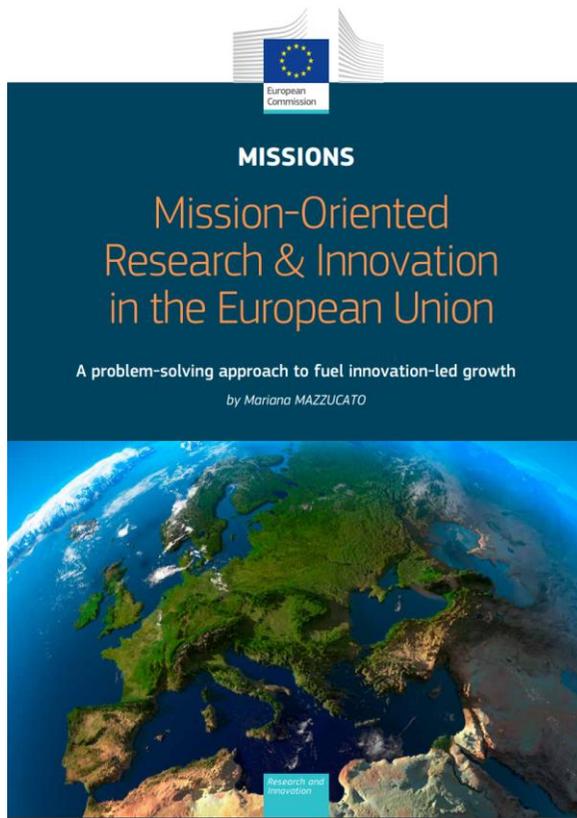


ENABLING MULTISTAKEHOLDER MISSION-ORIENTED RESEARCH & INNOVATION FOR BETTER HEALTH CARE

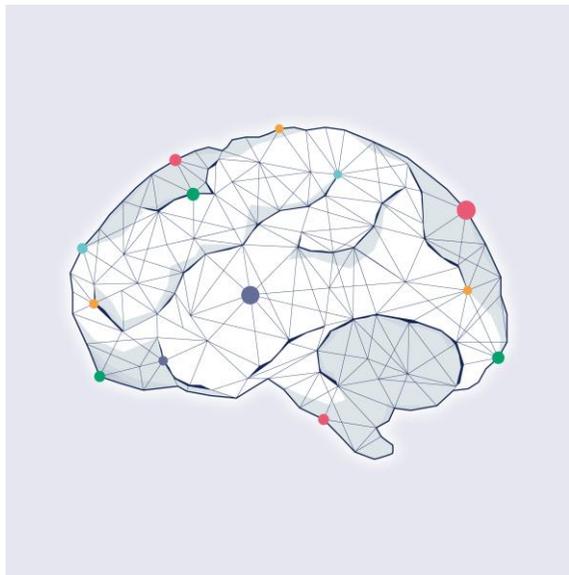
Professor Giancarlo Comi
President, European Charcot Foundation

NEED FOR MISSION-ORIENTED MULTISTAKEHOLDERS GOVERNANCE MODELS



In a time of challenges that call for mission-oriented research, the future of healthcare sustainability requires new multi-stakeholder and multidisciplinary managerial models of cooperation that guarantee a long-term return on investment, not only economic

THE CHALLENGE OF BRAIN DISORDERS



179 million Europeans live with brain disorders



Brain disorders cost Europe over 800 billion euro^{*2}



1 in 3 Europeans will have a brain disorder



Responsible Research Innovation
encourage stakeholders to work together during the whole research and
innovation process to better align R&I and its outcomes with the values,
needs and expectations of society



Contact details:

SCIENTIFIC COORDINATION

Italian Multiple Sclerosis Society Foundation
Paola Zaratini
multi-act@aism.it

PROJECT DISSEMINATION

European Brain Council
multiact@braincouncil.eu

Website: www.multiact.eu

The MULTI-ACT project started on 1 May 2018 and will continue for three years. It brings together leading European society, patients, patient organizations, research/academic institutions, governmental organizations, and technological organizations. The consortium forms a **multidisciplinary network** that integrates and coordinates various competences in related areas of the work that will be undertaken.

