

## The challenge of citizens' participation in health systems in Southern Europe: a literature review

O desafio da participação cidadã nos sistemas de saúde do Sul da Europa: uma revisão da literatura

El desafío de la participación ciudadana en los sistemas de salud del sur de Europa: una revisión de la literatura

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### Abstract

*The current article analyzes existing mechanisms for public participation in health systems in the countries of Southern Europe. Results are presented from a literature review focusing on public participation in health systems, highlighting the potentialities and challenges emerging from the principal national experiences in the respective countries: Spain, Greece, Italy, and Portugal. The article begins by characterizing the health systems, then presents the methodology followed by the results of the analysis in each country, emphasizing the different forms of participation, both institutionalized and non-institutionalized. The study's principal conclusion is that a legislative discourse has prevailed, which in most cases has not materialized in actual participatory practices; meanwhile, non-institutionalized forms of participation have emerged with a special leading role in the health area, featuring protests, largely spurred by the current economic crisis.*

*Health Systems; Public Health Policy; Citizen Participation*

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## Introduction

For more than 20 years, approaches that prioritize participation in decision-making processes based on different possibilities for citizens' participation have been discussed as central to democratization. These have ranged from institutionalized forms, with or without binding power, to more recent non-institutionalized forms with the potential to influence decisions. A conviction has emerged from this process that participatory arrangements based on the interdependence of actors are capable of solving collective problems competently, since they improve the quality of decisions, allowing them to be backed by the voice, experience, and forms of knowledge of new actors that can now intervene in public decisions.

The issue of public participation has thus highlighted the relevance of collectives affected by the definition of the common good, helping promote models for active citizens' participation in institutions and public services <sup>1,2</sup>, notably in public decision-making contexts. To be a citizen thus means to enjoy the adequate means to participate in social and political life, since the exercise of citizenship is closely associated with the promotion and development of rights to personal capacity-building <sup>3,4</sup>. Although no common definition exists for the terms "public participation", "citizens' participation", and "users' or patients' involvement" in this article, they are used to refer to direct involvement by the population (patients and non-patients) in decisions on public health planning and organization. The term "patient" also refers to users of health services, those who can speak with the authority that comes from experience with the service <sup>5</sup>, while the term "citizen" refers to all persons that have the right to receive health care from the state. Users' interests are thus centered more on the care they receive and are only a small part of citizens' interests <sup>6</sup>.

In the health domain, the results achieved thus far are still quite modest, particularly because not all citizens have the same means and/or the adequate means to exercise the right to participate in decision-making processes in health. In this context, citizens' participation was formally established as a right during the Conference of Alma-Ata <sup>7</sup>, the International Conference on Primary Health Care, organized by the World Health Organization (WHO), in 1978. The *Declaration of Alma-Ata* affirmed participation not only as a right, but also as a duty to be exercised individually or collectively in planning and implementing health care <sup>8</sup>. However, in most cases when this possibility has materialized, the main beneficiaries of participation have not belonged to the most underprivileged social classes, with the greatest need to make their voices heard <sup>9</sup>.

Boosting participation is an important strategy for overcoming the democratic deficit <sup>10</sup> that still plagues many health systems. More shared responsibility and increasing transparency in services through participatory mechanisms have been emphasized as good practices <sup>11,12</sup>, especially considering that the incorporation of users' knowledge and experiences improves the quality of health care decisions and the provision of such services <sup>13,14</sup>.

This article deals with the issue of public participation in health based on a literature review in countries of Southern Europe, focusing on the importance of such participation in health systems reform in these countries and highlighting the potentialities and challenges emerging from the respective national experiences. The article characterizes the health systems, presents the methodology used in the analysis, and addresses the results for each country, emphasizing the different forms of institutionalized and non-institutionalized participation in the region.

## Health systems in the countries of Southern Europe

Various scientific publications have acknowledged that the countries of Southern Europe (Spain, Greece, Italy, and Portugal) share important characteristics, particularly a specific welfare state model – partly resulting from similar historical processes – and geographic and socioeconomic characteristics. Without denying the validity of social welfare models developed by Esping-Andersen <sup>15</sup>, Ferrera <sup>16</sup> has emphasized the need for progress with a new approach capable of addressing these distinctive aspects of social protection systems in Southern Europe.

