

OFSEP

Observatoire Français de la Sclérose en Plaques

FROM LIFE TO SCIENCE
MS DATA IS OUR COMMITMENT

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Observatoire Français
de la Sclérose en Plaques

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The French MS registry

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Observatoire Français de la Sclérose en Plaques

Visit us at booth 703



…represented at…

MSToronto2026
10th Joint ACTRIMS-ECTRIMS Meeting

Plenary Session - Closing Lecture and Awards

- **Three Decades of Women's Health in MS**

Sandra Vukusic - ID PL2 - October 23rd | 06:45 PM - 07:15 PM CEST

Industry Supported Satellite Symposium / Non-CE Presentation

- **Treating MS in the Current Era - Is Emerging Data Enough to Shift Behaviors?**

Sandra Vukusic - October 21st | 07:35 PM - 07:45 PM CEST

Oral presentations

- **Brain- versus Spinal Cord–Predominant Phenotypes in Multiple Sclerosis: Demographic Characteristics and Associations with Disability Progression in a Large Cohort with Brain and Whole Spinal Cord Imaging**

Mathilde Liffran - ID O006 - October 21st | 05:57 PM - 06:04 PM CEST

- **Comparative Effectiveness of Ofatumumab vs Ocrelizumab in Relapsing Multiple Sclerosis : A Target Trial Emulation Using MSBase and OFSEP**

Chao Zhu - ID O092 - October 21st | 09:20 PM - 09:30 PM CEST

- **Serum GFAP and age accurately distinguish AQP4-IgG positive and double seronegative NMOSD from MOGAD after a recent attack**

Manon Rival - ID O036 - October 22nd | 09:41 PM - 09:48 PM CEST

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Paper Poster Session 1

- **Comparative Effectiveness of Initial Therapies in Treatment-Naïve Relapsing-Remitting Multiple Sclerosis: a Multi-Arm Target Trial Emulation with Causal Mediation Analysis For Relapse Contribution -** *Antoine Gavoille* - ID P0394
- **Air pollution and the risk of multiple sclerosis relapse risk in the Paris region: insights from the CONFISEP study -** *Edouard Januel* - ID P0151
- **Measurement of Quantitative Susceptibility Mapping of the spinal cord in people with Multiple Sclerosis and Association With Clinical Disability -** *Anne Kerbrat* - ID P0207
- **Automated Detection of New Spinal Cord Lesions Between Two Longitudinal MRI Scans in people with MS could Improve Radiologists Sensitivity -** *Louis Padé - ID P0250*
- **Post authorization drug safety monitoring using multiple sclerosis patient registries -** *Elena Flavia Mouresan - ID P0413*

Paper Poster Session 2

- **Escalation vs induction therapeutic strategy in patients with late onset multiple sclerosis -** *Nicolas Collongues* - ID P1451

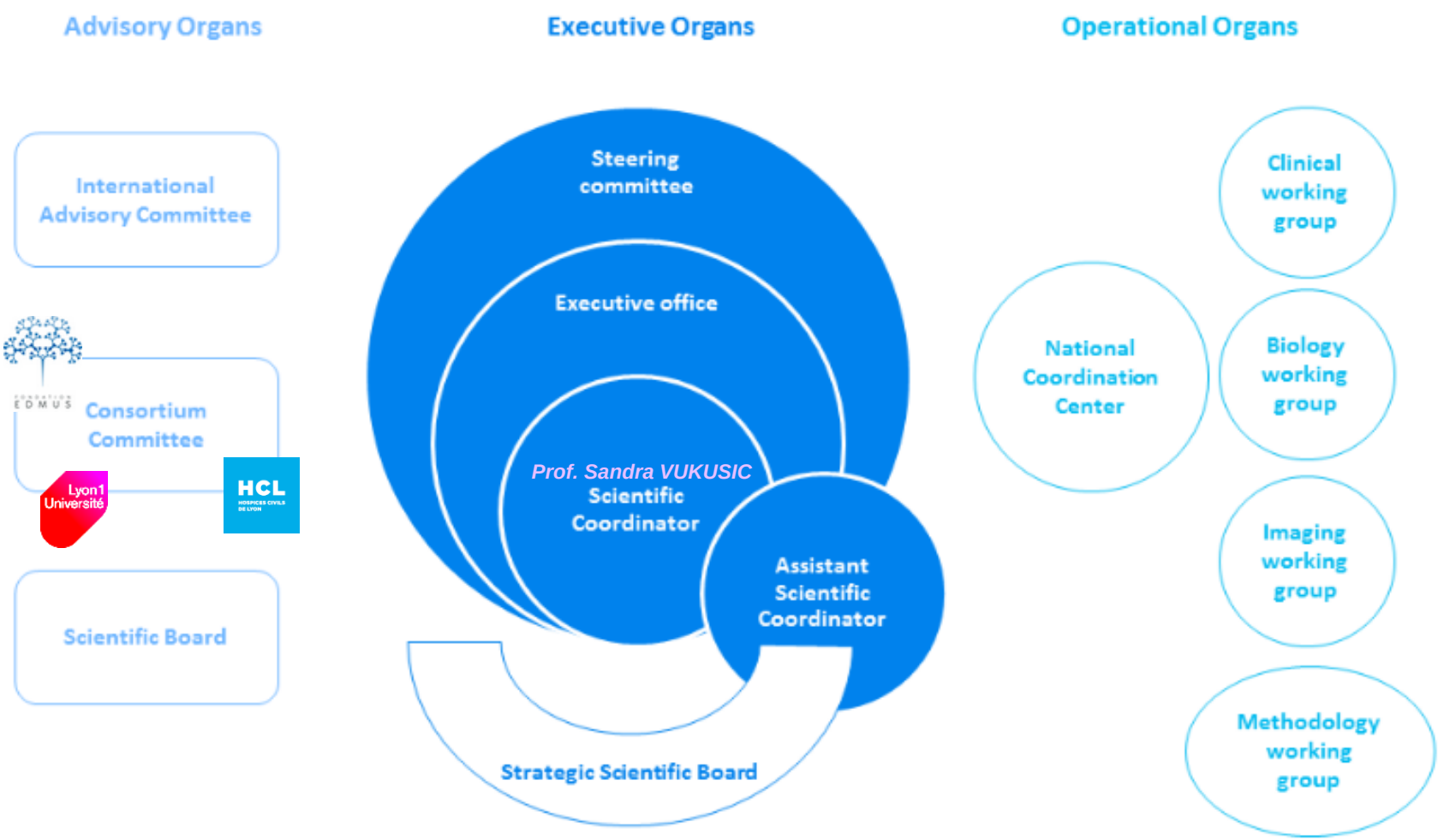
LB Paper Poster Session 2

- **From Incidental MRI Findings to Multiple Sclerosis: Do the 2024 McDonald Criteria Outperform the 2023 RIS Definition? -** *Christine Lebrun-Frenay* - ID P1494

