



Leveraging Medical Records to identify patients at risk of neurodegenerative diseases

The LeMeReND project

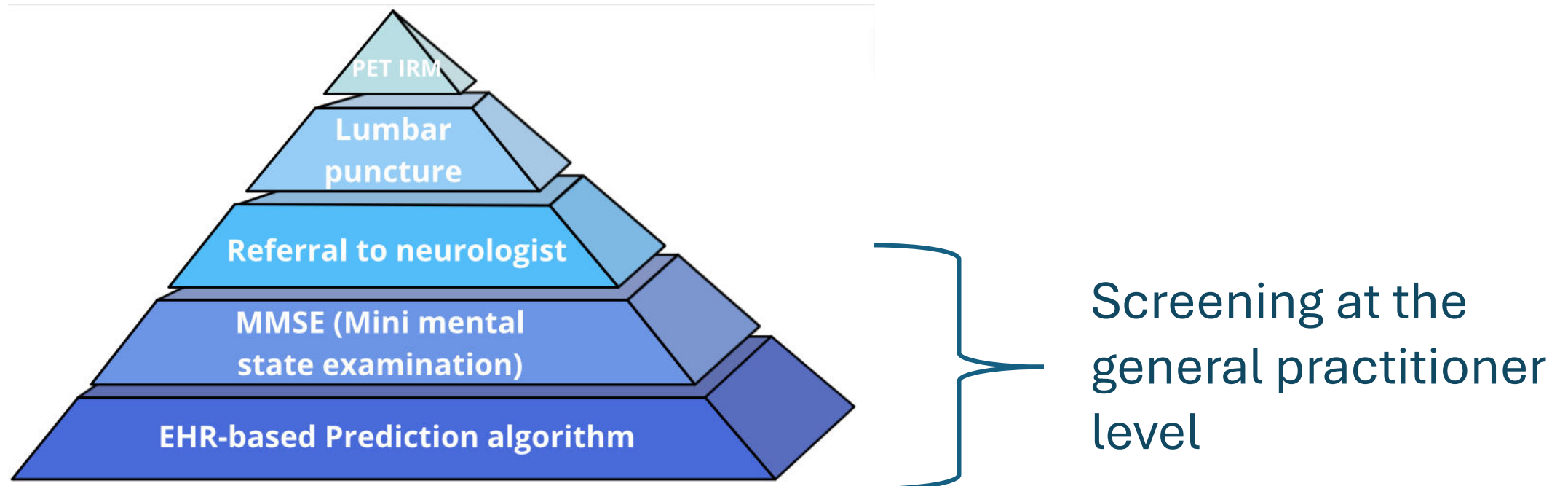
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Objectives

Identify people at risk of developing neurodegenerative diseases at the point of care, years before the disease onset

- Identify the health conditions predicting the occurrence of a diagnosis of a NDD
- Assess the predictive power of a screening algorithm
- Study the acceptability of algorithmic screening from the general population



