

# Outcome comparability in real world settings: Defining a core data set for standard medical history assessment

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# Introduction

Reshaping care pathways and healthcare systems around patients' needs requires a standardized database on patient-centered outcomes. Standard sets as proposed by ICHOM serve as a basis for developing datasets that allow for comparisons across different patient populations thus drawing meaningful conclusions for enhancing quality of care.

However, standardization of outcomes and statistical analyses require a common medical history set based on case-mix variables capturing demographic details, information on health status, lifestyle and social factors. These case-mix variables are a fixed component of every ICHOM set, nevertheless they vary in terms of domain name and corresponding question across sets.

As the largest provider of software for patient-centered outcomes in German speaking countries, Heartbeat Medical has accumulated profound expertise in implementing ICHOM sets. To support the interoperable collection of standardized high quality data allowing for adequate benchmarking, we propose a core medical history set based on the most commonly used case-mix variables in adult ICHOM sets.

### Method

- Review of 31 adult ICHOM sets (June 2022)

  → Overview of non-condition- specific patient-reported measures & corresponding case-mix variables
- Grouping of identical variables with different domain names (e.g. smoking, smoking status, tobacco smoking status), Quantitative analysis of all items
- Independent expert revision of items appearing in >1 sets, discussion based on clinical relevance

  → First draft of core medical history set
- Interoperability check, Literature search on valid wording of questions for corresponding measures
- Structured interviews with N=17 clinicians to collect practical feedback → Revision, final adjustments

**Core Medical History Set** 

# Results

- Overall 312 different case-mix variables were identified in 31 adult sets (76 patient-reported, 236 clinical)
- The variables proposed in ≥10% of the sets that built the base for a first draft of a standard medical history set are presented in Table 1, column 1+2.
- ❖ Importance ratings from clinicians for all variables are presented in Table 1, column 3. Further comments are not displayed.
- The final revision by an expert commission resulted in 9 items to be included in the final set (Table 1 column 4)
- ❖ Decisions on wording as adequate or to be adapted (adapt.) are presented in Table 1, column 4 (Based on the clinicians' interviews, results from an interoperability check as well as the literature search).

# Adjustments:

- Biological Race (14 sets) was classified as optional depending upon the cultural context
- Year of birth and biological sex were added to the patient-reported variables being formerly classified as clinician-reported
- Relationship status was deleted after feedback from the clinicians
- The wording of the specific questions for four items will be adapted

### Final medical history set:

- ❖ 9 items: 5/9 will be adopted, the wording of the remaining 4 items will be adapted
- Next steps: Discussion of adding further items named by the clinicians and discussed in the expert group as well as presenting the set to patients

Item / Measure	% (absolute nr) of presence in ICHOM sets	% of experts that rated item as important	Final set
Year of Birth	100 (31)	100	~
Biological Sex	93.5 (29)	100	~
Educational Level	80.6 (25)	91.2	<b>✓</b>
Comorbidities (SACQ)	77.4 (24)	100	~
Height/Weight for BMI	61.3 (19)	100	~
Smoking Status	54.8 (17)	94.1	🗸 adapt.
Ethnicity	48.4 (15)	/	X
Living Arrangements	35.5 (11)	94.1	🗸 adapt.
Alcohol Intake	22.6 (7)	97.1	🗸 adapt.
Work Status	19.4 (6)	100	🗸 adapt.
Relationship Status	16.1 (5)	70.6	X

## Conclusions

Here, we present a minimum core data set for the standardized patient-reported assessment of general medical history set across different patient populations. While individual questions for specific conditions will remain necessary, a consensus regarding a core set may support the development of new sets.

Using this proposed standard as a foundation could facilitate **benchmarking** and **cross-cultural implementation** by enabling standardized translations as well as interoperability. Further, it might incentivise clinics and IT companies to simplify the implementation of ICHOM sets in clinical practice.

We recommend further validation of the proposed core set including collecting feedback also from patients.

