

Newsletter #3

June 2024

AI-PROGNOSIS -

Towards Parkinson's risk assessment and prognosis through Al



Newsletter highlights

User Research and Co-Creation

> **Horizon Results Booster**

3rd Plenary meeting

> Parkinson's **Awareness Month**

Learn more on www.ai-prognosis.eu













AI-PROGNOSIS receives funding from the European Union under Grant Agreement No. 101080581.





Project updates

Ongoing preparation for the Digital biomarkers development, validation and verification study (dBM-DEV study)

The AI-PROGNOSIS project partners Fundación Iniciativa Para las Neurociencias (FOUNDATION FOR INITIATIVES IN NEUROSCIENCE) and TECHNISCHE UNIVERSITAET DRESDEN (Dresden University of Technology), achieved a significant milestone by receiving ethical approvals for the Digital biomarkers development, validation and verification study (dBM-DEV study) in Spain and Germany.

Ethical approval has already been granted for the Centre Hospitalier Universitaire de Toulouse (CHUT) in France and is in progress for King's College London (UK).

The study will be conducted on 90 participants who will undergo **daily-life digital biomarker tracking**. It is anticipated that the identification of robust digital biomarkers in this study will have a favourable impact on the Parkinson's disease community in the future by enabling the daily-life detection and monitoring of PD symptoms, including the early signs of the disease, such as REM behaviour disorder (RBD).



Read more here.

Unlocking the Complexity of Parkinson's: AI-PROGNOSIS's Multidisciplinary Approach

Let's take a closer look at AI-PROGNOSIS's approach. Prof. Leontios Hadjileontiadis, the project coordinator, highlights the complexity of Parkinson's disease and emphasises the multidisciplinary approach of the AI-PROGNOSIS consortium.



The consortium includes clinical representatives, regulatory experts, and small-to-medium-sized companies investing in technology. Additionally, patient representatives are actively involved in the co-creation process.

AI-PROGNOSIS approach focuses on understanding the holistic scope of the Parkinson's disease problem, prioritising user needs, and applying solutions in real-world scenarios to achieve tangible outcomes that benefit individuals and provide insights for policymakers.





AI-PROGNOSIS digital health tools

AI-PROGNOSIS aims to **develop an AI-enabled digital health ecosystem to advance PD diagnosis and care**. The ecosystem will comprise three tools: mAI-Health and mAI-Care Mobile Apps and mAI-Insights Web App.

More about the tools here.



mAl-Health Mobile App

Purpose

For individuals without PD to track their personalised risk of acquiring the disease.

Functionality

Provides quantitative PD risk assessments based on user profiles, smartphone/watch-tracked digital biomarkers (dBMs), and occasional self-reports, in collaboration with attending physicians.



mAl-Care Mobile App

Purpose

For people with PD to monitor disease progression and medication efficacy.

Functionality

Enables PwP and their caregivers to track symptoms, treatment effects, and access personalised projections of PD progression using dBMs, self-reports, and clinical data.



mAl-Insights Web App

Purpose

For healthcare professionals (HCPs) to support PD screening, patient follow-up, and medication optimisation.

Features

- Enables non-expert and expert HCPs to track and identify persons at risk of PD with explainable estimations based on clinical data and data shared via mAl-Health.
- Provides expert HCPs to monitor patients' status, view progression projections, and receive individualised predictions of patients' response to medication regimens through the Al-assisted Medication Decision support (AIMED) module.





User Research and Co-Creation in Al-PROGNOSIS

User research and co-creation are crucial to AI-PROGNOSIS, ensuring our tools effectively meet diverse needs in managing Parkinson's disease (PD). Here's how we integrate user-centric principles and collaborative methodologies:



Partner Stakeholders

Clinical Partners: Provide PD management expertise and contribute to clinical validation. **User-Oriented Partners:** Represent patient advocacy groups and individuals affected by PD, ensuring their insights guide development.

Technical Partners: Contribute AI, digital biomarker, and app development expertise.



Non-Partner Stakeholders Involved

Persons with PD (PwP): Offer insights into symptoms and treatment effectiveness.

Persons without PD (PwoP): Contribute to risk assessment and app usability testing.

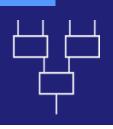
Carers: Provide perspectives on caregiving challenges.

Relevant Healthcare Professionals (HCPs): Offer clinical insights and feedback.