5 real-world databases from 4 countries

**Pharmaceutical
Benefits Scheme
(PBS)**

**French National
Health Data
System (SNDS)**

**The Health
Improvement
Network (THIN)**

**Swedish Patient
Register (NPR)**



Diagnostics



@hospitals



@hospitals

Prescriptions



1984-

2009-

1996-

2005-



Cases

7,000

210,000

20,000

164,000

Controls

70,000

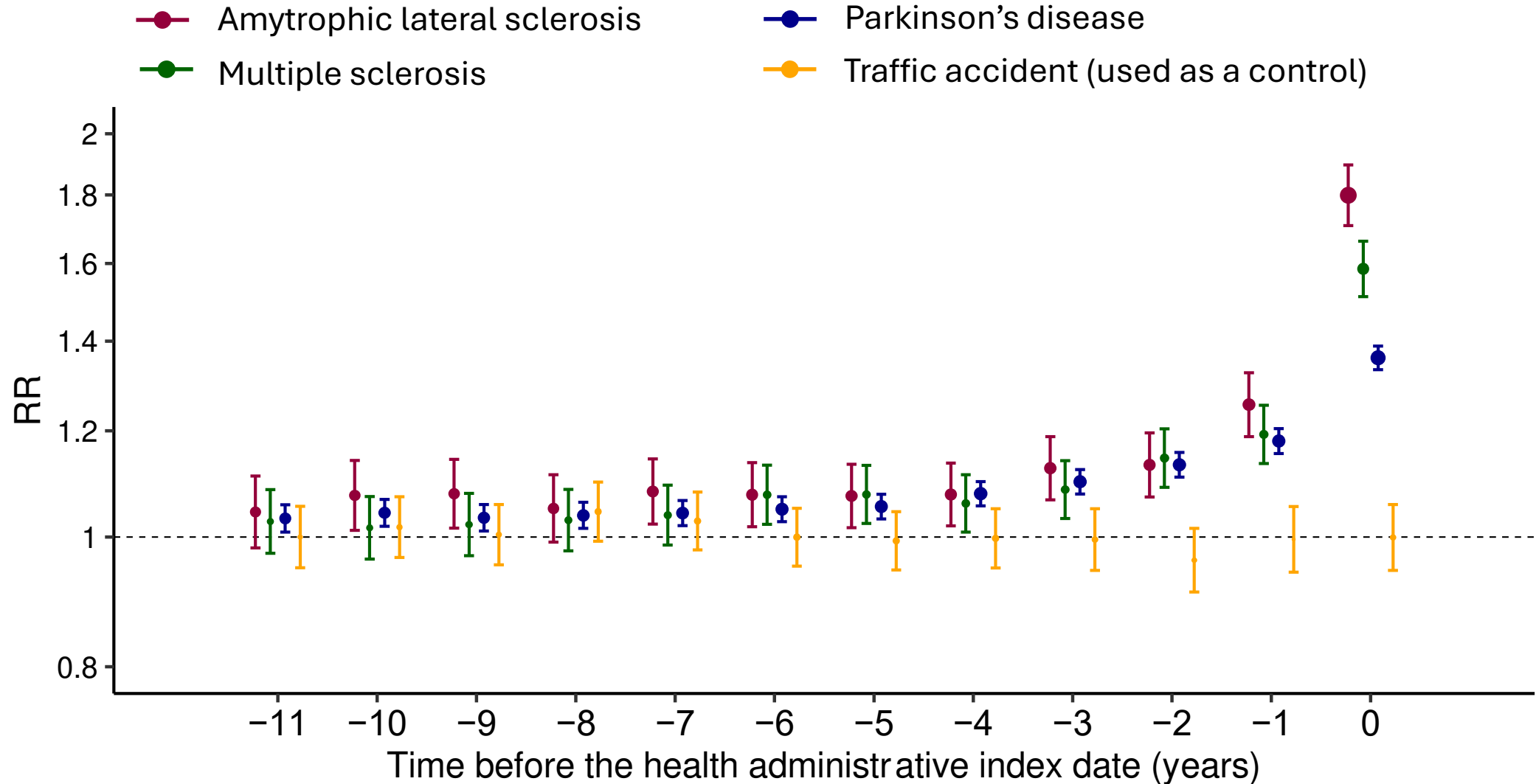
330,000

40,000

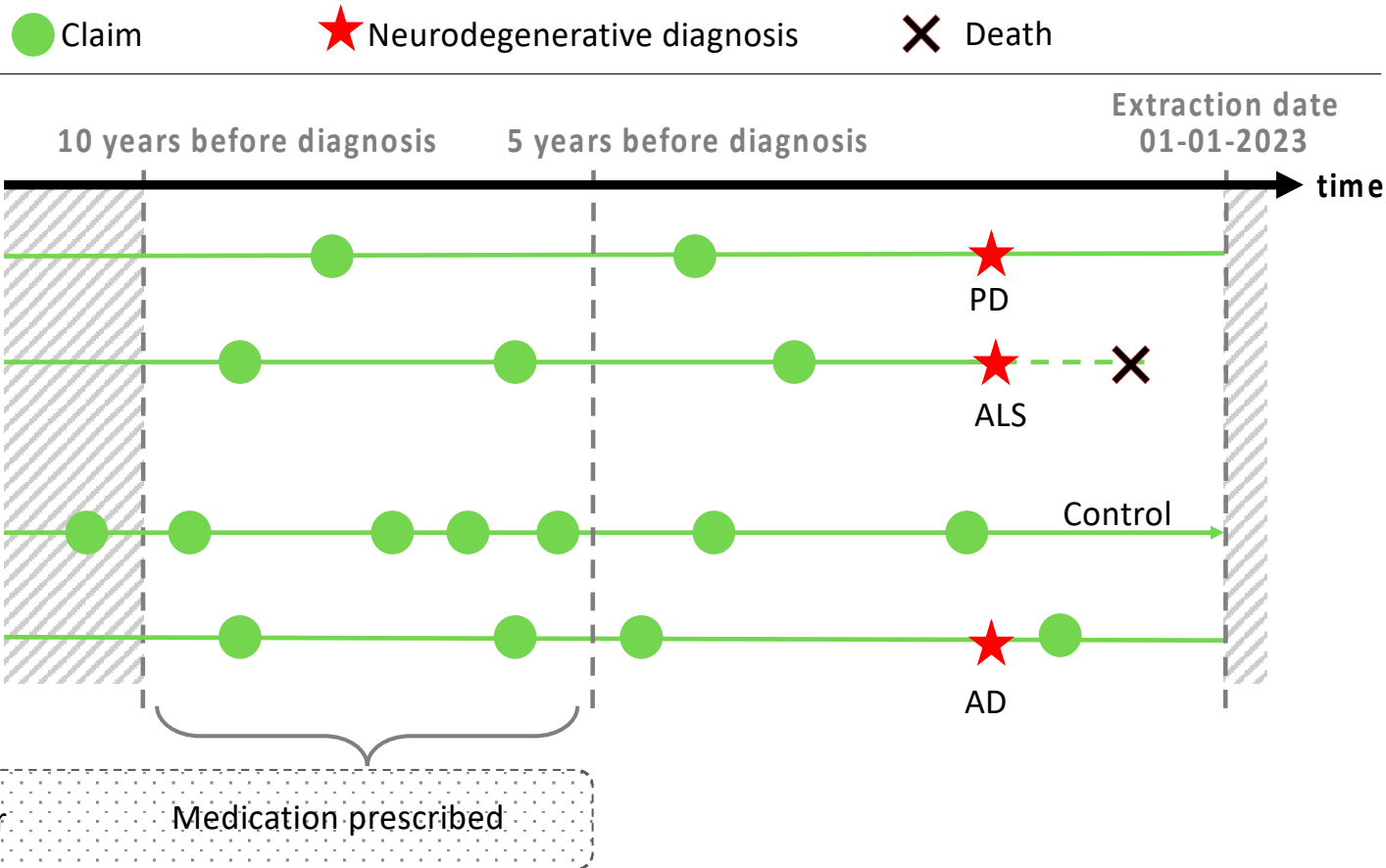
1,164,000

Evidence of the prodrome of neurodegenerative diseases

Onset of NDD is associated with more frequent visits to the GP 7 years before diagnosis



