

# Public participation in health and COVID-19 in Portugal

## *Participação pública em saúde e Covid-19 em Portugal*

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DOI: 10.1590/0103-11042022E4081

**ABSTRACT** In the last decades, public participation in decision-making processes has been an ongoing theme, assuming more or less centrality, within the political agendas in several democratic contexts around the world. In the health domain, public participation has been considered a political strategy with the potential of ensuring greater co-responsibility among the actors involved, as well as to increase health services' transparency, thus being emphasized as one of the best practices that should be implemented towards the quality of decisions, especially those oriented to the real health problems of the populations. The COVID-19 pandemic brought additional pressures to health systems, constituting itself as a conducive context to the analysis of citizen participation in health decision-making processes. This essay presents an exploratory analysis on the evolution of citizen participation practices in health policies in Portugal, highlighting some of its current and future challenges. The present analysis aims to understand how the pandemic resonated in the way in which participation in the health domain had been carried out in the country, assessing whether, in a singular global period of crisis, the pandemic as a collective problem expanded or contracted these participatory practices.

**KEYWORDS** Citizen participation. COVID-19. Pandemic. Portugal.

**RESUMO** Nas últimas décadas, o tema da participação pública em processos de decisão tem estado presente nas agendas políticas, com mais ou menos centralidade, em vários contextos democráticos do mundo. No campo da saúde, a participação pública apresenta-se como estratégia política com potencialidades para garantir maior corresponsabilização entre os atores envolvidos e para incrementar a transparência dos serviços, sendo enfatizada como boa prática que deve ser implementada em prol da qualidade das decisões, mas também de decisões que sejam orientadas para os reais problemas das populações. A pandemia da Covid-19 trouxe pressões adicionais aos sistemas de saúde, constituindo-se como contexto propício à análise da participação cidadã nos processos de decisão que enquadram problemas de saúde na sua relação com a pandemia. Este ensaio apresenta uma análise exploratória sobre a evolução das práticas de participação cidadã nas políticas de saúde em Portugal, destacando alguns dos seus desafios atuais e futuros. Procura-se, assim, compreender como a pandemia teve ressonância na forma como a participação em saúde vinha decorrendo no País, aferindo se, em um período global de crise com características singulares, a pandemia, enquanto problema coletivo, distendeu ou contraiu essas práticas participativas.

**PALAVRAS-CHAVE** Participação cidadã. Covid-19. Pandemia. Portugal.

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## Introduction

The issue of public participation in decision-making processes has been present on political agendas, with more or less centrality, in various democratic contexts over the last few decades. This discussion around the involvement of citizens in decision-making processes has not only animated more than four decades of theoretical approaches around public participation in its relation to democracy, but has also proved to be more pertinent and dynamic in some areas of social life.

The issue of public participation has, therefore, brought out the conviction that the possibility of operationalizing participatory arrangements, based on the interdependence of actors (experts, lay people and policy makers), is an effective way of solving collective problems. This participation has been conveyed as a democratic strategy that contributes to increase the quality of decisions, ensuring that the citizenry has an active voice in these types of processes, allowing decisions to be based on their experience and knowledge of reality.

In this context, the health domain has proved to be a dimension of social life of particular relevance in its relationship with the issue of public participation, demonstrating great dynamism, being fertile ground for experimentation with regard to different possibilities of putting in motion participatory devices. The leading role of public participation in the health domain, however, assumes a precise and unavoidable time frame – the Alma-Ata Conference.

Held by the World Health Organization (WHO) in 1978, and dedicated to the topic of primary health care, in the declaration resulting from that meeting, it was stated for the first time that it is a right and a duty of people to participate individually and collectively in the planning and implementation of their health care. Despite the institutionalized experiences that have since

been consolidated, it is important to point out that, in most cases, even when participation takes place, its main beneficiaries do not belong to the most disadvantaged social strata, that is, those most in need of making their voice heard in health decisions.

It should also be noted that, despite the aforementioned dynamism of public participation in health in political agendas, there are issues that must be taken into account in this analytical context. Firstly, the conventional and unconventional possibilities of participating in health – as will be explained later in this article – but, above all, the different degrees of institutionalization of these processes in various health systems.

