

University of Minnesota Nursing Knowledge Big Data Science

Encoding-Modeling Work Group 3-11-2021

Standardized Scale/Survey New Term Request Rules/Heuristics

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Standardized Assessment Instrument/Scale New Term Requests

Nursing assessments contain valuable data. These assessments are entered into electronic health records and other clinical data systems in structured formats such as flowsheets. Assessment documentation frequently includes standardized assessment scales or survey instruments, such as pain scores, fall risk assessments, and skin integrity assessments. Standardized assessment scales have been researched as valid and reliable for use in one or more patient populations and use of the content typically requires permission. This document will detail the workflow for assessment scale review and new term requests.

The Office of the National Coordinator for Health Information Technology identified LOINC as the accepted terminology for validated standardized instruments or scales (<https://www.healthit.gov/isa/sites/isa/files/inline-files/2020-ISA-Reference-Edition.pdf>). New terms may be requested from LOINC if exact matches are unavailable in the current release. The new term request process from LOINC is included in this document.

Assessment scale or survey instruments are represented in LOINC using a panel structure (<https://loinc.org/kb>). Standardized assessment scales consist of specific observations or assessment questions, with normative answer lists. Normative answer lists are those defined within the validated instrument. These answer sets must remain exactly as developed and validated, and cannot be modified because the validity and reliability testing results would no longer apply. Examples of assessment scales include the FLACC pain assessment scale, the Morse fall risk scale, and the NPUAP pressure injury stage.

Nursing instruments/scales approved by the Knowledge Modeling Work Group (see addendum) will undergo review, heuristics development, and mapping by the Encoding-Modeling Work Group (EMWG). First, a EMWG leader or designated member will contact the developer or designated copyright owner to discuss the LOINC submission process time commitment, which may include multiple requests for additional definition of terms and multiple reviews of the content by the developer or a designated clinical reviewer.

If the copyright owner agrees to the anticipated time commitment, the EMWG will then broker the copyright request between LOINC staff and the copyright owner. LOINC staff members are contacted by email for clinical scale submissions: submissions@loinc.org. The copyright owner information is provided to LOINC staff, and they conduct the formal copyright permission process. The EMWG will assist to answer questions that arise during the copyright permission process. Once the copyright permission process is completed, the Encoding-Modeling Work Group will create a LOINC submission from the materials provided by the developer or copyright owner. The basic build rules are as follows:

- The set of questions (observations) and answers (values) in a scale/instrument are created as a LOINC panel.
- Instruments composed of more than one independently scored scale will be built as separate scales/panels.
- Instruments composed of two or more panels contributing to a single total score will be built as sub-panels.
- When the interpretation of a score is not part of the standardized scale, but is appropriate and important to include in LOINC, the EMWG will work with the developer to create an interpretation LOINC code to represent the nurse's judgment of the obtained score. Example: The Neonatal Pain Agitation Sedation Scale (NPASS) pain/agitation score interpretation was defined by the developer:

| 95628-4 Pain/agitation level NPASS | |
|---|----------------------------|
| Score Ranges: | Interpretation (judgment): |
| • Score +1 to +3 | • Mild Pain |
| • Score +4 to +6 | • Moderate Pain |
| • Score +7 to +10 (or +11 for premature infant) | • Severe Pain |

- The scale developer or designated clinical reviewer is responsible for providing clear descriptions of the instrument, its components, and the score interpretation, and to ensure the representation of the scale is accurate and complete.
- The EMWG contact who developed the LOINC submission spreadsheet will continue to act as a liaison between the developer/designee and LOINC staff for questions, will review the completed LOINC panel, and will communicate status to the Knowledge Modeling Work Group.

