**Consolidated Health Informatics Initiative**
**Final Recommendation Information Sheet [1]**

## Domain Title and Team Lead

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## Scope

Disability terms are used in the federal health care sector for payment, policy development, surveys, public quality reports, external quality monitoring, internal quality monitoring, and eligibility determinations.

## Alternatives Identified

1. SNOMED CT (Systematized Nomenclature of Medicine Clinical Terms)
2. ICF (International Classification of Functioning, Disability and Health)
3. UMLS (Unified Medical Language System) Metathesaurus.

## Recommendation

At this time, the workgroup does not endorse either SNOMED CT or ICF as the standard for disability content needed by the Federal Government. The workgroup recommends support for research that will facilitate the development of (i) needed disability and functional content into core terminologies, and (ii) algorithms that can be used to equate the alternative scaling concepts used across federal classification systems.

## Rationale and Study Findings:

The disability workgroup conducted a content coverage analysis using a sample of disability concepts and phrases provided by workgroup members. The analysis involved determining the degree of content coverage provided by SNOMED CT, ICF, and other sources available in UMLS Metathesaurus. Specifically, the workgroup used the MetaMap Transfer (MMTx) Program, developed by the National Library of Medicine, a highly configurable program that maps biomedical text to concepts in the UMLS Metathesaurus. MetaMap works by parsing text into simple noun phrases, identifying variants (acronyms, abbreviations, synonyms, etc.), listing candidate strings within the UMLS Metathesaurus that contain at least one of the variants, and finally identifying the most likely concept match within the UMLS Metathesaurus.

The Workgroup approached a content coverage analysis of SNOMED CT, ICF, and the UMLS Metathesaurus by sampling disability terms/concepts used across participating federal agencies. Sampled terms included those used in Medicare and Medicaid

[1] Information Sheet designed specifically to facilitate communication between CHI and NCVHS Subcommittee on Standards and Security resulting from May 20, 2003 testimony. CHI may seek assistance to help further define scope, alternatives to be considered and/or issues to be included in evaluation process.

programs, Social Security Administration, Veterans' Health Administration, and surveys conducted by the National Center for Health Statistics (NCHS). In sampling terms, the Workgroup identified disability terms/phrases/content that were applicable to physical and mental disability, children and adults, and are used by the Federal Government to meet a variety of purposes (e.g., payment, quality, eligibility, research, statistics, and policy development). Specifically, disability terms and concepts were sampled from the:

1. Nursing Home Minimum Data Set (MDS);
2. Home Health Outcome and Assessment Information Set (OASIS); and
3. Functional Independence Measure (FIM) for Rehabilitation;
4. Residual Functional Capacity Form (RFC); and
5. National Health Interview Survey and National Health and Nutrition Examination Survey.

NLM performed the analysis using the MetaMap Transfer Program.
No Validation was performed on results.
Match rates were reported as complete, partial, or none.

FINDINGS

At best, the Workgroup found that SNOMED CT and ICF provided a partial match of Scaling concepts because at a minimum, and in all cases, both SNOMED CT and ICF would require the development of algorithms to translate the scaling embedded in the terminology/classification scheme to support the scaling needs of SSA (i.e., the metric needed by) SSA. Neither ICF nor SNOMED CT includes the scaling concepts needed by SSA. The Workgroup concluded that this would be the same result for SNOMED CT and ICF coverage of the scaling embedded in the FIM, OASIS, and MDS.

Some times the scaling content was either unavailable or only partially available.

The table below summarizes the results of the CHI Disability Workgroup content coverage analysis.

