From participation to social control: reflections based on the indigenous health conferences

Da participação ao controle social: reflexões a partir das conferências de saúde indígena

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Abstract

Even though the Federal Constitution of 1988 guarantees indigenous peoples the right to social policies, health care remains a field of tension in their relationship with the State. The need to ensure a participation guideline for the Brazilian National Health System and the inclusion of indigenous people in mechanisms of social control are widely defended. Thus, this article seeks to discuss the meanings of participation and reflect on the challenges of its configuration as social control within the scope of indigenous health. The analysis was based on health conference reports, bibliography related to the subject, and interviews with key actors. The research sought to shed light on the diversity of contexts, actors, and agendas involved in the five indigenous health conferences. We concluded that there was a shift in the conferences and their participation, which moved towards a more bureaucratic performance within the strict boundaries established by the government. Even so, it is essential to value the power contained in the mechanisms of social control, which not coincidentally are the objects of disputes brought forward by the most conservative groups in society. In this sense, it is necessary to value, occupy, and transform these spaces.

Keywords: Health of Indigenous Populations; Social Control; Social Participation; Health Conferences.

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Resumo

Embora a Constituição Federal de 1988 assegure aos povos indígenas o direito às políticas sociais, a saúde permanece um campo de tensão no trato desses povos com o Estado. Muito se tem defendido a necessidade de garantir a diretriz de participação no Sistema Único de Saúde e a inserção dos indígenas nos mecanismos de controle social. Dessa forma, este trabalho busca contribuir com o debate sobre os sentidos da participação e refletir sobre os desafios da sua configuração como controle social no âmbito da saúde indígena. A análise foi feita com base nos relatórios das conferências de saúde, na bibliografia afeita ao tema e em entrevistas realizadas com atores-chave. A pesquisa buscou lançar luz sobre a diversidade dos contextos, dos atores e das pautas das cinco conferências de saúde indígena realizadas. Concluímos que houve um deslocamento na participação nas conferências para uma atuação mais burocrática dentro dos estritos limites estabelecidos pela gestão. Ainda assim, é fundamental valorizarmos a potência contida nos mecanismos do controle social, que não à toa são objetos de combate dos grupos mais conservadores da sociedade. Neste sentido, há que se valorizar tais espaços, ocupá-los e transformá-los.

Palavras-chave: Saúde de Populações Indígenas; Controle Social; Participação Social; Conferências de Saúde.

Introduction

The fight against the dictatorship in Brazil also proved to be a fight against social inequalities, being expressed in the constitutionalization of social rights such as health care. As a result of a possible consensus, the 1988 Constitution (Brasil, 1988) expresses certain ideals, such as universality and equality. For indigenous peoples, this Constitution also represented the recognition of their socio-cultural and territorial rights, overcoming the integrationist and assimilationist paradigm that prevailed in the history of the Brazilian State. At the same time, this legal framework guaranteed the indigenous populations' right to social policies, which should be formulated and implemented considering their socio-cultural diversity.

However, in order to achieve these ideals, it is necessary to insert citizens in the democratic process of conducting public affairs. To this end, the design proposed in the health care field was based on the community participation guideline. This was reinforced as a principle in Law nº 8,080/1990 and regulated as a permanent body, called "social control," in Law nº 8,142/1990 (Brasil, 1990a, 1990b). These three terms (universality, equality and participation) are key elements for the analysis of health policies in Brazil.

It is important to highlight that "until 1999, the provision of health care services to indigenous peoples occurred sporadically, developed by teams that traveled through indigenous lands providing medical assistance and other specific actions" (Pontes, 2013, p. 61). Universality and equality still did not apply to the native peoples. It was only after the approval of Law nº 9,836 in 1999, known as the Arouca Law, that the Indigenous Health Care Subsystem (Sasi), which is a part of the Brazilian National Health System (SUS), was implemented in the form of 34 Special Indigenous Health Districts (Dsei).

The formulation and implementation of the Sasi-SUS went hand in hand with the Brazilian health care reform (Pontes et al., 2019), emphasizing the same guidelines. The agenda for consolidating and expanding indigenous participation in the subsystem would then be present at all National Indigenous Health Conferences. This represented an achievement for the struggles of indigenous peoples. The intention was to overcome the Brazilian State's tutelary perspective, which denies, ignores, and considers indigenous peoples unfeasible as subjects in the decision-making of matters that refer to them. It is worth mentioning that the participation and consultation of indigenous peoples is an international guideline for their relationship with the State, determined in Convention nº 169/1989 of the International Labor Organization (OIT, 1989), and promulgated in Brazil only in 2004.

