

How to engage patients in research?

MULTI-ACT answers via
the Patient Engagement Guidelines



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The MULTI-ACT Guidelines for Patient Engagement

? WHY use the MULTI-ACT Guidelines for Patient Engagement?

Over the last decade, along with the democratisation of health sciences, patient engagement has become increasingly more important. Patients have been actively engaged as co-researchers and can now share their own experience of the disease, which translates into a new form of knowledge that integrates both scientific and experiential knowledge.

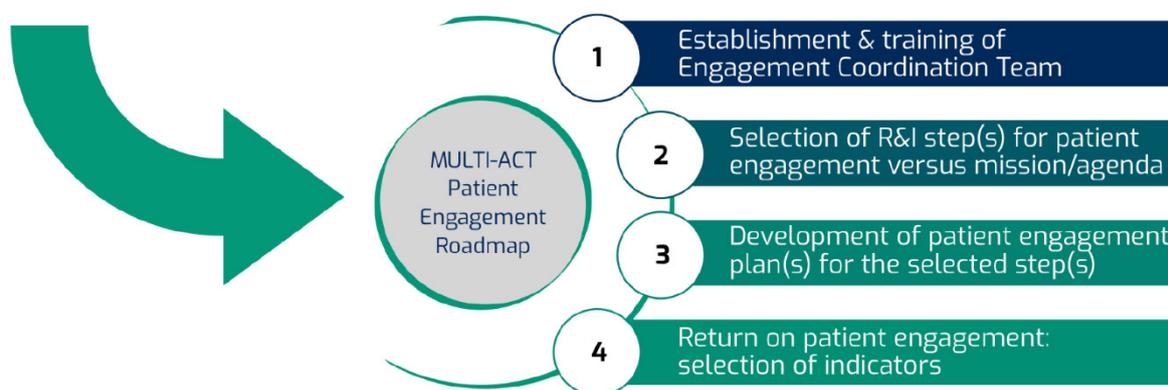
The MULTI-ACT project aims at leveraging both patients' and other stakeholders' experiences and at increasing their ability to co-create and participate in decision-making processes in health research.

🔍 WHAT is the MULTI-ACT Guidelines for Patient Engagement?

The MULTI-ACT Patient Engagement Guidelines provide a roadmap to constructively capture, understand and draw on the knowledge patients acquire through their experience with and of the disease ('experiential knowledge') for co-creation purposes. Patient engagement actions are enablers for multi-stakeholder research initiatives that aim to have a more participatory governance and effective methods for stakeholder engagements, in line with the MULTI-ACT Governance Model and related criteria.

🔧 HOW to use the Patient Engagement Guidelines' Roadmap?

The roadmap consists of four fundamental actions:



ACTION 1 THE ENGAGEMENT COORDINATION TEAM

Health research initiatives should set up an Engagement Coordination Team that manages stakeholder engagement and designs patient engagement strategy to empower the experiential knowledge of patients.

The Engagement Coordination Team is a neutral body responsible for the management of stakeholder engagement, including the design and implementation of the patient engagement strategy, in charge of creating commitment and moderating the dialogue between interdisciplinary and different (sometimes competing) voices.

The Composition of the team depends on the specificity of individual programmes and/or projects. It should be a multi-stakeholder board, with the patients as the key stakeholders of the Team, ensuring representativeness of their community.

The Team will need key skills, such as motivational and coaching abilities, **and competence** in moderating and facilitating the management of diverse engagement methods (online and offline).

The Team is an experimental new board that requires innovative **training and education** on communication, learning and co-working techniques, and provides evidence of the value of patient and stakeholder engagement. Training should include information about the programme's and/or project's mission and strategy, the expectations for patients and other stakeholders, the expected outcomes of the multi-stakeholder initiative and how those outcomes relate to the patients' needs in the given disease area.

ACTION 2 THE PROCESS FOR PATIENT ENGAGEMENT IN THE 7-STEPS' RESEARCH & INNOVATION (R&I) PATH

The second action of the roadmap is to define the steps where patient engagement is instrumental in achieving the mission and agenda of the research initiative.

MULTI-ACT has identified the following steps as relevant for patient engagement (i.e. 7-steps R&I path):



1. Breaking down boundaries between patients and stakeholders, by providing an overview of the facilities and infrastructures they need to be engaged in R&I and by reviewing the related policies and guidelines.



