WHO SHOULD HAVE A SAY IN HEALTH POLICY? A collaborative approach to public participation

Sofia Crisóstomo
Iscte — University Institute of Lisbon, Lisbon; GAT — Portuguese Activist Group on Treatments, Lisbon, Portugal

Margarida Santos
Iscte — University Institute of Lisbon, Lisbon; GAT — Portuguese Activist Group on Treatments, Lisbon, Portugal

Ana Raquel Matos
Faculty of Economics of the University of Coimbra, University of Coimbra; Centre for Social Studies of the University of Coimbra, University of Coimbra, Portugal

Abstract Using a participatory action research approach, this study examines support for public participation in health policy decision-making in Portugal. Strong support was observed, with key predictors including empowerment orientation, participation-related stereotypes, advocacy beliefs, membership in patient organisations, and prior participatory experience. Findings underscore the need to promote participatory spaces, adopt collaborative and inclusive approaches, raise awareness of public participation and the role of representative organisations, and foster citizen engagement.

Keywords: public participation, health, public policy, Portugal.

Quem deve ter voz nas políticas de saúde? Uma abordagem colaborativa à participação pública

Resumo Adotando uma abordagem de investigação-ação participativa, este estudo analisa o apoio à participação pública nas decisões sobre políticas de saúde em Portugal. Verificou-se um elevado nível de apoio, tendo como principais preditores a orientação para o empoderamento, estereótipos relacionados com a participação, crenças em matéria de defesa de direitos, afiliação em organizações de doentes e experiência prévia de participação. Os resultados salientam a necessidade de promover espaços participativos, adotar abordagens colaborativas e inclusivas, aumentar a sensibilização sobre a participação pública e o papel das organizações representativas, e fomentar o envolvimento cidadão.

Palavras-chave: participação pública, saúde, políticas públicas, Portugal.

Qui devrait avoir voix au chapitre dans les politiques de santé ? Une approche collaborative de la participation publique

Résumé En adoptant une approche de recherche-action participative, cette étude examine le soutien à la participation publique dans les décisions relatives aux politiques de santé au Portugal. Un niveau élevé de soutien a été observé, les principaux prédicteurs étant l'orientation vers l'autonomisation, les stéréotypes liés à la participation, les convictions en matière de plaidoyer, l'affiliation à des organisations de patients et l'expérience participative antérieure. Les résultats mettent en évidence la nécessité de promouvoir des espaces participatifs, d'adopter des approches collaboratives et inclusives, de renforcer la sensibilisation à la participation publique et au rôle des organisations représentatives, et de favoriser l'engagement citoyen.

Mots-clés: participation publique, santé, politiques publiques, Portugal.

¿Quién debería tener voz en las políticas de salud? Un enfoque colaborativo de la participación pública

Resumen Utilizando un enfoque de investigación-acción participativa, este estudio examina el apoyo a la participación pública en la toma de decisiones en política sanitaria en Portugal. Se observó un fuerte apoyo, cuyos principales predictores incluyen la orientación hacia el empoderamiento, los estereotipos relacionados con la participación, las creencias sobre la defensa de derechos, la pertenencia a organizaciones de pacientes y la experiencia participativa previa. Los hallazgos subrayan la necesidad de promover espacios participativos, adoptar enfoques colaborativos e inclusivos, sensibilizar sobre la participación pública y el papel de las organizaciones representativas, y fomentar la implicación ciudadana.

Palabras-clave: participación pública, salud, política pública, Portugal.

Introduction

Since the Alma-Ata Declaration, in 1978, public participation has gained increasing importance in health decision-making (Pagatpatan and Ward, 2017; Malfait *et al.*, 2018; Gram, Daruwalla and Osrin, 2019; Baker *et al.*, 2021; Kemper *et al.*, 2021; Baumann, Reinhold and Brütt, 2022) and has been progressively incorporated into policy agendas (Fredriksson and Tritter, 2017; Mira *et al.*, 2018; Baker *et al.*, 2021; Kemper *et al.*, 2021).

In Portugal, the advancement of participatory democracy and citizens' right to engage directly in policymaking, particularly in health, are enshrined in the Constitution, as well as in the legal framework governing the health system and the National Health Service (Serapioni and Matos, 2014; Crisóstomo, 2016; Falanga, 2018; Matos and Craveiro, 2022). The Charter for Public Participation in Health (Law No. 108/2019 of 9 September 2019) further reinforced this by legally mandating the participation of citizens and organisations representing patients, health service users and consumers at both policy and institutional levels.

These organisations, especially patient organisations, have been pivotal in advancing this agenda (Matos and Serapioni, 2017). They have consistently advocated for the enforcement of legal rights and for greater openness in decision-making processes, while emphasising the value of patients' expertise and lived experience in shaping health policies (Serapioni and Matos, 2014; de Freitas, 2017; Matos and Serapioni, 2017; Crisóstomo and Santos, 2018; Matos and Craveiro, 2022).

This study analyses support for public participation in health policy decision-making in Portugal — encompassing the participation of citizens and organisations representing patients, health service users and consumers — and investigates how individual views, experiences and characteristics shape such support.