Therefore, the 1st National Conference on the Protection of Indigenous Peoples' Health (CNPSI) calls for the "participation of indigenous nations" (Brasil, 1986, p. 2). The 2nd National Health Conference for Indigenous Peoples recommends the structuring of the "social control of the district network, exercised through the District Councils for Indigenous Health" (Brasil, 1993, p. 3). One of the results of this process was Law nº 9,836/1999, which included Article 19-H of Law nº 8,080/1990, considering that "indigenous peoples will be entitled to participate in the formulation, monitoring and evaluation of health policies at collegial bodies, such as the National Health Council and the State and Municipal Health Councils, when applicable." Two years after the implementation of Sasi-SUS, the 3rd National Conference on Indigenous Health (CNSI) reaffirms the relevance of social participation in this area, recommending the implementation of local and district councils on indigenous health (Brasil, 2001). In the 4th and 5th CNSI, the term "participation" appears in several proposals with different meanings, and the instances of indigenous social control are reinforced (Brasil, 2006, 2013).

The structure of this control is consolidated through Ordinance nº 755/2012 by the Ministry of Health, which establishes the Local Councils for Indigenous Health, the District Councils for Indigenous Health (Condisi), and the Forum of Condisi Presidents (Brasil, 2012). The Forum is a structure that began in 2006 at the request of indigenous leaders, strengthened by the creation of the Special Secretariat for Indigenous Health (Sesai) in 2010.

The literature on the subject has shown that indigenous participation is a key aspect for the health care model's consolidation because "the different peoples had to organize themselves in the form of Health Councils, so as to exercise social control" (Langdon; Diehl, 2007, p. 21). At the same time, indigenous participation in municipal, state, and national health councils is still a challenge for social control within the SUS.

Thus, despite having reached a significant statutory body, we have recently observed serious attacks on the instances of participation in public policies and indigenous social control. Decree nº 9,759/2019 (Brasil, 2019a) extinguished hundreds of collegial bodies that were not created by law, and established rules and limitations for different collegial bodies, severely restricting the participation of society in the management of social policies. Among the extinct bodies is the Forum of Condisi Presidents, which conducted regular meetings and was in charge of organizing the 6th CNSI, which would have been held in May 2019. This Conference was postponed twice, and due to the current context of this pandemic, does not have a new established date. In addition, indigenous social control was also weakened by the Sesai's expense contingency measures, which planned for only two Condisi meetings in 2020 (Brasil, 2019b).

This task dialogues with a need already pointed out in different studies, such as the one by Teixeira (2017), for whom the issue of indigenous participation is central. Souza Lima (2015, p. 441) states that "since the constitutional text the principle of social participation has become, via several channels, a key element in the political scene, without a doubt an expression of the social movements operating within the framework of the constituent process." In addition, this author considers that the possibility of indigenous participation "poses different challenges, has limitations," but at the same time "offers opportunities [...] and an increasing autonomy, at least in relation to local powers" (Souza Lima, 2015, p. 451). This in fact constitutes a double aspect of participation posed for the entire reality of the SUS, since at first it implies an "entry into the field," to use a term by Bourdieu (2000). This allows the second step to provide access to previously unavailable rights. However, as the sociologist warns us, this entry into the field assumes that the possible responses to problems are previously signaled by the field itself, and the emergence of innovative and differentiated proposals by the State is unlikely (Bourdieu, 2000). It is also because of this finding that:

> on behalf of many [indigenous people] there is an understanding that social participation is important, but that it requires another action to complement it: activism outside of state bodies that is mobilized by indigenous associations and articulations, thus expressing a distrustful confidence [...] in the political possibilities of social participation. (Teixeira, 2017, p. 726)

Therefore, this paper seeks to contribute to the debate on the meanings of participation, and reflect on the challenges of its configuration as social control within the scope of indigenous health. It is part of the research project Health of Indigenous Peoples in Brazil: Historical, Sociocultural and Political Perspectives (CAAE 61230416.6.0000.5240) which, based on a historical-anthropological approach, intends to investigate the trajectory of the actors and current contexts of health policies aimed at indigenous peoples. In this article, we rely on reports from health conferences, bibliography on the subject, and interviews with key-actors conducted using a semi-structured script, which took place between March 2018 and September 2019. These actors, indigenous and non-indigenous, actively participated in the organization of indigenous health conferences and other instances of social control between the late 1980s and early 2000s.

