Resources review

PartecipaSalute, an Italian project to involve lay people, patients’ associations and scientific-medical representatives in the health debate

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Introduction

Consumers and patients are increasingly demanding an active role in health-care access and quality, and associations and pressure groups are interacting directly with national health services and with researchers, doctors and scientific or professional societies.1–4 This article describes an Italian project aimed at creating a partnership among lay people, patients’ associations and the scientific/medical community.

In Italy, consumers are generally passive recipients of health information from various sources: doctors and health-care professionals, the health system, media, web and parents or peers. This information is often contradictory and non-evidence-based, leading to misunderstandings and confusion. The Di Bella case, the outcry about an alleged new cure for autism, and the increasing number of health awareness campaigns are all clear examples of the lack of an evidence-based culture among Italian consumers and patients’ associations (see Box 1). To cope with this, lay people must learn how to develop their scientific literacy, becoming familiar with clinical and epidemiological research and acquiring instruments to critically appraise and understand health information. Although these activities are in their infancy in Italy, there are some good examples of empowerment efforts (see Box 2).

The number of consumer’ and patients’ associations is steadily growing: a survey in 2003 by the Italian National Statistical Institute5 identified about 21 000 non-profit organizations across the country, a 50% increase compared with a 1997 survey. These organizations cover a wide spectrum of activities corresponding to a broad definition of health, including psychosocial support and direct services, and the findings confirm the deeply rooted Italian tradition of mutual aid in the health-care field. In the last 10 years, consumers’ and patients’ associations have extended their interventions from self-help and care to advocacy, including important efforts to convey more information to the public, and organize awareness raising campaigns.

In common with other European and American countries, patients’ federations are emerging in Italy to boost the impact of individual organizations. Some now lobby at local, national and international level, drawing health authorities’ attention to the need for improvement in a given area.6–10 This has led to the introduction of patients’ charters and the mandatory presence of lay representatives on local ethics committees, yet the medical and scientific community still fails to see patients and consumer groups as partners with ‘equal rights and weight’. Consumers, patients and their associations, on the other hand, often lack...
critical appraisal skills and they struggle to make their voice heard in the health-care debate. There are also very few opportunities for the medical community and patients’ associations with meet and work together. Experiences of this kind are not collected and shared, so they are unlikely to be used in the development of new projects.
In planning a project involving consumers’ and patients’ associations with the scientific and medical community, we reviewed consumer involvement initiatives in countries such as United States, United Kingdom and Australia (http://www.cochrane.org/consumers/homepage.htm, accessed on 27 October 2006). We were particularly inspired by: (i) the UK-based CASP initiative (Critical Appraisal Skills Programme) that offers courses for health-care professionals, for trainers and for consumers; (ii) the US-based LEAD initiative where a course developed by the National Breast Cancer Coalition empowers breast cancer activists to influence research and public policy, and by courses and initiatives of the American Association for Cancer Research (http://www.aacr.org/home/survivors–advocates/about-the-survivor-and-patient-advocacy-program.aspx). We have also learned from the interesting James Lind Alliance in the United Kingdom, a coalition of patients’ associations, researchers and clinicians working together to identify areas of uncertainty in medicine and define priorities for clinical research.

The aim of this article was to present PartecipaSalute (‘Participate in Health Care’) a pilot project initiated at the end of 2003 following some pilot experiences (http://www.pnlg.it, accessed on 8 May 2006). The project – funded by a non-profit bank foundation (‘Compagnia San Paolo’) – aims at involving patients’ associations and is co-ordinated by the Mario Negri Institute, in collaboration with the Italian Cochrane Centre and the medical journalism agency Zadig. A multidisciplinary Scientific Committee, composed of representatives of consumer/patients’ associations, medical associations, media, researchers and experts advises all the project activities. The project’s main aim was to foster a strategic alliance between patients’ groups and professional societies, with the goal of promoting better health and shared decision-making. Throughout its different phases PartecipaSalute involved patients, associations and lay people.

Methods

The overall goal was to create the cultural and methodological conditions essential to support and increase shared initiatives between consumer/patients associations and scientific community. The project focused on the following main areas.