Public participation in health policy decision-making

Definition

Public participation remains inconsistently defined and unevenly applied across policy and practice (Halabi *et al.*, 2020; Baumann and Brütt, 2021; Usher and Denis, 2022; Fredriksson, Sampaio and Moberg, 2025). In the literature, the concept is also referred to as public involvement or engagement (Mitton *et al.*, 2009; Conklin, Morris and Nolte, 2015; Ocloo and Matthews, 2016; Fredriksson and Tritter, 2017; Pagatpatan and Ward, 2017; Bobbio, 2019; Halabi *et al.*, 2020; Kemper *et al.*, 2021; Baumann, Reinhold and Brütt, 2022; Usher and Denis, 2022). Other terms, such as lay participation or community participation, are also used (Charles and DeMaio, 1993; Butterfoss, 2006; Fredriksson and Tritter, 2017; Malfait *et al.*, 2018; Daruwalla and Osrin, 2019).

In this study, we use the term *public participation* to refer to the participation of individuals who may be affected by, or have an interest in, collective decision-making (Florin and Dixon, 2004; Fredriksson and Tritter, 2017; Lee and Sun, 2018; Kemper *et al.*, 2021; Fredriksson, Sampaio and Moberg, 2025). This predominantly includes citizens, although some groups, such as refugees and recent immigrants, may not hold citizenship in legal sense (Butterfoss, 2006; Fredriksson and Tritter, 2017). We adopt the term *participation* rather than *involvement* or *engagement* following Arnstein (1969) and subsequent authors (Charles and DeMaio, 1993; Rowe and Frewer, 2000; Thompson, 2007; Mitton *et al.*, 2009; Pagatpatan and Ward, 2017; Mira *et al.*, 2018; Bobbio, 2019; Gram, Daruwalla and Osrin, 2019; Halabi *et al.*, 2020; Falanga and Ferrão, 2021), who define participation as a process co-determined by citizens and conventional decision-makers, characterised by reciprocal relationships of dialogue and shared decision-making (*i.e.*, power redistribution).

Accordingly, public participation encompasses the involvement of lay individuals who are not conventional decision-makers, including subgroups with specific perspectives and interests (Charles and DeMaio, 1993; O'Keefe and Hogg, 1999; Daudelin *et al.*, 2011; Baumann, Reinhold and Brütt, 2022). In health decision-making, these subgroups include patients, health service users, health consumers, carers and family members (Charles and DeMaio, 1993; Mitton *et al.*, 2009; Carman *et al.*, 2013; Fredriksson and Tritter, 2017; Mira *et al.*, 2018; Baumann, Reinhold and Brütt, 2022; Usher and Denis, 2022; Fredriksson, Sampaio and Moberg, 2025). In addition, at the health policy level, organisations representing patients, health service users and consumers are also recognised as key stakeholders (Mitton *et al.*, 2009; Carman *et al.*, 2013; Fredriksson and Tritter, 2017; Mira *et al.*, 2018; Fredriksson, Sampaio and Moberg, 2025).

In the context of health policy decision-making, public participation takes place at the system (macro) level — national, state, or provincial — where health policies are formulated. This includes activities such as health services planning, resource allocation and priority-setting (Charles and DeMaio, 1993; Carman *et al.*, 2013; Baumann, Reinhold and Brütt, 2022; Fredriksson, Sampaio and Moberg, 2025). In this sense, public policies encompass laws, regulations, plans and programs (Weible, 2014).

Participation, power and representation

Although public participation is frequently framed as intrinsically democratic and emancipatory, sociological scholarship has long emphasised that participation is neither normatively neutral nor structurally equalising. Arnstein's (1969) seminal "ladder of participation" already highlighted that participatory arrangements may range from symbolic inclusion to effective power redistribution, thus distinguishing between tokenistic consultation and genuine decision-making influence. Subsequent analyses have similarly warned against equating institutionalised participation with empowerment, noting that participatory mechanisms may function as instruments of legitimation rather than as vehicles of structural change (Ocloo and Matthews, 2016; Bobbio, 2019).

In the field of health policy, these tensions are further shaped by the historically entrenched authority of professional and technocratic expertise. Empirical studies across different national contexts consistently show that support for public involvement often coexists with strong endorsement of medical or expert decision-making authority (Dolan, Cookson and Ferguson, 1999; Mossialos and King, 1999; Litva *et al.*, 2002). This suggests that participation does not necessarily challenge epistemic hierarchies but may instead operate within hybrid governance arrangements, where democratic legitimacy and technical authority are negotiated rather than opposed.

Moreover, participation mediated by organisations introduces additional sociological questions concerning representation and inequality. As Fredriksson and Tritter (2017) argue, the distinction between "public" and "patient" involvement is not merely semantic but reflects different logics of representation and legitimacy. Organised actors may accumulate expertise, professionalise their advocacy, and gain institutional recognition, thereby increasing their influence within policy arenas. From this perspective, participation can be understood as unfolding within a structured field in which actors occupy differentiated positions according to their resources, institutional access and forms of symbolic capital (Bourdieu, 1998). Such asymmetries may shape not only influence but also the boundaries drawn between organised constituencies and broader publics (Daudelin *et al.*, 2011; Baumann, Reinhold and Brütt, 2022).

Acknowledging these dimensions allows participation to be analysed not simply as a normative democratic good, but as a socially structured process shaped by power relations, institutional arrangements and competing forms of legitimacy. This perspective provides an analytical lens for interpreting citizens' preferences regarding the involvement of different stakeholders in health policy decision-making.

The public's perspective

Empirical research on public preferences regarding participation in health policy decision-making reveals recurring patterns across national contexts rather than entirely distinct country-specific configurations. Three analytically relevant trends

can be identified: preference for collaborative arrangements, persistence of professional authority, and ambivalence toward political actors.

