Participation in health and COVID-19: international studies on Pandemic response and reflections on the brazilian context

Participação em saúde e COVID-19: estudos internacionais sobre o enfrentamento à pandemia e reflexões sobre o contexto brasileiro

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ABSTRACT
Participation in health encourages preventive behaviors that contribute to the proper functioning of health systems. The Covid-19 pandemic has made the importance of such strategy explicit by determining adherence to preventive practices, including social distancing. The present study discusses the frameworks used by scientific publications that addressed the practices of participation in health during the pandemic in different countries. To this end, they used a database of a bibliometric review of the literature, in addition to a complementary narrative review with articles that connected participation in health and Covid-19. The VOSviewer software was used to organize the material. The studies show how important participation in health is for the resilience of
health systems in times of epidemics and disasters. In the pandemic, we see the integration of participation in health in the process of guaranteeing the functioning of services, the adherence to isolation and vaccination recommendations, encouraging volunteering, designing public transportation policies, designing research, and educating health professionals. Other works demonstrate the social inequalities in terms of access to health care, especially for the Black and elderly population, and, on the other hand, the action of community leaders and institutional arrangements, such as the National Health Council in Brazil, which were essential to ensure equity in health. The importance of participation in health to face crises such as the Covid-19 pandemic is undisputed, leading to the conclusion that it should be more fostered to guarantee Health Sovereignty.

**Keywords**: public health, community engagement, social participation, COVID-19.

**RESUMO**
A Participação em Saúde estimula comportamentos preventivos que contribuem para o bom funcionamento dos sistemas de saúde. A pandemia da Covid-19 explicitou a sua importância pelo fato de determinar a adesão às práticas preventivas, incluindo o distanciamento social. Este estudo discute os enquadramentos utilizados pelas publicações científicas que abordaram a Participação em Saúde durante pandemia em diferentes países. Para isso, foi utilizado um banco de dados de uma revisão bibliométrica da literatura, além de uma revisão narrativa complementar com artigos que relacionaram participação em saúde e Covid-19. A organização do material foi realizada pelo software VOSviewer. Os estudos mostram a importância da Participação em Saúde em momentos de epidemias e desastres para a resiliência dos sistemas de saúde. Na pandemia, vemos a integração da Participação em Saúde na garantia do funcionamento dos serviços, na adesão às recomendações de isolamento e vacinação, no estímulo ao voluntariado, no desenho de políticas públicas de transporte, no desenho de pesquisas e na educação de profissionais de saúde. Outros trabalhos mostram as desigualdades sociais para o acesso ao cuidado em saúde, em especial à população negra e idosa, e por outro lado a movimentação de lideranças comunitárias e de arranjos institucionais, como o Conselho Nacional de Saúde no Brasil que foram fundamentais para garantir a equidade em saúde. É unânime a constatação de que a Participação em Saúde é importante para o enfrentamento de crises, como a pandemia da Covid-19, e que deve haver mais ações para seu fomento para garantir a Soberania Sanitária.

**Palavras-chave**: saúde pública. engajamento comunitário, participação social, COVID-19.
1 INTRODUCTION

Participation in health has a political dimension that seeks to make the way communities access care more democratic, allowing these communities to have a voice in decisions regarding priorities and the use of health resources, ensuring actions and services that dialogue with social and cultural characteristics, along with creating a sense of belonging to a collectivity surrounded by knowledge and practices. However, in addition to the political dimension, it is also important to highlight its technical dimension, which contributes to the quality of the decision-making process and the organization of the health system and, consequently, to the effectiveness of health care actions.

This participation involves the ability of individuals to collectively reproduce preventive behaviors recommended by health professionals to contribute to the improvement of health conditions. These recommendations are based on clinical protocols and therapeutic guidelines that establish specific actions and are widely disseminated among the health team with the aim of establishing indicators that the team should pursue. If the definition of such conducts takes place in a participatory manner, that is, through a channel where professionals and community members can jointly develop strategies, the conducts will be more legitimized and accepted, making participation a continuous and circular movement.