Thus, based on the social welfare model designed by Esping-Andersen <sup>15</sup> and later improved by Ferrera <sup>16</sup>, it is now possible to identify four major European regions, including their health systems:

Northern, Central Western, Southern, and Eastern Europe, the latter including the former socialist countries that more recently joined the European Union <sup>17</sup>.

The health systems of Southern Europe are thus characterized by the fact that were created more recently (Italy – 1978; Portugal – 1979; Greece – 1983; and Spain – 1986) and by their services' low level of administrative efficiency. Non-professional resources also play an important role, such as family and primary networks <sup>18,19</sup>, showing the existence of a support network that complements the state, also known as a social security society <sup>20</sup>. The systems in Southern Europe also display low levels of citizens' participation in health decisions, a peculiarity not analyzed by Esping-Andersen or Ferrera. However, one cannot ignore the diversity of social and health policies between states with similar welfare systems, or the diverse paths followed by the different countries. An example is the different levels of government spending in health as a share of total expenditure, varying significantly: Italy (75.5%), Spain (69.4%), Portugal (66%), and Greece (60.6%) <sup>21</sup>.

## Methodology

This study of citizens' participation was based on a literature review of publications (scientific journals and book chapters) from 1998 to 2015, on experiences in the health area in the four countries. We analyzed 52 publications, distributed more or less evenly between Spain (17), Italy (16), and Portugal (15), while for Greece only four publications were identified.

The study was based on the scoping review method proposed by Arksey & O'Malley <sup>22</sup>, with the following phases: (i) identification of the research questions; (ii) search for relevant studies; (iii) selection of studies; (iv) qualitative data description; and (v) collection, summary, and report of the results.

The material resulted from searches in the following electronic sources: Web of Science, PubMed, Scopus, SciELO, and Google Scholar, with the terms "citizens' participation", "participation in health", "users'/patients' involvement", and "health system reform". The search was done both in English and in the national languages of the countries covered by the respective studies. In addition to the available online sources, the literature review also drew on a manual search in publications from thematic journals on participation in health. The reference lists from the articles were also analyzed to identify other relevant publications.

The analysis included all publications focusing on public participation, defined here as participation by patients, users, caregivers, citizens, and patients' associations in the processes of needs identification, priority-setting, planning, organization, monitoring, evaluation, and development of health services.

The selected literature was organized according to the four countries and based on the identification and systematization of the principal characteristics/dimensions of participation in the health area. The analysis used a qualitative approach to the selected publications to produce a brief description of the results, with a report of the analyzed material. We also conducted a document analysis of national and regional health plans and legislative initiatives in the four countries.

Considering the objective of mapping the experiences with participation in health in Southern Europe, the analysis summarized the main results from the literature, linked to the theoretical framework elaborated in the sphere of citizens' participation in health systems.

## Citizens' participation in health systems in Southern Europe

### Spain

The Spanish Constitution of 1978 acknowledges citizens' participation as a fundamental right. In the health, the General Health Law defined citizens' involvement as a founding principle of its legal order, establishing the Health Councils to be implemented in the health areas and health zones of the Autonomous Communities <sup>23</sup>. These participatory structures have received some criticism, especially the legal definition adopted by each Autonomous Community, which limits actual participation by social actors, reducing them to members of the health advisory bodies <sup>24</sup>.

As a way of legitimizing citizens' participation in drafting national health policy, the Cohesion and Quality Law created the Advisory Committee on Participation in the Council of the National Health System, dependent on the Ministry of Health<sup>25</sup> and consisting of representatives from the General Health Administration and the Autonomous Communities, business organizations, and trade unions, but excluding patients' and health service users' representatives<sup>26</sup>. Despite a favorable legal framework, Spain still shows a striking lack of citizens' participation in the National Health System<sup>24,26,27</sup>. However, since 2010 some Autonomous Communities, such as Aragon and Castilla-La Mancha, have introduced mechanisms for participation in health.