e-Posters

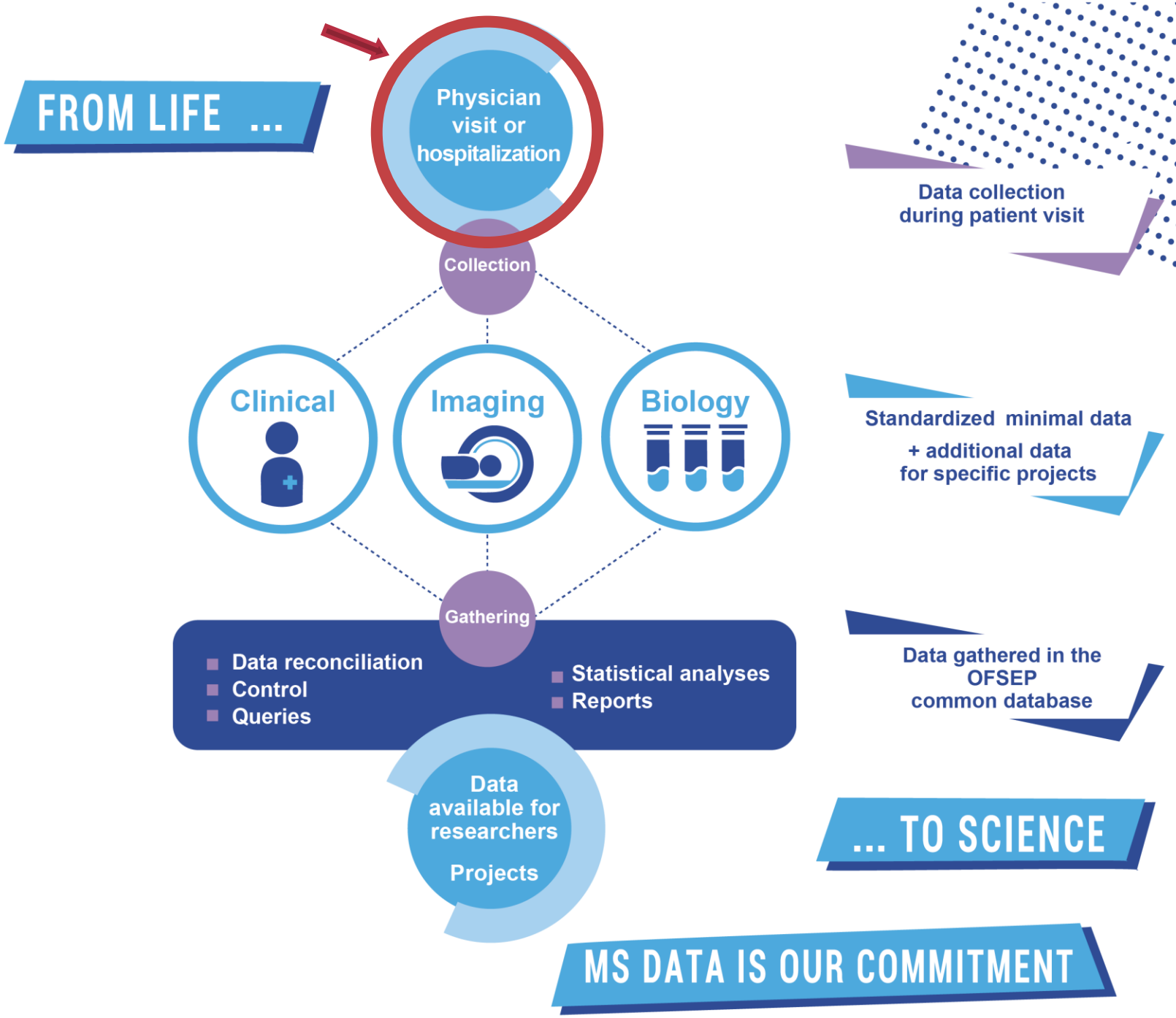
- **Real-World Persistence With Ofatumumab in Patients With Relapsing Form of MS in France: Interim Results From the ASTREOS Study Based on OFSEP Data (EDMUS Database) -** *Jonathan Ciron* - ID EP2651
- **Should annual brain MRI monitoring be performed in all treated people with MS? Real-World detection rates of subclinical disease activity by treatment, duration, and age -** *Françoise Durand-Dubief* - ID EP2375
- **Ovarian Reserve in Women with Multiple Sclerosis: A Cross-Sectional Study -** *Pierre Clavelou* - ID EP2251

