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Citizens' participation in the Italian health-care system: the experience of the Mixed Advisory Committees

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Abstract

Background In 1994, the region of *Emilia-Romagna* recognized the importance of citizens' participation in the regional health-care system and recommended the institution of Mixed Advisory Committees in the health districts and hospitals with the objective of monitoring and assessing health-care quality from the users' perspective.

Design This paper reports findings from a qualitatively based evaluation involving direct observations of the committees and 39 semi-structured interviews: 20 with representatives of patients and users' associations and 19 with health professionals and managers involved in the activities of the committees.

Results The Mixed Advisory Committees introduced for the first time in the Italian health system an ongoing deliberative approach that gave patients and users' representatives the opportunity to be involved in health service governance. The committees enabled the creation of a method of collective participation that overcame the reductive individualistic 'approach' to health-care participation. MAC participants evaluated the committees positively for their *mixed* composition, which integrated different cultures, experiences and professional profiles with the potential to contribute to solving health-care problems, in a consultative role. Although patients and users' representatives were able to exert some form of influence, their expectations were greater than the results obtained. The study illuminated some weak points of public consultation, such as a decline in participation by citizen representatives and a weak influence on decision making.

Discussion and conclusions MACs developed a mechanism of participation that provides health-care users' representatives with the opportunity to contribute to the identification and analysis of critical points of the health-care system. A strength of the MACs is their level of institutionalization within the health system in the region of Emilia-Romagna. However, they contain a problem of representativeness, lacking a formal system of determining a representative composition from among patients and users' associations. The case study also illustrates that participation without the cooperation of the health service, and financial and organizational support, will result in a decline in citizen participation, given the resources required of these volunteer citizens in return for limited results.

Introduction

Issues of public involvement and governance have assumed a great relevance within Western countries. In recent years, demand for more participation from civil society has increased. This debate, which has been very intense among social scientists since the 1980s, is also actively present within the health-care system.

This article studies the participation approach adopted by the Regional Health System of Emilia-Romagna (in north–east Italy), based on the involvement of patients' associations in Mixed Advisory Committees (MACs). In Italy, patients' associations are a growing phenomenon, increasing in number from 1603 in 1999 to 3265 in 2006[1], although they are not yet highly visible. In the Emilia-Romagna region, one of the regions with the largest number of voluntary associations, there are 341 self-help and mutual-aid health associations, accounting for approximately 10% of organizations surveyed nationally. In addition to disease-specific patient associations, for example for cancer, hypertension or disability, there are also various organizations that develop an advocacy role in favour of all patients and health-care users, such as Health Tribunal, European Association of Patient's Rights and Centre for the Rights of Patients.

MACs are composed of representatives of patients and users' associations and of other advocacy groups, one of which is responsible for the coordination of the committee. In addition, the MACs are also made up of a minority component appointed by health authorities, which consists of managers and health professionals. For this reason, they are referred to as *mixed*. Their objective is to monitor and assess health-care quality from the users' perspective.

As background, this study briefly reports on the role of citizens' participation in the process of the Italian health system reform. Then, the methods used to study the Mixed Advisory Committees are described, the results of the research are presented, and the potential of this public participation approach, as well as some critical points, is discussed. The article aims to contribute to knowledge on the effectiveness and failings of contemporary public participation approaches within the health system. Insights derived from the cases examined here serve to advance our understanding of the multifaceted contextual factors influencing the effectiveness of participative processes, and potential deficits of representativeness.

Before turning to a review of the literature in this area, a few key definitions are necessary. Although there is no common definition of the terms *public participation*, *public involvement* or *user involvement*[2], in this article we use these terms to indicate a direct engagement of the population in public health programming decisions.[3,4] We use the term *patients* to refer to the current users of health-care services[5], those who can 'speak with the authority drawn from experience of service'.[6 p. 585] The term *citizens* refers to people who have the right to receive health care from the state[5]: they are not defined by being users of services, but for their legal and social status in the community. In contrast, *users*' interests are more focused on the care they receive. As Calnan[7 p. 2] pointed out, 'users' interests are only a small part of citizens' interests'.

