

INFORMATION NOTE

PRO-MEASURE Study

Dear participant,

You are invited to participate in the online PRO-Measure Study. This information note aims to answer any questions you may have regarding your participation. If you have further questions, please contact:
astrid.chevance@aphp.fr

What is this study?

This study aims to understand how researchers select patient-reported outcome measures (PROMs) to measure mental health outcomes in their study.

This research is part of a broader project, funded by the Wellcome (C-013403). It aims to develop an open-access platform providing a living synthesis of evidence on the measurement properties of PROMs for the research community.

This research is led by :

1. Dr Astrid Chevance, Associate Professor of Public Health, Université Paris Cité, France
2. Karolin Krause, Researcher, Centre for Research in Epidemiology and Statistics, France
3. Corentin Gosling, Associate Professor of Psychology at Université Paris Nanterre, France
4. Dr Suneeta Monga, Professor of Psychiatry, University of Toronto, Toronto, Canada.

Why have I been invited to take part?

You are eligible to participate if:

- You professionally contribute in research (e.g., junior or senior researchers, research assistant, PhD student)
- Have experience selecting or using PROMs to measure mental health in research studies.

What does my participation involve?

If you agree to take part, you will be asked to complete around 25 close-ended questions for an approximative duration of 10 to 15 minutes.

The survey asks you to reflect on the most recent study in which you selected PROMs to measure mental health.

Participation is entirely voluntary. You can decline to participate without justification and any consequences. You are free to stop the survey at any time without giving a reason.

What are the expected risks or benefits?

There are no anticipated risks or benefits associated with taking part in this study beyond the time required to complete the survey.

How will the data be collected and used?

Participation is entirely confidential. Personal data that will be collected as part of the study include: gender, and professional settings. At the end of the questionnaire, you can opt to share your email address if you like to contribute to the development of the platform or to be kept informed on its development.

Data collection is carried out by IPSOS. Data will be analysed by IPSOS and by Dr Astrid Chevance at the CRESS, Inserm UMR1153, Université Paris Cité, APHP, France. The results will be used for academic publications and scientific presentations only.

How can you exercise your rights?

You will have the right to access, rectify, restrict, delete or object to the processing of your email information to the IPSOS Data Protection Officer contact: survey@ipsosresearch.com. The information you provide will be treated in accordance with the European General Data Protection Regulation (GDPR): <https://cdn.ipsosinteractive.com/deploy/i-say/ppamp/en-us.html>. Once data collection is complete and the survey has closed, you can contact the principal investigator, Dr Astrid Chevance: astrid.chevance@aphp.fr or the APHP Data Protection Officer : protection.donnees.dsi@aphp.fr to request your email address be deleted. Your email address will automatically be deleted two years after the end of the study.

If you believe, after contacting us or IPSOS, that your data protection rights (“Informatique et Libertés”) are not being respected, you may lodge a complaint with the CNIL (more information at www.cnil.fr), online or by post at: CNIL – 3 Place de Fontenoy – TSA 80715 – 75334 PARIS CEDEX 07

Thank you for considering taking part in this research. Your contribution is valuable in helping to improve how mental health outcomes are measured and used in research.