World Health Organization (WHO)
Contact Information	World Health Organization Coordinator Classification, Assessment Surveys and Terminology Unit 20, Avenue Appia 1211 Geneva, Switzerland E-mail: ustunb@who.int

ICNP	
Purpose Reported by Developers	Facilitate the crossmapping of local terms and existing nursing vocabularies and classifications.
Copyright	International Council of Nurses
Contact Information	ICNP® Programme Director Marquette University, College of Nursing P.O. Box 1881 Milwaukee, WI 53201 FAX: (414) 288 1939 E-mail: amy.coenen@marquette.edu

APPENDIX F.

Terms Abstracted from the MDS

MDS TERMS CLASSIFIED AS “ADMINISTRATIVE INFORMATION” (n= 87)

- MDS
- Identification Information
- Resident Name
- First
- Middle
- Last
- Jr/Sr
- Gender
- Birthdate
- Race/ethnicity
- Social security number and Medicare Number
- Facility Provider Number
- State number
- Federal Number
- Medicaid Number
- Reasons for Assessment
- Primary reason for assessment
- Admission assessment
- Annual assessment
- Significant change in status assessment
- Significant correction of prior full assessment
- Quarterly review assessment
- Significant correction of prior quarterly assessment
- Medicare 5 day assessment
- Medicare 30 day assessment
- Medicare 60 day assessment
- Medicare 90 day assessment
- Medicare readmission/return assessment
- Other state required assessment
- Medicare 14 day assessment
- Other Medicare required assessment
- Signature of Persons Completing a Portion of the Assessment
- Signature
- Title
- Date
- Demographic Information
- Date of Entry
- Admitted from
- Zip Code of Prior Primary Residence
- Date Background Information Completed
- Not applicable no MR/DD
- Identification and Background Information
- Middle initial
- Room Number
- Assessment Reference Date
- Last day of MDS observation period
- Marital Status
- Medical Record Number
- Current Payment Sources for NH Stay
- Medicaid per diem
- Medicare per diem
- Medicare ancillary part A
- Medicare ancillary part B
- CHAMPUS per diem
- VA per diem
- Self or family pays for full per diem
- Medicaid resident liability of Medicare co-payment
- Private insurance per diem
- Other per diem
- Significant change in status assessment
- Discharged return not anticipated
- Discharged return anticipated
- Discharged prior to completing initial assessment
- Reentry
- Codes for assessments required for Medicare PPS or the state
- Responsibility/Legal Guardian
- Legal guardian
- Other legal oversight
- Durable power of attorney/health care
- Durable power attorney/financial
- Family member responsible
- Advanced Directives
- Living will
- Do not resuscitate
- Do not hospitalize
- Organ donation
- Autopsy request
- Hospital Stay(s)
- Emergency Room (ER) Visit(s)
- Physician Orders
- Assessment Information
- Participation in Assessment
- Resident
- Family
- Significant other
- Signature of Person Coordinating the Assessment
- Patient responsible for self

MDS TERMS CLASSIFIED AS “RESIDENT HISTORY” (n= 143)

