EU project MULTI-ACT presents first results and launches policy brief

Rome, Italy – 27 May 2019

Over the next two days (27-28 May 2019), the MULTI-ACT Project will hold its 3rd Consortium Meeting in Rome, Italy. Since its launch in May 2018, the ambitious project and its 11 partners have been working hard to meet the goal of the project: to create and implement a new model allowing for the effective cooperation of all relevant stakeholders to increase the impact of health research on people with brain diseases. The expected projects outcomes, in line with the EU's Responsible Research Innovation (RRI) - Horizon 2020 programme, are:

- New governance criteria allowing for the effective cooperation of all relevant stakeholders in multi-stakeholder research initiatives and transformative governance;
- Innovative guidelines for effective patient engagement across the health research and innovation pathway;
- A new tool for the assessment of research impact across different dimensions, including: excellence, efficacy, social, economic and patient-reported and to better tie the research results to the objectives of the initiative;
- A digital toolkit that integrates the MULTI-ACT model and tools; designed to support multi-stakeholder research initiatives, including research funding and performing organizations.

Marking just over a year since the project has launched, this month a number of Work Package are concluding work and presenting their results today. Below are the summaries of the work to come out of Work Packages 1, 3 and 5:

Innovative guidelines for effective patient engagement across the health research and innovation path (WP1)

A dedicated group of experts has been established in the patient engagement group to guide WP1 activities and identify R&I processes where patient engagement is instrumental to reach impact. A landscape analysis of existing patient engagement experiences in R&I, focused on Multiple Sclerosis (MS) and brain disorders, has been performed to identify areas of unmet needs and come up with a prioritization of intervention. The landscape analysis was developed with different methodological steps: literature review, web research, interviews, surveys and outreach to other relevant Responsible Research & Innovation (RRI) initiatives.

Although the landscape analysis has identified the great potential of patient engagement in clinical and healthcare research projects, which are mainly medicine lifecycle driven, there is still limited evidence of the impact and value of engagement (return on engagement) and a lack of standardized procedures, particularly

in the areas of brain-related research. Moreover, in the identified experiences, patients have been involved and consulted for feedback rather than engaged through decision-making and co-design roles from the very beginning of the research.

Current "best experiences" of patient involvement in clinical and healthcare research will be used as a basis for developing innovative solutions to engage patients in the governance of wider R&I programs (i.e. MULTI-ACT Patient Engagement guidelines). **Empowering the experiential knowledge of patients, as co-researcher and key stakeholders, is the root of the MULTI-ACT patient engagement strategy and related guidelines.**

A new tool for the assessment of the research impact across different dimensions including excellence, efficacy, social, economic and patient reported dimension and to better tie the research results to the objectives of the initiative (WP3)

WP3 has developed a Master Scorecard of indicators that applies a multi-stakeholder perspective to assess the impact of health research in the field of brain diseases, using MS research as a case study. The Master scorecard consists of five dimensions of accountability. In line with RRI guidelines, the mission dimension focuses principally on better aligning research and innovation (R&I) and its outcomes with the values, needs and expectations of patients and society. The excellence dimension considers the quality of research. The social dimension refers to the long-term impacts of MS research for the whole society, engaging different types of the stakeholders. The economic dimension considers the long-term economic sustainability and the financial resources needed for the pursuing the given mission. Finally, the patient-reported dimension works as a core element guiding the research impact assessment on domains that matter most to patients and acts as an overarching dimension in which the other four dimensions should be rooted.

The first release of the Master Scorecard considers and includes four dimensions (social, mission, efficiency and excellence) and for each dimension it proposes a set of 115 indicators presented according to different aspects (45) to be measured.

The Master Scorecard has been developed through a process that involves a comprehensive review of the literature and the relevant initiatives, as well as stakeholder interviews in participatory and reflective way. By its nature, the Master Scorecard is dynamic, allowing for flexibility and adaptation. It has to be general/universal for customizing purposes: it can be applied to different multi-stakeholder research initiatives and indicators' relevance depending on the needs and mission of each user.

A new governance criterion allowing effective cooperation of all relevant stakeholders in multi-stakeholder research initiatives and transformative governance (WP5)

Through a co-design process carried out with MULTI-ACT partners, Work Package 5 has developed the MULTI-ACT Governance Model for the implementation of multi-stakeholder engagement and collaborative initiatives in brain disease research. The Model is structured according to 5 main criteria and 19 sub-criteria, which focus on the definition of a shared agenda, the structuring of a participative governance model, the development of a methodology to engage stakeholders, the efficient management of the initiative and the assessment of its results.

The Model contains detailed recommendation to guide the user in the application of criteria and sub-criteria; furthermore, when possible, it also offers practical solutions for implementation, considering best practices emerging from a long list of multi-stakeholder initiatives, applicable to the purposes of MULTI-ACT. Thanks to a balanced mix of principles and hands-on solutions, the Model constitutes an innovative approach to organize participative multi-stakeholder governance structure of health research and performing

organizations, considering the relevance of the engagement of stakeholders, in particular patients, both in the definition of the research agenda and in the assessment of research outcomes.

In the upcoming steps of the projects, in particular within WP4, the Model will be tested in an existing Multiple Sclerosis (MS) multi-stakeholder research initiative and further refined.

Improving and strengthening policy with the MULTI-ACT solution

Lastly, as we mark the end of the European Union election cycle, with voting coming to a close yesterday, MULTI-ACT today launches its Policy Brief for the incoming members of the European Parliament and other policy institutions, hoping to draw attention and awareness to the realities of the 179 million Europeans living with brain conditions and how RRI projects like MULTI-ACT are working to help meeting the challenge. The Policy Brief will be printed and distributed to all incoming MEPs and is available online for sharing.

(Link: https://www.multiact.eu/wp-content/uploads/2019/05/MULTI-ACT-Policy-Brief-Final.pdf)