Estonian experience in translating ICD-11 and thoughts on the implementation of the updated classification

Ruth Erm

National Institute for Health Development (TAI in Estonian) Competence Center of Medical Terminology Project Manager

30.05.2024



Competence Center for Medical Terminology

- Established in 2020 as the successor of Medical Terminology Commission which actively operated 42 years
- State budget funding, incorporated to Department of Registries in TAI
- Areas of expertise: terminology work and management, also as advisory body, both for our inhouse and outhouse partners in medicine, health care and public health domains. As of the beginning of 2024 also social field
- The main goal is to develop usable agreed-upon terminology for both real-life and machine communication
 - the use of several international standards, like ISO 13940:2016 (ContSys standard) Health informatics: system of concepts to support continuity of care; FHIR resources for data exchange, SNOMED CT)



Main tasks at the moment

- ICD-11 translation project
- Concept work and harmonization (FHIR concept group and upTIS team (upTIS = new generation health information system; preparing
 the movement to event-based data exchange))
- **Terminology work and harmonization** (for developing business glossaries and/or publishing in online health dictionary; public health and clinical health terminology; social field terminology)
- Terminology partner and advice (for SNOMED translation team; ICF local coordination team; Coordination body of classification management; Statistics Estonia (European Health Interview Survey, etc)
- Developing the positive language glossary (to reduce labeling and discrimination in health care and social field)



ICD-11 translation project

TAI is responsible for translating ICD-11 into Estonian. We do not have the local owner status. Project is funded by Estonian Health Insurance Fund's innovation fund. 300 000 euros, 01.01.2022-01.06.2025.

- Translating the whole ICD-11, the main chapters (except Supplementary Chapter Traditional Medicine Conditions) and most of the necessary extension codes for postcoordination, plus user interface.
- The diagnostic criteria of psychiatric disorders, ICD-11 Reference Guide and some subchapters in the Extension Codes will be translated later. The chapter of traditional medicine will not be translated.
- Translating and editing titles, synonyms (index terms), descriptions, diagnostic criteria, additional information in WHO translation platform.
- Translation team: three part-time expert terminologists (practicing doctors), fixed term employment
 contract with TAI, fixed monthly salary. Editing team: editors from professional medical associations for
 each chapter, work contract with legal person (association), billing after work is done, association pays for
 their editors. Language reviewing in TAI.



The challenges in ICD-11 translation project

Management challenges:

- Translators and editors are busy with their everyday work. This makes the project deadline uncertain and possibly not cost-effective.
- Translation platform is not meant for work-management. Impossible to keep track of the work, unable
 to see evaluate whether the material is approved or just forgotten to be approved. The underlying Excel
 file only saves last translator.
- WHO adds material to the articles and doesn't inform about it. Completion rates tend to change. The
 diagnostic criteria of psychiatric disorders which added almost 400 000 words to the chapter.
- The content is not completely final, there are mistakes, mixups, #draft material. No feedback of mistakes notified.
- It is not possible to extract the MMS part in the translation web (if you choose to translate only that)
- Slow and confusing communication with WHO team. Confusing WHO terminology (foundation, linearization, tabular version): which is which and why is it so and who needs it, and how is this useful.



The challenges in ICD-11 translation project #1

Translation challenges:

- Translation platform is not quite suitable for term harmonization, translation memory is very limited.
- The quality level of terminology varies between medical specialties: some have systematically developed terminology, some only need-based terminology, some not at all.
- Editing choices and differences between editors' preferences: Estonian word vs foreign word (also, English influence vs the habit of using Latin), reuse of ICD-10 translations vs new translations.
- Language editing is time-consuming, we've switched to end-user preview for deciding case by case.
- Estonian preview in translation platform is not the same as published ICD-11 browser view (not the same amount of content)



The challenges in ICD-11 translation project #2

Translation challenges:

- You cannot always say what is meant to be coded contact or activity (service) behind the contact (QA21
 Contact with health services for contraceptive management might be contraceptive counseling, appointment for contraceptive counseling or both)
- Title-synonym switch is not that straightforward in case of multiple parents, the choice to use synonym as title may result in the need to change primary parent. This makes translating not just translating but thinking as coder. Also, it may result in double codes (secondary thrombocytosis as original title is switched to the synonym relative thrombocytosis, but this is coded as other specified category).



The challenges in ICD-11 implementation #1

It's not clear

- how much the national implementation of ICD-11 will cost, and how much money the end-users will have to allocate for their developments (the implementation business analysis is under discussion)
- who will be the local owner whose responsibility will be to educate users, manage update information,
- how ICD-11 API will work. WHO suggests the browser use of ICD-11, and not the XML files.
- how the version releases will be managed, or updates informed.
- how the simultaneous use of ICD-10 and ICD-11 will work (mapping between ICD-10 and ICD-11 and ICD-11 and different code systems and terminologies (Orphanet, SNOMED CT)).



The challenges in ICD-11 implementation #2

It's not clear

- how the postcoordinated codes will run in the HIS or which type (how long) of codes is needed for billing. Different needs for MMS and for health assessment.
- thus, what type of codes are needed for global statistics (pre- or postcoordinated)
- how the ICD-11 and ICF joint use is meant to be (Supplementary section for functioning assessment) or if at all (there are no use cases).
- ICD-O use cases unclear while it's now incorporated to ICD-11 extension codes.
- how the cross-border data exchange will work with other Nordic countries (different timetables for implementation, ICD-10, ICD-11 data exchange, etc).



Thank you!

ICD-11 translation project contact in Estonia Ruth Erm ruth.erm@tai.ee