The dialogue excerpts cited in this text were edited to provide a better understanding for the reader, and the names of the participants were also omitted. The interviewees will be identified according to their social role, such as indigenous leader, anthropologist, health professional, and manager. We focus on content analysis that allows to explore the context, actors, and proposals under debate at the conferences, also revealing the relationships between the indigenous health conferences and other instances of social control within the SUS.

Indigenous health conferences

Even though we narrate the Conferences sequentially, it is essential to emphasize that these are absolutely different events. The research sought to shed light on these distinctions, emphasizing the different contexts, actors, and guidelines. In this way, the more general political context helps us understand the dilemmas of indigenous participation in the health field during the Conferences. We also observed the permanent links between instances of indigenous social control and the rest of the SUS.

The interviewees stressed that the 1st CNPSI, the initial milestone for the creation of the Sasi-SUS (Cardoso et al., 2012; Garnelo, 2014), was negotiated and articulated during the 8th National Health Conference (CNS). This dialogue took place between indigenous leaders and the event's organizers, particularly Sergio Arouca – who gave the opening speech at the indigenous conference. In this way, the 1st CNPSI is a thematic conference of the 8th CNS, which aimed to acknowledge "that the indigenous way of life has singularities which must be respected and [...] that the SUS was not adequately prepared to attend to them" (Garnelo; Pontes, 2012, p. 24).

According to one of the interviewees:

> *when the group I was closest to was invited to participate in the 8th National Health Conference, I understood that the available draft simply could not capture our idea of what health care meant. Our idea of care as health could not be captured by that universal SUS design, which needed to have a subsystem. That was when I claimed that an "indigenous" health conference should be held.* (Indigenous Leader 1)

Sergio Arouca, in a statement for the *Programa de Índio* (USP Radio), highlights that the objective of the 1st CNPSI was to contribute with an indigenous perspective in the health care reform, which shows a close articulation between this reform and the debates on a new health policy for indigenous peoples (Pontes et al., 2019). According to Arouca (1986, 5min40s):

> The eighth conference was based on an expanded concept of health, in which it is almost equal to the standard of living [...] and it seems to me that the indigenous peoples' conference must then face the concept of health that the indigenous nations are taking on, and as a result, that they [state]

> what proposals they have for organizing health care services, so that these proposals can then be included in the health care reform.

Cruz and Coelho (2012, p. 197) point out that, even though the SUS aims at universality, "the insertion of indigenous peoples in this system occurred in a tense way, in view of the need to adapt the universal structure of the SUS to their specificities." The relationship between power and rights is composed by the tension between homogenization and specificities. In order to discuss this tension, Garnelo (2014, p. 113) reclaims the idea of "positive discrimination," in order to "benefit groups harmed by homogenizing social policies." In addition, the author would impose a necessary "revision of the concept of simple equality, in favor of a notion of 'complex equality,' in which gender, race, ethnicity, and other differences must be treated as singularities that demand special treatment in social policies of universal character" (Garnelo, 2014, p. 113).

At the 1st CNPSI, the elaboration of frameworks for a health policy that would guarantee the specificities of native peoples in the new health care system was made possible by the indigenous protagonism in this event, its final report being based on the proposals by the Union of Indigenous Nations (UNI) (Pontes et al., 2019). Ailton Krenak (1986, 1min20s), UNI leader present at the 1st CNPSI, reports in the *Programa de Índio* from November 30, 1986 that:

> When the Ministry of Health consulted us on the initiative of holding this conference about indigenous health, the first issue which we pointed out was that it was not possible to discuss and set up a program or define guidelines, even general ones for the health issue, if they were unrelated to what was happening in the daily life of the *aldeias*. It was necessary to enable indigenous participation in the conference.

This conference based itself on an analysis by indigenous peoples and indigenists, which stated that the National Indigenous Foundation (Funai) was not addressing the health needs of the indigenous population, in addition to reproducing a medical and curative model of care (Pontes et al., 2019). The proposals by the indigenous peoples (UNI, 1988) and their partners (CIMI, 1988) emphasized that health for indigenous peoples involved guaranteeing constitutional rights, such as territorial demarcation, and the recognition of their socio-cultural specificities in health.