Participation in health decisions is thus presented as a political strategy with the potential to guarantee greater co-responsibility and increase the transparency of services, being emphasised as a good practice that must be implemented in favour of the quality of decisions, but also of decisions that are oriented to the real problems felt by the populations.

Here, we address the issue of public participation in health in its relationship with the COVID-19 pandemic. More specifically, the exploratory analysis that is proposed, focusing on the Portuguese reality, aims to understand how the pandemic registered on a global scale had an impact on the way in which participation in health was taking place in the country, assessing, in a unique period of crisis, whether the pandemic as a collective problem has stretched or contracted these participatory practices.

This essay aims to present the analysis on the evolution of citizen participation practices in health policies in the context of a pandemic, highlighting some current and future challenges. Methodologically, literature searches in selected databases were used as a basis, as well as press searches using the descriptors “participação cidadã”, “Covid-19”, “participação dos pacientes” and “Portugal”. Additionally, a literature

review was carried out in PubMed and Google Scholar databases oriented towards the theme of citizen participation in decision-making processes in the context of COVID-19, using keywords (MeSH), with Boolean language (AND): “citizen participation” AND “patients’ participation” AND “COVID-19” AND “Portugal”. In the context of the press research, the same keywords were used. We defined as inclusion criteria in the analysis: documents dealing with the issue of citizen participation in political decision-making in the context of the COVID-19 pandemic in Portugal.

It should also be noted, however, that the search carried out on PubMed did not yield any results, which is justified by the contemporaneity of the topic under analysis. The Google Scholar search resulted in 20 documents, but when we applied the aforementioned inclusion criteria, none fit. The evident limitations in the results obtained account not only for the need for a more extended reflection in time, since the phenomenon is still being felt, but are themselves indicators of what we consider to be a retraction towards the expansion of participation that had been making feel.

This exploratory analysis begins by framing the main theoretical debates around participation, with a special focus on participation in health, and then proceeds to the characterization of the Portuguese reality regarding this issue, showing the trajectory of the participation in health in Portugal, its main characteristics, and the way in which these practices have been implemented and how they could be useful in the fight against COVID-19. A brief overview of the literature on public participation in the scope of the pandemic is presented, as well as the analysis of the data collected in order to discuss the concrete impacts of COVID-19 on the phenomenon of participation in health in the country, an analytical basis that, despite the limited results, will give us the anchor to move forward with some conclusive notes on the thematic under analysis.

## The main theoretical strands concerning the debates on public participation in health

For about 40 years, in a transdisciplinary logic, deliberative and participatory approaches framed within the debates on democracy, discussing possibilities of public participation with different impacts on decisions, have assumed centrality not only theoretical, but also at the level of national and international political agendas, encouraging the most diverse democratic institutions to foster regular opportunities to involve citizens in decision-making processes on matters that directly concern them and in the formulation of public policies. The issue of public participation, also commonly known as citizen participation, has thus been fuelling dense theoretical debates since 1980. This issue, in recent years, has been recognized as an inseparable part of the good development of a society<sup>1</sup>, with some participatory mechanisms being highlighted as strategies that contribute to the reinforcement of social inclusion, of the feeling of belonging to a community, and of social emancipation. Participation, therefore, is recognized as the ability to contribute to possibilities of direct control of decision-making processes, therefore, greater control over the political system and democratic institutions<sup>2</sup>.

From these debates, over the last few years, a new social actor has emerged, defined as a participatory individual, product of this new form of governance<sup>3</sup>. This is, therefore, an individual endowed with a new set of rights and duties, who, in articulation with experts, is responsible for presenting opinions, proposing solutions, controlling processes and social dynamics, but also evaluating, judging, and deciding. It is, in fact, this new social actor that gives life to this innovative strategy of democratic States and that emerges from new forms of interaction between political decision-makers, scientists and citizens. Such

individuals constitute what become known as hybrid forums, presenting themselves more democratic, since they are anchored in the co-production of knowledge, capable of informing and consolidating decisions that are more adjusted to the real problems of the populations<sup>4,5</sup>. It is also the emergence of this new actor that has made possible, on a theoretical level, to think about strengthening and surveillance of democracy. Participation is, then, a kind of guarantee seal for reaching decisions with more quality<sup>6</sup>.

