Mapi™
Research Trust

Supporting developers and copyright holders with the strategic and operational management of their Clinical Outcome Assessments (COAs)

PROTECT PROMOTE

Assure Integrity of Clinical Outcome Assessments   Increase Awareness of Clinical Outcome Assessments

Enhancing the use of COAs in health research and practice

Mapi Research Trust is a non-profit organization founded with the mission to **facilitate access to information in the field of Clinical Outcomes Assessments (COAs)** for the entire scientific community. Our services cover the needs of COA users, COA developers and copyright holders alike.

By promoting the use of COAs (PRO, ObsRo, ClinRo, PerfO) in health research and practice, Mapi Research Trust ultimately aims at **improving patients' quality of life by making their voice heard.**

Pioneers in supporting COA developers and copyright holders

With 30 years of experience in the field of COAs, Mapi Research Trust has developed **comprehensive expertise in the strategic and operational management of COAs and derivatives:**

- Protection
- Curation
- Promotion

Acting on behalf of developers and copyright holders according to their own terms, we adapt our services to the **specificities of any profiles** who developed, own and/or control one or more COAs:

- Scientific experts (individual author or group of developers)
- Universities
- Pharmaceutical companies
- Publishers
- National and international disease specific societies and organizations, charities

670+	200+	30+
COAs distributed by Mapi Research Trust	Developers/copyright holders who trust us with their COAs	Years of experience in the COA field

See the catalogue of COAs distributed by Mapi Research Trust

COA protection

Intellectual property and copyright protection aim to preserve the **integrity of the COAs.**

However, copyright is not always enough to protect COAs. To **prevent misuse or abuse,** it must be supplemented with access to critical information on COAs, such as copyright ownership, conditions of use, availability of translations and eCOAs*, validation status, scoring guidance and other material that are paramount to the proper use of COAs.

*Anfray et al., Health and Quality of Life Outcomes (2018) 16:224

Protection of the copyright and authorship

- Due diligence for copyright ownership
- Recommendations for publication based on good practices
- Licensing conditions set according to the developers' and copyright holders' terms
- Copyright watch

Protection of the questionnaire's integrity and quality control

- Management of derivative versions: translations, electronic versions, adaptations

Management of requests for information and use

- International distribution and licensing process
- Monitored use of COAs
- Support provided to users from COA licensing to implementation
- Invoicing and royalty fees collection

"Mapi [Research Trust] has been a great collaborator with me for translation and distribution of the NPI. Their approach to maintaining the integrity of the instrument through the translation process is impressive and has made them my preferred partner for NPI translation and international management."

Jeffrey Cummings, developer of the Neuropsychiatric Inventory (NPI).

"GL Assessment has been collaborating successfully with the Mapi Research Trust for more than ten years. GL decided to contract with [MRT] in order to utilize their skills and experience in both distributing but also translating and validating GL Assessment's PRO questionnaires of which the HADS has been very successful worldwide and is now available in 115 languages thanks to the excellent services provided by Mapi. Mapi Research Trust ensure very robust User Agreements are used with all licensees to provide extensive protection of a publisher's intellectual property which we at GL Assessment believe to be of paramount importance."

Patrick McGuire, GL Education Group, publisher of the HADS, GHQ and PI-ED.

COA curation

The success of patient-centered outcomes research depends a great deal on the **choice of appropriate COAs,** for their measurement properties (domains measured, populations, therapeutic areas) and for their validity (official versions).

The **centralization of comprehensive, up-to-date and reliable information on original and derivative versions** is therefore critical for the entire scientific community.

COA information watch

- Collection, centralization and updates on all information related to the COAs

Support tools for COA users

- User manual, including scoring instructions
- Guidance for electronic implementation
- Guidance for linguistic validation
- COA specific FAQs

"*I have appreciated the way that Mapi [Research Trust] staff brings questions to my attention that potential users of the measure have raised. There is a commitment by MAPI staff in conducting all their activities the right way.*"

Steven Zarit, developer of the Zarit Burden Interview (ZBI).

"*During the past 15 years I have had the pleasure of working with the Mapi Research Trust on the international distribution of the Pediatric Quality of Life Inventory™ (PedsQL™) instruments. Mapi's commitment to excellence, including all aspects of the users' experience, has been superior [and their] collaborative work style with developers has always been a strong point.*"

Jim Varni, developer of the PedsQL™.