Organisation

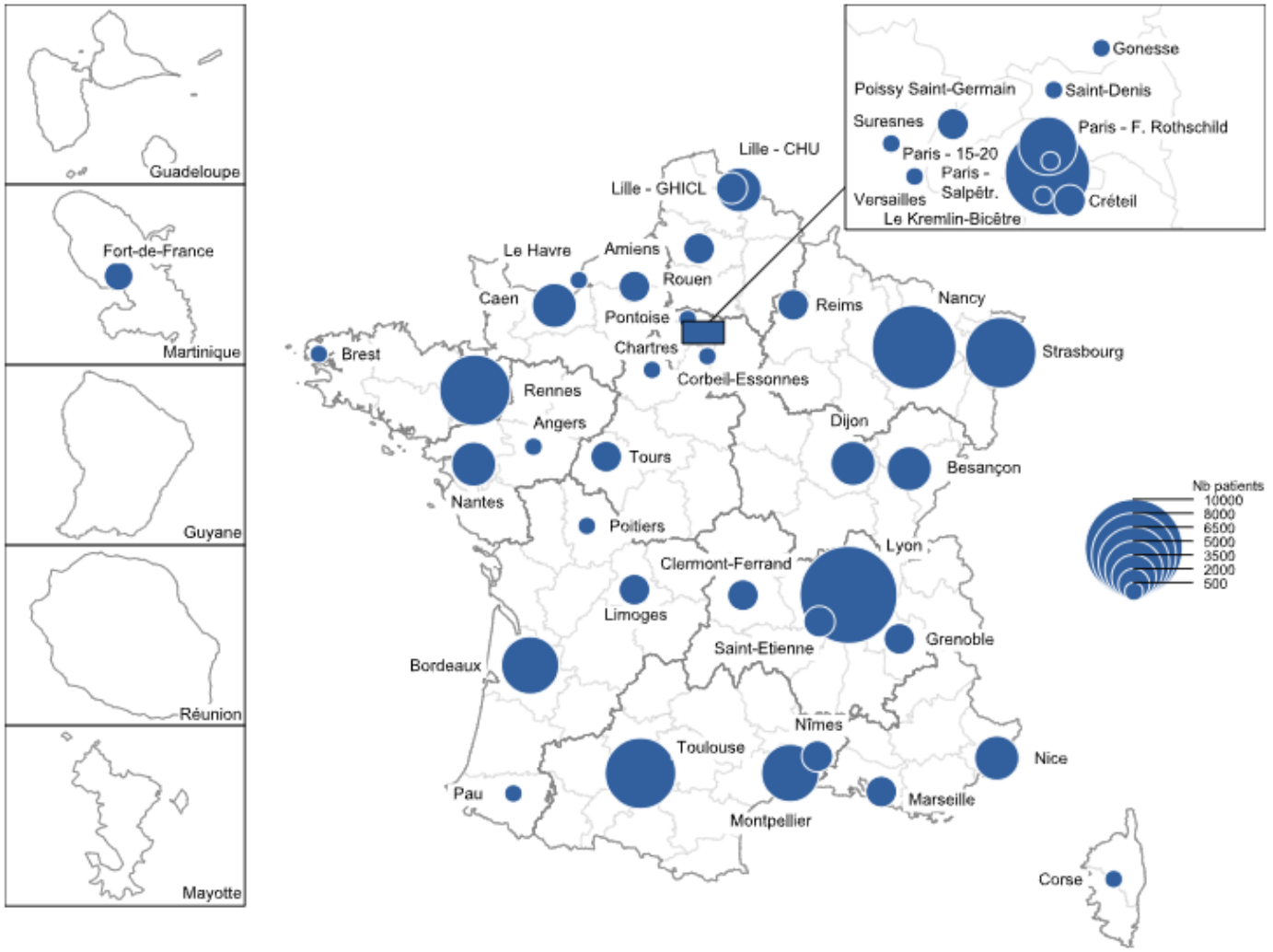


The French MS registry

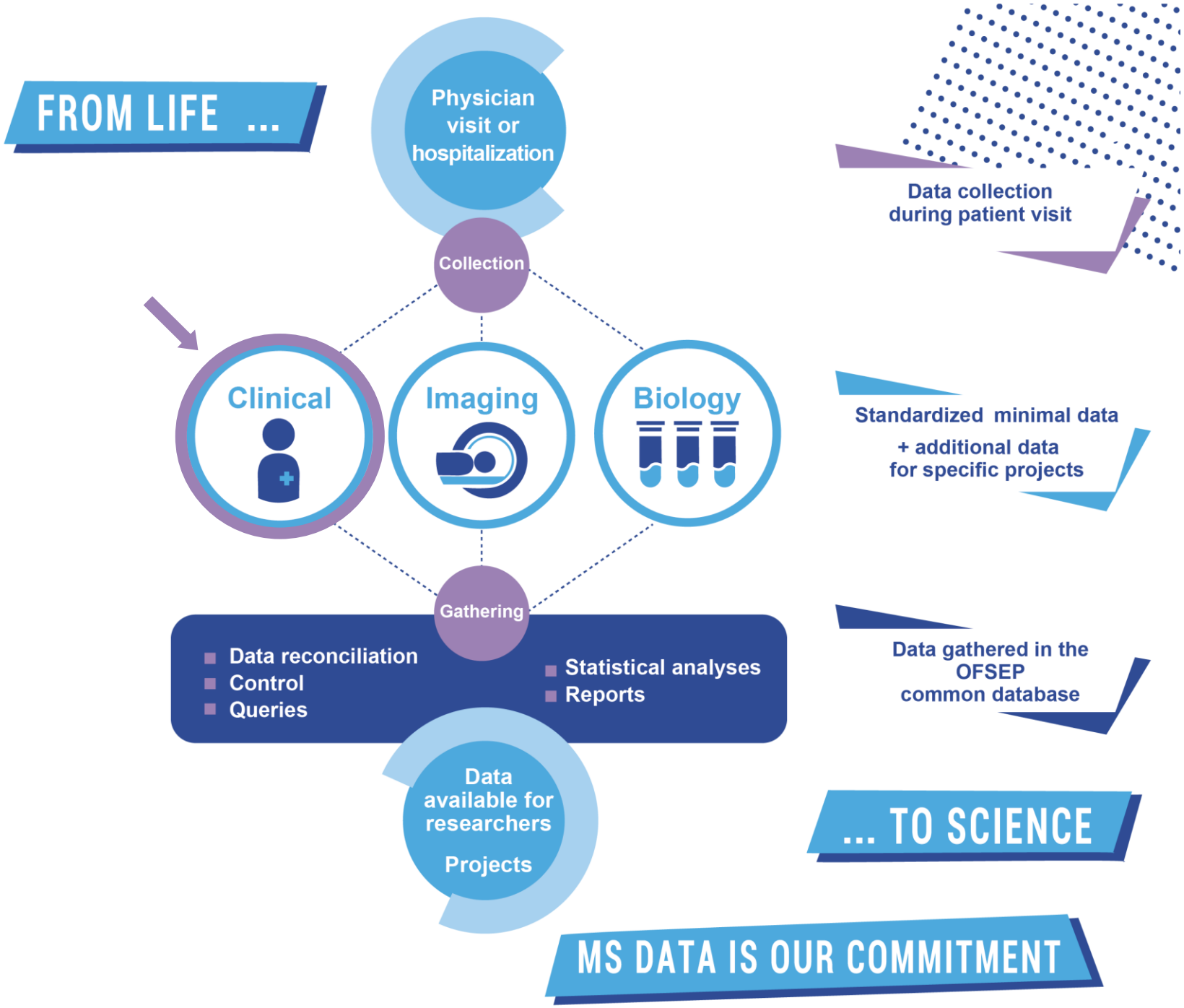
Collected data


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
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50 centers


Guadeloupe
Martinique
Fort-de-France
Guyane
Réunion
Mayotte
Gonesse
Poissy Saint-Germain
Saint-Denis
Suresnes
Paris - F. Rothschild
Paris - 15-20
Paris - Salpêtr.
Versailles
Créteil
Le Kremlin-Bicêtre
Lille - CHU
Lille - GHICL
