

TOOLBOX

STRATEGIC FOCUS AREA 1

Cataloguing and publishing descriptions of data sources

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Information quality is in the eyes of the beholder

FIT FOR PURPOSE



Information quality is defined as the degree to which the data is “fit for purpose” for the correct operation of the application

ABBREVIATIONS

CEMCAT

Centre D'esclerosi
Multiple De Catalunya

CIS

Clinically isolated
syndrome

CLIMB

Comprehensive
Longitudinal Investigation
of MS

EPIC

MS genetics-, expression,
proteomics, imaging
clinical

NARCOMS

North American Research
Committee on MS

NARCRMS

North American Registry
for Care and Research in
Multiple Sclerosis

OFSEP

Observatoire Francais de
la Sclérose en Plaques

PROMOPROMS

new functional PROfile to
MOnitor the PROgression
of disability in MS



Regional- or National Longitudinal follow-up

British Columbia MS Database, Danish MS
Registry, Italian MS Registry, New York State
MS Consortium, OFSEP, Swedish MS Registry

Many other existing and emerging (Canadian
Progression Cohort in MS, Corrona MS Registry,
Czech MS registry, German MS registries (>3),
MS Clinical Database and Registry Health
Sciences Centre Winnipeg, SJ MS Center Face
to Face Registry, Sonya Slifka Longitudinal MS
Study, United Kingdom MS Registry, ...)



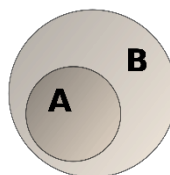
Patient-centered

Australian MS Longitudinal Study, iConquerMSTM
People-Powered Research Network, NARCOMS,
PatientsLikeMe, PROMOPRO-MS, ...



Deep phenotyping/ Biobanking

Accelerated Cure Project Registry,
CEMCAT CIS Cohort, CLIMB Study,
John Hopkins Precision Medicine
Center of Excellence for MS, MS
EPIC Study, MS Partners Advancing
Technology and Health Solutions
(MSPaths), MS Sunshine Study,
NARCRMS, Norwegian MS Registry
& biobank, Swiss MS Cohort, ...



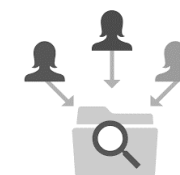
Special target population

MS in the Hispanic Population (USC
Registry), Pediatric MS and Other
Demyelinating Diseases (PeMSDD),
Sylvia Lawry Centre for MS Research,
Veterans Health Administration MS
Surveillance Registry (MSSR), ...



Research Collaborations

Big MS Data Network (BMSD), International MS
Genetic Consortium (IMSG), MSBase Neuro-
Immunology Registry, MultipleMS, Remote
Assessment of Disease and Relapse (RADAR-
CNS), Serially Unified Multicenter Multiple
Sclerosis Investigation (SUMMIT), ...



Improve care path concept

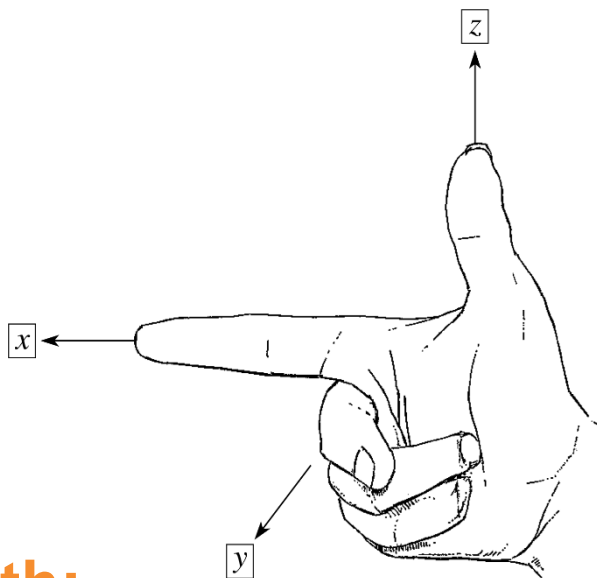
Cleveland Clinic Knowledge program, MS
Documentation System, OptimiseMS, ...



Maturity:

Nb of years follow-up

Danish MS Registry (1956)
British Columbia MS Database (1980)
NARCOMS (1993)
CEMCAT CIS COHORT (1995)
Swedish MS Registry (1995)
NY State MS Consortium (1996)



Depth:

Nb of variables

CEMCAT CIS Cohort
CLIMB Study
John Hopkins Precision Medicine Center of Excellence for MS
MS EPIC Study
MS Partners Advancing Technology and Health Solutions (MSPaths)
MS Sunshine Study
NARCRMS
Serially Unified Multicenter Multiple Sclerosis Investigation (SUMMIT)

Size:

Nb of patients

Big MS Data Network (>180.000)
MSBase Neuro-Immunology Registry (>60.600)
OFSEP (>58.000)
Italian MS Registry (>51.000)
PatientsLikeMe (>50.000)
Veterans Health Administration MS
National Data Repository (>50.000)
NARCOMS (>41.000)



ELSEVIER

Contents lists available at [ScienceDirect](https://www.sciencedirect.com)