Characteristics of the prodrome of three neurodegenerative diseases



Prescription-wide association study

Agnostic testing of a series of prescriptions

- in the 2-5 years period
- in the 5-10 years period before diagnosis

for

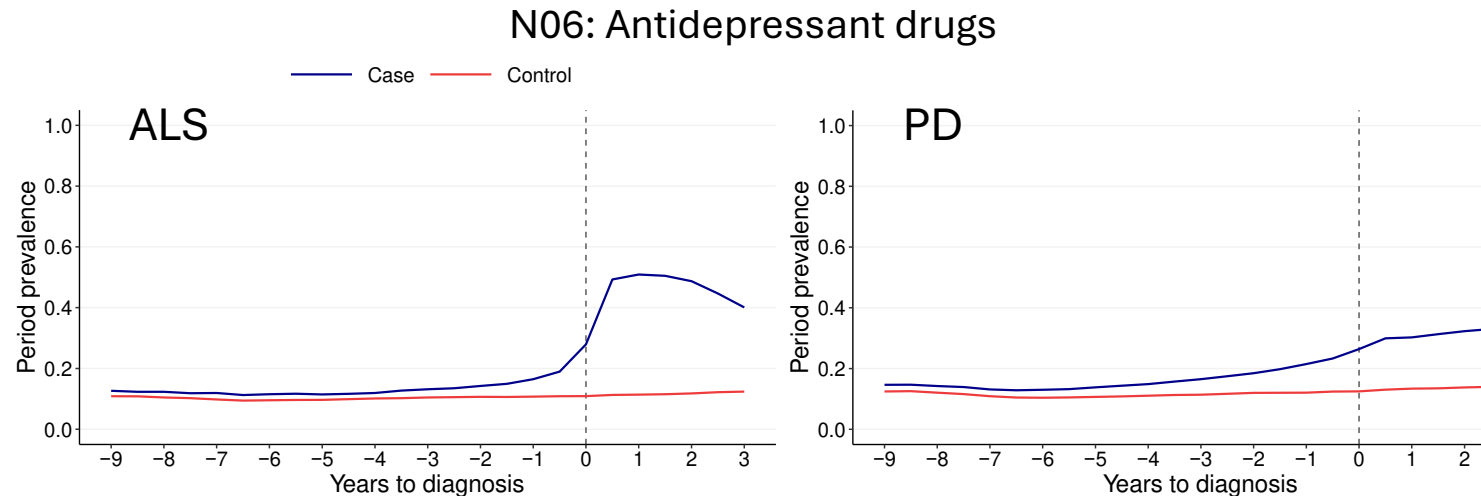
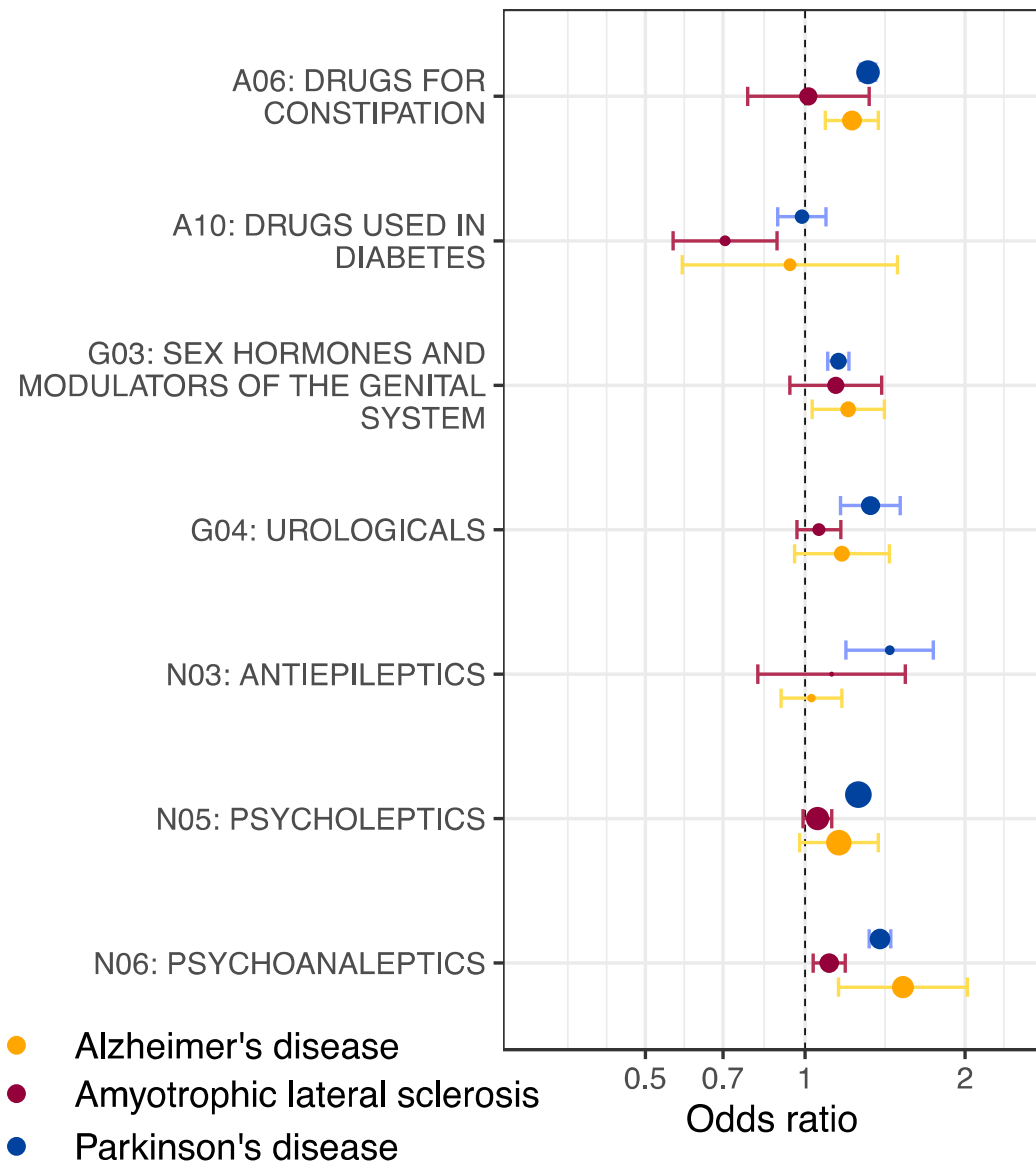
- Alzheimer's disease
- Parkinson's disease
- Amyotrophic lateral sclerosis