The Covid-19 pandemic has made explicit the importance of social participation for the structuring and functioning of health systems, most of all because it is a defining element for their resilience, which refers to the system's ability to adapt to situations of precariousness, crises, emergencies, transformation, and expansion of demand (Haldane et al., 2021). The situations in which health systems need to be more resilient involve the capacity of actors to improve management techniques and mobilization of resources and technologies, but also involve relational capacities that can cope with the cultural specificities of conflicts and political interests.

The participation of individuals and communities was the key to tackling the pandemic. Health managers and leaders reinforced, with wide repercussion
from the media and social networks, the importance of community adherence to prevention strategies, such as contact tracing, mask use, respiratory etiquette and hygiene, attitudes to take in case of symptoms and other recommendations that, established by specialists, caused conflicts. The controversy around the vaccination also highlighted the importance of the community for the effectiveness of immunization when it comes to coping with the pandemic (Vignoli et al., 2022). In addition, we must highlight the call for social sensitivity and political pressure for equity actions that respond to the unequal impact of the pandemic on the lives of social minorities and specific population groups, such as peripheral residents, Black people, Indigenous people, sex workers, etc.

Aspects such as these emphasize the importance of participation in health strategies and mechanisms aimed at bringing stakeholders closer together in the handling of health policies. In the Brazilian case, marked by questionable attitudes of a denialist and authoritarian government, the participation and organization of the actors was still decisive to overcome the absence of a national command and to contain the damage of the pandemic. The National Health Council was strongly committed in this context, working to inform the population, articulate actors and put pressure on government officials. This work is part of a set of actions articulated by the National Health Council, and its authors carried out a bibliometric review on participation in health in the Americas (CEAP, 2022; Machado et al., 2023), as part of the project “Covid 19 e controle social no SUS1: impactos, dinâmicas, pautas e estratégias”2, developed by the Center for Education and Popular Counseling (CEAP) with the support of the National Health Council and the Pan American Health Organization/World Health Organization in Brazil (PAHO/WHO).

Among the research findings, it was noticeable that Covid-19 was the subject of several articles (CEAP, 2022), including the review by Yuan et al. (2021), which also sought to learn the dynamics of bibliographic production on this topic. The aim of this paper is to grasp the frameworks used by publications

1 Sistema Único de Saúde (Unified Health System).
to address participation in health in the context of the pandemic, as we see the possibility to offer elements to rethink the approaches of studies on participation in health and the Brazilian participatory tradition.

To assist in the construction of this article, a narrative review of the discussions on participation and Covid-19 was carried out considering the articles (table 1) that appeared in the previous review (CEAP, 2022) with a new, more specific search on the Web Of Science (WOS) for articles published until October 2021 on “Covid-19” combining this descriptor with the terms “social participation” OR “social control” OR “community engagement” OR “community participation”. Only the most cited articles were selected, due to their relevance to the debate.

Table 1 – Database studies correlating participation in health and Covid-19.

