

ORIGINAL RESEARCH



## Patient associations and clinical oncology research: how much does a patient's voice really matter?

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### ABSTRACT

**Background:** New trends are emerging in clinical research, such as patient empowerment and an active role in influencing health and research ethics. Patients' involvement is considered pivotal by stakeholders and institutions because they can channel the voice of those they represent, empowering their starring role in the different research activities.

**Objectives:** To obtain an overview of the real involvement of Italian patient associations in clinical research.

**Methods:** In January 2019, the Working Group 'Clinical Research Coordinators' of the Italian Association of Medical Oncology spread an online questionnaire consisting of 16 questions on the active involvement of patient associations in clinical research.

**Results:** The involvement in clinical research working groups, in the organization and implementation of specific activities and training initiatives is very limited (21.7% in both cases), as well as the active involvement in the conduct and/or definition of clinical trials (0.3%). Moreover, few associations (15.2%) have joined projects on patient involvement in clinical research in collaboration with other associations. **Discussion:** Although the current involvement of the associations may have been somewhat underestimated, there is no doubt that much more can be done in terms of training and identification of common objectives between patients and professionals.

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