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The Challenge of Public Participation in European Hospitals: A Portuguese Case Study

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Keywords
Public participation · Health policy · Public hospitals · National Health Service · Portugal

Abstract

Introduction: This article presents the results of an empirical study designed to examine the current state of public participation in hospital institutions of Portugal's National Health Service (NHS) and to assess the level of implementation and functioning of Advisory Councils. ***Methods:*** The study combines a review of the literature on participation experiences in hospitals across several European countries with a questionnaire administered to the presidents of hospital institutions within the Portuguese NHS. Together, these methods provide a basis for identifying the status of public participation in Portugal in light of relevant European experiences. ***Results:*** The findings indicate that participation is largely confined to communication and the provision of information to users, as well as consultation processes through which patients can express their preferences. However, the active involvement of patients and their representatives in healthcare decision-making remains limited and underdeveloped. ***Conclusion:*** Hospitals across Europe, and particularly in Portugal, face the challenge of fostering more effective forms of user participation. This requires moving beyond consultation towards meaningful involvement of patients and their representatives in healthcare decision-making processes.

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O desafio da participação pública nos hospitais europeus: um estudo de caso português

Palavras Chave
Participação Pública · Políticas de saúde · Cuidados de Saúde · Hospitais Públicos · Serviço Nacional de Saúde · Portugal

Resumo

Introdução: Este artigo apresenta os resultados de um estudo empírico que teve como objetivo compreender o estado atual da participação pública nas instituições

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hospitalares do Serviço Nacional de Saúde (SNS) em Portugal e avaliar o nível de implementação e o funcionamento dos Conselhos Consultivos. ***Métodos:*** O estudo combina uma revisão da literatura sobre experiências participativas em hospitais de vários países europeus com a aplicação de um questionário aos presidentes das instituições hospitalares do SNS português. Em conjunto, estes métodos permitem identificar o estado da participação pública em Portugal à luz de experiências europeias relevantes. ***Resultados:*** Os resultados indicam que a participação se encontra, em grande medida, limitada à comunicação e à prestação de informação aos utentes, bem como a processos de consulta através dos quais os doentes podem expressar as suas preferências. No entanto, o envolvimento ativo dos doentes e dos seus representantes na tomada de decisão em saúde permanece limitado e pouco desenvolvido. ***Conclusão:*** Os hospitais na Europa, e particularmente em Portugal, enfrentam o desafio de promover formas mais efetivas de participação dos utente e seus representantes, indo além da consulta e avançando para um envolvimento significativo nos processos de decisão em saúde.

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Introduction

Democratic innovations that involve citizens in decision-making processes are increasingly widespread, and over the last few decades, a wide range of participatory experiences, promoted both by public institutions and by civil society, have been implemented in many countries of the Global South and North. This debate, particularly intense among political and social scientists [1, 2], is actively present in health systems, where public participation (PP) has assumed a relevant role at the international level and has been considered an essential strategy in the process of reforming health systems [3].

This article is based on the results of an empirical study promoted by the *Associação Portuguesa dos Administradores Hospitalares* (APAH; Portuguese Association of Hospital Administrators) and carried out by the authors within the framework of the Centre for Social Studies of the University of Coimbra, with the collaboration of the initiative "More Participation, Better Health," between 2019 and 2020. The study aimed to understand the state of participation in hospital institutions (HI) in Portugal, to assess the level of implementation and functioning of Advisory Councils (ACs) in the HI of Portugal's National Health Service (NHS), and to identify barriers and critical issues concerning citizen participation. Although there is no standard definition of the terms "PP" or "public involvement," in this article we use them to refer to the direct participation or involvement of the population or its representatives in decisions regarding the planning and organisation of health services, namely, of HI [4].

Methods

The study aimed to understand the state of participation in HI in Portugal, to assess the level of implementation and functioning of AC in the HI of Portugal's NHS, and to identify barriers and critical issues concerning citizen participation. The study was grounded on a literature review and a questionnaire. In the initial phase of the study, a literature review was conducted in order to identify the state of the art and obtain in-depth information to analyse the challenges of PP in hospitals across European countries and in Portugal. This review not only provides contextual background but also informs the methodological design of the study, particularly the selection of the dimensions explored in the questionnaire.

The review focused on empirical studies, comparative reports, and policy analyses published in peer-reviewed journals, institutional reports, and international databases. A total of 38 articles, published between 2008 and 2022, were identified through searches in Scopus, SciELO, and Google Scholar. We examined the strategies implemented to involve patients and health service users, the extent and forms of participation, and the barriers and challenges identified. These recurrent dimensions in the literature were used to structure the questionnaire. Particular attention was given to studies that explored the role of PP in quality improvement processes, decision-making, and governance structures within HI.

