

IDEA
FAST

 innovative
health
initiative

efpia

IDEA-FAST FINAL CONFERENCE

17 June 2026

8:30 - 17:30

 *Erikahaus | Hamburg,
Germany*

 *Online*



Co-funded by
the European Union

IDEA FAST



Identifying **D**igital **E**ndpoints to **A**ssess **F**atigue,
Sleep and **a**ctivities in daily living in
Neurodegenerative disorders and Immune-
mediated inflammatory diseases

Welcome to the **IDEA-FAST Final Conference!** This event is an opportunity to share key project results, reflect on our journey, and discuss how digital endpoints can shape the future of clinical research and care.

Through presentations, panel discussions, and an interactive exhibition area, we will explore what we have learned so far and what comes next. We look forward to you joining us in Hamburg or online.

Wan-Fai Ng | University of Newcastle
IDEA-FAST Scientific Coordinator

Walter Maetzler | University Hospital Schleswig-Holstein
IDEA-FAST Scientific Co-coordinator

Nikolay Manyakov | Johnson & Johnson
IDEA-FAST EFPIA Project Lead

Geert Van Gassen | Takeda Pharmaceuticals
IDEA-FAST EFPIA Project Co-Lead

David Wenn | iXscient Ltd
IDEA-FAST Project Manager

Mike Jackson | iXscient Ltd
IDEA-FAST Project Manager

...and the IDEA-FAST Consortium

IDEA-FAST

KEY PROJECT FACTS

2019 - 2026 Project Duration

€42 Million Project Funding

48 Consortium Partners

Coordinator: University of
Newcastle Upon Tyne

Industry Lead: Johnson &
Johnson

ABOUT IDEA-FAST

IDEA-FAST has received funding from the **Innovative Medicines Initiative 2 Joint Undertaking (JU)** under grant agreement No 853981. This Joint Undertaking receives support from the European Union's Horizon 2020 research and innovation program, EFPIA and PARKINSON'S UK.

Objectives:

1

Identify digital endpoints for the assessment of fatigue and sleep disturbances, as well as to investigate digital correlates of selected activities of daily life in patients with Immune Mediated Inflammatory Diseases and Neurodegenerative Diseases, and seek scientific/qualification advice from the EMA on such digital endpoints.

2

Ensure long-term impact by developing a large, real-world digital dataset of biophysiological, neurocognitive, personal, environmental, behavioral, and socialisation observations, along with comprehensive clinical data and data analytics to support future research and drug development.

WHY ATTEND THE IDEA-FAST FINAL CONFERENCE?

Whether you are working in research, healthcare, industry, policy, or digital innovation, the IDEA-FAST Final Conference offers a unique opportunity to engage with one of Europe's most ambitious projects on digital endpoints for fatigue, sleep disturbances, and daily functioning.

Join us to explore how real-world data collected through wearables, monitoring devices, and apps can transform the way symptoms are measured, understand the challenges and lessons from running a large-scale, multi-country digital study, and discover how these insights can shape the future of clinical trials and patient care.

At the conference you will:

- **Discover** key results from a large-scale European study on digital endpoints for fatigue, sleep disturbances, and daily functioning
- **Learn** how digital technologies can capture real-world patient experience more accurately
- **Explore** the development and future potential of composite digital endpoints in clinical research
- **Gain** insights into challenges, lessons learned, and best practices from a multi-country study
- See how **patient input** has shaped the research and outcomes
- **Engage** with experts across research, healthcare, industry, and policy
- **Experience** live demonstrations and interactive showcases of digital tools

**Be part of the conversation on the future of digital
health and clinical trials!**

CONFERENCE COMMUNICATIONS


Heads up

We will be taking photos and videos of the sessions and attendees during the conference events, which we will use for communication and dissemination purposes on our official social media channels. **By attending the conference, you agree to be included in these materials.**