<table>
<thead>
<tr>
<th>Reference/year</th>
<th>Country where the study was conducted</th>
<th>Objective</th>
<th>Lessons on participation in health and Covid-19</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alberti, et al. (2020)</td>
<td>United States of America</td>
<td>To propose a model of health system response to new waves of Covid-19 aiming to reduce social and health inequity impact</td>
<td>Actions were proposed to adjust the response of the health system in addressing the social determinants of health, in addition to maintaining participation in health in decision-making in crisis situations.</td>
</tr>
<tr>
<td>Bispo Junior &amp; Morais (2020)</td>
<td>Brazil</td>
<td>To discuss the foundations and possibilities of participation in health to address covid-19.</td>
<td>Participation in health in Brazil must consider the emergency context, which seeks to quickly control the disease, to valorize, and to strengthen the SUS and act to strengthen the social protection system.</td>
</tr>
<tr>
<td>Carson et al. (2020)</td>
<td>United States of America</td>
<td>To facilitate among academic centers and community leaders the discussion about the participation in a translational science research group and the changes needed to adapt their work in the face of the pandemic.</td>
<td>Researchers should see the present situation as an opportunity to reimagine Participation in Health through remote means, creating strategies to maintain links to continue giving voice to research subjects, integrating them into decision-making in research, practice, and the creation of new policies.</td>
</tr>
<tr>
<td>Dannenberg et al. (2021)</td>
<td>United States of America</td>
<td>To present twenty research priorities on transportation in public health.</td>
<td>One of the priorities concerns is how to ensure a better presentation of projects in this area to the community and how to include more stakeholders in decision-making processes.</td>
</tr>
<tr>
<td>Author(s) et al. (Year)</td>
<td>Country</td>
<td>Objective</td>
<td>Findings</td>
</tr>
<tr>
<td>------------------------</td>
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<tr>
<td>Dikaios, et al. (2020)</td>
<td>Canada</td>
<td>To evaluate the effectiveness of a telehealth program delivered by Canadian volunteers to assess the mental health of older adults in quarantine.</td>
<td>This program was able to evaluate Mental Health and has the capacity to be scaled up for care and can be used as a model for other telehealth programs.</td>
</tr>
<tr>
<td>Ehmann et al. (2020)</td>
<td>United States of America</td>
<td>To describe the application of a health system resource allocation algorithm in crisis situations in the hospital network.</td>
<td>Participation in health was essential to ensure the provision of services through financial support for the purchase of equipment. The working group understood the importance of including community consultations in the protocols.</td>
</tr>
<tr>
<td>Haldane et al. (2021)</td>
<td>28 countries representing 6 continents</td>
<td>To assess the resilience of twenty-eight National Health Systems regarding the pandemic response.</td>
<td>Participation in health is at the heart of the health systems resilience model, as it requires society's adherence to the measures recommended by health authorities, as well as participation in the construction of health policies.</td>
</tr>
<tr>
<td>Henry Akintobi et al. (2020)</td>
<td>United States of America</td>
<td>To detail the life context of African Americans and its connection with Covid-19 from the perspective of the actions of a research center.</td>
<td>Those responsible for the design and implementation of public health policies must build culturally tailored responses to Covid-19 control among African Americans, promoting community engagement through local actions.</td>
</tr>
<tr>
<td>Machado et al. (2021)</td>
<td>United States of America e México</td>
<td>To evaluate the perception of twelve students graduating from a course about migratory movements on the border between Mexico and the United States of America.</td>
<td>The course proposal is to focus, through theoretical-practical approaches and field visits, on participation in health, preparing graduates to deal with situations of health inequity in a humanized way.</td>
</tr>
<tr>
<td>Mao et al. (2021)</td>
<td>United Kingdom</td>
<td>To review the scientific literature to understand the impact of volunteering in the fight against covid-19 in the United Kingdom.</td>
<td>Connection through social media, local knowledge and trust were key dimensions for the emergence of volunteer groups. There was little interaction of volunteer groups with each other and with other organizations.</td>
</tr>
<tr>
<td>Martins et al. (2021)</td>
<td>Brazil</td>
<td>To reflect on the role of nursing in ensuring participation in health in Brazil in the face of the Covid-19 pandemic.</td>
<td>Nursing has a potential in strengthening participation in health by participating in health councils and doing popular education activities in communities.</td>
</tr>
<tr>
<td>Pimentel Walker et al. (2020)</td>
<td>United States of America</td>
<td>To describe the history of participatory research work in three refugee community organizations.</td>
<td>These organizations offering essential services have been able to provide protection against the clinical, social, and economic worsening of Covid-19.</td>
</tr>
</tbody>
</table>

Source: The authors (2023).
2 WHAT DOES RESEARCH SAY ABOUT PARTICIPATION IN HEALTH AND THE COVID-19 PANDEMIC?

In the last four decades, the development of the participation in health literature in public health has attracted a significant increase in interest worldwide, especially since 1980 (Yuan et al., 2021), highlighting the gains of using this approach for public health, whether to improve maternal and child health (Rosato et al., 2008), to control endemic diseases (Gazzinelli et al., 2012) or to improve community involvement in academic research (Michener et al., 2012), among other topics. More recently, the novel coronavirus pandemic has heightened public health challenges, considering the pressure on health systems and the catastrophic damage caused by Covid-19.

