

# Annual conference EMSP

April 24–25, 2026  
Berlin, Germany

From Diagnosis to Access:  
Data-Driven Solutions for  
MS, NMO and MOGAD

Building Fairer Future for Patients

#EMSP2026



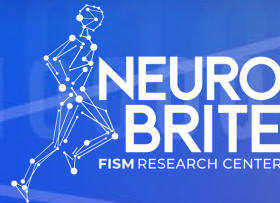
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# How PROs contribute to clinical practice and research

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Italian MS Society – NeuroBRITE Research Center

RiMS President



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# Establishing the standard for the patient voice

## FDA Definition

Any report of the status of a patient's health condition that comes directly from the patient, **without interpretation** of the patient's response by a clinician or anyone else.

## EMA Definition

Any outcome evaluated directly by the patient him/herself and based on **patient's perception** of a disease and its treatment(s).

**What is a PROM?** Measures or tools that record health-related data from patients—passively or actively.

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# The MS 'Iceberg' Concept: Unmasking hidden symptoms



## Traditional Clinical Measures

- Relapses
- Lesions on MRI
- EDSS steps

## Hidden Patient Burdens

- Fatigue
- Sleep Disturbance
- Anxiety
- Depression
- Cognition
- Social Roles & Relationships
- Stigma
- Social Determinants of Health

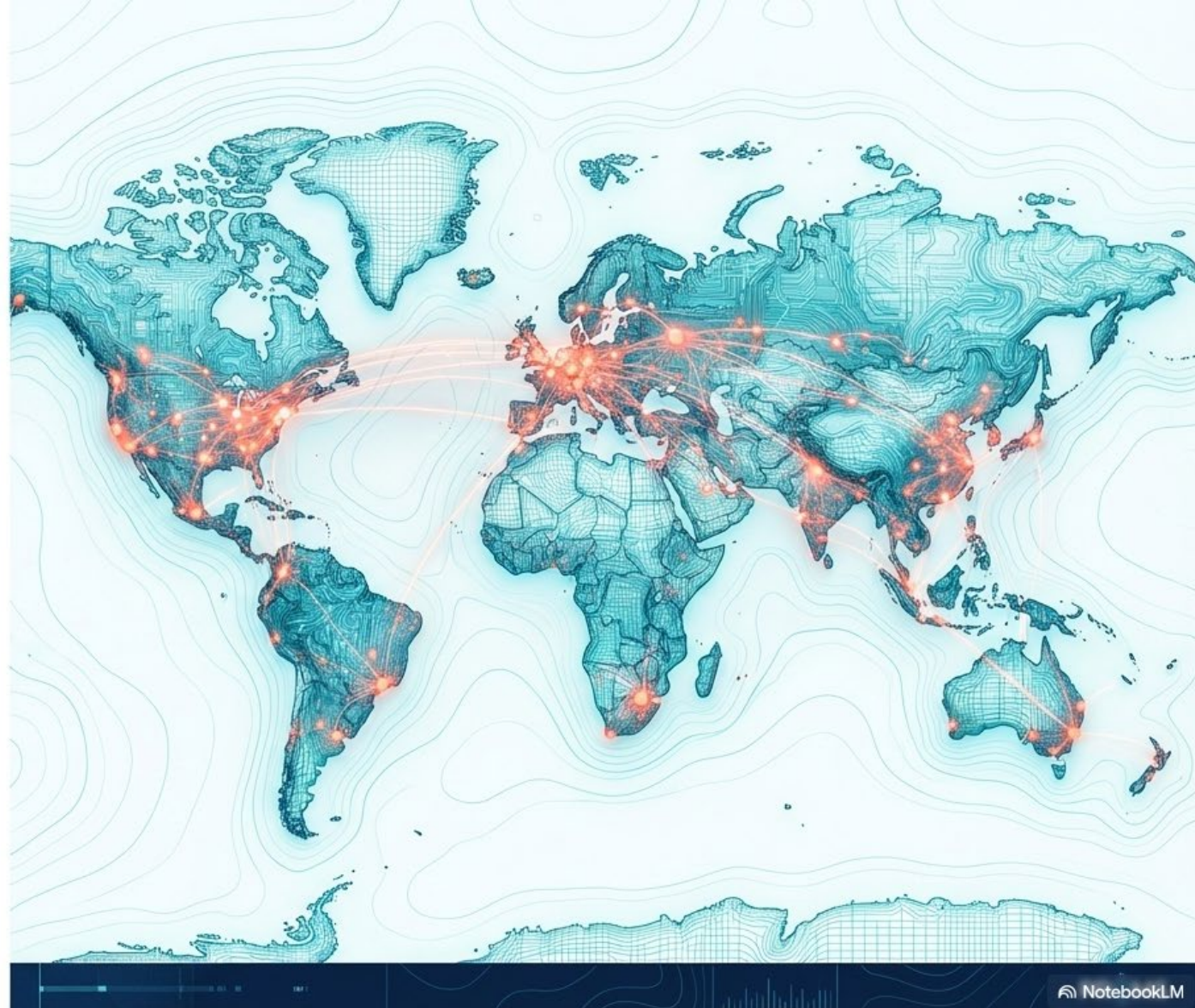
PROMs uncover progression by making the hidden part of the iceberg visible, capturing changes over time that current clinical snapshots miss.