The project is coordinated by the **Italian Multiple Sclerosis Society Foundation**, as member of the International MS Federation, a "boundary organization" between science and patients.

The MULTI-ACT partners are:



Fondazione Italiana Sclerosi Multipla FISM Onlus



Università degli Studi di Trento



Ernst & Young Financial Business Advisors SpA



Universidad de Burgos



Tampereen Yliopisto



The European Brain Council AISBL



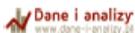
Intrasoft International SA



European Health Management Association



Fondation Pour L'aide a la Recherche sur la Slerose en Plaques



Dane-i-Analyze.pl sp zoo



Universidade Catolica UCP Portuguesa



European Charcot Foundation



A Collective Research Impact Framework and multi-variate models to foster the true engagement of actors and stakeholders in Health Research and Innovation



This project has received funding from the European Union's Horizon 2020 Research and Innovation Programme under the Grant Agreement No. 787570

#EHMA2020

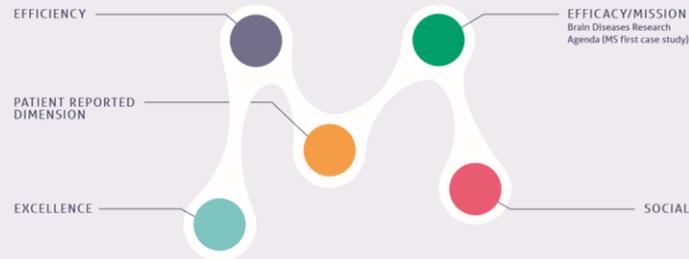
The MULTI-ACT FRAMEWORK

The governance model



The MULTI-ACT patient engagement strategy across the seven steps of the R&I path

The impact assessment scorecard



A suite of tools for Multi-Stakeholder Health Research Initiatives

A digital toolbox to support multi-stakeholder health research promoters applying the MULTI-ACT framework

A set of guidelines to assist multi-stakeholder health research promoters in the use of integrated collective research impact framework





MULTI-ACT CASE STUDY MULTIPLE SCLEROSIS CARE UNIT

This project has received funding from the European Union's Horizon 2020 Research and Innovation Programme under the Grant agreement No. 737370

multi-act

EFFICIENCY

PATIENT REPORTED DIMENSION

EXCELLENCE

EFFICACY/MISSION
Brain Diseases Research
Agenda (MS first case study)

SOCIAL

MS Initiatives

European Charcot Foundation

MS Care Unit

The Multiple Sclerosis Care Unit

Per Seelberg Sorensen, Cavin Giovannoni, Xavier Montalban, Christoph Thalheim, Paola Zaratin and Giancarlo Comi

Abstract: Treatment of multiple sclerosis (MS) has become increasingly multifaceted and comprises not only a variety of disease-modifying drugs with different mechanisms of action but also a wide range of symptomatic therapies. Today, it is not possible for the family physician or even many general neurologists to master the current treatment algorithm, and this calls for the establishment of multi-disciplinary MS Care Units. The core of the MS Care Unit would, in addition to MS neurologists and nurses, typically comprise neuropsychologists, clinical psychologists, physiotherapists, occupational therapists and secretaries, and will work together with a group of different specialists on formalized diagnostic workup procedures, protocols for initiation and follow-up of disease-modifying therapies. It is obvious that the terms of performance of different MS Care Units will vary across regions and need to be balanced with clinical practice according to local conditions. Although the main objective for establishment of MS Care Units will be to offer the single MS patient seamless and correct management of the disease to increase patient satisfaction and quality of life, it may even be cost-effective for the society by maintaining the working ability and reducing the costs of home help and custodial care by keeping people with MS resourceful.