However, some researchers have already warned, in the light of other outbreaks and epidemics, of the contribution of community engagement for the shaping of policies for disasters and health emergencies involving large populations. In the case of the influenza epidemic that occurred in 2007 in the United States, Schoch-Spana et al. (2007) highlight the potential of participation for epidemic control and recommend how leaders of the United States of America (USA) could, by adopting this approach, improve at all levels their ability to govern during a crisis and mitigate losses throughout the community. In this same line, Barker et al. (2020) highlight the contributions of community engagement in moments of health system crises, such as that experienced in the Ebola outbreak in Liberia in 2014-15. The authors showed how the implementation of this approach contributed to creating the necessary conditions for health system resilience, providing empirical evidence for the formulation of policies and programs aimed at improving health systems, especially in situations where resources are scarce. Respondents of this qualitative research reported that the key variable for promoting meaningful community engagement is that

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3 Community engagement is understood as “the process of working collectively [people, governments and organizations] with groups of people who have geographic proximity, a common special interest, or similar living situations to achieve a better quality of life” (Centers of Disease Control and Prevention, 1997, p. 9).
communities are active participants and that communication channels with communities exist prior to health crises.

Gilmore et al. (2020) reviewed the evidence to identify how, since 2000, community engagement has been used for infectious disease prevention and control during the Ebola, Zika, Severe Acute Respiratory Syndrome, Middle East Respiratory Syndrome and H1N1 Influenza Type A epidemics. The authors conclude that community engagement has been a key component in controlling previous outbreaks, and that this approach can be particularly important for reaching marginalized populations and shoring up equity-based responses, corroborating the way in which communities can play important and active roles in the prevention and control of Covid-19. Given that even before the development of vaccines or their widespread coverage, this method has proven effective in controlling outbreaks of infectious diseases. As in the case of Covid-19, the effectiveness of particularly important procedures such as testing, contact tracing and case isolation depends directly on public involvement (Megnin-Viggars et al., 2020).

Among the lessons learned in the response to Ebola in African countries, Anoko et al. (2020) highlight the importance of community engagement in overcoming outbreaks with actions such as: the involvement of social scientists and the local population in building response strategies from the beginning, grassroots leaders and the media in preparing; the implementation of measures and well-articulated communities to overcome dissent; the mobilization of family leaders for surveillance, case detection, contact identification and follow-up and quarantine, as well as the recruitment of local personnel in the response.

Community engagement has also proved its value in armed conflict contexts, as in the case of northwest Syria, which is marked by a lack of capacities and resources (Ekzayez et al., 2020). The researchers identified lessons learned from previous outbreaks in the region, such as polio in 2013 and the annual seasonal flu. According to the authors, resorting to innovative actions on social media such as WhatsApp and interactive websites, always keeping the focus on community involvement, has allowed the mobilization of local resources
and support from thousands of volunteers, increasing the capacity of the health system, even with limited resources.

In a quite different context, such as the United Kingdom, community volunteering was also a way out to control the pandemic. As in other countries, one of the main non-medicinal interventions used to face Covid-19 at its beginning was self-isolation managed by the communities themselves, a behavior that requires social support, an essential role of volunteers (Mao et al., 2021). However, the authors found that in addition to this action, volunteers conducted other activities that address the broader impact of the pandemic in areas not sufficiently served by public services, such as employment, social benefits, mental health, domestic violence, and housing.

Information and Communication Technologies have also facilitated connecting volunteers, according to a study by Dikaios et al. (2020). In this study, the authors presented a telehealth program delivered by volunteers to address the mental health of older adults in the province of Quebec during the Covid-19 pandemic. According to the authors, the results demonstrate the potential for such a program to significantly improve mental health capacity and care for hundreds of clients, serving to define the prominence of telehealth in the future of mental health prevention and care.

Other areas, such as public transportation and health equity, have also gained prominence in the research found on the impacts of Covid-19. According to Dannenberg et al. (2021), transportation policies and projects have multiple impacts on health, and conducting research on this incidence can help promote positive consequences and reduce adverse health consequences. This research demonstrates that the decrease in transit use during the Covid-19 pandemic was a threat to the maintenance of operations and development of transit systems. For the authors, conducting research involving the community as a primary actor can help raise the visibility of the impact of transportation on health and equity, and help guide health-friendly transportation policy choices.