The Role of the Patient Panel and Samka Framework

Patient Panel: Guided by Uppsala University, ensures representation and collaboration. **Samka Framework:** Guides with clear aims, trust-building, and long-term collaboration (General 2 - Collect! (samka.se))







User Research Flow and Co-Creation Process

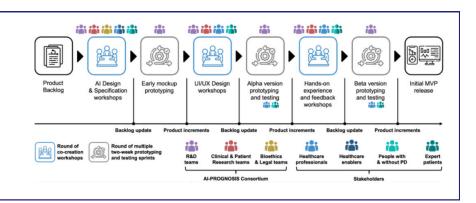
Iterative Approach: Focuses on identifying user needs and stories. **Co-creation:** Involves stakeholders in the agile design of MVPs.

Secondary Research Primary Research Outcomes • Identification of sources One-on-one interviews User requirements, empathy, Collection of existing material (clinicians) journey maps, and user · Analysis of material stories Focus groups Validation surveys **Final hypotheses** and assumptions people with/without PD, (greater carers, HCPs, healthcare population of Primary hypotheses and Product enablers, clinical and stakeholders) Backlog assumptions technical partners)

User research in AI-PROGNOSIS

Co-creation of MVPs in Al-PROGNOSIS.

People with PD and expert patients are now part of the patient panel



Key Findings from User Research and Co-Creation

To date:

- Three rounds of strategic co-creation
 workshops have been conducted using an
 agile methodology, engaging PwP,
 technical partners (The Aristotle University
 of Thessaloniki, AINIGMA Technologies),
 bioethics partner (University of Oxford),
 and facilitation by Uppsala University.
- Two focus groups, specifically with the patient panel, have been completed, focusing on identifying and prioritising user needs related to mAI-Health and mAI-Care tools.
- One co-creation session with Parkinson's disease patient representatives conducted with a focus on refining the active motor tests component intended for integration into the AI-PROGNOSIS app.

Recent user research initiatives have provided critical insights:

- Patient Panel Focus Groups: Identified preferences for personalised risk assessment and desire for gamification elements.
- HCP Interviews: Highlighted the importance of data visualisation and usability in clinical decision-making.
- Al Co-Creation Workshops: Revealed PwP's cautious optimism towards Al tools, emphasising the need for transparency and educational content.

The user needs identified were used to create the system requirements and, sequentially, the product backlog.

Read more.





Horizon Results Booster



The AI-PROGNOSIS application for the Horizon Results Booster (HRB), covering both dissemination (Service 1–Module A) and exploitation (Service 2 –Module C) services, has been approved. HRB is an initiative of the European Commission which aims to maximise the impact of public funded research within the EU.

On 18 June 2024, **AI-PROGNOSIS held an Exploitation Strategy Seminar** led by Horizon Results Booster expert Emmanuel Sofianopoulo. The workshop aimed **to introduce consortium partners to exploitation concepts** and help develop an exploitation strategy for project results.

Read more here.

Knowledge hub

Sex and Gender Impact in Parkinson's Disease

Understanding the influence of sex and gender differences on Parkinson's disease (PD) is vital. Here are the key highlights:

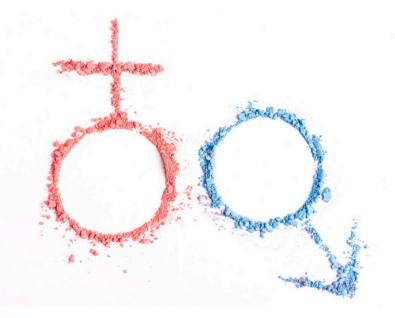
Symptom Differences: Women experience more severe and common symptoms, including restless legs, pain, loss of taste and smell, fatigue, depression, constipation, weight change, and excessive sweating. Prevalence and Phenotype: PD is 1.5 times more common in men. Women, however, tend to have a more benign phenotype and are more likely to experience tremors.

Treatment Complications: Women face higher risks of treatment-related complications, lower chances of effective treatment, and faster disease progression.

Neurological Differences: There are significant sex-related differences in cortical thickness and connectivity in PD, affecting diagnosis and treatment.

Gender Considerations: Social constructs and behaviors linked to sex differences impact care provision, patient-provider communication, and non-pharmacological disease management.

Research Gaps: Minimal sex and gender consideration in mHealth randomised controlled trials for chronic conditions like PD.



The AI-PROGNOSIS project **ensures inclusivity by identifying sex differences** for predictive models and focusing on balanced groups in needs mapping.

Read more.





Events

PETRA 2024

26-28 June 2024 Read the abstract here.