ECF MULTI-STAKEHOLDER INITIATIVE



Biogen
Merck

Roche
Almirall

TEVA
Celgene

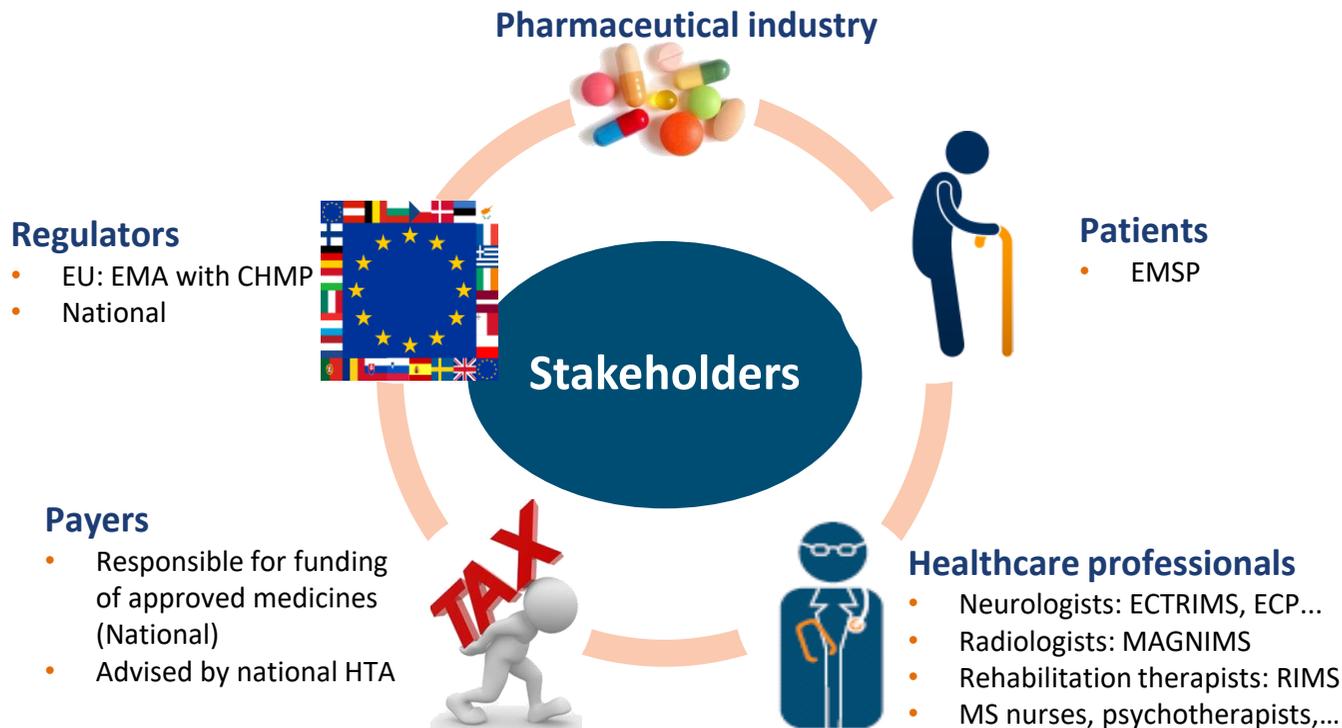
Sanofi
Actelion

Novartis

www.charcot-ms.org

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DIFFERENT STAKEHOLDERS...DIFFERENT PLATFORMS



THE MULTIPLE SCLEROSIS (MS) CARE UNIT INITIATIVE

LEAD THE WAY FOR PERSONALISED CARE

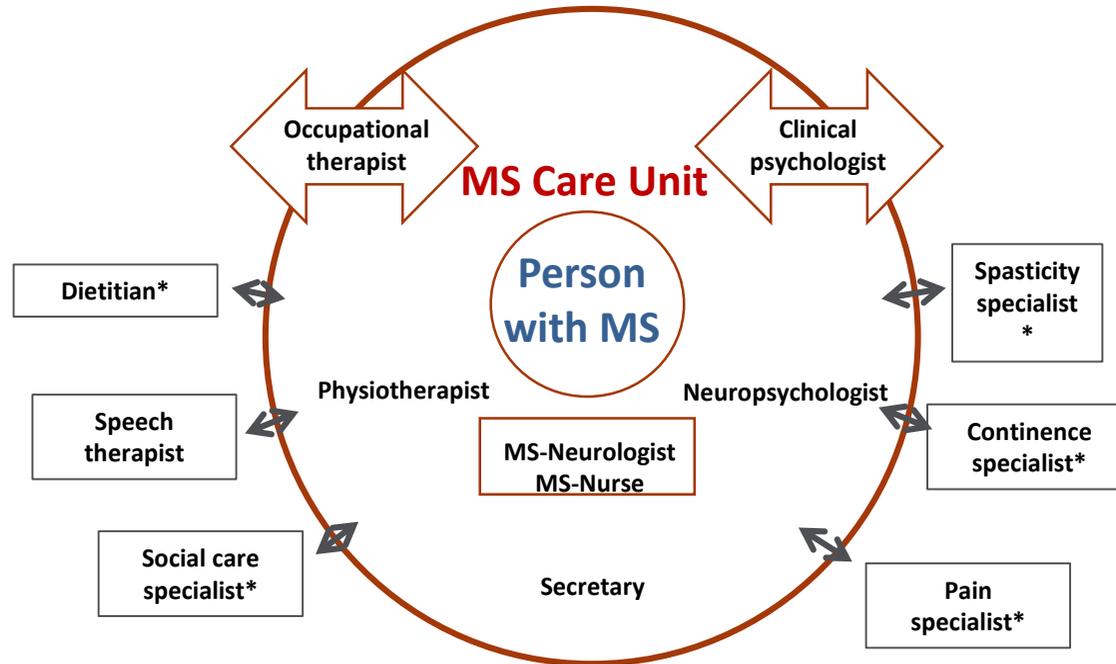




MS CARE UNIT MISSION

- MS Care Unit is a patient-centered initiative that aims to provide the highest