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





Launch of the Consultation on the MULTI-ACT Patient Engagement Strategy

MULTI-ACT has launched a web survey for the implementation of the strategy for engaging patients in research and innovation, reflecting the project's aim to make research on multiple sclerosis and other neurological diseases more effective and responsive to the needs of patients through their full engagement. We invite you to share it widely within your networks and to complete the consultation --accessible here-- by the end of November.



Project video premiered

The official MULTI-ACT project video was premiered during the first project event, "Does your research impact society responsibly?", held on 12 November 2019 in Brussels. <u>Watch it</u> above and join us in sharing the project through video across social media. A version with French subtitles is also available <u>here</u>--with more languages to come.

Latest Activities



Patient engagement at the Progressive MS Alliance workshop

MULTI-ACT and the model for patient engagement in research were presented during a workshop held in Amsterdam by the Progressive MS Alliance on 19 November.



MULTI-ACT Event: "Does your research impact society responsibly?"

On 12 November 2019, the MULTI-ACT consortium held its first project event, centred around introducing the project in greater depth and sharing the preliminary results of a number of work packages.

Read the full event report on the MULTI-ACT website.



MULTI-ACT at EPF Congress

MULTI-ACT was invited to present at the EPF Congress on 13 November 2019. Project Coordinator, Paola Zaratin, presented the project during the "Measuring the impact of patient involvement" breakout session.



MULTI-ACT at the Corporate Social Responsibility & Social Innovation Conference (CSRIS)

Project coordinators' FISM were present at Italy's largest Corporate Social Responsibility conference last October, where they were able to present the project on a number of occasions throughout the event.



MULTI-ACT in Lancet Neurology

MULTI-ACT was featured in a Lancet Neurology editorial on "Patient-reported outcomes in the spotlight". Read the full text here.

session on patient-reported outcomes in MS (PROMS) during the $\underline{\mathsf{ECTRIMS}}$ Congress.



EU Open Info Days

MULTI-ACT was invited to present at the "Ensuring successful Patient and Public Involvement in EU-funded Research" parallel session at the European Commission's Directorate-General for Research and Innovation's Open Info Horizon 2020: 'Health, on demographic change and wellbeing' on 3 July.

LATEST BLOGS



Responsible research and innovation – reducing the distance between science and society

Learn more about another key area of the MULTI-ACT project: responsible research & Innovation, and how MULTI-ACT is working to achieve a number of RRI themes such as governance, education and open access as well as engagement.

RRI seeks to openly raise issues associated with research and innovation in order to anticipate the consequences and involve society in the discussion of how science and technology can help create a society we would want for future generations.



Responsible research and innovation – MULTI-ACT's Patient Engagement Strategy

Learn more about another key area of the MULTI-ACT project: responsible research & Innovation, and how the establishment of a MULTI-ACT group of experts, the Patient Engagement Group (PEG), has developed guidelines to engage patients in activities throughout the Research & Innovation (R&I) Continuum.



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PROJECT LATEST

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

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.

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 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 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.

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

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.

Results will be available through the MULTI-ACT website soon.

Work Packages: Learn More

Upcoming Events

January/February 2020 - MULTI-ACT Workshop

'Tailoring of the MULTI-ACT framework to the Multiple Sclerosis case study'
Brussels, Belgium - Further information to follow

6-9 May 2020 - EMSP Conference

Madrid, Spain - Further information to follow

23-26 May 2020 - 6th Congress of the European Academy of Neurology

Paris, France - <u>Further Information & Registration</u>

11-15 July 2020 - 12th FENS Forum of Neuroscience

Glasgow, UK - Further Information & Registration

9-12 September 2020 - ACTRIMS-ECTRIMS Joint Congress

Washington DC, USA - Further Information & Registration













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