In reviewing the responses to the Covid-19 pandemic in 28 countries, Haldane et al. (2021) highlight the importance of assessing the resilience of
health systems so that policymakers can develop sustainable recovery and system strengthening plans, both to address the current and future crises, since the pandemic has globally challenged health systems and the communities they serve, requiring governments to create healthy populations, capable of preventing and responding collectively to crises. The expansion of this response is necessary to overcome the social effects and health inequity caused by the scarce resources of services and the vulnerability of certain ethnic-racial groups, especially African Americans (Alberti et al., 2020; Ehmann et al., 2020; Henry Akintobi et al., 2020). Thus, participation in health becomes a central element of system resilience, as it is up to society to conduct the protection recommendations issued by health authorities, in addition to contributing to the planning of the system itself (Alberti et al., 2020; Haldane et al., 2021).

Machado et al. (2021) also highlight that the increase in migration and immigration, particularly during the Covid-19 pandemic, requires global public health teaching experiences to facilitate the adequate preparation of future leaders, especially to address the structural inequalities faced by asylum seekers. Bispo Júnior and Morais (2020) stand out in the international literature with their approach to the topic of participation and the specificities of the Brazilian pandemic context. The authors emphasize that community participation in coping with Covid-19 has to consider three interconnected contexts: the emergency, generated by the pandemic; the strengthening of the Unified Health System (SUS) and the change in the country's economic and political matrix, with the defense of the social protection system and democracy. Still on the Brazilian context, it is also necessary to consider the reflections brought by Martins et al. (2021) about social control in health and the contributions that nursing can make to face the Covid-19 pandemic. The authors consider that the role of nurses in social control favors the strengthening of the struggle for the right to life above profits, especially through popular participation in the community context in Primary Care.

Even though we have identified few Brazilian articles with the focus presented in this topic, the political dimension related to participation has been
the topic of a vast discussion. Some analyses will follow below to situate the political framework of the pandemic and the importance of participation in health for the democratization of access to health services.

3 COVID-19, INEQUALITIES, AND THE FIGHT FOR ACCESS TO CARE

In addition to the evaluation of health systems, it is also necessary to consider that the effects of the pandemic were not the same in all countries, nor did they affect the population groups in each country in the same way, with the disease burden being heterogeneous between the regions of the world, as well as the initial responses to the Covid-19 pandemic by governments (Chen and Assefa, 2021), including some regions without the capacity to guarantee basic measures such as hand washing (UNICEF, 2020).

In the Brazilian case, the data show that social inequalities, especially racism, have accentuated the morbidity and mortality of the Black population, and the Covid-19 pandemic has aggravated it. According to Barreto et al (2020, p.2), “in Brazil, the challenges are even greater, since at the beginning of the pandemic little was known about the transmission characteristics of Covid-19 in a context of great social and demographic inequality”. These inequalities affect the Black population most of all, who, due to racism, face more difficulty in accessing rights such as basic sanitation, health, education, housing, employment, drinking water, food, sewage, adequate garbage collection, working conditions, which directly affects the incidence of Covid-19 in this population (Geledés, 2020). These aspects reflect the socio-spatial segregation to which the Black population is subject and which, according to Góes et al. (2020),

create adverse health conditions, since, historically, the places where most Black people live are precarious, lacking adequate housing in terms of structural conditions, with no access to basic sanitation services, drinking water, health facilities such as health posts, pharmacies, parks and recreational spaces, contributing to greater exposure to risk factors, in addition to high rates of violence, resulting in the accumulation of health problems (p. 4).

