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SKEZI

PARTNERSHIP

Press Release

July 5th, 2022

SKEZI and Mapi Research Trust to partner in obtaining and sharing of patient health data

SKEZI, the French data collection software developed by AP-HP (The Greater Paris University Hospital), and Mapi Research Trust, the leading database of patient questionnaires, have today announced a partnership that will better enable the obtaining and sharing of health data directly from patients for use in clinical research and routine care settings.

As part of the partnership, SKEZI's users will have access to the PROQOLID™ database, developed by Mapi Research Trust, thereby allowing them to select the most appropriate questionnaires to their work among the 5,000 questionnaires fully described. Mapi Research Trust will provide its academic research clients and questionnaire author partners with privileged access to SKEZI software, a French proprietary and secure solution, to collect data reported by patients and enrich their research work. As a result of this collaboration, more and better-quality data will be available to research and healthcare professionals.

"Health data is a critical component in the competitiveness and attractiveness of innovative solutions developed in France. Biomedical Research generates a huge amount of such data. The demand for data from patients, such as Patient-Reported Outcomes (PRO) is constantly increasing in both clinical research and routine care. Too few technological solutions allow for simple and reliable collection of health data directly from patients. This partnership will ensure important and relevant patient data is available to those clinical research and healthcare professionals who need it to progress their work," reports Dr. Jean-Philippe Bertocchio, COO of SKEZI and Laureate of the French National Academy of Medicine.

"For more than 30 years, our mission has been to facilitate access to questionnaires focused on the quality of life of patients, known as Clinical Outcome Assessments (COAs), including Patient-Reported Outcomes, and to support the authors of questionnaires through the distribution and centralization of reliable, relevant and exhaustive information on their questionnaires." said Sonia Bothorel, Managing Director at Mapi Research Trust. "We are therefore delighted to support the development of the SKEZI software project which is in line with Mapi Research Trust's mission."

Mapi Research Trust and SKEZI are working together to develop and secure the use of patient-reported data in clinical research and routine care. The two entities have developed a partnership to accelerate and ease the use of data reported by and for the patients.

About SKEZI (<https://skezi.eu>)

SKEZI is a French public-private partnership founded in 2020, combining technical software excellence with the expertise of AP-HP and the academic excellence of the Université Paris-Cité. SKEZI believes that enhancing the voice of

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patients, caregivers and careers will improve future health. SKEZI's mission is to develop the most efficient software to facilitate and accelerate the collection of data reported by patients in clinical research and routine care. Originating from AP-HP and Université Paris-Cité, 100% made in France, SKEZI software has been used by nearly 200 researchers and more than 58,000 patients and has helped advance medical knowledge through the publication of numerous scientific studies.

About Mapi Research Trust (<https://mapi-trust.org>)

Mapi Research Trust (MRT) is a non-profit organization created in 2004, and the author and curator of the PROQOLID™ database listing more than 5,000 patient questionnaires (COAs) and their translations, providing licenses for their use and distributing over 670 COAs on behalf of their authors. MRT's mission is to improve patients' quality of life by providing researchers and scientific experts with easy and rapid access to comprehensive and reliable information on COAs. MRT facilitates access to COAs by providing a centralized distribution system and by continuously and systematically updating COA information in PROQOLID™.

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