The final report of the 1st CNPSI proposes an indigenous health system that would be a part of the Ministry of Health, with effective indigenous participation in "all moments involving decision-making, formulation, and planning of health actions and services, as well as their implementation, execution, and evaluation" (Brasil, 1986, p. 2). Another general aspect was acknowledging the need to think about an indigenous health policy based on primary care proposals.

In 1991, during a process of reformulating the National Health Council, interinstitutional commissions for technical advice were created. These included the Intersectoral Commission for Indigenous Health (Cisi), composed of indigenous and academic representation, as well as governmental and non-governmental entities (Cardoso et al., 2012). The convening of the 9th National Health Conference in 1992 was a warning sign for indigenous peoples and their allies, as it brought forward municipalization as a guideline for the organization of the SUS. Historically, the municipal level is acknowledged as the instance in which the main conflicts of interest occur (Cunha, 2018). As a result, the proposition for indigenous health was to maintain federal management and its organization in Districts, a proposal arising from the discussions on Local Health Systems, which had great legitimacy within the scope of the health care reform (Pontes et al., 2019).

> *the issue of municipalization in relation to indigenous health was seen in a very critical way, so the indigenous movement itself created* [in the 9th CNS] *its own slogan, which was "Municipalization is not the path for indigenous health"* [...] *Then the discussions turned to the most communicated proposal, which was that of the Local Health Systems.* (Anthropologist 1)

The strength of this indigenous mobilization was able to inscribe in the final report of the 9th CNS that, within the scope of the SUS, the health care of indigenous peoples would be organized through the Dsei, and that another thematic conference on indigenous health be recommended (Brasil, 1993). Therefore, the convening of the second indigenous health conference is articulated within the scope of the Cisi:

> *there was a Cisi meeting, we wanted to hold the National Conference, the second one. We were mature by then, the indigenous peoples and indigenous health activists; it was time to hold a national conference for us to put it all on paper, in the same way that we did at the eighth conference for the SUS, for what will be the indigenous health care subsystem.* (Health Care Professional 1)

Therefore, in 1993, which was seven years after the first indigenous conference and one year after the 9th CNS, the 2nd National Health Conference for Indigenous Peoples takes place. This conference sought to define the principles and guidelines of the Differentiated Care Model for Indigenous Health, which determined the form in which indigenous citizens could access the SUS: through the special indigenous health districts (Brasil, 2006). It can be said that the 1986 report focused on what we call "doctrinal principles," that is, the values that would lay the foundation for the future of indigenous health care. On the other hand, the 1993 report advances in proposing strategies for the implementation of such a health care system.

According to the interviewees, since the start of its preparation the 2nd Conference was marked by an intense participatory process on behalf of the Cisi, within the scope of the organizing committee, and through the arrangement of regional conferences.

> [At] *the Cisi meetings, I used to gather indigenous movement activists who were in Brasilia at that time, and we expanded the discussion. We created an equal and macro-regional organizing committee.* (Health Care Professional 2)

> *And at this 2nd Conference, the biggest discussion happened. We were already organized here* [in Roraima], *we had already divided this state into regions.* (Indigenous Leader 2)

> *it was Luziânia's* [conference] *with a huge indigenous participation, a conference that came from our foundation, from the very base, and which was rediscussed, that is, in the good old indigenous model* [...] *We discussed with our bases, we held state and macro-regional conferences, and if we had to rediscuss everything, we would rediscuss it all over again. Because that is how it works to create a consensus, to generate knowledge.* (Health Care Professional 1)

This conference fulfills its role of consolidating the proposal for the indigenous health policy model within the scope of the SUS, particularly pertaining to the structure of the Dsei (Cardoso et al., 2012).

> *the issue of the Health Districts was already mature in the minds of the health care professionals who worked with indigenous communities. And the Conference was the process of analyzing this with indigenous leaders.* (Health Care Professional 2)

The 2nd Conference also proposes a method for creating the Districts through the Intersectoral Centers for Indigenous Health (Nisi). However, this strategy is not adopted by the administrative body, as is emphasized by the conference organizer:

> *The Second National Conference on Indigenous Health defined a methodology. In the states that did not yet have defined Districts, centers were created* [Nisi]. *These centers would lead a broad public negotiation to define the Districts. It was not in a workshop in Brasilia.* [...] [The idea of the Nisi] *came up basically from the articulations we used to conduct with the Cisi people* [...] *But no. The "expert" system option is chosen, the system of experts.* (Health Care Professional 2)

The strengthening of indigenous representation in the National Health Council is also highlighted by the indigenous leaders at the 2nd Conference, reinforcing the importance of participation:

> *the idea* [was] *to place an indigenous representative on the National Health Council* [...]. *The Cisi was a small, recommendation-based committee. So the National Health Council was a bigger agency* [and] *it could provide more security for us to have an indigenous representative on the council.* (Indigenous Leader 3)

However, this period is also marked by disputes, particularly regarding the management of the subsystem between the Funai and the National Health Foundation (Funasa) (Garnelo, 2006), generating tension among the indigenous people.