Participation, embodied in deliberative practices, has, however, assumed different configurations, in various spheres of social life, and is still shaped by different theoretical, despite their various intersections: the deliberative approach and the participatory approach to democracy.

On the one hand, the deliberative approach to democracy, developed since the 1980s, and which, despite its various reformulations in the face of criticism, is based on communication as a process that allows citizens to participate in the construction of the common good<sup>7-10</sup>. This approach, especially in the early years, values communication based on rational argumentation, excluding from these processes and vetoing the right to participate to those who are not able to reason rationally in deliberative contexts oriented towards consensus, reproducing a scheme of inequalities<sup>11,12</sup>.

On the other hand, and originating from the intensification of the globalization processes of the 1990s, which led to a reformulation of various aspects of national states, including decision-making processes, the participatory approach to democracy emerged.

In contrast to the deliberative approach, the participatory democracy approach is anchored in a project that shapes the formulation of public policies and proves capable of combating the various forms of social inequality more effectively through new participatory arrangements and practices. This approach develops from the assumption that citizens, despite being lay people, have specific knowledge

and skills to get involved, in articulation with experts and policy makers, in policymaking processes. Under this approach, the new participatory individual can influence and/or control technical decisions, even in the context of conflicts and even if rational argumentation in discussion forums is not valued. Viewed in this way, participation emerges here, contrary to the deliberative approach, as a universal right that must be freely exercised from different forms of expression, in which emotions, for example, take place<sup>13</sup>.

Although crystallizing different views on participation and deliberation, the two approaches support the argument that they are practices based on citizen involvement that complement representative democracy.

Such approaches thus serve to delimit what counts as participation. In this context, of the most widely used analytical tools for understanding public participation has been to distinguish between conventional and non-conventional participation<sup>2,14</sup>. Such a distinction coincides with institutionalized practices – as defended by the deliberative approach of democracy – and non-institutionalized practices of participating in deliberative contexts – as advocated by the participatory approach. Correspond to unconventional participation, forms of political behaviour in which indirect channels of influence are opened up from the bottom up, that is to say, through actions triggered by collective actors, in which action through protest and other actions by social movements are included<sup>15,16</sup>. It is important to emphasize that, depending on the democratic culture, collective action by social movements may be one of the only legitimate ways that citizens have to interfere in the political process, thus justifying the legitimacy of this form of unconventional action as effective participation and with potential effects on decisions<sup>17</sup>.

Participation has therefore become a corollary to many areas of social life; and healthcare has been no exception. Health, by the way, is a more prolific dimension of social life in the

way health systems and public participation are articulated. The potentials of participation in health systems are recognized, highlighted by the literature in this field, among which the following stand out: a) strengthening the voice of health service users as a strategy to overcome the democratic deficit that still characterizes health systems<sup>18</sup>; b) the experiences of users, and their knowledge, are essential to increase the quality of health decisions<sup>19,20</sup>; c) as a means that legitimizes the responsibility of health systems<sup>21</sup>; d) the fact that it has the ability to bring the needs of communities closer to the responses of health services<sup>22</sup>; e) ensure that public health systems are more effective when the decisions taken reflect the perspective of users experiencing problems<sup>2,22</sup>.

However, the implemented mechanisms operating in various parts of the world are still far from guaranteeing the realization of the theoretically recognized potential for participation in health. Certainly, participation translates into reality through various mechanisms, with very different impacts from decisions, ranging from citizen juries, deliberative voting processes, focus groups, health councils, among other possibilities. Participation in health has, therefore, also revealed constraints, of which the problem of representativeness stands out, since these participatory mechanisms have not been able to accommodate the social diversity of communities, contributing to the reproduction of inequalities, especially among groups that are already socially excluded<sup>11,12,21</sup>.

