

Does your research impact society responsibly?

Design your sustainable multi-stakeholder initiative using MULTI-ACT

Moderator



Pieter van Galen is from the Netherlands and studied Business & Management in Alkmaar. During his studies he traveled extensively doing various internships (Hungary, Spain, England and China). After his studies he started a training/consultancy company. He has now been living in Belgium for nearly 20 years and enjoys the international environment of Brussels. He was diagnosed with MS in 2006 and has been an active patient advocate, being a member of various steering groups related to MS and Big MS Data initiatives.



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Brussels, November 12th, 2019



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on behalf of MULTI-ACT Consortium

Multi-Act
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THE CHALLENGE OF BRAIN DISORDERS



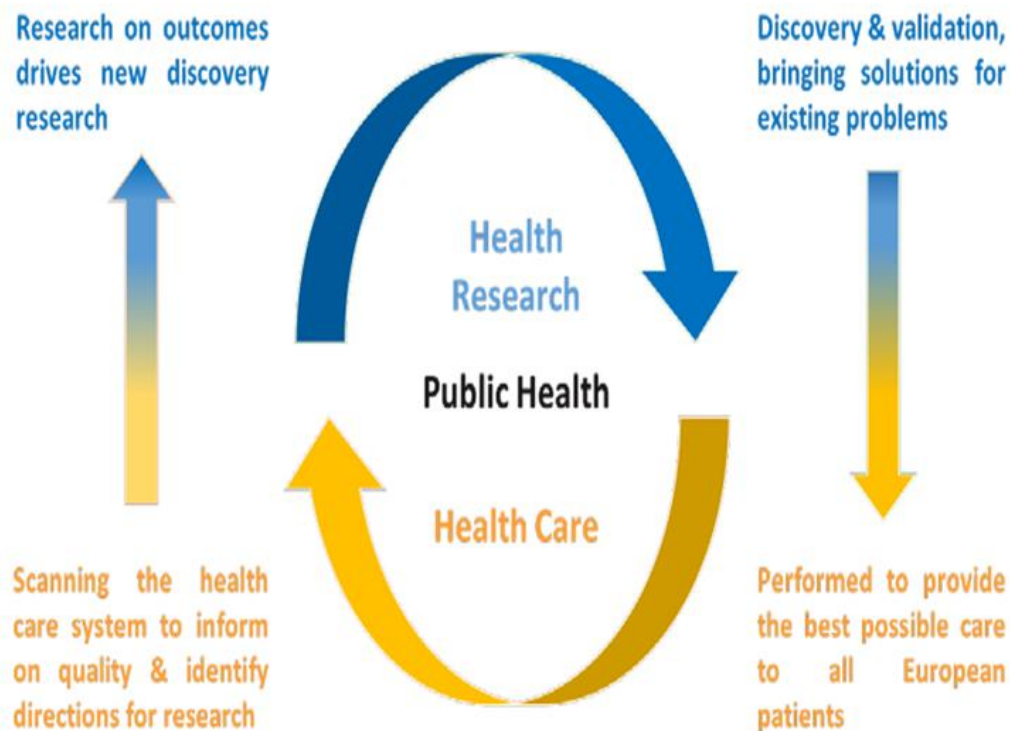
179 million
people in Europe

€800 billion
every year in Europe

26,6%
the burden of all
diseases in Europe

DESIGN WITH THE END IN MIND BETTER BRAIN RESEARCH FOR BETTER HEALTH

The discovery and implementation process: iterations between health research and health care



Adapted from Building the future of health research .Proposal for a European Council for Health Research. A consensus document of the H2020 Scientific Panel for Health, 2018



The thinking underling Responsible Research Innovation wants to challenge our notion of good science as such.