- Championing the role of consumer/patients’ associations in the health-care debate through a fact-finding exercise to unearth relevant experiences.
- Empowering patients, by launching a website and organizing courses for patients’ representatives and lay members of ethics committees.
- Organizing collaborative initiatives between consumers/patients and representatives of the scientific and medical community.

Patients’ federations survey

A survey was carried out in 2004 with the collaboration of 10 patients’ federations in the cancer, cardiovascular and nervous system fields together with associations with a long grassroots tradition (AIDS, breast cancer). Building upon previous experiences a working group developed a semi-structured interview. Topics covered included: structure and organization (i.e. type of activity, capacity, distribution of the centres); training courses, information, sources and attitudes to and beliefs about information sources. Presidents of patients’ federations were contacted by telephone and asked to participate in a one hour and half interview. Two researchers (PM and CC) conducted the interviews and analysed the data for open questions by extracting the principal themes and messages.

Medical societies survey

The second survey targeted the Italian federation of medical societies (FISM). It was designed to assess medical societies’ attitudes towards patients’ involvement in research and health care and to find out about projects conducted in
partnership with patients’ associations. A questionnaire was developed based on a review of relevant literature and the previous experiences of working group members. Topics included: characteristics of each society’s structure and organization, number and type of collaborations with patients’ associations and opinions about patients’ involvement in projects. All 204 medical associations belonging to FISM were contacted by e-mail with a covering letter explaining the survey. Non-respondents were sent a reminder. The survey was concluded in summer 2006 having obtained responses from 73 medical associations.

Training course

Based on experience at the Mario Negri Institute, the Italian Cochrane Centre and Zadig, a training course was developed for patients’ associations and lay member of ethics committees entitled ‘Decision-making about clinical research and health care’. The course covered some of the topics requested by patients’ associations during our preliminary interviews and meetings, such as technical aspects of clinical research and potential roles of voluntary organizations. The course was seen as an opportunity for the different associations with exchange information and foster collaborations. The course commenced in October 2005 and offered – within a 6-month period – a total of 9 days packaged in six modules dealing with:

- ABC of clinical research. Topics considered: critical aspects of clinical research on coxib drugs, flu vaccine, oncological screening, new oncological drugs and air pollution; developed through five working groups with plenary discussion, one lecture, two formal lessons, two debates.
- Uncertainty and conflict of interests in medicine. Topics considered: antibiotics for sore throat, cardiovascular risk cards, Prostate-specific Antigen; developed through three working groups with plenary discussion, three formal lessons and two debates.
- Strategies of health information. Topics considered: Hormonal replacement therapy, stem cells, lung cancer early diagnosis; developed through three working groups with plenary discussion, one formal lesson and one debate.
- Patients’ associations: credibility and strengths. Topics considered: history, role, credibility and experiences of patients associations; developed through one working groups with plenary discussion, three formal lessons and one debate.
- Lay people’s participation in ethic committees. Topics considered: history, regulations, role of lay people, informed consent; developed through three working groups with plenary discussion, one formal lesson and one debate.
- Ways to influence the research agenda. Topics considered: literature reviews, websites, independent research; developed through three working groups with plenary discussion, two lectures, three formal lesson and one debate.

The faculty was made up of researchers, doctors, medical journalists, associations’ representatives and activists. Throughout the course, we sought participants’ opinions using assessment forms, similar to those used by the Italian Ministry of Health in the Continuing Medical Education courses.

Website

A website was launched in September 2004 to empower patients, lay people, their associations and health-care professionals to take an active part in health-care decisions. In Italy, as in other industrialized countries, there are several health-related websites; simply using the word ‘health’ reported in the URL address we found 873 000 pages in Italian (Google, 5 December 2005), most of them ‘passive vehicles’, offering reports and news without any attempt to appraise the content or to enable readers to evaluate the information. The PartecipaSalute website is based on the concept of active
participation offering selected articles on debated health topics. It is organized in three main sections, analysing the topics from different aspects showing all possible implications of the medical news (see Box 3). The website offer guides and tools to critically appraise health information, to play an active role in health-care decisions, to understand the payoffs and limits of clinical research, and to collaborate with the medical-scientific community. The website is updated weekly; it does not accept any advertisements, and every 15 days a newsletter is e-mailed.