possible leading-edge interdisciplinary care model for people with and affected by MS, while advancing research to prove its cost-effectiveness for the society (sustainability)

ORGANIZATION OF THE MULTIDISCIPLINARY MS CARE UNIT: MINIMUM REQUIREMENTS FOR A MS CARE UNIT



Collaboration with external part-time specialist

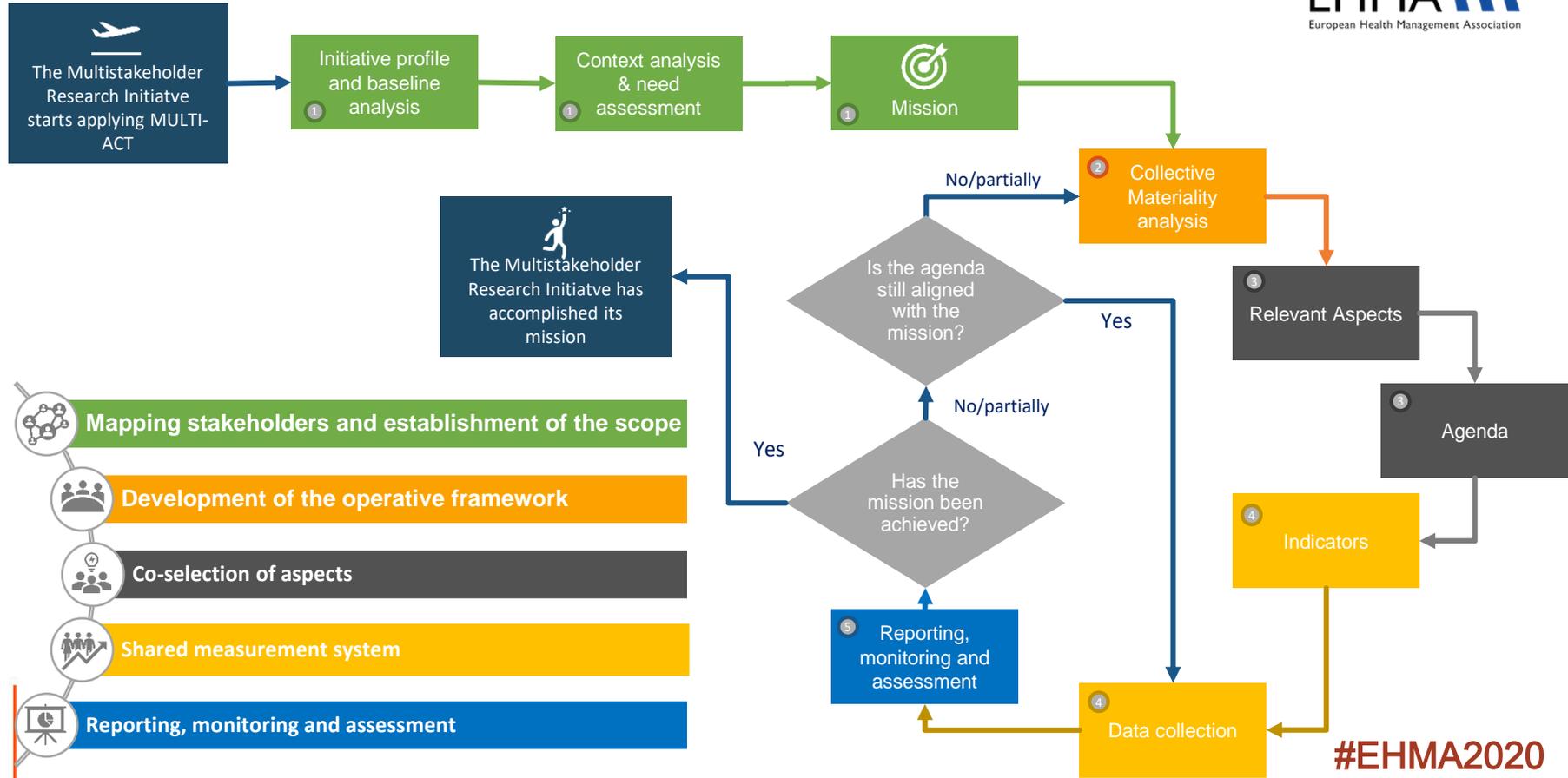
* Service that may be provided by a MS-Neurologist or MS-Nurse member of the multidisciplinary team with special education or interest