It argues that excellence, validity and relevance are connected by engaging patients and society in the research continuum as key stakeholder with decision making role

MONITORING THE EVOLUTION AND BENEFITS OF RESPONSIBLE RESEARCH AND INNOVATION (MORRI): UNMET NEEDS

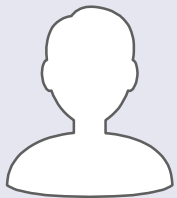
- **Governance:** existence of formal governance structures for RRI within research funding and performing organisations
- **Public Engagement:** models of public/patient engagement in Research and Innovation decision making

BETTER BRAIN RESEARCH FOR BETTER HEALTH

NEED FOR MODELS OF COLLECTIVE SUSTAINABILITY



Require attention and resources following a multistakeholder approach



It is increasingly important to consider patients' needs and perspectives throughout the research process



The conventional mechanisms for evaluating the results of health research are not able to represent the interests of all stakeholders

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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
Universidad de Burgos



University of Tampere
Tampereen Yliopisto



The European Brain
Council AISBL



Intrasoft International
SA



European Health
Management
Association



Dane-i-Analizy.pl sp z o.o.



Universidade Catolica
UCP Portuguesa



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

*A new business model
for collective sustainability in health research*



HELP MEETING THE CHALLENGE

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



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MULTI-ACT GOAL

- **Increasing the impact of health research on people with brain disorders, starting with the case study of Multiple Sclerosis**

MULTI-ACT EXPECTED OUTCOMES



A new **governance model** that can support **MSRIs** in improving their governance and better evaluate collective impact



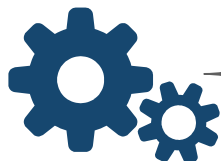
Guidelines for capturing “**patient experiential knowledge**” across the health research and innovation path



A new model for the assessment of the research impact across different dimensions (**mission, excellence, economic, social and patient-reported impacts**).

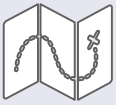


A digital **toolbox** that can support users from a multi-stakeholder perspective and the impact of research according to the patient's perspective



A set of **guidelines** to help in the **use of the Integrated collective research impact framework**, that can assist the users in applying the MULTI-ACT framework

MULTI-ACT EXPECTED IMPACTS



Fostering the implementation of the principles/best practices of *EU Responsible Research and Innovation (RRI)*



Enabling the mission to be the explicit driver for accountability: alignment of research results with the initiative's mission and agenda



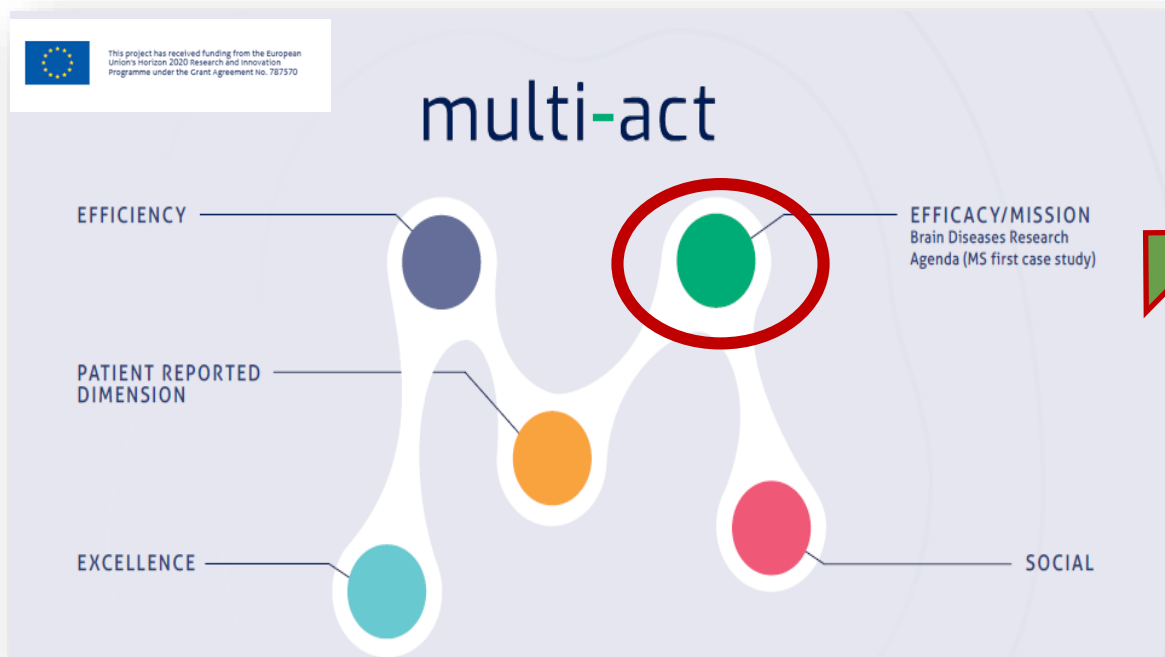
Enabling multi-stakeholder initiatives to increase *co-accountability* and ground its **impact** assessment in the outcomes that matter most to patients