- Private home without home health services
- Private home with home health services
- Board and care assisted living group home
- Nursing home
- Acute care hospital
- Psychiatric hospital MR/DD facility
- Rehabilitation hospital
- Lived Alone (Prior to entry)
- Residential History 5 Years Prior to Entry
- Prior stay at this nursing home
- Stay in other nursing home
- Other residential facility - board and care home, assisted li
- MH/psychiatric setting
- MR/DD setting
- Lifetime Occupation(s)
- Education
- No schooling
- 8th grade/less
- 9-11 grades
- High school
- Technical or trade school
- Some college
- Bachelor’s degree
- Graduate degree
- Language
- English
- Spanish
- French
- Primary language
- Down’s syndrome
- Autism
- Epilepsy
- Other organic condition related to MR/DD
- MR/DD with no organic condition
- Mental health history
- Conditions related to MR/DD status
- MR/DD with organic condition
- Other organic condition related to MR/DD
- MR/DD with no organic condition
- Customary Routine
- Cycle of Daily Events
- Stays up late at night
- Naps regularly during day
- Goes out 1+ days a week
- Stays busy with hobbies, reading or fixed daily routine
- Spends most of time alone of watching TV
- Moves independently indoors
- Use of tobacco products at least daily
- Eating Patterns
- Distinct food preferences
- Eats between meals all or most days
- Use of alcoholic beverage(s) at least weekly
- ADL Patterns
- No change in ADL function
- Improved
- Deteriorated
- In bedclothes much of day
- Wakens to toilet all or most nights
- Has irregular bowel movement patterns
- Showers for bathing
- Bathing in PM
- Involvement Patterns
- Daily contact with relatives/close friends
- Usually attends church, temple, synagogue
- Finds strength in faith
- Daily animal companion/presence
- Involved in group activities
- Past Roles
- Frequently incontinent
- Incontinent
- Disease Diagnosis
- Diseases
- Endocrine/metabolic/nutritional
- Diabetes mellitus
- Hyperthyroidism
- Hypothyroidism
- Heart/circulation
- ASHD
- Cardiac dysrhythmias
- Congestive heart failure
- Deep vein thrombosis
- Hypertension
- Hypotension
- Peripheral vascular disease
- Other cardiovascular disease
- Musculoskeletal
- Arthritis
- Hip fracture
- Missing limb
- Osteoporosis
- Pathological bone fracture
- Neurological
- Alzheimer’s disease

- Aphasia
- Cerebral palsy
- Cerebrovascular accident
- Dementia other than Alzheimer's disease
- Hemiplegia/hemiparesis
- Multiple sclerosis
- Paraplegia

- Parkinson's disease
- Quadriplegia
- Seizure disorder
- Transient ischemic attack
- Traumatic brain injury
- Psychiatric/mood
- Anxiety disorder
- Depression
- Manic depression
- Schizophrenia
- Pulmonary
- Asthma
- Emphysema
- Sensory
- Cataracts
- Diabetic retinopathy
- Glaucoma
- Macular degeneration
- Allergies

- Anemia
- Cancer
- Renal failure
- Infections
- Antibiotic resistant infection
- Clostridium difficile

- Conjunctivitis
- HIV infection
- Pneumonia
- Respiratory infection
- Septicemia
- Sexually transmitted disease
- Tuberculosis
- Urinary tract infection in last 30 days
- Viral hepatitis
- Wound infection
- Other Current or more Detailed Diagnoses and ICD-9 Codes
- Accidents
- Fell in past 30 days
- Fell in past 31-180 days
- Hip fracture in last 180 days
- Other fracture in last 180 days
- End-stage disease
- History of Resolved Ulcers

MDS TERMS CLASSIFIED AS “ASSESSMENTS” (n= 273)

- Cognitive Patterns
- Comatose
- Memory
- Short-term memory OK
- Long-term memory OK
- Memory/recall Ability
- Current season
- Location of own room
- Staff names/faces
- That he/she is in a nursing home
- Cognitive skills for Daily Decision Making
- Indicators of Delirium-Periodic Disordered Thinking/Awareness
- Easily distracted
- Periods of altered perception or awareness of surroundings
- Episodes of disorganized speech
- Periods of restlessness
- Periods of lethargy
- Mental function varies over the course of the day
- Change in Cognitive Status
- Communication/Hearing patterns
- Hearing
- Hears adequately
- Minimal difficulty hearing
- Hears in special situations only
- Highly impaired hearing

- Communication Devices/Techniques
- Hearing aid present and used
- Hearing aid present and not used regularly
- Other receptive comm. Techniques used
- Modes of Expression
- Speech
- Writing messages to express or clarify needs
- American sign language or Braille
- Signs/gestures/sounds
- Communication board
- Making Self Understood
- Understood
- Usually understood
- Sometimes understood
- Rarely/Never understood
- Speech clarity
- Clear speech
- Unclear speech
- No speech
- Ability to Understand Others

- Understands
- Usually understands
- Sometimes understands
- Rarely/Never understands
- Change in Communication/Hearing

