

FAQ to guide ICHOM clients in the translation of

ICHOM Sets of patient-centered outcome measures

This document is a proposal of FAQ to be added on ICHOM's website, at ICHOM's request.

→ location of this FAQ and final format to be validated with ICON Language Services and Mapi Research Trust before online publication.

The following content has been validated by ICON Language Services and Mapi Research Trust, and developed after the "ICHOM Sets of patient-centered outcome measures translation" Word document.

ICHOM has developed a variety of reference guides (sets) covering different conditions and specific patient populations. Each set includes an introduction specifying the context, working group members and supporting organizations, a list of sets, follow-up timelines, the list of collecting Clinical Outcome Assessments (COAs), ICHOM framework for implementation of the Set as well as a comprehensive data dictionary and scoring guides in the Appendix.

Some COAs might not be available in your language(s) of interest. This FAQ explains how to request translations and linguistic validation by ICON Language Services in collaboration with Mapi Research Trust, the leading curator and license distributor of over 670 COAs.

1. How to use individual COAs listed in our Sets?

In order to be able to use a COA, you may sign a **licensing agreement** with the copyright holder:

- a. As the leading curator and license distributor of over 670 COAs, Mapi Research Trust can manage the licensing process for any COAs (distributed by Mapi Research Trust or not)
- b. Or you can choose to process the licensing agreements directly with each COA copyright owner.

The licensing agreement ensures respect of copyright ownership and conditions of use, as well as proper use of the official COA versions (e.g. respect of the measurement properties) as well as the validity of derivative works (e.g. translations, electronic versions).

2. How to request the translation of an ICHOM Set or a specific COA?

- a. In order to translate an ICOM Set or a single COA, you must first request permission of use and sign a **licensing agreement** with:
 - ICHOM, as the copyright owner for the Set
 - the copyright holders of each COA included in the relevant reference guide. Mapi Research Trust can manage for you the licensing process for any COAs (distributed by Mapi Research Trust or not).
 - Make a request on ePROVIDE™, the online COA platform developed by Mapi Research Trust: <https://eprovide.mapi-trust.org/> (see instructions at the end of the FAQ).

- b. Then, once the license is granted, you can request a translation and linguistic validation:
 - We recommend you to work with ICON Language Service because of their certified linguistic validation process. ICON Language Services works in collaboration with Mapi Research Trust who can collect your translation request along with your license request.
 - ➔ Request translations on: <https://eprovide.mapi-trust.org/> (see instructions at the end of the FAQ).

3. How can ICON Language Services ensure certified COA translations?

- a. Different methodologies can be considered for linguistic validation of COAs:
 - Forward and backward translation steps only
 - Forward and backward translation steps, and clinician's review, proofreading-finalisation
 - Forward and backward translation steps, cognitive interviewers, proofreading-finalisation
- b. Each COA is costed individually. If, for example, an ICHOM set includes 3 PROM questionnaires, then the translation costs will apply for each COA. To request a quote, please visit <https://eprovide.mapi-trust.org/> and follow the instructions at the end of the FAQ.
- c. Costs may vary according to the languages and the methodological options (and complexity to solicit cognitive interviewers and/or clinicians for a specific disease).
- d. Please note that a few COA developers work with their own translator providers instead of ICON Language Services. In this case, Mapi Research Trust can coordinate the translation with the developer but the certification of this translation cannot be guaranteed.

4. How to reach out to Mapi Research Trust for licensing agreements and translations in collaboration with ICON Language Services?

- a. Go to the ePROVIDE™ platform: <https://eprovide.mapi-trust.org/>
- b. Click on "Submit a request". Submitting a quote request is completely free of charge and will ensure an optimized service. It does not commit to purchasing a questionnaire.
- c. If you haven't registered yet, you'll be asked to sign up for free.
- d. Complete the request form. You may attach documents if need be.
- e. For any further help, please contact: eprovidetechnicalsupport@mapi-trust.org

About Mapi Research Trust

[Mapi Research Trust](#) is a non-profit organization that promotes the use of Clinical Outcomes Assessments (COAs) in health research and practice and encourages exchanges of Patient-Centered Outcomes and COA information among academics, pharmaceutical companies, health care organizations and health authorities. With the web-based platform [ePROVIDE™](#) that includes the databases PROQOLID™, PROLABELS™, and PROINSIGHT™, Mapi Research Trust has become the preeminent source of reliable, up-to-date and comprehensive information about COAs.

About ICON

[ICON plc](#) is a world-leading healthcare intelligence and clinical research organisation. From molecule to medicine, we advance clinical research providing outsourced services to pharmaceutical, biotechnology, medical device and government and public health organisations. We develop new innovations, drive emerging therapies forward and improve patient lives. With headquarters in Dublin, Ireland, ICON employed approximately 38,330 employees in 142 locations in 53 countries as at December 31, 2021.

ICON is the only full-service, ISO 17100 and ISO 9001 certified translation provider within a global top-tier CRO, offering total harmonisation between product development processes and translation methodology. We have flexible scalability with a global network of over 2,500 trusted medical and clinical translators, including linguistic validation specialists, covering over 300 languages across every location where clinical research takes place. For further information about ICON Language Services, visit: <https://www.iconplc.com/solutions/language-services>