Preference for collaborative configurations

Several studies indicate that citizens favour participatory arrangements that combine the involvement of multiple stakeholders rather than assigning exclusive decision-making authority to a single actor. In Canada, Abelson *et al.* (1995) found that while many participants were willing to assume responsibility in principle, they tended to favour consultative or shared arrangements once the complexity of decision-making was discussed. Similarly, Barg *et al.* (2017) reported a dominant preference for greater public input without sole decision authority.

In Australia, Shrimpton *et al.* (2008) observed strong support for collaborative models involving a broad range of actors, including professionals, policymakers, patients and community groups, with minimal endorsement of exclusive authority. Comparable findings were reported by Wiseman *et al.* (2003), who highlighted public support for incorporating citizens' preferences alongside those of other stakeholders. In Sweden, Broqvist and Garpenby (2015) likewise found that collaborative decision-making approaches were preferred over single-actor models. Similar orientations toward joint or active involvement at the health system level have been identified in Germany (Baumann and Brütt, 2022).

These findings suggest that support for participation often reflects a preference for hybrid governance configurations rather than for a transfer of exclusive authority to lay actors.

Persistence of professional authority

Despite broad endorsement of participation, many studies point to the enduring legitimacy of professional authority in health decision-making. Mossialos and King (1999), analysing multiple European countries, found that doctors were consistently ranked among the most preferred decision-makers, often above politicians and sometimes above the public. Similar patterns emerged in the United Kingdom (Bowling, 1996; Dolan, Cookson and Ferguson, 1999; Litva *et al.*, 2002), where respondents frequently assigned responsibility for priority-setting to medical professionals even while supporting public consultation.

In Greece, Theodorou *et al.* (2010) reported that although citizens believed their views should inform decisions, doctors were ranked highest as decision-makers. Earlier Swedish research (Rosén, 2006) also highlighted shifts in citizens' evaluations of different decision-makers over time, while maintaining recognition of professional expertise.

Portuguese studies show comparable trends: while support for public consultation is strong (Pinto and Aragão, 2004; Botelho, Pinho and Veiga, 2013), doctors are often preferred over politicians and other actors in priority-setting processes. Among people living with HIV in Portugal, strong support for involvement has been associated with proximity to the issue and collective efficacy beliefs (Crisóstomo,

2009). More recent evidence from Portuguese patient organisations further underscores the importance attributed to participatory roles, while also revealing the structured nature of involvement processes (Roquette *et al.*, 2024).

Taken together, these results indicate that public support for participation does not necessarily displace professional authority but coexists with it, reinforcing the hybrid character of governance arrangements in health policy.

Ambivalence toward political actors

A third recurring pattern concerns the comparatively weaker legitimacy attributed to political actors. Across several studies, politicians and parliamentary actors are frequently ranked below health professionals and, in some cases, below the public itself (Mossialos and King, 1999; Dolan, Cookson and Ferguson, 1999; Theodorou *et al.*, 2010). In Australia, politicians' preferences were most frequently rated as "not at all important" in priority-setting (Wiseman *et al.*, 2003). Portuguese evidence similarly indicates limited support for politicians as primary decision-makers (Botelho, Pinho and Veiga, 2013).

This pattern suggests that participation preferences may be shaped not only by democratic aspirations but also by differentiated levels of institutional trust and perceived legitimacy among actors.

While these recurring patterns provide important insights into how citizens position different actors within health policy decision-making, existing research remains limited in several respects. Comparative evidence has focused predominantly on single-actor preferences or on specific policy domains, often without examining how support for citizens and representative organisations may converge or diverge within the same analytical framework. Moreover, the determinants shaping support for broader configurations of public participation remain underexplored, particularly in the Portuguese context.

Methods

Public participation

This study adopted a participatory action research methodology. From the outset, a Community Advisory Board (CAB) was established to validate the research objectives and study design, and to contribute to the questionnaire development. The CAB comprised representatives from 11 patient organisations (covering Alzheimer disease, cancer, depression, diabetes, heart disease, HIV and other infectious diseases, Parkinson's disease, rare diseases, respiratory diseases, rheumatic diseases and stroke) and one consumer organisation. Members met with the research team on two occasions and provided additional feedback via e-mail. Study findings were subsequently shared and discussed with CAB members.

Research questions and study design

Based on the literature reviewed and identified research gaps, this study addressed the following questions:

Q1: To what extent do citizens support the participation of key stakeholders in health policy decision-making?
Q2: Does support for public participation in health policy decision-making encompass the participation of citizens and organisations representing patients, health service users and consumers?
Q3: Do citizens' views on public participation and representative organisations, along with their participation experience and individual characteristics, influence their support for public participation in health policy decision-making?

The analytical framework guiding the study is presented in figure 1.