- Vision Patterns
- Vision
- Adequate
- Impaired
- Moderately impaired
- Highly impaired
- Severely impaired
- Visual Limitations/Difficulties
- Side vision problems
- Experiences any of following:
- Mood and Behavior Patterns
- Indicators of Depression, Anxiety, Sad Mood
- Verbal expressions of distress
- Resident made negative statements
- Repetitive questions
- Repetitive verbalizations
- Persistent anger with self or others
- Self deprecation
- Expressions of what appear to be unrealistic fears
- Recurrent statements that something terrible is about to happen
- Repetitive health complaints
- Repetitive anxious complaints/concerns
- Sleep cycle issues
- Unpleasant mood in morning
- Insomnia/change in usual sleep pattern

- Sad, apathetic, anxious appearance
- Sad, pained, worried facial expressions
- Crying, tearfulness
- Repetitive physical movements
- Loss of interest
- Withdrawal from activities of interest
- Reduced social interaction
- Mood Persistence
- Change in Mood
- Behavioral Symptoms
- Wandering
- Verbally abusive behavioral symptoms
- Physically abusive behavioral symptoms
- Socially inappropriate/disruptive behavioral symptoms

- Resists care
- Change in Behavioral Symptoms
- Psychosocial Well-Being
- Sense of Initiative/Involvement
- At ease interacting with others
- At ease doing planned or structured activities
- At ease doing self-initiated activities
- Establishes own goals
- Pursues involvement in life of facility
- Accepts invitations into most group activities
- Unsettled Relationships
- Covert/open conflict with or repeated criticism of staff
- Unhappy with roommate
- Unhappy with residents other than roommate
- Openly expressed conflict/anger with family/friends
- Recent loss of close family member/friend
- Does not adjust easily to change in routines
- Strong identification with past roles and life status
- Expresses sadness/anger/empty feeling over lost roles/status
- Resident perceives that daily routine is very different from prior pattern in the community
- Physical Functioning and Structural Problems
- ADL Self Performance/ADL support provided
- Bed mobility
- Transfer
- Walk in room
- Walk in corridor
- Locomotion off unit
- Dressing
- Eating
- Toilet use
- Personal hygiene
- Bathing
- ADL self-performance
- Independent
- Supervision
- Limited assistance
- Extensive assistance
- Total dependence
- Activity did not occur
- ADL support provided
- No setup or physical help from staff
- One person physical assist
- Two + person physical assist
- Test for Balance
- Balance while standing
- Balance while sitting
- Functional Limitation in Range of Motion
- Neck
- Arm
- Hand
- Leg
- Foot
- Other limitation or loss
- Modes of Locomotion
- Cane/walker/crutch
- Wheeled self
- Other person wheeled
- Wheelchair primary mode of locomotion
- Modes of Transfer
- Bedfast all or most of time
- Bed rails used for bed mobility or transfer
- Lifted manually
- Lifted mechanically
- Transfer aid
- Task Segmentation
- ADL Functional Rehabilitation Potential
- Resident believes he/she is capable of increased independence
- Direct care staff believe resident is capable of increased in
- Resident able to perform tasks/activity but is very slow
- Difference in ADL self-performance or ADL support, comparing mornings to evenings
- Change in Function
- Continence in Last 14 Days
- Continence Self-Control Categories
- Continent
- Usually Continent
- Occasionally incontinent
- Bowel continence
- Bladder continence
- Bowel elimination pattern
- Regular
- Constipation
- Diarrhea
- Fecal impaction
- Did not use toilet room/commode/urinal
- Change in urinary continence
- Health Conditions
- Problem Conditions
- Indicators of fluid status
- Weight gain or loss of 3 or more pounds within