> *There were disagreements, but because Funai's people articulated with people from the South and Southeast.* (Indigenous Leader 3)

> *at that time there was a kind of team rivalry between Funasa and Funai.* [...] *And that was very complicated, because Xavantes, the entire Midwest wanted Funai. The Northeast did not know much what it wanted because it had nothing. The South also wanted Funai, it had nothing, but* [...] *it had a relationship with Funai, it did not know what Funasa was, Funasa did not exist in the South, it did not exist in the Northeast. So for the Amazon, where Funai's presence was not significant, Funasa appeared with an important role.* [...] *This was also something that really wore out the movement.* (Health Care Professional 3)

This impasse is resolved with the enactment of the Arouca Law (Brasil, 1999) -given its name because it was presented by Sergio Arouca in 1994 - and which created the current Sasi-SUS (Cardoso et al., 2012; Garnelo, 2006). According to several interviewees, the bill was forwarded by the 2nd Conference and based on its report:

> *our proposal was implemented at the* [2nd National Conference on Health for Indigenous Peoples]*. The final report described the whole reality of health for indigenous peoples. Therefore, it was very decisive in demonstrating that the SUS exists, but it needed a SUS "extension," which was the indigenous health subsystem that reached communities which were difficult to access. Then* [...]*, Doctor Sergio Arouca took, at the time when he was a federal congressman, he took this report and turned it into a bill for indigenous health.* (Indigenous Leader 3)

Almost 10 years after the 2nd Conference, the 3rd CNSI takes place in 2001. This conference is linked to the beginning of the implementation of the Dsei, after the Arouca Law's approval in 1999, and focused on conducting an assessment - more along the lines of the social control idea - on the implantation of the districts.

> *The third was a conference like this, "let's evaluate," and the evaluation was positive, because things were moving; there were problems, but they were moving.* (Health Care Professional 1)

> *The third was at the beginning of this implementation process, there was an effervescence, everyone wanted to participate, they wanted to come and a crowd came* [...]*. So the third had the role of ratifying the policy.* [...] *there was a big demand in that sense, that it was very slow and needed to move forward.* (Administrator 1)

As an advancement of the 3rd CNSI, we can point out the establishment of the demand for indigenous representation in the National Health Council:

> *And several requests were made through the Cisi, and then at the 3rd National Conference on* [Indigenous] *Health we articulated all the bases. Then the election was carried out, and I was elected.* (Indigenous Leader 3)

In 2006, three years after the 12th CNS, the 4th CNSI takes place. This conference was the result of efforts made in response to the recommendation of the 12th CNS for the indigenous conference to continue to happen. It was the first conference under the scope of a progressive federal government. As a result, there were many expectations for the advancement and consolidation of issues historically addressed by the sector. At this conference, 1,228 representatives from more than 100 ethnic groups were present, and from the 34 Dsei. However, at that time a general change occurred in the methodology of the thematic conferences, and the forms of participation and social control gained different characteristics in relation to previous conferences:

> *On the fourth there was a change in the thematic conferences, the council voted on full regulations for the thematic conferences.* [...] [The Indigenous

> Health Conference] *is now framed with a thematic conference, and as such, you no longer discuss at a national level what came from the locals and such.* (Health Care Professional 1)

The 4th CNSI takes place during a period of much criticism to Funasa's performance and the problems faced by indigenous organizations in the execution of services (Garnelo; Sampaio, 2003). This Conference's final report systematically reiterates Funasa's place, pointing out this scenario. In addition, there was a disagreement between the participants that led to the preparation of a parallel report, as stated below:

> [At] *the Fourth* [Indigenous] *Health Conference an evaluation was made,* [and there was] *a huge fight, they wanted get rid of Funasa, to create a secretariat. There was confusion and we voted, but afterwards a conclusion was not reached. Then a protest happened there, people from the North, from Coiab* [Coordination of Indigenous Organizations in the Brazilian Amazon], *Cimi* [Indigenist Missionary Council], *we protested against this situation, which in the report* [...] *Funasa could stay in the management of indigenous health through some criteria, as long as the service was improved then they would continue, if it did not improve they would be evaluated and get out.* (Indigenous Leader 2)

> *Now, the division was so strong in the fourth conference that, as soon as the final plenary session ended, the group from the North, Midwest, and part of the South and Southeast came together and created a document denying the conference, saying "this conference does not represent us."* [...] *this ended up not being widely reported.* (Health Care Professional 1)

The 5th CNSI took place in 2013, seven years after the last indigenous conference and two years after the 14th CNS, and it was the first held by the Sesai, which was created in 2010. This conference had 1,952 participants, and approved 446 proposals from 36 district stages and 306 local stages, which should serve as a subsidy for the reformulation guidelines aimed at the National Policy on Health Care for Indigenous Peoples.

The time gap in relation to the previous conference once again marks the fragility of institutionalized indigenous participation in health. The 5th CNSI inherits the methodology change for conducting thematic conferences, with less room for debates and no room for new proposals, in which the statistical parameters prevail over the need for further debate. Unlike the other conferences, in which there was a very broad final plenary session, in the 5th edition lasted less than two hours, mainly revisiting points articulated by the administrators.

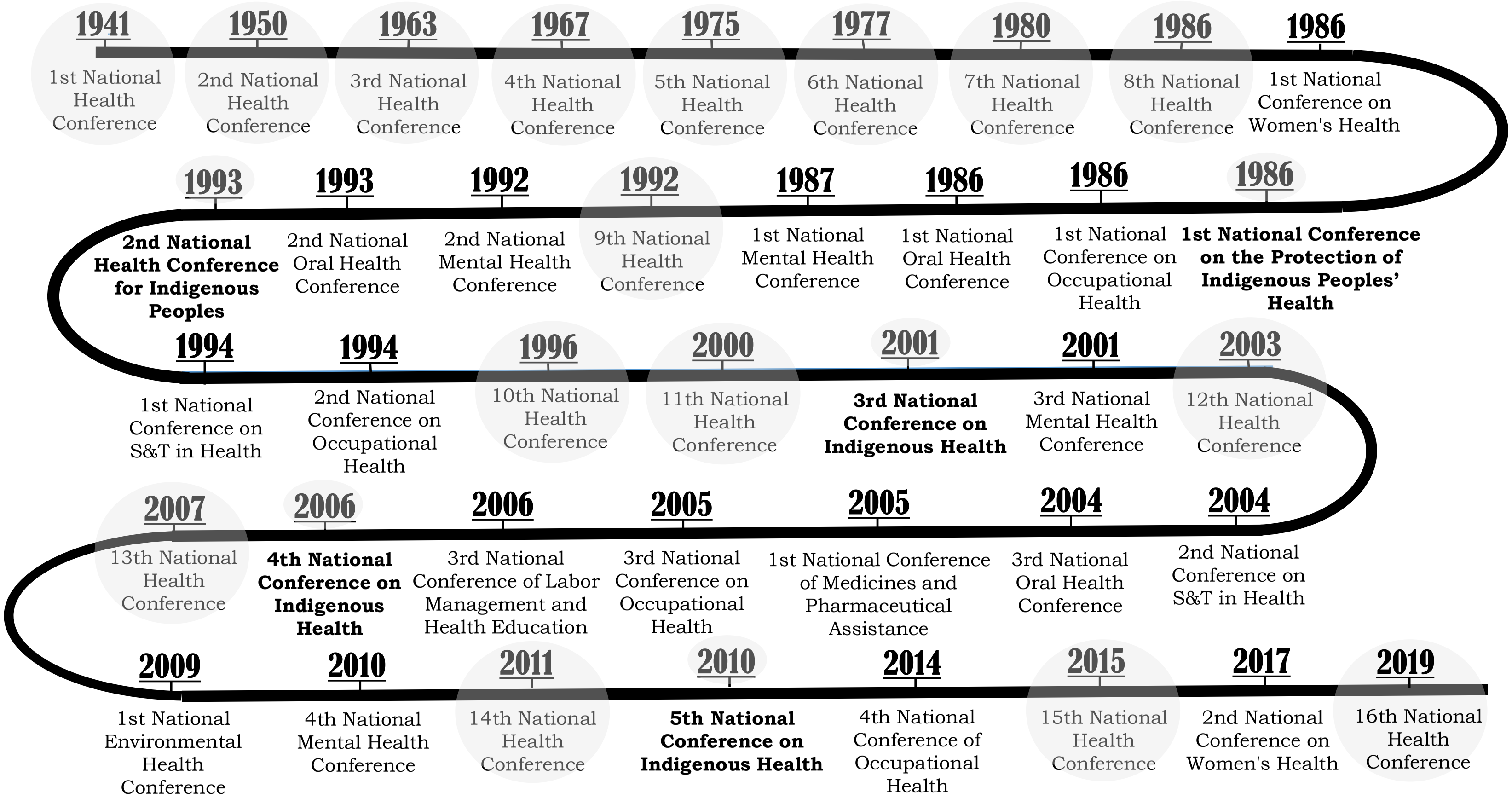
> *Yes, the fifth was that way and it will be like that, because this is the rule. It turns out that the indigenous movement, the indigenous peoples, generally are not used to this discussion and this form of representativity. So, let's say you discussed it there, but I want to discuss it again, I have to discuss it again! And if after two times I want to have a discussion again, I have to discuss it again! And this logic is not allowed, it is divisive.* (Health Care Professional 1)