THE MS CARE UNIT COCREATING WITH MULTI-ACT CONSORTIUM

- **To refine its agenda** (research transformative strategic priorities and action plan) that will fulfil its mission and meets its stakeholders' priorities
- **To define relevant impact indicators** associated with its stakeholder's priorities (return on investment/engagement)



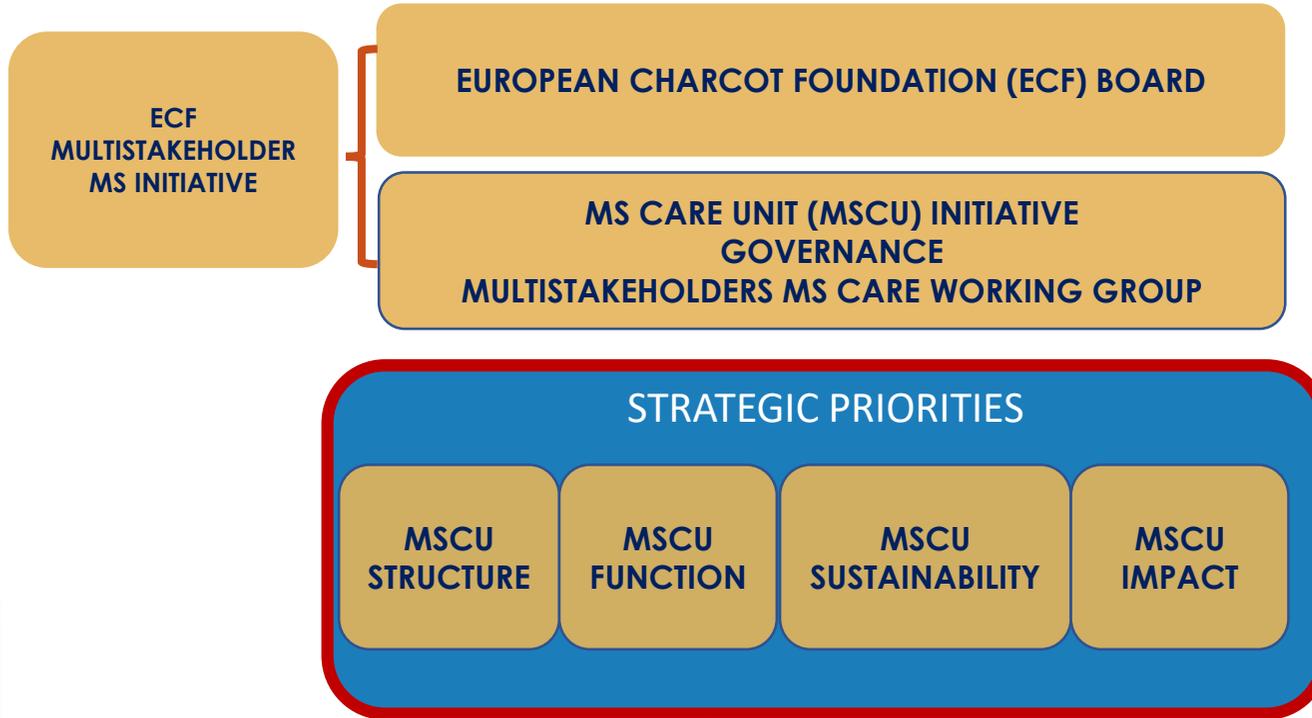
The MULTI-ACT: OPERATIVE FRAMEWORK



- Mapping stakeholders and establishment of the scope
- Development of the operative framework
- Co-selection of aspects
- Shared measurement system
- Reporting, monitoring and assessment



MS CARE UNIT INITIATIVE STRATEGIC PRIORITIES



BRIDGING EXCELLENCE WITH VALIDITY AND RELEVANCE: IMPACT

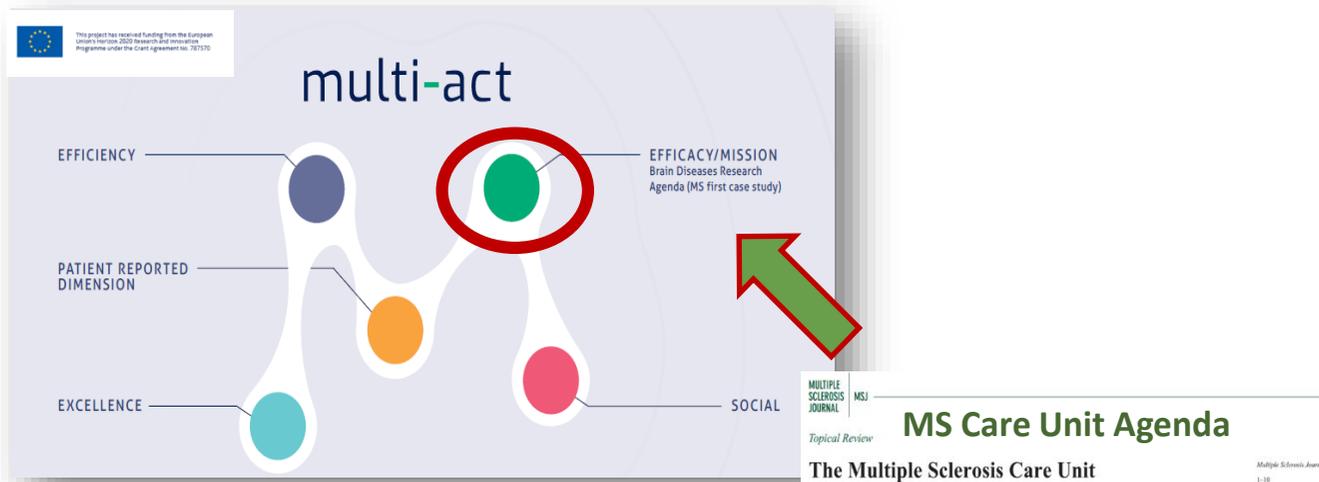


Table 2. Measures of effects of the establishment of multidisciplinary MS Care Units.

Short-term measures

- More uniform choice of therapies in line with published international treatment guidelines
- Better quality of life measured on a recognized quality-of-life scale or visual analogue scale
- More seamless care of people with multiple sclerosis
- Regularly repeated data analysis of a minimal set of PRO(M)s, which will be agreed by and implemented into all willing MS registries globally
- Regularly repeated analysis of a European minimal data set of RWE data (beside the PROs) which will be agreed by and implemented into all willing MS registries Europe wide

Long-term measures

- Improved therapeutic effectiveness of disease-modifying therapy – measured using big data from several MS registries
- Increased safety for patients on disease-modifying therapy – measured by prospectively collected safety data reported to EMA by European MS registries
- Reducing claims for disability benefit

PRO(M): patient-reported outcome (measure); RWE: real-world evidence; EMA: European Medicines Agency.