At the national level, an initial impetus for participation was the implementation of a new Primary Care model based on Family and Community Medicine, beginning in 1990. The program was based on the joint identification of health needs with the community and evaluation of the results. However, a study later concluded that only 6% of the Health Centers developed participatory activities<sup>24</sup>. Heterogeneity, limited participation by associations and civil society organizations, and insufficient support from public administrations were also identified as weaknesses in this participatory process<sup>28</sup>.

In order to strengthen users' participation, in 2007 the Autonomous Community of Castilla-La Mancha developed a new model for decision-making participation in the city of Puertollano. Three new participatory mechanisms were created as part of this strategy: the Health Forum (consisting of representatives of associations and individual users); the Participatory and Administrative Council, a mixed forum consisting of representatives of associations belonging to the Health Forum and health professionals' and administrators representatives; and the Virtual Forum. A positive feature of the new model was that citizens' interests and the local associative fabric were now involved in the process<sup>29</sup>. However, the mechanism has received some criticism, especially the lack of necessary training for participation in the process, which is not provided by the respective levels of authority, besides the need for greater involvement by policymakers. Despite positive assessments following the initial years of the model's implementation, a change in the regional government administration in 2011 paralyzed this experience and limited its potential extension to other regions<sup>30</sup>.

In the Autonomous Community of Aragon, in 2008-2009, a health reform process was implemented to promote citizens' participation in the Health Councils. Various activities were conducted, such as situational analyses in specific health contexts, debates, and the organization of workshops and working groups<sup>31</sup>. This process culminated in the elaboration of a participatory model that was expected to be applied throughout the region. However, here too the regional government change in 2011 interrupted the process.

## Italy

In Italy, the discourse surrounding participation has inspired the process triggered by the National Health Reform Law (*Law 833/1978*), a legislative initiative that resulted from intense political activity, mainly involving trade union struggles and demands by social movements, although many of these were not turned into institutionalized mechanisms<sup>32</sup>.

After a long absence from the political debate, the issue of participation in health regained visibility with *Law 502/1992*, which introduced a quality-control system based on services assessment by users. In addition to individual participation, based on the recording of complaints, proposals, and demands, the Law encourages new forms of collective participation, such as the presence, in hospitals and health centers, of associations of volunteers involved in patient care activities, as well as in advisory bodies. Twenty-four years after the law was passed, there are few innovative experiences in citizens' participation in the regional health systems. One of the most advanced regions is Emilia-Romagna (*Regional Law 19/1994*), which provides that health centers and hospitals should create adequate conditions for users' associations to conduct advocacy work to propose increases in the services. The law further recommends the creation of Mixed Advisory Committees consisting of patients and users' representatives, together with health professionals and administrators.

Despite the innovative nature of this decision-making approach, the experience has shown some critical aspects: (i) a decrease in participation by associations' representatives in the Mixed Advisory Committee; (ii) difficulties in the representation of all social groups in the participatory forum; and (iii) dissatisfaction on the part of some representatives due their limited influence in health decisions<sup>32,33</sup>.

In the Tuscany region, Integrated Health Plans were developed, creating: (i) Participatory Committees, involving advocacy and self-help associations; (ii) the third sector Advisory Council, consisting of representatives of volunteer organizations that provide social and health services; and (iii) the Agora, which encourages local residents' individual involvement, meeting twice a year. However, the legislation governing the new system of participation in Tuscany has not provided a detailed definition of the methods for citizens' participation and decision-making in the various mechanisms, nor has it provided the resources for their materialization. Having concluded the experimental phase, insufficient organizational definition and insufficient investment in capacity-building and promotion of participation have weakened this participatory experience <sup>34</sup>.

### **Portugal**

In the case of Portugal, the Health Guidelines Law <sup>35</sup> of 1990 and the statute of the National Health Service <sup>36</sup> of 1993 define advisory participation in various areas and levels of the system. An example is the hospital boards, in which an advisory committee includes a representative from the users' association <sup>37</sup>, and at the primary care level the creation of an advisory council to promote public participation <sup>38</sup>. However, participation remains largely confined to the legislation <sup>39</sup>. "Low participation by citizens" in the health system and the "strong influence of structured interest groups" are factors accounting for the power imbalance within the system, contributing to the lack of political discussion and pluralism in health policy-making <sup>40</sup>.