Ensuring continuity of multi-stakeholder research initiative by ensuring **commitment and engagement of the stakeholders**

IMPACT OF RESEARCH

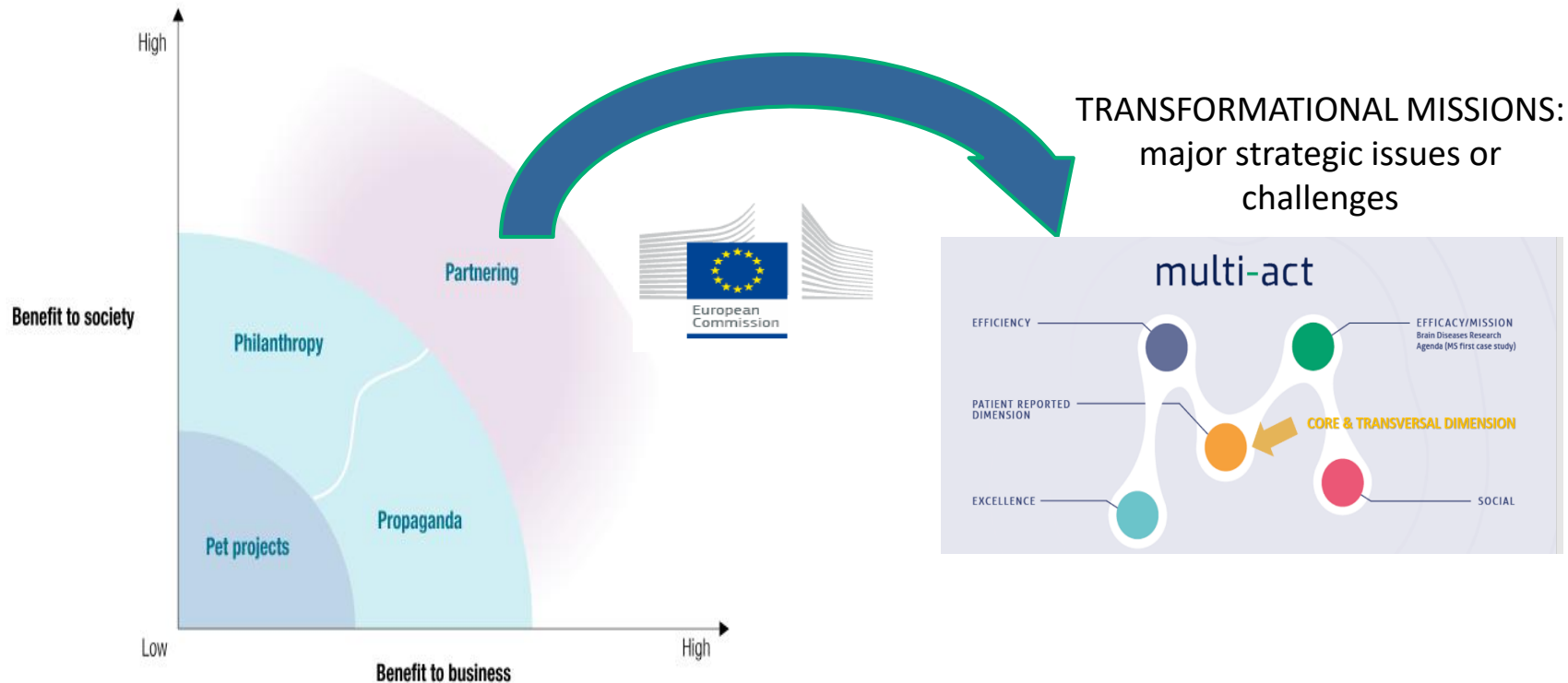
THE MISSION: THE EXPLICIT DRIVER



“When people talk about missions, I always warn them: if this is something that makes you feel comfortable and happy and cosy, then you haven't understood it, because it's actually about fundamentally changing how we think about innovation.”

Mariana Mazzucato 2019, <https://www.wired.co.uk/article/mariana-mazzucato>

“ACT LIKE AN ORGANIZATION AND THINK LIKE A MOVEMENT”



- In such ventures the focus of the business moves beyond avoiding risks or enhancing reputation and towards improving its core value creation ability by addressing major strategic issues or challenges

than in deploying competitive metrics for the marketplace.

Governments are much to blame because of their decreasing budgets for tertiary education. However, the professoriate (to which I belong) should have seen the danger these shifts posed sooner and, when it did, it should have fought harder for the intellectual heart of the system.

Some evidence-based metrics are useful. In my view, however, a return to the methods of peer-driven intellectual assessment that worked well for centuries should remain part of the answer to evaluation woes—even though that could mean retrieving the system from the grasp of university bureaucrats and the burgeoning bibliometric industry.

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Evaluation woes: start right

In our view, we need to move from a single system for assessing research performance (see J. Tregoning *Nature* 558, 345; 2018) to a prospective model implemented at the start of a research initiative. This would engage stakeholders in defining metrics for the project's mission and agenda.

An example is the European Commission's MULTI-ACT project, which is a collective research-impact framework of multivariate models for health research and innovation (see go.nature.com/2mdkqgt). This integrates conventional metrics related to excellence with new measures relating to economic and financial efficiency and to social efficacy.

