

Are Italian medical societies bridging the distance from citizen and patients' associations? Results of a survey

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Key words

Survey • Medical societies • Partnership

Summary

Introduction. In the framework of *PartecipaSalute* – an Italian research project aimed to involve lay people, patients' associations and scientific-medical representatives on the health debate – we carried out a survey with the Italian Federation of Medical Societies. The aims of the survey were to know medical societies attitude vs. patients involvement in research activities and healthcare setting and to find out possible projects conducted in partnership with patients associations.

Results. A web-questionnaire with 17 closed questions, and three open questions has been prepared on the basis of some experiences published on the literature and through the collaboration of members of the Italian Federation of Medical Societies. A total of 205 medical societies has been contacted by e-mail with a cover letter explaining the aims of the survey. At the end 74 medical societies completed the survey. Medical societies participating to the survey varied widely in terms of

years of activity, number of members, and geographical distribution. Remarkably, 36 medical societies respondent organized collaborative initiatives with patients/consumers associations during the last three years. Among these, the most frequent were the preparation of written material for patients, organization of conferences or workshops, and health awareness campaigns. Moreover, 6 medical societies published documents on patients' rights but patients or their associations were involved in only 2 of these initiatives. Advantages and disadvantages reported by medical societies answering are also presented and discussed.

Conclusions. In conclusion, to our knowledge this is the first survey on the value of patients' involvement conducted together with medical societies in Italy, and the results point the way to stronger collaboration in future between patients' associations and medical societies.

Introduction

In Italy, consumers' associations' involvement in the health and clinical research debate is still limited, partly due to the research community's paternalistic approach, and partly because of the patients' associations' limited awareness of their own rights and potential as active partners in setting health priorities.

PartecipaSalute is a research project launched in 2003 to foster a strategic alliance between citizen and patients' associations, and the scientific community. The principal investigation areas are: to increase knowledge and awareness of the role of citizen/patients' associations in health care, to empower groups of associations and lay people working in ethics committees and, finally, to organize joint initiatives of research between citizen/patients' associations and the medical scientific community [1].

This article presents the findings of a *PartecipaSalute* survey of the medical societies' attitudes toward patients' involvement in research.

Methods

Between 2005 and 2006 an e-mail survey was conducted in collaboration with the Italian Federation of Medical Societies (FISM) [2] counting a total of 205 members. An *ad hoc* questionnaire was assembled considering the relevant medical literature and the experiences of working group members. The final version of the questionnaire was structured with 17 closed questions, and three open questions. The open questions were revised by two independent reviewers, extracting the principal keywords and messages. All the medical societies belonging to FISM were contacted by e-mail with a cover letter explaining the aims of the survey. Non-responders were solicited twice, and in the end 74 (36%) medical societies replied. The list of responders, together with a long report, is available in Italian on the web site www.partecipasalute.it [3].

Results

The characteristics of the medical societies contacted and responders are listed in Table I. They vary widely as regards year of constitution, number of members

Tab. I. Medical societies contacted for the survey.

	Responders (N. = 74)		Non responders (N. = 131)	
	N.	%	N.	%
Years of constitution				
Before 1994	45	63.38	101	77.09
After 1995	26	33.61	30	22.90
Location				
Northern Italy	36	49.31	44	42.72
Central Italy	30	41.09	54	52.43
Southern Italy	7	9.58	5	4.85
With a own centre	18	24.65	81	89.01
With regional centres	37	52.85	65	67.01
Activities				
Continuous medical education	63	85.13	—	—
Training	62	83.78	—	—
Clinical studies	40	54.05	—	—
Public awareness campaigns	33	44.59	—	—
Lobbying	28	37.83	—	—
Other	11	14.86	—	—

Some discrepancies in the table are due to missing data.

(ranging from 30 to 24,590 persons) and geographical location. All the medical societies, except one, have a board of directors, 63 have an executive board and 52 a supervisory board. The medical societies organize many activities: first of all events related to continuing medical education (organized by 85%), followed by training courses or events (84%), clinical studies (54%) and public awareness campaigns (45%). Most of the medical societies have institutional websites (93%), mainly intended for their members, though 18 (24%) have an area specifically for patients or lay people. Thirty-six medical societies (51% of the 71 medical societies answering to this question) had organized joint initiatives with citizen/patients' associations in the last three years. As shown in Table II, the most common joint initiatives were drafting patients' information leaflets and organizing conferences. The joint initiatives were distributed differently for the older medical

Tab. II. Joint initiatives in the last three years.

	N.	% on 74 responders
Information materials	33	44.59
Congresses, conferences	30	40.54
Workshops	19	25.67
Health awareness campaigns	19	25.67
Guidelines	16	21.62
Sensitisation initiatives	10	13.51
Epidemiological studies	10	13.51
Consensus conferences	7	9.45
Clinical trials	7	9.45

societies and younger ones (established before 1994 or after 1995). The younger ones were more involved in guidelines (86% and 53%) and consensus conference initiatives (33% and 24%). The older medical societies were more engaged in producing information materials (93% and 78%), organising health awareness campaigns (71% and 50%) and workshops (67% and 56%), and conducting clinical studies (epidemiological 47% and 14%, randomised trial 35% and 14%). Six medical societies had published documents on patients' rights but patients or their associations were directly involved in only two of these initiatives.