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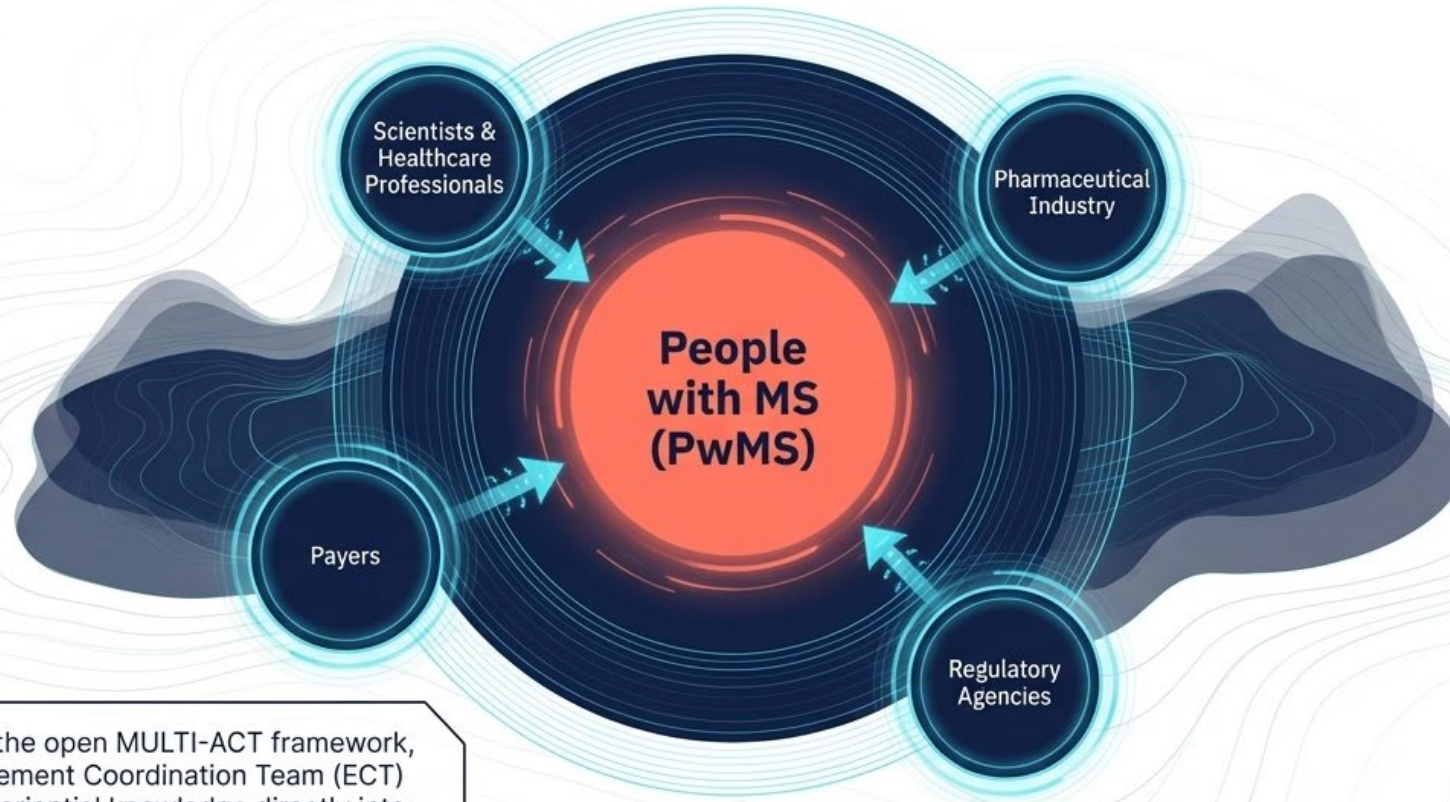
# The PROMS Global Initiative