2. Setting research priorities to co-design research agendas, advance their interests in a specific research domain and to exercise prioritization.



3. Steering institutions to provide guidance on key issues, advise steering and advisory committees in defining ethical issues as well as anticipating risks and barriers for patient engagement.

-  **4. Research design and planning** to suggest endpoints, outcomes and specific objectives of research, and to define the relevance and acceptability of proposed research to patient community.
-  **5. Improving research execution** by assisting in developing and monitoring research at Programme Level (e.g. release of calls for proposals, selection of projects to be funded, monitoring of funded projects) and at Project Level (e.g. development of research project, such as clinical trials or development of ICT devices).
-  **6. Research evaluation** to measure the impact of research on outcomes that matter to patients, align results to the mission/agenda, and/or to assess new approaches and products arising from research and work with other stakeholders on research reports.
-  **7. Translating to the community** the research results with easy-to-use and easy-to-understand (lay) material.

ACTION 3 THE PATIENT ENGAGEMENT PLAN

The third action of the roadmap is to develop specific Patient Engagement Plan(s) for the identified steps of the R&I path, to provide a tool(s) to integrate patient experiential knowledge in research. Patients, as members of the Engagement Coordination Team and key stakeholders, ensure representativeness of their community in the implementation of the Patient Engagement Plan.

Minimum requirements of the Patient Engagement Plan

The Patient Engagement Plan is a management tool to support operationalisation of patient engagement in research, and contains the following minimum requirements:

-  Select actions of patient engagement that need to be implemented to achieve the **vision** and **mission of the project**.
-  Define the **roles** and **responsibilities of the team** that should manage and implement such patient engagement actions.
-  Design methods to value and acknowledge the **experiential knowledge of patients**, including the establishment of appropriate recognition of patient contribution, and avoid tokenism.
-  Choose clear and measurable **targets**.
-  Present a clear **timeline** of activities and a sustainable budget.
-  Define a clear **review** process.



Method to engage patients

The MULTI-ACT approach foresees dedicated trainings that will build on historical methods for patient engagement with relevant features to capture the experiential knowledge and give voice to patients, such as Focus Group and the Democs card game.

The Focus Group method is used to determine the preferences of people or to evaluate strategies and concepts. Participants are selected according to certain common characteristics that relate to the research topic and are grouped into 8-10 people to discuss either face-to-face or in a virtual space.

Example: Selected patients and stakeholders are invited to a meeting to discuss about a topic

The Democs is both a card game and a policy-exploration tool that enables small groups of people to engage with complex public policy issues. It aims to help people learn about a topic, express their views, seek common ground with other participants, and state their preferred policy position.

Example: Patients are provided with discussion cards that help them to express their views on a topic, to seek common ground with the other participants, and to express their preferences.

ACTION 4 MEASURE THE PERFORMANCE AND EFFECTIVENESS OF PATIENT ENGAGEMENT

Finally, key indicators can be used for assessing the return on engagement and to monitor if patient engagement has reached the expected impact on the initiatives. In particular, MULTI-ACT provides a list of metrics to evaluate the performance of patient engagement (i.e. the success of the initiative in terms of participation) and its effectiveness (i.e. the success of the initiative in term of the real impact of the participation on the research process).

The metrics that emerged as more reliable from our research are:



Performance Assessment



The number of different phases of the **research process** in which patients were engaged.



The number and type of patients engaged to assess the capacity to **engage diverse groups**, including the most vulnerable ones.



The number of **engagement actions** (online/offline) in which patients could express their views.



Effectiveness and value assessment

Quantitative:



The number of changes in the **research process**.



The number of research initiatives, programmes and projects that include and show an effect on **Patient Reported Outcomes**.



The number of research initiatives, programmes and projects involving patients in research activities, according to the needs of the **mission**.

Qualitative:



Whether **patients' expectations** of the research and mission of the initiative are met.



Achievement in terms of **new knowledge produced**, from the perspective of all the stakeholders.

TO READ THE PATIENT ENGAGEMENT GUIDELINES (SHORT VERSION) [CLICK HERE](#).

TO READ OUR CALL TO ACTIONS FOR POLICY MAKERS [CLICK HERE](#).

TO SEE OUR VIDEO ON PATIENT ENGAGEMENT [CLICK HERE](#).