Regardless of the little information available on the connection between racism and Covid-19, Góes et al. (2020) present a diagnosis that discuss how the
Black population suffered the impacts of the pandemic much more severely. Initially, the authors highlight data from Farmer's (2020) research on the racialization of the pandemic in the American context:

In Michigan, for example, where African Americans are 14% of the population, they account for more than 30% of positive Covid-19 cases and more than 40% of deaths. In Chicago, African Americans - 29% of the city's population - account for 70% of Covid-19 deaths [...]. On the other hand, African Americans are the population group less tested for Covid-19. Racial inequalities in the access to testing display a warning sign of implicit racial bias, according to some professionals on the frontlines of the pandemic. The study reveals that African Americans are less likely to be referred for Covid-19 testing when they search for care with signs of infection (Góes et al., 2020, p. 3).

Considering the Brazilian context, the authors use data from the National Health Survey to highlight the most prevalent risk factors among the Black population in addition to sickle cell disease, such as hypertension (44.2%) and diabetes (12.7%), compared to the White population (22.1% and 6.2%, respectively), heart disease (7.0%), asthma (8%) and neglected diseases, such as tuberculosis (Brazil, 2017). These data indicate that the Black population is more likely to develop severe forms of this disease, considering that hypertension, diabetes, heart disease and asthma are aggravating factors, together with the social condition of the population.

Kalache et al. (2020) argue that, unlike European countries, where Covid-19 has mainly affected older adults over 60 years of age, in Brazil the disease has been shown to be: (a) "younger", as comorbidities arrive earlier; (b) much "darker", as blacks are the majority among the poorest population and with less access to resources to face the pandemic; (c) more feminine, due to occupational risks, family care, labor informality and increased domestic violence; (d) "even more ageist, as economistic choices determine the exclusion of older people from access to health services" (Kalache et al., 2020, p. 1); e) more suffering, given the precariousness of palliative care in the Unified Health System (UHS).

As in Brazil, the Covid-19 pandemic in the U.S. has also disproportionately affected underserved and minority populations, in part due to limited access to diagnostic testing and in part due to deep-rooted structural inequities that
precipitate higher rates of infection and mortality (Brewer et al., 2021). Against this backdrop, the academic-community partnership between a medical institution and a federally qualified health center in Minnesota to ensure the provision of Covid-19 testing for a socioeconomically disadvantaged racial/ethnic minority population and low-income essential workers stands out. According to the authors, this intervention proves the potential of existing strong academic-community partnerships to rapidly respond to community health emergencies, concluding that:

> to cultivate health equity, it is critical to merge the resources of well-equipped medical institutions with culturally rich, community-centered organizations to jointly address structural and systemic inequities (Brewer et al., 2021, p.661)

Integrated research with participation in health also stands out in the USA. During the pandemic, there were efforts to scientifically understand the impacts of the pandemic, as well as to develop plans for coping with it. Carson et al. (2020) presented the strategies of research centers for the continuity of work, involving community leaders representing the research subjects in the discussion. Pimentel Walker et al. (2020) and Henry Akintobi et al. (2020) presented the work organizing the experience of monitoring community centers for refugees and African Americans respectively and how these centers offer protection against the clinical, social, and economic aggravations of the pandemic.

In Brazil, studies have also highlighted the work of community leaders who, at the time of coping with the pandemic, showed both their potential and their weaknesses. Research indicates that these individuals, in cooperation with the solidarity of residents, as well as other civil society initiatives, have found the necessary cooperation to face the minimization of the presence of democratic institutions, assuming the role that the neoliberal capitalist state is failing to fulfill, especially in actions aimed at combating hunger (Yagiu et al., 2021; Oliveira et al., 2021; Castro-Silva et. al 2021). In recent research in contexts of vulnerability in Baixada Santista/SP, Yagiu et al. (2021, p.7) found that:
the active presence of women leaders from the beginning, based on awareness-raising processes, has been opening possibilities for a new praxis, including effectively participating in collective organization and mobilization in the current context of the Covid-19 pandemic.

In the global scenario, Loewenson et al. (2021) found that responses to Covid-19 included top-down command and control measures, laissez-faire approaches and bottom-up, community-driven solidarity and support. However, the authors identified that, beyond command and control, community engagement is achieved with comprehensive actions that include social determinants and rights, presenting promising models of effective responses to address the pandemic (Loewenson et al., 2021).

