

The SURVIMUS study

A large multicenter study on long-term mortality of multiple sclerosis patients in France

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Disclosures

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Background

- Survival in MS (registries and large databases, USA & EU)
 - Median time: 24 to 45 years after MS clinical onset
 - Standardised Mortality Ratio (SMR) ~ 2.5 to 3
 - Life expectancy reduced ~ 6 to 12 years
- Our experience in West France, 2004 (Leray *et al.*, Mult Scler, 2007)
 - 1879 patients, followed up for 13 years after MS onset
 - Death rate: 2.8 per 1000 patients-years; SMR = 1.3 [1.0-1.7]
 - Limitations: short follow-up duration, selection bias?

→ Initiation of a large multicenter study : the SURVIMUS study





Objectives

The SURVIMUS study aimed to:

- Measure death rate and life expectancy in MS patients,
- Describe causes of death,
- Assess prognostic factors for MS mortality,
- Compare mortality in MS patients to that of the general French population, matched for age, sex, and calendar period,
- Assess for some geographic variations in MS mortality.





Study population

French EDMUS users



~ 33,000 MS patients

Inclusion criteria:

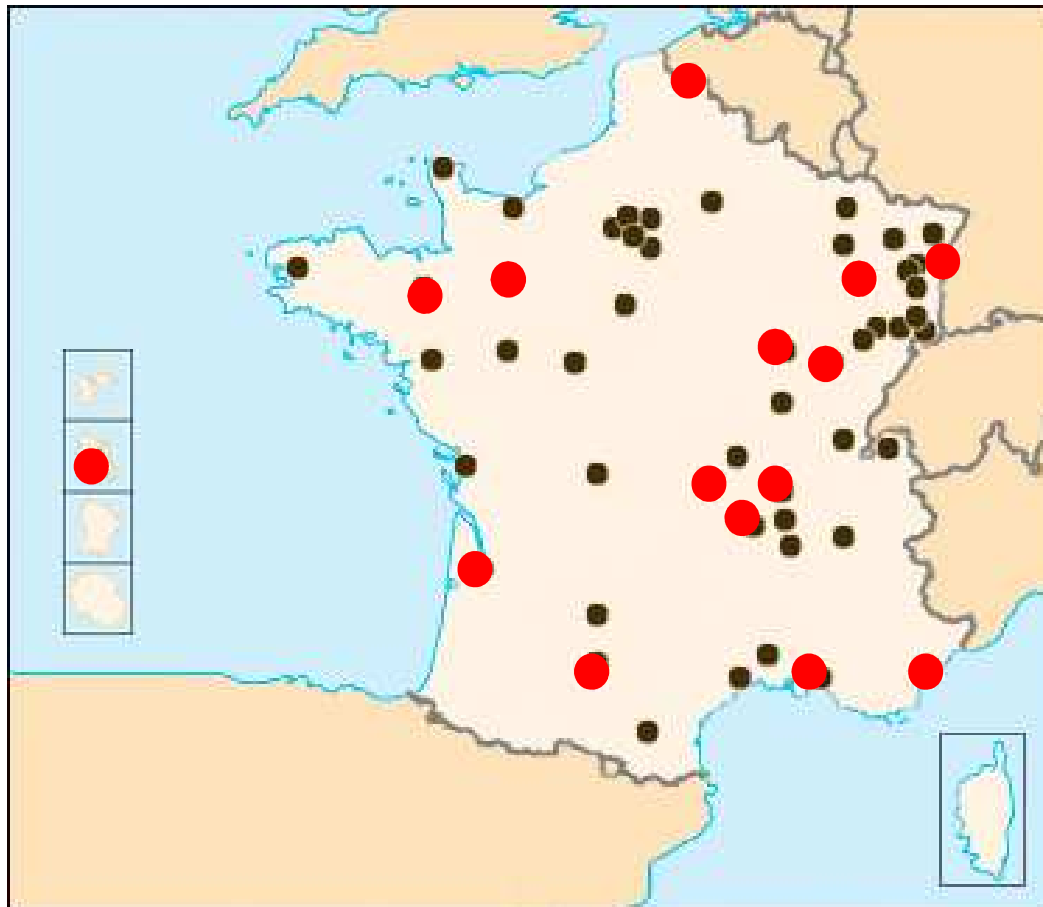
1. Definite diagnosis of MS (Poser, McDonald 2005)
2. MS clinical onset < 2009
3. Vital status known