To maximize the impact of science and patient input on health, healthcare, and quality of life for people living with MS, presenting a unified view relevant to all stakeholders.

## 60+ Partner Organizations Worldwide



# Participatory Governance: PwMS at the center of the agenda



Rooted in the open MULTI-ACT framework, the Engagement Coordination Team (ECT) brings experiential knowledge directly into the scientific agenda.

PROMS

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N > 5,000 PwMS

# The Global Survey: Quantifying the experiential reality of >5,000 patients



PROMS

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# Symptom hierarchies shift based on the disease course

*\*Mean symptom prevalence excludes fatigue (a baseline constant).*



Relapsing MS is heavily dominated by unseen cognitive and mood burdens, while progressive courses are dominated by mobility and physical decline.

# The evolving burden: Symptom hierarchies by age

\*Mean symptom prevalence excludes fatigue.\*



Younger demographics face profound mood and cognitive challenges, underscoring the need for early psychological intervention, while older demographics prioritize mobility and physical function.

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# The Digital Bridge: eHealth tools for real-world capture

Living catalogue of 16 validated eHealth tools

**Highly Motivated  
to Monitor:**  
3 minutes/day  
4 days/week

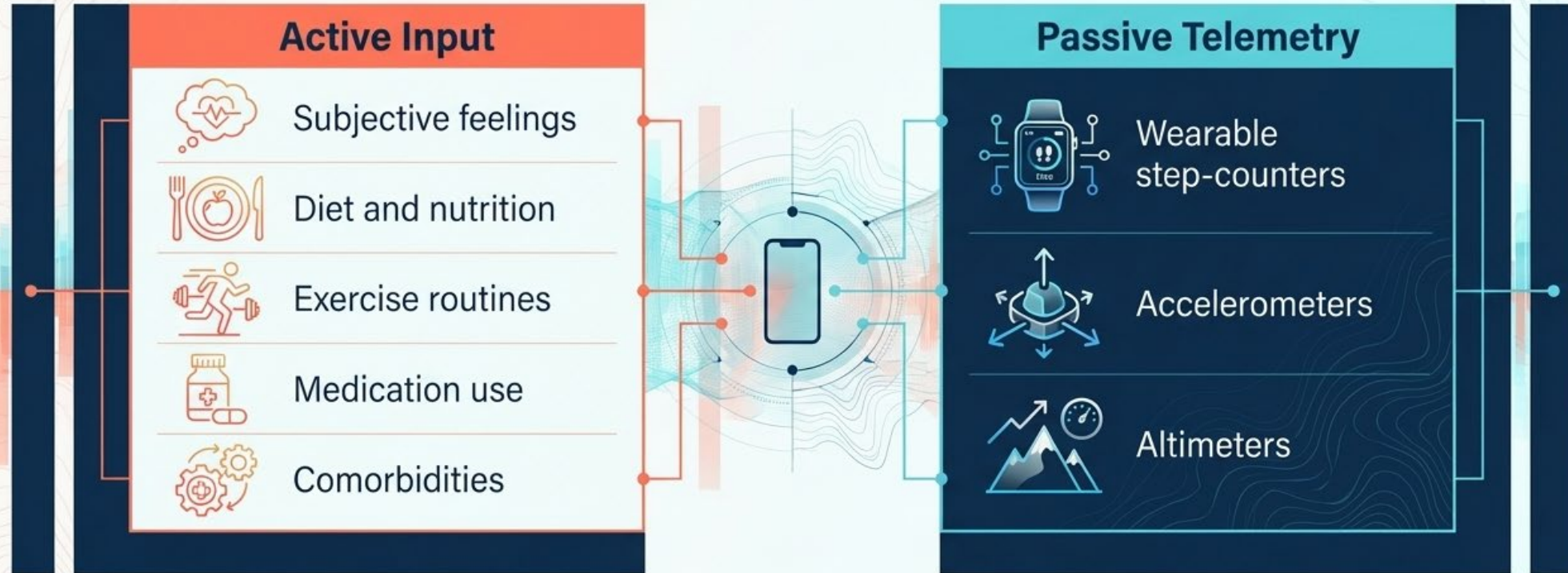


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# 360-degree capture: Active input vs. passive telemetry



**Insight:** Interrogating this integrated data uncovers hidden patterns, identifying symptom triggers for self-management, and signaling subtle disease progression to prompt clinical referral.

# The Next Frontier: Integrating PROs with Clinical Data

**Clinician-Assessed Outcomes**

(EDSS, MoCA, FIM, SDMT)

+

**Patient-Reported Outcomes**

(MFIS, ABILHAND, HADS, LSI, OAB-Q)

=

**Predictive Power**

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Neurological Sciences (2020) 41:459–462  
https://doi.org/10.1007/s10072-019-04093-x

BRIEF COMMUNICATION

The hidden information in patient-reported outcomes and clinician-assessed outcomes: multiple sclerosis as a proof of concept of a machine learning approach

Giampaolo Brichetto<sup>1,2</sup> · Margherita Monti Bragadin<sup>1,2</sup> · Samuele Fiorini<sup>1</sup> · Mario Alberto Battaglia<sup>4</sup> · Giovanna Konrad<sup>2</sup> · Michela Ponzio<sup>1</sup> · Ludovico Pedulla<sup>1</sup> · Alessandro Verri<sup>1</sup> · Annalika Barla<sup>3</sup> · Andrea Tacchino<sup>1</sup>