As the literature shows, participation in health is a fundamental element for controlling the pandemic, bringing together different actors, but above all the local population, to face the damage caused by the new coronavirus. The discussions presented so far show us how relevant the practice is from a technical, scientific, and political point of view for the management and improvement of health policies. Community engagement is effective regardless of the social reality and is even more important in contexts where governments demonstrate inability or insufficiency to deal with the problems arising from or aggravated by the pandemic. In the next section, we will discuss the Brazilian experience, which stands out for the presence of municipal, state, and national health councils, that has institutionality contributed to the resilience of the health system in a context of increasing attacks on democratic institutions and social rights and dismantling of public services.

4 PARTICIPATION AND SOCIAL CONTROL IN HEALTH IN BRAZIL AND THE BATTLE AGAINST COVID-19

As discussed in the previous topic, participation in health has contributed to coping with the pandemic in several ways. Considering the multiplicity of forms of participation, especially in relation to social movements, community organization and popular education (Lima et al., 2020), we found a number of Brazilian publications that studied Covid-19. However, these studies can hardly
be framed as articles that discuss participation in health in a dialog with concepts and research traditions in the area, such as those we present in the second topic of this article.

The Health Reform that gave rise to the SUS has an intrinsic relationship with popular participation. The 8th National Health Conference held in 1986 had many of its guidelines transposed into the 1988 Constitution and is a milestone of this movement. The participatory process that brought organized actors of society closer to the State pushed for the creation of a hybrid political system of representation and participation that crosses all fields of public policies with participatory devices provided by law. In health, the two most present mechanisms are conferences and health councils. The legal framework of the SUS was extremely successful in ensuring the existence of municipal health councils in most Brazilian municipalities. A number of researchers have dedicated themselves to studying Brazilian participationism and, in the case of health, we have a consolidated field of research on the subject, with most studies on institutionalized participation, but with a greater focus on health councils (CEAP, 2022).

In recent years, the idea of “social control” may be the one that best describes the functioning of participatory democracy arrangements. Unlike the participatory practices of the 1980s, which were dynamic, instituting, and propositional (Ricci, 2010), Lisboa (2014) summarizes the work of Guizardi et al. (2004) by stating that, after the IX National Health Conference, held in 1992, “the sense of social control became much more inspection and external evaluation, as opposed to participation in the entire construction process, as before” (p. 35). Four years later, at the X National Health Conference, this sense is consolidated, and a normative stiffening is observed, since “the report refers to the Health Councils as instances of monitoring and inspection, strengthening the conception of exteriority to the process, being responsible only for monitoring, inspecting or even approving and authorizing” (Lisboa, 2014, p. 35). The focus of participation via councils and under the concept of “social control” are, in this perspective,
associated with the neoliberal bias that marked the public policy scenario after the 1990s.

The practices that characterize this space seek less solutions, proposals and joint constructions for collective problems and participatory management than the control of the State by an external body. In this sense, one of the critiques often made of these arrangements refers to the bureaucratization and plastering of participatory practices. It is not a recent discussion. Maccacaro (1979) argues that participatory instances only contribute if the actors create conditions for the composition of discussion objects that make sense to the participants. The author argues that the bureaucratization of participation spaces is precisely one of the practices that act to prevent users and citizens from being part of the decision-making process (Machado et al., 2020). Taking into consideration the authoritarian and little participatory tradition of Brazilian political culture, based on the naturalization of inequalities, welfarism and clientelism (Chauí, 2000), we add some obstacles to the effectiveness of institutionalized participation and, consequently, to the resilience of the health system.

However, unlike lightly institutionalized participation experiences that tend to demobilize quickly (Matos and Serapioni, 2017), councils in Brazil are persistent and resilient, resisting even executive attacks thanks to legal guarantees, but also because they have organized social movements that support and legitimized the activity of the councils. Bezerra et. al (2022), analyzing the attacks against the councils during the Bolsonaro government, classify Health Councils as resilient because they have a robust design, with solid legal guarantees, and because they are part of the policy communities related to the health field.