In addition, the review examined the state of PP in Portugal's NHS and the challenges associated with implementing effective mechanisms for patient and user involvement. To this end, national legislation, health policy documents, and previous empirical studies were analysed to map existing participatory frameworks, identify gaps between legal provisions and actual practice, and assess the main limitations and opportunities for strengthening PP in the Portuguese context. The gaps identified informed the empirical focus of the study,

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which centred on NHS HI and the perceptions of their presidents.

The primary research instrument of the study was a questionnaire designed to gather information on the perceptions of the Presidents of NHS HI regarding the state of participation in HI in Portugal. The decision to focus on this population was largely due to the fact that the study was promoted by the APAH, whose objective was to identify areas and initiatives with the greatest potential for PP from the perspective of senior management of NHS HI. The direct involvement of hospital administrators in the research process is considered a strength of the study, since, as recommended by Patton [5], this is a key strategy to facilitate the uptake and integration of research findings into organisational practices.

The questionnaire (Appendix 1) that was specifically designed drawing on the literature review and taking into consideration the study's objectives is structured in two parts and comprises 20 questions. Its structure reflects the main dimensions of PP identified in the literature: formal participatory bodies, modalities of participation, institutional practices, and perceived effectiveness. The first part focuses on the presence of ACs and their functioning, as well as the perceptions regarding their performance. The second part addresses the opinions and perceptions of the presidents of NHS HI regarding the role of users' associations' (UAs) participation modalities within these institutions. The questions are drawn on international experiences identified in the scientific literature.

The first part of the questionnaire includes questions on the existence of an AC in the institution managed by the respondents, reasons for its non-appointment or difficulties in its establishment, whether a patient representative is included, the appointment process, whether the representative is a patient of the HI, whether the representative receives allowances covered by the HI, the frequency of AC meetings, opinions on the frequency of meetings as established by law, the activities carried out by the AC, its influence on hospital management, and its effectiveness in representing patients. In the second part, the questions address the opinions on the role of patients' associations with regard to decision-making power, the obligation to consult them, and the modalities of their participation. They also explore the existence of hospital activities involving patients' associations, the types of activities carried out, and views on which activities should be undertaken by these associations within HI. Additional questions focus on participation of patients' associations in hospital quality management strategies, as well as on factors that may facilitate the effective implementation of PP in HI and strengthen the involvement of patient representatives in the HI decision-making processes. These topics were selected because the literature consistently identifies them as critical for understanding the effectiveness of PP in hospital governance.

The questionnaire was designed in collaboration with representatives from the initiative *Mais Participação, Melhor Saúde* ("More Participation, Better Health"), a network of patient associations. The APAH provided logistical support by contacting presidents of NHS HI, sharing the survey link, and encouraging participation in the survey. The questionnaire was implemented online using the LimeSurvey platform and pretested by two hospital administrators selected by APAH; their feedback was incorporated, and the survey was finalised at the end of December 2019.

The dissemination of the survey – which guaranteed the anonymity of respondents and included a checkbox for informed consent – was carried out by APAH starting on January 21, 2020, with an initial response deadline of February 7. In the first week, the response rate was considerably low, leading APAH to send a reminder on January 29, and the survey was definitively closed on February 16.

The questionnaire was sent to all 49 presidents of NHS HI (the universe of the study). Of these, 45 questionnaires (91%) were returned, and 33 (67%) were fully completed. All returned questionnaires were included in the final analysis, and missing responses were handled accordingly in the statistical analysis.

Data from closed and multiple-choice questions were analysed using SPSS software, including descriptive and bivariate statistical analyses. To examine the qualitative information from the open questions, a thematic content analysis was performed.

Results

State of the Art of PP in European HI

The benefits of PP have been widely recognised and discussed in the literature. The involvement of patients and users not only contributes to improving the quality of professionals' decisions but also enhances the delivery of health services [6]. Other important arguments in favour of PP include (i) increasing local accountability and transparency of health services [7]; (ii) strengthening health promotion activities [8]; and (iii) reinforcing the

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representation of under-represented groups [9], thereby contributing to reducing health inequalities [10].

However, findings from several studies indicate that, despite good intentions and certain efforts undertaken, the degree of institutionalisation of PP remains far from satisfactory [11–13]. This situation did not improve during the COVID-19 pandemic, when, due to the urgent need to act, policymakers engaged only groups of public health experts, disregarding the experience and knowledge of patients' association and UA [14] and failing to promote mechanisms of consultation with civil society [15].