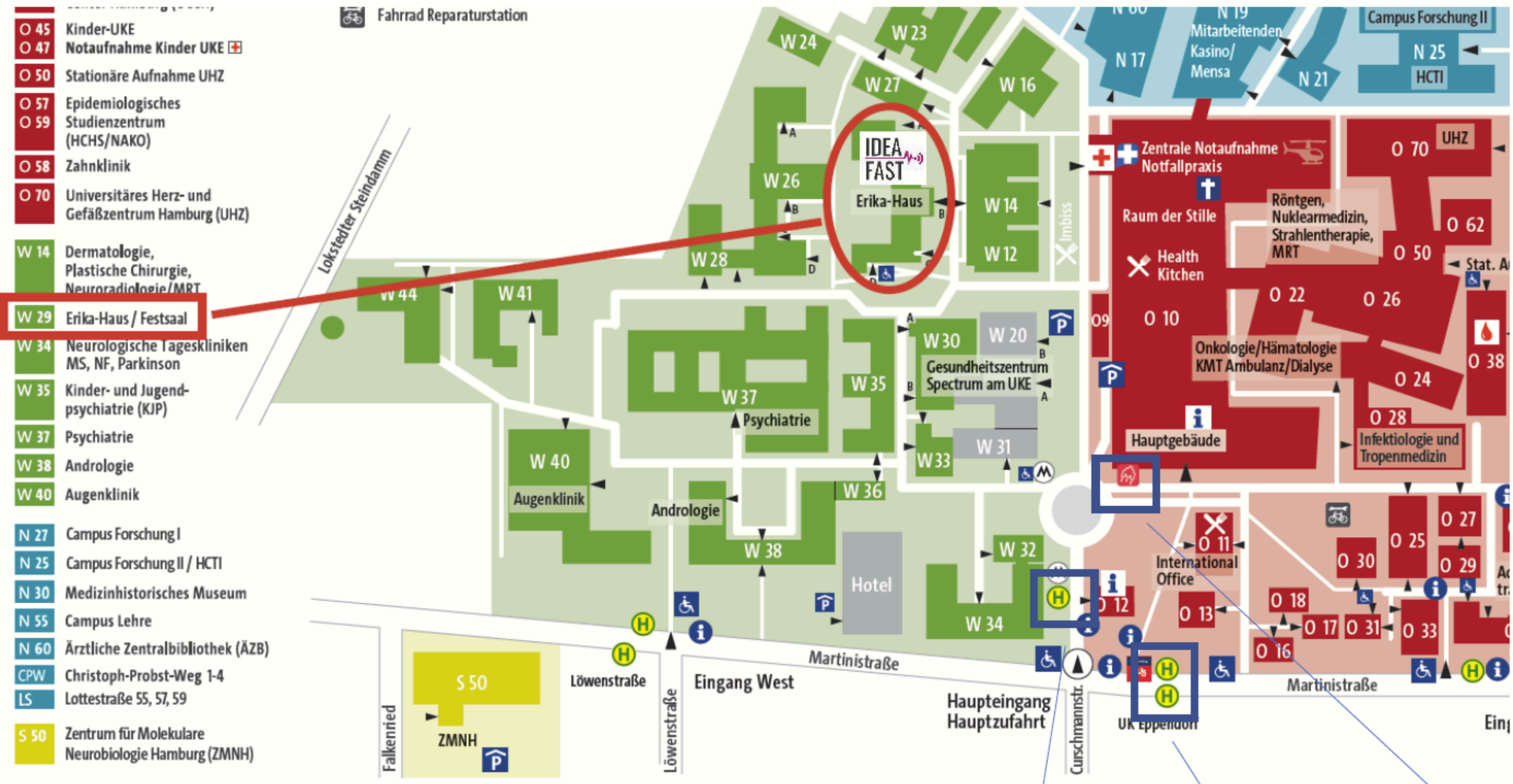
If you do not wish to be included under any circumstances, reach out to us at idea-fast@empirica.com. We will do our best to accommodate your request.