Collaborative initiatives

In 2005, during the preparation of the Consensus Conference ‘People with severe cerebral injury consequences (GCLA) and their relatives: needs for rehabilitation and assistance during the post-hospital period’, PartecipaSalute co-ordinated a working group on ‘Family’s quality of life’. This conference was promoted by the Italian Society of Physical Medicine and Rehabilitation (SIMFER) in collaboration with some patients/families’ associations. Three working groups were organized to deal with

<table>
<thead>
<tr>
<th>Box 3 The PartecipaSalute website</th>
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<tbody>
<tr>
<td>The website is organized in three main sections</td>
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</table>

**Core sections**

**Our activities**: information on main activities of the project, with documents, links and comments  
**Patients’ rights**: information on patients’ rights and on the activities of patients’ associations  
**Good use of health information**: (among the topics discussed: the media alarm about avian flu, sensationalism on stem cell research, disease educational campaign)  
**Rules and methods of clinical research**: this section deals with clinical research, with particular emphasis on patients’ participation in clinical trials. It also provides information on ethics committees and on the role consumers can play  
**Patient and consumers’ associations**: this section provides information on patients’ associations in Italy. Associations are listed according to medical specialty and a brief description and contact information is given for each. A brief historical background on how these associations developed in Italy is given, together with statistical information on volunteering  
**Health data bank**: shared decision-making research database; Mario Negri project database; systematic review database

**Columns**

**Conflicts of interest**: explains conflicts of interest in medicine (e.g. research on lung cancer financed by tobacco companies is liable to suffer interpretation bias to the advantage of the tobacco industry)  
**Myths to disprove**: refutes old wives’ tales without proof (like: more births take place at full moon)  
**Uncertainty in medicine**: explains that many trial outcomes do not have only one implication but people will have many choices (e.g. PSA screening does not imply a reduction of mortality)  
**Shared decisions**: discusses new research about shared decision-making  
**Good websites**: analyses the best websites on health topics  
**Current trials**: lists trials that are recruiting  
**Participation stories**: collect readers’ tales about their own disease and empowerment

**The Evidence-based Message of the Month (EBMoM)** reports the abstract sections of two EBM sources in Italian: Cochrane Reviews (CRs) and Clinical Evidence (CE), a compendium of the best available evidence published by the BMJ Publishing Group. Abstracts and plain language summaries of 33 CRs were translated and packaged together with the 14 relevant chapters of CE. The Italian version of a questionnaire to evaluate users’ satisfaction developed by the Canadian Cochrane Centre (http://www.cochrane.uottawa.ca/) and the Cochrane Muskuloskeletal Group (http://www.cochranemsk.org/) is available online.  

**Tools**

This is the most innovative section of the site, providing a collection of instruments to evaluate, for example, the quality of medical information reported by magazines, newsletters and newspapers (Misuratesti, to evaluate articles), quality of contents of websites (Misurasti, to evaluate sites), the validity and credibility of patients–consumers’ associations (Misurassociazioni, to evaluate associations). The **Press release machine (Generatore automatico di comunicati stampa)** is a half serious tool about disease mongering: it offers promotional communications on new diseases and drugs that the reader can personalize. The result is similar to industrial press releases. We want to show that companies’ announcements have similar structures and one purpose only: to alarm the public about the danger of a disease, offering information on the latest cure.
different research issues: (i) epidemiological data on long-term outcomes of cerebral injuries and the available health-care services; (ii) social and health-care needs of people with severe cerebral injury and their relatives, according to the severity of their condition and kinds of outcomes; (iii) critical aspects of social rehabilitation after injury, focusing on independence, social life, family role and quality of life. The PartecipaSalute multidisciplinary working group – involving relatives of patients with severe brain injury consequences, health-care professionals and GCLA patients’ associations’ representatives – identified two specific areas of interest investigated by ad hoc surveys. The first focussed on associations contacting all 68 Italian GCLA associations; the second targeted 453 families. The aim of the working group was to collect information on GCLA patients’ and families’ needs, and suggestions for quality improvements interventions. Further details about the procedures and areas investigated are shown in Box 4.