Even more complex and with lesser impact is the involvement of patients and users in HI, as described in the literature [16, 17]. Both in quality improvement strategies and in the evaluation of hospital care itself, the participation of patients, users, and their representatives is considered unsatisfactory and still incipient [18, 19]. In Portugal, as in other Southern European countries, the involvement of patients, users, and carers in health system decision-making is a recent phenomenon and not yet sufficiently developed [20], compared to other European countries, such as the UK, Scandinavian countries, and the Netherlands [12, 21]. As some studies highlight, there is a gap between the recognition of public involvement – enshrined both in the Portuguese Constitution and in national health plans – and the scarcity of effective participation channels [20, 22]. Nevertheless, over the last 10 years, several initiatives have been promoted to stimulate citizen participation, notably the effective implementation of the National Health Council (NHC) in 2017 [15], as well as the role played by patients' associations, which have become an important social actor demanding new spaces for participation [22]. On the other hand, participatory experiences in long-term care, primary care, and hospitals remain poorly developed [20].

Improving quality and safety in hospitals has always been one of the main objectives of health policies. In recent decades, hospitals in European countries have adopted a variety of strategies to improve the quality of care, such as accreditation systems, organisational quality management programmes, audits, patient safety systems, clinical guidelines, performance indicators, and others. In some cases, particularly in the context of pilot projects or research, co-creation initiatives between patients and professionals have also been developed. However, the literature highlights that the results of the strategies implemented remain limited, and evaluations conducted are also scarce [18]. According to Coulter and colleagues [23], it is not common practice to listen to patients and seek their opinions about the quality of care provided. "Failing to listen to patients' and families' complaints" – the authors warn – represents "a key factor in the failure of hospitals" [23].

These findings have encouraged new lines of research focused on studying the effectiveness of quality improvement strategies, raising some central questions: "which quality tools are most effective?", "which factors influence the implementation of quality strategies at hospital level?" [19]. This debate has required a clearer definition of the concepts of "quality" (and its components) and "quality improvement." The US Institute of Medicine [24], renamed in 2015 as the National Academy of Medicine, adopted six dimensions of quality: effectiveness, timeliness, safety, equity, efficiency, and patient-centredness. The NHS reports High Quality Care for All [25] and the 7th Framework Programme of the European Community [26], including clinical effectiveness, safety, and patient experience as the main dimensions of quality. It is widely agreed that it is no longer possible to assess the quality of healthcare solely on the basis of clinical effectiveness or evidence-based medicine; it is indispensable to include the perspectives and experiences of patients and users concerning the quality of care [27]. Today, the potential benefits of their involvement in health decision-making are widely recognised and discussed in literature. In this respect, patients' and users' experiential knowledge is considered complementary to professional knowledge and essential for the success of treatment and care more broadly [6], and is expected to contribute to improving the quality of decisions and health outcomes [20]. Thus, patient-centredness has become one of the most important goals in promoting quality of care. In this regard, the pioneering experience developed by the Picker Institute [28] is noteworthy, identifying 8 dimensions to assess patients' experiences of hospital care: information and education, coordination of care, physical comfort, emotional support, respect for patient preferences, involvement of family and friends, continuity and transition, and overall impression. In sum, improving patients' experience is regarded as a priority in advancing the quality of hospital services. Along the same lines, Wiig and colleagues [26] recommend adopting patient experience and involvement as a central pillar of care quality and as a source of improvement. Nevertheless, as Groene and colleagues [16] noted, current levels of patient and representative involvement in quality management activities "in European hospitals are, in general, low".

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Several studies have highlighted the challenges and difficulties in promoting PP in the hospital context across these countries. Malfait and colleagues [17] argued that PP at hospital level "is a complex process and should not be taken lightly". From their study of six Belgian hospitals, the authors present the following recommendations concerning participants in PP processes: (i) they should have the opportunity to choose the issues to be discussed and not only address strategic matters that silence the voices of user representatives; (ii) they should have access to the necessary resources, knowledge, and training; (iii) they should be supported by patient organisations external to hospitals; and (iv) they should have greater autonomy.

Another study conducted in hospitals in eight European countries (Belgium, Czech Republic, France, Ireland, the Netherlands, Poland, Spain, and the UK) highlighted the strong enforcement of patients' rights but their low level of involvement in issues related to quality management [18]. This study observed wide implementation of policies guaranteeing patients' rights, such as privacy and confidentiality, but an insufficient implementation of strategies to involve patients in quality improvement activities or to learn from them through surveys of their opinions. According to the authors, "Patient involvement in quality improvement activities (. . .) so far seems to be more a rhetorical exercise than a practice" [18].