↔ Age and sex matched (incidence density sampling)

🔍 Validated case-finding algorithms

Agnostic testing of prescriptions 5-10 years before diagnosis

Treatment classes associated with at-least one NDD

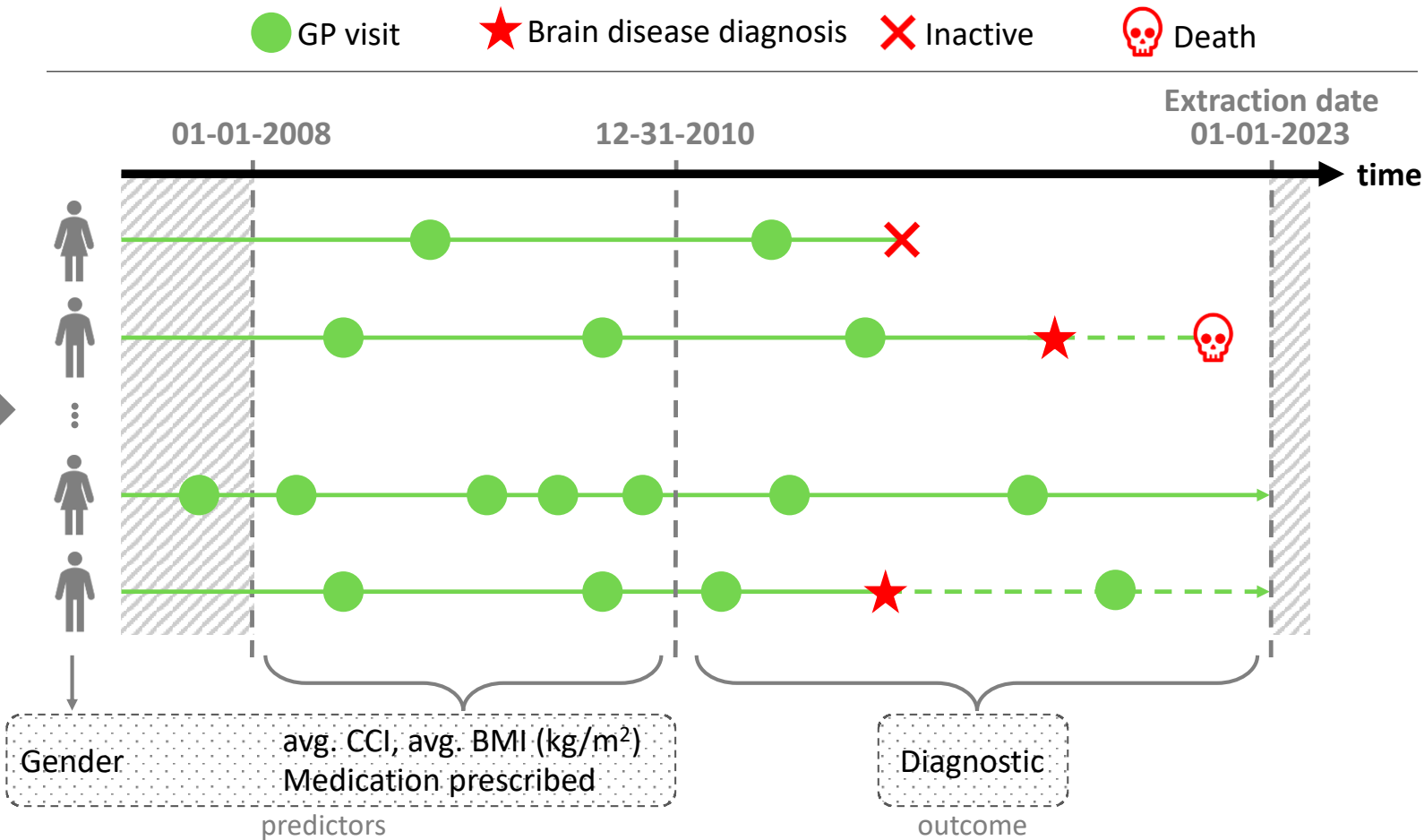


Increased use of **psychoanaleptics** are **common** predictors of AD, PD, and ALS 5-10 years later.