Literature review

Citizens' participation in health-care decision making

Among the numerous arguments highlighted by the literature in favour of citizens' participation in health-care decision making, it is worthy to mention the following: (i) experience and knowledge of patients improve the quality of decisions[8,9]; (ii) public health is most effective when decisions are shared with those affected by these decisions[4]; (iii) communities' health needs should be more closely matched to the health services[10]; (iv) the patient perspective should be an aspect to value during the process of decision making[11]; (v) patients' and citizens' participation increases the legitimacy and accountability of health-care services[12]; and (vi) strengthening the voice of service users is an important strategy to overcome the growing 'democratic deficit' in European countries, an issue that has characterized health-care systems following the managerial reforms of the 1990s.[13]

But how should participation in health systems be designed and implemented? The experience in this field shows that despite some good intentions and appreciable efforts, public involvement is unlikely to be fully implemented.[4,14] In this sense, several limitations are noted as a result of factors both on the side of the health system and on the side of users and patients' associations, who experience difficulties in performing their representation task.[10,12] In relation to the latter, according to some authors, there is a risk of idealizing the community's involvement and considering it a magic formula that is able to solve all the problems of the health system.[7,14] In the same direction, Contandriopulous[15 p. 328] criticizes the literature about participation in health as it assumes that citizens have an 'implicit desire' to be involved. For Coulter,[16 p. 720] there are patients who 'do not want to play an active role because they do not feel able to take responsibility and make decisions.' In this regard, many scholars question whether citizens really want to get involved in health-care decisions. Regarding the responsibility of the health system, research findings highlight that some types of organizational behaviour are still connected to a traditional and bureaucratic organization that certainly 'require a shift at the cultural level'.[17 p. 2004] Among the different constraints, it is also important to stress the resistance of professionals and health managers to implementing the outcomes of public involvement processes[18 p. 1857] and using it more as a 'technology of legitimation'.[19 p. 67]

Deliberative processes

In recent years, from the perspective of governance, deliberative methods have received much interest as an innovative strategy to enhance the interaction between decision-makers and users. Deliberative democracy aims to create the existence of a decision-making process based on discussion and reviews – preferably in small groups (face-to-face discussion) – in which participants can express various arguments freely in a democratic environment.[20,21]

Deliberation has been seen as an important attribute of democracy. In the words of Chambers,[22 p. 308] 'talk-centre democratic theory replaces voting-centric democratic theory'. Thus, discussing, explaining and justifying replace consent and voting as the conceptual cores of legitimacy. The deliberative approach is evoking a great interest in the health sector where there is a growing understanding of the need to create an appropriate 'public sphere'[23] to encourage dialogue among the different actors in the health system.

However, it is worth noting, as emphasized by Abelson *et al*.[24 p. 241], that deliberation 'is more than merely a discussion of the issues'. The deliberative process is also concerned about the discussion's outcome – namely, about the proposed decisions and recommendations – and about the process that generates that result. Among the benefits of the deliberative processes highlighted by the literature[4,22,25,26], the following should be noted: a greater involvement of citizens in health policies, the potential to change participants' opinions, the ability to increase the level of tolerance and understanding between groups in accepting the different points of view, and a qualified mechanism to produce collective decisions and to increase the legitimacy of decisions. Lehoux *et al*.[27] recommend the adoption of deliberative processes for their potential to maximize mutual learning both within expert groups and among experts and non-experts. However, besides the widespread support for deliberative methods and for its potential to improve legitimacy, accountability and decision-making processes, it is also important to mention some critical aspects of deliberative exercises identified by the literature, such as the problem of representativeness, the potential for influence and the unavoidable power imbalance between the sponsor of the deliberative process and the participants.

The citizens' jury is one of the most common deliberative methods used in the British health system.[28,29] In Canada, dialogue sessions ('Choice Work dialogue') with representatives of the public have been adopted to elicit the views of Canadian population on health-care policy.[30] In the Netherlands, patients' organizations have been asked to represent the interests of patients in health-care decision making.[9] In Italy, the Emilia-Romagna region recognized the importance of users and patients' associations and their role in promoting and representing the interest of patients, users and caregivers in health policy-making and created an ongoing (institutionalized) deliberative forum: Mixed Advisory Committees.