Le Havre
Amiens
Rouen
Caen
Pontoise
Reims
Nancy
Strasbourg
Chartres
Brest
Corbeil-Essonnes
Rennes
Angers
Dijon
Tours
Besançon
Nantes
Poitiers
Lyon
Clermont-Ferrand
Limoges
Grenoble
Saint-Etienne
Bordeaux
Nîmes
Toulouse
Nice
Pau
Marseille
Montpellier
Corse
Nb patients
10000
8000
6500
5000
3500
2000
500

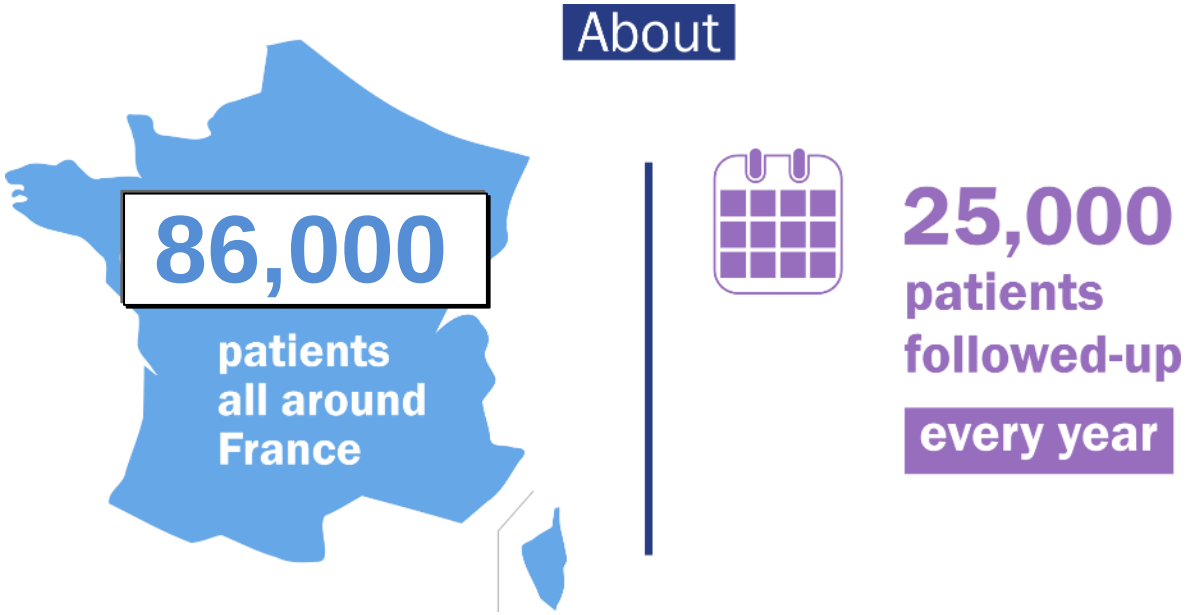
Clinical data collection


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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