The increased use of **laxatives** is **specific** to AD and PD, while the decreased use of **antidiabetics** is **specific** to ALS.

Prescriptions steadily increase before diagnostics.

Predicting neurodegenerative diseases at age 65

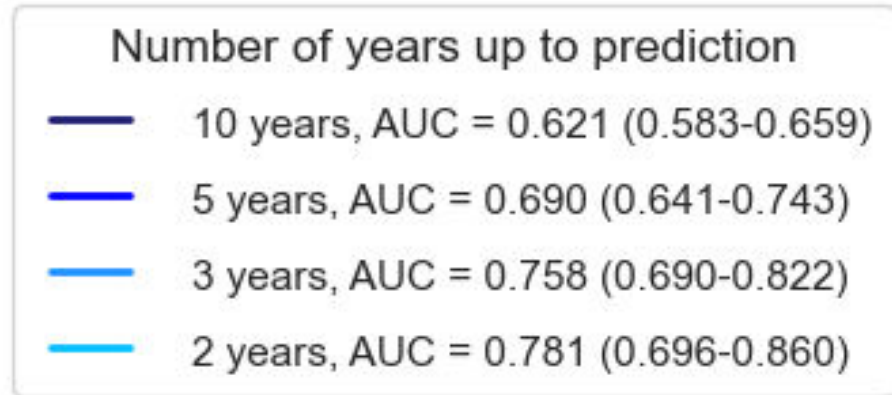
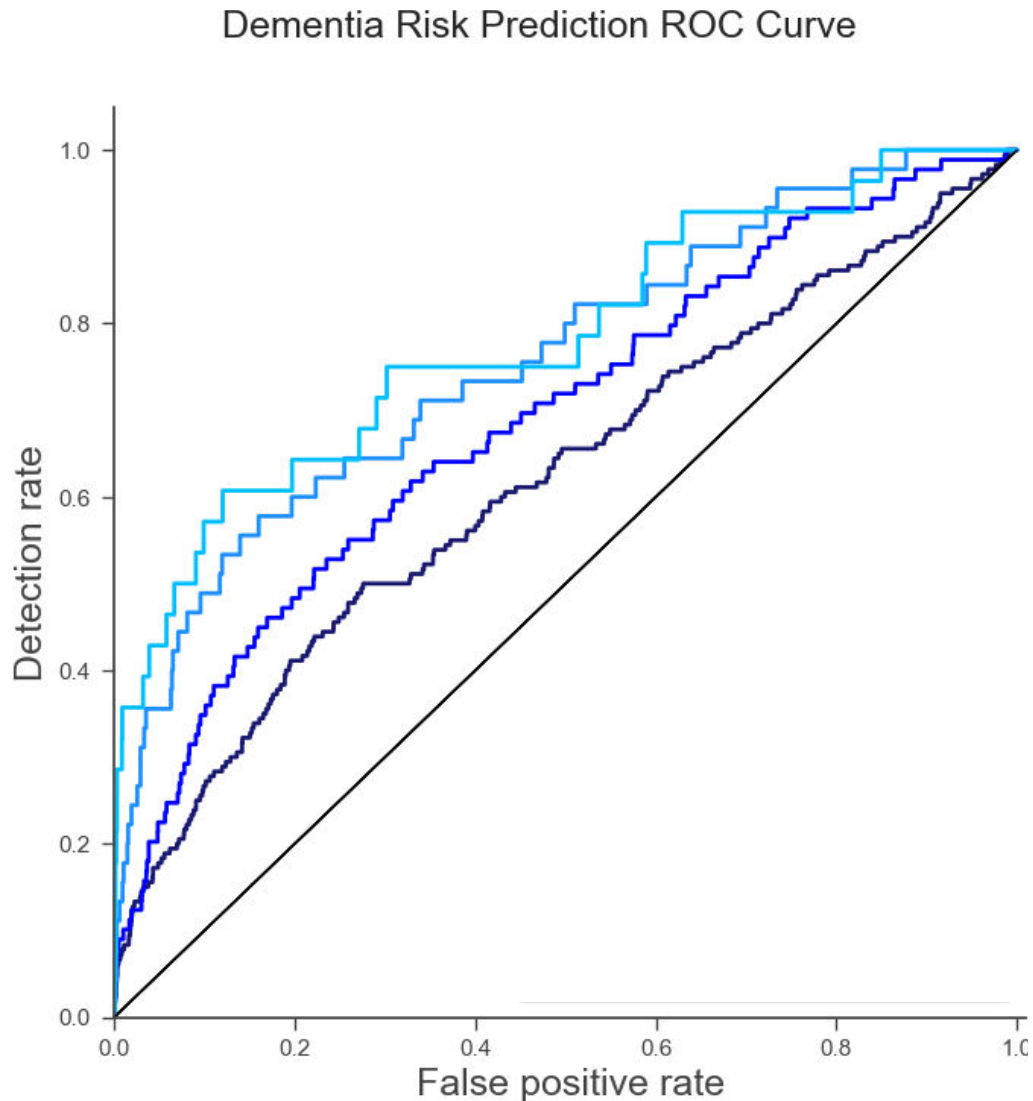