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Sage Journals

Original Research Paper

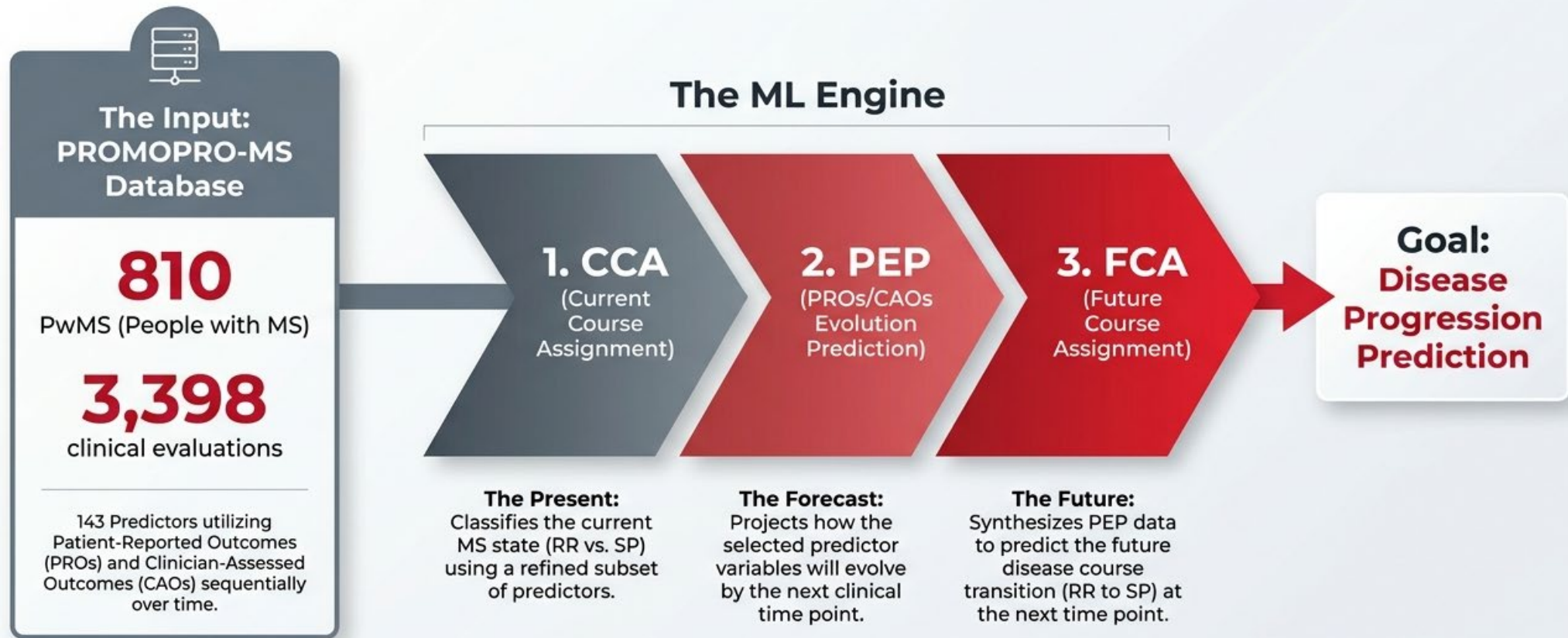
Patient-reported outcomes as predictors of disability evolution in Multiple Sclerosis: An interpretable machine learning approach

Federica Di Antonio<sup>1</sup> · Giampaolo Brichetto<sup>2</sup> · Andrea Tacchino<sup>1</sup> · Ludovico Pedulla<sup>1</sup> · Jessica Podda<sup>2</sup> · Erica Grange<sup>1</sup> · Alice Bollini<sup>1</sup> · Margherita Monti Bragadin<sup>1</sup> · Valeria Prada<sup>2</sup> · Matteo Bauckneht<sup>1</sup> · Silvia Morbelli<sup>1</sup> · and Andrea Chincarini<sup>1,2</sup>

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# Unlocking Hidden Data: A 3-Step Machine Learning Methodology



# Clinical Impact: High-Accuracy Disease Progression Prediction

# 86.0%

## Current Course Assignment (CCA)

Accurately diagnosing the present MS state (RR vs. SP) using a significantly reduced set of PRO/CAO predictors.

# 82.6%

## Future Course Prediction (PEP + FCA)

Successfully forecasting the exact MS course at the next consecutive time point (4 months into the future).



### Uncovering Hidden Information

PROs and CAOs hold immense predictive power for disease progression, uncovering hidden symptoms (fatigue, cognition) without relying exclusively on expensive instrumental measures like MRI.



### Clinical Decision Support

Equips clinicians with a reliable, quantitative tool to navigate the highly complex transition phase from Relapsing-Remitting (RR) to Secondary Progressive (SP) MS.



### Proactive Personalized Medicine

Shifts MS care from a reactive approach to a highly personalized, predictive model, allowing for timely, tailored pharmacological and rehabilitative interventions.