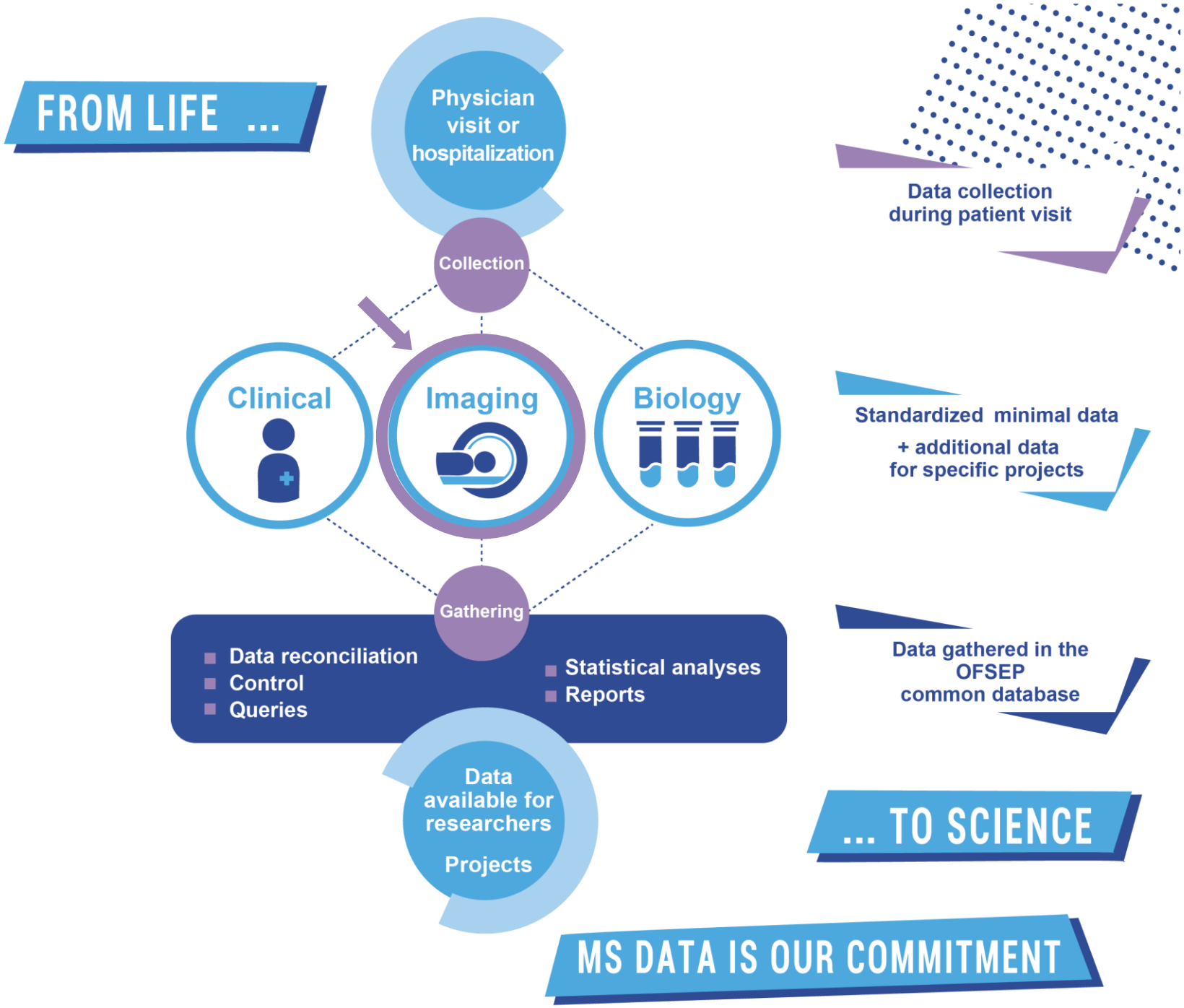
Clinical data collection



1,250,000 person-years of disease

> 690,000 person-years of prospective follow-up

Imaging data collection (MRI)


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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, DWI, 3D T2* GRE or 3D SWI, 3D T1 gado *(if necessary)*
- **Spine:** 3D T1, T2 SAG, T2 AX, T1 gado SAG *(if necessary)*

DICOM files stored on a centralized neuroimaging platform

Lecler A, Mondot L, Homo C, Tourdias T, Vukusic S, Durand-Dubief F, et al. Updated French OFSEP Recommendations for Multiple Sclerosis MRI: Alignment with the 2024 McDonald Criteria. Journal of Neuroradiology. 2026; 53(5)

MRI

Last year

> 2,500 new patients

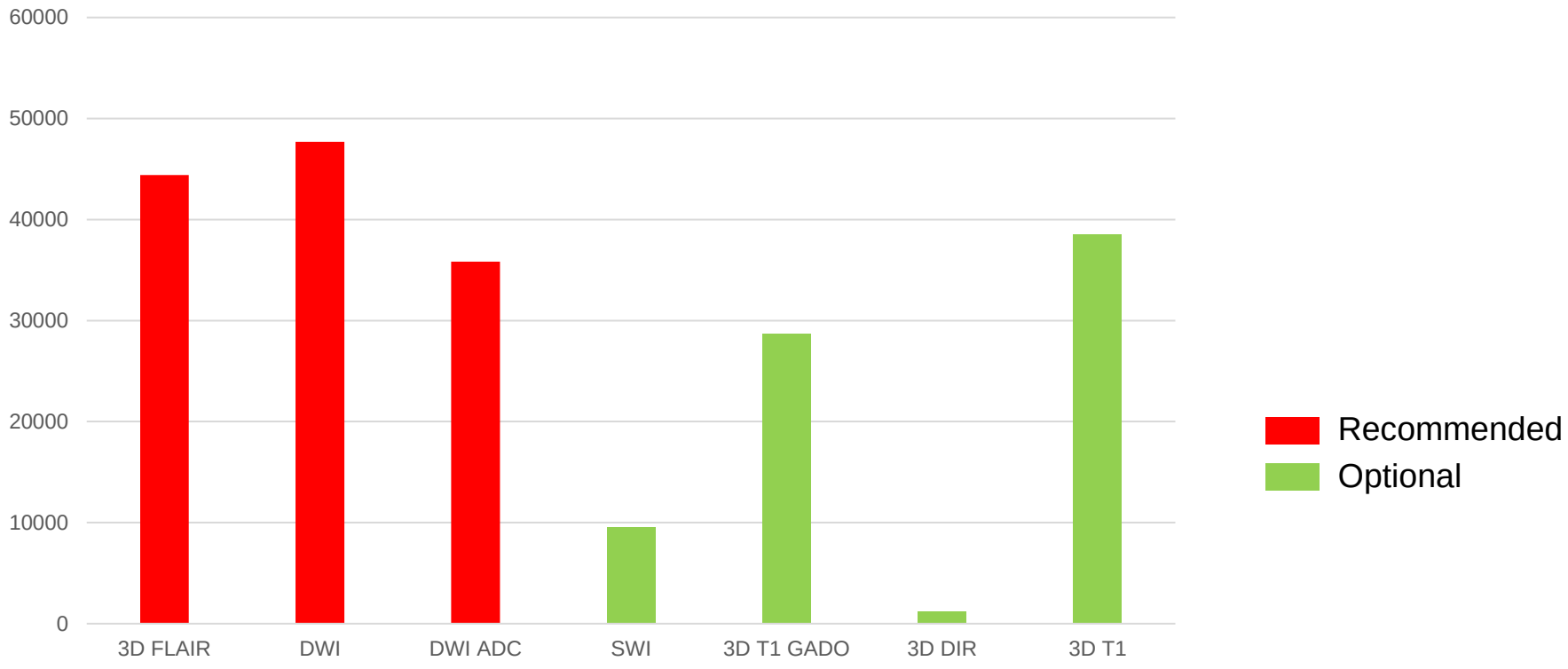
> 15,000 exams

15,561
patients with at least one MRI scan

89,230 exams

- ✓ 62,724 brain exams (70%)
- ✓ 26,506 spinal cord exams (30%)

