How to engage patients in research?

MULTI-ACT answers via the Governance Model

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The MULTI-ACT Governance Model

? WHAT

The MULTI-ACT Governance Model is the result of a co-design process carried out by the MULTI-ACT project partners.

It is a tool to facilitate and improve the efficiency of the implementation of multi-stakeholder engagement and collaborative initiatives in health research.

🔍 BACKGROUND

The MULTI-ACT Governance Model is developed within the framework of Responsible Research & Innovation (RRI). The RRI is a research and technological development approach which aims to encourage societal actors to work together during the whole Research & Innovation (R&I) process to better align R&I and its outcomes with the values, needs and expectations of society.

Early in 2014, the European Commission appointed an expert group to monitor the evolution and benefits of Responsible Research and Innovation (MoRRI) in the dimensions of governance, ethics, public engagement, open access, science literacy and scientific education to identify and/or propose indicators and gaps.

The MoRRI project had the aim of establishing a monitoring system that measures how, where, and to what extent RRI has become integrated within European research practices. The monitoring of the evolution and benefits of RRI has highlighted, among other things, that one specific unmet need is to have formal governance structures for RRI within research funding and performing organizations. The MULTI-ACT Governance Model has been developed to address this need.

🎯 THE GOAL

The Governance Model aims to meet the different (and sometimes competing) needs of all the stakeholders involved in the R&I process, involving all interested stakeholders that want to adopt a participatory, multi-stakeholder structure, according to MULTI-ACT recommendations.

The Model is originally intended for health sector research funding and performing organizations that may already be grouped in a multi-stakeholder initiative or that are willing to start conducting their R&I with a multi-stakeholder and co-accountable approach. Beyond the MULTI-ACT focus on brain disease and the health sector, the Governance Model could also be applicable for all future initiatives with transformational missions seeking to maximize the impact of research and to explore and assess the impact of research beyond financial return.

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THE STRUCTURE

The MULTI-ACT Governance Model is composed of 5 main criteria and 19 sub-criteria reflecting the key characteristics that multi-stakeholder initiatives should consider in order to maximize the impact of R&I toward a transformational mission. According to this framework, an initiative applying the MULTI-ACT Governance Model should:

- **Define its mission and shared agenda** considering the MULTI-ACT Governance Model recommendations.

- Guarantee an **inclusive and equitable governance model**, which allows the involvement of all interested parties under a co-design approach.

- Guarantee a **comprehensive, balanced and efficient stakeholder engagement process**, ensuring also the participation of patients, their families and care givers, and patients' organizations.

- Guarantee an effective, cooperative and efficient **coordination and alignment of the objectives and actions** required to pursue the vision and the agenda of the initiative.

- Establish a shared and **effective assessment system**, including a set of indicators that allows improvement and communication, and set a mechanism to receive feedbacks.

The Governance Model contains detailed recommendations to guide the user in the application of such criteria and sub-criteria. Furthermore, when applicable, the Model also offers practical solutions for implementation applicable to the purposes of MULTI-ACT.

CLEAR, EFFECTIVE AND INCLUSIVE METHODOLOGY OF STAKEHOLDER ENGAGEMENT

1. Define and approve a methodology to engage stakeholders
2. Engage intended beneficiaries
3. Differentiate the level of engagement according to involved stakeholders
4. Ensure a balance between engagement of involved stakeholders and agile management of the initiative

MISSION AND AGENDA	PARTICIPATORY GOVERNANCE	EFFECTIVE MANAGEMENT AND COORDINATION OF THE INITIATIVE	CO-ACCOUNTABILITY ASSESSEMENT
1. Identify intended beneficiaries, analyze the operating context of the initiative and understand the needs of stakeholders 2. Define a shared mission and common agenda 3. Promote a movement-building approach to achieve transformative changes 4. Guarantee ethical acceptability and social justice	1. Allow the involvement of intended beneficiaries 2. Adopt a multi-stakeholder approach enabling co-creation 3. Implement a participatory structure 4. Guarantee equity and mechanisms to avoid self-interest	1. Enable involved stakeholders to coordinate their efforts and perform activities 2. Set clear and transparent processes and timeline 3. Maintain flexibility 4. Ensure the presence of secure funding, solid organizational structure and resource management	1. Define a shared assessment system 2. Set effective feedback machanism 3. Ensure continuous learning, communication and disclosure of knowledge

READ THE FULL GOVERNANCE MODEL HERE

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