Background of citizens' participation in the Italian health system

The *Servizio Sanitario Nazionale* (SSN – National Health Service) was created in 1978 (Law No. 833/78) to replace a health system strongly fragmented into more than a hundred health insurance companies. The reform of 1978 introduced for the first time universal health care and developed a decentralization process based on regional and local authorities. The reform recognized citizens' participation as a guiding principle and a strategic point in the whole process of reorganizing the health system. The introduction of the new SSN no doubt represented a great advance for the most vulnerable sectors of the Italian population. However, the system also showed evident signs of inefficiency and a limited quality of health-care provision. In relation to participation, the experience showed the difficulty in translating the guiding principle into institutional and operational mechanisms. For instance, the participatory channels designed by the reform were monopolized by representatives of the political parties without involving citizens' representatives, with the exception of some regions in the centre and north of the country.

An increase in the dissatisfaction of different sectors of society prompted the government to undertake a second 'reform' of the health-care system in 1992. After a long absence from the political and health debate, the topic of citizens' participation was reintroduced by Legislative Decree No. 502/92, which outlined a system of quality of health care to be evaluated by users and their representatives as well as by health managers and professionals.

Rising financial and managerial constraints as well as the introduction of a more pronounced decentralization process in favour of the regions led the national government to launch the third reform of the health-care system in 1999 (Legislative Decree n. 229/99). Among the different changes, the Permanent Conference for Social and Health Planning at a regional level was set up with the purpose of assuring the participation of representatives of municipalities and local communities.

The region of Emilia-Romagna, through Regional Law No. 19 of 1994, recognized the importance of citizens' participation in the regional health-care system. The law prompted local health authorities to provide users' associations with appropriate office space so that they could perform their activities of representing and promoting patients' rights. The law also recommended the institution of the Mixed Advisory Committees (MACs) in both health districts and hospitals with the objective of monitoring and assessing the quality of health care from the users' perspective.

Methods

Research design

In this research, we sought to investigate four important questions: (i) To what extent is the organizational model of the MAC capable of ensuring a proper space for discussion and deliberation among the different actors?; (ii) To what extent do representatives of users' associations participate in the MACs' activities?; (iii) To what extent do the MACs' proposals influence the health-care decision-makers?; and (iv) To what extent are MACs representative of the general interest of the communities?

A qualitative approach was employed to study public participation within the health-care system of the region of Emilia-Romagna.

Qualitative research is needed to develop a rich and broad analysis of beliefs and experiences.[31–33] The overall research design involved two complementary methods: semi-structured interviews and direct observations. This approach allowed us to develop a comprehensive appreciation of the Mixed Advisory Committee in its natural setting and to focus as much as possible on the points of view of the main actors involved: the users' representatives, professionals and managers. The objective of the interviews was to learn the perceptions of different actors on the strengths and weaknesses of the participatory mechanism implemented. The interviews sought to understand the following: (i) the level of participation of professionals, managers and users' representatives; (ii) the themes and issues discussed and analysed in these forums; (iii) the level of conflict or consensus among different stakeholders; and (iv) the views of different stakeholders about the limits and potential of these institutional spaces. Direct observations allowed us to focus on the dynamics of the meetings and capture relevant information such as the level of participation in the debate and the level of agreement or conflict between the different actors that compose the MACs. These approaches were supported by an analysis of documents produced by the national, regional and local health systems relating to the MACs.