Another investigation carried out in hospitals in seven European countries (Czech Republic, France, Germany, Poland, Portugal, Spain, and Turkey), between May 2011 and January 2012, confirmed the limited level of involvement of patients and their representatives in quality management activities [16]. The results show that they are "rarely involved in the development of quality criteria," in the "definition and organisation of care processes," in "participation in quality committees," or in "discussion of quality improvement project results."

Another study carried out in three hospitals in Greece sought to investigate the perceptions of nursing staff regarding patient participation [29]. The results of this study highlight the limited way in which nursing staff understand participation, i.e., as a "process of providing information to patients, patients reporting symptoms, and compliance with team guidance" [29]. A study carried out in the UK [30] points in the same direction, suggesting that nursing professionals may maintain an "ambiguous relationship" with patient participation in decision-making – while claiming to be "in partnership with patients during consultations or at the bedside," they appear "disengaged from their empowerment."

These findings, according to Kolovos and colleagues [29], reinforce the need to operationalise participation systematically, promoting educational or training activities for nurses, who are in a privileged position to "facilitate the implementation of participation in practice." A study conducted in a hospital in the Emilia-Romagna region of Italy highlighted the slowness of health authorities in incorporating suggestions and proposals presented by Mixed Advisory Committees, bodies representing the interests of patients and users: "there are extremely long waiting times and a certain inertia on the part of hospital management in implementing the suggested proposals" [31].

The findings of another study conducted in a Swedish university hospital show that patient participation is "hindered by medical jargon" during ward rounds, with the risk of "the team speaking over patients' heads" [32]. In this study, barriers to participation were attributed to the lack of teamwork, the passive role assumed by patients, and the style of communication adopted during ward rounds [32]. Similarly, another investigation carried out in a different Swedish hospital pointed to insufficient communication between professionals and older people in situations of frailty but cognitively sound, particularly regarding perceived deficiencies in the information provided during hospitalisation [33]. This study further demonstrates the importance of information and participation for perceptions of well-being and satisfaction among this population group. Indeed, the authors argue, if "person-centred care is not fully implemented, the frail older patient cannot participate in their own healthcare" [33].

Another study conducted in five Dutch hospitals explored how patients and health professionals are involved in co-creation activities, in which patients become partners of professionals and thus contribute to the design and organisation of health services with the aim of improving their quality [34]. According to the authors, the areas of improvement proposed by patients were often already known, but it is the co-creation process that encourages hospitals to reflect on how to improve quality: "the active role of patients and the way they express their experiences creates a sense of urgency to act on the issues identified for improvement."

Another study carried out in five Finnish university hospitals reaffirmed the important role of professionals in encouraging patient participation, providing relevant information, and confirmed that "there is still an outdated paternalistic culture in health practices" [35]. Finally, it is worth highlighting the recent experience outside the European context, developed in the public

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hospital of Ontario, Canada, where hospital management successfully shared technical information on health policies with the community represented in the citizens' advisory panel and achieved effective citizen participation in decision-making processes [36]. For the authors, such results underline the importance of carefully designing the policy-making process so that there is sufficient information and time to address technical issues as well as questions related to the power asymmetry between hospital management and community members. It is also essential "to have facilitators who support members in expressing their views, in understanding the objectives of decision-making processes, and in valuing the perspectives of others" [36].

Challenges of PP in Health in Portugal

Law No. 56/1979, which created the NHS, envisaged democratic management and the promotion of users' participation in the planning and management of services [37]. However, it was the 1990 Health Basic Law that established the existence of an NHC (only instituted in 2016), a governmental advisory body that includes user representatives elected by Parliament. The Basic Law also enshrined the right of patients to form entities that represent them, defend their interests, and collaborate with the health system [38].

In 1993, the NHS Statute recognised population participation in health policy-making and created consultative bodies at both regional and sub-regional levels [39]. At regional level, Regional Health Councils were foreseen as advisory bodies to the respective Regional Health Administrations (*Administrações Regionais de Saúde*), including municipal representatives [39]. At the sub-regional (municipal) level, a Municipal Health Committee was envisaged, composed of a municipal representative and a users' representative elected by the Municipal Assembly [39].

Although legislation since the 1990s has included numerous provisions designed to guarantee formal mechanisms for encouraging participation in the Portuguese health system, in practice these were not implemented. In this context, the 2004–2010 National Health Plan, acknowledging the insufficiency of participatory mechanisms in the Portuguese health system, emphasised the importance of placing people at the centre of policy decisions.