- a 7 day period
- Inability to lie flat due to shortness of breath
- Dehydrated; output exceeds input
- Insufficient fluid; did not consume all/almost all liquids provided during last 3 days
- Delusions
- Dizziness/vertigo
- Edema
- Fever
- Hallucinating
- Internal bleeding
- Recurrent lung aspirations in last 90 days
- Shortness of breath
- Syncope
- Unsteady gait
- Vomiting
- Pain Symptoms
- Frequency
- Intensity
- Pain Site
- Back
- Bone
- Chest pain while doing usual activities
- Headache
- Hip
- Incisional pain
- Joint pain
- Soft tissue pain
- Stomach pain
- Stability of Conditions
- Conditions/diseases make resident's cognitive, ADL, mood or behavior patterns unstable
- Resident experiencing an acute episode or a flare-up of a recurrent or chronic problem
- Oral/Nutritional Status
- Oral Problems
- Chewing problem
- Swallowing problem
- Mouth pain
- Height
- Weight
- Weight Change
- Weight loss
- Weight gain
- Nutritional Problems
- Complains about the taste of many foods
- Regular or repetitive complaints of hunger
- Leaves 25% or more of food uneaten at most meals
- Oral/Dental Status
- Oral Status and Disease Prevention
- Debris present in mouth prior to going to bed at night
- Has dentures or removable bridge
- Some/all natural teeth lost
- Broken, loose, or carious teeth
- Inflamed gums
- Daily cleaning of teeth/dentures or daily mouth care
- Skin condition
- Ulcers
- Stage 1
- Stage 2
- Stage 3
- Stage 4
- Type of Ulcer
- Pressure ulcer
- Stasis ulcer
- Other skin Problems or Lesions Present
- Abrasions
- Burns
- Open lesions other than ulcers, rashes, cuts
- Rashes
- Skin desensitized to pain or pressure
- Skin tears or cuts
- Surgical wounds
- Resident has one or more foot problems
- Infection of the foot
- Open lesions on the foot
- Activity Pursuit Patterns
- Time Awake
- Average Time Involved in Activities
- Preferred Activity Settings
- General Activity Preferences
- Prefers Change in Daily Routine
- Type of activities in which resident is currently involved
- Extent of resident involvement in activities
- Intake/output
- Evaluation by a licensed mental health specialist in last 90 days
- Transfer
- Walking
- Dressing or grooming
- Eating or swallowing
- Amputation/prosthesis care
- Communication
- Abnormal Lab Values
- Discharge Potential and Overall Status

- Discharge Potential
 - Resident expresses/indicates preference to return to the community
 - Resident has a support person who is positive
- towards discharge
 - Stay projected to be of a short duration
 - Overall Change in Care Needs

MDS TERMS CLASSIFIED AS “TREATMENTS” (n= 93)

- Feeding restrictions
- Medication restrictions
- Other treatment restrictions
- Visual Appliances
- Glasses
- Contacts lenses
- Magnifying glass
- Appliances and programs
- Any scheduled toileting plan
- Bladder retraining program
- External catheter
- Indwelling catheter
- Intermittent catheter
- Pads/briefs used
- Enemas/irrigation
- Ostomy present
- Nutritional Approaches
- Parenteral/IV
- Feeding tube
- Mechanically altered diet
- Syringe
- Therapeutic diet
- Dietary supplement between meals
- Plate guard, stabilized built-up utensil
- On a planned weight change program
- Parenteral or Enteral Intake
- Code the proportion of total calories the resident received through parenteral or tube feedings in the last 7 days
- Skin Treatments
- Pressure relieving device for chair
- Pressure relieving device for bed
- Turning/repositioning program
- Nutrition or hydration intervention to manage skin problems
- Ulcer care
- Surgical wound care
- Application of dressings
- Application of ointments/ medications
- Other preventative or protective skin care
- Foot Problems and Care
- Received preventive or protective foot care
- Medications
- Number of Medications
- New Medications
- Injections
- Days Received the Following Medications
- Antipsychotic
- Antianxiety
- Antidepressant
- Hypnotic
- Diuretic
- Special Treatments and Procedures
- Special Treatments, Procedures, and Programs
- Special care
- Treatments
- Chemotherapy
- Dialysis
- IV medication
- Monitoring acute medical condition
- Ostomy care
- Oxygen therapy
- Radiation
- Suctioning
- Tracheostomy care
- Transfusions
- Ventilator or respirator
- Programs
- Alcohol/drug treatment program
- Alzheimer's/dementia special care unit
- Hospice care
- Pediatric care
- Respite care
- Training in skills required to return to the community
- Therapies
- Occupational therapy
- Physical therapy
- Respiratory therapy
- Psychological therapy
- Intervention Programs for Mood, Behavior, Cognitive Loss
- Special behavior symptoms evaluation program
- Group therapy
- Resident-specific deliberate changes in the environment to address mood/behavior patterns
- Reorientation
- Nursing Rehabilitation/Restorative Care
- Range of motion (active)
- Range of motion (passive)
- Splint of brace assistance
- Training and skill practice in:
- Devices and Restraints
- Bed rails
- Full bed rails on all open sides of bed
- Other types of side rails used
- Trunk restraint
- Limb restraint