Participatory practices in the health area have, in some way, been romanticised, that is, participation has been linked to the effective resolution of problems, when this is not yet effective<sup>16</sup>, namely due to the resistance on the part of health professionals and managers to the implementation of the results of public participation in the deliberative processes of health care<sup>23</sup>, an area that is still recognized as a stronghold of expert knowledge. From this context, there emerges, therefore, an imbalance of power under these mechanisms in

the health area, which is legitimised in the absence of evaluation processes that measure the effectiveness of participation in health decisions<sup>20</sup>. In this sense, it can be said that citizen involvement has been instrumentalized, serving only as a technology of legitimation<sup>24</sup>, in correspondence, albeit partial, to the definition of technology of arrogance in the scope of governance, especially if it involves scientific and technological questions<sup>25</sup>, which leaves no room for citizen interference. Both technologies approach the most elementary levels of participation conceived by the timeless ladder of participation by Sherry Arnstein<sup>26</sup> – also called false participation or illusion of participation –, far from the possibility of the new participatory subject interfering or controlling the decision-making processes in health.

Despite the vitality of this debate and interest in participation in health, over the last decades, the level of institutionalization of participatory mechanisms in the health domain has been admittedly low. These are mostly activated occasionally at the initiative of health authorities, but they end up being discontinued due to the financial and human costs they entail, which devalues the results they can produce. In the context of southern Europe, which includes Portugal, many of these limitations are even more intense and visible, mainly due to the lack of financial resources to implement mechanisms of this type and the lack of tradition of citizen participation in the health area<sup>14</sup>.

## Public participation in health in Portugal

In Portugal, the guarantee of the right to participate has been enshrined since the Constitution of the Portuguese Republic (CRP) of 1976 (including its successive amendments) which followed the authoritarian regime deposed with the Revolution of April 1974. In this context, public participation is framed in

its relationship with Portuguese democracy as a determining factor in solving certain national problems (article 9, paragraph c), insofar as all citizens have the right to take part in the political life and in the management of the country's public affairs, directly or through freely elected representatives (art. 48, n° 1). However, despite the guarantee enshrined in the CRP, the transposition of this right into effective practices has only recently been taking shape, and institutionalized mechanisms for participation in health in Portugal are still scarce or dysfunctional. The prevalence of participation in health is not only recent, but it has been difficult to leave political discourses and take an effective form, despite the growing demand by the Portuguese population for more participation in this specific area<sup>27</sup>.

In the health domain, it is the Health Basis Law (*Lei de Bases da Saúde*), of 1990, as well as the Statute of the National Health Service (SNS) of 1993, that define the possibilities of public participation, even though of a consultative nature, at various levels and in multiple instances. Notwithstanding the Basis Law that frames these possibilities to participate, referring to the 1990s, it was only recently, on April 7, 2016, that the Decree-Law establishing the legal regime of the National Health Council (CNS) was approved, thus implementing the provisions of the Health Basis Law, that is, about 26 years later. The creation of the CNS is presented as a strategy to strengthen the power of the citizen in the SNS, guaranteeing the participation of citizens who use the SNS in the definition of policies, but with the intervention of local authorities and professionals, as well as universities and higher polytechnic institutes, in addition to representatives appointed by the Permanent Commission for Social Dialogue, National Ethics Council for Life Sciences and Autonomous Regions, as a way of promoting a culture of transparency and accountability to society. It is, therefore, an independent government advisory body, composed of 30 members, aiming to guarantee participation, but leaving little room for

individual citizen participation in the design of health policies.

Another of the existing mechanisms is the general councils of hospitals, also of a consultative nature, which includes only one representative of the users' association, once again a space that tends not to expand the definition of public participation, which is understood to be broader. In this way, the participation of citizens in the health system does not find an echo in institutionalized spaces, prevailing a strong influence of structured interest groups, which causes an imbalance of power within the political system that has greatly contributed to the lack of political discussion and of pluralism in the formation of health policies.

In the national context, new initiatives have been implemented over the last decades with the aim of promoting citizen participation, of which Decree-Law n° 28/2008 - which establishes the Groups of Health Centers (ACEs) - stands out. These are presented as structures guided by the objective of reducing inequalities in health and overcoming the marginalization of primary care. The Decree also establishes Community Councils (CC) with the aim of encouraging the participation of different local actors in the decisions and organization of health services, however, once again with one place at the table for representatives of users. In addition to corroborating the tendency to institutionalize hermetic spaces of participation in health in Portugal, other barriers are associated with this type of mechanism, including its recognized inability to make this structure work<sup>28</sup>.