To address the research questions, an exploratory survey was conducted using a questionnaire specifically developed for this study and made available in both paper and online formats. Organisations representing patients, health service users and consumers were identified through desk research. The questionnaire was distributed to 211 organisations by e-mail and post, followed by telephone reminders. Organisations were also asked to disseminate the questionnaire among their constituencies through their communication channels. In addition, the invitation to participate was shared on social media, and users were encouraged to disseminate it further. Participation was voluntary, with the study objectives communicated in advance to participants, and responses

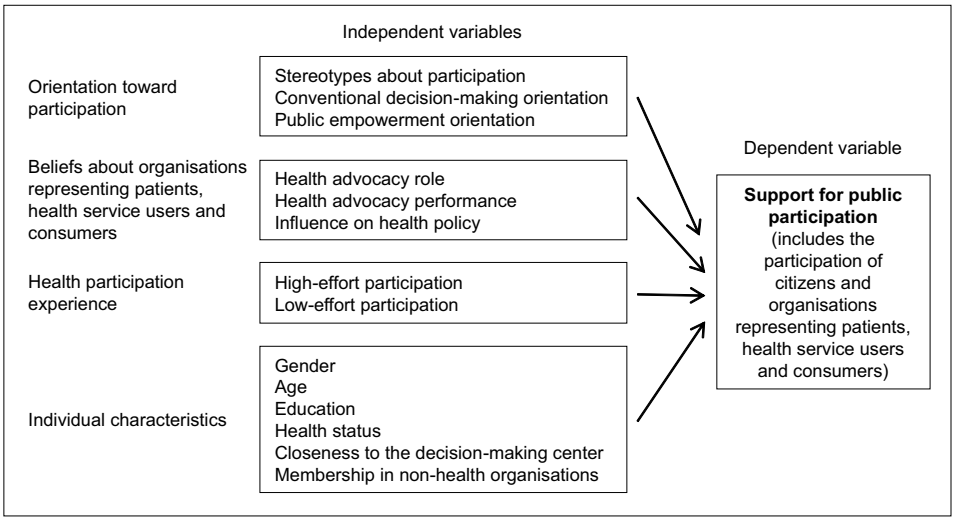

Figure 1 Analytical framework of citizens' support for public participation in health policy decision-making

were collected anonymously. In total, a non-representative sample of 606 citizens completed the questionnaire.

The instrument

The questionnaire was designed to elicit citizens' perspectives on public participation in health policy decision-making and on organisations representing patients, health service users and consumers. In addition, it also collected data on experiences with health participation processes and relevant individual characteristics.

Building on previous studies that examined *who* should participate in decision-making rather than simply *whether* the public should participate (Abelson *et al.*, 1995; Dolan, Cookson and Ferguson, 1999; Wiseman *et al.*, 2003; Shrimpton *et al.*, 2008; Theodorou *et al.*, 2010), one questionnaire item measured agreement with the participation of each key stakeholder. To assess the orientation toward public participation, items from the Patient-Provider Orientation Scale (Krupat *et al.*, 2000) were adapted to the policy context, capturing three dimensions: (i) participation-related stereotypes, (ii) conventional decision-making orientation, and (iii) public empowerment orientation. Additional questions assessed beliefs about organisations representing patients, health service users and consumers: (i) the perceived importance of their advocacy role, (ii) perception of their performance in health advocacy, and (iii) perception of their influence on health policy. All responses were recorded on five-point Likert scales (1 = lowest, 5 = highest).

To measure health participation experience, activities were categorised according to the level of effort required (Klandermans, 1997). High-effort participation (yes/no) encompassed launching a petition, attending a municipal assembly or parliamentary session, taking part in participatory budgeting, attending a public hearing, contributing to a consultation, or joining a protest — all within the health context. Low-effort participation (yes/no) included signing a petition, filing a complaint or holding membership in a patient organisation or other non-profit health organisation. Additional activities were captured through a free-text field.

Data were also collected on respondent's gender, age, education, health status, district of residence and membership in other organisations.

A pre-test (n = 33) was conducted to assess comprehension, relevance, and completion time. The sample included members of patient organisations (n = 12), other non-profit health organisations (n = 2), consumer organisations (n = 4), and individuals with no such memberships. Participants found the questionnaire easy to complete, with no major issues identified. Following the feedback received, the questionnaire was refined. Pre-test data were excluded from the analysis.

Data analysis

Descriptive statistics were calculated for all variables, as appropriate, including absolute and relative frequencies, means (M) and standard deviations (SD). Normality was tested using the Kolmogorov-Smirnov and Shapiro-Wilk tests. Due to

significant deviation from normality, the Wilcoxon matched-pairs signed rank test was used to test for differences.

To reduce groups of variables into composite variables, two multivariate methods were used: (i) principal components analysis (PCA) with varimax rotation and Kaiser criterion for extraction for Likert scale variables, and (ii) multiple correspondence analysis (MCA) for categorical variables. Before conducting PCA, the factorability of each matrix was assessed using the Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) and Bartlett's test of sphericity (Hair *et al.*, 2019). Reliability was tested with Cronbach's alpha or the Spearman-Brown coefficient (for two-item composite variables).

Assuming linear relationships between the independent variables and the dependent variable, multiple linear regression was performed. Independent variables, clustered by topic (see figure 1), were entered in blocks. All assumptions for regression were checked. Absence of multicollinearity was tested using variance inflation factor (VIF). To ensure robustness despite non-normal residuals, regression coefficients were estimated by bootstrapping with 2000 samples.

Data were analysed using IBM SPSS Statistics (version 29.0).

Results

Of the 606 participants, most were female (n = 427; 71.3%), held at least a bachelor/university degree (n = 389; 64.6%) and reported good or very good health status (n = 369; 61.1%). Participants were aged between 16 and 84 years (M = 42.0; SD = 13.2) and nearly one-third resided in the Lisbon district (n = 182; 30.3%). Membership in a patient organisation or in another non-profit health organisation was reported by 32.3% (n = 196) and 22.4% (n = 136), respectively.

