



NEWSLETTER

July
2025

idea-fast.eu

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FOREWORD

The IDEA-FAST project is a 6½-year IMI-2 project (total budget €42 million) that started in November 2019 and is due to end in April 2026.

For patients with chronic neurodegenerative disorders (NDD) and immune-mediated inflammatory diseases (IMID), a key attribute for any successful therapeutic intervention is its ability to improve patients' activities of daily living (ADL) and health-related quality of life (HRQoL). Fatigue and sleep problems are among the most disabling symptoms identified by patients that affect their ADL/HRQoL. Current evaluations of fatigue and sleep problems rely mainly on subjective reports provided by patients, often prone to recall bias, reliability issues, and poor sensitivity to change. It can also be burdensome to patients.

Advances in digital technology, data analytics and wearable devices provide unparalleled opportunities to identify digital correlates of fatigue and sleep problems that are objective, reliable, quantifiable, individualized, can be used semi-continuously over prolonged periods of time in the patients' home environment, and are responsive to day to day variations, and thus potentially more sensitive to change.

The objective of IDEA-FAST is to identify digital endpoints that provide a reliable, objective, and sensitive evaluation of fatigue and sleep problems for the following NDD: Parkinson's disease (PD), Huntington's disease (HD); and the following IMID: Rheumatoid arthritis (RA), systemic lupus erythematosus (SLE), primary Sjögren's syndrome (PSS), and inflammatory bowel disease (IBD).

Our partner, Empirica, which is responsible for overseeing the dissemination and exploitation activities within IDEA-FAST, produces regular newsletters that aim to inform various stakeholders of progress and key developments in the project. The latest newsletter is presented here.

Yours sincerely,

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

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

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IDEA-FAST Project Lead

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David Wenn | iXscient Ltd
IDEA-FAST Project Manager

Mike Jackson | iXscient Ltd
IDEA-FAST Project Manager

CLINICAL OBSERVATIONAL STUDY

As the IDEA-FAST Clinical Observation Study (COS) is slowly approaching its end, our clinical partners are tirelessly working to ensure maximum patient recruitment and a smooth transition to data analysis. Coming off the heels of this year's General Assembly, there have been updates to the status of the project's COS:

The COS recruitment has been continuing steadily, thanks to the strong recruitment strategy that has been implemented, and all mitigation actions undertaken. All 19 sites are still active and recruiting. There has been a substantial improvement in recruitment rates for previously under-recruiting cohorts. As of June 2025, 1,795 participants out of a target of 2,000 (90%) have been recruited.

While the clinical research team is working to reach the 2000 participants goal, the statistics and data management teams are working on cleaning the data and extracting features.



PEOPLE OF IDEA-FAST

Whether it be the project partners and members who work to make IDEA-FAST a reality, or the patients and our advisors who bring their invaluable perspective, our project is the people who are involved in it. We aim to highlight their work and experiences as much as possible.

EARLY CAREER RESEARCHER SPOTLIGHT - INTERVIEW SERIES



Young researchers play a pivotal role in the delivery of the ongoing Clinical Observational Study. In a conversation with Dr. Ekaterina Sorkina, a clinical research fellow in Infectious Diseases at the Newcastle Upon Tyne Royal Victoria Infirmary, we learned more about her outlook on IDEA-FAST.

Read more: emp.onl/r8bom

PEOPLE OF IDEA-FAST

INSIDE THE IDEA-FAST PROJECT: PERSPECTIVES FROM THE PRINCIPAL INVESTIGATOR AT ASOCIACIÓN PARKINSON MADRID

Miriam Grande is a Researcher at the Unidad de Innovación e Investigación at Asociación Parkinson Madrid (APM), with degrees in Physiotherapy and Psychology and experience as a lecturer at the Complutense University of Madrid (UCM).

In the IDEA-FAST project, she serves as the principal investigator at APM, focusing on patients with Parkinson's disease across all aspects of the COS, particularly in participant recruitment and conducting visits. She shared her insights on the IDEA-FAST project and participant recruitment.



Read more: emp.onl/-j0n2

PEOPLE OF IDEA-FAST

REAL WORLD STORIES - ULLI FUNKEN

In our new series titled “Real World Stories”, we will showcase patients’ participation and experience within IDEA-FAST through a set of conversations.

Our first chat is with Ulli Funken, a member of our Patient Specialist Advisory Board. Involved with Parkinson’s UK, he has been part of the IDEA-FAST project for years. He was diagnosed with Parkinson’s Disease almost 20 years ago, and since then has been a fierce advocate and avid participant in clinical trials and projects.