At hospital level, ACs were created in 2005 and included a users' representative appointed by their association, with the competence to review hospital activity plans and issue recommendations for improving the services provided to the population [40]. Within the framework of primary healthcare reform, the Health Center Groups (*Agrupamentos de Centros de Saúde* [ACeS]), created in 2008, provided the establishment of a Community Council involving, among others, a representative of the ACeS UA – with the aim of bringing primary care closer to the community and encouraging the participation of various actors, namely, institutions and/or associations [41].

Regarding the gap between discourse and participatory practice, the European Observatory on Health Systems and Policies [42] had already noted that, despite certain initiatives undertaken to encourage patient involvement in order to foster population responsibility for their own health and to achieve better quality in the care provided, in Portugal participation remained largely confined to legislative references and to the intentions expressed in official documents. This gap is reaffirmed in the latest review of the Portuguese health system by the European Observatory on Health Systems and Policies, in 2017: "PP and patient empowerment have been major health goals inscribed in fundamental legal documents over the past 2 decades in Portugal, but with little practical impact" [43].

Nevertheless, some relevant experiences promoted in recent years deserve attention. At national level, the activation and regular functioning of the NHC since 2017 – already foreseen in the 1990 Basic Law but never established – stands out. The NHC is composed of patient representatives (6 out of 32 members at present), health professionals, representatives of municipalities and parishes, universities, and other key health actors, representing an important step towards democratising the NHS and towards civil society participation in the planning and evaluation of health policies.

Among the less active participatory spaces are the Community Councils of the ACeS, many of which do not include representatives of UAs, and the ACs of NHS hospitals, which display insufficient levels of involvement in planning, evaluation, and consultation activities, as envisaged in national legislation [20, 22]. Meanwhile, in recent years, in the absence of institutional spaces capable of promoting regular participation, patient associations within civil society have begun to stand out as significant social actors, exerting increasing pressure on national health institutions and demanding collective claims and new channels of participation. In this regard, it is worth mentioning the approval of the Charter for Public Participation in Health by Parliament in 2019, as a result of the political advocacy campaign led by the initiative "More Participation, Better Health" [22]. The Charter seeks to foster the participation of patients,

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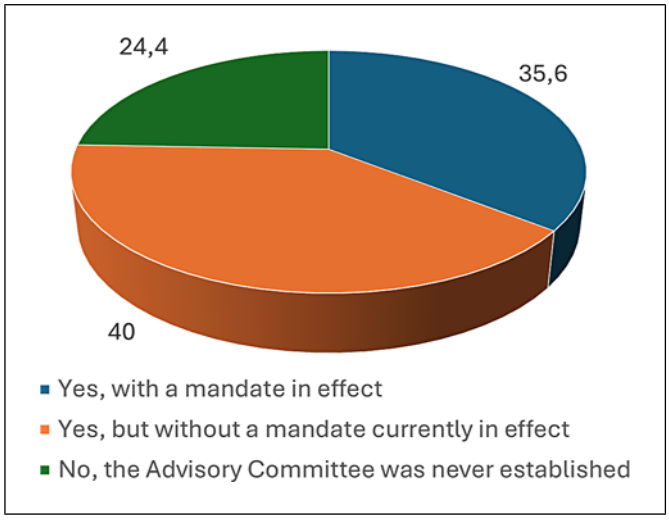


Fig. 1. Proportion of HI reporting the existence of an AC.

users, and citizens more broadly in decisions affecting population health at national, regional, and municipal levels.

Participation in Portugal's HI: Experiences and Limitations

The survey results, relating to 2020, reveal that in Portugal, the main assumptions highlighted in the literature regarding PP in European hospitals are confirmed. ACs were present in most of the HI that responded (34 of 45, i.e., 75.6%), but only 16 (35.6%) had a mandate in force. Eighteen ACs (40%) were without a valid mandate, and 11 (24.4%) had never been established [44] (Fig. 1). In most HI (74.1%), ACs included user representatives, but these did not receive any type of support or reimbursement to facilitate their participation.

As regards the number of AC meetings, it is noteworthy that around 60% in 2019 never met (Fig. 2). This insufficient level of performance translates into the weak participation of ACs in the activities provided for in Decree-Laws No. 233/2005 and 18/2017. In fact, ACs "review the activity plans" in only 22 HI (51.1%). Moreover, only 21 (46.7%) "issue recommendations for the better functioning of the HI", and just 11 (24.4%) "review the annual report on complaints, suggestions, and compliments from users."