COA promotion

Benefit from the visibility of the leader in the field of COAs!

Driven by the mission to facilitate access to information on COAs, Mapi Research Trust has developed the **ePROVIDE™ platform** – interconnecting PROQOLID™, PROLABELS™ and PROINSIGHT™ databases, which has become the **preeminent source of reliable, up-to-date and comprehensive information about COAs.**

PROQOLID™: COA webpage

- Facilitated access to COAs and enhanced use
- 80,000+ ePROVIDE™ users
- 45,000 visits per month on ePROVIDE™
- 15,000+ requests per year
- Specific SEO strategy for COAs distributed by Mapi Research Trust

Extra promotional activities*

- News on Mapi Research Trust's website
- Dedicated posts on social media
- Webinars

*Conditions to be discussed with our team.

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"Finally, my measure has had far wider distribution that would have been possible had I managed it myself."
Steven Zarit, developer of the Zarit Burden Interview (ZBI).

"I am very happy with Mapi [Research Trust] and my involvement with them with PDSS, PDSS-2, NMSS, NMSQuest and now KPP scale. They are a world class professional organization devoted to measurement in clinical practice, a crucial area of clinical research and translation."
Ray Chaudhuri, developer of the PDSS-2.

"I began cooperating with Mapi Research Trust many years ago when standardized and authorized translations of the ESS were needed in many different languages. In more recent years I have engaged Mapi Research Trust as my agents for managing the use of the ESS, worldwide. I can highly recommend their services to anyone who is a similar situation to me."
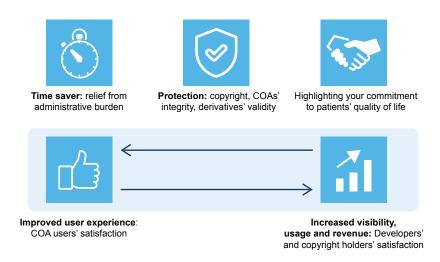**Murray Johns, developer of the ESS.**

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Our commitment to you

- **Dedicated team and single point of contact**
- **Reports and dashboards**
  - COA use
  - Derivative works
    - COA upgrade and versioning
    - Translations and e-versions
- **Author's portal in PROQOLID™** monitoring COA activity and administrative documents
- **Governance meetings and business reviews**
- **Management of royalty fees** and fiscal declaration, when applicable
- **Satisfaction follow up**

Your benefits

Time saver: relief from administrative burden

Protection: copyright, COAs' integrity, derivatives' validity

Highlighting your commitment to patients' quality of life

Improved user experience: COA users' satisfaction

Increased visibility, usage and revenue: Developers' and copyright holders' satisfaction

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"*The services provided by the MAPI Research Trust have been invaluable to me. The staff at MAPI has been a pleasure to work with - they are much better organized than I am, and have saved me many hours.*"

Albert Wu, developer of the MOSHIV.

"*The services of the Mapi Research Trust are pivotal for the distribution to companies and clinical research groups. Mapi is accurate, fast and reliable in its services.*"

Thys van der Molen, developer of the BHQ, CCQ, ICQ.
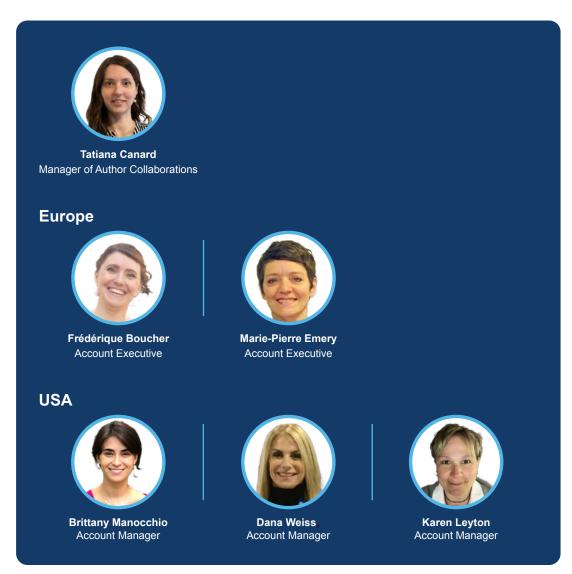
Let's discuss your challenges

Would you like to learn more on how we can help you with your COAs?

Please contact:

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Our team

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Mapi Research Trust

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Distribution	Protection
Curation	**Promotion**

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