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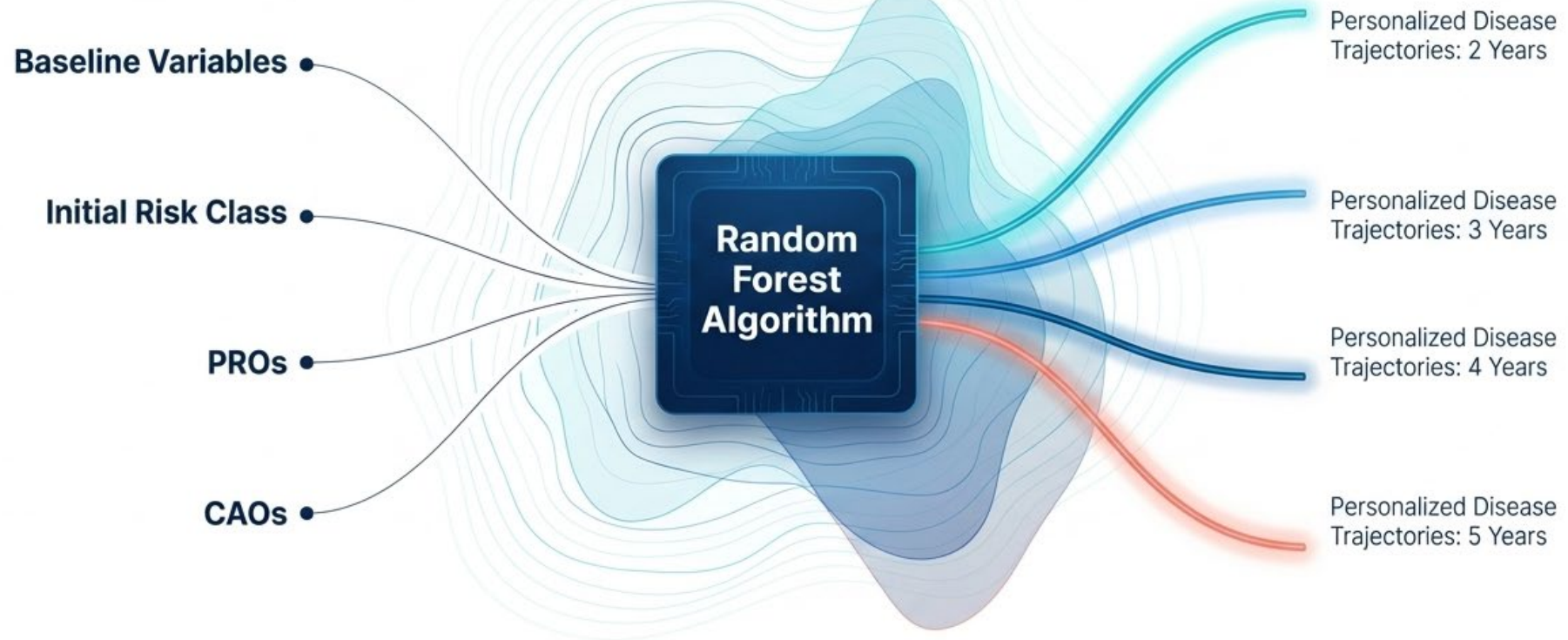


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# Interpretable Machine Learning in MS



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Sage Journals

Original Research Paper



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# The Predictive Breakthrough: 82% Accuracy

# 82%

accuracy in predicting disability changes at 2 years (95% CI: 0.77–0.86).

73% accuracy at 5 years.

**Key drivers:** Initial risk class and baseline EDSS, enriched immensely by PROMs.

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# Impact: Transforming Trials and Patient-Centered Care

PROMs phenotype MS into precise, functional clusters.

## Accelerating Clinical Trials



Hyper-targeted patient recruitment based on subtle functional changes.

## Personalized Patient Care



Proactive, data-driven, individualized treatment plans.

**PROs** are not just supplementary surveys; they are the **key to truly personalized medicine** in MS.

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# Thank you!

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