When asked about the level of influence exerted by AC proposals and their potential to represent the rights and interests of users, respondents' opinions were divided: 50% positively evaluated the role of the CCs (giving a score between 6 and 10 on the predicted scale), and 50% negatively evaluated it (giving a score from 1 to 5). The second part of the questionnaire sought to collect the perceptions of HI Presidents regarding the role of UAs and modalities of participation in HI.

Most Presidents of NHS HI (54.6%) did not agree with "granting greater power to UA to make decisions" (Fig. 3), of which 45.5% disagreed and 9.1% strongly disagreed. This opposition was even more evident in HI with ACs with a mandate in force (69.3%), compared to those with an AC without a mandate (53.3%) or where ACs had never been implemented (20%). These findings point to the need for further qualitative research to understand the impact of the experience of HI where ACs exist, particularly regarding perceptions of granting greater power to UA in decision-making processes.

However, most respondents support strengthening consultative participation of users and their representatives in HI, regarding surveys, institutional priorities, and decisions affecting users (Table 1). Another set of questions sought to assess respondents' views on the possibility of involving UA in certain decision-making moments in HI. The results suggest a high level of consensus among respondents (above 70%) regarding UA involvement in decision-making processes (Table 2).

In only two aspects of the decision-making process did HI Presidents show low levels of interest in encouraging UA participation: "decisions on hospital service (re)organisation" (28.1%) and in "HI Ethics Committees" (28.1%). With regard to quality management strategies promoted by HI, the questionnaire asked participants about possible UA involvement in activities aimed at improving and evaluating the quality of health services. There was not a high level of agreement concerning user representatives' involvement in these activities. Only with respect to participation in quality improvement projects and discussion of their results did most respondents consider that UA should be "always" or "generally" involved (Table 3).

Opinions were also gathered on how to strengthen user participation in HI. Most answers – respondents could choose more than one – identified the important role of professionals (26 responses) and managers (20 responses) in promoting participation in HI. This finding confirms the results of others international research [7, 11].

At the end of the questionnaire, an open question invited contributions on how to reinforce the participation of patient and user representatives in HI decision-making processes. Analysis of the 23 suggestions allowed us to distinguish two categories of perceptions and critical issues: (i) limits and barriers which, according to

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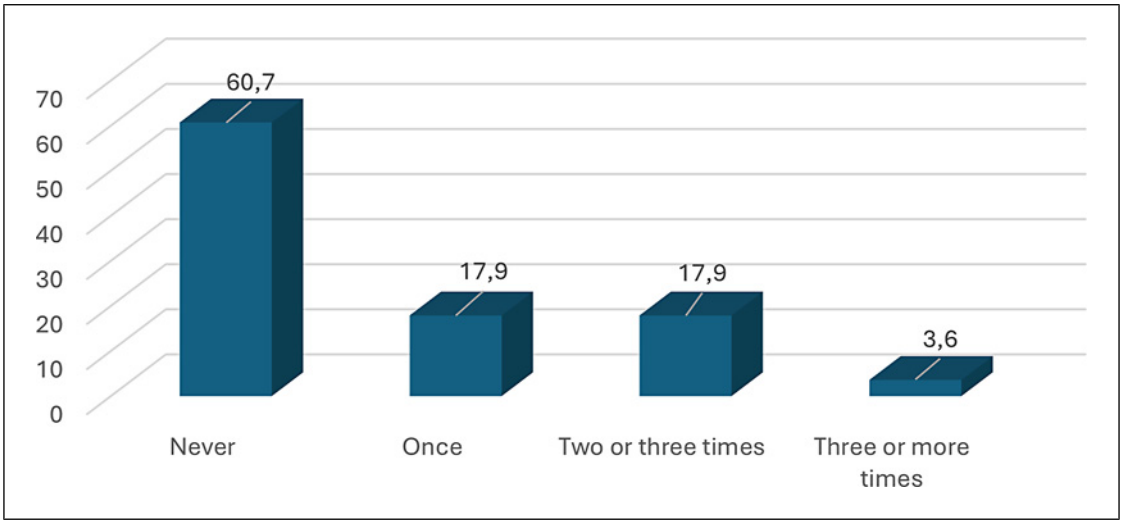


Fig. 2. Number of AC meetings held in 2019.