- Chair prevents rising

MDS TERMS CLASSIFIED AS “OTHER” (n=43)

- Section
- If other, specify
- Not applicable
- Unknown
- Face Sheet Signatures
- Signatures of persons completing face sheet
- Signature of RN assessment coordinator
- Title
- Original or corrected copy of form
- Date of Reentry
- other
- none of above
- None
- 1% to 25%
- 26% to 50%
- 51% to 75%
- 76% to 100%
- Code the average fluid intake per day by IV or tube in last 7 days
- 1 to 500 cc/day
- 501 to 1000 cc/day
- 1001 to 1500 cc/day
- 1501 to 2000 cc/day
- 2001 or more cc/day
- Morning
- Afternoon
- Evening
- Own room
- Day/activity room
- Inside NH/off unit
- Outside facility
- Cards/other games
- Crafts/arts
- Exercise/sports
- Music
- Reading/writing
- Spiritual/religious activities
- Trips/shopping
- Walking/wheeling outdoors
- Watching TV
- Gardening or plants
- Talking or conversing
- Helping others
- Physician visits

APPENDIX G.

Terms Provided by Domain Experts, Partial or No Matches

Terms From Domain Experts, Partial Match or No Match to MDS		
Terms from Domain Experts	Partial Match MDS	No Match MDS
Pressure Ulcer Terms		
Adequacy of treatment		Adequacy of treatment
Air-fluidized bed	Pressure relieving device for bed	
Avoid positioning directly on the trochanter		Avoid positioning directly on the trochanter
Body control		Body control
Bony prominences		Bony prominence
Braden scale		Braden scale
Cellulitis		Cellulitis
Characteristics of support surfaces		Characteristics of support surfaces
Clean dressings	Application of dressings	
Complete history		Complete history
Complete physical examination		Complete physical examination
Debridement (sharp, mechanical, enzymatic, or autolytic)	Ulcer care	
Dietary intake of protein		Dietary intake of protein
Depression score		Depression score
Dietary intake of calories	Calories received through parenteral or tube feedings in last 7 days	
Dynamic support surface	Pressure relieving device for bed	
Educational program for prevention of pressure ulcers	Nursing rehabilitation/restoration "other"	
Electrical stimulation therapy	Ulcer care	
Eschar		Eschar
Exudate		Exudate
Film dressing	Ulcer care	
Friction		Friction

Terms from Domain Experts	Partial Match MDS	No Match MDS
Friction injuries		Friction injuries
Hydrocolloid dressing	Ulcer care	
Hydrotherapy	Ulcer care	
Hyperbaric oxygen	Ulcer care	
Inspect skin at least once a day, if early treatment		Inspect skin at least once a day, if early treatment
Irrigation pressure		Irrigation pressure
Lifting devices		Lifting devices
Low air-loss bed	Pressure relieving device for bed	
Lubricants to reduce friction injuries		Lubricants to reduce friction injuries
Modular products		Modular products
Moisture exposure on intact skin		Moisture exposure on intact skin
Mineral supplements		Mineral supplements
Normal saline for cleansing	Ulcer care	
Norton scale		Norton scale
Oral intake goals		Oral intake goals
Periodic reassessment (at least weekly)		Periodic reassessment
Poor meal intake		Poor meal intake
Positioning devices		Positioning devices
Positioning techniques		Positioning techniques
Postural alignment		Postural alignment
Protective films		Protective films
Protective dressings		Protective dressings
Protective padding		Protective padding
Range of motion		Range of motion
Risk for delayed healing		Risk for delayed healing
Risk for moisture exposure		Risk for moisture exposure

