OFSEP

Observatoire Français
de la Sclérose en Plaques

FROM LIFE TO SCIENCE
MS DATA IS OUR COMMITMENT

OFSEP
The French MS registry

ECTRIMS 2025

ECTRIMS 2025

41st Congress of the European Committee for Treatment and Research in Multiple Sclerosis

30th Conference of Rehabilitation in Multiple Sclerosis

24-26 September 2025 | Barcelona, Spain

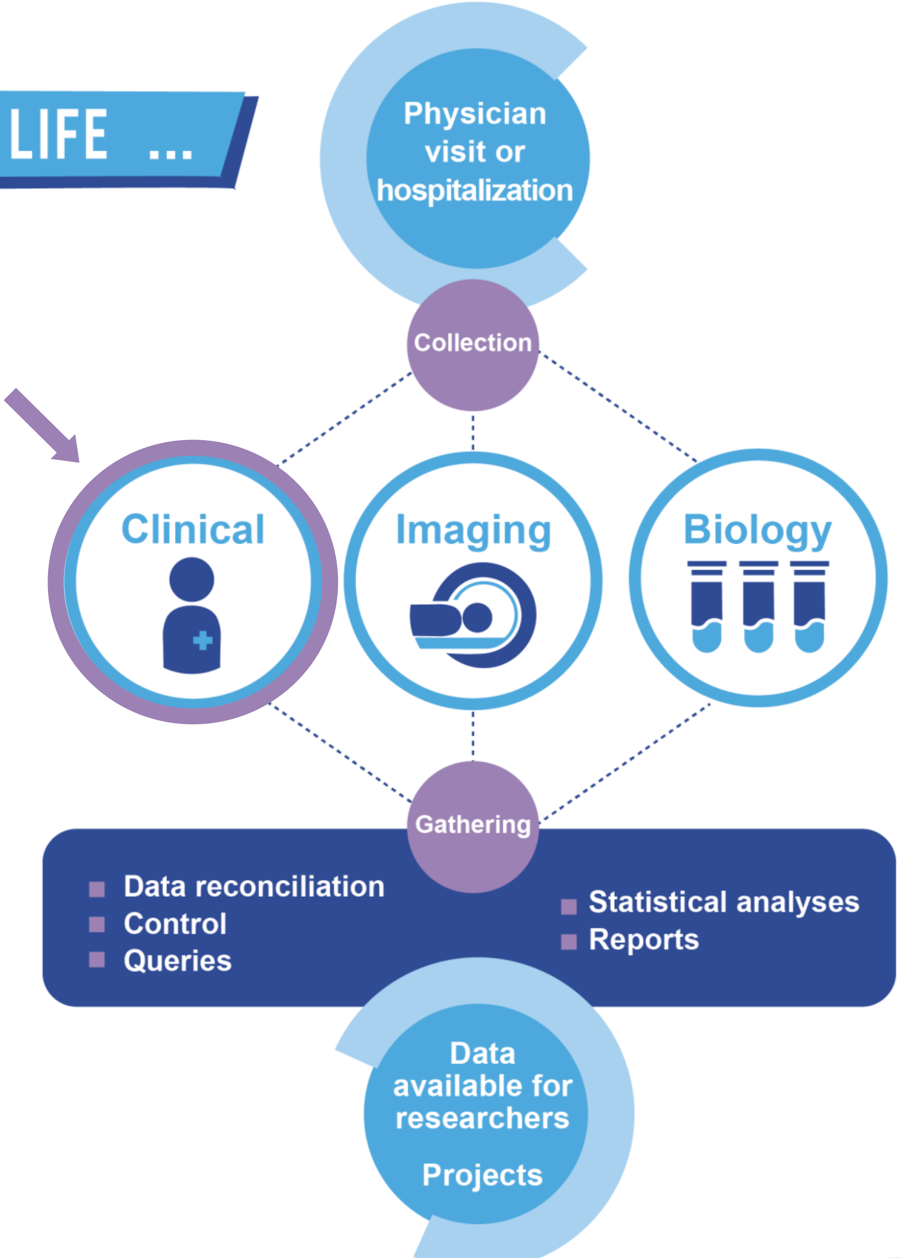
Visit us at stand N34

The French MS registry

Collected data

Clinical data collection

FROM LIFE ...