End-of-study date: 1st January 2010





Study population



- EDMUS users
- SURVIMUS centers

Potential
=
30,000

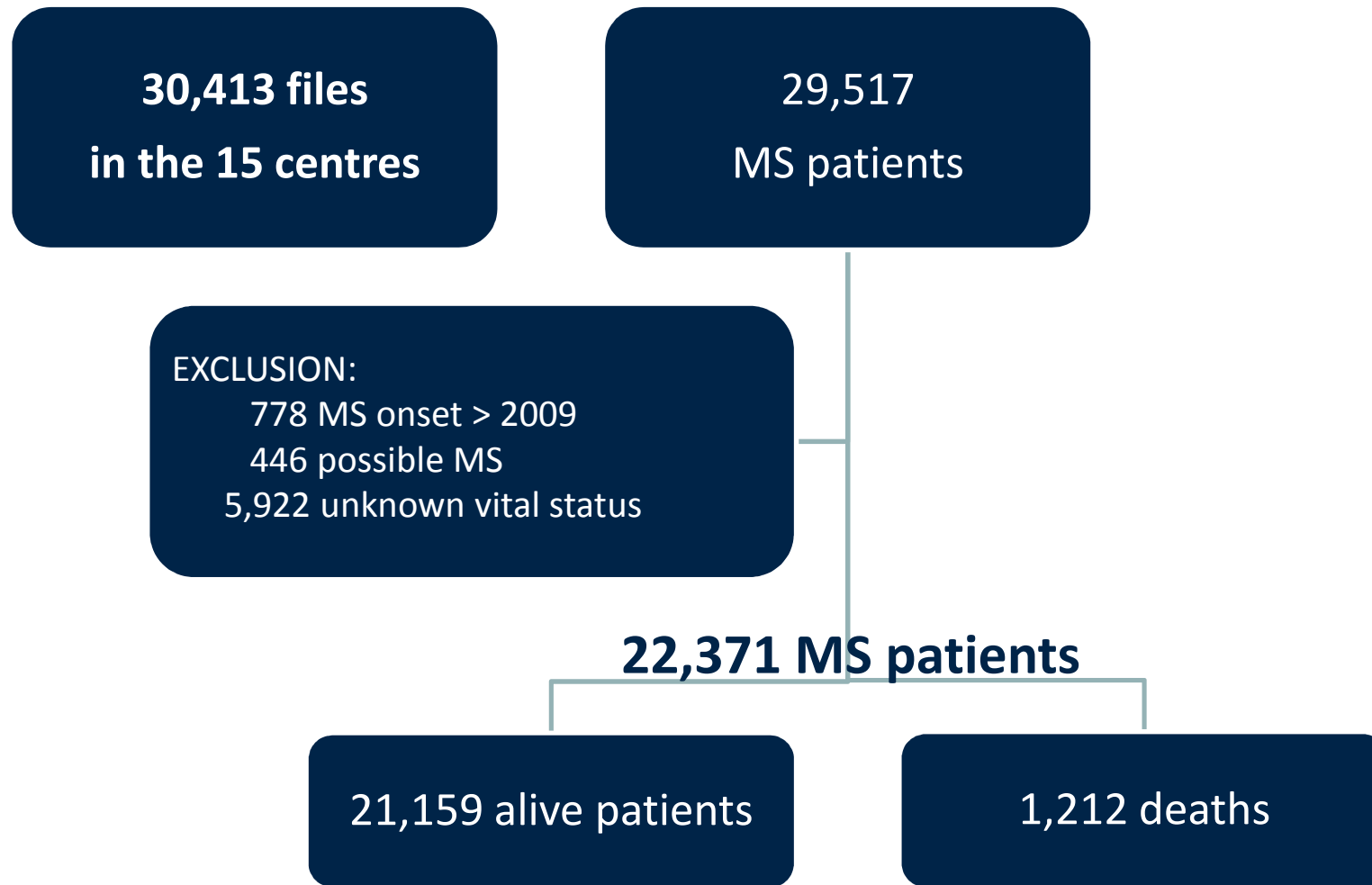


Methods

- Registration of deaths
 - Not exhaustive in EDMUS databases
 - Linkage to two national registers (vital status and causes of death), after ethics committee approval
- Statistical analysis
 - Death rates
 - Kaplan-Meier analysis
 - Comparison to the general French population using probabilities of dying from the life tables (sex, age, calendar year), SMR calculation (ratio observed/expected)



Flowchart of the study population





- Characteristics of the 22,371 MS patients
 - Sex ratio F:M = 2.3
 - Mean age at MS onset: 31.9 ± 14.8 years
 - Mean follow-up duration from MS onset: 15.8 ± 10.3 years
 - Median 13.7 years; Range: from 6 months to 70 years
 - Phenotype at onset:
 - 85.6 % relapsing onset
 - 14.4 % progressive onset



Results

Up to 1st January 2010: 354,111 patients-years (PY) of follow-up

1,212 deaths

5.4 % of MS patients

3.4 per 1000 PY

Out of the 773 available
death certificates:

401 MS-related deaths
(51.9 %)

SMR ~1.5





Preliminary results

- Large study ($> \frac{1}{4}$ MS cases)
- Characteristics comparable to most of MS populations
- Exhaustivity of deaths
- Mortality results close to those from West France...
- Selection bias ?

Perspectives

- Decrease the exclusion rate (20% patients with unknown vital status... missing data/mistakes...)
- How to precisely estimate the number of expected deaths?
- Which risk factors for death? Demographic, clinical, DMDs ...
- What is an MS-related death?





Thanks for your attention