CONFERENCE PROGRAMME

Welcome and Setting the Scene			Theme 2: People and Participants What Does Patient-Centered Digital Research Really Look Like?		
08:45-09:00	Registration and Coffee		11:10-11:30	Patient Centered by Design: How Patients Shaped IDEA-FAST	Patient Involvement and Engagement Group Laura Jacobs, <i>Parkinson's UK</i>
09:00-09:30	Opening and Welcome	Wan-Fai Ng, <i>University of Newcastle</i> Nikolay Manyakov, <i>Johnson & Johnson</i>	11:30-12:15	Panel Discussion: Living Patient-Centered Research, Voices from IDEA-FAST Participants	IDEA-FAST Study Participants Moderator: Corina and Walter Maetzler
	Introduction to the IDEA-FAST Project	Wan-Fai Ng	12:15-13:30	Lunch and Interactive Poster Area	
09:30-10:10	Setting the Scene: Why Fatigue Matters?		Theme 3: Data Analysis Making Sense of Complexity		
	Patient Perspective	Cate Titterton, <i>Patient Specialist</i>	13:10-13:20	Understanding Fatigue: Conceptual Challenges	Stefan Avey, <i>Johnson & Johnson</i>
	Clinician Perspective	Andrea Pilotto, <i>University of Brescia</i>	13:20-13:30	Extracting Digital Measures from Multi-Modal Sensor Data	Teemu Ahmaniemi, <i>VTT</i> Christoph Kanzler, <i>BioGen</i>
	Societal Perspective	Prof. Anne Letsch, <i>Kiel University</i>	13:30-14:00	Current Results of the Clinical Observational Study and Lessons Learned	Clémence Pinaud, <i>Let it Care</i>
	Industry Perspective	Sebastian Holst, <i>Roche</i>	14:00-14:35	Panel Discussion: Interpreting Results	Nikolay Manyakov, Wan-Fai Ng, Clémence Pinaud, Stefan Avey; Moderator: Alexandra Prodan
Theme 1: Running a Large Digital Biomarker Study Lessons Learned from the Clinical Observation Study			14:35-14:50	Coffee Break	
			Theme 4: From Research to Future Use Achievements and the Future Impact of IDEA-FAST		
10:10-10:30	KEYNOTE: Digital Biomarkers Transforming Disease Measurement in Neurodegenerative and Inflammatory Diseases	Lucy Cesnakova, <i>Digital Medicine Society</i>			
10:30-10:50	Overview of the IDEA-FAST Feasibility and Clinical Observation Studies: Lessons Learned	Walter Maetzler, <i>University Hospital Schleswig-Holstein</i>	14:50-15:30	Panel Discussion: From Project to Paradigm Shift, the Future We Enabled	Cate Titterton, Fred Baribaud, Nick Taptiklis, Philip Gribbon; <i>Lucy Cesnakova</i> Moderator: Wan-Fai Ng
10:50-11:10	Coffee Break and Opening the Interactive Area		15:30-15:40	Closing the Conference	
			15:40 Onwards	Open Interactive Area and Post-Conference Networking	

VENUE MAP



POSTERS

The CANTAB APP: Supporting Site and Participant Engagement

Freyja McClenahan | Cambridge Cognition

Wildkey Social: Insights from Privacy-Preserving Smartphone Measures in ND and IMID

Tiago Guerreiro | FCIências.ID

Test-Retest Reliability and Validity of the Digit Symbol Substitution Task in Parkinson's and Huntington's Disease

Martina De Lillo | Cambridge Cognition

Association of Mood and Gait Parameters in Healthy Adults: An Ecological Momentary Assessment Study

Lotta Wöbke | University Hospital Schleswig-Holstein

Factors Influencing Adherence in a Remote Observational Study with Multiple Immunology and Neurology Disease Cohorts

Nick Taptiklis | Cambridge Cognition

Data Management for Multi-Organization Research: The IDEA-FAST Data Management Platform

Shuojie Fu | Imperial College London

How Do People with ND and IMID Type? Insights into Typing Behaviours Across Neurodegenerative and Immune-Mediated Conditions