Physician visit or hospitalization

Data collection during patient visit

Collection

Clinical

Imaging

Biology

Standardized minimal data

+ additional data for specific projects

Gathering

- Data reconciliation
- Control
- Queries
- Statistical analyses
- Reports

Data gathered in the OFSEP common database

Data available for researchers

Projects

... TO SCIENCE

MS DATA IS OUR COMMITMENT

Clinical data collection

- Clinical data collected during routine follow-up visits, usually at least once a year, retrospectively at the first visit and prospectively thereafter
- Minimal mandatory data set:
  - demographic and socioeconomic characteristics
  - neurological episodes
  - disability
  - brain and spinal cord MRI reports
  - disease-modifying treatments
  - serious adverse events
- Patients with RIS, CIS, MS, NMOSD or MOGAD followed up in a participating centre are eligible
- All French MS expert centers and several peripheral centers participate in data collection

Clinical data collection

About

85,000

patients all around France

25,000

patients followed-up

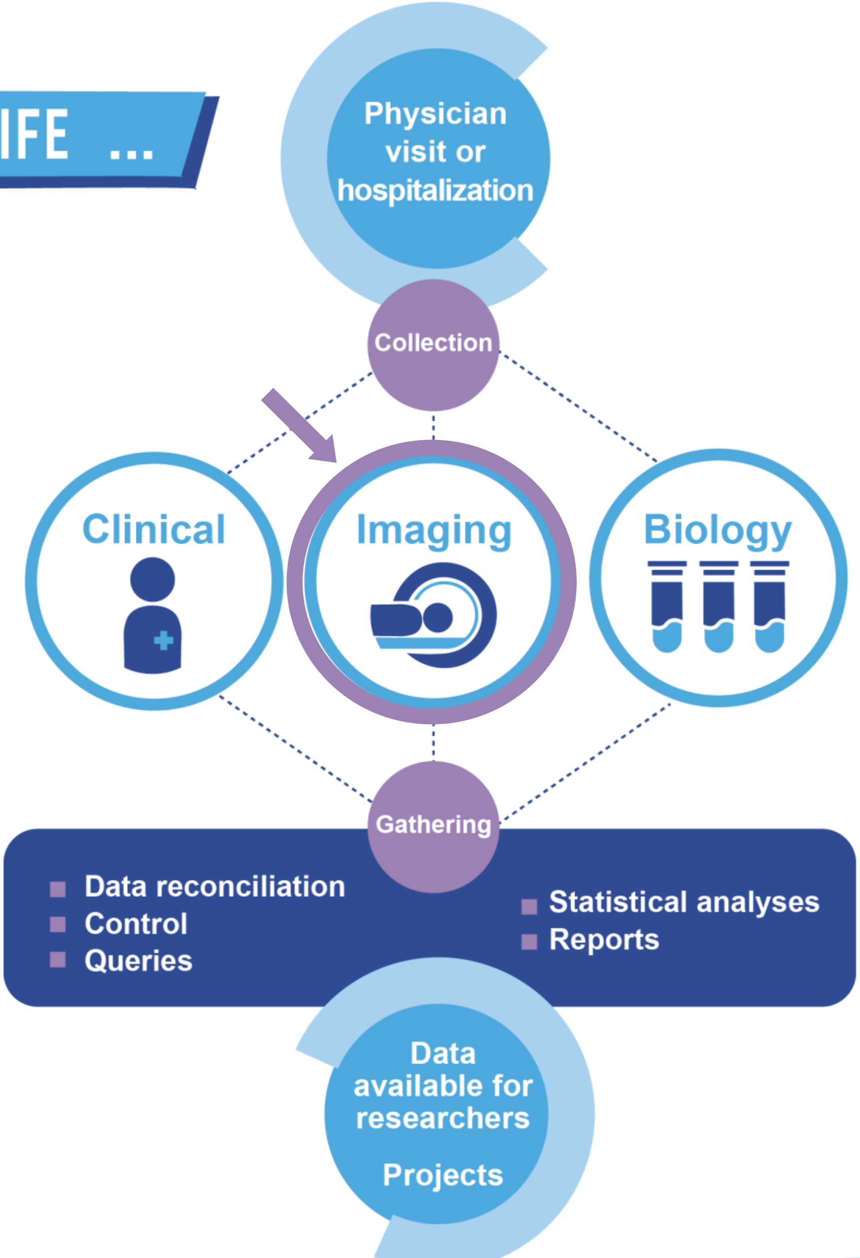
every year

1,200,000 person-years of disease

> 650,000 person-years of prospective follow-up

Imaging data collection (MRI)

FROM LIFE ...