Medical societies were also asked to report advantages and disadvantages of involving citizen/patients' associations. The results are summarised in Table III with some quotes from the questionnaires. It seems that medical societies consider the involvement of patients' associations useful and desirable, and most of them (N. = 13) find no disadvantages. The others indicate three main kinds of disadvantages: effects on the health care system, such as an increase in false expectations for patients and increased healthcare demand; difficulties in multidisciplinary groups, due to patients' lack of technical and medical knowledge and to physicians' and patients' different points of view; risks taken by medical societies in establishing close relations with patients' associations, such as the risk of focusing the medical societies' activities on the policy and needs of the patients' association that is the main partner. Finally, one medical society indicated the risk of patients' associations being manipulated by medical societies themselves, and one noted the difficulty of working with associations often in disagreement with each other.

Advantages covered nine main areas (Tab. III). Among the most frequent were increased patients' and public awareness about disease; obtaining more knowledge of patients' health needs; developing collaboration between medical and patients' associations; promoting the medical society's activities and mission; influencing public opinion and mass media; and, finally, making for better health assistance.

As regard the suggestions to strengthen patients' involvement, most medical societies propose organizing events, congresses, conferences and workshops together with patients' associations in order to boost communication between healthcare professionals and patients; others suggest raising public awareness through training courses for citizens and patients. Some medical societies suggest collaborative projects and activities, such as consensus conferences or definition of guidelines, or multidisciplinary working groups. A small group proposes improving activities related to doctor-patient communication.

Discussion

Interest in the involvement of patients' associations is rising among Italian medical societies. Joint activities are in their infancy in Italy and patients' associations

Tab. III. Advantages and disadvantages of involving citizen and patients' associations.

<p>Disadvantages</p> <ul style="list-style-type: none"> • difficulties in the multidisciplinary group (18) <i>"Difficulties in the debate because of patients' effort to distance themselves from their personal experience and emotions; lack of training about clinical issues; disagreement among patients' associations"</i> • effects on the healthcare system (14) <i>"If not well managed informative initiatives or awareness campaigns could lead to an increase in health services demands"</i> • no disadvantages (13) • risks taken by medical societies in establishing close relationships with patients' associations (5) <i>"To be conditioned by patients about therapies and scientific debate"</i>
<p>Advantages</p> <ul style="list-style-type: none"> • increasing patients' and public awareness about the disease (27) <i>"Awareness about prevention and right health behaviour, for example appropriate drugs use"</i> • increasing knowledge of patients' health needs (12) <i>"Learn needs and expectations of the national health service users"</i> • developing collaboration between medical and patients' associations (8) <i>"Develop and promote research and health assistance programmes together with patients' associations"</i> • promoting the medical society's activities and mission (6) • influencing public opinion and mass media (6) <i>"Strongly influence public authority and media on patients' and citizens' needs"</i> • making for better health assistance (6) <i>"Develop and share healthcare assistance programmes with patients and their associations"</i> • lobbying (6) • improving doctor-patient relationships (3) • less risk of legal disputes (1)
In brackets the number of medical societies answering

still play a secondary role, mainly reviewing information documents, organizing fund raising or supporting events organized by the medical societies themselves. The study has some limitations related to the small number of responders (74 out of the 205 medical societies contacted), that means the sample is not representative of all the societies belonging to FISM. Therefore, no conclusive considerations about these data can be drawn, as usually happens in surveys based on data collected on a voluntary basis.

Nonetheless, some interesting points emerge. Many medical societies say they work with patients and their associations at different levels, showing a propensity towards involving patients. However, it is difficult to find

publicly available reports or data about joint initiatives, for example on medical societies' websites or newsletters, so the movement to disseminate and implement collaboration is still in its infancy. Most of the activities are in the information field, especially awareness campaigns.

More than 120 open comments were reported about the pros and cons of patients' involvement, the advantages being more frequent than the disadvantages. Enhancing patients' awareness about the disease was the most frequent statement, followed by the possibility of raising clinicians' knowledge of patients' needs.

Among the disadvantages, the first regards the difficulties due to physicians' and patients' different points of view. This is partly disproved by a study conducted in the United States on patient involvement in scientific review panels for proposals on breast cancer research: the voting patterns were similar for patients and scientists [4]. On the other hand, a recent study showed that patients' and clinicians' points of view still differ in the research area [5]. Patients attending cancer treatment centres in the United Kingdom were involved in consultation and focus groups about research priorities. They identified the impact of cancer on daily life, how to live with cancer, risk factors and causes of cancer, early detection and prevention as top-priority areas, but there was a mismatch between the patients' and medical scientific research agenda. As the authors infer from their results, it is essential to take the priorities defined by patients into account in future research strategies.

The PartecipaSalute project is moving towards this goal during 2007, considering a similar experience developed in the UK, the James Lind Alliance experience [6]. The project is organizing the "Spazio Parita", a patients-oriented clinical research group, where participants collect unanswered questions, identified by citizen/patients and their associations together with scientific community, with the aim of developing a research protocol.

As regards work in a multidisciplinary group of lay people and healthcare professionals, training courses for patients and their representatives are demanded both by medical societies, as shown in this survey, and by patients' associations, as emerged from a survey conducted by the PartecipaSalute project with 11 patients' federations in Italy [7]. During 2007 the PartecipaSalute project has organized the second edition of a training course in decision-making about clinical research and health care for patients associations' representatives [8].

Conclusions

In conclusion, to our knowledge this is the first survey on the value of patients' involvement conducted together with medical societies in Italy, and the results point the way to stronger collaboration in future between patients' associations and medical societies.

Authors' contributions

PM, CC, FG and FV planned the initiative, designed and implemented the survey, discussed and developed the questionnaire; PM and CC collected data and organized the data analysis; BP provided the data analysis; PM and CC wrote the manuscript, and all Authors read and approved the final version.

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