Over 95% agreed or totally agreed with the participation of health professionals, patient organisations and the Ministry of Health (MoH) in health policy decision-making. Nevertheless, support for the MoH was significantly lower than for health professionals (p = 0.003). Support for health user organisations and citizens was lower and significantly different from that for the aforementioned stakeholders (p< 0.001), except for health user organisations *vs.* the MoH (p =0.047). Support for the participation of consumer organisations was significantly lower than for all the above (p < 0.001). The lowest levels of support were observed for insurers and pharmaceutical/health technology companies (p < 0.001). Still, all stakeholder groups were recognised as relevant actors in health policy decision-making by at least some respondents (table 2).

Sampling adequacy for principal component analysis (PCA) was confirmed by the Kaiser-Meyer-Olkin measure (KMO = 0.62-0.75) and Bartlett's test of sphericity (p< 0.001 in all cases). PCA yielded a one-component solution capturing support for public participation (table 3), explaining 53.8% of the variance. Although the PCA supports the empirical coherence of this composite variable, it brings together actors with distinct institutional recognition, resources, symbolic capital and modes of representation. The aggregation therefore reflects respondents' normative orientation

Table 1 Participant characteristics (*N* = 606)

Characteristic	*n*	%	*M* (*SD*)
Gender			
Female	427	71.3	
Male	172	28.7	
Age (years)			43.0 (13.2)
Education			
Basic (1-9 grade)	49	8.1	
Secondary (10-12 grade)	164	27.2	
Bachelor/university degree	292	48.5	
Master/PhD	97	16.1	
Health Status (self-reported)			
Very bad	5	0.8	
Bad	73	12.1	
Neither good, nor bad	157	26.0	
Good	306	50.7	
Very good	63	10.4	
Place of residence			
Lisbon district	182	30.3	
Other	419	69.7	
Membership			
Patient organisation	196	32.3	
Other non-profit health organisation	136	22.4	
Cultural, recreational or sports association	110	18.2	
Professional organisation	99	16.3	
Consumer organisation	75	12.4	
Union	61	10.1	
School parent association	57	9.4	
Political party	39	6.4	
Neighbourhood association	13	2.1	
Environmental organisation	8	1.3	
Other	22	3.6	

toward a broader participatory arena rather than an assumption of sociological equivalence between citizens and representative organisations.

For orientation toward public participation, PCA revealed a three-component structure: (i) participation-related stereotypes, (ii) conventional-decision-making orientation, and (iii) public empowerment orientation. The item *citizens/patients should trust decision-makers* showed cross-loadings and was excluded (table 4).

PCA also revealed a one-component solution for the health advocacy role, advocacy performance and influence on health policy of organisations representing patients, health service users and consumers, explaining 69.7%, 75.6% and 77.7% of the variance, respectively, with factor loadings ranging from 0.75 to 0.92.

Table 5 presents descriptive statistics and reliability for the composite variables derived from PCA and used in the hierarchical multiple regression. To improve reliability, two items were excluded: *health professionals are the ones who should make decisions* (from the *conventional decision-making orientation* scale) and *decisions*

Table 2 Support for stakeholder participation in health policy decision-making

Stakeholder	All sample		Subsample: agree or totally agree	
	n	*M (SD)*	*n*	*%*
Health professionals	606	4.70 (0.54)	592	97.7
Patient organisations	606	4.66 (0.57)	587	96.9
Ministry of Health	606	4.62 (0.65)	579	95.5
Health user organisations	606	4.56 (0.65)	571	94.2
Health policy experts	606	4.45 (0.75)	553	91.3
Academia/researchers	606	4.42 (0.66)	554	91.4
Citizens	605	4.39 (0.78)	533	88.1
Health managers	604	4.02 (1.03)	470	77.8
Consumer organisations	604	3.84 (1.01)	398	65.9
Local government authorities	606	3.81 (1.04)	410	67.7
European Union	604	3.79 (1.07)	398	65.9
Members of Parliament	605	3.77 (1.08)	395	65.3
Pharmaceutical/health technology companies	605	3.21 (1.28)	287	47.4
Insurance companies	605	2.77 (1.28)	189	31.2

Note: Scale ranged from 1 (totally disagree) to 5 (totally agree).

Table 3 PCA-derived solution of support for public participation

Item	1-Factor
Agreement with participation of patient organisations	0.770
Agreement with participation of health user organisations	0.806
Agreement with participation of consumer organisations	0.671
Agreement with participation of citizens	0.675

Note: *N* = 604

are not effective when they are at odds with the lifestyle or values of citizens/patients (from the *public empowerment orientation* scale). Reliability was *adequate* ($\alpha \approx 0.70$) or *very good* ($\alpha \approx 0.80$) (Kline, 2011), except for *conventional decision-making orientation*. However, given the exploratory nature of this study and the mean inter-item correlation (0.45) falling within the recommended range (Clark and Watson, 1995), this composite was retained. Average support for public participation was high ($M = 4.36$), *as was public empowerment orientation* ($M = 4.34$). In contrast, participation-related stereotypes participation and conventional-decision-making orientation were low ($M = 1.98$ and $M = 2.70$, respectively). Organisations representing patients, health service users, and consumers were perceived as having an important advocacy role ($M = 4.52$), satisfactory performance ($M = 3.25$), but low influence on health policy ($M = 2.81$).