Physician visit or hospitalization

Collection

Clinical

Imaging

Biology

Gathering

- Data reconciliation
- Control
- Queries

- Statistical analyses
- Reports

Data available for researchers

Projects

Data collection during patient visit

Standardized minimal data

+ additional data for specific projects

Data gathered in the OFSEP common database

... TO SCIENCE

MS DATA IS OUR COMMITMENT

MRI

OFSEP cerebral and spinal cord MRI acquisition protocol*,
a consensus within the scientific community, feasible on all equipment and compatible with clinical acquisition times

Recommended sequences:

- **Brain:** 3D FLAIR, 3D T1, DWI, 3D T1 gado *(if necessary)*
- **Spine:** T2 SAG, T1 gado SAG *(if necessary)*

DICOM files stored on a centralized neuroimaging platform

** Brisset JC, Kremer S, Hannoun S, et al. New OFSEP recommendations for MRI assessment of multiple sclerosis patients: special consideration for gadolinium deposition and frequent acquisitions. J Neuroradiol. 2020;47(4):250-258.*

MRI

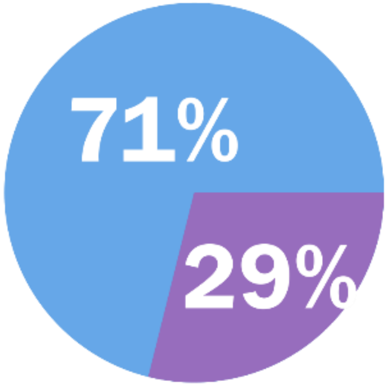
Last year

> 1,800 new patients | **> 12,500** exams

13,159 patients with at least one MRI scan

76,388 Total exams

53,925 brain exams

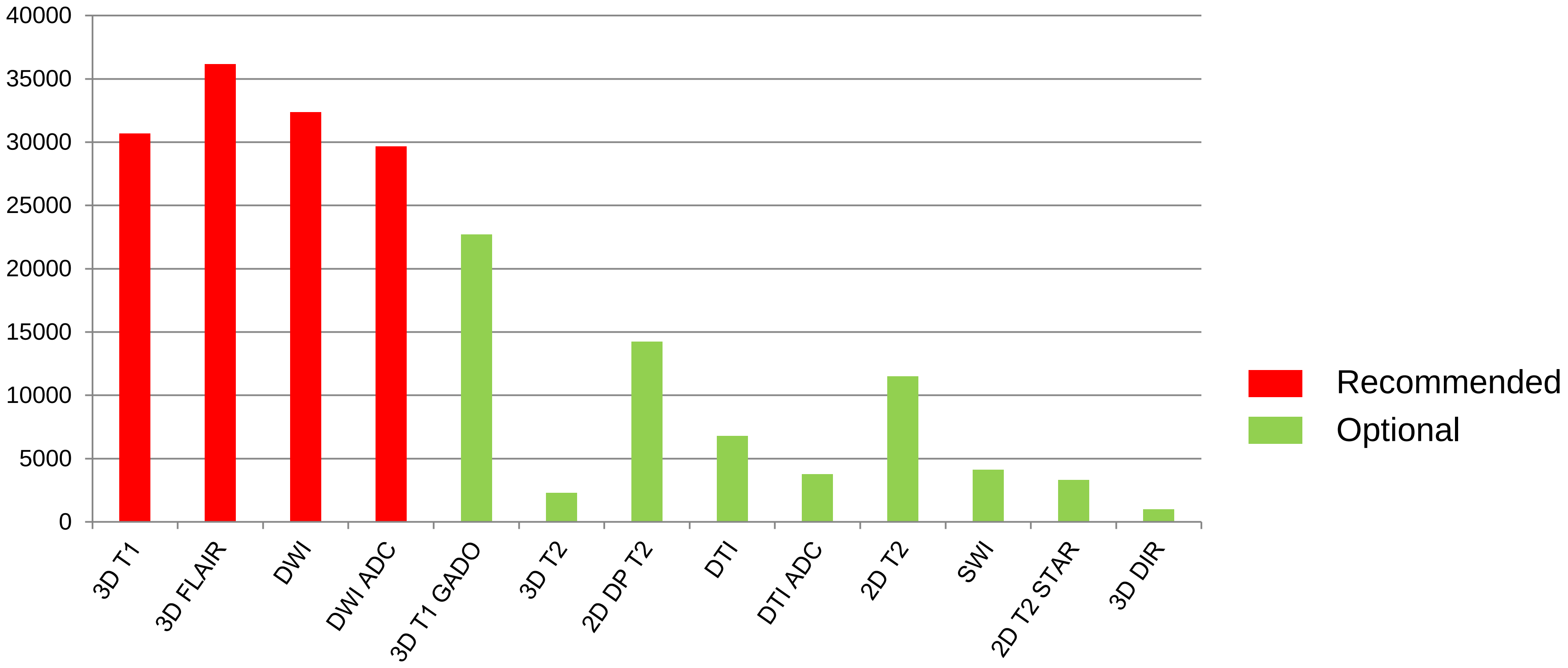


22,463 spinal cord exams

Brain MRI

Main sequences

53,925
brain exams



Siemens: 52%
Philips: 23%
GE: 24%

1.5T: 51%
3T: 49%

Brain MRI

53,925
brain exams

Number of patients						
	1 TP*	2 TP	3 TP	4 TP	5-10 TP	> 10 TP
Brain IRM	3,163	2,225	1,712	1,247	3,720	782

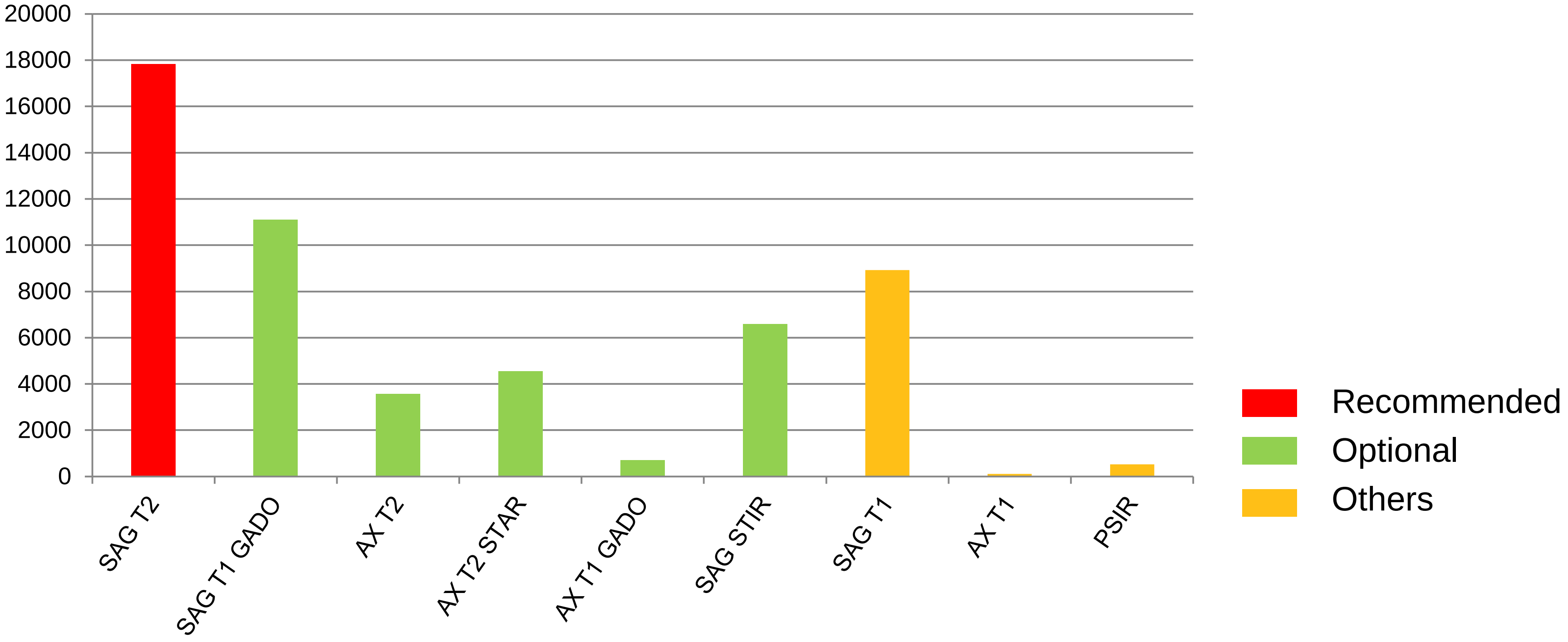
* Time point

Disease form at the first MRI	N
RIS	197
First attack	3,609
RRMS	6,057
SPMS	1,127
PPMS	966
NMOSD	344
MOGAD	372
Not currently identified	177