| Content Coverage Table | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | SNOMED CT | | | ICF | |
| | | Complete | Partial | None | Complete | Partial | None |
| FIM (n=100) | Quality | 58 | 40 | 2 | 30 | 64 | 6 |
| | Total | 58 | 40 | 2 | 30 | 64 | 6 |
| | | | | | | | |
| FIM -(IRF-PAI) | | | | | | | |
| | Payment | | | | | | |
| | Total | | | | | | |
| | | | | | | | |
| OASIS (n=39) | Payment | 7 | 1 | 1 | 1 | 6 | 2 |
| | Quality | 8 | 13 | 9 | 6 | 9 | 15 |
| | Total | 15 | 14 | 10 | 7 | 15 | 17 |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| MDS (n=31) | Payment | 10 | 16 | 0 | 3 | 17 | 6 |
| | Quality Indicators | 8 | 3 | 0 | 3 | 5 | 3 |
| | Quality Measures | 8 | 3 | 0 | 3 | 5 | 3 |
| | Care Planning | 8 | 3 | 0 | 3 | 5 | 3 |
| | Total | 14 | 17 | 0 | 4 | 21 | 6 |
| | | | | | | | |
| RFC (n=81) | Eligibility Adults | 41 | 8 | 2 | 39 | 11 | 1 |
| | Eligibility Children | 17 | 13 | 0 | 25 | 5 | 0 |
| | Total | 58 | 21 | 2 | 64 | 16 | 1 |
| | | | | | | | |
| NCHS (n=70) | Survey | 32 | 34 | 4 | 12 | 40 | 18 |
| | Total | 32 | 34 | 4 | 12 | 40 | 18 |
| | | | | | | | |
| Grand Total (n=321) | | 177 | 126 | 18 | 117 | 156 | 48 |

(*) Columns don't add up because items are used for multiple purposes.

As a classification system, the ICF often bundles multiple concepts. However, in many cases, the Federal Government needs disability data for only a part of the bundled concepts. Thus, a classification system will not always permit the extraction of data needed by the Federal Government.

The ICF is intended to be complementary to the International Statistical Classification of Diseases and Related Health Problems (ICD).

The Workgroup was concerned about whether the multi-axial hierarchies that are the foundation of SNOMED CT presently support or could be modified in the future to support disability terms and constructs needed by the Federal Government (and by health care providers). This issue was raised in part because of the origins of SNOMED CT (i.e., a model originally intended to represent diseases and procedures and its continued emphasis on medical content) and also because we found SNOMED CT providing more complete coverage of medically-related terms compared to the ICF (e.g., the provision of Nursing, Rehabilitative, Restorative Care such as in the areas of active and passive range of motion, and training and skills practice in amputation/prosthesis care).

Further, even to the extent that all relevant disability and functioning terms were included in SNOMED CT (or some other terminology) endorsed for future federal use, additional work would be needed to map to the classification systems used by federal agencies (including, but not limited to, classifications (derived from patient assessment tools) that are used to generate Medicare and Medicaid

payments, and the ICF). The Workgroup notes the terminology itself would also not be sufficient by itself to provide a conceptual framework for understanding functioning and disability (i.e., a strength of the ICF).

The Workgroup is aware of recent research completed by the Mayo Clinic that found, in a review of the domains of pressure ulcer, incontinence, and pain, most of the information collected using the MDS for these domains is not captured by either SNOMED CT or ICF. Specifically, SNOMED CT was found to provide a complete match for 46% of the MDS terms. The ICF was found to provide a complete match rate of terms in the MDS 2 percent of the time.

The Disability Workgroup recommends the following:

1. At this time, we do not endorse either SNOMED CT or ICF for future use in the federal health care IT enterprise.
2. We recommend future research that:
    a. examines whether the underlying hierarchies of SNOMED CT will support the incorporation of disability terms, concepts, and phrases needed by the Federal Government, and if not, whether the underlying hierarchies could be modified to support the incorporation of needed disability terms, concepts, and phrases;
    b. conducts a more complete content coverage analysis of SNOMED CT, ICF, and other sources within the UMLS Metathesaurus for disability terms needed by the Federal Government for inclusion in a core terminology;
    c. develops terminology content that will support the scaling concepts embedded in federal classification systems and assessment instruments;
    d. once needed scaling concepts are included in a core terminology, develop algorithms that can be used to equate alternative scaling concepts across federal classification systems;
    e. if the research under item (a) above finds that SNOMED CT will support the incorporation of needed disability terms, concepts, and phrases; supports research that will incorporate the needed disability content identified under items (b) and (c); and
    f. if the research under item (a) above finds that SNOMED CT will not support the incorporation of needed disability terms, concepts, and phrases, develops a disability terminology that meets the criteria of reference terminology (as specified above) using the disability content identified under items (b) and (c).