Read more: emp.onl/z-Gjd

PEOPLE OF IDEA-FAST

REAL WORLD STORIES - JORDI CRUZ GOMEZ

In the second instalment of the Real World Stories series, we had a conversation with Jordi Cruz Gomez, a physiotherapist at the Asociación Parkinson Madrid (APM) who also lives with Parkinson's disease himself.

Jordi is currently training to represent Spain in climbing at the 2028 Paralympic Games in Los Angeles. In this interview, he recounts the impact of fatigue and sleep disturbances on daily life and tells us how physical activity - in his case, climbing - has become a powerful strategy to manage both symptoms physically and mentally.



Read more: emp.onl/S09ef

DELIVERABLES

DELIVERABLE 4.5 - Performance assessment of candidate device-specific digital endpoints data – part B

This deliverable aims to perform a first evaluation of the available DHT data in the COS. This includes the evaluation of data availability, coverage of meaningful data, and technical performance characteristics of features derived from the DHTs. In addition, this deliverable reports on a preliminary correlation analysis of features with patient-reported outcome measures.



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IDEA-FAST

Identifying Digital Endpoints to Assess FAatigue, Sleep and acTivities in daily living in Neurodegenerative disorders and Immune-mediated inflammatory diseases.

Grant Agreement No. 853981

WP4 – Device Specific Data Analytics and Performance Assessment

D4.5: Performance assessment of candidate device-specific digital endpoints data – part B

DELIVERABLE 5.8 - DMP V3, with pipelines for integrated analysis

This document presents the changes and improvements made to the IDEA-FAST Data Management Platform (DMP) Version 3. In particular, it introduces significant enhancements in the data management and analytical capabilities of the software as well as key developments to enhance the security posture of the system overall, while maintaining compliance and alignment with external frameworks such as the GDPR.


Full Deliverables are Confidential

DELIVERABLE 9.6 - Interim Sustainability and Exploitation Plan


This interim sustainability and exploitation plan builds on the initial sustainability, exploitation, and socioeconomic impact framework established earlier and outlines strategies to ensure the long-term impact of IDEA-FAST’s outputs beyond the project’s funded period.

The document examines pathways for integrating validated digital biomarkers into clinical research, regulatory submissions, and healthcare applications while considering the maintenance of project-generated datasets and infrastructures. The document also incorporates insights from industry collaborations, regulatory discussions, and stakeholder interviews to provide a comprehensive evaluation of digital biomarker adoption prospects.

The strategies outlined here will inform the final sustainability and exploitation plan, which will be refined based on ongoing stakeholder engagement and emerging developments in digital health technologies.



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 innovative medicines initiative

IDEA-FAST

Identifying Digital Biomarkers to Assess FA-tigue, Sleep and acTivities in daily living in Neurodegenerative disorders and Immune-mediated inflammatory diseases.

Grant Agreement No. 853981

WP9 – Dissemination, Impact, Sustainability and Exploitation

D9.6: Interim Sustainability and Exploitation Plan

Full Deliverable is Confidential

PUBLICATIONS

New publications are continuously on the way. From papers to posters and presentations, there are quite a few new publications where the IDEA-FAST consortium contributed:

Research Article - Association of Real Life Postural Transitions Kinematics with Fatigue in Neurodegenerative and Immune Diseases by Romijnders et al.

Fatigue is a prominent symptom in many diseases and is strongly associated with impaired daily function, but current measurement methods via questionnaires are subjective and imprecise. Wearable sensors provide a method to monitor and evaluate daily activities.

This study aims to quantify the association between kinematic features of sit-to-stand and stand-to-sit transitions and self-reported physical and mental fatigue. Over 4 weeks, participants wore a wearable sensor and reported fatigue levels four times daily. The results of this study are explored in this paper.

npj | digital medicine

Article

Published in partnership with Seoul National University Bundang Hospital



<https://doi.org/10.1038/s41746-024-01386-0>

Association of real life postural transitions kinematics with fatigue in neurodegenerative and immune diseases

 Check for updates

Robbin Romijnders¹✉, Arash Atrsaei², Rana Zia Ur Rehman³, Lea Strehlow¹, Jérôme Massoud¹, Chloe Hinchliffe⁴, Victoria Macrae⁴, Kirsten Emmert¹, Ralf Reilmann⁵, C. Janneke van der Woude⁶, Geert Van Gassen⁷, Frédéric Baribaud⁸, Teemu Ahmaniemi⁹, Meenakshi Chatterjee¹⁰, Bruno Kuszniur Vitturi¹, Clémence Pinaud¹¹, Jérôme Kalifa¹¹, Stefan Avey¹⁰, Wan-Fai Ng^{4,12}, Clint Hansen¹, Nikolay V. Manyakov¹³ & Walter Maetzler¹

Read the paper: emp.onl/kG2UF

PUBLICATIONS

Research Article - **Characterizing Patient-Reported Fatigue Using Electronic Diaries in Neurodegenerative and Immune-Mediated Inflammatory Diseases: Observational Study** by Bennetot et al.