Terms from Domain Experts	Partial Match MDS	No Match MDS
Risk for pressure ulcers		Risk for pressure ulcers
Shearing		Shearing
Sepsis		
Severity of illness		Severity of illness
Shift weight every 15 minutes	Nursing rehabilitation/restoration "other"	
Skin cleansed at routine intervals		Skin cleansed at routine intervals
Skin cleansed at time of soiling		Skin cleansed at time of soiling
Static support surface		Static support surface
Stryker frame		Stryker frame
Tissue viability of the surgical site (if operative repair of pressure ulcer)		Tissue viability of surgical site
Topical treatment with iodine containing agents	Application of ointments/medications	
Transferring support	Modes of transfer	
Treatment goals		Treatment goals
Ulcer care plan evaluated		Ulcer care plan evaluated
Vitamin supplements	Number of medications	
Whirlpool treatment	Ulcer care	
Chronic Pain Terms		
Contractures		Contractures
Drawing of pain location		Drawing of pain location
Energy/fatigue		Energy/fatigue
Faces pain scale		Faces pain scale
Facial expressions (wrinkled forehead, tightly closed eyes, grimacing, frowning)	Sad, pained, worried facial expression	
Fibromyalgia		Fibromyalgia
Grunting	Making self understood	

Terms from Domain Experts	Partial Match MDS	No Match MDS
Headaches		Headaches
Impact of pain on (quality of life outcomes, physical function, sleep, appetite, interpersonal relationships/interactions with others, mood, mental status)		Impact of pain on (quality of life outcomes)
Irritability	Verbal expressions of distress (e.g., repetitive anxious complaints/concerns)	
Knees pulled up		Knees pulled up
Lasting minutes or hours		Lasting minutes or hours
Low back pain		Low back pain
McGill pain questionnaire		McGill pain questionnaire
Monitoring pain intensity	Pain intensity	
Myofascial pain syndromes		Myofascial pain syndromes
Non-pharmacologic interventions		Non-pharmacologic interventions
Nonverbal behaviors (bracing, rubbing, guarding)		Nonverbal behaviors (bracing, rubbing, guarding)
Numbness		Numbness
Osteoarthritis	Arthritis	
Pain behaviors		Pain behaviors
Pain intensity	Pain intensity	
Pain map		Pain map
Patient satisfaction associated with pain management		Patient satisfaction associated with pain management
Pattern of pain		Pattern of pain
Peripheral neuropathy		Peripheral neuropathy
Phantom limb pain		Phantom limb pain
Post-herpetic neuralgia		Post-herpetic neuralgia
Radiating pain		Radiating pain
Rheumatoid arthritis	Arthritis	

Terms from Domain Experts	Partial Match MDS	No Match MDS
Risk of unrecognized and thus untreated pain		Risk of unrecognized and thus untreated pain
Screening procedures		Screening procedures
Spinal stenosis		Spinal stenosis
Stabbing pain	Pain symptom	
Throbbing pain	Pain symptom	
Tingling		Tingling
Vasculitic pain syndromes		Vasculitic pain syndromes
Vasogenic claudication		Vasogenic claudication
Verbal descriptors scale		Verbal descriptors scale
What starts pain		What starts pain
What makes pain better		What makes pain better
What makes pain worse		What makes pain worse
When pain starts		When pain starts
Urinary Incontinence Terms		
Ability to toilet	Toilet use	
Characteristics of voiding and non-invasive bladder diagnosis		Characteristics of voiding and non-invasive bladder diagnosis
Factors associated with UI		Factors associated with UI
Genital system exam to identify physical abnormalities that may explain incontinence (e.g., pelvic prolapse)		Genital system exam to identify physical abnormalities that may explain incontinence (e.g., pelvic prolapse)
How often person voids when prompted on a routine basis		How often person voids when prompted on a routine basis
Importance of problem to resident		Importance of problem to resident
Lab reports		Lab reports
Non-invasive diagnoses of bladder function		Non-invasive diagnoses of bladder function
Primary care provider notes		Primary care provider notes