Multiple Sclerosis and Related Disorders

journal homepage: www.elsevier.com/locate/msard



Multiple sclerosis registries in Europe – An updated mapping survey

A. Glaser^{a,*}, A. Stahmann^b, T. Meissner^c, P. Flachenecker^d, D. Horáková^e, P. Zaratin^{f,g}, G. Brichtetto^{g,h}, M. Pugliatti^{i,j}, O. Rienhoff^c, S. Vukusic^{k,l,m,n}, A.C. de Giacomoni^{k,l,m,n}, M.A. Battaglia^{f,g,o}, W. Brola^{p,q}, H. Butzkueven^r, R. Casey^{k,l,m,n}, J. Drulovic^s, K. Eichstädt^b, K. Hellwig^t, P. Iaffaldano^u, E. Ioannidou^v, J. Kuhle^w, K. Lycke^x, M. Magyari^y, T. Malbaša^z, R. Middleton^{aa}, K.M. Myhr^{bb,cc}, K. Notas^{v,dd}, A. Orolugas^{dd}, S. Otero-Romero^{ee,ff}, T. Pekmezovic^{gg}, J. Sastre-Garriga^{ff}, P. Seelldrayers^{hh}, M. Soilu-Hänninenⁱⁱ, L. Stawiarz^x, M. Trojano^u, T. Ziemssen^{ij}, J. Hillert^a, C. Thalheim^{kk}

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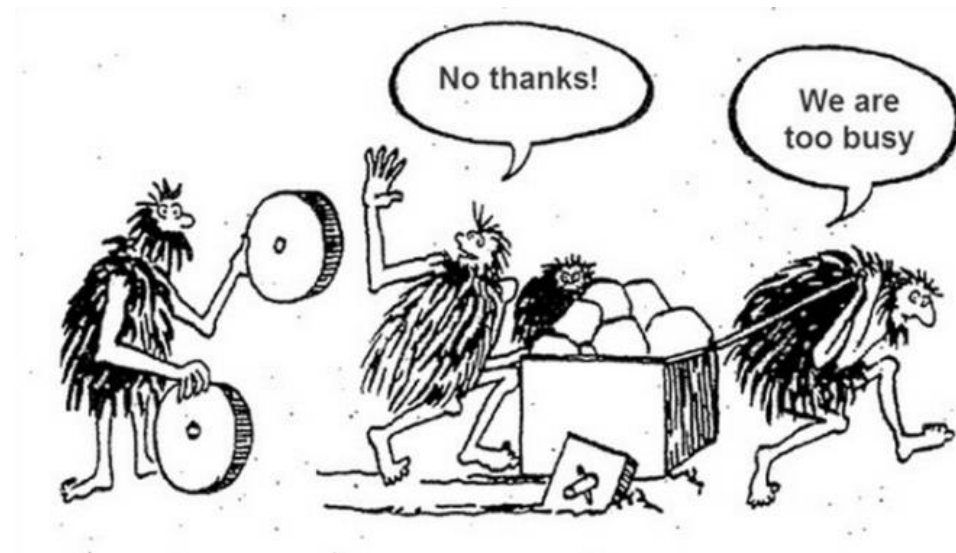
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^f Italian Multiple Sclerosis Foundation, Via Operai 40, Genoa 16149, Italy

^g MS International Federation, London, UK

^h Scientific Research Area, Italian MS Society, Genoa, Italy





European Medical Information Framework - Catalogue



- EMiF one of the largest IMI1 projects
- 57 partners in 14 countries
- EUR 56 million in matched public/private funding
- 2013-2018
- One of the most cited IMI projects

<https://emif-catalogue.eu>



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REQUEST A NEW COMMUNITY

**ELECTRONIC HEALTH RECORD DATA**

19 entries

EMIF-EHR intends to explore how the massive data available in pan-European EHR systems can improve biomedical research.

+ JOIN


**ALZHEIMER'S DISEASE COHORTS**

63 entries

The overall aim of EMIF-AD is to build an IF for studies on neurodegeneration in order to discover and validate AD biomarkers.

Leave

+ OPEN


**EPAD**

European Prevention of Alzheimer's Dementia Consortium

25 entries

EPAD aims to develop an infrastructure to undertake adaptive studies for early and accurate decisions on the development of drug candidates or combinations.


+ JOIN

**ADVANCE**

106 entries

Accelerated development of vaccine benefit-risk collaboration in Europe


+ JOIN

**MOCHA - Models of Child Health Appraised.**

149 entries

A Study of Primary Healthcare in 30 European countries


+ JOIN

**BigData@Heart**

1 entries

BigData@Heart develops a data-driven translational research platform for improving patient outcomes and reducing societal burden of atrial fibrillation, heart failure and acute coronary syndrome.

+ JOIN

**MS DATA ALLIANCE**

2 entries

The Multiple Sclerosis Data Alliance (MSDA) is a multistakeholder collaboration working to accelerate research insights for innovative care for people with MS.

+ JOIN



WE WANT YOU!

Call-to-action

Check it out !

- Go to www.emif-catalogue.eu
- Request access to the MSDA community
- Provide feedback on user-friendliness & questionnaire

Join us !

- Share your meta-data
- Give your registry and cohorts the visibility it deserves

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Or add me on linkedin!