Various initiatives have attempted to promote citizens' participation: (a) the creation of an Observatory in each of the five regional administrations, aimed at improving services and promoting user satisfaction; (b) creation of direct telephone lines between patients and physicians; (c) formalization of procedures for demands and complaints; (d) creation of advisory councils with users' participation, aimed at supporting the management of health centers and hospitals from the service users' perspective.

More recently, *Decree-Law 28/2008* established the Health Center Groups (ACES) with the aim of reducing health inequalities and overcoming the marginalization of primary care. This decree established the Community Councils to encourage participation by different local actors in decision-making and organization of health services.

The barriers to the functioning of Community Councils have included inertia in selecting representatives, excessive influence by local authorities in the participatory process, and lack of users' associations for participation in the Councils. The most critical issue is the persistently limited presence of users' associations in the work areas of the ACES <sup>41</sup>.

In Portugal, patients' associations have begun to play an important role in participation in health, with an extremely relevant role in representing and defending patients <sup>42</sup>. Given the absence of institutional channels capable of promoting regular participation, as emphasized in the last two national health plans (2004-2011 and 2012-2016), the role played by these associations in the health decision-making processes has proven essential, especially because it has exerted growing pressure since 2000 in opening the health decision-making process to their participation, valuing their special expertise. Some studies in Portugal highlight the activism in the associative movement in HIV/AIDS <sup>43</sup>, diabetes, fibromyalgia, chronic fatigue syndrome, hepatitis <sup>44</sup>, and rare diseases and in defense of humanized childbirth <sup>45</sup>.

### **Greece**

In Greece, the 1983 reform (*Law 1,397/1983*) established the National Health Service, providing mechanisms to involve local communities in decisions, specifically the creation of Regional Health Councils (which never materialized in practice). The Greek case is thus especially interesting, because decisions on public health expenditures are not even based on criteria that consider the population's real needs <sup>46</sup>.

The absence of experiences in citizens' participation in Greece illustrates the inability, in the last 30 years, to implement the reform as designed in the law, including the promotion of health system decentralization, the development of policies capable of mitigating inequalities, strengthening pri-

mary health care, adoption of measures to improve health services efficiency, and overcoming fragmentation of the National Health Service, which is structured in various subsystems – the National Health System, Social Health Insurance, and Private Health Insurance.

The reform that created the Greek National Health Service in 1983 thus ended up limited to the hospital sector and proved incapable of establishing health centers in urban areas or introducing the Family Physician as a figure in the National Health Service <sup>47</sup>.

Although the Regional Health Councils were provided for by law, they were not actually created. Since then, the issue of participation has not appeared in the legislative intentions in the recent Greek government administrations <sup>46</sup>. The country still lacks mechanisms and the legal framework capable of promoting public participation in decision-making processes in health.

Users' and patients' associations still play a very weak role in Greece. The majority of the population is not represented by any such organization, since the existing ones are small self-help associations related to some specific diseases. There are volunteer associations and nongovernmental organizations that conduct interesting activities in the field of health and social inclusion. However, their role in planning and regulation is extremely limited <sup>48</sup>.

The lack of tradition in citizens' participation in the Greek health system should not overshadow the many examples of social solidarity, as in the case of the popular clinics oriented to helping citizens who are suffering financial constraints that prevent them from paying their health insurance premiums. Another issue that has conditioned the development of participatory practices in the Greek health system is lack of preventive and health promotion services in the community, as well as the lack of qualified professionals in primary health care <sup>49</sup>.

The year 2010 marked the beginning of Greece's financial bailout by the International Monetary Fund, European Union, and European Central Bank. Since then, all the public sectors are under financial adjustment measures, decided without the involvement of the various social stakeholders, as occurred in Portugal and Spain. In health, the economic crisis added to the many existing weaknesses and further weakened the Greek National Health Service.