Although not the "quick fix" Tregoning mentions, such multidimensional measures should help early-career researchers to tie their work more effectively to a meaningful research agenda.

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Evaluation woes: metrics beat bias

We disagree with the contention that publication metrics should be condemned as the bane of research-evaluation practices (see J. Tregoning *Nature* 558, 345; 2018). In countries with a long-rooted tradition of nepotism and patronage, such metrics provide objective and consistent evaluation—particularly advantageous for early-career researchers. They can also help overstretched funding agencies and review panels to arrive at fast, fair and transparent decisions.

The conventional combination of qualitative review and quantitative metrics can be expensive and time-consuming, not least because it is hard to find genuinely impartial reviewers and to achieve consensus.

We acknowledge that misuse of metrics such as journal impact factors and citation counts can discredit creative research, encourage citation gaming and provoke research misconduct. But the striking increase in the popularity of metrics as an evaluation tool worldwide indicates that they offer benefits, too.

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Patient-reported outcomes in the spotlight

The importance of patients' perspectives on their disease status and quality of life is well recognised as an essential part of research studies and neurological practice. How best to incorporate patient-reported outcomes (PROs) in clinical studies and, eventually, into clinical practice remains a matter of debate. The use of PROs is especially challenging for neurological diseases, considering that patients are usually old, fragile, with comorbidities, and often have cognitive or communication impairments. The Patient Reported Outcomes Initiative for Multiple Sclerosis (PROMS) has been launched to tackle this challenge for patients with this disease. Expectations are high because efforts to enable uptake of PROs could be greatly enhanced by a common strategic agenda, and PROMS' achievements could also influence clinical research in other subspecialties.