Spinal cord MRI

Main sequences

22,463
spinal cord exams



Siemens: 57%	1.5T: 66%
Philips: 22%	3T: 34%
GE: 20%	

Spinal cord MRI

22,463
spinal cord exams

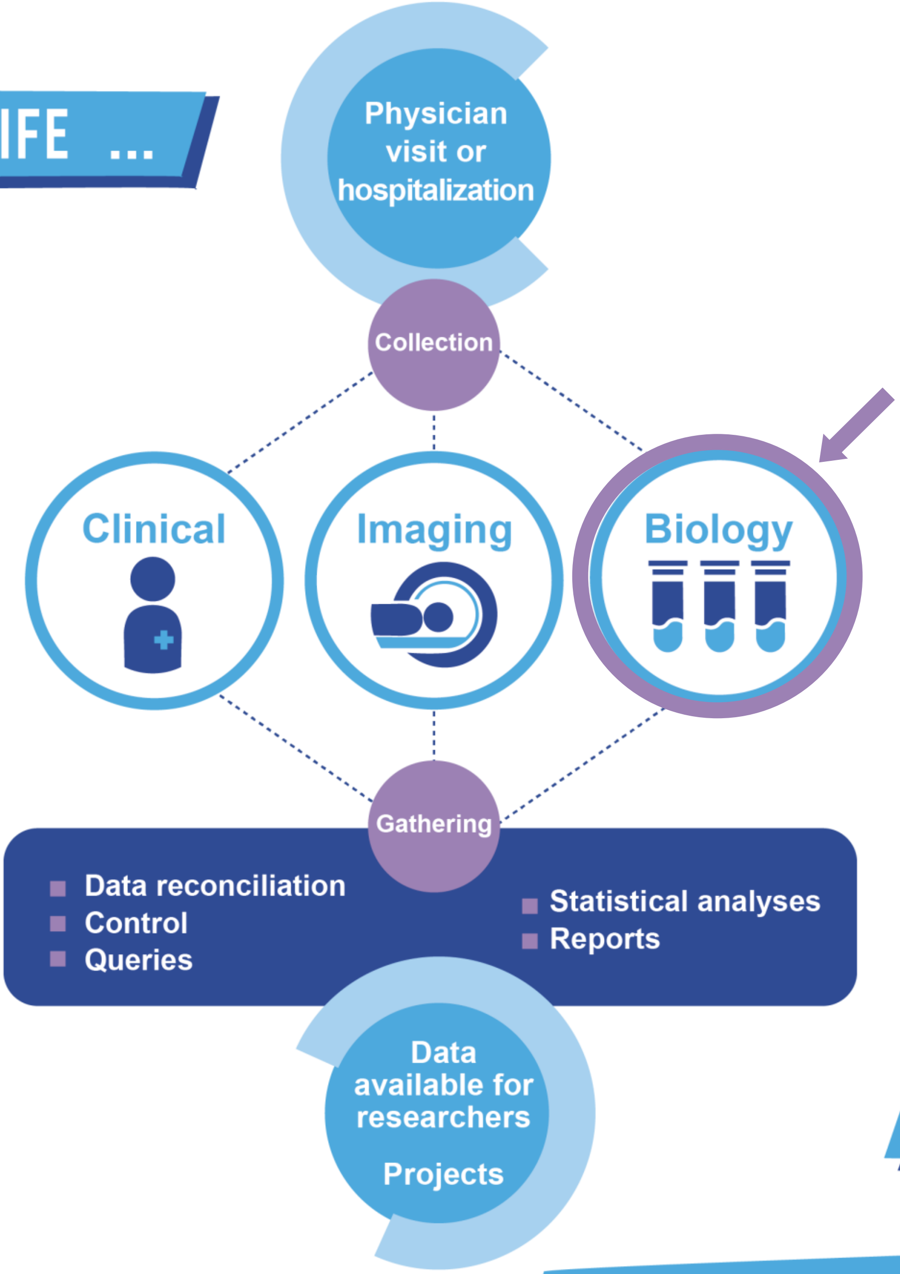
Number of patients						
	1 TP*	2 TP	3 TP	4 TP	5-10 TP	> 10 TP
Spinal cord MRI	4,014	2,057	1,173	676	1,052	34

* Time point

Disease form at the first MRI	N
RIS	119
First attack	2,541
RRMS	4,213
SPMS	770
PPMS	707
NMOSD	288
MOGAD	276
Not currently identified	92

Biology samples collection

FROM LIFE ...