### **The “invisibility” of citizens' participation: social movements and protests on health issues**

Institutionalized forms of participation in health in the countries of Southern Europe have been affected by various factors that limit their continuity. The difficulties in consolidation of such participation arising from partisan political changes in the electoral cycles and the resulting austerity measures slowed down the dissemination of institutionalized mechanisms of participation in health across territories. Meanwhile, the reduction in health investment has resulted in alternative forms of participation, especially protests, mainly since 2008 <sup>41</sup>, which have enriched the phenomenon of participation and function as a strategy for demanding more and better participation in decision-making contexts, besides showing the potential to influence decisions <sup>50</sup>. These protests in the health area have been motivated by various issues, such as the closing of services, shortage of health care staff, and deterioration of health systems in Southern Europe. The protests, held by both the population and health professionals, do not guarantee stable results in influencing decision-making processes, but they have drawn on strategies for monitoring health policies, with a watchdog role over democracy and the way it works.

In Italy, collective action by social movements in health has displayed great dynamism and potential to effect change. An example is the institutionalization of Permanent Citizens' Hearings in the context of the Family Clinics operating in Rome since 1994. This mechanism resulted from demands by the region's feminist and women's movements since the 1970s, claiming more attention from the public health institutions towards the importance of gender differences and the need to implement a “democratic medicine”, capable of allowing women to intervene in health services and in the processes of medical investigation of their bodies. Despite their institutionalization, the Permanent Citizens' Hearings have been weakened by their lack of linkage with various health services, having proven incapable of influencing the Italian health system's routines and logics. The hearings are now marginalized from decision-making in health, and their participation is merely symbolic <sup>51</sup>.

Portugal, despite recent legislative strides such as *Decree-Law 28/2008* establishing the Community Councils in the context of the ACES, still has scarce opportunities for citizens' participation in health. Prevailing state authoritarianism has limited greater opening of decision-making contexts to institutionalized forms of citizens' participation. Since 2006, health is an area that has most mobilized citizens to protest in the attempt to influence decision-making processes<sup>52</sup>.

The various actions, challenging policies that closed health units and the deterioration of the National Health Service, did not lead to stable results in terms of their influence on public policies, but they cannot be considered illegitimate or devoid of potential to influence decision-making. Such actions contribute to the redefinition of participation in health, since in the absence of other communications channels they assume the leading role of giving voice to the populations affected by certain decisions, who can thus express their needs, such as manifesting their disagreement with the direction of policies as implemented<sup>53</sup>.

As mentioned above, patients' associations also act in Portugal (as in other countries of Southern Europe) as prime spaces for citizens' participation, given their capacity to produce knowledge and influence health governance<sup>44</sup>.

The history of participation in health in Spain also lends legitimacy to the central role of social movements and their action in conquering and implementing mechanisms for participation in health. However, the path to participation has been a troubled one. The democratic transition in Spain spawned a process of state democratization, largely resulting from the collective action that in 1980 led to a set of experiences with local participation in health. Although some of these experiences have been institutionalized, others have their action limited by lack of funding or eliminated by the neo-liberal project<sup>26</sup>. In Spain, participation in health has become a key demand by the social movements, featuring the *Mareas Blancas* or "White Tides" a movement that defends public health care services.

Having emerged in 2012, the *Mareas Blancas* answer to the set of collective movements with their ways of defining public health. Organized on the basis of regional platforms, these collectives emerged from waves of protest against the austerity measures in the 2008 crisis, largely triggered by the consequences of structural health system reform (*Royal Decree-Law 16/2012* of April 2012). Since then, health professionals and the population at large have organized intense regular demonstrations in defense of the National Health System, demanding universal coverage and an end to budget cuts, fighting privatization of these services.

In Greece, the shortcomings in the National Health System and health inequalities have increased in an unfavorable economic context in which private services have proliferated in response to the state's obvious inability to deal with the system's growing fragmentation<sup>47</sup>. Greece's financial bailout in 2010 heavily affected the public health sector, which continues to operate with various weaknesses, aggravated by drastic budget cuts. As a result, the Greek health system, accumulating serious structural problems for more than a decade, is mired in aggravated crisis<sup>54</sup>. For the Greek people, protests have become one of the few opportunities for participation whereby they can mobilize to make their voices heard and express their demands. In addition to the population's various protests against the austerity measures – with consequences at various levels, including health –, since 2013 the country has witnessed more demonstrations organized by health professionals, on grounds that the budget cuts are leading to the collapse of the Greek health system. In the most recent demonstration, in June 2016, the Pan-Hellenic Federation of public hospital employees announced to the media that the Greek people's lives are in danger, since many health services are still closed, while in others patient safety is in jeopardy due to shortages in human resources.