The multiple correspondence analysis (MCA) yielded a one-dimensional solution for health-related high-effort participation ($\alpha = 0.69$), but not for the low-effort participation ($\alpha = 0.34$). As a result, low-effort participation items — membership in

Table 4 PCA-derived solution of orientation toward public participation

Item	Factor		
	1	2	3
It is better for citizens/patients not to know the details of decisions	**0.728**	0.243	-0.126
There is information that citizens/patients cannot access	**0.752**	-0.058	0.045
Citizens/patients should only participate when called upon	**0.659**	0.294	-0.196
Citizens/patients don't want to be involved in decisions	**0.435**	0.244	-0.270
Politicians are the ones who should make decisions	-0.059	**0.800**	-0.074
Managers are the ones who should make decisions	0.237	**0.736**	-0.078
Health professionals are the ones who should make decisions	0.183	**0.550**	0.072
Citizens/patients should trust decision-makers	0.317	0.345	0.304
Citizens and organisations that represent them should be treated as partners in decision-making	-0.329	0.082	**0.695**
Patients and organisations that represent them should be treated as partners in decision-making	-0.311	0.054	**0.737**
Decisions are not effective when they are at odds with the lifestyle or values of citizens/patients	0.200	-0.161	**0.696**

Note: N = 604. Factor 1 – Participation-related stereotypes. Factor 2 – Conventional decision-making orientation. Factor 3 – Public empowerment orientation.

Table 5 Descriptive statistics and reliability for composite variables derived from PCA

Composite variable	*M (SD)*	Cronbach's alpha	Spearman-Brown coefficient
Support for public participation	4.36 (0.55)	0.68	
Participation-related stereotypes	1.98 (0.73)	0.67	
Conventional decision-making orientation[1 2]	2.33 (0.91)		0.62
Public empowerment orientation[1 3]	4.50 (0.62)		0.70
Health advocacy role	4.52 (0.56)	0.73	
Health advocacy performance	3.25 (0.81)	0.84	
Influence on health policy	2.81 (1.00)	0.86	

Note: The scores for the composite variables ranged from 1 to 5.

[1] Two-item composite variable.

[2] *Item health professionals are the ones who should make decisions* excluded from composite variable (Cronbach's Alpha if item not deleted of 0.57).

[3] Item *decisions are not effective when they are at odds with the lifestyle or values of citizens/patients* excluded from composite variable (Cronbach's Alpha if item not deleted of 0.59).

a patient organisation, membership in another non-profit health organisation, petition signing and filing a written complaint — were introduced individually into the hierarchical multiple regression model. At least one high-effort participation activity was reported by 29.5% of participants (n = 179). Regarding low-effort participation, 43.2% (n = 262) reported having signed a petition and 33.0% (n = 200) reported having filed a complaint.

Table 6 Results of hierarchical multiple linear regression on support for public participation

Independent variables	Dependent variable: Support for public participation			
	Model 1 B (SE)	Model 2 B (SE)	Model 3 B (SE)	Model 4 B (SE)
Participation-related stereotypes	-0.109 ** (0.036)	-0.114 *** (0.035)	-0.126 *** (0.035)	-0.129 *** (0.035)
Conventional decision-making orientation	-0.001 (0.024)	0.008 (0.024)	0.017 (0.024)	0.019 (0.025)
Public empowerment orientation	0.338 *** (0.049)	0.278 *** (0.049)	0.276 *** (0.050)	0.279 *** (0.050)
Health advocacy role		0.157 *** (0.048)	0.162 *** (0.047)	0.159 *** (0.050)
Health advocacy performance		-0.017 (0.027)	-0.021 (0.028)	-0.020 (0.028)
Influence on health policy		0.066 ** (0.023)	0.061 ** (0.023)	0.061 * (0.023)
High-effort health participation			0.173 *** (0.048)	0.189 *** (0.049)
Petition signing			-0.023 (0.044)	-0.037 (0.045)
Complaint (in writing)			-0.026 (0.045)	-0.041 (0.046)
Patient organisation membership			-0.134 ** (0.044)	-0.131 ** (0.046)
Membership in other non-profit health organisation			-0.029 (0.053)	-0.028 (0.053)
Male				0.043 (0.042)
Age				-0.002 (0.002)
Bachelor/university or more				-0.066 (0.047)
Very bad/Bad health status				0.097 (0.059)
Lisbon district				0.032 (0.045)
Membership in Cultural, recreational or sports				0.010 (0.051)
Professional organisation				0.149 (0.056)
Consumer organisation				0.000 ** (0.051)
Union				-0.029 (0.087)
School parent organisation				0.034 (0.065)
Political party				-0.085 (0.095)
$\Delta R2$		0.033	0.026	0.018
ΔF		8.099 ***	3.990 **	1.261
R adj	0.201	0.230	0.250	0.253
F	48.927 ***	29.429 ***	18.290 ***	9.822 ***

Note: N = 573. Bootstrap results based on 2000 samples.
* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Table 6 summarises the hierarchical multiple regression analysis exploring the relationship between the independent variables (entered in blocks) and support for public participation.

Model 1 examining orientation toward public participation was significant and explained 20.1% of the variance (R^2 *adj* = 0.201; $F_{(3,569)} = 48.927$, $p < 0.001$). Predictors were participation-related stereotypes ($B = -0.109$, $p = 0.003$) with a negative effect, and public empowerment orientation ($B = 0.338$, $p < 0.001$) with a positive effect.