Results
In the first two years of the project, PartecipaSalute accomplished worthwhile results in terms of:

- knowledge of the role of patients’ associations in health debate and decision-making;
- dissemination of critical medical information gathering practical tools to evaluate medical information thought the website, and organizing training course and
- growth of a sound group of patients/lay people’ representatives working together with scientists in collaborative initiatives (courses, consensus, research projects, etc.).

The findings from the patients’ federation survey are presented in Table 1. The structure and organization of participants varied considerably in terms of number of members (associations or enrolled members), representativeness in the boards and existence of a scientific committee. ‘Conflict of interest’ emerged as an unfamiliar concept to patients’ associations and transparency of fund raising is rarely discussed.17 When associations or federations were asked whether they had a policy on transparency towards the sponsor, or a document on competing interests, only five stated they had an explicit statement on transparency and only two had one on competing interests.

In general, associations and federations have two main targets: patients and their families and the public, to increase awareness on a specific illness or health problem. Activities such as supporting and caring for patients and families, disseminating information on the disease (epidemiological burden, prognosis, disability,
<table>
<thead>
<tr>
<th>Organization</th>
<th>Year of constitution</th>
<th>Number of associations</th>
<th>Directive Board</th>
<th>Technical Scientific Board</th>
<th>Document on transparency of sponsorship</th>
<th>Document on competing interests</th>
<th>Information on the disease to the public</th>
<th>Political lobbying</th>
<th>Training courses for volunteers</th>
<th>Involvement in research project/surveys</th>
<th>Collaboration with scientific societies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer Italia Federation</td>
<td>1993</td>
<td>47</td>
<td>Most members are patients/relatives</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>AICE (Italian association against epilepsy)</td>
<td>1974</td>
<td>25</td>
<td>Most members are patients/relatives</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>AIMA (Italian Alzheimer Association)</td>
<td>1985</td>
<td>30</td>
<td>Most members are patients/relatives</td>
<td>On demand</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>AISM (Italian Multiple Sclerosis association)</td>
<td>1968</td>
<td>130</td>
<td>Minority members are patients/relatives</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>ANLIDS (National Association against AIDS)</td>
<td>1985</td>
<td>22</td>
<td>Minority members are patients/relatives</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>CONCAUCORE (National coordination heart associations)</td>
<td>1999</td>
<td>77</td>
<td>Most members are patients/relatives</td>
<td>On demand</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>EUROPA DONNA Italian forum (breast cancer coalition)</td>
<td>1996</td>
<td>100</td>
<td>Half members are patients/relatives</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>FAVO (Italian federation of voluntary associations in oncology)</td>
<td>2003</td>
<td>44</td>
<td>Most members are patients/relatives</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>LISA (Italian league against AIDS)</td>
<td>1987</td>
<td>22</td>
<td>Minority members are patients/relatives</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>LILT (Italian league against cancer)</td>
<td>1922</td>
<td>103</td>
<td>Minority members are patients/relatives</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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</table>
etc.), and on interventions are their main interest. Advocacy, increasing disease awareness, circulation of information on particular topics and lobbying are examples of the second type of activity. Almost every organization provides information for patients or families. Lobbying has grown in recent years and is nowadays the main activity of some organizations. This stems from the associations aim to strengthen their influence by achieving benefits for all their members.

The associations consider the scientific literature as an important source of information, but, as most of them lack critical appraisal skills, they rely on clinical experts to appraise the quality of information. Patients’ associations rarely get involved in research process, such as defining priorities or developing clinical trial protocols. There are only few examples of active collaboration, mainly assembling questionnaires for surveys, conducting qualitative surveys among patients or reviewing informed consent forms. Rarely are patients’ and consumers’ associations involved in debates about guidelines, consensus documents or clinical research. Challenges to medical and scientific dominance remain limited, as patients’ associations depend on medical expert opinions to decide what part to play in health debates and how to organize the association’s initiatives. They do not yet know how to assess the validity of health-care information using standards of critical evaluation. Most of associations had collaboration arrangements with scientific societies.