In the Portuguese context, it has been, above all, the patients' associations that dynamize demanding initiatives around more participation, standing out as relevant social actors in terms of participation in health, playing an extremely important role in the representation and defence of patients. In the absence of institutionalized channels capable of promoting a regular and widespread citizen participation in health, it is the associations in the health domain that have positively marked

the debate on public participation in decision-making processes, particularly because they have exerted growing pressure, since 2000, to open up health decision-making processes to their participation, in a strategy of valuing the knowledge they hold

More recently, some positive signs have marked the opportunities for participation in health in Portugal, with the Council of Ministers having approved the Decree-Law approving the SNS Statute – which, at the time of writing this article, was in the public consultation phase –, beginning to contemplate, in its article 4, the recognition of the rights and duties contained in the law and, in particular, the rights contained in the Charter of Rights of Access to Health Care by SNS Users and the Charter for Public Participation in Health. In this way, in article 25, the public participation of citizens in the SNS is also guaranteed under the terms of the Charter for Public Participation in Health. The mentioned participation can therefore occur individually or through entities representing the beneficiaries or users.

The aforementioned Charter for Public Participation in Health – which content is available at <https://www.participacaosaude.com/carta> – is, therefore, the concrete result of an action research project, called ‘More Participation, better health’, having been approved by Law No. 108, of September 9, 2019. This document encourages participation by people, with or without disease and their representatives, in decisions that affect the health of the population, and encourages decision-making in health based on broad public participation. This letter also intends to promote and consolidate public participation at the political level and at the different State bodies and entities in Portugal, through the deepening of existing participation processes and the creation of new participatory spaces and mechanisms.

In recent years, participation in health has gained new impetus, namely through the results achieved by the mobilization and action

of some associations active in the health area and which have stimulated strategies for the broad participation of citizens and their representatives in the health area. These initiatives aimed to make health policies more effective and, in this way, to obtain better health results, in addition to promoting the transparency of decisions and accountability by those who decide, bringing the State and civil society closer, deepening the dialogue. and the regular interaction between the two.

Portugal has a long history of participatory claims in the health domain, with normative gains, but still lacking concrete possibilities, able of operationalize the effective participation of all citizens, especially the most disadvantaged. This is a trajectory characterized by the scarcity of institutionalized opportunities to participate, recently marked by new gains, although only legislative

In countries like Portugal, the tendency to involve patients, users, care providers and the general public in the elaboration of health policies is a relatively new phenomenon, with concrete opportunities for citizens’ participation in health decisions being scarce. In this recent history, inhabited by some participatory health initiatives, mechanisms that give little space to individual and broad citizen participation stand out. The existence of alternative approaches to participation in health systems that go beyond technocratic and academic formulas cannot be ignored. Protests and other forms of collective action introduced into the debate the concept of something neglected of civil society, reflected in the mobilization of the lower classes in the struggle to participate and have a voice in decisions about health care<sup>2,27</sup>. More recently, participation has found new legislative echoes that are important to follow in the outlining of this trajectory of public participation in health in Portugal, in the sense of measuring its implementation in effective and innovative practices, capable of positively marking this debate in Portugal.

In this sense, it is important to emphasize that health has asserted itself, over the last two

decades, as one of the areas that most mobilizes the Portuguese population for protest.

These protests, although localized and translating unstable results in terms of their potential to influence public health policies in Portugal, cannot fail to be considered legitimate ways of participating in health decision-making processes. Such forms of participation, often classified as unconventional by the scientific literature, have been one of the most activated resources to interfere in decision-making processes, precisely because of the scarcity of institutionalized channels in which citizens could participate.

The health protests, which have marked Portuguese society, are thus constituted as strategies for monitoring the processes of implementation of health policies in Portugal, capable of setting in motion the necessary political surveillance, on the part of the population, as well as the surveillance of democracy and the way it works. These forms of collective action have made it possible to sensitize public opinion to the problems that affect health governance in the country, revealing the collective capacity of the Portuguese population to intervene, when necessary, in deliberative processes on health, placing the main problems that mobilize them in the political agenda, both local and national, influencing the course of politics and electoral cycles<sup>2</sup>.