Physician visit or hospitalization

Collection

Clinical

Imaging

Biology

Gathering

- Data reconciliation
- Control
- Queries

- Statistical analyses
- Reports

Data available for researchers

Projects

Data collection
during patient visit

Standardized minimal data

+ additional data
for specific projects

Data gathered in the
OFSEP
common database

... TO SCIENCE

MS DATA IS OUR COMMITMENT

Integrated cohorts with biological samples

Cohort	Iterative sample
Radiologically isolated syndromes (RIS)	Every year until conversion
Clinical isolated syndromes and relapsing-remitting MS (CIS / RRMS) ‘First Attack’ - Sample at less than 6 months of the first inflammatory event of the central nervous system - DMT naive at first sample	At year 1, 3 and 5 and during a relapse
Primary progressive multiple sclerosis (PPMS) - Less than 6 years disease duration - Untreated patient	At year 3 and 6
Neuromyelitis optical spectrum disorders (NMOSD) and Myelin oligodendrocyte glycoprotein-IgG (MOG-IgG) associated disorder (MOGAD) – NOMADMUS cohort	At year 1, 3 and 5 for patients included after the first relapse and before the second one. Additional sample during a relapse.
Acute Disseminated EncephaloMyelitis (ADEM)	No
Progressive Multifocal Leukoencephalopathy (PML)	No
Covid-19 - Sampling within 3 months after biological confirmation of the diagnosis by PCR or onset of symptoms	No
MS patients included in High Definition (HD) cohort	Every 2 years

Biological samples

Blood
- Serum
- EDTA plasma
- PBMC*

Cerebrospinal fluid
- CSF

Others
- Saliva
- Stools

  Collection ended Q2 2022
- Urine

  Collection ended Q2 2022

*Peripheral blood mononuclear cells

Biological samples

8,523 biological samples collected among 5,235 patients in 28 biobanks.

Patients‡	N. of patients	Blood*	PBMC	CSF**	Saliva	Urine***	Stools***	N iterative
RIS	247	247	238	121	82	133	6	39
First attack	1,272	1,272	886	652	143	681	33	349
RRMS	2,241	2,241	313	178	36	219	29	1,244
SPMS	434	434	25	14	3	22	2	229
PPMS	431	431	291	193	27	225	13	173
PML	10	10	10	2	0	9	0	0
NMOSD	400	400	371	28	79	223	3	66
MOGAD	334	334	328	20	90	168	4	72
ADEM	22	22	22	5	2	15	0	1
Covid-19***	66	66	65	0	0	21	0	0

‡ some patients could be counted several times if they enter an new cohort during the follow-up (ex : RIS => FA)

* serum, EDTA plasma, DNA

** cerebrospinal fluid

*** closed collection

Merging with medico-administrative database

French National Insurance database

Merging with medico-administrative database

- **French National Insurance database (SNDS)**
    - Reimbursements made by all health insurance plans (consulting, drug dispensing, medical procedures, biological exams, issuance of technical aids, long-term disease)
    - Hospital medical activity (hospitalizations, diagnoses, medical procedures, external consultations)
    - Death causes

- **Allows to access non-specific MS data** including comorbidities, co-prescriptions, recourse to care…

Merging with medico-administrative database

SNDS extraction

2009 ~ 2023 (planned each year)