MS Care Unit Agenda

The Multiple Sclerosis Care Unit

r Soelberg Sorensen, Gavin Giovannoni, Xavier Montalban, Christoph Thalheim, Paola Zaratin and Giancarlo Comi

Abstract: Treatment of multiple sclerosis (MS) has become increasingly multifaceted and comprises not only a variety of disease-modifying drugs with different mechanisms of action but also a wide range of symptomatic therapies. Today, it is not possible for the family physician or even many general neurologists to master the current treatment algorithm, and this calls for the establishment of multidisciplinary MS Care Units. The core of the MS Care Unit would, in addition to MS neurologists and nurses, typically comprise neuropsychologists, clinical psychologists, physiotherapists, occupational therapists and secretaries, and will work together with a group of different specialists on formalized diagnostic procedures, protocols for initiation and follow-up of disease-modifying therapies. It is obvious that the terms of performance of different MS Care Units will vary across regions and need to be balanced with clinical practice according to local conditions. Although the main objective for the establishment of MS Care Units will be to offer the single MS patient seamless and correct management of the disease to increase patient satisfaction and quality of life, it may even be cost-effective for society by maintaining the working ability and reducing the costs of home help and custodial care keeping people with MS resourceful.

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EMPOWERING STAKEHOLDERS VIA MATERIALITY ANALYSIS

The materiality analysis: the bridge

Make the bridge walkable between the mission/agenda and the outcome of multi-stakeholder research initiative



Through materiality analysis, the Master Scorecard allows the selection of impact indicators prioritised by MS Care Unit stakeholders and in line with the project's mission & agenda

The Master Scorecard: a tool to measure research impact according to 5 dimensions



Materiality analysis

List of selected aspects



Selection of indicators

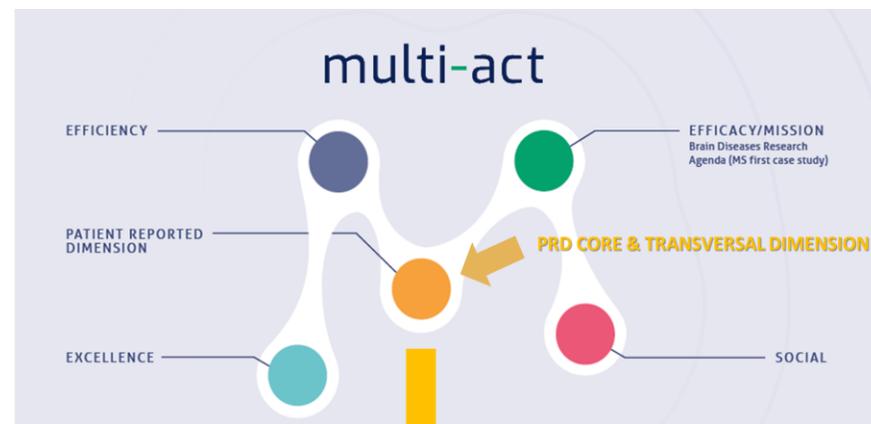
AGENDA

Core indicators
Additional indicators

All dimensions should be covered.
maximum number of indicators: 12.