Medical associations responding to the second survey varied widely in terms of year of activity, number of members and geographical distributions. Remarkably, 36 medical societies (49% of the total) had 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, eight medical societies had published documents on patients’ rights, but patients or their associations were involved in only 50% of these initiatives.

The training course was challenging to organize given the lack of previous experience to build upon. Twenty-three representatives of different patients’ associations (17) and lay members of Ethics Committees (6), of the 24 enrolled, attended the whole course. Participants’ feedback about the quality and usefulness of the course are reported in Table 2. It was generally well received, although technical issues, such as basic statistical concepts, were deemed too difficult to follow more time and practical exercises were required. Participants also asked for more time for discussion and for exchanging their own views. More information is available at http://www.partecipasalute.it/attivita/cms/?q=node/58.

The PartecipaSalute website registered monthly between April and October 2006 a mean of 14,000 contacts and an average of over 200 people a month subscribed to the weekly newsletter. Furthermore, every month the website receives about 40 comments and at least one new patients’ association asks to be included in the website database. To our satisfaction we recently found out that when searching through Italian Google engine the words ‘Incertezza in medicina’ (’Uncertainty in medicine’) PartecipaSalute is the first website listed from about 303,000 pages reported (accessed on 30 October 2006).

Finally, in respect of our goal to foster a strategic alliance between patients’ groups and professional societies’, the Consensus Conference working group has represented an encouraging example of effective collaboration between clinicians, scientists and patients’ associations. Briefly, the results (http://www.partecipasalute.it/attivita/conferenza-001.php, accessed on 8 May 2006) of the two surveys showed organizational shortcomings in the post-hospital/post-acute period, difficulties in finding clear information about rehabilitation and future conditions of patients, practical,

*Articles are forthcoming to report full presentation of the results.
Table 2 PartecipaSalute training course: participants’ self-assessments

<table>
<thead>
<tr>
<th>Module</th>
<th>Description</th>
<th>Before the course (mean)</th>
<th>After the course (mean)</th>
<th>How would you rate your knowledge level before and after the course? (1 = none, 10 = the best)</th>
<th>How would you evaluate the importance of the topics discussed in relation to your information needs? Range (1 = not important, 2 = not very important, 3 = enough important, 4 = important, 5 = very important)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>ABC of clinical research</td>
<td>3.8</td>
<td>6.3</td>
<td>3.2–4.8</td>
<td>4–7</td>
</tr>
<tr>
<td></td>
<td>First day</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Second day</td>
<td>3.8</td>
<td>6.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>B</td>
<td>Uncertainty and conflicts of interest in medicine</td>
<td>3.7</td>
<td>6.2</td>
<td>4.3–4.6</td>
<td>3.6–4.3</td>
</tr>
<tr>
<td></td>
<td>First day</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Second day</td>
<td>5.1</td>
<td>8.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>The strategies of health information</td>
<td>5.3</td>
<td>8.0</td>
<td>4.0–4.8</td>
<td>3.2–4.7</td>
</tr>
<tr>
<td>D</td>
<td>Patients’ associations: credibility and strengths</td>
<td>6.0</td>
<td>7.9</td>
<td>3.6–4.3</td>
<td>3.2–4.7</td>
</tr>
<tr>
<td>E</td>
<td>How lay people can participate as peers in ethic committees</td>
<td>4.4</td>
<td>7.6</td>
<td>3.2–4.7</td>
<td>3.2–4.7</td>
</tr>
<tr>
<td>F</td>
<td>How to influence the research agenda</td>
<td>4.8</td>
<td>7.4</td>
<td>3.5–4.4</td>
<td>3.5–4.4</td>
</tr>
</tbody>
</table>

