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MULTI-ACT Project brings research closer to patients and society

The EU-funded¹ MULTI-ACT project aiming to increase the impact of health research on people with brain diseases kicks off today. It will create and implement a new model allowing for the effective cooperation of all relevant stakeholders and be applicable in defining the scope of health research and innovation as well as new metrics for the evaluation of its results.

Higher life expectancy among Europeans has caused an increase in the number of patients with brain diseases, such as Alzheimer's, Parkinson's, Multiple Sclerosis and many other disorders. Brain ill-health currently affects 179 million individuals in Europe and will affect one in three Europeans during their lifetime. The five most prevalent brain diseases in Europe are anxiety disorders, migraine, mood disorders, addiction and dementia. It is therefore of utmost importance to develop a research model that produces results that have a real impact on the lives of these patients and their caregivers.

“Scientific research is crucial in taming the effects of these diseases; the time has come to make the research more effective, inclusive and to take on board all the stakeholders involved,” says Paola Zaratin, Director of the Italian MS Society Foundation and Coordinator of the MULTI-ACT project. “Beginning with patients, their needs and experiences”.

So far, most multi-stakeholder initiatives have faltered, in most cases due to the lack of appropriate infrastructure and shared means of aligning efforts and results. This is why the MULTI-ACT project will work with patient associations, academics, private stakeholders and the public to develop brand new tools to assess the value of research from four different aspects: stakeholder agenda, scientific excellence, economic efficiency and social impact.

“An effective organizational structure, clear engagement tools and goals are key strategic elements for any successful multi-stakeholder initiative” adds Riccardo Giovannini, Partner of the EY's Italian Climate Change and Sustainability team that will support the design and implementation of the MULTI-ACT stakeholder engagement policies and initiatives.

“This will be instrumental in forging a common research agenda and best practices to share with research institutions in the EU and beyond,” says Frédéric Destrebecq, Executive Director of the European Brain Council (EBC), a MULTI-ACT project consortium partner.

“The Italian MS Society and its research Foundation will bring into the Multi Act project the experience of key leadership of people with disability (and people with MS) that is “patient engagement” at all levels of strategic decisions and activities. Along this, we will bring the experience of stakeholder engagement both at national and international level”, says Mario Alberto Battaglia, President of The Italian MS Foundation.

The MULTI-ACT project will last 36 months (1 May 2018 – 30 April 2021), with a budget of €3.5 million. It brings together leading European society and patient organizations, research and higher education institutions, governmental organizations and technological organizations. MULTI-ACT will be coordinated by the Italian Multiple Sclerosis Society Foundation (FISM), as member of the International MS Federation (MSIF), a “boundary organization” between science and patients.

¹ Multi-Act project has received funding from the European Union's Horizon 2020 Research and Innovation Programme under the Grant Agreement No. 787570.

The Partners of MULTI-ACT project:

The **Italian Multiple Sclerosis Society Foundation (FISM)** is the leading funding agency of research in multiple sclerosis (MS) field in Italy and the third funding agency worldwide (after US and Canada MS Societies) to better understand 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 health care government agencies and thus to support people with MS in making decisions for their treatments and quality of life.

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, 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, a Spanish young, medium-sized university with the mission to contribute to a sustainable society through the pursuit of research at the highest international levels of excellence.in the area of the social and environmental accounting and organizational accountability and governance. Universidad de Burgos' Research Results Transfer Office-Knowledge Transfer Office (RRTO-KTO) core mission is to support and promote the production and transfer of knowledge from the University to companies and other stakeholders.

Tampereen Yliopisto, the University of Tampere, UTA, 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. Its research activities address key issues in contemporary society, and its nationally recognized areas of strength are 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. The 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, a Belgium based non-profit membership organisation that focusses on enhancing the capacity and capability of health management 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 Aide à la recherche sur la Sclérose en plaques, ARSEP is the leading funding agency of research in Multiple Sclerosis (MS) field in France. ARSEP, taking advantage from its international network, including the International MS Federation (MSIF) and the Progressive MS Alliance (PMSA), will have the role to enable patient reported dimension throughout then proposal and to communicate/disseminate 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 the Jagiellonian University academics. It focuses mainly on health care sector, dealing mostly with data analysis, producing analysis and reports on data presentation and innovation, providing modern solutions for public administration.

Universidade Católica 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 center of research excellence in management and economics and the leading Business School in Portugal since 2008.