Fatigue is a prevalent and debilitating symptom in many chronic conditions, often fluctuating significantly within and between days, yet traditional patient-reported outcomes (PROs) typically rely on recall periods of a week or more, potentially missing these short-term variations. Digital tools like electronic diaries (eDiaries) offer a unique opportunity to collect granular, real-time data.

This study evaluates the acceptability of high-frequency eDiaries to capture intraday variability in fatigue and compares eDiary data with scores obtained from the Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F), a validated weekly recall PRO.

Read the Paper: emp.onl/shl8J

Systematic Review - **Clinical dashboards for Parkinson's Disease monitoring: a systematic review** by Ferreira-Brito et al.

Dashboards have been used in clinical settings to monitor Parkinson's, serving to visually represent collected data. However, a deeper understanding of the relationship between the data collected and appropriate visualisation formats, and tailoring the dashboards to the needs of both patients and healthcare professionals, is needed.

This paper presents a systematic review of 47 studies focused on developing and designing clinical dashboards for PD monitoring. This review highlights a gap in end-user involvement in dashboard design, which impedes the advancement of knowledge regarding the optimal visual representation of clinical data.

Read the Paper: emp.onl/My-h0

PUBLICATIONS

Research Article - Evaluation of walking activity and gait to identify physical and mental fatigue in neurodegenerative and immune disorders: preliminary insights from the IDEA-FAST feasibility study by Hinchliffe et al.

Many people with neurodegenerative and immune-mediated inflammatory disorders experience significant fatigue, but current assessments often rely on subjective patient-reported outcomes. In the IDEA-FAST feasibility study, wearable inertial measurement units were used to objectively assess gait characteristics and their connection to fatigue in participants with various conditions like Parkinson's, rheumatoid arthritis, and inflammatory bowel disease.

This study highlights interesting patterns in gait rhythm and postural control for further investigation and underscores the need for more research to better understand fatigue using objective measures.

Hinchliffe et al.
Journal of NeuroEngineering and Rehabilitation (2024) 21:94
<https://doi.org/10.1186/s12984-024-01390-1>

Journal of NeuroEngineering
and Rehabilitation

RESEARCHOpen Access

**Evaluation of walking activity and gait to identify physical and mental fatigue in neurodegenerative and immune disorders: preliminary insights from the IDEA-FAST feasibility study**

Chloe Hinchliffe¹, Rana Zia Ur Rehman², Clemence Pinaud³, Diogo Branco⁴, Dan Jackson⁵, Teemu Ahmaniemi⁶, Tiago Guerreiro⁴, Meenakshi Chatterjee⁷, Nikolay V. Manyakov⁸, Ioannis Pandis⁹, Kristen Davies¹, Victoria Macrae^{10,11,12}, Svenja Aufenberg¹³, Emma Paulides¹⁴, Hanna Hildesheim¹⁵, Jennifer Kudelka¹⁵, Kirsten Emmert¹⁵, Geert Van Gassen¹⁶, Lynn Rochester^{1,11,12}, C. Janneke van der Woude¹⁴, Ralf Reilmann¹³, Walter Maetzler¹⁵, Wan-Fai Ng^{1,10,11,12} and Silvia Del Din^{1,11*} on behalf of the IDEA-FAST Consortium

Read the Paper: emp.onl/8E2DC

RECENT EVENTS

Throughout the year various facets of IDEA-FAST's goals and achievements are presented in summits, congresses, and workshops.

Annual EuGMS Congress

September 18th - 20th, 2024, Valencia, Spain

The 20th EuGMS congress was themed "From Healthy Ageing to Complex Needs in Older Adults". The programme highlighted state-of-the-art clinical practices, recent advances, new data, and views from different stakeholders.

