

LETTER TO THE IDEA-FAST STUDY PARTICIPANTS

DEAR STUDY PARTICIPANTS,

We would like to once again express our sincere gratitude for your participation in the **IDEA-FAST** (“Identifying Digital Endpoints to Assess Fatigue, Sleep, and Activities of Daily Living in Neurodegenerative Disorders and Immune-Mediated Inflammatory Diseases”) **Clinical Observation Study**. Thanks to your commitment, we were able to collect valuable data that contributes to research on fatigue associated with Neurodegenerative and Immune-Mediated Inflammatory Diseases, as well as create one of the world’s largest combined clinical and digital datasets for future research.

So, a really huge **THANK YOU** ...
... for the time you dedicated to the study
... for the trips you were willing to take
... for sending bulky packages containing sensors back to us
... for the technical hurdles you took into account and overcame (at least in most of the cases)
... for your perseverance in following the study for 6 full months.

Some of you accepted our invitation to the Final Conference on 17 June 2026 in Hamburg, or participated online. For everyone who was not able to join but is still interested in learning more about what was discussed and shared, you can read our Blog, which provides a summary of the “[Key lessons from the IDEA-FAST Final Conference](#)”.

Below you can find a very brief summary of the central key lessons from the IDEA-FAST project:

What did the research achieve?

Better ways to study fatigue - We've identified practical lessons and insights that will improve how research into fatigue is carried out. From effective timings and insights into the devices to the required support and refining analysis processes, our learning will inform future research design.

Patterns associated with fatigue - So far, a digital biomarker that accurately measures fatigue across the different conditions has not been identified. However, there are some indications of weak signals that are associated with fatigue that can be measured digitally, for example changes in circadian rhythm. Further exploration is needed to understand if these signals can be used to study fatigue.

Valuable data about fatigue - IDEA-FAST created one of Europe's largest datasets on fatigue, sleep and daily functioning in long-term conditions. This dataset has the potential to help researchers uncover more about this understudied symptom.

Collaboration and shared learning - IDEA-FAST brought together people with a range of expertise from different countries and different conditions. Working together is critical to ensure research is as impactful and effective as possible. The partnerships and learning shared within IDEA-FAST will have ongoing impact beyond this project.

The IDEA-FAST project has created a vast and valuable dataset. Researchers are only just 'scratching the surface' of what can be learned. Making the data available to other researchers through fair, well-governed and transparent processes could encourage and accelerate research and deepen our understanding of fatigue and the different conditions.

Work is currently underway to develop the data sharing process, including anonymising the data. This step ensures that individuals cannot be identified from their data. If you did not consent to your data being shared, it will not be included in the shared dataset.

We are also establishing a Data Access Committee (DAC). The DAC will consist of academic and industry partners, as well as people with lived experience of the conditions. It will be responsible for making decisions about the sharing of the data, ensuring that it will be used in a fair and ethical way.

Further information and updates on the data release process will be shared on our website at <https://idea-fast.eu/>.

THANK YOU ON BEHALF OF THE IDEA-FAST CONSORTIUM!



The IDEA-FAST Consortium at the 2026 General Assembly.