Data sources

The research involved all the MACs of the cities of Bologna (9) and Imola (1) and a sample of the MACs of the cities of Ferrara (2 of 4) and Modena (2 of 4). The examination of 14 cases in the region allowed for a robust investigation of the state of the MACs. No significant variations were found between the cities, and all cases were considered together rather than compared. We carried out 39 semi-structured interviews with 14 coordinators (C) of MACs, 11 health professionals (HP) involved in the activities of the committees, 8 managers (M) and 6 leaders of the patients' organizations and advocacy associations (PO). The interviews took place between February and July 2003 and had an average duration of between 25 and 40 min. We also carried out direct observations in the period from April to July during the monthly meetings of two MACs at the district level (for a total of eight observations) and one MAC at hospital level (for a total of four observations). Through the direct observations, we had the opportunity to observe the dynamics of meetings and focus on some aspects relevant for our study, such as the level of participation of members in discussions and the level of agreement or conflict between the various actors. The direct observations also provided examples to confirm our informants' reports on various issues.

Analysis

The interviews were tape-recorded and then transcribed. Each interview was coded by type of informant (C, HP, M or PO) and a unique number (e.g. C1, C2, M8, etc.). The transcript text was organized within tables by theme to compare and analyse the perspectives of representatives of patients' organizations, managers and health professionals. These data enabled us to establish four thematic areas of analysis: (i) the organizational model of MACs, (ii) the level of participation of representatives of the users' associations, (iii) the representativeness of the MACs and (iv) the influence of MACs on health-care decision-making processes.

For the analysis of the data collected through direct observation during the forum's meetings, the following activities were developed[34]: (i) a chronological description of what was observed, (ii) description of the events observed in order of importance, (iii) description of the performance of individuals and groups (the units of our analysis) and (iv) organization of data according to the central questions of our research.

Results

The Mixed Advisory Committees introduced for the first time in the Italian health system an ongoing deliberative approach that gave patients' and users' representatives the opportunity to be involved in health service governance. Although they were able to exert some form of influence, their expectations went beyond the results obtained. This section presents key findings concerning the organizational model of the Mixed Advisory Committees, the participation of the users' associations in the MACs, the representativeness of the MACs and the extent to which the MACs' statements influence the decision-making process of the health authorities.

The organizational model of MACs

Overall, a satisfactory evaluation of the organizational configuration of the committees emerged based on experiences in the MACs' first years. Almost all of the interviewees mentioned the positive value of this collegiate body. The MACs usually meet once a month.

The innovative characteristic of MACs, compared with previous Italian experience on public involvement, is that they are *mixed*, composed of representatives of patients' and users' associations (one of which is responsible for the coordination of the committee) and a minority of professional and health managers. The mixed aspect, as a director of a health-care district pointed out, means 'to structure by principle the collaboration issue from the initial moment, from which other alternatives are not possible' (M3). This does not mean that there are no difficulties, incomprehension, language differences and sometimes even conflicts, but the continuity and institutionalization of the relationship favour, according to professionals' opinion, 'mutual understanding' (HP4), the 'maturation of all the actors involved in the process' (HP7) and the 'creation of trust relationships' (HP10) that could facilitate the analysis and resolution of identified problems.

A second aspect that is considered very positive is the *integration of different cultures, experiences and professional profiles* with the potential to contribute to solving health-care problems. For example, the technician analyses the means of access to services and the difficulties related to several possible options, while representatives of patients' associations, with less technical perspectives, can identify certain problems that, as a professional of a health unit recognized, 'the service may not always identify' (HP1). Such integration is only possible, however, if health services can give up, as one manager said, 'on their traditional self-centred attitude' (M1) and if the users' representatives avoid, as a representative of users' association pointed out, that typical behaviour 'of someone who presupposes that his own instances should always and in any way be accepted' (PO1).

A third key characteristic of the committees is their *consultative role*. The committees express their own judgments, pay visits to and monitor health facilities, and suggest proposals to health authorities who, however, keep their own responsibility and autonomy in decisions.[35]

Participation of the users' associations in the Mixed Advisory Committees

The level of participation of representatives of users' associations has been indicated as a problematic aspect of the MACs. After the first phase, during which a wide participation of numerous local associations was evident, most of the interviewees recognized a decrease in participation. There are several reasons explaining this change: first, the time and effort required by the activities of the MACs, such as the planned meetings, visits and inspections to the health facilities and working groups. Of course, we are talking about volunteers who already spend much of their time in their own association. Second, several informants, particularly those representing the associations, identified the limited influence that committees have on the health-care decision-makers as a possible reason for the lack of motivation of the associations' representatives. For example, two MAC coordinators noted:

> 'Many do not feel motivated because the proposals were often forwarded and unconsidered.' (C2)

> 'Sometimes we have the impression that the work done and the proposal suggested does not find an immediate solution.' (C6)

These comments reflect an emerging gap between the expectations and values of the volunteers, and the materialization of daily experience, a point that has been noted by the Ministry of Health.[36] Multiple factors play a role. First, the committees, being a forum for discussion, negotiation and analysis of identified problems, need considerably longer than the pace of daily work to resolve such issues. Second, they must interact with the health-care system, whose structure is still not agile enough and does not have adequate resources to solve its multiple problems. Third, some informants blame the health authorities for not having sufficiently informed public opinion about the importance of the committees and their social role. It is particularly important that the committees have a different image and greater social recognition of the role they are developing: 'I wanted the committee to be a point of reference, not only for the associations, but especially for the mayors' conference, which is responsible for local health' (C3). Another emerging aspect, which is related to the decrease in participation, is the inadequate professional training of volunteers. According to a significant number of informants, the volunteers clearly lack appropriate training in how to perform a complex and committed role. The interviewees, both representatives of health services and of associations, listed a series of competences and abilities that members of the committees should have in order to evaluate the quality of services and to promote patients' rights. These include being able to identify a quality indicator and monitor it (M5), to organize a visit to health facilities (HP6) and to lead discussion meetings in the health units (PO4).

Representativeness of the Mixed Advisory Committees

A critical aspect raised by analyses of other participation experiences in the health sector on an international level is *representativeness*.[14,27,30,37,38] Many public participation initiatives have been criticized for failing to represent some social groups and certain health needs of the population.

In this case, there was a wide consensus among interviewees that MACs face issues that interest users in general, and the research revealed that MACs were able to represent all users. Although there is a risk of self-centredness in some associations, particularly in the most active associations representing patients who have serious health conditions, it seems that the 'specialized associations' (e.g. disease-specific associations) have the capacity to point out the existence of general problems, although doing so from their particular perspective. No doubt, the presence of so-called generalist associations in the MACs, that is, those associations with an advocacy role in favour of all kinds of health users, such as the Health Tribunal, the European Association of Patients' Rights and the Centre for the Rights of Patients, contributed to the creation of a locus of representation of all users of health services. In fact, discussions about waiting lists or overcrowding, and hygiene problems of some health facilities certainly do not represent hyper-specialist issues and areas of interest of specific associations. Interviewees reported that the committees 'represent the citizens and not the associations' (PO2) and that committee members do not refer to their associations within the committees (C7). Further, it was felt that 'although the members of the associations usually deal with specific health pathologies, they have the competence to represent the general interest' (C9).

It is important to note, however, that recognition of the importance of the role of the MACs does not imply that they represent all health-care users. In relation to this point, two considerations are needed. First, representativeness does not exist in a formal sense because there are no formal mechanisms of delegation by which groups or categories of users choose their representatives. In this respect, as underlined by some informants, there is a risk that the lack of accreditation mechanisms and organizational filters can promote overgrowth of associations not representative of the population, which could ultimately undermine the representativeness of participation. Second, it is difficult to state that MACs represent all patients, because, as it was often pointed out, there is not a significant proportion of people and associations actively participating in the activities of the committees. In fact, our interviewees did not hide the difficulties of developing relationships with a wider sector of users. A closer relationship between users and their 'spokespersons' would certainly be able to reinforce the representativeness of the MACs.

The influence of MACs in the decision-making process of the health authorities

Participation necessarily requires the ability to influence the health-care service agenda.[39–41] In this case, a significant number of users' spokespersons showed a tendency to problematize the relationship with the decision-makers, citing the limited impact of their proposals and recommendations. Upon further discussion and by asking the users' representatives to give specific examples of what they have really obtained, a better situation was revealed. Most of them enumerated a series of proposals accepted and implemented by health managers. Among the results obtained and confirmed by our documentary analyses of reports produced by the local health systems, the following were reported: improvements concerning humanization and information, the reorganization of logistics and wayfinding signs, the control of hygiene in hospital areas and reduction in waiting lists for some medical specialties. However, the acquisition of such results required a remarkable investment in time and energy. A common concern that emerged from many informants relates to the long time that health authorities spend to implement the suggestions given. On this point, some professionals and managers agree, recognizing the existence of 'extremely long times' and a 'certain idleness' on the part of the hospital/health-care management.