> AI-PROGNOSIS was presented at **PETRA** 2024, a scientific interdisciplinary conference held on 26-28 June 2024 in Crete, Greece.

In particular, the Comprehensive Motor Function Test (CMFT) approach was introduced for the first time. It uses smartphone-based video analysis to assess the motor skills of Parkinson's disease patients, combining motion items (e.g., leg agility, posture, and gait).



King's Parkinson's Charitable Fund INAUGURAL EVENT

21 June 2024

On 21 June 2024, Al-PROGNOSIS was represented at King's Parkinson's Charitable Fund INAUGURAL EVENT in London, UK.

This scientific symposium, hosted by King's College London, Parkinson's Foundation Center of Excellence, King's College Hospital Charity, and King's College Hospital, addressed the unmet needs in Parkinson's disease.

Dr Dhaval Trivedi from King's College London presented the AI-PROGNOSIS project and shared insight on AI and its role in predicting Parkinson's disease.









IRBDG Annual Meeting 2024

19-21 June 2024 Read more.

> Prof. Maarten De Vos, the Al-PROGNOSIS project partner from KU Leuven, represented the project at the IRBDSG Annual Meeting 2024, held in Oxford, United Kingdom on 19-21 June, 2024.



Prof. De Vos presented the abstract "Parkinson's Disease Progression using RBD Biomarkers", which focused on the detection of REM sleep behaviour disorder (RBD) with the use of digital biomarkers.

International REM Sleep Behavior Study Group (IRBDG) is a non-profit organisation whose objective is to promote international scientific research in the field of REM sleep behaviour disorder and associated fields and to optimise medical care for patients by improving diagnostic and therapeutic measures.

AI-PROGNOSIS presented to PhD students from Faculdade de Motricidade Humana

In June 2024, an overview of the AI-PROGNOSIS project and ongoing research on digital motor skill assessment was presented to PhD students from Faculdade de Motricidade Humana (Lisbon, Portugal) in the context of the Physical Activity and Health program.











3rd Plenary meeting

3-4 June 2024 Read **more**.

> The 3rd AI-PROGNOSIS plenary meeting was held on 3-4 June 2024 in Toulouse, France. Over the course of two days, consortium members from across Europe came together for highly productive sessions, strategically planning the next steps towards advancing Parkinson's disease diagnosis and care.









Europe Biobank Week

19 May 2024

On 19 May 2024, Anna Clareborn from Al-PROGNOSIS partner Uppsala University participated in Europe Biobank Week (link: https://lnkd.in/eaMmSnV6) in Vienna. Her presentation highlighted **the integration of the six core principles of patient involvement** (link: https://lnkd.in/dBmYjDkX) into the collaborative activities of Al-PROGNOSIS, using it as a best practices case study.

During her presentation, Anna Clareborn focused on **the importance of showing willingness to remunerate patient collaborators**, an area where AI-PROGNOSIS had shown commendable initiative. Thanks to the willingness of all project partners, we are embracing the implementation of a remuneration strategy for patient stakeholders.











Parkinson's Day 2024

19 April 2024

On 19 April 2024, María Luisa Almarcha Menargues, MD, a neurologist at Hospital Ruber Internacional and researcher of <u>Al-PROGNOSIS</u>, presented the project at Parkinson's Days, organised by The Galicia-Coruña Parkinson's Association.

<u>AI-PROGNOSIS</u> is at the forefront of innovation and promises to revolutionise the field of Parkinson's disease by collecting data with a smartwatch and leveraging databases to analyse it with AI, generating predictive models.





Parkinson's Awareness Month

April 2024

Watch the short animation here.

April marked Parkinson's Awareness Month, a time dedicated to raising awareness about Parkinson's disease and supporting those living with it.

Parkinson's Awareness Month served as a reminder of the challenges faced by those living with Parkinson's and the importance of support and understanding within the community.

The AI-PROGNOSIS consortium shares the common goal of improving the lives of people with Parkinson's disease. By combining novel predictive models with digital biomarkers from everyday devices, we aim to advance Parkinson's disease diagnosis and care.





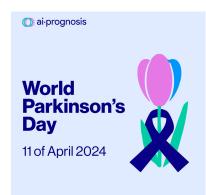


World Parkinson's Day 2024

11 April 2024

On 11 April 2024, AI-PROGNOSIS celebrated World Parkinson's Day. This significant day was dedicated to **raising awareness about Parkinson's disease**, and we united to support those living with Parkinson's disease and advocate for better care and research.





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