

**FORMATO EUROPEO
PER IL CURRICULUM
VITAE**



PERSONAL DATA



Name **ALESSANDRA SOLARI**
Address VIALE GRAN SASSO, 50 – MILANO
Telephone +39 02 2394 4664
E-mail alessandra.solari@istituto-besta.it
ORCID <https://orcid.org/0000-0001-9930-7579>

PROFESSIONAL EXPERIENCE

2014—present Head, Service of Neuroepidemiology, Scientific Directorate, Fondazione IRCCS Istituto Neurologico Carlo Besta (FINCB), Milan
1997—2013 Senior Neurologist, Unit of Neuroepidemiology, FINCB, Milan
1994—1997 Neurologist at Unit of Epidemiology, FINCB, Milan
1990—1993 Neurologist at Istituti Clinici di Perfezionamento, Milan
1981—1982 Physician at Department of Neurology, Fidenza Hospital (Parma)

EDUCATION

2005 Hospital Management Certificate. Institute of Economics, Administration and Management, Milan Bicocca University
1984 Post-graduation in Neurology, Specialty School in Neurology, University of Parma (*summa cum laude*)
1981 Certified Medical Doctor, University of Parma
1981 Degree in Medicine, Medical School, University of Parma (*summa cum laude*)

OTHER

2021— International Selection Committee of the National Institute for Health Research (NIHR), Department of Health and Social Care, UK: call 2021/22
2021— Scientific Committee of the Italian Society of Palliative Care (SICP)
2019— Coordinator Study Group ‘Bioethics and Palliative Care’, Italian Society of Neurology (SIN)
2018—2021 Ethics Committee Area Vasta Emilia Nord (AVEN), Reggio Emilia, Italy
2011—2018 Executive Board Rehabilitation in MS Network, RIMS (www.eurims.org)
2010—2018 Co-chair, co-founder RIMS Special Interest Group “Patient Autonomy”
2008—2017 Scientific Committee of the Italian MS Society Foundation (FISM), Genoa, Italy

Academic Editor for PLoS ONE and Frontiers Neurology. Member of the Editorial Board of International Journal of Environmental Research and Public Health—IJERPH.

Teacher and invited speaker at scientific seminars and international conferences (Charcot Foundation, Cochrane Collaboration, EAN/EFNS, Italian Ministry of Health, NIH, Italian NMSS, US NMSS, UK NMSS, RIMS, SIN, WFN).

RESEARCH INTERESTS

Dr. Solari's main area of research is the validation of instruments and outcome measures (chiefly patient-reported outcome measures, PROMs) for clinical, epidemiologic, and quality of care studies in neurological diseases, particularly multiple sclerosis (MS). Her other main interest is the design and conduction of independent randomised controlled trials (RCTs) mainly on rare diseases and complex interventions.

Quality of Life, Patient Satisfaction and Clinical Decision Making

Dr. Solari works is currently investigating methods of conducting outcomes research in studies on disease management and quality of care programs. As part of this field of research, she carried out a prospective study on community-based cohort of MS patients, examining relationships between disease status, quality of life and health care utilization. Dr. Solari's team devised a structured information aid for people with newly diagnosed MS, and is currently working on a program to ease advance care planning in MS. The team validated the Italian version of the 54-item MS Quality of Life (the most-used disease-specific health-related quality of life questionnaire); and a shortened version of the MSQOL-54 (MSQOL-29); the Italian version of the Chicago Multiscale Depression Inventory; and the Italian version of the Control Preference Scale, which was also devised in a revised electronic version (eCPS). Dr. Solari's team produced a short questionnaire on MS knowledge for patients and their significant others, the MS Knowledge Questionnaire (MSKQ), and, in collaboration with the team of Prof. C. Heesen (Hamburg-Eppendorf University) the risk knowledge questionnaire for relapsing-remitting MS (RIKNO). One further PROM validated and refined was the COSM (Comunicazione Medico-paziente nellala Sclerosi Multipla), probing patient satisfaction with MS diagnosis disclosure. Ongoing activities are the linguistic validation into Italian, German and Spanish of the following PROMs: the CompACT (Comprehensive assessment of Acceptance and Commitment Therapy processes) and the DDS (Drexel Defusion Scale); linguistic validation into Italian of the QoC (Quality of Communication), 4-item ACP-E (Advance Care Planning Engagement), and of the PROM-Ataxia.

Clinical Trials and Guidelines

Dr. Solari's experience in this area includes the design, management and analysis of phase II/III RCTs on rare diseases and complex interventions, and participation in national and international guideline panels.