Naturally, as some representatives of the associations pointed out, this causes 'skepticism and distrust', and perhaps it could help to understand the somewhat pessimist attitude regarding the impacts of their actions, as mentioned above. Our informants reported the critical points – those 'largely discussed' (C5) and 'continuously proposed' (C12) during the meetings of the MACs – that were still not resolved. The following problems were cited the most: (i) the reorganization of mental health services, (ii) the improvement of integrated homecare services for elderly and (iii) the reduction in waiting lists for certain types of surgeries. How can one explain the MACs' difficulty in having an impact on decision-makers regarding the above-mentioned issues? According to the opinion of some informants, topics are often discussed that are beyond the competence of the local health district and that cannot be changed by a simple local committee. For example, homecare services for the elderly involve issues strictly related to the strategic policies of the regional health system which give little autonomy to district directors. At the same time, it is important to consider the financial restrictions that limit the implementation of some proposals presented by the MACs. Besides these constraints, it is worth asking whether the health authorities and professionals are really sensitive and open to the demands of MACs, a concern raised in some informants' comments:

> 'They cannot ask for our opinion nor incorporate them during the decision-making process. Therefore, we are only losing time.' (C10)

> 'Within the health organizations, a self-centred approach based on hierarchy and bureaucracy still exists.' (C13)

Discussion and conclusion

The institution of the MACs in the region of Emilia-Romagna enabled a method of collective participation to be created that overcame the reductive individualistic 'approach' to health participation, typical of consumer satisfaction approaches, which has been employed in recent years in the Italian and other Western health systems. MACs developed a mechanism of participation that provides users' representatives with the opportunity to contribute to the identification and analysis of critical points of the health-care system. During MACs' work sessions, health specialists are usually invited to analyse critical aspects of the health-care services and to respond to the concerns and claims of the citizens' representatives. This interaction process – as has been highlighted in the experiences of many deliberative processes[4,22,24–26] – improved participants' understanding of the most complex aspects of the health system.

Another strength of the MACs is their level of institutionalization within the health system in the region of Emilia-Romagna. They are recognized by a regional law, and they act, routinely, in all the health districts and hospitals of the region. This institutionalized or ongoing approach to public involvement, as stated by different scholars[24,26], seems to be a promising strategy to promote a more sustained relationship with users and patients' associations, compared to single (*ad hoc*) exercises. This strategy helps avoid public involvement becoming a sporadic exercise activated only by the health authorities, as has happened with many deliberative initiatives carried out in recent years. In this regard, according to McIver[42], citizens' juries could surely represent an effective exercise of participation, but only if they are integrated in a broader strategy of public involvement. Public consultation, as Rigge[43 p. 26] noted, should not be a 'one-time-only' event, but an 'important component of the quality of the health system'.

This study also revealed a few weak points of public involvement, such as a deficit of participation in users' representatives, a weak influence of MACs on decision making and a problem of representativeness. In relation to the latter, this study confirmed the results of many research studies carried out during the last 20 years that reported the limited use of formal representation in the initiatives of public involvement.[27,44,45] The British Community Health Councils were also criticized for failing to represent some health needs and social groups, such as users with learning disabilities and mental health problems, the immigrant population, young people and, in general, the segments of the populations with a low income level.[46–48]