## Public participation in the context of a pandemic: what do we know?

In the context of the COVID-19 pandemic, the theme of patient involvement in decision-making emerged in the context of global health, namely an editorial by BMJ<sup>29</sup>, according to which, during the pandemic, in England, there was the abandonment of political commitments towards the involvement of citizens in health decision-making.

The importance of community involvement has been made explicit before, and has been crucial in responses to Ebola virus disease in West Africa – e.g. in tracking and addressing rumours<sup>30</sup>.

In COVID-19 pandemic context, in which the need for quick decisions became evident, policy makers chose scientific knowledge to support the decision, to the detriment of those who root their ‘knowledge’ in experience, as is the case with patients, families, patients’ associations, health professionals and the social sector. In Portugal, this is exemplified by the technical meetings of ‘Infarmed’, which did not include representatives of civil society<sup>31</sup>.

This was a missed opportunity, precisely when the adverse effects of limitations on access to health services during the pandemic period were predictable. COVID-19, as a global pandemic context, was a moment that called for clarification, namely, on which services would be suspended and which would remain accessible, among other forms of reorganization of services and in the context of the disease itself that required greater involvement of the citizen sphere; but from literature to the press, the highlight is that citizen participation has been waived all over the world.

## Citizen participation and COVID-19 in Portugal

The CNS<sup>31</sup> published a report in which it recognizes the importance of public participation in health, alerting to the fact that the COVID-19 pandemic has relegated the regulation of the Charter for Public Participation in Health, translated into law in 2019, to the background, and which resulted precisely from the collaborative initiative ‘More Participation, better health’, created in 2015.

The CNS was formally requested to issue an opinion on the Health Plan only for Autumn-Winter 2020-21, and was not co-opted by the government to promote consultation mechanisms with civil society,

although it later contributed with a set of recommendations that it considered appropriate.

The Portuguese Association of Hospital Administrators (APAH) organized, in 2020<sup>32</sup>, a set of three online conferences dedicated to ‘Citizen Participation in the COVID-19 Era’ in the Health System. These conferences reiterated part of the participatory trend designed in the country, which tends to favour the influence of structured interest groups, especially patient associations. These organizational structures, in addition to claiming more participation, have also managed to find punctual echoes in some participatory spaces in health policies. The organization of these conferences, once again, corroborates this trend, since, in the three initiatives organized, both the organization of events and the management of those who participated in the discussions were exclusively ensured by representatives of the various patient associations operating in the national territory, with no room for the voice of other actors.

The first conference was dedicated to the theme ‘The health system’s response’, addressing the risks associated with non-diagnosis and disease progression due to reduced demand from health institutions in a pandemic period; representatives of chronic disease associations highlighted the responses of the national health service as a positive aspect, namely teleconsultations, renewal of prescriptions and home delivery of medicines. On the other hand, they also confirmed the installed fear, caused in particular by the lack of knowledge about the ways of transmission of the virus, which contributed to the patients not going to the consultations at the Health Centers.

A recently released study, promoted by ‘Movimento Saúde em Dia’ (consisting of the Physician’s Order, the Portuguese Association of Hospital Administrators and Roche) and carried out by GFK Metris<sup>33</sup>, presented indicators on access to the SNS

during the pandemic. According to it, between 2020 and 2021, 14 million consultations in Health Centers, 2.8 million contacts in hospitals, which includes consultations, surgeries, and emergencies, and 30 million exams were not carried out. These data now presented for Portugal are in line with what is reported in other contexts<sup>34</sup>.

A second conference addressed the theme ‘The return to normality’, focused on the SNS responses to the chronically ill during and after the pandemic. The debate revolved around ways to ensure improved communication between institutions, health professionals, patients and family members, but also on ways for patients to collaborate in the construction of new service offerings that aim to improve the experience and satisfaction of their needs. The central role of the patient was claimed. Problems related to cancer patients, namely what was lost in terms of early diagnosis, quality of treatment and follow-up. The value of patient participation was exemplified by the President of the Group of Activists in Treatments – GAT (Luís Mendão), emphasizing that they pose questions that may fail other specialists, thus being specialists in their condition.