IDEA-FAST WP2 Academic Lead Walter Maetzler represented IDEA-FAST as a contributor to the session titled Parkinson's Disease Across the Spectrum: Prevention, Cure, and Care. Walter's talk was on the use of sensors to support care in people with Parkinson's Disease.

Read more: emp.onl/KdPJH

GAMMA Workshop

November 8th - 9th, 2024, Kiel, Germany

The Neurogeriatrics team at the University Medical Center Schleswig-Holstein (UKSH) held this year's GAMMA Workshop of the Society for the Analysis of Human Motorics and its Clinical Application, titled "Motion Analysis in Neurology".

This GAMMA workshop focused on movement as a biomarker and its added value for clinical and scientific practice. IDEA-FAST Co-coordinator Dr. Walter Maetzler represented IDEA-FAST with the workshop's keynote lecture "Wearables and Clinical Cohorts".

Read more: emp.onl/XLhCe

RECENT EVENTS

7th Digital Rheumatology Days – Digital Rheumatology Network

March 21st - 22nd, 2025, Berlin, Germany

The Digital Rheumatology Day connects leading experts from a wide variety of disciplines like physicians, patients, pharma and MedTech industry, Health IT companies, associations, consultants and academia as well as research centers to discover new innovative practices.

IDEA-FAST Project Coordinator Prof. Wan-Fai Ng gave a presentation titled titled “Digital Biomarkers of fatigue in immune-mediated inflammatory diseases (IMID) and neurodegenerative diseases (NDD)”.

Read more: emp.onl/DwGmW

Deutscher Online Parkinson-Kongress

May 16th - 25th, 2025

The German Online Parkinson Congress is a free Parkinson’s Congress where 29 leading experts will provide attendees with easy-to-understand insights and practical solutions that will help patients understand their symptoms and how to manage them so that their quality of daily life is improved.

IDEA-FAST Co-coordinator Dr. Walter Maetzler was one of the congress’s leading experts. He held a lecture titled “Wearables und technische Hilfen bei Parkinson” on May 20th.

Read more: emp.onl/6-QnS

RECENT EVENTS

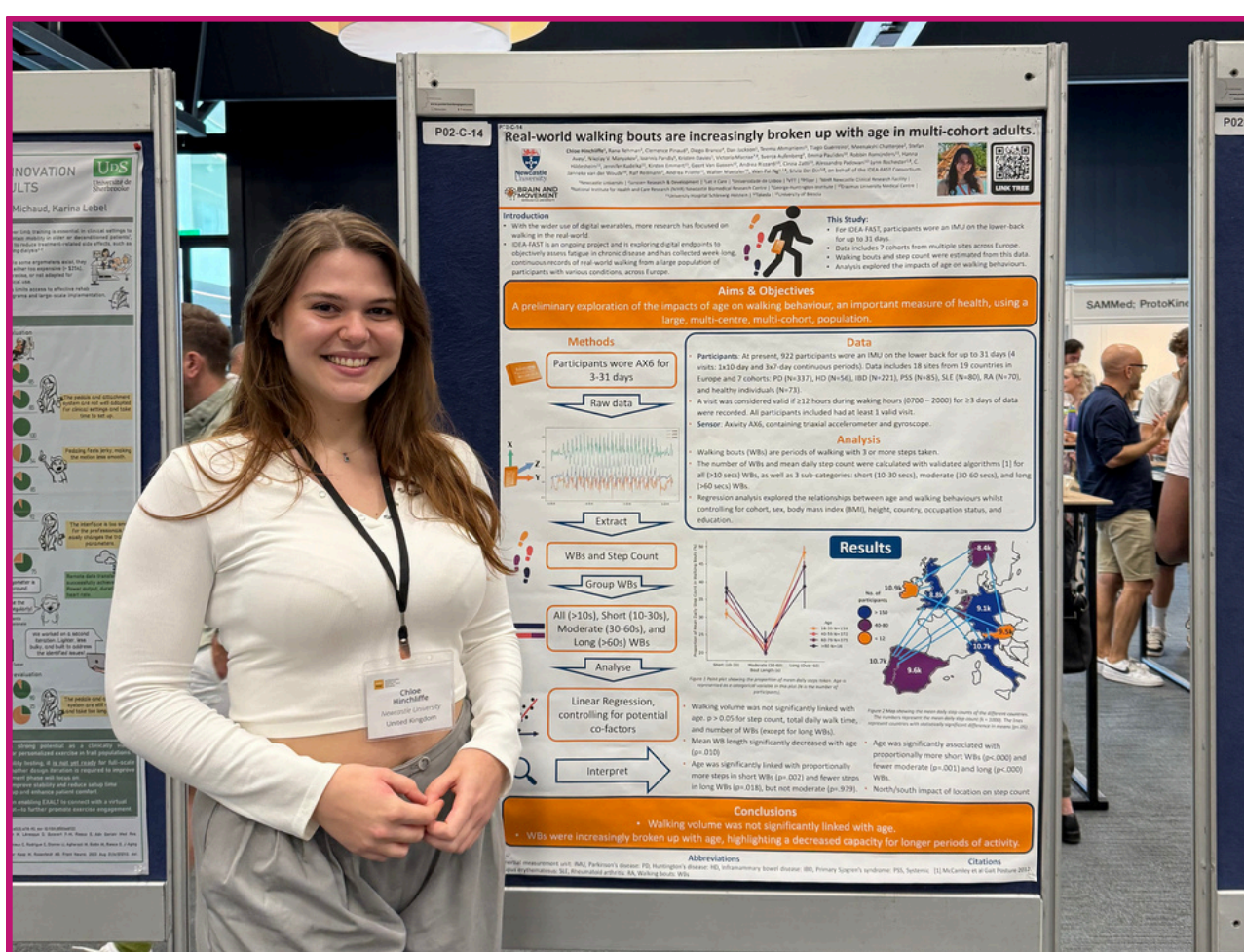
EMBL-EBI Industry Programme Workshop – Digital Biomarkers: Accelerating collaboration and reuse of technology EMBL-EBI Workshop March 19th - 20th, 2025, Cambridge, England