Terms from Domain Experts	Partial Match MDS	No Match MDS
Prior treatment for incontinence		Prior treatment for incontinence
Prompted toileting	Any scheduled toileting plan	
Prompted void		
Rectal exam to exclude fecal impaction		Rectal exam to exclude fecal impaction
Skin exam to evaluate skin problems associated with uninary incontinence		Skin exam to evaluate skin problems associated with uninary incontinence
Status of incontinence: day and night	Bladder continence	
Symptoms on urination		Symptoms on urination
Symptoms to distinguish between urge incontinence (short interval between sensation to void and bladder contraction) and stress incontinence (urine loss during physical movements)		Symptoms to distinguish between urge incontinence (short interval between sensation to void and bladder contraction) and stress incontinence (urine loss during physical movements)
Targeted history		Targeted history
Targeted physical		Targeted physical
Toileting responsiveness assessments		Toileting responsiveness assessments
Urodynamic analyses of bladder functioning		Urodynamic analyses of bladder functioning
Voiding record	Any scheduled toileting plan	Voiding record

Terms From Domain Experts, Partial Match or No Match to SNOMED CT		
Terms from Domain Experts	Partial Match SNOMED CT	No Match SNOMED CT
Pressure Ulcer Terms		
Activity	Type of activity	Activity
Adequacy of treatment		Adequacy of treatment
Awareness	Consciousness	(SNOMED term "state of awareness" is a retired concept)
Bed bound	Bed ridden	
Bony prominences		Bony prominences
Braden scale		Braden scale
Can request help	Request for Ability to ask questions (specific types of help)	Help
Chair bound	Confined to chair	
Characteristics of support surfaces		Characteristics of support surfaces
Condition factors		Condition factors
Difficulty with repositioning	Repositioning	Difficulty with repositioning
Distracted	Easily distracted	Distracted without modifier
Friction injuries		Friction injuries
Locomotion		Locomotion
Modular products		Modular products
Moisture		Moisture exposure
Motion of: neck, arm, hand, leg, foot	Motion Ability to move arm Ability to move hand Ability to move leg Ability to move foot	Motion
Norton scale		Norton scale
Periodic reassessment		Periodic reassessment
Poor meal intake	Food intake	Meal
Skin pliability	Skin assessment	Pliability

Terms from Domain Experts	Partial Match SNOMED CT	No Match SNOMED CT
Ulcer care plan evaluated	Care plan Evaluation	Ulcer care plan
Verbal responses	Uses verbal communication	
Viability of the surgical site		(SNOMED term "surgical site" has been retired)
Chronic Pain Terms		
Description	Symptom description NOS	Description
Drawing		Drawing
Faces pain scale	Finding of present pain intensity	Faces pain scale
Facial expressions (wrinkled forehead, tightly closed eyes, grimacing, frowning)	Grimaces	Wrinkled forehead Tightly closed eyes Frowning
Grunting	Vocalization	(SNOMED includes term grunting but "is_a" animal vocalization)
Impact of pain on quality of life outcomes	Pain Determination of outcome	Impact Quality of life
Lasting minutes or hours	Time frame Intervals of minutes Intervals of hours	Lasting
Negative vocalization	Negative Vocalization	Negative vocalization
Nonverbal behavior (bracing, rubbing, guarding)		Nonverbal behavior (bracing, rubbing, guarding)
Nonverbal indicators of discomfort	Discomfort	Nonverbal indicators
Pain map		Map
Physical function		Physical function
Risk of unrecognized and thus untreated pain	Risk of Pain	Unrecognized Untreated
Vasculitic pain syndomes	Pain	Vasculitic pain syndomes
Withdrawal from activities of interest	Loss of interest	Withdrawal from activities
Urinary Incontinence Terms		

Terms from Domain Experts	Partial Match SNOMED CT	No Match SNOMED CT
Importance of problem to resident	Problem	Importance Resident
Targeted history	History taking Has focus	Targeted
Targeted physical	Physical exam Limited	Targeted

APPENDIX H.

References Provided by Domain Experts

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