The final report takes two years to be published. Following the previous graphic design project, it consists of 383 pages permeated with images and many photos. Bureaucracy and standardization were the hallmarks of this conference, which obscured the approaches of participation and social control, very present in other conferences.

From participation to social control

The health care sector has been an important locus of social participation. Community participation is one of the philosophical principles that guided the construction of the SUS and expressed the desires for rights and democracy. Even though the 8th CNS is the most important in terms of bold proposals, the first experience of holding a health conference dates back to 1941 (Figure 1). However, at that time the health conference was a consultation forum assembled by the government. There was no participation from society and it was not a mandatory event, these being legislative achievements that were possible after the Federal Constitution, more specifically Law nº 8,142/1990 (Brasil, 1990b).

Figure 1 – Timeline of health conferences



S&T: Science and Technology.

Source: adapted from the National Health Council[1]

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[1] CONSELHO NACIONAL DE SAÚDE. Brasília, DF: Ministério da Saúde, [2020]. Available at: <https://bit.ly/36zTKsM>. Accessed on: Oct. 6, 2020.

It should be noted that, strangely enough, even though the three legal frameworks (Brasil, 1988, 1990a, 1990b) refer to **community participation**, the term has been transformed into "social control." It is not the aim of this article to analyze the conceptual history of this modification, but this change has led to repercussions in participatory practices within the health field, to the point that the idea of participation (which involves, among other things, reflecting on solutions for material problems) became limited to the technical and bureaucratic capacity to monitor the State's actions. This reduction in the sense of participation crowns the more conservative purposes of neoliberal thinking by transforming each citizen into a kind public affairs manager. Guizardi et al. (2004, p. 19) have already pointed out this conceptual difference, noting that "the population's participation is presented as being broader than control, as it involves the entire process, starting with the formulation of interventions in the field." Carvalho (2014, p. 15) notes that participation is "engagement through action, it is the challenge of the proposition." On the other hand, social control would be one of the participation aspects that is closely linked to the processes of policy implementation in management, evaluation, and control (Carvalho, 2014). Control ends up functioning as the "essence of citizen participation" (Carvalho, 2014, p. 50), even if the term does not appear in general or SUS legislation, in which we find only "community participation" and "popular participation."

Another important consideration about this conceptual phenomenon is the fact that the idea of social control necessarily entails action within institutional channels, eliminating other possibilities of activism or pressure. On the other hand, the idea of participation holds within itself a broader power of action that allows different strategies to be reconciled. Essentially, it must be stated that participation is a political act that looks to the future, and social control is a legal act that looks to the past.

> This conception of participation places the population as the protagonist of the social construction project for the right to health care [...]. Therefore, social control emerges as an effect of participation, as long as it is characterized by organization and access to decisions. (Guizardi et al., 2004, p. 20)

In a similar line of analysis, Cruz and Coelho (2012) point to the existence of two forms of indigenous participation, which they call "authorized" or "unauthorized": "When we refer to 'authorized' we refer to official indigenous participation, that is, the one that establishes a specific 'place' for indigenous peoples in the Local and District Health Councils and as 'users'"(Cruz and Coelho, 2012, p. 190). On the other hand, unauthorized strategies concern actions of occupation, blocking, "retention of the non-indigenous in the *aldeias*" (Cruz and Coelho, 2012, p. 195), among others. It can be said that we are facing two possible forms of participation: **institutionalized participation**, which operates in the spaces provided for by law; and the other is **instituting participation**, which seeks to use untraditional methods to expand the possibility of obtaining rights by "taking from the State," to quote a famous expression by Bobbio (1992).