The Brazilian National Health Council remained fully functional regardless of the attacks from the Bolsonaro government and managed to hold the 16th National Health Conference using actions in the Public Prosecutor's Office to guarantee the budget allocation provided for by law. In addition, the CNS strengthened its performance during the pandemic by mobilizing actors, investing in mass training of users and workers for the proper exercise of social control and
in the development of strategic research to improve participation, such as those presented in this book.

In the early months of the pandemic, the National Health Council mobilized leaders and built the “Documento Orientador para Conselhos Estaduais, Municipais e Distrital de Saúde sobre Novo Coronavírus” (Covid-19)” (Brazil, 2022). The document presents useful principles, evidence, and strategies for effective participation in health actions during the pandemic. At the end of the second year of the pandemic, the CNS made available on its website the “Especial CNS no Enfrentamento à Covid-19”, in which the number of documents prepared by the CNS for the Executive, Legislative and Judiciary bodies get systematized with a focus on combating the pandemic. It includes dozens of public notes, recommendations, letters, guidelines, motions, and campaigns that reflect the tireless work of the CNS in facing the pandemic.

5 FINAL CONSIDERATIONS

As verified in the studies reviewed, it is unanimous that participation in health processes contribute to effective responses to face humanitarian crises and epidemics, as in the case of the Covid-19 pandemic. The studies also highlight the importance of conducting research that helps raise the visibility of pandemic response measures and their impacts on health and equity, as well as helping to guide health-friendly policy choices that, while recognizing the root causes of social and health inequality, have a clear focus on initial and intermediate preparedness and rapid response efforts, prioritizing social equity and health.

We found that research conducted on different models of participation in health underway in the U.S. demonstrated that the Covid-19 pandemic presented a fantastic opportunity to prioritize and sustain approaches to promote community engagement of vulnerable African Americans and social minorities. The data demonstrate that innovative approaches adopted, based on community

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4 Guiding Document for State, Municipal and District Health Councils on New Coronavirus.
5 CNS Special on Coping with Covid-19.
participation, will prepare us for the next pandemic, and reinforce the importance of community-based participatory research as a key research methodology for promoting health equity.

In the Brazilian context and its focus on institutional forms of participation, despite criticism of the meaning of the term “social control” and the bureaucratization of health councils, we have seen that the National Health Council has not lost its capacity to mobilize and articulate actors. Its institutional design with legal guarantees allowed the consolidation of a broad, diversified political and institutional action with a decisive impact on the Unified Health System. We therefore defend the importance of strengthening the institutionalized participation in health system, since its existence does not prevent other forms of participation; on the contrary, councils inspire actions of permanent education, articulation between actors, social mobilization and broad representation of collective demands and projects. In spite of the constant attacks suffered, especially after the 2016 coup, social participation in Brazil resists conflicting interests that undermine the quality of health services, such as austerity policies, disrespect and undervaluation of health workers, chronic underfunding, moralization of health practices that are often based on essentialist and fundamentalist perspectives on subjects and life, and so on.

The answer to criticism must the fostering of a more participatory civic culture and by increasing citizen engagement in public policies. The existence of a participatory political culture can enhance the actions of health councils, as well as develop innovative strategies for social mobilization in defense of democracy and health as a right for all. We consider it important to invest in new social technologies that promote participation, community engagement and social organization on the various fronts of prevention, protection, and health promotion. The introduction of modern technologies will not happen without resources to fund appropriate tools and staff training, as well as projects aimed at this purpose. In addition to the dispute over the reform of the health system, a change of vision is needed with regard to individual care over community care, in order to achieve Sanitary Sovereignty (Gomez-Arias, 2022), which allows all knowledge to be
included in the construction of health care alternatives, in addition to articulating with the struggle to guarantee other sovereignties, such as food, environmental and territorial, articulating a large democratic network in support of good living.
REFERENCES


FARMER, B. The Coronavirus doesn't discriminate, but U.S. health care showing familiar biases. *NPR*. Available at: https://www.npr.org/sections/health-shots/2020/04/02/825730141/the-


LIMA, Luanda de Oliveira et al. Perspectivas da Educação Popular em Saúde e de seu Grupo Temático na Associação Brasileira de Saúde Coletiva