Prediction of a diagnostic of NDD in the next 2 to 10 years for all patients who turned 65 in 2010

using prescriptions identified before as predictors.

Contrary to most risk-prediction algorithm, age is not used as predictor!

Predicting neurodegenerative diseases at age 65 (cont'd)



Sensitivity for a 95% specificity at 5 years: 22.5%

Using the test for **screening people at 65** results in:

- the identification of 22,5% of patients who will have dementia in the next 5 years
- while discarding 95% of patients who will not have dementia in the next 5 years

NDD affects 7% of the population over 65.

Acceptability by the population of AI-based detection of at-risk individuals

Survey with 1,037 participants representative of the French adult population (quota non-probability sampling)

Discrete choice experiment with 5,085 scenarios tested depending on data used, lecturer, sensibility and specificity.

	Test with 95% specificity	Test with 70% specificity
Test based on EHR analysis vs. a saliva test	47,04%	47,67%
Test based on EHR analysis + consumption data on mobile devices vs. a saliva test	44,24%	28,18%

At 95% specificity, 47% people accept tests based on medical and non-medical personal data. At 70% specificity, people are reluctant to let the test analyse non-medical personal data.

Conclusion

We demonstrated the feasibility of screening individuals at-risk of neurodegenerative diseases within the general population.

Such a screening is acceptable by 47% of the population for 95% specificity. At this level, the screening provides a significant enrichment of future patients in the selected sub-population.

Publications

A Comparison Between Early Presentation of Dementia with Lewy Bodies, AD, and PD, Nedelec et al. Annals of Neurology, 2023

Association between diseases and symptoms diagnosed in primary care and the subsequent specific risk of multiple sclerosis, Guinebretiere et al., Neurology 2023

Does improving diagnostic accuracy increase AI adoption, Hswen et al. AI in Health, 2024

Ten years preceding a diagnosis of neurodegenerative disease in Europe and Australia, Wei et al., to appear eBioMedicine

Machine learning prediction algorithms for 2-, 5- and 10-year risk of AD, PD and dementia at age 65, Nedelec et al., in prep

Recent temporal trends in PD incidence, prevalence, and sex differences in France, Guinebretiere et al., ADPD 2025

We gather an open-source community
to share tools and best practices for real-world data analysis!

See Octave
Guinebretière's
poster