The third conference focused on the theme ‘Solutions for the future’, debating the inevitable reconfigurations of the system as we know it, focusing on necessary reorganizations within the SNS, but also on collaborations between the public and private sectors. Participants were challenged to think about the future, which according to Miguel Crato, President of the Portuguese Association of Hemophilia (APH), should include greater sharing of clinical decisions regarding the patient, with the hospital environment having to adapt to this change.

According to the study by Movimento Saúde em Dia<sup>33</sup>, between 2020 and 2021, there were 18% fewer mammograms performed, 13% less cervical cancer screenings and 5% fewer colon and rectal cancer screenings.

## Final considerations

Officially, participation in health refers to the history of the WHO, specifically to the subsequent results of the Alma-Ata conference, which laid the foundations of the right and duty to participate in decisions on health, individually or collectively. Even so, 43 years after Alma-Ata, the COVID-19 pandemic has demonstrated the already evident difficulties of operationalizing lay participation in the challenges that have posed, and still pose, to health.

Despite the sparse literature on the relationship between public participation in health/COVID-19, it is the devaluation, in this context, of other knowledge besides scientific knowledge is evident, making the global governance of the pandemic assert itself based on a clear resource to the technology of arrogance<sup>25</sup>, hermetically linked to science and specialist knowledge.

If, in the field of managing the pandemic as a disease, it is accepted that science is responsible for the search for the eradication of the virus, nothing prevents, however, that citizen participation could help in the reorganization of the services to be provided to the populations, namely in a national context, being they who can best propose solutions in terms of access to a service that was confined in the management of the pandemic, despite the fact that other pathologies continued to exist, such as the chronicity of certain diseases, their specific needs and the way in which they were affected in terms of access to health services, with expected impacts in terms of health outcomes.

In a national context such as Portugal, already marked by the scarcity and dysfunctionality of the few participatory spaces existing in the health area, the recent years of the pandemic seem to mean a delay in the possibility of putting into motion the operationalization of some legislative achievements. COVID-19, becoming a priority issue in health, has implications not only for the initiation of such conventional participatory initiatives, but

also has limited non-conventional participation. The collective action through protest that had been used as a participatory resource for the Portuguese population found in the measures to contain the pandemic (social distancing, ban on gatherings on public roads, etc.) an herculean force capable of locking the public spaces, making it harder, if not impossible, any citizen mobilization around claims in the health area, especially because they are not allowed to thrive in a context in which the centrality of managing the pandemic is evident and unavoidable in political agendas on a global scale.

In a context of high uncertainty, COVID-19 has worsened the quality of democracies on a global scale, and Portugal was no exception. The authoritarianism of certain measures and the lack of communication spaces obstructed the path that was being taken in the participation in health in Portugal.

Talking about participation in the context of COVID-19 in Portugal is talking about three online conferences on the subject, with no impact on the way the measures were taken, serving only to remind you that participation in health is once again part of a postponed agenda.

However, these conferences are in line with what is recognized for the English case<sup>29</sup>, although patient representatives and civil society were not represented in the group of experts who advised the Portuguese government in decision-making on measures to combat the pandemic, which would be a direct influence, they did not fail to position themselves in the public space, contributing to the discussion and search for solutions in times of a pandemic.

This moment of high pressure on health systems, in which innovative approaches could have been used to involve different stakeholders, including those who know the most about their health condition, such as the chronically ill, seems to have constituted a missed opportunity for a more powerful positioning of citizen participation.

In this context, more than an opportunity to test whether lay participation can make a difference, COVID-19 has further conditioned public participation to a legal framework already identified in the literature, as exemplified by the recent advances in the SNS Statute in Portugal, so the question remains: what is the use of participation as a right if it does not find space to be exercised?

## Collaborators

Matos AR (0000-0003-0350-7440)\* and Craveiro I (0000-0003-4348-1986)\* collaborated in the conception and design of the article, research and data analysis, review of the final version and writing in co-authorship. ■

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Received on 12/07/2021

Approved on 02/25/2022

Conflict of interests: non-existent

Financial support: Fundação para a Ciência e a Tecnologia for funds to GHTM - UID/04413/2020