Brain MRI
Main sequences



Siemens: 51%
Philips: 22%
GE: 25%

1.5T: 48%
3T: 52%

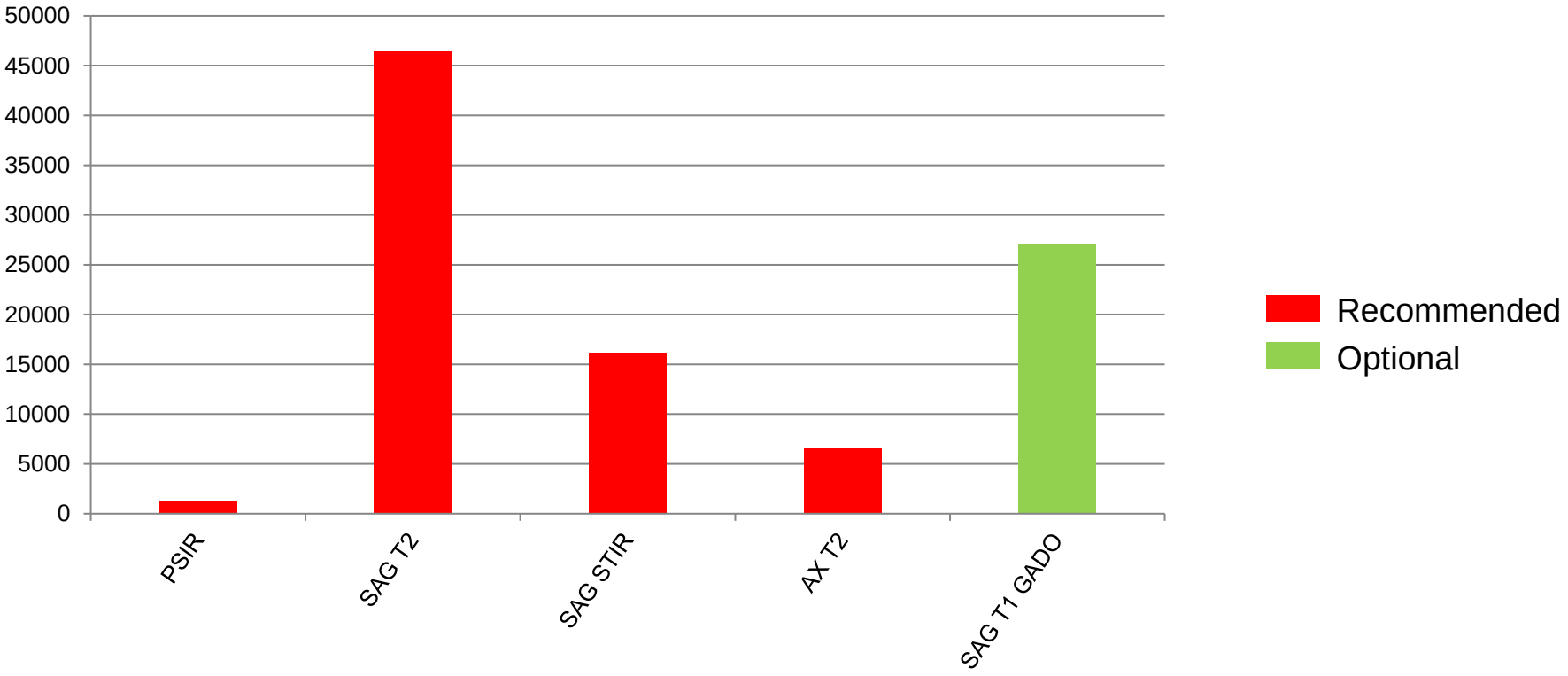
Brain MRI

Number of patients						
	1 TP*	2 TP	3 TP	4 TP	5-10 TP	> 10 TP
Brain IRM	3,375	2,152	1,473	1,202	3,264	526

* Time point

Disease form at the first MRI	N
RIS	308
First attack	4,210
RRMS	6,902
SPMS	1,266
PPMS	1,107
NMOSD	483
MOGAD	483
Not currently identified	220