With regard to institutionalized participation, it is worth discussing its limits, on which Souza Lima (2015, p. 448) points out that "some of the concrete problems and quite small things" are present and constitute important barriers for entry into the field. Cruz and Coelho (2012, p. 192) see an "imposition of participation forms that are inspired by Western criteria, which are very distant from the forms built within the scope of indigenous political organizations, constituting different cultural logics." Furthermore, Langdon and Diehl (2007, p. 30) suggest "that the view of the Indigenous on participation and social control is much more about exercising politics than conducting interventions that influence the formulation, execution, and evaluation of public policies for the health care sector."

In this same line of reasoning, Garnelo, Macedo and Brandão (2003, p. 80) claim that there is "an incongruity between the notion of generic representativity demanded by the health care system, and the traditional forms of legitimacy and representativity among indigenous leaders." Not coincidentally, there is

> a certain consensus among indigenous people, on one hand, about the low effectiveness of the decisions made there, and on the other hand, in an apparent paradox, on the political relevance

> of social control and the need to improve it - be it for its pedagogical role in political performance, or for the project of the indigenous people taking over the subsystem's management themselves, or for its power to guarantee differentiated rights. (Teixeira, 2017, p. 724)

This author draws attention to indigenous people's acknowledgement of the need for entering and mastering the "field." It is in this sense that André Fernando Baniwa highlights the need for indigenous representatives to count on "some strategic partners, that may be technicians who know how things in the government work" (Baniwa; Karipuna, 2012, p. 219). In addition, participation implies having knowledge and access to the information necessary for assisting in decision-making.

However, the risk remains that of falling into the clutches of bureaucracy, which would hamper participation. Souza Lima (2015, p. 444) highlights that if this participation was initially "eminently political and marked by the search for autonomy in dialogue with government agencies," it eventually acquired "a more technical, bureaucratic, and sometimes figurative character, one more piece in the staging of democratic life," very much in function of "the authoritarian ways of exercising State power."

Such considerations are important because they demand a different look at the institutional spaces for participation. What is at stake is the ability of indigenous peoples to self-determine in their relationship with the government.

Final remarks

In this text, we observed the shift of participation towards a more bureaucratic performance within the strict limits established by the administration. If the report of the 1st Conference held with it a power for radical transformation in the way of thinking about indigenous health, over the years (and conferences) this transgressive possibility started being limited by bureaucratization. Over the last decades, this has permeated the forms of participation in health care (indigenous and non-indigenous), and to a certain extent, the very conception of participation in the health area. It can be said that the set of rules established for the "proper functioning" of conferences serves, at the same time, as a straitjacket and blinker, which homogenizes and pasteurizes all social aspirations into insipid demands. It cannot be ignored that this was a vigorous response from the administration, which unable to respond to social demands, chose to neutralize them. Even so, it is essential to value the power contained in mechanisms of social control, which not coincidentally are the objects of disputes brought forward by the most conservative groups in society. In this sense, it is necessary to value these spaces, occupy and transform them.

Indigenous participation remains an important issue requiring further studies, especially regarding ways of overcoming the challenges inherent to "entering the field" of institutionalized participation. The Brazilian State has a historic debt to indigenous peoples. Therefore, promoting/guaranteeing their participation in the formulation, conduction, and evaluation of health policies is only one step towards overcoming the authoritarian history and tutelary perspective typical of our institutions.

However, indigenous peoples' political struggle is not restricted to the acknowledgement of their presence and the establishment of a space, but as expressed in the statement by Sandra Benites,[2] "it is necessary to consider what constitutes each people, respecting their well-being - the elements and references that constitute each people."

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[2] BENITES, S. *Speech given during the debate "Demarcação Já: Debate sobre os Retrocessos nos Direitos Indígenas no Brasil."* Rio de Janeiro: Ensp/Fiocruz, May 2017. Mimeographed.

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Authors' contributions

Abrunhosa and Machado performed the bibliographic review. Pontes conducted the interviews. All authors conceived the article, analyzed the data and wrote the text.

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