Diana Pimentel | FCIências.ID

Brief Digital Cognitive Assessment in Immune-Mediated Inflammatory Diseases (IMIDs): Findings from a Large Longitudinal Multi-Cohort Study

Alex Kaula | Cambridge Cognition

Temporal Network Properties of Self-Reported Fatigue and Mood, Activity and Pain Variables in Immune-Mediated Inflammatory Diseases

Francesca Cormack | Cambridge Cognition

Gait Parameters as Objective Markers of Fatigue? An Investigation of the Correlation Between Gait Parameters and the FACIT-F Questionnaire

Maribel Maruska | University Hospital Schleswig-Holstein

Digitalizing Fatigue: Revisiting the Literature to Innovate

Leonor Correia Guedes | Gulbenkian Institute for Molecular Medicine

A Multi-Agent QA System for Verifiable Clinical Study Data Analysis

Siyao Wang | Imperial College London



INTERACTIVE AREA

VTT Bedsensor

The VTT bed sensor is a device placed under or on a bed that automatically detects when someone is in bed, moving, or has gotten up.



VitalPatch

The VitalPatch is a small wearable sensor worn on the chest that continuously measures things like heart rate, breathing rate, activity, and body posture during daily life.



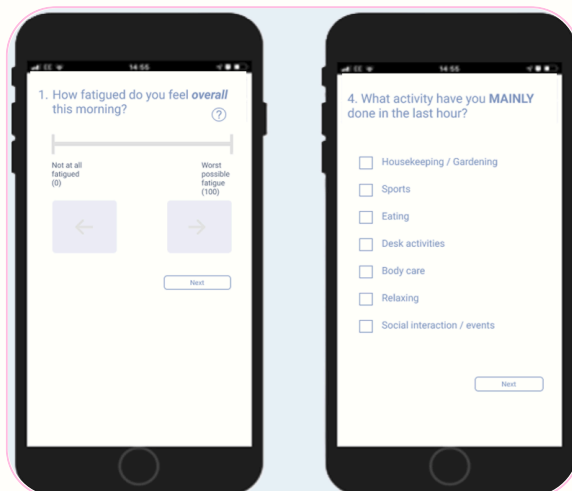
MoveMonitor

The MoveMonitor is an inertial sensing unit, placed in the lower back, that is designed for activity tracking, classification, and energy expenditure assessment.



CANTAB App

CANTAB is an iPad mobile application that is used once per participant on their first visit to capture a baseline assessment a suite of cognitive assessments.



KEYNOTE SPEECH

Digital Biomarkers Transforming Disease Measurement in Neurodegenerative and Inflammatory Diseases

Lucy Cesnakova

Associate Program Director
Digital Medicine Society



Lucy Cesnakova is an Associate Program Director at the Digital Medicine Society (DiMe), where she leads initiatives focused on digital measurements and digital endpoints for clinical research. With a background spanning software product development, digital biomarker innovation, and evidence generation, she has led the development and evaluation of digital measures across multiple therapeutic areas, including dermatology, chronic cough, pain, neurology, and gastrointestinal diseases.

This presentation explores how digital biomarkers are transforming disease measurement in neurodegenerative and immune-mediated inflammatory diseases by moving beyond episodic clinic visits to continuous, real-world monitoring. Using examples from Parkinson's disease, Huntington's disease, rheumatoid arthritis, lupus, Sjögren's syndrome, and inflammatory bowel disease, it highlights how wearable and connected technologies can capture meaningful, function-first and disease-agnostic aspects of patient's conditions, predict disease activity, and enable more sensitive, patient-centered endpoints for research and clinical care.