Spinal cord MRI
Main sequences



Siemens: 60%
Philips: 18%
GE: 20%

1.5T: 66%
3T: 34%

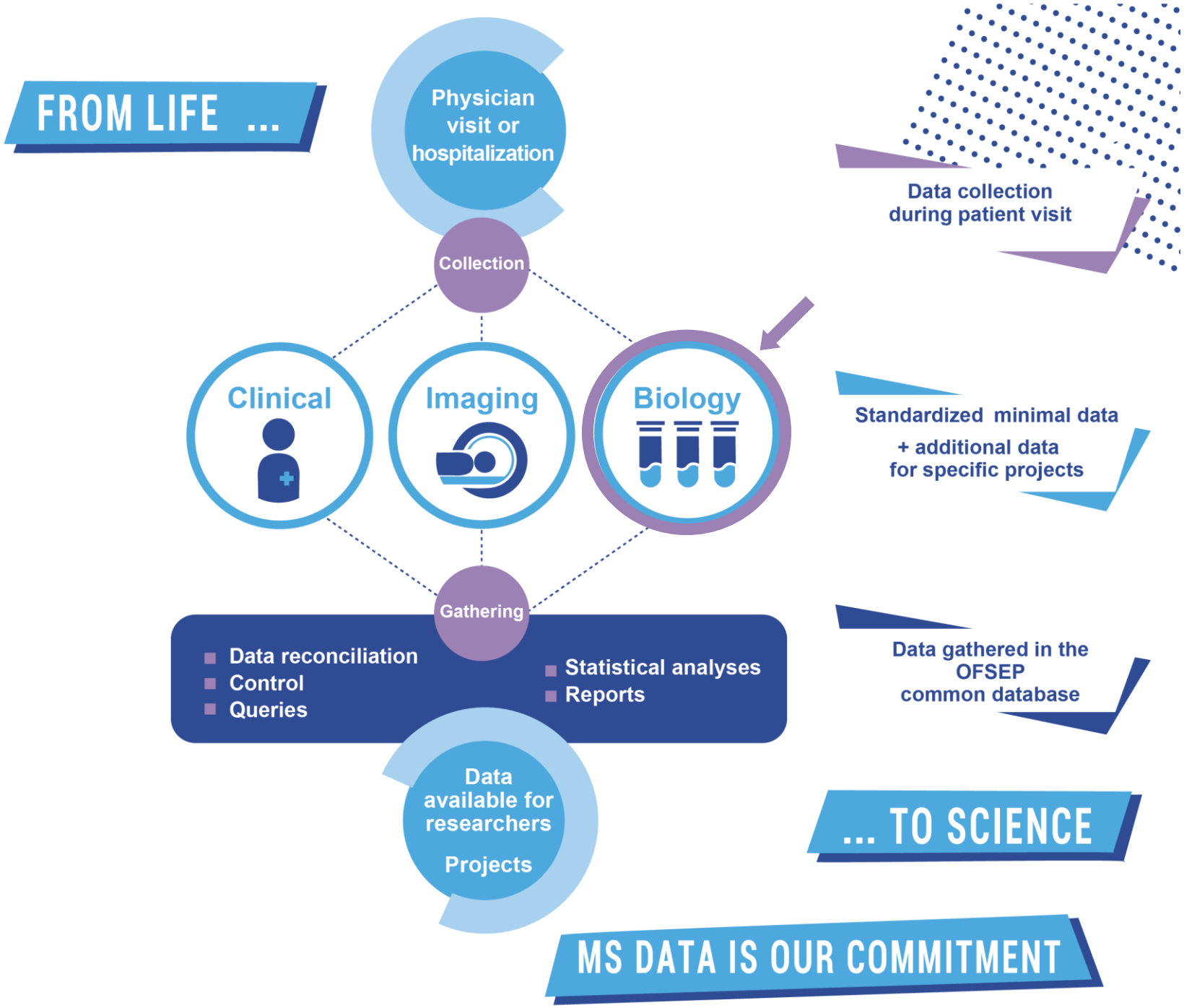
Spinal cord MRI

Number of patients						
	1 TP*	2 TP	3 TP	4 TP	5-10 TP	> 10 TP
Spinal cord MRI	3,547	1,748	886	536	766	23

* Time point

Disease form at the first MRI	N
RIS	192
First attack	3,031
RRMS	4,963
SPMS	930
PPMS	839
NMOSD	413
MOGAD	355
Not currently identified	126

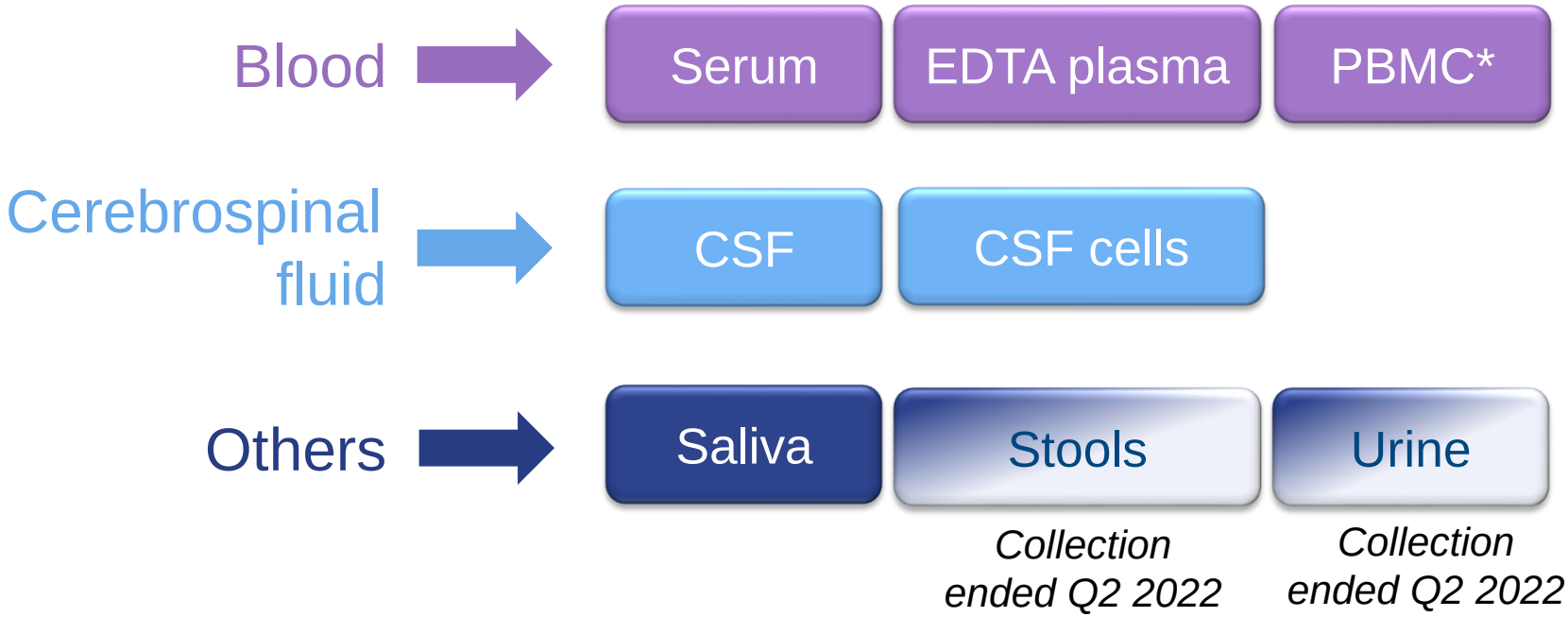
Biology samples collection


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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



*Peripheral blood mononuclear cells

Biological samples

9,639 biological samples collected among 5,417 patients.

