Establishing digital PROs in clinical routine care: Analysis and tackling of key challenges to the wide-scale implementation of ICHOM sets

Haneke, H.*, Nickel, S.*, Chlupka, L., Kirchberger, V.
*contributed equally
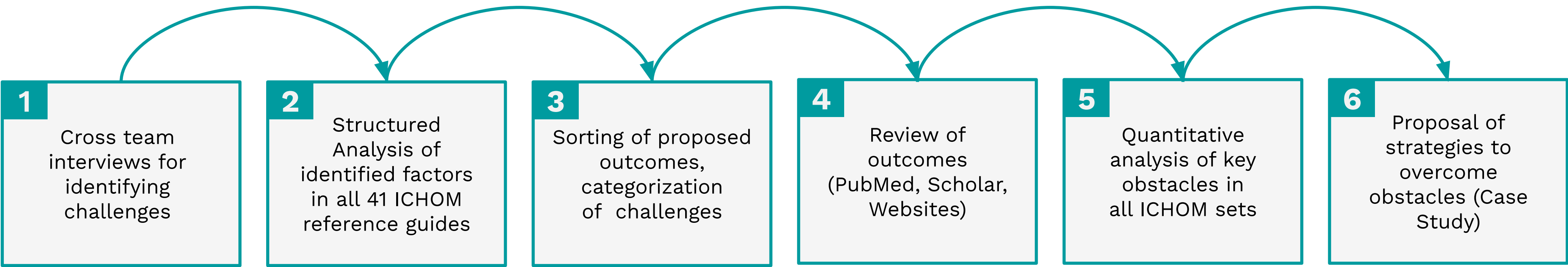HRTBT Medical Solutions GmbH, Berlin, Germany

Introduction

Promoting high-quality standardized outcome sets is crucial to re-organize care pathways around patients thereby leveraging the overall quality of routine clinical care. ICHOM proposes standard sets that aim to provide a holistic understanding of specific medical conditions by recommending a combination of relevant instruments, including patient- and clinician-reported outcomes. As they meet high methodological standards, interest in implementing those is huge but often face **practical challenges**.

As the leading software provider for patient-reported outcome data in German speaking countries, *Heartbeat Medical* (HRTBT Medical Solutions GmbH), has years of experience in the **digital implementation of outcome sets.** Of the 41 available ICHOM sets, 16 have been implemented to some degree. While intense effort went into overcoming methodological barriers of implementation on a broader organizational level, less emphasis has been placed on **practical considerations on an individual user level** so far.

This study presents our findings on key challenges for the wide-scale implementation of standardized outcome measures in clinical routine care and contributes to closing this gap.

Method

| 1 | Cross team interviews for identifying challenges | 2 | Structured Analysis of identified factors in all 41 ICHOM reference guides | 3 | Sorting of proposed outcomes, categorization of challenges | 4 | Review of outcomes (PubMed, Scholar, Websites) | 5 | Quantitative analysis of key obstacles in all ICHOM sets | 6 | Proposal of strategies to overcome obstacles (Case Study) |

Results

Identified key challenges: Licensing & language issues (as in missing validated German questionnaires)

- A total of **221 different outcomes** were proposed over all ICHOM sets
- **38 of 41** sets presented **at least one of the two identified issues**
- For **115 outcomes, no validated German translation** was found (52%)
- Results on licensing information are presented in Table 1: The majority of outcomes was free for use but **¼ could only be implemented with a fee**. Another 24.4% required an activity. For 11.3% no information was found.
- PROMIS questionnaires are a special case, since licensing has to be clarified with the national PROMIS center for digital use

Table 1: Overview on licensing status of ICHOM sets' outcomes

License status categories	Number of Outcomes
Free	82 (37.1)
With fee	56 (25.3) 30 of these are PROMIS
Activity required (e.g. registering on a website or contacting corresponding authors for permission)	54 (24.4)
Pending	3 (1.4)
License declined	1 (0.5)
No information	25 (11.3)

N = 221. Total numbers are displayed as well as corresponding relative numbers in brackets ().

Case Study: Identified challenges in ICHOM atrial fibrillation set:
(i) lack of German validated translations for two key measures
(ii) a declined license for one questionnaire
(ii) a high fee for another questionnaire

Strategies to overcome these obstacles:
(i) searching for similar instruments therefore adapting the set
(ii) performing a translation and subsequent validation ourselves
(iii) implementing a reduced set

Conclusions

This study provides first insights into challenges of implementing ICHOM sets from a technology provider's point of view. **Licensing and language barriers were identified as major obstacles for standardized outcome set implementation.** Besides serving as important groundwork for developing strategies to overcome these difficulties in implementation, the **results can be beneficial for the future development and revision of standardized sets.**
ICHOM sets could have an even bigger international impact in establishing outcome measurement in clinical practice if these difficulties are overcome, for example by including commonly used PROMs with a high methodological standard that avoid the obstacles identified here.

Haneke, H., haneke@heartbeat-med.de
Nickel, S., nickel@heartbeat-med.de

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Boston | USA

We have no conflicts of interests to declare.