SETTING THE SCENE

SPEAKERS

Wan-Fai Ng

Scientific Project Coordinator

Visiting Professor of Rheumatology
Newcastle University



Wan-Fai Ng is the Director of the Clinical Research Facility at Newcastle University. He is a consultant rheumatologist with globally recognized expertise and is a key opinion leader in Sjögren's syndrome and fatigue research. He has led numerous early-phase clinical trials and experimental medicine studies. Prof. Ng has published extensively in his field, with over 170 peer-reviewed articles, seven book chapters, and other notable contributions to the literature on Sjögren's syndrome.

Nikolay Manyakov

EFPIA Industry Lead

Senior Director Data Science
Johnson & Johnson



Nikolay Manyakov is a Senior Director in the Data Science and Digital Health organization at Johnson & Johnson's Innovative Medicine Research and Development, based in Beerse, Belgium. He holds a PhD in Computer Science, a PhD in Biomedical Sciences, and an MSc in Mathematics. Before joining Johnson & Johnson in 2013, he held various academic roles, focusing on machine learning, data science, and biosignal processing.

Anne Letsch

Head Medical Oncology and Cancer
Center
University Hospital Schleswig-Holstein



Prof. Anne Letsch (MD) is a Consultant Medical Oncologist and head of the Cancer Center at the University Hospital Schleswig Holstein, Kiel, Germany. She is Co-Director of the University Cancer Center Schleswig-Holstein (UCCSH). Prof. Letsch specialises in Supportive and Palliative Cancer Care, Tumour-Immunotherapy and the systemic treatment of gynaecological cancers.

SETTING THE SCENE

SPEAKERS

Cate Titterton

PSAB Member

Patient Specialist



Cate Titterton is a veterinary surgeon who lives and works in Northeast England. She was diagnosed with Crohn's Disease at the age of 18, and has suffered with chronic fatigue as part of her disease complex, which still remains a significant challenge. She joined the IDEA-FAST team in February 2020 as a patient advisor aspiring to support their work and improve awareness of the condition amongst clinicians.

Andrea Pilotto

Associate Professor of Neurology
University of Brescia



Andrea Pilotto is Associate Professor in Neurology since 2016 at the University of Brescia and research associate at the Karolinska Institute, Sweden. He developed a focus interest on new biological and digital markers in neurodegenerative disease, he is leading since 2023 the MDS Working group on Digital Technology, since 2024 this vice-chair of the Biomarker working Group of the Italian Society of Neurology, he is author of more than 200 published papers and he is leading different European and Italian Grants focused on advanced markers in neurodegeneration.

Sebastian Holst

Biomarker Experimental Medicine Lead
ROCHE



Sebastian Holst is a Biomarker and Experimental Medicine Leader at Roche, with a primary focus on the design and implementation of biomarkers for clinical trials in Neuroscience. In his work, he integrates physiological and digital measures to better understand how sleep, sleepiness and fatigue modify treatment response in patient populations.

THEME 1

RUNNING A LARGE DIGITAL BIOMARKER STUDY | Lessons Learned From a Large Clinical Observation Study

THE IDEA-FAST Clinical Observation Study (COS) stood at the forefront of the project's goals. The study aimed to analyse the connection between digital and clinical parameters of fatigue and sleep disturbances in neurodegenerative and immune-mediated inflammatory diseases. The COS provided digital tools to record and measure these symptoms directly and thereby more objectively.

In the COS, **1887 participants across 20 sites in Europe were recruited.** IDEA-FAST marks one of the largest clinical wearable sensor studies worldwide, specifically focused on validating digital endpoints across multiple chronic diseases.

Participants were monitored during several testing periods over 6 months using selected digital devices and connected mobile apps. Participants were also able to donate biosamples and were invited to keep a daily diary and answer questionnaires, reporting on their sleep problems and fatigue levels through multimodal measurements.

SPEAKER



Walter Maetzler

Scientific Project Co-Coordinator

Professor of Neurogeriatrics
Deputy Director of Neurology
University Hospital Schleswig-Holstein

Walter Maetzler is a neurologist and a professor of neurogeriatrics at the University Hospital Schleswig-Holstein and Kiel University. The main focus of his research group is developing and validating algorithms that 'translate' human behaviour, as measured by digital tools, into meaningful and interpretable outcome parameters. His group's research work lies at the intersection of neurology, cognition, mobility and daily life function.