IMPACT ASPECTS SELECTED BY MS CARE UNIT: PRELIMINARY SELECTION HIGHLIGHTS THE IMPORTANCE OF THE PRD DIMENSION

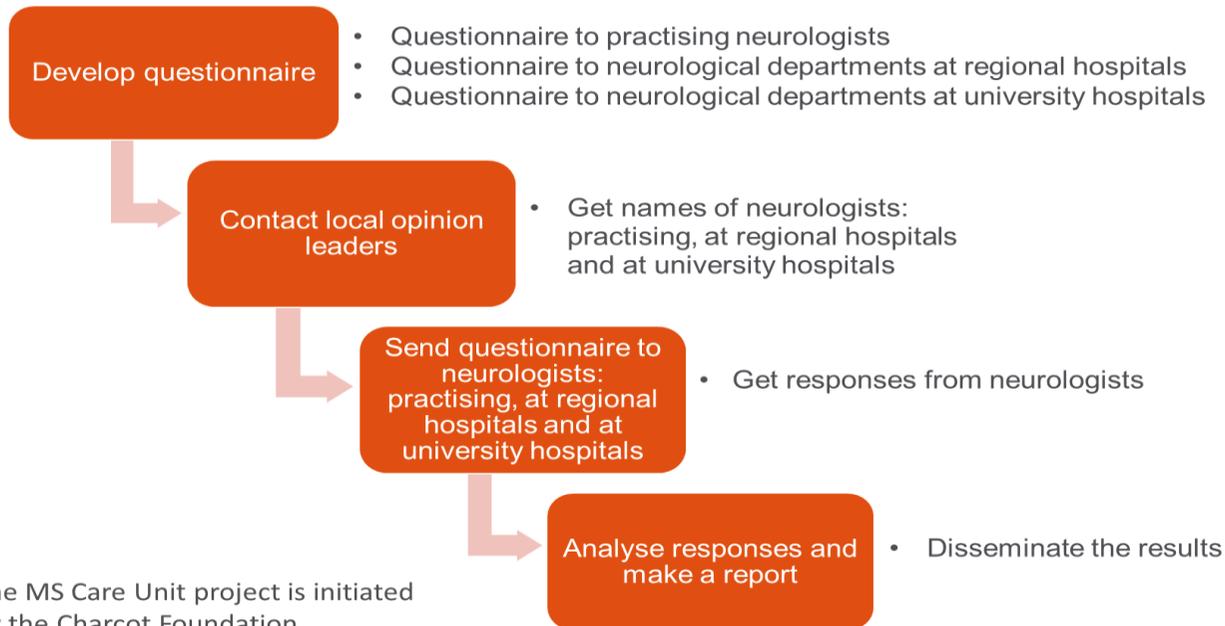
LIST OF RELEVANT ASPECTS
ASPECT *
Patient quality of life - Mission dimension
Quality of life - Patient reported dimension
Cognitive function - Patient reported dimension
Locomotion - Patient reported dimension
Informing healthcare practice decision making - Excellence dimension
Improvement of health services - Economic dimension
Fatigue - Patient reported dimension
Drug supply to patient - Mission dimension
Health services and products accessibility - Mission dimension
Patient satisfaction - Mission dimension
Stakeholder engagement - Mission dimension
Healthcare practitioners human capital - Mission dimension
Influence on patient behaviour - Mission dimension
Financial resources - Excellence dimension
Political externalities - Social dimension
Research partnership - Excellence dimension
Improvement of health services - Mission dimension
Ethics and integrity - Excellence dimension
Anxiety and Depression - Patient reported dimension
Stakeholder engagement - Excellence dimension
Financial performance - Economic dimension



MEASURING IMPACT ON OUTCOMES THAT MATTER MOST TO PATIENTS (e.g. PRO) THE SCIENCE OF PATIENT INPUT

TOWARD MS CARE UNIT GOLD STANDARD: LANDSCAPE ANALYSIS TO INFORM THE AGENDA

Overview of the current status of neurological care of people with MS: World-wide questionnaire project



The MS Care Unit project is initiated by the Charcot Foundation



TAKE HOME MESSAGES

- In a time of challenges that call for mission-oriented research, the future of healthcare sustainability requires new multi-stakeholder and multidisciplinary managerial models of cooperation that guarantee a long-term return on investment, not only economic.
- The ECF MS Care Unit is a multistakeholders and multidisciplinary Initiative that aims to meet a transformational mission, leading the way for personalized care.
- The MULTI-ACT project represents a timely opportunity and an important reference for structuring a model of mission-oriented collective sustainability in cocreation with the MS Care Unit stakeholders.



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<https://www.charcot-ms.org>



<https://www.multiact.eu>



THANK YOU

Professor Giancarlo Comi
President European Charcot Foundation

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