Although clinicians acknowledge the importance of PROs to facilitate understanding of treatment effects or compare treatment options, patients are frustrated that functional domains that matter most to them are often not addressed. Regulatory authorities recognise that current research outcomes (eg, the Expanded Disability Status Scale, relapse rate, and MRI features) do not fully capture the lives and experiences of people with multiple sclerosis; Healthcare Technology Assessment agencies aim to integrate the patient voice in coverage decisions; and pharmaceutical companies have acknowledged the importance of including PROs in the lifecycle management of experimental therapies. Practical issues include how to capture the pertinent data (eg, by use of technology), the need for a clear definition of which between-group differences and within-subject changes are clinically meaningful, and understanding of how domains of interest purportedly assessed by a PRO measure are affected by unrelated contextual factors (eg, how marital issues or depression might affect self-reported disease status).

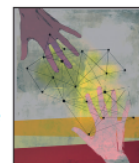
In recognition of the need for a common strategic agenda and roadmap shared by all relevant stakeholders to tackle these issues and facilitate the uptake of PROs into decision-making processes, the PROMS initiative was born—a project aiming to provide a unified view on and maximise impact of patient input on the health, healthcare, and quality of life of people affected by multiple sclerosis. The Multiple Sclerosis International Federation,

the Italian Multiple Sclerosis Society, and the European Charcot Foundation launched PROMS on Sept 12, 2019, at the 35th Congress of the European Committee for Treatment and Research in Multiple Sclerosis, held in Stockholm, Sweden. The strategic priorities of PROMS are centred around the validation and development of PROs that matter most to people with multiple sclerosis; implementation and support of initiatives aimed at validating and harmonising PROs across cultures; and translation of standardised data into a performance measure that captures the results most important for improving long-term wellbeing.

The PROMS initiative aims to learn from best practices of other ongoing relevant initiatives. For example, the European Charcot Foundation has experience providing a joint approach to coordinate existing initiatives in multiple sclerosis (such as MS Brain Health, MS in the 21st Century, Neuro-Compass, and ParadigmMS Foundation); and the MULTI-ACT project, launched in 2018, is facilitating a collaborative approach to develop brand new tools to assess the value of research in neurology from the patients' perspective—the impact of research in multiple sclerosis will be assessed as a first step. PROMS could also learn from established initiatives that focus on patients' priorities in neurological research.

For instance, the James Lind Alliance has been facilitating partnerships between patients, carers, and clinicians to set research priorities since 2004. Also, a Dutch initiative with a similar ethos for patient advocacy in Parkinson's disease—ParkinsonNet, established in 2004—is trying to include patients in health-care decisions and make specialist-care choices easily available for all patients with the disease. The model has already begun to spread, with adjustments made for cultural and system-specific needs to enable implementation in Germany and the USA.

Several previous initiatives have faltered, in most cases due to the lack of appropriate infrastructure and shared means of aligning efforts and results. There is a need for a global approach, across countries, stakeholders, and disciplines. A goal to accelerate shared learning is by no means an easy one, but will be essential to maximise the potential benefits of patient involvement in neurological research. With PROMS planning to deliver results in July, 2022, this goal can hopefully begin to be realised soon. ■ *The Lancet Neurology*



For more on PROMS see <https://www.mslf.org/news/2019/09/12/global-initiative-places-the-patient-voice-front-and-centre-in-ms-research-and-care/>

For more on the ECF MS Initiative see <https://www.charcot-ms.org/research-initiatives/multi-stakeholder-initiatives>

For more on ECTRIMS 2019 see <https://www.ectrims-congress.eu/2019.html>

For more on MS Brain Health see <http://www.msbrainhealth.org/>

For more on MS in the 21st Century see *J Neurol* 2013; 260: 462–69

For more on Neuro-Compass see <https://www.neuro-compass.education/en-gb/home/>

For more on the ParadigmMS Foundation see <http://paradigmms.foundation/>

For more on the MULTI-ACT Initiative see <https://www.multiact.eu>

For more on the James Lind Alliance see <http://www.jla.nihr.ac.uk/>

For more on ParkinsonNet see *Editorial Lancet Neurol* 2014; 13: S75 and http://www.parkinsonnet.info/media/15290577/rompen_on_the_move_2015_parkinsonnet_concept.pdf



multi-act

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