Model 2 added beliefs about organisations representing patients, health service users and consumers in health policy decision-making. This significantly improved the model's explanatory power ($\Delta R^2 = 0.033$, $\Delta F_{(3,566)} = 8.099$, $p < 0.001$). Beliefs about the organisations' advocacy role ($B = 0.157$, $p < 0.001$) and their influence on health policy ($B = 0.066$, $p = 0.006$) were significant positive predictors.

Model 3 incorporated health participation experience, further increasing explained variance ($\Delta R^2 = 0.026$, $\Delta F_{(5,561)} = 3.990$, $p = 0.001$). Previous high-effort participation had a positive effect ($B = 0.173$, $p < 0.001$), while patient organisation membership showed a negative effect ($B = -0.134$, $p = 0.003$).

Model 4 controlled for participant characteristics, explaining 25.3% of the variance (R^2 adj = 0.253; $F_{(22,550)} = 9.822$, $p < 0.001$), but did not significantly improve the overall model ($\Delta R^2 = 0.018$, $\Delta F_{(11,550)} = 1.261$, $p = 0.244$). Only membership in a professional organisation was a significant positive predictor ($B = 0.149$, $p = 0.007$).

Model 4, which controlled for individual characteristics, was also used to explore the relationship between patient organisation membership and support for the participation of each stakeholder included in the composite variable of public participation (citizens and organisations representing patients, health service users and consumers). Membership in a patient organisation was a significant negative predictor of support for participation of both citizens
($B = -0.292$, $p < 0.001$) and consumer organisations ($B = -0.275$, $p = 0.005$) but did not predict support for participation of patient or health service user organisations.

Discussion

Support for individual stakeholder participation

Most respondents supported the participation of citizens and organisations representing patients, health service users and consumers in health policy decision-making, a finding consistent with previous studies conducted in Portugal (Crisóstomo, 2009; Botelho, Pinho and Veiga, 2013; Roquette *et al.*, 2024). Such strong support underscores the democratic imperative for governments to consolidate and expand spaces for meaningful participation. This requires policymakers to demonstrate genuine commitment by actively supporting public participation and incorporating citizens' input into practice, which entails an effective redistribution of decision-making power to citizens (Pagatpatan and Ward, 2017; Baumann, Reinhold and Brütt, 2022). It further requires enabling conditions, including supportive policies and legal frameworks,

adequate institutional capacity and sufficient resources (Mira *et al.*, 2018; WHO, 2021; Baumann, Reinhold and Brütt, 2022).

On the other hand, high support for health professionals, patient organisations and the MoH — the health system governance triangle (WHO, 2021) — alongside broad support for other conventional and non-conventional decision-makers, points to a preference for collaborative health policy decision-making, that also includes citizens and organisations representing patients, health service users and consumers (Wiseman *et al.*, 2003; Shrimpton *et al.*, 2008; Broqvist and Garpenby, 2015; Baumann and Brütt, 2022). Thus, consistent with other studies (Abelson *et al.*, 1995; Dolan, Cookson and Ferguson, 1999; Wiseman *et al.*, 2003; Shrimpton *et al.*, 2008; Theodorou *et al.*, 2010), assessing preferences across multiple stakeholders — rather than restricting responses to a single actor — enables a more nuanced understanding of public views.

Views on political actors were more heterogeneous. While support for the Ministry of Health was high, support for local authorities and members of Parliament (MPs) was weaker. In the case of local authorities, this pattern may reflect the recent start of decentralisation in Portugal. The lower support for MPs, despite their central legislative role, may be associated with perceptions that parliamentary policies are less effective than government action. Although only a limited number of studies have differentiated between levels of political decision-making (Abelson *et al.*, 1995; Bowling, 1996; Mossialos and King, 1999), this distinction warrants further examination in future research.

Support for public participation

PCA revealed that support for public participation in health policy decision-making can be operationalised as a composite variable combining preferences for the participation of citizens and organisations representing patients, health service users, and consumers. Although this study did not differentiate between active, joint, or passive forms of participation, the observed level of support is comparable to that reported by Baumann and Brütt (2022) when active and joint decision-making are considered together. Using a composite variable provides a broader understanding of the determinants of participation, while stakeholder-specific analyses remain necessary depending on the research objectives, as indicated by the regression results.

As the composite operationalisation captures a shared orientation toward participatory inclusion, it necessarily aggregates actors occupying structurally different positions within the health policy field. Citizens, patient organisations and consumer organisations differ in terms of institutional recognition, access to decision-making arenas, professionalisation and symbolic capital. The empirical convergence identified in the PCA should therefore be interpreted as a normative alignment at the attitudinal level, rather than as evidence of structural symmetry between these actors.

Predictors of support for public participation

The hierarchical regression model confirmed that empowerment orientation and participation-related stereotypes are significant predictors of support, highlighting the importance of awareness-raising and education. Beliefs about the health advocacy role and policy influence of organisations representing patients, health service users and consumers, along with prior high-effort participation, were also important. These findings underscore the need for organisations to enhance their visibility, demonstrate their impact, and mobilise constituents to engage more actively in decision-making processes.

Membership in a patient organisation was negatively associated with support for broader public participation, as well as with support for the participation of citizens and consumer organisations. Beyond a purely attitudinal interpretation, this finding may reflect the structured nature of participation within the health policy field. Patient organisations, particularly when institutionalised and recognised as legitimate interlocutors, may develop specific advocacy agendas, organisational identities and established channels of access to decision-making arenas. In such contexts, broader or less organised forms of participation may be perceived not simply as complementary, but as potentially diluting representational clarity or redistributing influence across actors with different degrees of expertise, recognition and symbolic capital.

