A Collective Research Impact Framework to foster the true engagement of actors and stakeholders in Health Research and Innovation
WHAT IS MULTI-ACT?

The EU-funded MULTI-ACT project aims to increase the positive impact of health research on people living with brain disorders. It creates a new model allowing for the effective cooperation of all relevant stakeholders in defining the scope of health research as well as new metrics for the evaluation of its results.

The MULTI-ACT project works with patients and patient organizations, academics, private and public stakeholders to develop innovative tools to assess the value of research.

The term “brain conditions” is here used as an umbrella for diseases that encompass both neurological and psychiatric conditions. These include, for instance, diseases such as: anxiety, bipolar disorder, dementia, depression, epilepsy, headache, multiple sclerosis, Parkinson's disease, psychosis and stroke. All together, these conditions equal the number one burden in Europe.

*Neurological and mental alike

*Cost of disorders of the brain in Europe 2010
**THE MULTI-ACT MODEL**

Governance model: five criteria

- Shared vision and agenda
- Participatory governance
- Effective stakeholder engagement
- Efficient management and coordination
- Co-accountability measurement

**EFFICIENCY**

**EXCELLENCE**

**PATIENT REPORTED DIMENSION**

**EFFICACY/MISSION**

**SOCIAL**

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**PATIENT ENGAGEMENT**

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

**Transformational Mission**

- Breaking down boundaries
- Research priorities
- Steering institutions
- Design & Plan
- Research execution
- Evaluation
- Translation to community

**Governance program**

- Patient Advisory Board
- Engagement coordination team
- Other bodies

**Single project development**

- Design & Plan
- Conduct & Operate
- Evaluation
- Translation to community

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Outcomes that matter most patients (experiencial knowledge)

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\text{Cost of achieving the outcomes} = \text{Value}
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MULTI-ACT EXPECTED IMPACTS

- Fostering the implementation of Responsible Research and Innovation (RRI) by promoting public engagement
- Improving co-accountability of initiatives by aligning the research results with mission and agenda
- Improving co-accountability of research initiatives by assessing impact on outcomes that matter most to patients
- Ensuring continuity of multi-stakeholder research initiative by ensuring commitment and engagement of the stakeholders

MULTI-ACT EXPECTED OUTCOMES

- A new governance model to support the management and collective evaluation of multi-stakeholder initiatives
- 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
- A digital toolbox for using the MULTI-ACT framework
- A set of guidelines to assist multi-stakeholder health research promoters in the use of the integrated collective research impact framework
MULTI-ACT CONSORTIUM

MULTI-ACT brings together leading European societies, 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.

Project Coordinators

The Italian Multiple Sclerosis Society Foundation (FISM) is the leading funding agency of research in the field of multiple sclerosis (MS) in Italy and the third worldwide (after MS Societies in the USA and Canada). Their work revolves around improving the understanding of the causes of the disease, to improve the quality of life of people with MS (“PwMS”) and to provide better treatments toward a definitive cure for a MS. The overall goal of the MS Society is to make the bridge walkable between PwMS and governmental healthcare agencies and thus to support people with MS in making decisions for their treatments and quality of life.

Project Partners

Università degli Studi di Trento, UNITN, will be responsible for the coordination among academic partners. The Department of Economics and Management (DEM) of the University of Trento is the participating body in the MULTI-ACT Project. DEM features a multidisciplinary research environment where researchers apply a vast array of different approaches to describe the choice of economic agents, investigate their determinants and analyze their effect at the individual, sectoral and aggregate level.

ERNST & YOUNG Italy, EY, is the partner responsible for the design and implementation of the health collaborative initiatives’ approach and policies. EY is a global leader in advisory, assurance, tax, and transaction services. The insights and quality services EY delivers help build trust and confidence in the capital markets and in economies all over the world.

Universidad de Burgos, UBU, contributes to the MULTI-ACT Project with theoretical insights and empirical evidence about accountability, indicator measurement and impact assessment of research across different dimensions. UBU is committed with the highest standards in higher education, produces research and knowledge that contributes to a better society and to a more competitive productive sector.
**Tampere University** is a culturally-committed, higher education institution with the social mission of educating visionaries who understand the world and are able to change it towards the better. It is nationally recognized for its strength in research activities addressing key issues in contemporary society.

The **European Brain Council, EBC**, a non-profit organization aiming to promote brain research in Europe, improve treatment, care and quality of life of people living with brain disorders. EBC stimulates dialogue between scientists, society and all interested parties by promoting collaboration of member organizations with the European Commission, the European Parliament and other relevant EU and international institutions.

**INTRASOFT International S.A., INTRA**, is a leading European IT Solutions and Services Group with strong international presence, offering innovative and added-value solutions of the highest quality to a wide range of international and national public and private organizations. It has proven expertise in conceptual system architecture and system design, advanced application development and integration services, information portal management and communication services and project management.

**European Health Management Association, EHMA**, is a Belgium-based non-profit membership organisation that focuses on enhancing the capacity and capability of health management in order to deliver high quality healthcare. EHMA operates at an international, European and national level, with a membership of over 80 organisations and individuals and a broader network in excess of 5,000. Its activities revolve around three key work streams: membership-focused actions and network engagement; research and EU project work focused on dissemination and stakeholder engagement; and events and workshops, such as our EHMA Annual Conference or our Yearly Programme Directors’ Group Meeting.

**Fondation pour l’Aide à la recherche sur la Sclérose en plaques, ARSEP** is the leading funding agency of research in the Multiple Sclerosis (MS) field in France. ARSEP, taking advantage of its international network, including the International MS Federation (MSIF) and the Progressive MS Alliance (PMSA), has a leading role in enabling patient-reporting and in communication and dissemination of scientific results to people with Multiple Sclerosis, families, friends, and caregivers.

**Dane-i-Analizy.pl Sp. z o.o., DiA**, is a company developed by Jagiellonian University academics. It focuses mainly on the health care sector, dealing with data analysis, producing analysis and reports on data presentation and providing modern solutions for public administration.

**Universidade Catolica Portuguesa, UCP**, is an autonomous higher research and education institution in Portugal. The Católica Lisbon School of Business & Economics at UCP is an internationally recognized centre of research excellence in management and economics and the leading business school in Portugal since 2008.
This project has received funding from the European Union’s Horizon 2020 Research and Innovation Programme under the Grant Agreement No. 787570.