Comments from participants:
Module A: Knowledge of these topics is essential to be able to play an active role in ethics committees; the language used by speakers and some of the lessons were too difficult and technical for lay people.
Module B: Dealing with these themes is necessary to develop a culture of transparency; results were excellent, discussions with the group very helpful and interesting.
Module C: It is a good idea to ask medical journalists and the staff of magazines and websites to describe and analyse the strategy of medical information; journalists themselves have to understand medical and clinical research information/data/results to improve health information in the media; it might also be interesting to involve the editor.
Module D: Participants are too tied and limited to their own association and experience during the discussion; the experiences described were very interesting and useful; this forum is very rich in subjects, experiences described and speakers; more time is needed for discussion; the use of the experiences of some associations as examples for other associations is constructive.
Module E: More time is needed to discuss; as a non-member, it was difficult to understand the role and workings of ethics committees; ethics committees should have a stronger role in all phases of research, and also need better training to weigh the scientific value of studies; I would prefer more involvement of lay members, instead of medical doctors or experts; it would be great to spread this information to all citizens.
Module F: It would be useful to go deeper into this topic to demonstrate all the barriers to citizens’ active participation in health decision-making; it is also useful to find the place in local health agencies where patients’ associations can meet each other; a future step could be to organize collaborative initiatives with political representatives, to spread the value of clinical research; my suggestion is to extend the duration of the modules and to involve a greater number of patients, because people can become aware of their strengths when they are informed and working together; the discussions were very interesting, particularly the experiences reported by patients association representatives. The discussion about the definition of research areas to be investigated and how to collect the participants’ points of view was very important; this can be a real boost towards research starting from patients needs.

economic and bureaucratic difficulties faced by families and, finally, the heavy impact on family’s quality of life. These data – as underlined by the Jury during the Consensus Conference held on June 2005 – provided a broader picture of the consequences of severe cerebral injury, focusing on the true needs of patient and family for rehabilitation and assistance during the post-hospital period.

Discussion

To our knowledge, this is the first project fully involving patient and public advocates and the scientific community in Italy. Participation in the surveys, satisfaction with the empowerment activities, the valuable results of collaborative initiatives and, finally, the large number of PartecipaSalute website visitors, show that interest in public involvement is increasing in Italy. Considering the debate about consumer involvement (http://www.cochrane.org/consumers/homepage.htm, accessed on 27 October 2006),4,14 and the monitoring of advocates about strength and impact (http://www.cancerworld.org/CancerWorld/moduleStaticPage.aspx?id=754&id_sito=5&id_stato=1, accessed on 27 October 2006)18 we believe that the Partecipa-
Salute project has in concrete terms evolved into a new voice in the Italian panorama.

However, during the development of PartecipaSalute several critical issues have emerged:

- consumers’ and patients’ associations are still not fully accepted as active players by health professionals or clinicians; their experiences and collaboration are still under valued in health debate;
- the involvement of consumer and patients associations with health-care institutions is still unsatisfactory;
- consumer and patients’ associations should promote participation in the health-care debate following the principles of ‘Evidence-based advocacy’, but this is still too rarely an integral part of the discussion within consumers’ and patients’ associations;
- opportunities for training members of consumers’ and patients’ associations should become routine in order to create groups equipped to participate in meetings, discussions or research projects;
- when members of patients’ associations are involved in working groups, the extent to which they felt enabled to actively participate should be assessed and
- explicit criteria that consumer and patients’ associations should meet, in order to qualify as truly representative and independent representative bodies, are urgently needed in order to increase the transparency of their inclusion in working groups.

As recently discussed in a consensus study on principles of successful consumer involvement in research, these critical points represent a challenge for future initiatives in Italy.

PartecipaSalute will now offer a second edition of its training course specifically targeted at consumers’ and patients’ associations and at non-medical members of ethics committees, and will continue to develop the website. During 2007 research activities will be concentrated on the development of the ‘Spazio Parita’, a patient-oriented clinical research group. Following the James Lind Alliance example, we are organizing a multidisciplinary working group that will build upon unanswered questions (drugs or health care) identified by consumers/patients and their associations together with the scientific community. In order to start this new activity readers of PartecipaSalute website, in particular consumer and patients’ associations, are invited to answer two questions regarding the priority of clinical research, relatively to pathology of their interest.

Acknowledgement
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