THEME 2

PEOPLE AND PARTICIPATION | What Does Patient-Centered Digital Research Really Look Like?

Since the project's conception, patients have been at the forefront and centre of IDEA-FAST. The ultimate goal of this project is to develop measures for fatigue and sleep that are meaningful and relevant to patients' lives. **Patient involvement and engagement are thus embedded in all aspects of our work.** By actively engaging patients in research, the project has leveraged their unique perspectives and experiences to drive impactful outcomes.

The **IDEA-FAST Patient Involvement and Engagement (PIE) Group** comprises a diverse range of stakeholders, including patients, members of patient organizations, researchers, and consortium partners. The group aims to foster open discussions on Patient and Public Involvement and Engagement strategies and issues among consortium partners and external organizations, such as Lupus UK and the European Huntington's Association.

PANEL MODERATOR



Corina Maetzler

PhD Fellow and Research Assistant
University Hospital Schleswig-
Holstein

Corina Maetzler is a PhD fellow and research assistant at the University Hospital Schleswig-Holstein.

In this role, she was responsible for managing the IDEA-FAST Clinical Observational Study, and is currently involved in analyzing the Clinical Observational Study data.

THEME 2

SPEAKERS

Laura Jacobs

PIE Group Coordinator

Research Involvement Manager
Parkinson's UK



Laura Jacobs is Research Involvement Manager at Parkinson's UK. She helps to deliver the charity's Patient and Public Involvement programme, supporting researchers from academia and industry and people affected by Parkinson's to work together to improve Parkinson's research outcomes. She works closely with other charities and organisations to help drive forward patient and public involvement in research.

Heather Hunter

PIE Group Member

Senior Research Physiotherapist
Clinical Ageing Research Unit
Newcastle upon Tyne



Heather Hunter is a research physiotherapist specialising in Neurology and Older People's medicine. She has worked as a researcher on the IDEA-FAST project, recruiting and assessing the Parkinsons' cohort. She is also a member of the PIE group and a patient. She has had Sjogren's for 18 years and experiences fatigue as part of her condition.

THEME 3

DATA ANALYSIS | Making Sense of Complexity

One of the main goals of the IDEA-FAST project is to identify novel digital measures for fatigue and sleep disturbances. To achieve this goal, a large amount of data, including clinical and device data, was analysed.

The COS Data Analysis had two primary goals:

- identifying a digital biomarker of fatigue (primary) as well as daytime sleepiness or sleep quality (secondary)
- evaluating the digital biomarkers by characterizing their behavior in each cohort, reliability, validity, and responsiveness.

SPEAKERS

Stefan Avey

WP7 Co-Lead

Director Data, Science, and AI
Johnson & Johnson



Teemu Ahmaniemi

WP4 Co-Lead

Research Team Leader
VTT

Teemu Ahmaniemi leads the Human Sensing Solutions team in VTT focusing on physiological measurements and signal analysis. He holds a PhD in biomedical engineering and MSc in signal processing. Before joining VTT, he held different positions in Nokia Research Center and GE.

Stefan Avey leads a team of data scientists at Johnson & Johnson Innovative Medicine who are working to measure what matters to patients in clinical trials through the development of novel digital endpoints and biomarkers. He holds a PhD in computational biology and bioinformatics from Yale University and has 9 years of experience working in the Pharmaceutical industry.

THEME 3

SPEAKERS

Christoph Kanzler

WP4 Co-Lead

Lead Machine Learning Scientist
Biogen Ltd



Christoph Kanzler is a Lead Machine Learning Scientist (Associate Director) at Biogen, where he leverages digital health and ML/AI to facilitate drug development in Neurology and Immunology. Christoph holds a PhD in biomedical engineering from ETH Zurich and has over 10 years of combined experience in academia and industry.