Patients‡	N. of patients	Blood*	PBMC	CSF**	Saliva	Urine***	Stools***	N iterative
RIS	256	256	241	124	94	130	5	48
First attack	1,301	1,301	879	674	169	680	33	385
RRMS	2,275	2,275	328	186	50	220	29	1,360
SPMS	448	448	25	14	4	22	2	274
PPMS	436	436	282	194	30	225	13	187
PML	11	11	11	2	0	9	0	0
NMOSD	449	449	368	33	117	222	3	94
MOGAD	397	397	333	23	139	165	4	93
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 with or without CSF cells
*** 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

Data since 2009

Updated yearly extraction

84%

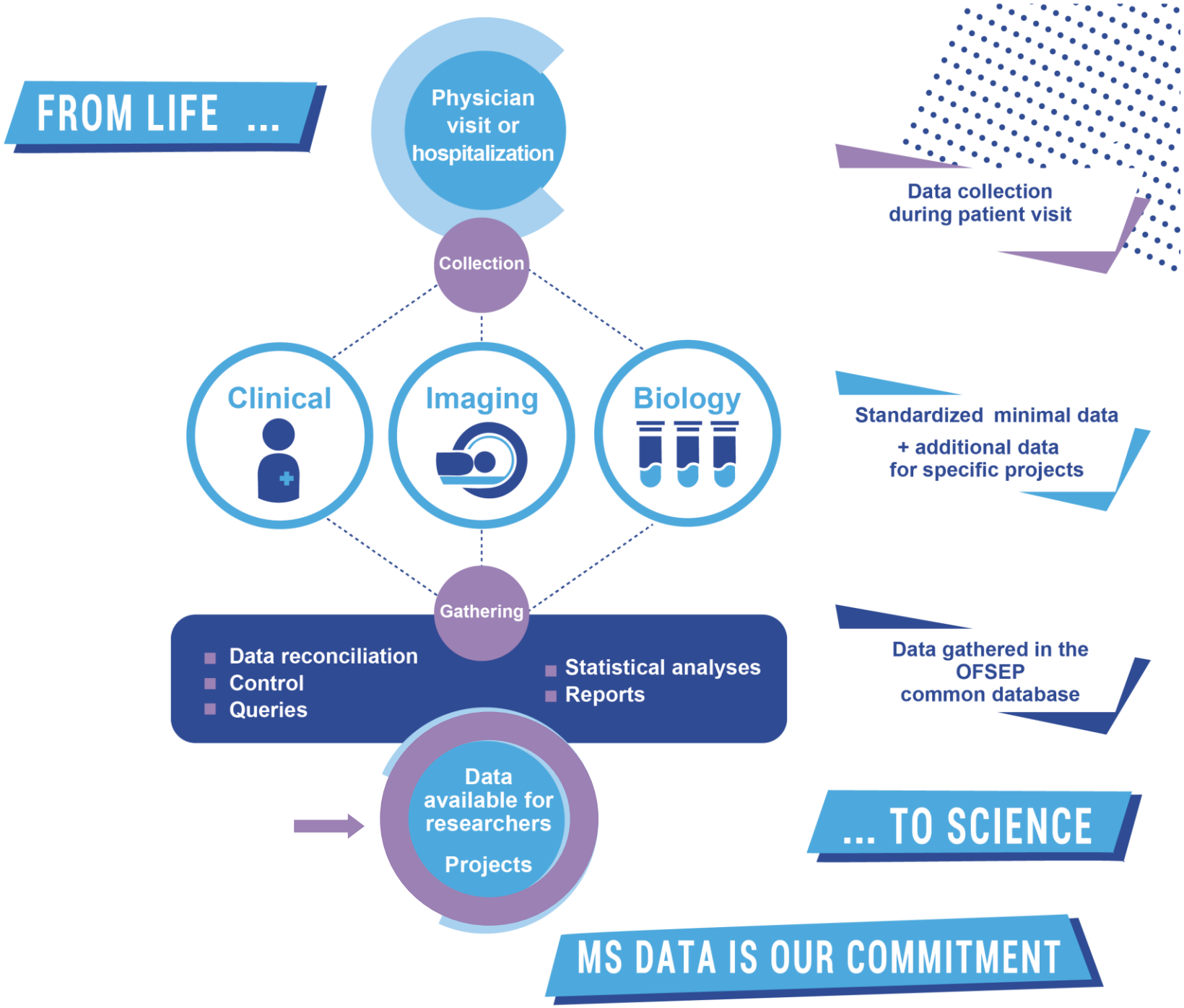
successfully merged

> 55,000

merged patient files

The French MS registry

Projects
and nested cohorts


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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

- 3009 patients included : 34% AQP4+ / 50% MOGAD
- 50% of patients with biological samples (serum, plasma, PBMC, CSF…) in a dedicated biobank or in the OFSEP biobank
- 60% of patients with at least one MRI in a dedicated imaging bank or in the OFSEP imaging bank

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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)

- 797 RIS 2023 patients including 285 MS conversion

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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

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

Leray E, Drezen E, Casey R, Vukusic S, Ofsep. **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.

Guillemin F, Casey R, Epstein J, Foucher Y, Laplaud D, Achit H, 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.

Lecler A, Mondot L, Homo C, Tourdias T, Vukusic S, Durand-Dubief F, et al. **Updated French OFSEP Recommendations for Multiple Sclerosis MRI: Alignment with the 2024 McDonald Criteria.** Journal of Neuroradiology. 2026; 53(5)

Publications

All publications

OFSEP publications are available on our website:

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

Acknowledgements

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OFSEP THANKS THE PARTNERS FOR THEIR SUPPORT TO THE FRENCH MS REGISTRY

Biogen

Roche

NOVARTIS

JUVISE® pharmaceuticals

ALEXION

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