Southern Europe, the region hit hardest by the economic crisis dragging out since 2008, has witnessed the emergence of alternative forms of citizens' participation as compared to the conventional approaches characterizing other European regions, where institutionalized participatory methods enjoy a longstanding and widely acknowledged tradition. In some cases, these non-institutionalized alternatives for participation in Southern Europe may not have directly influenced decisions, but they have proven their capacity to influence the electoral cycles<sup>52</sup>.

Such initiatives, in addition to resulting in clear pressure to expand participation, are strategies for participatory communication whenever citizens see policy decisions as backsliding from acquired rights, especially given citizens' perception that the quality of services has deteriorated<sup>55</sup>.

## Conclusions

Citizens' participation today is a recurrent theme on the national agendas and in legal frameworks of health systems in the various countries of Southern Europe. Nevertheless, according to this study's findings, participation in decision-making in health is still limited to legislation, with little expression in actual practices. In the four countries analyzed here, although the legislation provides for citizens' participation, most of the initiatives are still highly dependent on the impulses of regional political power, especially in Spain and Italy.

The financial crisis since 2008 has affected Southern Europe especially hard, with an impact on participation in health. The lack of financial support has limited the continuity of many experiences previously under way. However, the same crisis has triggered collective action, especially through protests in the various countries, fueled by the population and by health workers in defense of the national health systems, against the closing of services, staff shortages, and budget cuts, factors that have jeopardized the quality of services.

An analysis of the literature on mechanisms of public participation in health in Southern Europe showed that a major portion of the attention still focuses on institutionalized mechanisms, largely overlooking an analysis of non-institutionalized forms of participation, such as collective action through protests or even the dynamic of social health collectives such as associations acting in the area. Although some studies are beginning to focus on this dimension of participation, pointing to trends, such studies are still scarce and do not allow capturing, with the necessary rigor and detail, the social segments that are mobilizing or the actual impacts their actions produce on decision-making contexts in health.

## Contributors

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## Resumo

*O presente artigo versa sobre a análise de mecanismos de participação pública existentes nos sistemas de saúde dos países do Sul da Europa. Apresentam-se os resultados de uma revisão da literatura incidindo na questão da participação pública nos sistemas de saúde, realçando as potencialidades e os desafios que emergem das principais experiências nacionais identificadas, nos países considerados: Espanha, Grécia, Itália e Portugal. O artigo começa por caracterizar os sistemas de saúde, apresenta a metodologia utilizada e, posteriormente, os resultados da análise em cada país, com destaque para as diferentes formas de participação, institucionalizadas e não institucionalizadas. Como principal resultado da investigação, conclui-se que tem prevalecido um discurso legislativo que, na generalidade dos casos, não corresponde a práticas de participação efetivas, mas, por outro lado, têm emergido, com especial protagonismo na área da saúde, formas de participação não institucionalizada, nas quais se destacam ações de protesto, em grande parte, impulsionadas pela atual crise econômica.*

*Sistemas de Saúde; Políticas Públicas de Saúde; Participação Cidadã*

## Resumen

*El presente artículo versa sobre el análisis de mecanismos de participación pública existentes en los sistemas de salud de países del sur de Europa. Se presentan los resultados de una revisión de la literatura, incidiendo en la cuestión de la participación pública en los sistemas de salud, realzando las potencialidades y los desafíos que emergen de las principales experiencias nacionales identificadas en los países considerados: España, Grecia, Italia y Portugal. El artículo comienza por caracterizar los sistemas de salud, presenta la metodología utilizada y, posteriormente, los resultados del análisis en cada país, resaltando las diferentes formas de participación, institucionalizadas y no institucionalizadas. Como principal resultado de la investigación, se concluye que ha prevalecido un discurso legislativo que, en la mayor parte de los casos, no corresponde a prácticas de participación efectivas, sin embargo, por otro lado, ha emergido, con especial protagonismo en el área de la salud, formas de participación no institucionalizada, en las que se destacan acciones de protesta, en gran parte, impulsadas por la actual crisis económica.*

*Sistemas de Salud; Políticas Públicas de Salud; Participación Ciudadana*

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