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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 MULTI-ACT Patient Engagement Guidelines

On the occasion of World MS Day, 30 May 2020, the MULTI-ACT project released its <u>Patient Engagement Guidelines</u>, accompanied by a video (in English and Italian) outlining the key messages and core aims of the guidelines:







Patient Report Outcomes (PROs): patients should not only share their voice but co-create

Patient Reported Outcomes represent a unique opportunity to measure the impact of health research, treatment and care on outcomes that matter most to people with multiple sclerosis (MS). An important driver of this change is enabling *science with* and of *patient input* via a multi-stakeholder and multidisciplinary organizational models. Read more <u>here</u>.

M multi-act

Guidelines for Patient Engagement in Health Research & Innovation

MULTI-ACT launches Patient Engagement Guidelines on World MS Day

On the occasion of World Multiple Sclerosis Day (30 May 2020), the MULTI-ACT project was pleased to release its <u>Patient Engagement Guidelines</u>, which provide a roadmap to enable patient engagement actions within the multistakeholder research initiatives that apply

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World Multiple Sclerosis Day: MULTI-ACT broadcasted on Italian TV

The Italian Multiple Sclerosis Society Foundation (FISM) – as the MULTI-ACT coordinator and the leading funding agency of research in the field of multiple sclerosis (MS) in Italy – was live broadcasted on the Italian regional television, TeleGenova, on the occasion of World Multiple Sclerosis Day on 30 May 2020. Find more <u>here</u>.

INTERNATIONAL PROGRESSIVE MS ALLIANCE

Partnership with the International Progressive MS Alliance announced as part of World MS Day celebrations

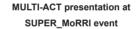
The International Progressive MS Alliance, an unprecedented global collaboration of multiple sclerosis (MS) organizations, researchers, clinicians, pharmaceutical companies and people with progressive MS, has created <u>a partnership with MULTI-ACT</u> that was announced on the occasion of World Multiple Sclerosis Day.



Engaging patients in Multi-stakeholder Research Initiatives

MULTI-ACT presentation at EAN Virtual Congress 2020

Due to COVID-19, the 6th Congress of the European Academy of Neurology (EAN) was held virtually for the first time ever on 23-26 May 2020. MULTI-ACT, including the MULTI-ACT Patient Engagement Guidelines, was presented by Prof. Mario Battaglia (Chair of the Italian MS Society Foundation) during the Scientific Theatre sessions. Find more information here.



MULTI-ACT was <u>invited to make a</u> <u>presentation</u> on 29 January 2020 at the H2020 Project SUPER_MoRRI (*Scientific Understanding and Provision of Enhanced Monitoring for Responsible Research and Innovation*) event held at the University Leiden on '*RRI across Europe: exploring the science society interface*' to share our work toward enhancing responsibility and public engagement in health research.



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Project Deliverable

M	11 05 2020 MULTI-ACT Project Brochure	$\rho \sigma$	55838	÷.
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M	2010512020 MULTI-ACT Patient Engagement Guidelines	p#f	005 kB	Ŧ

Latest project deliverables now online The following MULTI-ACT project deliverables are now available on <u>the MULTI-ACT website</u>: Project Quality and Stakeholder Engagement Plan, MULTI-ACT Master Scorecard, Consolidated mapping of existing patient engagement initiatives and analysis of gaps and barriers to patient engagement in current health R&I processes and the Patient Engagement Guidelines.

about the MULTI-ACT model, patient engagement strategy and the expected outcomes of the project. Check out the brochure here.

M multi-act Implement the MULTI-ACT framework to the MS Care Unit Initiative WORKSHOP May 19th, 2020 a Zaratin and Giancarlo Comi

Discourses in a

Workshop with the MS Care Unit

A workshop with the MS Care Unit (MSCU) took place in the second half of May in the form of three two sessions (in replacement of a face to face meeting initially scheduled on 4 March). Most MSCU stakeholder categories were represented in the workshop as well as most partners of the MULTI-ACT consortium.

LATEST BLOG

To ToC or not to ToC?

India, West Bengali. It is a sunny morning and a brand-new project is about to start: it is a capacity building initiative that aims at training judges, social workers, paralegals, lawyers and NGOs on human trafficking rules, laws and regulations. Everything is ready: the classroom is equipped, there are pens, notebooks and background materials on the desk. There is coffee, tea and water, and a bunch of flowers on the welcoming desk. Some local authorities have been invited and should attend the training's kick-off. But when the time came, none of the trainees showed up...

Wrong venue? Wrong date? Wrong timing? No. Simply, lack of a strong Theory of Change (ToC)



Upcoming Events

23 June 2020 - Enhancing the early detection of Alzheimer's disease through digital technologies Webinar, Further Information & Registration

> 4 - 7 July 2020 - 28th European Congress of Psychiatry Virtual Meeting, Further information & Registration

9 July 2020 - Stronger Together: Adapting Patient-Oriented Research during COVID-19 Webinar, Further Information & Registration

> 11-15 July 2020 - 12th FENS Forum of Neuroscience Virtual Meeting, Further Information & Registration

11 - 15 July 2020 - 12th FENS Forum of Neuroscience Virtual Meeting, Further Information & Registration

15 July 2020 - Neuroscience Research Funding in Europe Post-COVID-19 Virtual Meeting, Further Information & Registration

> 19-21 August - 7th annual Patients as Partners US Virtual Meeting, Further Information & Registration

1-3 September - 7th Annual Pharma Customer Experience Management Summit Vienna, Further Information & Registration

7 - 11 September 2020 - HIMSS & Health 2.0 European Conference Virtual Meeting, Further Information & Registration

9-12 September 2020 - ACTRIMS-ECTRIMS Joint Congress Washington DC, USA - Further Information & Registration

12 - 15 September 2020 - 33rd ECNP Congress

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Past Issues	
	21-24 September 2020 - NEURO 2020 Summit Salamanca, <u>Further Information & Registration</u>
	22 - 24 September 2020 - European Research and Innovation Days 2020 Virtual Meeting, <u>Further Information & Registration</u>
	25 September 2020 - KT Connects: Co-creating dissemination materials with patients Webinar, <u>Further Information & Registration</u>
	13 - 14 October 2020 - Brain Innovation Days Brussels, <u>Further Information</u>
	19 - 24 October - ISOQOL Annual Conference - 2020 THE FUTURE IS NOW: A Vision for the Future of Outcomes Measurement and Quality of Life Research Virtual Meeting, <u>Further Information & Registration</u>
	16 - 18 November - Geneva Health Forum Geneva, <u>Further Information & Registration</u>
	17 - 19 November 2020 - EHMA 2020 Annual conference - Health management: realigning systems, context and players Rotterdam, <u>Further information & Registration</u>
	8 December 2020 - Encephalitis Conference London, Further Information & Registration
	21 - 22 December 2020 - ICRRI 2020: 14. International Conference on Responsible Research and Innovation Istanbul, <u>Further Information & Registration</u>
	12 March 2021 - European Life After Stroke Forum Barcelona, <u>Further Information & Registration</u>
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