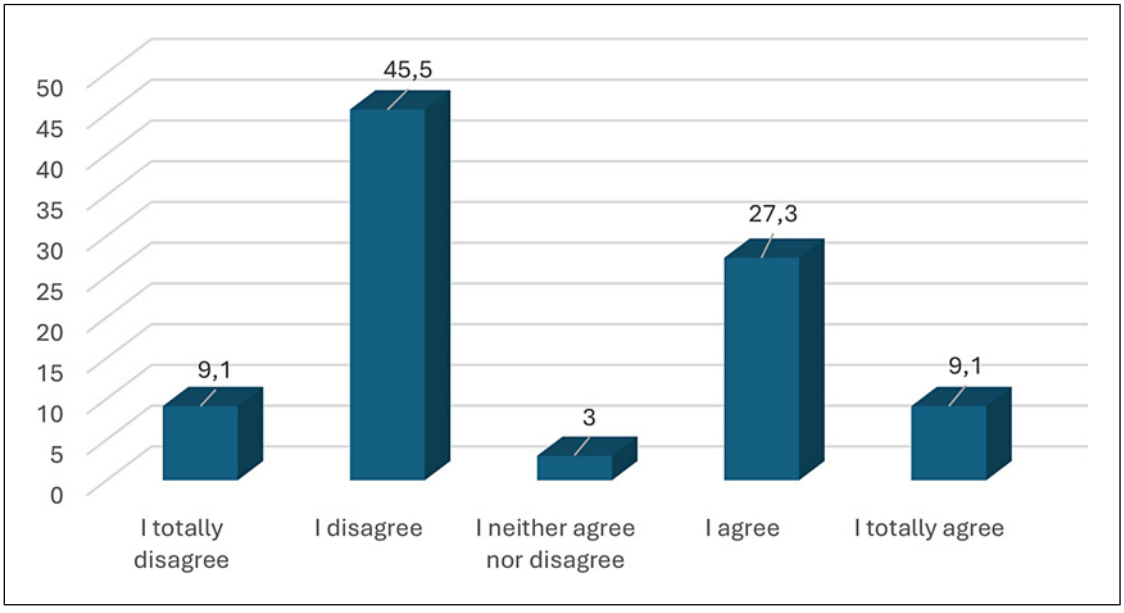


Fig. 3. Level of agreement with the statement: "ACs should be given greater decision-making power."

Table 1. Opinions on the role of users and UAs in NHS HI

Statement	% agreeing
They should be systematically consulted through surveys	84.9%
They should participate in public consultations on institutional priorities	76.9%
Consultation of UAs in decisions affecting users should be mandatory	69.2%

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Table 2. Opinions on UA involvement in decision-making processes

Statement	% agreeing
Collaboration in humanisation projects for services	87.5%
Collaboration in identifying barriers and ways of improving patient pathways	84.4%
Participation in the analysis of user satisfaction reports	78.1%
Collaboration in defining institutional communication addressed to users	71.9%

Table 3. Opinions on UA involvement in quality management

Statement	% agreeing
They should participate in the discussion of quality improvement project results	58.0%
They should be involved in quality improvement projects	51.6%
They should participate in developing quality criteria, standards, and protocols	48.4%
They should participate in hospital quality committees	45.2%

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13 respondents, stem from an institutional culture still insufficiently prepared to value patients' and users' perspectives, highlighting in particular the attitudes and resistance of professionals but also of managers; (ii) limitations and difficulties inherent to the UAs themselves, mentioned by 10 respondents.

Discussion

The survey results provide a clear picture of the limited functioning of ACs in NHS HI in Portugal, in terms of both the number of meetings held and the scarcity of activities developed. This participation deficit has a significant impact on hospital governance, as it undermines the voice of patient associations and user representatives, thereby calling into question essential principles recognised by national law [45] and international literature [18], such as patient-centred care, patient representation, and the important contribution of patients to defining and evaluating the quality of healthcare. This reinforces the gap between the discourse on PP in healthcare systems and the empirical experiences actually implemented, as highlighted by several scholars [7, 12].

However, these findings offer relevant insights for promoting awareness-raising activities on PP in HI. In this context, hospital boards have an important role to play in strengthening and consolidating PP, by creating new ACs; renewing ACs currently without a mandate; increasing the number of meetings; encouraging user representatives' participation in legally established activities; ensuring reimbursement and other support, including logistical; and developing training activities for professionals, managers, and members of patient, user, or other citizen associations. In this way, the potential and benefits of participation can be reinforced.

These data reveal the urgent need to increase both the number of meetings and AC involvement in planning, evaluation, and consultation activities, as provided for by legislation. Most respondents acknowledged the need to increase the frequency of AC meetings in order to strengthen user representatives' participation in hospital management oversight.