Chief investigator of the following trials: RCT trial to assess the efficacy of physiotherapy in people with MS; the CRIMS double-blind RCT on computer-aided retraining of memory and attention in people with MS; the SIMS-Trial (Effectiveness of a structured information interview in people with newly-diagnosed MS; ISRCTN81072971); PeNSAMI Trial (multicenter phase II/III single-blind randomized controlled trial of home-based palliative care vs. standard care for people with severe MS and their carers, and nested qualitative study; ISRCTN73082124). Co-chief investigator of the CMT-TRIAAL (multicentre double-blind placebo-controlled RCT of ascorbic acid treatment in Charcot-Marie-Tooth disease type 1a – granted by Telethon Italy and Agenzia Italiana del Farmaco, AIFA) and CMT-TRAUK (CMT-Trial with Ascorbic acid United Kingdom– Granted by University College London and University College London Hospitals Trust). Member of the Steering Committee of the following: FIRST Trial (multicentre RCT on antiepileptic treatment started at first tonic-clonic seizure); Placebo-controlled double- controlled RCT on the efficacy of 4-phenylbutyrate in spinal muscular atrophy); RCT on idebenone in patients with Friedreich's ataxia; SMART trial (multicentre RCT on the efficacy of gabapentin in spinal muscular atrophy); SMA-

Trip trial (double-blind placebo-MAIN-Trial (multicentre randomised controlled study of azathioprine versus interferon beta in relapsing-remitting MS) granted by AIFA.

Chair of the EAN/EAPC/RIMS Taskforce on Palliative Care of People with Severe MS. Member of the following panels: SINch/AINO/SIN Panel on Italian consensus and recommendations on diagnosis and treatment of low-grade gliomas; Italian consensus on treatment of spasticity in MS; Consensus on Chiari 1 Malformation.

- GRANTS**
- 1995 *FISM* - Randomized controlled clinical trial on the efficacy of physical rehabilitation in patients with MS
 - 1996 *Italian Ministry of Health* – Randomized controlled clinical trial on the efficacy of physical rehabilitation in patients with MS
 - 1997 *FISM* - Cross-sectional population study on health-related quality of life in MS patients
 - 1997 *Italian Ministry of Health* - Validation of the Italian MS Quality of Life-54 Survey
 - 2000 *FISM* – Short battery for cognitive assessment in MS patients: A national validation study
 - 2001 *US National MS Society* – Randomized controlled clinical trial on the efficacy of computer-assisted cognitive rehabilitation in patients with MS (CRIMS trial)
 - 2001 *FISM* - Accuracy of two MS-specific brief neuropsychological batteries compared to an evidence-based criterion
 - 2002 *FISM* – Health-related quality of life of people with MS: The Italian MSQOL-54 Database and a longitudinal survey in the province of Milan
 - 2005 *US National MS Society* - A structured information interview for people with newly diagnosed MS
 - 2006 *FISM* – Responsiveness of MS-specific health-related quality of life measures
 - 2006 *Telethon-UILDM, AIFA, University College London and University College London Hospitals Trust* – Multicentre randomised double blind placebo controlled trial of long term ascorbic acid treatment in Charcot-Marie-Tooth disease type 1A (CMT-TRIAAL and CMT-TRAUK) (co-primary investigator: Davide Pareyson, FINCB)
 - 2007 *FISM* – Effectiveness of a structured information interview in people with newly-diagnosed MS (SIMS Trial)
 - 2009 *FISM* – Participants’ perspective on information aid for newly-diagnosed MS patients: a qualitative study within the SIMS-Trial (SIMS-Qual)
 - 2009 *FISM* – A postal survey of self-assessed health of adults with MS and their significant others: long-term follow-up (POSMOS Study)
 - 2010 *Hertie Foundation* – Autonomy preferences, risk knowledge and decision making performance in MS patients (AutoMS) (co-primary investigator: Cristoph Heesen, University of Hamburg, Germany)
 - 2011 *FISM* – Autonomy preferences, risk knowledge and decision making performance in MS patients (AutoMS) (co-primary investigator: Cristoph Heesen, University of Hamburg, Germany)
 - 2011 *FISM* – The Italian version of “The Motherhood Choice”: A decision aid for women who are considering motherhood
 - 2012 *FISM* – Home-based palliative care for people with severe multiple sclerosis: Developmental phase of the Palliative Network for Severely Affected Adults with MS in Italy (PeNSAMI) study
 - 2013 *FISM* – Development of an abbreviated, computerized version of the MSQOL-54 (co-primary investigator: Rosalba Rosato, University of Turin, Italy)
 - 2013 *FISM* – The Palliative Network for Severely Affected Adults with MS in Italy (PeNSAMI) Phase 2: A multicenter phase II/III single-blind randomized controlled trial of home-based palliative care vs. usual care for people with severe MS and their carers, and nested qualitative study
 - 2015 *FISM* – Managing the transition (ManTra) - A multifaceted resource for persons with secondary progressive MS and their health professionals. Phase 1: Construction of the resource
 - 2016 *FISM* - EAN Guideline on Palliative Care of People with Severe MS
 - 2017 *FISM* – Italian set up of the program “RESilience and Activity every DaY for MS”, of outcomes, and pilot assessment of efficacy using a mixed methodology (READY-It-MS; Principal Investigator: Ambra M Giovannetti, PhD student at the Neuroepidemiology Unit FINCB, Milan / Psychology Unit University of Queensland, Australia)

PUBLICATIONS

Publications: **234** H-Index (Scopus): **39** Citations: **4,699** Highly Influential Citations: **156**
For a list of recent publications, see [PubMed](#)

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Milano, 20 giugno 2021

ALESSANDRA SOLARI