The situation is no better in the case of deliberative methods, whose virtues are being questioned by the representation deficit that should be a key element of participatory democracy.[4,10] In the Italian context, Altieri[49] expressed the same concern about the representation model adopted by the MACs, which, according to the author, brought about a substantial transformation in the participation conception, now understood as 'a type of co-determination through representations not chosen through democratic mechanisms and not delegated' (p. 16). This case is consistent with the Netherlands' public participation approach defined by Bovenkamp[9 p. 74] as a 'neo-corporatist model'. In fact, patients and users' associations need to be recognized by the regional government to participate, as public consultants, in the activities of MACs. However, it is important to point out that although the members of MACs are not formally elected or delegated, they represent several volunteering and advocacy organizations and are therefore recognized as an important reference (a sort of qualitative representation). The tension associated with representation in public participation could be overcome, according to Thurston *et al.*[40], by 'making a distinction between representing a population and bringing a perspective as a member of a particular population' (p. 2). This description of representation is consistent with what different authors define as 'experiential participation'. As Wharf Higgins[50 p. 32] argued, it is not necessary for decision-makers to be representative of their constituency if they understand 'the needs and experience of those they represented'. Experiential participation – as stressed by Frankish *et al.*[10 p. 1476] – is legitimated by acknowledging that electoral representation is also limited, 'because there is no guarantee that such representatives share similar constituent gender, ethnic or socio-economic status'. Experiential participation could represent a step towards achieving a better representation of different perspectives.

The most problematic aspect of the experience of MACs is probably the reduction in levels of participation. We should not forget that the spokespersons of the organizations participating in MACs are volunteers; this implies that (i) participants can dedicate a limited amount of time to the MACs' activities, (ii) there is a large request for participants in face of a limited number of volunteering persons and (iii) the kind of participation that is requested implies adequate competence and strong motivation on the part of the volunteers. A similar situation was described by Bovemkamp[9 p. 82] in regard to the Dutch health system: 'There are too many opportunities for participation and many organizations simply cannot cope with this demand'. Moreover, public involvement structures can inhibit participation because it 'demands so much time and energy that many organizations fail to meet expectations' (p. 82).

One year after the conclusion of our study, regional health authorities started a process of reorganization of the regional health system, which led to a reduction in the number of health districts and of Mixed Advisory Committees through merging them together into larger units. In the city of Bologna, for example, the initial five health districts were aggregated into a single, larger district. Once again, efficiency was the principle behind the reform of the health system. This process will probably improve management and economies of scale – as different health services personnel reported during our study – but will this new configuration be a better solution for fostering both the public involvement of users and the level of representativeness? It seems, in fact, that the opposite is occurring with respect to the large debate on the importance of the 'health district' and of the 'process of decentralization' that followed the WHO-UNICEF Alma Ata Conference[51], which estimated 40-50,000 inhabitants to be the ideal population for a health district in order to balance the efficiency criteria with principles of local community participation. In this regard, Milewa *et al.*[45 p. 515], commenting on managerial flexibility and the internal market introduced into the British National Health Service, argued that the reform had only implemented an 'internal decentralization' rather than an 'external decentralization' that could have helped strengthen the relationship between communities and health authorities.

Finally, we turn to the question of influence. An important principle of the deliberative democracy approach rests on the assumption that participants gain knowledge and expertise to achieve reasoned argumentation and informed conclusion. But another key principle of deliberative democracy exercises is the ability to produce recommendations and exert an influence on policy-makers. In this case, even if MACs have the role of indirect participants, in the sense that they are public consultants whose perspectives are solicited to inform decisions and not to participate directly in the decision making[24], they have exerted some influence on health authorities. However, the expectations of the users' representatives went beyond the results obtained. These findings are coherent with the results of several studies that have reported the limited impact of the users' voice on the resolutions adopted by health authorities, which are usually influenced by other factors.[4,19,52,53] Decision making, argued Thurston *et al.*[40], is a complex political process influenced by both internal and external factors. Public institutions have always had a self-centred tendency in relation to their social environment,[46] and this attitude is still present – according to our informants – in the type of relationships that health authorities have with users' representatives participating in the MACs. It is a relationship that, in spite of the reforms advanced, still contains some characteristics typical of a traditional bureaucratic organization. How else to explain the great difficulty that MACs have in introducing their proposals or the long time needed by health authorities to implement the suggestions given by users' representatives?

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