Furthermore, valuing user/patient experience and their involvement in quality management programmes could constitute a starting point for promoting active citizenship in NHS hospitals. However, the results of this research show a low level of user/patient representatives' involvement in quality improvement initiatives, corroborating the findings of the literature review. Among the main problems and barriers highlighted by the literature analysis, it is interesting to highlight the followings: (i) the persistence of a symmetry of power

between the hospital management and patients and their representatives; (ii) the adoption of medical and overly technical jargon can also hinder participatory processes; (iii) the insufficient level of information available to patients and the communication style adopted during visits. In short, managers and decision-makers should ensure adequate resources and training to prevent participation from becoming more of a rhetorical exercise than effective practice. It would also be important for ACs to be supported by patient organisations outside of hospitals.

As the literature shows, participation is a complex social phenomenon with multiple dimensions: economic, social, political, and cultural [46]. Responsibility for the failure of participatory processes, including the low levels of participation recorded internationally, is shared between health systems – still marked by organisational cultures poorly attuned to the demands of the social environment – and the still fragile forms of social protagonism and participatory practice of associations [47]. The views of HI Presidents in this study are aligned with this perspective. When asked how user participation in HI decision-making could be improved, they identified as critical issues both the responsibility of health institutions (professionals and managers) and the difficulties faced by UAs in exercising representation and defending citizens' rights.

Nevertheless, the first step towards triggering significant and sustainable change over time must come from the health system itself, in this case, from the HI. It is therefore urgent to implement reforms in Portugal's NHS hospitals to give new impetus and strength to the citizenship project, understood as active participation in decision-making and in defining collective objectives.

A limitation of this study is its exclusive focus on the heads of HI within the Portuguese NHS, which means that the findings primarily reflect top managerial perspectives. Further research on PP in hospital contexts should also incorporate the views of healthcare professionals and service users.

Conclusion

The research carried out in the NHS HI in Portugal shows that the participation of users/patients and their associations is still incipient and underdeveloped, as acknowledged by the hospital managers involved in the study. This situation does not differ greatly from the levels of participation recorded in the European context, as shown by the literature reviewed.

However, in the last decade, within the framework of quality improvement projects in HI, the experience of patients and users and its potential benefits in decision-making processes have gained increasing recognition. Yet, this acknowledgement has not translated into the design and implementation of new channels and strategies for the participation of patients and their representatives.

Based on the definition of "public involvement" by Rowe and Frewer [48], and on the three possible types of involvement identified by the authors (public communication, public consultation, and PP), in the case of hospitals in Europe and Portugal analysed in this article, involvement activities are mainly characterised by public communication – where information is transmitted by managers and professionals to patients [20]. To a lesser extent, public consultation is also practised, whereby users/patients are invited to express opinions and preferences, particularly through questionnaires or other data collection tools. In this regard, public access to information has been progressively improved by hospitals through accessible institutional websites and interactive tools. With regard to public consultation, hospitals have set up help desks and websites through which users/patients and carers are consulted and their suggestions, complaints, and grievances collected. This function is often shared with volunteer organisations, "hospital friends' leagues" and associations promoting patients' and users' rights, which also manage to give voice to vulnerable social groups.

However, involvement practices based on the active participation of users'/patients' representatives in decision-making processes about care and the organisation of health services are far less developed. This remains the major challenge for hospitals in Europe, and particularly in Portugal, which must create more effective participatory spaces to engage patients and their representatives in decision-making processes, and promote meaningful involvement in the management, planning, and co-creation of services and health care.

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Statement of Ethics

Ethics approval was not required for this study as it only explored the views of human participants, in their capacity as hospital managers, and not as health professionals or health service users, and did not collect individual health data or other personal sensitive data. Furthermore, this study does not qualify as a clinical study, under the Law on Clinical Research (Law No. 21/2014, of 16 April, as amended), as it was not aimed at discovering or verifying the distribution or effect of health factors, health states or outcomes, health or disease processes, the performance and/or safety of interventions, or the provision of healthcare. Written informed consent to participate was obtained online from all participants as part of the online questionnaire, which could not be replied to if previous consent was not given by the participant. Data was collected and treated anonymously.

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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Author Contributions

Author 1 is responsible for the article's conception, writing, critical review, and approval of the final version. Authors 2 and 3 are responsible for the study design, analysis, critical review, and approval of the article. Author 4 participated in the study design and analysis of the results. Author 5 participated in the study design, critical review, reformulation, and approval of the final version.

Data Availability Statement

Requests to access the data should be directed to the corresponding author.

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