IDEA-FAST Project Coordinator Prof. Wan-Fai Ng held a presentation at the EMBL-EBI Industry Programme Workshop on Digital Biomarkers titled “Digital Biomarkers of fatigue in immune-mediated inflammatory diseases (IMID) and neurodegenerative diseases (NDD)”.

ISPGR 2025 World Congress June 29th - July 3rd, 2025, Maastricht, the Netherlands

The ISPGR World Congress brings together posture and gait researchers and clinicians from around the world. This year the ISPGR placed a special emphasis on building New Connections from Muscles to Minds to Drive Discoveries in Posture & Gait Research.

Dr. Chloe Hinchliffe from the University of Newcastle represented IDEA-FAST with a poster titled “Real-world walking bouts are increasingly broken up with age in multi-cohort adults”.



Check out the poster: [Website Link](#)
Read more: [LINKEDIN post](#)

2025 GENERAL ASSEMBLY

On March 25th – 26th, the IDEA-FAST consortium gathered for the 2025 General Assembly in Lisbon to discuss the project's developments over the past year and plans for the upcoming months.

Around 100 participants from over 50 partner organizations attended the sessions, in person and online. The discussions enabled us to review the project's progress, discuss challenges and future steps, identify new growth opportunities and links to be strengthened, and support interaction among consortium members.

The fruitful discussions brought attention to collaborative efforts that should be pursued throughout the following year to ensure IDEA-FAST will have a lasting impact after its conclusion.



The IDEA-FAST Consortium during the 2025 General Assembly

Read the GA outcomes: emp.onl/-7gFj

ANNOUNCEMENTS

IDEA-FAST Zenodo Community is now Available

We are happy to announce that the IDEA-FAST Zenodo repository is now up and running! This platform is your gateway to a treasure trove of knowledge from the IDEA-FAST project, dedicated to changing the way we understand and monitor fatigue and sleep disturbances.

What can you find in the repository?

- Open-access publications, project deliverables, and reports
- Key insights into the development of digital endpoints
- Presentations and posters from major events

Zenodo is a trusted platform for hosting and sharing research outputs, ensuring accessibility, visibility, and long-term preservation. Whether you're a researcher, healthcare professional, industry partner, or policymaker, this repository provides a comprehensive collection of resources to inform, inspire, and ignite collaboration.

Access the Repository: emp.onl/Dx4d4

Read More: emp.onl/2M7cd

IDEA-FAST Series on Project Publications

In our weekly social media series, we are exploring IDEA-FAST published papers, old and new, which showcase our project efforts and results. Each week, we highlight one publication and its main outcomes.

Keep up with the series on LinkedIn: emp.onl/ZLDGd



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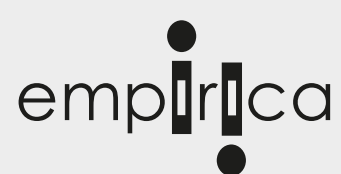
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innovative
medicines
initiative



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