84%

success

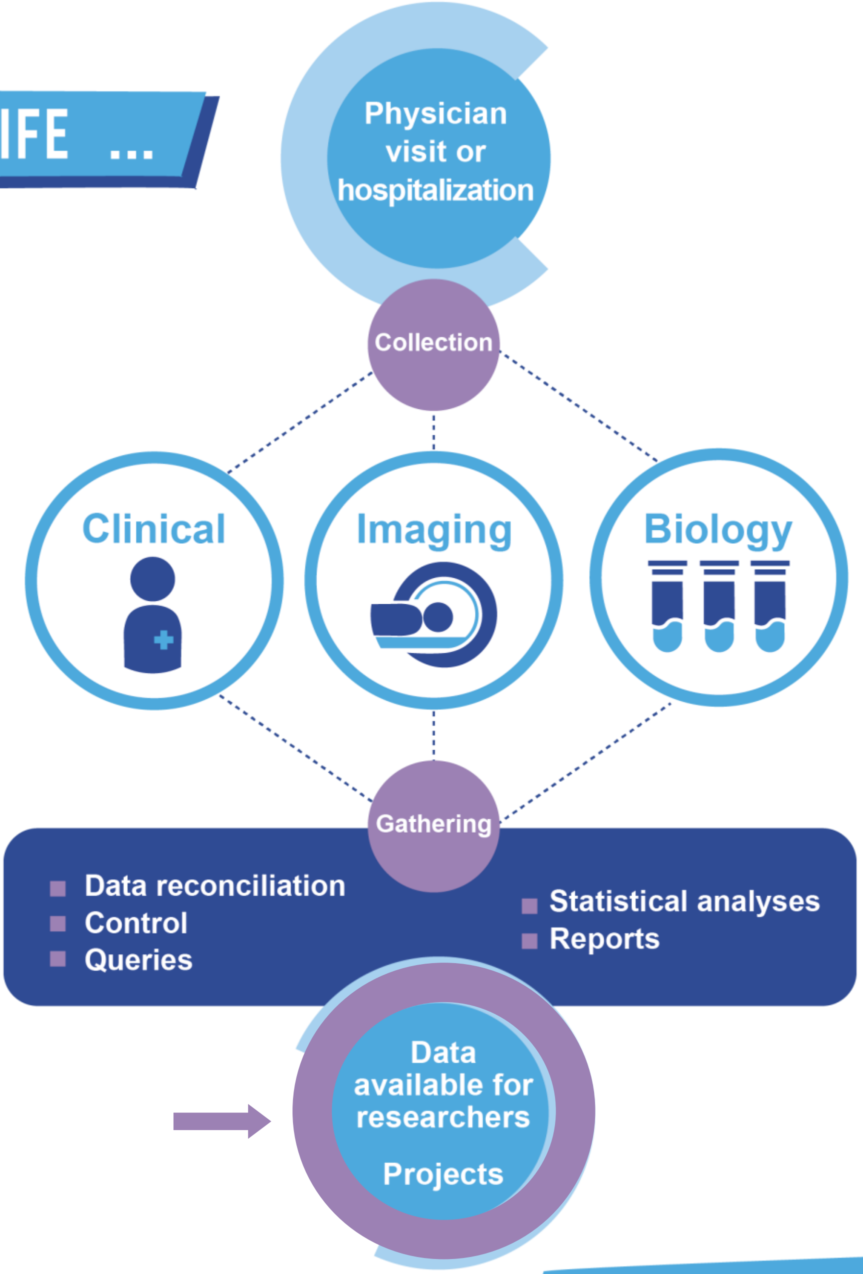
> 55,000

successfully merged patient files

The French MS registry

Projects
and nested cohorts

FROM LIFE ...



Physician visit or hospitalization

Collection

Clinical

Imaging

Biology

Gathering

- Data reconciliation
- Control
- Queries

- Statistical analyses
- Reports

Data available for researchers

Projects

Data collection during patient visit

Standardized minimal data

+ additional data for specific projects

Data gathered in the OFSEP common database

... TO SCIENCE

MS DATA IS OUR COMMITMENT

OFSEP HD cohort

OFSEP HD cohort
Inclusion criteria

- **Diagnosis of multiple sclerosis** according to the most recent criteria
- Age ≥ 15 years
- **Irreversible disability ≤ 7.0 (permanent use of a wheelchair) on EDSS**
- Followed up in one **MS expert center**
- New cases diagnosed after the beginning of the study

or

- For patients diagnosed before the beginning of the study, **regular follow-up** (at least one visit every two years since the date of the first EDSS assessment) with **prospective collection of minimal dataset in EDMUS since 2011**

OFSEP HD cohort

Follow-up

- Annual follow-up (± 2 months) with rebaseline at the first disease activity
- Continuation of the study at least until the end of 2026