Adding a Standardized Scale or Survey to LOINC

| Action or Decision | Responsible Party | | | |
|--|------------------------------------|-------------|--------------------|-------------------|
| | Copyright Owner or Scale Developer | LOINC Staff | Knowledge Modeling | Encoding-Modeling |
| Request to add new scale/survey to knowledge model(s) & to LOINC (*See note below) | X* | | X* | |
| Confirm scale/survey is not in LOINC | | | X | X** |
| Evaluate scale/survey evidence | | | X | |
| Decision: sufficient evidence? | | | X | |
| Gather required information from copyright owner or developer: <ul style="list-style-type: none"> • Copyright owner name/information • Graphic representation of scale • 2-3 key references (publications) • Copyright status (free versus fee) • Clinical Reviewer (if copyright not managed by the developer) | | | X | |
| Provide copyright information to Encoding-Modeling WG | | | X | |
| Indicate priority of request | | | X | |
| Ensure developer or designated copyright owner understands and agrees to time requirements for submission | | | | X |
| Provide copyright owner information to LOINC staff member | | | | X |
| Obtain formal copyright permission | | X | | |
| Assist LOINC staff as needed during copyright permission process | | | | X |
| Draft submission spreadsheet from reference materials | | | | X |
| Validate submission spreadsheet (working with the EMWG liaison): <ul style="list-style-type: none"> • Scale description • Term definitions • Key references/citations • Nursing assessment/judgment (interpretation of score) | X | | | X |
| Update submission spreadsheet based on clinical validation process | | | | X |
| Request pre-submission review by Susan Matney & Lisa Anderson | | | | X |
| Submit scale request to LOINC: <ul style="list-style-type: none"> • Spreadsheet • Graphic representation | | | | X |

| | | | | |
|--|--|--|--|---|
| • Key references list | | | | |
| Notify LOINC Nursing Subcommittee about submission | | | | X |
| Liaison for submission clarifications (between LOINC staff & developer or clinical designee) | | | | X |
| Finalize project-specific heuristics & provenance information | | | | X |
| Notify Knowledge Modeling WG when scale submitted to LOINC | | | | X |
| Review completed LOINC panel report for accuracy | | | | X |
| Communicate to Knowledge Modeling WG when scale available in LOINC | | | | X |

*Another work group for Nursing Knowledge Big Data Science or a scale developer could also request to add a scale/survey.

**The Encoding-Modeling WG can check in LOINC on behalf of the Knowledge Modeling WG

Mapping New LOINC Terms

When the requested new terms are confirmed in the target terminology (LOINC), mappers will refer to the project-specific heuristics document for mapping guidance. The list of requested new terms will also be added to the Provenance section of the mapping document for further reference.

Addendum: Knowledge Modeling Work Group Policies

Nursing assessment scales are normally identified and prioritized by the Knowledge Modeling Work Group (KMWG) as part of information/knowledge model development and validation processes. For example, over one dozen pain assessment scales used in participating healthcare organizations' electronic health records were identified and evaluated during the pain information model development. Some pain assessment scales were not included in the final model due to insufficient published evidence. In other cases, outdated versions of standardized assessment scales were still being used. The Knowledge Modeling Work Group created policies to guide decisions regarding standardized assessment scales, as follows:

- If insufficient evidence exists, the KMWG has the authority to exclude a scale/survey instrument from their nursing knowledge model.
- Only the most recent version of a scale or survey instrument will be included in the knowledge model. Scale developers communicated their support of this policy statement, as scales are typically revised based on new evidence.
- Only instruments in use by KMWG members or their contacts are initially included
- Knowledge/Information models are updated every 3-5 years, so requests to add new instruments/ scales will not be accommodated immediately.

When the Knowledge Modeling work group receives the request for a scale to be included in a knowledge model, the first step is check in LOINC. If the scale is not in LOINC, and the evidence is sufficient to proceed with a submission request, the copyright information must be gathered by the KMWG. This process is not always straightforward. For example, the original

scale developer(s) might not be aware whether the original journal or textbook publisher actually owns the copyright. Sometimes the developer has asked the hospital or university where the scale was developed to manage the copyright. Copyright ownership must be ascertained, including whether the scale is free for use. If the scale/survey instrument is proprietary (fee required for use), LOINC will not be able to accept the submission. However, the copyright owner might permit the total score and the interpretation (without the individual observations or questions) to be included LOINC at no charge, so copyright owner information is needed even when the scale/instrument is proprietary. If the copyright owner is non-clinical and the developer is not available, the copyright owner must provide a clinical expert reviewer. This information is provided to the Encoding-Modeling workgroup along with the requested priority for the scale submission to LOINC.