From a sociological perspective, this pattern may be interpreted in light of dynamics of boundary-making and differentiation within a structured participatory field, where organised constituencies seek to consolidate their legitimacy and authority vis-à-vis both institutional decision-makers and other civic actors. Rather than contradicting support for participation *per se*, this finding suggests that participatory arenas are shaped by internal hierarchies and differentiated claims to representation.

Membership in a professional organisation also influenced support for public participation. However, the lack of detailed information on participants' professional background limits the interpretation of this finding. Given that data collection predominantly involved health-related organisations, and considering available evidence of strong support for public participation among health professionals (Wiseman, 2005; Theodorou *et al.*, 2010; Botelho, Pinho and Veiga, 2013), it is plausible that many respondents reporting professional membership were themselves health professionals. If this is the case, it may be hypothesised that their professional background, rather than professional membership *per se*, accounted for the observed effect.

Limitations and future work

Although the multiple regression controlled for participants' characteristics, the findings are based on the study sample and cannot be generalised to the Portuguese population. Replication with a representative sample is therefore needed. To gain a more nuanced understanding of public preferences and enable cross-study comparisons, it is also important to distinguish between support for shared decision-making and support for involvement without decision authority.

Moreover, future research should also consider additional factors that may enhance the model's explanatory power, including perceived social justice, political trust, political ideology, political knowledge, political participation, perceptions of individual and collective efficacy, and outcomes of previous participation experiences. Further investigation is also necessary to clarify the role of patient organisation membership and health professional background in shaping support for public participation in health policy decision-making. Finally, the low levels of support observed for local government authorities and Members of Parliament warrant closer examination to understand the underlying reasons for this pattern.

Conclusions

This study provides a comprehensive analysis of preferences regarding public participation in health policy decision-making in Portugal, as well as the factors influencing its support, among the 606 survey participants. Strong support was found for the participation of health professionals, patient organisations and the MoH, followed closely by other conventional and non-conventional stakeholders. This pattern suggests a preference for collaborative approaches to health policy decision-making.

The results also demonstrate that support for public participation can be operationalised as a composite variable combining preferences for the participation of citizens and organisations representing patients, health service users, and consumers. Nevertheless, depending on research objectives, stakeholder-specific analyses may still be required.

Concerning factors associated with support for public participation, positive predictors included empowerment orientation and beliefs about the health advocacy role and policy influence of organisations representing patients, health service users and consumers, as well as prior high-effort participation and membership in a professional organisation. Negative predictors were membership in a patient organization and participation-related stereotypes.

Beyond its implications for health policy, this study contributes to the sociological understanding of public participation by demonstrating that support for participatory arrangements does not necessarily entail a displacement of professional authority but rather coexists with it in hybrid configurations of governance. Furthermore, the findings highlight that participatory arenas are internally differentiated, structured by unequal resources, institutional recognition and forms of symbolic capital. In this sense, participation emerges not as a homogeneous or inherently emancipatory space, but as a field of negotiated legitimacy in which actors advance distinct claims to representation. By analysing support for citizens and representative organisations within the same analytical framework, the study advances a more nuanced understanding of democratic participation in contemporary health governance.

The findings carry several implications for policymakers and other stakeholders. First, governments must consolidate and expand meaningful spaces for public participation in health policy decision-making, ensuring redistribution of decision-making power is effective and enabling conditions are guaranteed.

Second, organisations representing patients, health service users, and consumers need to increase the visibility of their work and its impact, among both their constituents and the wider public. Third, it is crucial to raise awareness not only of the importance of public participation but also of the principles that should underpin its implementation. Finally, promoting high-effort participation (*e.g.*, active membership in civil society organisations or engagement in participatory spaces) is essential to foster broader support for public participation in health policy decision-making.

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Sofia Crisóstomo. PhD student, Iscte — Lisbon University Institute (Iscte — Instituto Universitário de Lisboa), Lisbon, Portugal, and member of GAT — Portuguese Activist Group on Treatments (GAT — Grupo de Ativistas em Tratamentos), Lisbon, Portugal.
E-mail: sofia_crisostomo@iscte-iul.pt
ORCID: https://orcid.org/0000-0002-1907-1883
Contributions to the paper: conceptualisation, data curation, formal analysis, investigation, methodology, original draft preparation, review and editing.

Margarida Santos. Invited assistant professor, Iscte — Lisbon University Institute (Iscte — Instituto Universitário de Lisboa), Lisbon, Portugal, and member of GAT — Portuguese Activist Group on Treatments (GAT — Grupo de Ativistas em Tratamentos), Lisbon, Portugal.
E-mail: margarida_couto_santos@iscte-iul.pt
ORCID: https://orcid.org/0000-0002-1907-1883
Contributions to the paper: conceptualisation, investigation, methodology, review and editing.

Ana Raquel Matos. Assistant professor, Faculty of Economics of the University of Coimbra (Faculdade de Economia da Universidade de Coimbra), University of Coimbra, Portugal, and researcher, Centre for Social Studies of the University of Coimbra (Centro de Estudos Sociais da Universidade de Coimbra), University of Coimbra, Portugal.
E-mail: ana.matos@fe.uc.pt
ORCID: https://orcid.org/0000-0003-0350-7440
Contributions to the paper: methodology, review and editing.

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