Clémence Pinaud

WP7 Co-Lead

Engineer, Applied Mathematics
Let it Care



Clémence Pinaud is an engineer specialized in applied mathematics for healthcare. She worked for several years at Dreem, a start-up dedicated to improving sleep through connected objects, where she led the Algorithms team, focused on the development of digital sleep biomarkers for clinical research. She then joined Lixoft in 2020, when the IMI Idea-Fast project was launched.

THEME 3

PANEL DISCUSSION: Interpreting Results

Wan-Fai Ng

Scientific Project Coordinator

Visiting Professor of Rheumatology
Newcastle University



Stefan Avey

WP7 Co-Lead

Director Data, Science, and AI
Johnson & Johnson

Nikolay Manyakov

EFPIA Industry Lead

Senior Director Data Science
Johnson & Johnson



Clémence Pinaud

WP7 Co-Lead

Engineer, Applied Mathematics
Let it Care

Cate Titterton

PSAB Member

Patient Specialist



Walter Maetzler

Scientific Project Co-Coordinator

Professor of Neurogeriatrics
Deputy Director of Neurology
University Hospital Schleswig-
Holstein

THEME 4

FROM RESEARCH TO FUTURE USE | Achievements and the Future Impact of IDEA-FAST

PANEL DISCUSSION: From Project to Paradigm Shift, the Future We Enabled

Cate Titterton

Patient Specialist



Lucy Cesnakova

Associate Program Director
Digital Medicine Society



Philip Gribbon

Head of Discovery Research
Fraunhofer Hamburg
Director General EU-OPENSREEN

Philip Gribbon is Head of Discovery Research at the Fraunhofer Institute for Translational Medicine and Pharmacology in Hamburg, Germany and Director General of the European Infrastructure for Chemical Biology, EU-OPENSREEN.

Currently Philip coordinates the IDERHA project which is building an EHDS aligned secure processing environment for analysis of health data including RWD. Previously, Philip was Chief Scientific Officer of the European ScreeningPort. Previously, Philip has worked at GSK developing new drug discovery and development workflows and at Pfizer covering multiple therapeutic areas. He has a PhD and undergraduate degrees from Imperial College London and Post-doctoral experience from the University of Manchester.

Philip is highly engaged in open science initiatives and the application of advanced data analysis methods and has > 120 publications. He has served on the Board of the Society for Laboratory Automation and Screening, including as President in 2025.

THEME 4

PANEL DISCUSSION: From Project to Paradigm Shift, the Future We Enabled

Fred Baribaud

Member of the Scientific Advisory Board



Nick Taptiklis

Head of R&D Technology
Cambridge Cognition



Frederic Baribaud is Executive Director and Translational Medicine Head at Beeline Medicines. He is a seasoned R&D leader with over 20 years of progressive responsibility across early translational research, clinical development, and digital innovation. Adept at transforming complex scientific data into compelling narratives, he has successfully built bridges between bench and boardroom by translating biomarkers, pipeline milestones, and collaborative innovation into investor-focused communications.

Nick Taptiklis is Head of R&D at Cambridge Cognition, where he has spent fifteen years translating cognitive neuroscience into scalable digital assessment products. He supported the smartphone-based cognitive assessments used in the IDEA-FAST Clinical Observational Study. His current work areas are the early detection of Alzheimer's disease — including Cambridge Cognition's contribution to the international AD-RIDDLE consortium — and enabling measurement of the cognitive impact of autoimmune disease.

CONSORTIUM PARTNERS



The IDEA-FAST project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No. 853981. This Joint Undertaking receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA and associated partners.



www.ih.europa.eu

PROJECT RESOURCES

Over the years, the IDEA-FAST project has produced a wealth of resources, including deliverables, publications, newsletters, posters, and more, which you can find on our website and Zenodo community.



[Check out the IDEA-FAST Resources Section on our website.](#)



[Check out the IDEA-FAST Zenodo Community.](#)

Learn more about IDEA-FAST and stay updated on our achievements



IDEA-FAST



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