Specific data every year

- PRO : sociodemographic data, medical background, quality of life (EQ5D-5L, SF-12, MusiQoL), tobacco, cannabis and alcohol consumption
- Walk test (T25FW), test of upper extremity function (9HPT), test for the detection of information processing speed (CSCT)
- MRI (post-processing) : T2 and new T2 lesions, cerebral volume and atrophy

OFSEP HD cohort

Population

- 2840 patients included between July 2018 and September 2020.
- At inclusion
  - 73% ♀
  - age = 43 years (± 12)
  - disease duration = 11 years (± 9)
  - prospective follow-up = 8 years (± 7)
  - 80% RRMS, 14% SPMS, 6% PPMS
  - untreated patients or all types of ongoing treatments

Biocollection

  - Blood sample and dosages (at inclusion and every two years) : NF-L, GFAP, vitamin D

NOMADMUS cohort

NOMADMUS cohort

- **Inclusion criteria**

  Patients meeting the international NMOSD criteria (Wingerchuk criteria 1999 and 2006, IPND 2015) including Aquaporin 4 – IgG positive patients (AQP4+)

  or Isolated, recurrent or not, acute extensive transverse myelitis

  or Isolated atypical optic neuritis

  or Myelin Oligodendrocyte Glycoprotein – IgG positive patients associated disease (MOGAD)

  or MOGAD-like patients (MOG-IgG negative patients presenting clinical and/or radiological MOGAD features)

- The **NOMADMUS expert group** validates inclusions with a focus on double seronegative (AQP4 and MOG) patients and MOGAD-like patients

- **Minimal mandatory data** set specific to NMOSD/MOGAD

NOMADMUS cohort

- 2604 patients included
- 1264 patients with biological samples (serum, plasma, PBMC, CSF…) in a dedicated biobank or in the OFSEP biobank
- 1610 patients with at least one MRI in a dedicated imaging bank or in the OFSEP imaging bank

RIS cohort

RIS cohort

Inclusion criteria

- MRI lesions suggestive of multiple sclerosis according to 2005 and 2017 MS DIS criteria
- EDSS=0
- Index MRI indication not consistent with demyelinating disease

Exclusion criteria

- Any focal neurological manifestation prior to the acquisition of the MRI

Mandatory data set specific to RIS and RIS conversion

- The **RIS expert group** validates all inclusions
- The RIS expert group is member of the Radiologically Isolated Syndrome Consortium (RISC)

- 810 RIS 2023 patients including 281 MS conversion

Publications

Publications

Reference publications

Confavreux C et Al. **EDMUS, a European database for multiple sclerosis.** J Neurol Neurosurg Psychiatry 1992; 55: 671-676

Vukusic S et Al. **Observatoire Français de la Sclérose en Plaques (OFSEP): A unique multimodal nationwide MS registry in France.** Mult Scler. 2020;26(1):118–22

Brisset JC et Al. **New OFSEP recommendations for MRI assessment of multiple sclerosis patients: Special consideration for gadolinium deposition and frequent acquisitions.** J Neuroradiol. 2020;47(4):250-258. doi:10.1016/j.neurad.2020.01.083

Brocard G et Al. **The biological sample collection of the OFSEP French MS registry: An essential tool dedicated to researchers.** Multiple Sclerosis and Related Disorders. 2023 Sep;77:104872

Guillemin F et Al. **Prognostic factors of disability progression in multiple sclerosis in real life: the OFSEP-high definition (OFSEP-HD) prospective cohort in France.** BMJ Open. 7 avr 2025;15(4):e094688.

Leray E et Al. **Data linkage between the French multiple sclerosis cohort (OFSEP) and the French national health insurance database (SNDS).** Rev Neurol (Paris). 5 juin 2025;S0035-3787(25)00537-5.

Publications

All publications

OFSEP publications are available on our website:

https://www.ofsep.org/en/publications-en

Acknowledgement

This work was done within the framework of OFSEP, the French multiple sclerosis registry

Data collection has been supported by a grant provided by the French State and handled by the "Agence Nationale de la Recherche", within the framework of the "France 2030" programme, under the reference ANR-10-COHO-002 OFSEP; and the support of the "Eugène Devic EDMUS Foundation against multiple sclerosis"

OFSEP

Observatoire Français
de la Sclérose en Plaques

FROM LIFE TO SCIENCE
MS DATA IS OUR COMMITMENT